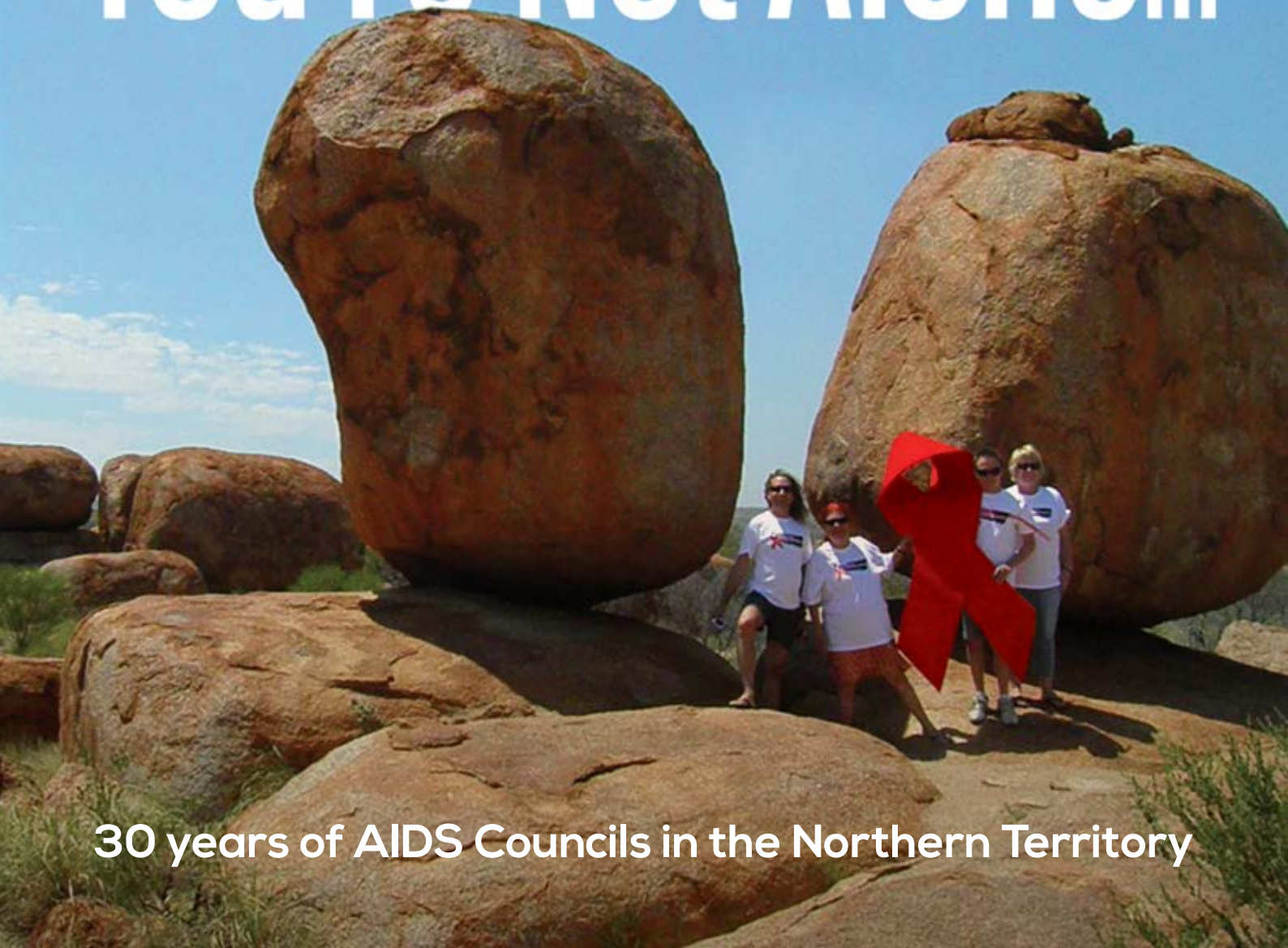


You're Not Alone...



30 years of AIDS Councils in the Northern Territory

You're Not Alone ...
30 years of AIDS Councils in the Northern Territory

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Front Cover: World AIDS Day Road Show: Tobin Saunders,
Bev Greet, Daniel Ward, Jan Holt, at Devils Marbles Central
Australia. November 2010 (Photo Greta Enbom)

Back Cover: Joanne, Mt Bundy Sistergirl retreat, 2006.

Opposite: Hot Gossip Hooker's Ball, December 1987.

**Aboriginal and Torres Strait Islander people should
be aware that this document contains images or names
of people who have since passed away.**

Dedicated to all people who have passed away from
AIDS-related illness in the Northern Territory.

You're Not Alone ...

30 years of AIDS Councils in the Northern Territory



A collection of stories remembering the NT AIDS Action Group (NTAAG), Central
Australian AIDS Action Group (CAAAG), NT AIDS Council (NTAC), AIDS Council of Central
Australia (ACOCA) and the Northern Territory AIDS and Hepatitis Council (NTAHC).

Curated and Edited by Panos Couros

Editorial Associate **Dino Hodge, PhD**

Northern Territory AIDS and Hepatitis Council



Foreword

In this series of interviews titled *You're Not Alone...* Panos Couros has elicited a fascinating history and development of the Northern Territory AIDS and Hepatitis Council.

The interviews are from many different perspectives from a range of people who have been involved with NTAHC at varying times during its 30 year history.

In the early days of NTAC a group of dedicated visionary people set up a community based organisation to help the increasing numbers contracting and dying with AIDS, often without care or support. A disease that was so frightening and for which there was no known cure. A disease which evoked so much discrimination and hostility based on ignorance.

The interviews move through to the present day covering developments in both Alice Springs and Darwin and how their respective Councils became unified. The inclusion of Hepatitis which was becoming a significant problem adds a new dimension. The issues affecting people of every nationality and every sexual identity.

The interviews are raw and honest expressions of how a variety of dedicated people experienced their role in NTAHC, whether in Alice Springs or Darwin and serving the whole of the Northern Territory.

Staff members, clinicians, medical advisers, counsellors, carers, board members, those involved with the needle exchange program, sistergirls, education programs, sex

workers, Aboriginal health workers, those providing a "safe haven", those distributing free condoms or promoting good diet and well-being, those establishing good governance and protocol systems, volunteers in a range of areas – all have been interviewed and told their story.

Medical research has provided much in the way of medication since the start of the epidemic.

NTAHC now has the important role of prevention, education, counselling, caring, providing support, assistance and advice and addressing the issues of stigma and discrimination that still accompanies these diseases.

As happens to many organisations there have been personality conflicts. There have been ups and downs. There have been great problems to overcome. There have been great achievements to celebrate.

Through the good and the bad years NTAHC have organised some brilliant events. There are vivid descriptions of Candlelight Vigils, World AIDS Day events, Dance Parties and much else.

Ultimately NTAHC has come through stronger than ever, thanks to so many, including those in these very inspiring interviews.

Sally Thomas, May 2016
NTAHC Patron



Introduction

2016 marks thirty years since the incorporation of the Northern Territory AIDS Council, now known as Northern Territory AIDS and Hepatitis Council. This organisation is the culmination of five distinct entities that emerged from two local responses to a global crisis, in Alice Springs and in Darwin.

The Central Australian AIDS Action Group (CAAAG) grew into the AIDS Council of Central Australia (ACOCA). The Northern Territory AIDS Action Group (NTAAG) became the Northern Territory AIDS Council (NTAC), with all organisations finally emerging into the current Northern Territory AIDS and Hepatitis Council (NTAHC).

These AIDS Councils, and the organisations that they grew from, were the labour of many people and it is their experiences through time that really make the substance of this story.

The recollections and memories within these pages come from an array of truly spectacular people who all faced and battled the menace of HIV (and later viral hepatitis) with all the fear, stigma, discrimination, illness and death that these situations had to throw at them.

The photo opposite marks one of the highlights of my time working at NTAHC (2010 – 2012) – a transgender awareness workshop run by Samuel Lurie, brought here from the USA in August 2011 by then executive director Alison Edwards. A truly enlightening and transformative few days and testament to how this ever-shifting organisation continues to strive towards a healthy and progressive world.

The stories you read here have been constructed from edited transcripts of interviews that I conducted with each person. Oral histories transformed for the page.

These are stories of resilience, courage, tenacity, humility, humour and much sadness – but most of all they combine to form one story of enormous conviction founded on the most basic yet advanced human principles: love and compassion.

Many of the people who are not with us are remembered with great fondness and more than a touch of sadness. This book is dedicated to them.

The blood-borne viral threats have not gone away, so whilst we commemorate and heal from the past we must continue to look firmly and vigilantly to the future.

I thank all of the wonderfully generous participants for their time and memories. Without you this greater story would never had been told. We know that we are indeed not alone.

Panos Couros
Curator & Editor
History Project Coordinator

Front Row: Andrew Ewing, Samuel Lurie, Panos Couros
Middle Row: Crystal Johnson, Unknown, Sianne McLaughlin, Be Andrews, Unknown, Lana (Pocock) Richardson, Gill Ling, Leece Johnson
Back Row: Bronwyn Clee, Daniel Burton, Benni Graham

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John (Norman) Turner

NORTHERN TERRITORY AIDS ACTION GROUP / NORTHERN TERRITORY AIDS COUNCIL
1984-1991

Some of the doctors were not very happy with our presence, to say the least. I said, "What are we going to do when we get our first AIDS case?" And they said, "Oh put them on a plane and get rid of them, send them down south." At that stage you couldn't get on a plane ... later on, a man who was infected with HIV was smuggled out of Alice Springs without telling them.

My name now is John Turner, but whilst I was in Darwin I was known as John Norman. I arrived with my partner John Goodall in September 1982. We stayed with the man who was running the Darwin Gay Society. It was just him running it, and it was basically monthly bar nights at the Darwin Hotel. We stayed originally in Ross Smith hostel which was in Parap Road. He asked us to look after his house in Parap, just over the back of the hostel. So we said, "Yes, we'll do it", anything to get out of the hostel. We stayed for about six weeks, and when he came back he said, "Well there's an empty room downstairs you can go and move into that." We stayed there and helped him with the Society.

In early 1984 he said, "I'm tired of doing this." He put out a monthly magazine as well. So I said, "All right, I'll do it, keep me off the streets during the day time." John had got work by then but I was on a pension.

I got a phone call from NT Health saying that Neal Blewett, the then Federal Health Minister, had said that each State

had to have a committee involving local community to look into dealing with HIV when it arrived. So we went along, me and Doug [Raethal]. They said afterwards they were relieved that we did turn up in a business shirt and pair of dress shorts. I'd worked in offices at Sydney, so I had the gear, and so they were pleased with that. We had fairly regular meetings after that with various people. The fellow who was in health was very good; I could go and see him at any time, which people in the Health Department were amazed. He was head of clinical studies, but some of the doctors were not very happy with our presence, to say the least.

I said, "What are we going to do when we get our first AIDS case?" And they said, "Oh put them on a plane and get rid of them, send them down south." At that stage you couldn't get on a plane if you had HIV. And I said, "They can't travel on Ansett or TAA, because they refuse to carry them." I said, "You can't put them on the domestic airlines."

John Norman, Peter Smith, John Goodall - Stonewall Film Evening 1986 (photo courtesy Sim Lee)

"Oh, we'll put them on a light aircraft." I said, "It will be four days to Melbourne." And they said, "Oh that doesn't matter." Later on, a guy who was infected with HIV was smuggled out of Alice Springs without telling them. We came across as sensible without being overbearing – let them talk clinical things when they wanted to and we just shut up. So we got a reasonably good reputation with them.

We were very fortunate Neal Blewett was the Federal Health Minister because he pushed things. I got a phone call from Canberra saying, "We want you to go to Melbourne at federal government expense and attend a meeting of all the AIDS action committees," which were all round Australia. There we were told by our federal health person that we were to incorporate as an "AIDS council" so we could receive federal funding. We weren't allowed to have "action" in our name. That was the start of NTAC itself, and I came home and incorporated NTAC.

I felt there were people in town who were very unhappy with us because we had sort of made a bit of a mess of the beat, to put it politely. In those days in Darwin the power station down on the wharf was terribly unreliable, and in any electrical storm the power went off for a couple of hours. So all the boys would rush down to Vestey's Beach to get a blowjob while they were waiting for the power to come back on again. After the Grim Reaper Campaign, which was April in 1986 it absolutely killed it, it died, nobody went down there at all. Non-gays didn't go near the place. So there were some gays who were very anti – you know, "We'll pretend it doesn't happen" and, "It won't come here." Eventually it did come of course. So, I was always "responsible" for the killing of beat life in Darwin.

At one stage they formed their own group and insisted that they were going to control me, and I had to go through them. As the elders of the Darwin gay community, they were going to stop "this upstart from down south" from speaking to the newspaper. When Kenny S was diagnosed with HIV, I was called to one of their homes and was told what they were going to do, and that I was not to say anything to the media – but that sort of backfired on them rather badly. They said to me, "We know a certain journalist at the NT News" – which in those days was an afternoon paper out about two-thirty. We're going to feed him information about Kenny for him to discreetly put in the NT News". And I thought, "I've had some dealings with the media in Sydney and this is not going to work."

But anyway, they fed everything they knew about Kenny, absolutely everything, to this journalist with the idea it would be handled discreetly. Well, the next afternoon there it is all over the front page of the paper, Kenny's life story. It had a different by-line. He'd given everything to an offsider who printed it. Everyone rang me up and said, "That's Kenny isn't it?" I said, "Yes, it is Kenny." And straight people knew it was Kenny; he was well known. I mean, you don't tell journalists this type of thing and not expect them to use it. So yes, that was the end of their intervention anyway. We sort of rolled our eyes and said, "Well, stupid poofs. What did you expect?"

Meetings with NT Health became less and less often, and we were just simply not invited maybe because we asked too many difficult questions. The last few months before we opened the office, we probably didn't go to any meetings at all with the Health Department. I use to go and see Iain [St Ives, then Director of Epidemiology].

He knew what was what, and when the story came out about Kenny on the front page of the paper I said, "That was a bit of mess." He said, "Yes it was, and it came from your people didn't it?" So he knew where it came from and he said, "You can't throw stones. You gave it to him, they printed it."



Kenny Spence (died 29 Feb 1992 - photo courtesy Dino Hodge)

After that we published a few things, talked to people, I got lots of stuff up from Melbourne and Sydney, and people asked me questions about what was going on. We initially didn't do a great deal until the NTAC office was set up. It was mainly gathering information and passing information out when it was asked for. We didn't actually have any strategy or systems. Also, my health at the time was starting to give me concerns and make it more difficult for me to spend a lot of time on it. This was the reason why when NTAC was incorporated that I took on the treasurer role rather than president, because it was just too much for me to do it successfully.

That first guy we employed was a disaster as a co-ordinator. We should have done more research on him. "I don't read newspapers, I don't do this, I don't do that, I don't do anything." Well I said, "How are you going to know what's going on to respond?" "Oh you didn't tell me that when I applied for the job." He lasted about six weeks. Canberra sent up their co-ordinator John Westlund for a few months until we got a new one, Ian Lauchlan.

We had a receptionist/office lady. She was very straight. When we employed her I thought, "Oh, this is going to be interesting. She's so terribly straight and people are going to come wandering in asking all sorts of strange questions and language, and everything else". So in the interview I said to her, "You might get strange phone calls from people using colourful language, how are you going to deal with it?" Because I thought if she heard the magic word she'll sort of fall off her chair. "Hang up on the bastards." – "Oh, okay." And she was perfect. She ran the office like clockwork. We couldn't have done it without her, she was an excellent employee. I said to her a couple of times,

"Have you had any interesting phone calls?" She'd say, "No." And I thought you must have done, because I heard people had done it but she was good, very good.

There was meetings of the hierarchy. Quite often we'd discuss what we're going to do. A lot of communication was from down south about what they were doing. Some of the stuff we printed was actually a joint print run with South Australia. Because we were so small, they printed the stuff, and then they'd take off a quantity and put our name and address as the contact number. So that was how a lot of it was done. We went out to the health centres and distributed there. At the gay nights, we had literature there.

We managed to get a very good phone number. One of our straight supporters worked for Telecom in those days, and when we were organising the office, he said to us, "I've reserved a phone number for you, 411 711." You couldn't ask for a better number. Terry McC went down to Melbourne to an AIDS councils conference and said, "Oh here's our phone number, it's (089) 411 711." And they all looked at it, "How the bloody hell did you get that number?", because everywhere else had ordinary numbers. "We have friends." So the number got reasonably known that way. I think there was a small sign downstairs inside the door saying AIDS Council with the number on it.

We lost several people. Kenny died. Chris L was a schoolteacher, and he was very closeted but apparently he was having a fun time in the steamies in Sydney and he got HIV. In those days people didn't last very long, and suddenly he was gone and there was a lot of talk about it because everyone said, "How did he get HIV?" Darwin is like a leaky sieve and it's impossible to contain information

like that. And there was lots of problems as it was suddenly in the paper.

I had some guys who had become infected coming to me for counselling. At that stage we were saying only 10% of people died, and then it was 15%, then 20%. And several of them came to me and said, "What is your gut feeling?" And I said, "It's going to be very much higher." At that stage, we had nothing to treat them with. It was just antibiotics and they didn't do much good. There was one guy, Peter H, who actually stayed in the house I was at. He had a good time in town during his visit, and then suddenly we got news from Cairns that he had AIDS and he died a fortnight later, which was common in those days. People went fast. That caused a bit of a ruckus in town and people were more careful, and we did get more people asking questions around that time. But a lot of them said, "I had sex with him, what can I do?" And I said, "Well, cross your fingers. I'm sorry but there's nothing the medical side can do. Just be careful and have safe sex whenever you do anything to protect others."



Kenny Spence quilt (detail), 1992

I was involved in a straight motorcycle club. They had a bike show out at the showgrounds, and I said, "I'd like to put a stand up, unmanned, with literature about AIDS on it." And they all said, "Oh, yeah, great." So I had literature and condoms on it and I said, "Well I'll put near the club stand so you can keep an eye on it and people don't walk off with handfuls." And at the end of the first day I said, "How's things going?" They said, "We've replenished once, everyone takes a couple as they go past." So the message was getting out.

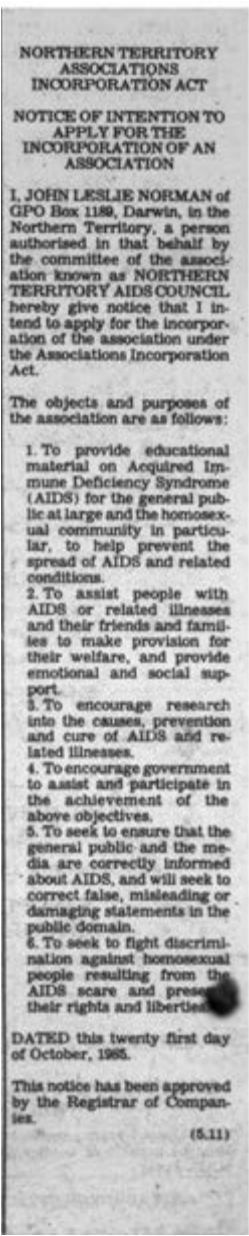
I think we were very lucky that we encountered less problems than we really expected. I did expect problems like threats of violence from straight community but that never really eventuated. I think it was Darwin's laid back atmosphere that helped us do what we were doing and, I like to think, successfully. We were fortunate in that way.

I never really stopped to think how out there we really were until people from Sydney said, "You are really being very out there, like having a stand in the Darwin mall." And people were quite open about it, and people were genuinely interested because it was - well, Darwin in those days was very heavy male population and so I think they just seemed to be a bit more open about it.

I had dealings with the nurses who ran the clinic in Alice Springs, because the Health Department rang me up one day and said, "The two nurses from Alice Springs are here and they want to ask you a favour." So they come out and see me in the government car. "We want to buy some dildos from the sex shop to demonstrate how to put on a condom. We want you to escort us." I said, "Oh, okay." So we went to the sex shop owner, and they told him what they wanted. He said, "Oh yes, you can have the biggest." They said, "Well,

we prefer it to be black, because it's for the black community." He brought out the biggest black dildo you've ever seen in your life. You know, hug it and cry type material. And she looked at it and said, "We don't want to make them feel inadequate, thank you." He brought out a candle-sized one which was a much more respectable one and so they bought two of those.

They use to ring me up from time to time for stuff and I'd say, "How's the black candles going? Be a bit soft by now!" because Alice Springs is very hot and candles soon melt. They said, "Oh no, we gave them away and we got ceramic ones from the ladies of the Alice Springs ceramic group, which was basically a ladies-well-to-do class, who did ceramics to fill in their time. They gave them the dildo and said, "We want twenty of these, please, in ceramic." So the ladies made the black dicks in ceramics to take out to show how to use a condom. ♦





John Hobson

CENTRAL AUSTRALIAN AIDS ACTION GROUP / AIDS COUNCIL OF CENTRAL AUSTRALIA
1987–1991

A detailed history of ACOCA written by John Hobson can be accessed at: www.indigoz.com.au/qotd/acoca.html

The AIDS conference that we held ... was enormous, and it was nationally significant. People came from all over the country because there was such a thirst ... and then we had the good matrons of Alice Springs, I won't name any names – Aboriginal women – getting up and going, "It's a dirty, filthy homosexual, drug user practice", and, "It's those dirty white fellas and all the filthy things that they do, non-Christians that they are, who are spreading this disease." These Aboriginal gay guys with tears streaming down their faces, got up and spoke out ... "No, it's not true. We're here and we're not some kind of aberration."

My name is John Hobson. I was the founding president of what became the AIDS Council of Central Australia from 1987 through to 1991. That organisation then became a part of NTAHC some years after I'd ceased to have involvement with it.

Back in about 1987 there was a group of medical professionals who had recognised that HIV and AIDS was going to be an issue. I don't think HIV was a term that was in use at that time; we were calling it HTLV1. So they were probably charged by the Northern Territory Health Department to work out what they were supposed to do. They'd been reviewing papers and telling each other AIDS jokes, it turns out. But one of them – a sexual health nurse, Sister Shirley Anne Bailey – realised that the only sensible thing to do was to have some community participation.

Jim Buckell and I and others had not long before formed Central Network as a central Australian gay and lesbian group in the region. Shirley Anne approached us and negotiated with that group, to suggest that we go along to one of their meetings and work out could we assist each other. So we went along to that. We were somewhat aghast by what was going on there, and they clearly had no community connection. They were clearly a bit intimidated by us. They thought we were gay activists who were going to sweep in and try to take over everything. But we were completely intimidated by this room full of doctors. It was a bit comical really. Anyway, we worked out that we weren't each other's enemies and we could be each other's friends. So that little group then set about recognising that we needed to do something a bit more substantial.

Warren Talbot, who was the initial executive officer of the Australian Federation of AIDS Organisations, came through from seeing ACSA [AIDS Council of South Australia] on his way up to see NTAC. He got wind of the fact that there was something developing in Alice Springs, a kind of midway point between the two, so he dropped in. We met with him, and he encouraged us to try and do something a bit more concrete and formal. He recognised straight-away, like most people do in Alice Springs, that you need to do things locally and relatively autonomously. Darwin and Adelaide are largely too far away to provide you with day-to-day services; it just doesn't happen. So that became the Central Australian AIDS Action Group.

We toyed with the idea of calling ourselves the Central Australian AIDS Council. At the same time Warren had suggested to the committee of NTAC that they should provide us with some funds so that we could operate. There was a bit of argy bargy about them wanting us to become a branch of NTAC, and us saying, "Well, no thanks. We're quite happy down here. And, you know, if somebody here needed medical assistance, for most services people would go to Adelaide from Alice Springs, they don't go to Darwin." To this day, if you get evacuated, you get evacuated to Adelaide, you don't get evacuated to Darwin. So Alice Springs has always been a place apart.

NTAC parted with \$5000 to allow us to get going. We rented a little space on a casual basis from the Family Planning Association and employed Jim Buckell for a few hours a week – ostensibly to do outreach work, but probably most of his time was occupied in trying to write more grant applications to anyone we could think of in order to get funds enough to do something meaningful.

At the same time, around 1987/88, we were getting AIDS refugees from Sydney and Adelaide and Melbourne. People were popping up at the airport, ringing the gay group – they'd just been given a positive diagnosis and then walked to the airport and got on a plane, thinking, "I'll go to the middle of nowhere, where I'll be safe." People were driving into town. They were landing on our doorstep. The gay line rang in my lounge room, and we were getting people on the phone. And then Shirley Anne disclosed there were a few people in town who had had the virus for some time. There were people who were starting to develop Kaposi's Sarcomas and other more obvious symptoms.

About a year later, we held an AGM and the AIDS Action Committee became the Central Australian AIDS Action Group (CAAAG). Shirley Anne Bailey's replacement Sarena Ruediger was absolutely fantastic. She became a committee member, as did David Batty from Central Australian Aboriginal Media Association, (a good friend), and Jim and me. The four of us made up the committee. Jim also was public officer and chief staff member until we got about \$12,000, and then we hired Megan Brooks and got space in what was then Grandad's Arcade. It was a little shopfront.

So that was the very early days. Hidden away down in the little arcade. It worked fairly well. At this period, to walk into an AIDS Council, we didn't have signage on the door. We called the shopfront SafeSexWorks. There was nothing that said AIDS or anything like it on the window. Then when we moved upstairs in to the Heenan Building, it was a very subtle little sign on the door. If you didn't know, you didn't know – but all the people who needed to know, knew. That was quite successful. Margie Collins and Gavan Dale were working for us at that time as well.

The Central Australian AIDS Action Group incorporated in 1988, so we had to hold an election. That's when those four office holders were appointed, and that's when I became founding president. The only documents from meetings that I have are from at the end of my involvement, the AGM in 1990, when relations really soured with NTAC. They reneged on a deal which saw us get representation on the Australian Federation of AIDS Organisations. And so at that AGM we went, "Well, our agreement not to call ourselves an AIDS Council is now officially ended and we declare ourselves to be the AIDS Council of Central Australia. How do you like them apples?" I think that changing the name of the organisation was not problematic because we already were an incorporated body. Anyway, the politics were quite thorny.

We had a lot of support nationally. People recognised that there was a great advantage in having an autonomous organisation in central Australia and that we were in contact with our communities. At that time, there was as much likelihood of an organisation in Darwin connecting with local communities in Alice, as there was being serviced from Adelaide by the AIDS Council of South Australia. And there were actually discussions on that front, unbeknownst to NTAC. We looked at maybe becoming a branch of the AIDS Council of South Australia because it made more sense. If we had people who needed treatment, we were liaising with South Australian Health in order to send people with Kaposi's Sarcoma down for radiation treatment and getting them back again. So most of our interaction was to the south, and they were pretty generous with assistance. Whereas, we tended to get a lot more argy bargy from Darwin about "How dare you exist independently."

Federally, people were happy to have us at the table. It wasn't an issue for them; they didn't see the state jurisdiction issue. Commonwealth Health probably found it a bit frustrating, that they had to balance funds between the two. And NTAC certainly found it frustrating, because any money that went to us was 'rightfully theirs'. Northern Territory politics! I'm sure they haven't changed one iota.

I left Alice Springs about the middle of 1990. My partner and I decided we'd had enough. It was not long after the Central Australian AIDS conference, which was largely organised by Jo Harrison. One of the last things I did was resign at the 1990 meeting when CAAAG became ACOCA. I was the one who put the motion to change the name. Then we drove out of Alice Springs the next day to Perth.

I'd been working in the STD clinic in Perth when the position as the executive officer in NTAC became vacant, and people from Darwin contacted me. Because I'd been out of the picture and they knew I was out of the picture in Alice Springs, they said, "Why don't you come up here." What I didn't realise was that at the time there was a great deal of conflict happening within NTAC, and there were people on the committee who were in a very bitter dispute with people who were on the executive. I was seen as a potential champion for one side. John Dunham was the president then. He actually came down and met me in Alice Springs. We were making the drive back up from Perth to Darwin. But yes, without going in to the politics, there was a lot of animosity between the executive and the committee, but it was long-standing friends on the committee who had encouraged me to apply for the position.

When I arrived, I found I was in a position of immediate conflict with the executive – piggy in the middle. I lasted about three months and we just looked at each other and went "This is no kind of life", and went back to Alice Springs.

In that period Elden Chamberlain and Ian Butterworth were around. Simon Nish had been on the committee and I think Terry McClafferty had moved to Perth. Simon was trying to keep well away. In fact, when there was some episodes of high conflict in committee meetings, he came in to try and give me a bit of moral support because he'd been a long-standing friend. I think then a woman called Faeywen Goyen took over from John, and that I think was a mechanism to mediate the conflict. I have to say it wasn't me that caused the conflict, it was in full flight when I arrived. But nobody had warned me that they were recruiting me to fight for one side over the other.

The NTAC executive, when I was there, was acting pretty unilaterally. They had complete control over all aspects of day-to-day management, and the executive officer wasn't permitted to expend any funds. I couldn't write a cheque; I had to get it signed by the treasurer. When the battle reached fever pitch, the treasurer started refusing to sign the superannuation cheques for the staff. That caused the staff – including me – to lodge a complaint with the industrial arbitration body, whatever it was at the time. And then in came the union, and also in came a notice to me that I was to appear before the Industrial Relations Tribunal to explain why NTAC the employer was breaching its obligations to pay superannuation to its staff. That, I think, was a device to try and get me out of the chair, and it was pretty successful. I just went "If that's the level of toxicity, if that's the kind of thing that people are going to

try to do to get rid of me, then I don't have to put up with it. I'm going to step away and they can just kill each other. I'll go back to Alice Springs where things are safe and pleasant."

My involvement with ACOCA after that was largely on the sidelines. After I left, a new committee was elected. Relations between them and the then principal staff member, Megan Brooks, soured considerably. Within the next six months or so, Megan decided that her relationship with the management of ACOCA had broken down irretrievably and that she was to leave Alice Springs and return to Sydney. I think most of the gay men who'd been on the committee resigned. They really disengaged, although it's not universally the case because I think Jim and Tony Hand were doing some work there.

Things had changed quite radically, and an interesting professionalisation and bureaucratisation of ACOCA took place. A lot of gay men were quite disaffected; they were meeting for cups of coffee in the café next to the AIDS Council but they wouldn't walk in the door of the AIDS Council. And by now NT Health had expanded considerably its sexual health team in the area, and most of the staff of that unit were either on the committee of ACOCA or were staff of ACOCA. It was quite a problematic situation. I knew those people and I'd worked with them for some time. They had been very frustrated by the restrictions that NT Health placed on what they could do. So ACOCA, in my impression, became a vehicle for them to pursue – away from their employer's reach – strategies and interactions with the community that they thought they should be doing. So I think the lines between NT Health and the community agency became extremely blurred.

The other thing for me was they seemed, in a very short space of time, to become substantially disengaged from local community. Stats had plummeted, and it came to a head when they decided they wanted to network the computer system in the office, and that's something I knew how to do. So I was in there crawling around under desks for a week or so assisting in a voluntary capacity. I wanted to *not* be involved, but people said, "Oh, John knows how to do that", so I went in to do it. I noticed that everyone was really busy planning furniture purchases, or looking at superannuation investment options, or planning brochures. But there were no clients walking in the door, and they were reporting at meetings that the client stats were way down, and they didn't know why.

I said, "Well, there's a number of things. You seem to have pissed off some quite significant clients in town." At that stage, HIV was still largely restricted to the gay male population. Gay men had stopped walking in the door and were not interested in interacting with ACOCA. I thought that's hugely problematic. So the stats were down – and because of the location of the place as well, anyway. I pointed this out at a meeting and, next thing, one of the staff put a motion to the committee of ACOCA. I'd agreed to go on as a guest committee member on ACOCA committee when I came back. They kind of said, "Oh well, why don't you occupy a nondescript position. We'll just co-opt you as an ordinary member of the committee so we can have access to your historical knowledge and stuff." It had not been that long since I'd been gone. The next thing there was a motion from one of the staff, who had up until recently worked for Northern Territory Health, that committee members

should not enter the premises at any time. So I just went, "Oh okay, you're joking."

But also, half the staff or the committee were employees or former employees of NT Health. This was supposed to be an independent community-driven organisation, not an organisation driven by the interests of staff from NT Health. The staff were frustrated, they couldn't do this, they couldn't do that, if they did anything that smacked of being a bit risky, if it's stated publically that people actually inject drugs, or people have anal sex or something – NT Health couldn't be associated with anything like that. That was just too out there. But of course ACOCA could.

People who had been a health education person, nurse, or clinical consultant working for the health department, now worked for the AIDS Council. The guys had been in to have their warts treated or have their HIV blood test done in the Health Department – now that that person was working in the AIDS Council. It wasn't a good thing, that was a bad thing, from their point of view. Because they'd be going to the STD clinic and telling whatever stories about their sexual behaviour and practices, and then they come and get services from the community organisation. All of a sudden the distinctions are gone. I don't think people saw that, the fact that gay men were having difficulty being on the committee, when the STD clinic sister was sitting there looking across the table at them and they'd just done something to them with some liquid nitrogen or a cotton bud. I was like, "Um guys, this is really not working."

We ended up with a mass loss of staff from NT Health, straight in to ACOCA. Other people will disagree with me

vehemently about that – tough – but that's why I stopped turning up at the premises, after there was a motion directed at me.

So I devoted myself largely to the gay community, yeah. And then liaised. I just went back to, "Well, you give me the brochures and the materials, and I'll make sure they get circulated. We'll take care of ourselves, thanks." But then when Christopher Rowe came and started to work, he actually lived in my house. And he did the *Summer of Safer Sex* campaign, which was a raging success. And then we had the *You're Not Alone* campaign, which set the world on fire in Alice Springs; that was about '93. And that marked my last ever involvement with the place.

The *You're Not Alone...* campaign that Christopher Rowe ran in 1992 marked the end of my involvement with ACOCA. That campaign featured a photograph of two guys together, and it just brought down the wrath of the Christian fundamentalists like you wouldn't believe. Northern Territory Health turned its back on ACOCA and Commonwealth Health turned its back on ACOCA, and they were reassuring the rabid right. It had been sent down to Commonwealth Health, and they said, "Oh, it's a bit too confronting. We think you need to change it." The ACOCA committee – not me, I didn't have a vote – made a decision that they were going to proceed with it, and then all hell broke loose. Just a disaster in terms of the reaction. Chris Rowe almost had a breakdown – not that it was his fault. Any kind of suggestion of normalisation – and this had been in the context of the two boys kissing ad on the trams in Melbourne. We were inspired by that.

ATTRACTED TO OTHER GUYS?



YOU'RE NOT ALONE ...

A lot of guys do it with other guys. It's been happening for ages and always will. It's OK, and if you practise safe sex you'll save yourself a lot of worries.

For more information on safe sex and support groups for young men who have sex with men, or just for a chat, phone Mark on 52 4755. Don't worry - it's totally confidential, so nobody else need ever know you've called.

AIDS FOUNCIL OF CENTRAL AUSTRALIA

"Caring for our Community"

I took the photograph for the advert, "not alone, lots of guys have sex with other guys". We had two straight guys that we hired for something like \$10 an hour each. They looked all right, they were from the youth hostel. We said, "Do you want to be in an ad but the implication will be that you're

ACOCA Advertisement, 1992 (image courtesy ALGA)

gay." They said, "We're leaving town tomorrow", and so, "Great. Why don't you take your shirt off", and they said, "No problem." So we went and photographed them sitting on a tree stump or something, not even looking in to each other's eyes or anything. Just a couple of guys together, attracted to other guys. You're Not Alone.

It was on a visit later I got the gossip, and people told me that money was being redirected to paying rent. So that somebody had voted themselves rental subsidy and was doing two roles – something like doing executive officer and gay men's outreach – and so drew both salaries. Then there's something about a fire. After that I heard that Northern Territory Health swept in, emptied all the filing cabinets, and put everything into archive boxes and whisked it away.

Everything that ACOCA had – went. Apparently it was taken by NT Health. I tried to get the records of ACOCA when I did the history project. I wrote repeatedly to Northern Territory Health because I got told they came when the fraud was discovered. I think they went in to lock down, "We need to bury this as deeply as we can and we don't want any publicity over this." So God knows where those archive boxes went in NT Health, but they won't let you have them. That would have been the financials and everything; they just buried it. So all those documents, unfortunately – and there would have been vast amounts and the original photographs and everything – would have been there.

Oh, it was a fun ride! In the early days we did some fabulous stuff. We would have prevented a whole lot of people from getting sick. The whole thing could have been much worse than it was.

We did some fabulous things like the AIDS conference that we held. It was enormous, and it was nationally significant. People came from all over the country because there was such a thirst. We had people who came in from Broome, Port Hedland, Perth, Adelaide, Sydney. They came from all over the shop to be with us. We had what was probably the only ever unfurling of the AIDS quilt in central Australia, and we added three panels to it at the time.

Initially there was a bit of suspicion and we didn't get direct Aboriginal involvement. On the day though, people turned up in their droves. A lot of Aboriginal gay men and sister girls turned up to the event, and then we had the good matrons of Alice Springs, I won't name any names – Aboriginal women – getting up and going, "It's a dirty, filthy homosexual, drug user practice", and, "It's those dirty white fellas and all the filthy things that they do, non-Christians that they are, who are spreading this disease." These Aboriginal gay guys with tears streaming down their faces, got up and spoke out in a large public auditorium at these senior women. They said, "No, it's not true. We're here and we're not some kind of aberration."

Malcolm Cole was there, Ronnie White was there. It was as much people from out of town. Heaps of people, yeah. I can't remember them all. So we said, "What do you want us to do? How can we facilitate?" They said, "Give us meeting space, and let us do our own thing", so we said, "Here's another room now designated as Aboriginal space. Do your own thing. Work it out." What they did out of that was recognise that they needed to organise an event for themselves. That was the beginning of the Anwernehekene conferences – which still run today. ♦



Sim Lee

NORTHERN TERRITORY AIDS COUNCIL

1985-1988

This is an excerpt of an oral history interview conducted by the Australian Lesbian and Gay Archives. The interviewers are Graham Carbery and Gary Jaynes. The interview was conducted on Tuesday 25th of March 2014 at Mont Albert, Melbourne.

GJ: When I read your chapter in the book *Being Different* (edited by Garry Wotherspoon), not having ever been to Darwin, the situation you described particularly around 1984 reminded me a little of Melbourne in its early days of Gay Liberation, with fairly distinct splits among people who wanted visibility versus those who didn't, and I wondered if you saw the onset of AIDS as being really the trigger for the arrival of those ideas, those Gay Liberation ideas in Darwin, or were they there but just perhaps in a less manifest form before AIDS?

SL: Difficult to say, I would tend to the former, that it did catalyse things, you know, because it pushed me out of the closet, you know, like I'd been so long going along, going to the Boomer things, going to the Darwin Gay Society functions, and even being part of the organisation but not saying anything and not saying anything at work and not saying anything to my parents. And then when the AIDS crisis broke and then I became president of the AIDS Council I thought, you know, this can't go on, so something has to happen, so

it pushed me at a personal level certainly, and I suppose it would have been the case for many other people.

GC: Before the AIDS period arrived were you aware of any issues that impinged on gays that prompted people to say, write letters to the newspaper or do anything that could be classified as a form of activism?

SL: Absolutely not. No concept of activism at all.

GJ: ...My reading of your notes, or was it the diaries, is that a lot happened in a very short space of time from that initial conflict to the holding of a public meeting which did gain that resolution [as to who was a legitimate spokesperson]. That seemed to happen in quite a short space of time.

SL: Yes, I think it was from August of 1984 to January of 1985, a very short space of time, yes, and I mean, to be fair to the conservatives, one of the things I did put up as something I wanted to say is that, ok, in

the initial meeting that John called there were very few people, like eight or ten or twelve people turned up.

GC: Which John?

SL: John (Norman) Turner. He actually called the meeting in August,

GC: Of '84?

SL: a public meeting of '84, and because he was tired of, actually this is documented in *Did you meet any Malagas?*, he'd been running the Gay Society for a year or so and he was tired of it and he felt that other people needed to do it. So he called a public meeting, it was published, the call, and he said, "you know, who wants to take over these thingos and we need to give the Society more structure, and also by the way we need to address this thing about the Northern Territory Department of Health wanting a representative." So, eight of us, twelve of us came, you know, personal friends of John and John [John (Norman) Turner and John Goodall], people who had been working in it anyway and so Doug and John were formally appointed as the representatives for us on the Northern Territory Department of Health Committee.

GC: John (Norman) Turner?

SL: John (Norman) Turner and Doug Raethel, but I think the most important thing out of that meeting is that nobody understood the importance — — I certainly

didn't understand the importance of this, this was just like item number fourteen A or something like that, just tick it off, ok, it's done. So, later when John and Doug started speaking to the press and [things] were being said, then the conservatives said, who are these people, who is this spokesman, who appointed him, and nobody appointed him. But it was totally unfair in terms of the formality of it, but in terms of reality in a way they did have a point, you know, they didn't know that this was going to blow up, they didn't know that that meeting was the one that was going to be the formal appointing of these people so they didn't show up, so they did have a point feeling unconsulted.

GC: But even if they had known, the importance of that, given their conservatism they're unlikely to have been willing to participate in it because of the risk of publicity. Is that fair to say?

SL: Definitely. Definitely, they wouldn't have realised it themselves, so I think in the end if we consult Doug's diary¹ it has a really blow-by-blow account of the second meeting which was public and was meant to meet their objections: – so, ok, you want a public meeting we have a public meeting now, and there they made up this little sub-committee of DGS [Darwin Gay Society] which would be the AIDS vetting/media sub-committee or something like that, and it had this incredible structure with four or five people in it and X had to ring Y before they

made any statement, etc, etc. And you know, it was just completely unworkable, but it was their response trying to make sure that nothing wild – what they saw as wild – happened.

GJ: A new president emerged at that time I think?

SL: Yes that's correct.

GJ: Who was, what, more of a bridge to the conservatively-minded people?

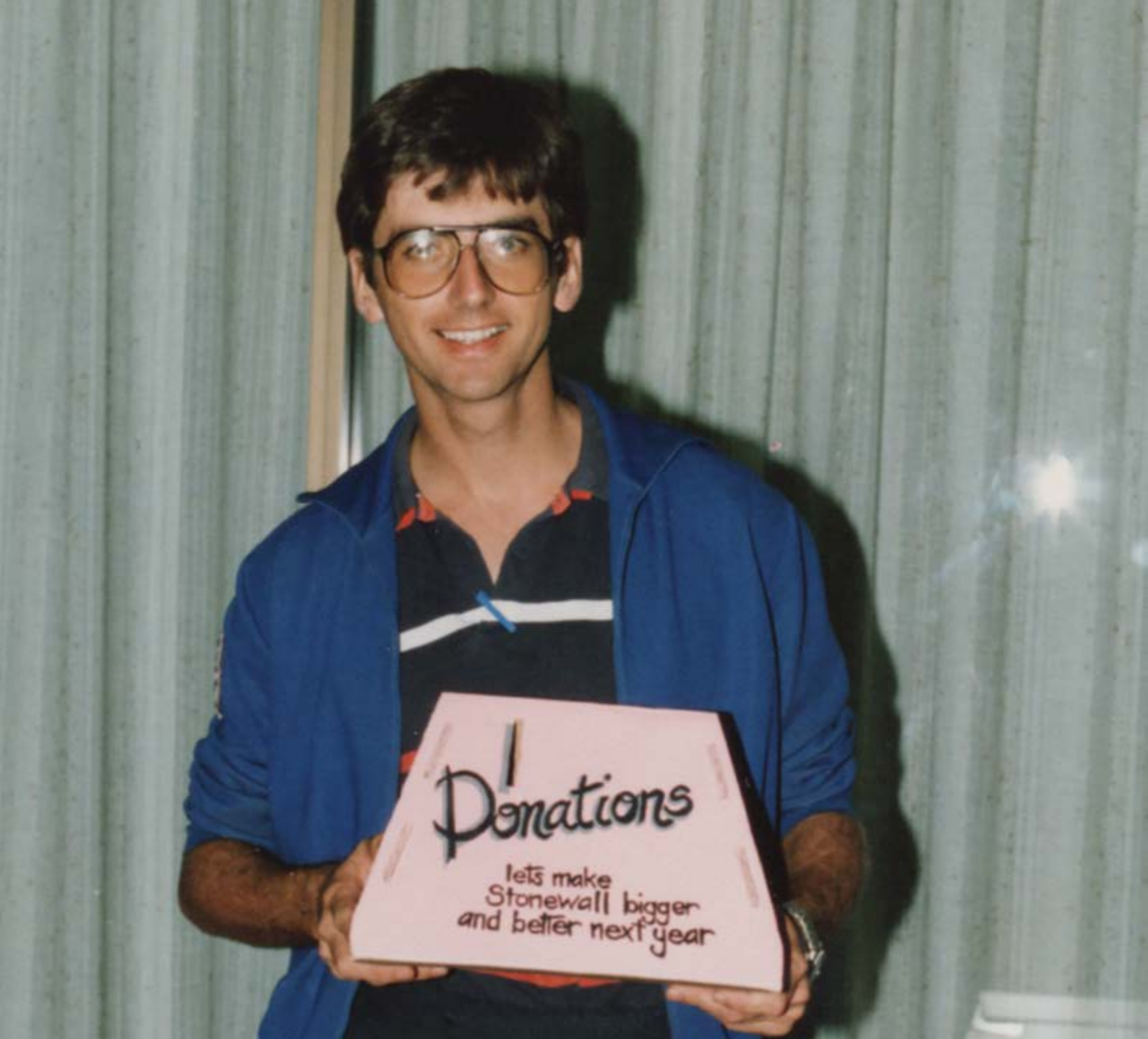
SL: Yes, John M, he was definitely of the conservative bent but not the rabid sort of shut them up, stop these rat bag radicals, you know, he wouldn't have used words like in Doug's diary, red banners on the streets, Marxist banners on the streets, because that was their perception of us, you know, in the old days this Marxist distinction. John even came onto the Stonewall Collective, the Stonewall Collective was actually made up of eight people, six of us were the standard left-wing, liberal sort of people, progressive people, and John and his partner, Kevin, were more like the staid, middle-class, slightly conservative people. I welcomed them, but it's only in the last ten years that Dino Hodge revealed to me that they actually came on the collective to monitor us. I'm a completely naive person, you know, I don't know anything about people's ulterior motives. I never see ulterior motives in people and I just bumble through life, so when they came on I thought "oh, cool, you know, come join us", and I don't remember that they actually did very much, I mean they offered, they were good enough to bill the DGS event as a Stonewall event, so that was nice, but I don't think they [did] all

Stonewall Collective: Back: John (Norman) Turner, Brad Weis, John Malone, Dino Hodge, Kevin (John Malone's partner)
Front: Sim Lee, John Goodall, Ian Lauchlan



the ground work of doing hard slog to get a festival going, I don't think they did any of that. But yeah, Dino actually said that there was a confrontation between him and John where John said "we don't want any of this to happen, we don't want any of this rat bag radical stuff to happen in Darwin", and Dino said to him "well, try and stop me, I'm just a free agent and I'm going to organize whatever festival I want to." And yet by the time they came on to the Stonewall Collective they were just perfectly nice to everybody else – and Dino hid that all from me for twenty years. ♦

¹ Diary kept by Doug Raethel covering the period late 1984 to early 1985, kept by Doug at Sim's suggestion. Doug Raethel died from complications of AIDS in the late 1980s or early 1990s. The diary is in Sim's possession. Sim has prepared annotations 'to provide additional background information which might not be known to others not directly involved to provide additional background information which might not be known to others not directly involved in the events described.'



Terry McClafferty

NORTHERN TERRITORY AIDS COUNCIL / NORTHERN TERRITORY AIDS & HEPATITIS COUNCIL
1985-2014

Terry McClafferty, Stonewall Film Night, Darwin Community College - June 26, 1985 (photo courtesy Dino Hodge)

The majority of gay people wanted to be phantoms, and what I mean by that is the idea of being identified, as a gay person was poisonous, and dangerous. "You're a fucking poofter" ... The public officer at that stage was John (Norman) Turner. His name went on the advertisement in the NT News on Melbourne Cup Day in 1985. You had to give notice to incorporate, and you have to wait for objections. So the strategy was to fly under the radar. It was his brilliant idea – if we place the advertisement on Melbourne Cup Day, that day, the newspapers are all torn up because it's got the sweep picks, and everybody will either be tearing the newspaper up for sweeps or later drunk from the Cup Lunches. They won't be looking at the others parts of the newspaper and the public notices will be lost on the office floor. That was the whole tactic.

My name is Terence (Terry) McClafferty. I first arrived here in Darwin in January 1976, from Sydney, and I was appointed as a science teacher at Darwin High School by the Commonwealth Teaching Service.

I've always worked in radical gay politics since my youth. I was involved in a gay group at the University of New South Wales in 1971, Campus Camp, and I can still remember meeting Dennis Altman at a meeting, just after he returned from the United States and published his book, *Homosexual: Oppression and Liberation*. Dennis came to talk to the University of Sydney's Campus Camp. University of Sydney had the first gay student group in

Australia, and UNSW were the second. In those days it was just a group away of people who could identify being "camp" – because the word "gay" didn't exist – and meet in safe space where they could feel comfortable.

During the 1980s period I was living at Quandong Crescent, Nightcliff. Two other gay guys who owned the home formed the Boomer Motor Club. It was really just a group of guys who'd say, "Let's go camping. We'll go to Edith Falls for the weekend and we'll have a campsite", and the rest of it. It wasn't a whole group of debauchery or anything like that, it was just a group of gay guys who would go away together, and sit, think and drink

a few beers around a fire and chill out, and maybe take in swimming in a waterhole. So they felt comfortable amongst themselves, and that's really that side of the Boomer Motor Club.

Dix [nightclub] was occurring - John Spellman had that venue up on the Stuart Highway in Stuart Park. At that stage, it operated as a restaurant/steakhouse, and by about 11:00pm it turned in to a nightclub with a disco. On Monday nights, Spellman opened it for hospitality trade night, and the majority of the patrons were gay guys and many worked in the hospitality industry. Monday night was the gay bar night and Dix was where gay people met and many knew each other from socialising there. It was the main venue for the DGS - the Darwin Gay Society.

It was in that period of the bar nights on Monday nights that the ground swell started happening. There was more chatter about the "gay plague". I did not know people who were suffering from the "gay plague", but John (Norman) Turner did. He was an older gay man of the group and had more contact with people in Sydney who were aware what



was occurring. We only had a small group and we had John Turner who was literally shaking the can, "Hey, there's something going on here, and we've going to have this problem". We found out through John that many gay men in Sydney and Melbourne were very ill, and he knew that gay guys in Sydney and Melbourne had formed organisations to support people who were sick and were quite ill.

At the same time, the medical board up here had vision. There was an epidemiologist who was aware of the disease spread in Sydney and Melbourne, and was concerned that at some stage there was a chance of the disease getting out of hand in Darwin. John Norman knew a lot about men's health, and was a very intelligent man, and through the NT Dept. of Health (NTDH) was co-opted into a health group to oversee gay men. The NTDH said to him, "Well, you're a gay man who seems to have his head screwed on, can you talk to the staff about it because we need to act and not be reactionary, but to have planning and strategy, because this disease may eventually end up here". So from what I knew, that's where the discussion happened. I have vivid memories of sitting on the floor at John Turner's home, drinking a cup of tea, and he was elaborating what's happening or what he's heard from his friends down south, or from his mates that had written to him about guys getting ill.

It was through John that I learnt that Melbourne had formed the Victorian AIDS Council (VAC) and Sydney had formed the AIDS Council of NSW (ACON) and that he was pushing for the establishment of a council in Darwin. "Terry, we have to get a group of people who are functional here to establish an AIDS council in Darwin similar to down south". He was told what was needed to be done,

Alan Davidson, Terry McClafferty, Gregory Thomas Harland - Stonewall 1985 Splash of Pink Evening

and that there was going to be federal government money for this. At that stage, as far as I knew, we didn't have anybody ill here in the Northern Territory. So John started the paperwork for the incorporation of the Northern Territory AIDS Council.

The VAC and ACON were not able to directly advise the federal minister for health (Hon Neil Blewett) because as state bodies they advise the state minister. As a consequence, VAC and ACON initiated the forming of a federated body, the Australian Federation of AIDS Organisations (AFAO) to represent the state and territory AIDS Councils to the Federal minister. Warren Talbot was the first executive officer and he put the call out for AIDS council to be formed in every state and territory.

We put together a committee to establish NTAC, and one of John's arguments was that unless we as a group of gay men take this action, the funding for AIDS councils will be given to benevolent Christian groups, for example the Salvation Army or the St Vincent de Paul Society. These groups will establish their own AIDS Council and it will not include gay people on its management. So there was an urgency to establish NTAC before these "do gooders" get control. At the same time in Queensland, the Premier, Joh Bjelke-Petersen was in control and was not giving money to dirty poofers! So, the Queensland Health Department gave the Commonwealth money to a group of Roman Catholic nuns, and the nuns passed the funds to the gay men operating the Queensland AIDS Council (QAC). I don't know the whole arrangements there, but one of the groups there passed the money, so they could run a committee and outreach to the people who were ill. Though it's still very much driven

from a benevolent Catholic organisation or church group, the prejudice caused them to believe that they're the right sorts of people to look after these situations, and this was their thinking at the time. So, a pressure or expediency existed to establish NTAC.

I can still remember another meeting, and I think Simon Nish was there too, and it was at the home of a female infectious disease doctor. Here home was at East Point Road in one of the townhouses there looking out to sea. I don't remember much about it, but part of the discussion that evening was we had to get a group of gay men together. The outcome of that evening was to establish NTAC and that there was an urgency to take action before any benevolent organisation seized the opportunity.

The majority of gay people wanted to be phantoms, and what I mean by that is the idea of being identified as a gay person was poisonous, and dangerous, especially to one's employment. "You're a fucking poofert" - and I had my "self-oppression" belted out of me from my period in Canberra (1978 -79) through ACT Gay Solidarity. This group delivered consciousness-raising programs to gay men as a way to improve and validate their self-identity. Not that I knew that the current state of affairs would change, but through this group I learnt that I had human rights and that I was a respectable and functioning member of society. When I taught at Darwin High School, I held a Commonwealth appointment, and the Commonwealth during the Whitlam era were the first to end discrimination of sexuality in employment. So I did not fear being identified as a gay person at school. And one of the issues I quickly learnt was "it's not who you are, it's what you do which counts".

I got involved, and I think I got elected at the first meeting as the public officer, because I put my name to paper. However, when you actually formulate to go for incorporation, somebody has to be on that unelected loose group, and the public officer at that stage was John Turner. His name went on that advert in the NT News on Melbourne Cup Day in 1985. You had to give notice to incorporate, and you have to wait for complaints. So the whole idea was to fly under the radar. It was his brilliant idea – if we put it on Melbourne Cup Day, that day, the newspapers are all torn up because it's got the sweep picks, and everybody will either be drunk or tearing the newspaper up. They won't be looking at the others parts of the newspaper. That was the whole tactic.

Once NTAC had incorporated, funds were granted for operations. In these early days, Warren Talbot (AFAO) visited Darwin, and he was happy that NTAC had been established and incorporated. Warren's approach was that NTAC was as a business, and he had a real business mind for that work, and I'd never thought like that. He said that you have money, you spend it – and I can still remember we bought a computer, and a printer, and then secured an office space, which was upstairs in the Burns Philp Building, corner of Smith and Knuckey Streets. And I remember a girl was here in town for some reason, and she had previously had worked with ACON [AIDS Council of NSW], and she always used this word, which I never heard before at school, because I'd never worked in an organisation that run public programs. And she kept on saying to start a number of "initiatives", so you had to then apply for funding so we could actually deliver activities. So apart from

having an office, we had an employee and the council could begin its task.

Warren Talbot also said, "You have to find a prominent community person to be your patron", and this is where Sally Thomas comes into the NTAC story. The committee members knew few prominent community persons' and I suggested Sally because her son, Nick, was in my pastoral care group at Darwin High School, and I had met her a few times at parent evenings. Sally Thomas at that time was a magistrate and it was agreed that she would make an excellent patron.

I had to first speak to her personal assistant and request a time that I could call and speak with her. I was later able to call her and arrange to meet in her chambers. So I went up to see her, and said, "Look, I'm involved with a group of people setting up the Northern Territory AIDS Council, and you may be aware of this disease which is currently amongst mostly gay men. But it's around the place, and it may turn up here in Darwin. We need a patron, and I thought you'd be a good person for the job." I pointed out to her that AIDS is currently occurring within gay men, drug users and prostitutes, clearly, the downtrodden of current society. I can remember saying to her, "You'll probably have to speak to others, to see whether this is appropriate for a magistrate." And she said, "That's fine, Terry. I'll find out. I'll give you a call back later." I can still remember getting a message at school, and returning to her chambers. Sally advised that she was very pleased to be the patron of NTAC. ♦



First NTAC Office, Burns Philp Building, Knuckey St, Darwin 1986



Hon Sally Thomas AC

PATRON

1988–CURRENT

I remember meeting a number of parents or relatives, and it was so terribly sad for them as well but at least they had the comfort of knowing their son or their brother was somewhere he could get some care. I was just so surprised that in a relatively small community we had so many people who were prepared to be carers and, of course, as we all know, that could be a very full time job.

Trevor Miller, Anthony Smith, Sally Thomas, Jenny Norris, 1987 (photographer unknown)

My name is Sally Thomas and I have the honour of being the patron of the NT AIDS and Hepatitis Council. I've been patron since 1988. Originally, of course, it was the NT AIDS Council, and then later on changed to include hepatitis and became the AIDS and Hepatitis Council.

I had the opportunity to attend many events, including annual events that are still going. There will also be a welcome or a farewell to a particular staff member, or the committee would just decide we'll get together and have a drink and they would talk about what was happening, and explain what the developments were and how it was all progressing.

Terry McClafferty actually came round to the house where I was living. I did know Terry, although I wasn't really aware of his involvement with the AIDS Council. At that time, I was Chief Magistrate in the Northern Territory and he asked if I'd be prepared to become a patron. He explained what the AIDS Council was, their aims, and what they were achieving and why they'd been established, and I felt that it sounded an extremely worthwhile organisation. So I was very happy to accept the offer.

I noticed that sometimes if I'd mention to colleagues that I was going to have drinks or cocktails after work, everyone would say to me, "Well make sure you don't eat and drink anything or you'll get AIDS," and I'd say, "That's not how AIDS is transmitted. It's not a problem," but at that time no-one really believed that. They said, "Oh yeah, I bet it is. You just be very careful." I think a lot of people wondered why on earth I would be involved in the AIDS Council because there really was something of an attitude that, "Well, those people deserve to get it". Not in all quarters, of course. There were a lot of people who were sympathetic to the situation, but it is just amazing when you suddenly find somebody who talks in that way. "Oh well, they deserve it so what are you trying to do?" and really having no idea about it or how it had arisen or how you transmitted it.

I remember once the AIDS Council had a function in the mall. There were some journalists there and there was a particular journalist who came over to me – and there'd been a talk about the importance of using condoms – and I think they may have thought that I would be embarrassed

to say that. I mean, I don't feel embarrassed about that at all. So they asked me, knowing full well what the answer was, and I said, "Yes, it's very important to use a condom." I thought you're only asking me this because you think it's going to be embarrassing or sensational – but it was just the information that was being disseminated. But they thought, "Oh well, she won't answer this because it'll be too embarrassing", and I thought, "Well, that's the message that's coming out, and it's very important for people to know and understand that."

There is an enormous difference now because there are drugs that will prolong life. At that time, when the AIDS Council was first established, there was no known cure at all or anything that could even prolong life in any way, and it was a horrible illness. I remember meeting quite a few fairly young men who had come into Darwin. They'd lived elsewhere and I was absolutely stunned because, for some of them, their families didn't want to know them and they had come here because it was known that there would be people here who were carers, and that there was a community here that would welcome them and be able to provide care.

I also remember meeting a number of parents or relatives, and it was so terribly sad for them as well but at least they had the comfort of knowing their son or their brother was somewhere he could get some care. I was just so surprised that, in a relatively small community, we had so many people who were prepared to be carers and, of course, as we all know, that could be a very full time job.

I was such an admirer of Bill McMahon because he was very much involved in coordinating and being involved in

that caring. I used to think then, well it's all very well for me to be patron but the real people are these people who actually will take in someone with HIV and will care for them right through to the end of their life – and the end of their life was a very horrible experience. It was certainly very, very sad, particularly when you think that families would reject somebody – a son or a brother – you couldn't believe that they could really do that.

At that time it was more young men but, of course, that changed over time. It was predominantly young men but also a relative of theirs would come here – because the young men had chosen to come here for all the reasons that I've just outlined – and maybe they had a family that really just couldn't cope with it, but they still had a bond.

And then, of course, there were people over periods of time who were HIV-positive, it affected their job or they lost their job and so it was understandable nobody would ever want to say if they were HIV-positive. I don't blame anyone. I mean, people don't necessarily want to go round advertising or talking about their illnesses, whatever it might be. It can be something you don't want to be discussing but there were, certainly in those earlier times, ones I met that had lost their employment or knew that, if ever they disclosed it, it would mean the loss of job.

I've had dealings with all of the presidents over many years and I think they've all been remarkable people. Many of them have been very active in the health area and, of course, Bill Paterson, our immediate past president, was a nurse working in intensive care at Darwin Hospital.

Lots of women have also been involved with the committee and, of course, many of the women were actually doing the

caring but they've also taken a committee role and been very active and very supportive of the committee and involved voluntarily.

I think certainly some years ago and in earlier years, there were some very strong feelings really about how a number of the issues that affected those living with AIDS, and that was a whole issue in itself was that you should never say 'dying of AIDS', it should be 'living with AIDS'. That became a big issue and then, of course, yes, it was 'living with HIV', but all of those were issues of the time.

During the thirty years there have been times when the organisation experienced turmoil, and opinions were very divided. From time to time there might be an individual who would come to me and perhaps they were feeling a bit angry about something or wanting to put their point of view across. I would always treat that as completely confidential.

I can understand people have very strong feelings and they do need to let it off. I was made well aware that there were a couple of AGMs where some very passionate feelings would be coming out, and had suggested that it would be probably better that a patron didn't go to the AGM. I think probably as a general rule it's not always a good idea for a patron to go the AGM.

Over the years, there've been some absolutely beautiful functions that the AIDS Council have organised. There were some really lovely functions that we've had down at Lake Alexander, and putting the candles on to the lake. Usually there would be a speaker and, of course, perhaps a drink or something afterwards. It went from being such a few people who came to any of these events and then suddenly there was a lot of people, and then there were a lot of politicians.

One of the other candlelight ceremonies I remember was when it was in this phase of lots of people were coming. They had a ceremony out at East Point and the idea was we all had big baskets of Bougainvillea flowers – and we were to throw the Bougainvillea flowers over the cliff into the sea, which would have been a lovely thing to have occurred. But just at the crucial moment, quite a strong sea breeze came in and all these Bougainvillea flowers got blown back on to all of us waiting on the cliff edge. [laughs]

And then in more recent years the AIDS and Hepatitis Council have put on events where there have been interesting films presented. People are still wanting to commemorate ... but so many tears were shed for so much time that it's better to do it in a way that you can become a little bit more informed and enlightened, and still feel a sense of community.

Of course, in the earlier times there would always be individual people who had died in that year that people specifically wanted to remember, and it was very emotional for them because often they would be very close to the person who died. That aspect is different now because that's not happening in the same way.

I guess I never really expected, when I first agreed to being patron, that it would be such a rewarding experience. I'm a person who didn't work in the health area but it meant that I met a lot of people working in that area, and also met a lot of people who were really just so amazing in what they were prepared to volunteer to do. Not just the carers but those who were volunteering for committee positions and giving a lot of their time in a very dedicated way. It's very rewarding to see what human beings will do. You know how wonderful human beings can be. ♦



Jim Buckell

CENTRAL AUSTRALIAN AIDS ACTION GROUP / AIDS COUNCIL OF CENTRAL AUSTRALIA
1984-1992

There weren't conversations about this stuff – there was no language for it, there was no public health sentiment or culture around those issues. So we started to not so much agitate as have conversations.

My name is Jim Buckell and I was involved in the Central Australia AIDS Action Group back in the mid-to-late 1980s, when I was working in Alice Springs as a journalist. Also I was involved socially in the gay network which we called Central Network.

I had been working on and off for the Central Australian Aboriginal Media Association. I went to Alice Springs to set up the news service on the radio station that became CAAMA, 8KIN FM. We also had a big initiative in the Aboriginal organisations in those days on the anti-alcohol and violence movement that was in its very early stages.

Through that involvement, I began working with some of the big public health figures in Central Australia. At the same time we were doing *Beat the Grog*, *Rock without Grog* – CAAMA's grog promotions – all this stuff which was groundbreaking. No-one had done this stuff as far we were aware anywhere in the world, certainly not in Australia before. We were starting to get a little bit of a reputation as a 'go to' crew at CAAMA, at Congress, at Tangentyere – at the Aboriginal organisations for public health initiatives.

At this time as gay men we were reading in the press and in the media about AIDS. I don't even think we knew it as AIDS in those days, I'm talking '83/84. Then this percolated through, especially Congress (the Aboriginal Medical Organisation), CAAMA with its work in grog, and the public health team at Northern Territory Health Department. It started to percolate through: "hey we think we have a bigger threat than alcohol to Aboriginal health here in Central Australia. If this pans out the way that we're starting to hear that it has done in other vulnerable communities – and we're talking injecting drug users, gay men, Indigenous people that said red flags all over it – big issues here if we don't get on top of it."

So we started to read and we started connecting up with organisations interstate. At that stage I think the Australian Federation of AIDS Organisations had just started or was in its early days, and there were some connections through that. And we started to say: well, we've got an issue here in Central Australia. I remember the thinking on our part was "hey listen, you know we live in a tourism community that we know that there are a

Jim Buckell (Photo by David Haigh)

whole lot of public health issues and risks factors here already where there's something called nesting season: every winter we get 250,000 visitors to Central Australia from all over the world and in that period there's a lot of sexual activity" – we presumed on the basis of our own experiences most of it unprotected. Then you throw into that mix vulnerable Aboriginal people, and huge numbers of STIs largely never talked about. The only people that know this are those who work in the clinics in remote communities and those who are involved in infectious diseases and sexual health in the NT Health Department, Congress, the Aboriginal medical services.

There weren't any conversations about this stuff – there was no language for it, there was no public health sentiment or culture around those issues. So we started to not so much agitate as have conversations. At the same time John Hobson and his partner Paul Smith were involved in helping to set up Central Network.

So we've got three things happening at once here. We've got an awareness in terms of public health risk in Indigenous communities in Central Australia in general; we've got the coalescing socially and politically of the gay and lesbian network and movement in Central Australia; and we've got the spectre of AIDS/HIV. So you put those three things together and naturally those of us who are socially/community/politically minded start to go: "wow, okay let's get organised".

So in our own clumsy way that's what we did. We actually got all those things happening. I don't claim that we did it alone; far from it, we did it in a loosely formed, very broad coalition with the key players in public health in the Northern Territory Health Department, that was then part

of the offices around the hospital. We did it through the Aboriginal organisations, particularly Congress, CAAMA and Tangentyere, which is the housing association. And we did it through the gay men's network, which was just starting to get off the ground. And those three forces loosely came together and backed us when we said we want more than just a little voice: we want to have an office, we want to have some outreach, we want to have access to professional health workers. We've got a whole lot of factors here that are unique to Central Australia and they need to be addressed and they can't be addressed from Darwin. Cost factors, the geographical differences, the cultural differences, all sorts of things, meant that we felt that we needed our own special place in the umbrella of what was going on.

It just happened because we were there; public health needed us and we needed them and, without having said that, we both intrinsically understood that. So I think they were impressed. I genuinely think we were impressed by them and they were impressed by us. I would say there was mutual respect, understanding that we're all in this together, and that we're going to do a much better job united than we are fighting our own battles and fighting for our own patches, which is what you had to do anyway. But if we can add voice to each other's work we'll get respect, and because the situation here in Central Australia is unique they're going to have to address it in a unique way.

I think there were three key things that happened. The first was that we got organised so we lobbied for funds. We got ourselves together a committee of management, and we set up an organisation under some formal terms of reference. We lobbied for funds, we had a meeting with the then health minister Daryl Manzie.

The CLP was in government at the time. It's probably worth saying these were not exactly our political friends. We were all from a Labor or further left background – that was just who you were in those days when you were active in the community and active in Aboriginal organisations. So we had to go into the lion's den and argue our case. We got a really good hearing from those people and we were surprised because we thought: "Oh well, they'll just see us as a bunch of pinko poofters and they'll sideline us", but they didn't. They understood because I think the lobbying and the effort that had gone on through Neal Blewett, the federal minister for health, and his key players in Australia at that time that had filtered down to state and territory government, and then state governments started to look at the risk factors and see that they had some major public health issues. And if they were going to get a bunch of gay men and their friends and lesbians in Central Australia doing community outreach work, then they were happy to back us, as it didn't cost them much and it was a very cheap way for them to do that. And they recognised that they needed strong advocates on the ground.

Basically we didn't ask for much because we were so modest and humble and so used to working for nothing that we just asked for the minimum that we thought they'd ever give us and they gave it to us. But the other thing that happened is when these conversations started to become a little more sophisticated and we'd set up the AIDS Council, then we got some key people involved in our board of management; one of whom was Kerry Leitch. The reason Kerry was so important is that she was employed as a sexual health educator-counsellor within NT Health,

which was something that none of us had ever heard of; we'd been to a few friendly GPs and that was it.

I became the first co-ordinator of the AIDS Council. So Kerry, I think, had already got herself on to the board of management. There were other people like Sarina Ruediger who was a key player as head of the AIDS/HIV response team in Central Australia. Alexa Young, who was also a nurse educator, was very significant. So these people came on the board of management and they added professional nous, but Kerry was especially special because community was her background. I think I'm right in saying that the community health role that she was playing at the time was the first time that she'd actually been employed in the public sector; she'd been a financial counsellor, she'd been an AIDS counsellor or an AIDS educator in Canberra. So she was the link for us between someone who we could work with and talk as we do as gay men about our stuff without her flinching or blinking. Plus she had the links into the professional services and the models that you use to get things done in the public service. She was a key person in coalescing us as an effective group and providing that board of management guidance as to how we would operate and how we would govern ourselves.

We acted from our guts and our hearts and our mouths, and we sort of put it together. And we set up a little counselling room in the AIDS Council office and painted it light blue because the counsellors told us you need a calming colour. At that stage no one was doing the outreach. They were doing testing but we couldn't be sure that if someone, a gay man or other, got tested in Central Australia, that then they were going to get any counselling in those days, certainly before the AIDS Council was set up.

So all those things were really critically important, and we were doing work that no-one else was doing. We were doing the outreach through our social networks, and we set up the needle exchange with Tony Hand to run it. I think it was one day a week he came on board. And that kick-started Tony's career; from when I knew him, he was a roustabout and a wool classer and a camp cook, and now he's one of the best trainers in the Northern Territory and he goes all over the Territory training Aboriginal and community people into how to do community health and welfare.

So it was a critical time for all of those groups, and how to work together successfully to create services.

We did community education. Alexa would go out and talk – we employed her as a community educator – to community groups. We were working with people like Relationships Australia who were then called the Marriage Guidance Council. We didn't care where people came from – all we cared was that they were going to listen to us, and that they would provide us with access to resources, with some professional advice when we needed it, and perhaps just give us some ideas on how we were going to go about doing this stuff. So we worked with community health and all their various bodies, the nurses, the doctors. A physician called Mohamed Patel was the head honcho of public health in Central Australia. And he would come to some of our committee meetings or we would set up meetings with him and say: "How do we crack this one?" and they would give us really good advice. So, for me, that was one of the key things that we did: we worked out how to be effective in public health in a new area by getting the resources and the people together from whatever was available to us in Alice Springs.

So we got the budget together to set up the office, we put the office together, and we employed staff. Most of us were part-time; I think I might have been full-time or I might have been four days a week.

So from '85 to '88 was more the activist group, the Central Australian AIDS Action Group. We didn't have an AIDS Council, and we didn't have an office, and we didn't have staff. Then, during that period that I'm away, somehow that coalesced into the first mini office and Megan handled that. The Marriage Guidance Council gave us an office before that, access to an office for one or two days a week and I remember working from there when we were setting things up.

And then David Ben David came on board. He was this intense, passionate but lovely Jewish/Australian man who was a sexual health educator. He and I somehow we fetched up on top of the chemist shop and that lasted maybe three to six months, and it was really stinking hot and we had the steep stairs and it wasn't particularly good but at least it was central.

So that's when we found the office down Gap Road opposite the Melanka Lodge. Gagliardi owned it and there was this big old creaking evaporative air-conditioner that you had to fill up with water. But it was great because it was opposite where the buses used to pull up at Melanka Lodge so everyone would see, AIDS Council, and they'd go: "oh." And these Swedish young women would come: "ah condoms" – this sort of stuff. So it was a really good place for us to be. This now became a serious effort, we had our own sign, we were the AIDS Council, we were then serious – we'd go to public, World AIDS Day we'd create events, we'd dress us in condom suits, we'd hand out condoms, we'd have games, we'd just do stuff.

Quilt panel of Eric Michael, author of the AIDS memoir *Unbecoming*.

Look, it was a closeted town: they didn't want to have to talk about AIDS, they didn't have to have to talk about sex and sexuality, they didn't want to admit that they might have been sucking dick if they were straight men. They weren't engaging with us at all, not in public. In private a few of them would have dropped in for condoms, needles, whatever. The public was engaging when we set something up that was fun, like I remember one of the pubs down the Gap where we had a World AIDS Day event. We were invited or we might have just forced ourselves onto the agenda and they were having some sort of event and we just said we need to be there or we need to run it or whatever. I think it was probably through Kerry and Sarena and Alexa in the Health Department. And we went down there and we spoke and we had fun things for people to do. We had a series of games. Probably Kerry and Sarina thought them up, and we just went along and did them and engaged people who were just drinking in the beer garden. So in that way they were engaged.

We had also started to become aware of members of our own community were HIV-positive. One of them was the US anthropologist Eric Michaels. David Batty and I had worked quite closely with Eric when he was employed at CAAMA during the mid-1980s, and then he went out to Yuendumu and was working with the community on developing Aboriginal video and media. That became Warlpiri Media which then became PAW, Pintubi, Anmatjere and Warlpiri Media. So Eric lobbed into town, quite big in terms of anthropology. A very sophisticated thinker, gay man, intellectual, anthropologist and we were like: "Wow, who is this guy", and became friendly with him. He went out to Yuendumu and did really good work and then became sick. He never talked to us, I think I might have been away in

Perth when he actually became sick and then he went to Brisbane. He was working at one of the universities there. And before long he became hospitalised. I remember we were having phone conversations and David and I said: "Okay, where do you want to die?" He was dying. We said, "Where do you want to die?" And he said, "I want to die in Central Australia." I'm going to tear up – so I said 'We're driving you back'. <crying> it's really sad. We were having this conversation with Eric and David and I said, "We'll try and – <crying> – he died before we had a chance to bring him back to Central Australia. He was first person that I knew really well who died. He was such a brave man. He wrote all about dying of AIDS in his book *Unbecoming*.



So yeah, and that's when I think the quilt came to town. We had vigils and we would name people that we knew. And I would always talk about Eric because he'd been such a key player in all of that stuff.

There were three big things for me about this time from 1988 on, transitioning from the AIDS Action Group to the AIDS Council and setting up a full-time office with full-time staff, even if I was the only one, and a few part-time staff,

was really significant. Having the presence and having the signage 'AIDS Council of Central Australia' in black and white across the top of a shop front in not the middle of town but just on the edge of town in a prominent position that lots of people drove past – to me, that was priceless. "We're here, we're queer, we're not going shopping" – we're serious about this and we're here to help. I think in terms of the development and the awareness that was a critical thing because we were the only AIDS Council outside of a capital city in the entire country. So that's number one.

Number two I think is bringing on professional people who got gayness and who didn't flinch about it, and who were perfectly happy about it, on to our board of management. So that allowed us to not just go to the key players in public health, but to have them come to us. That was a first and that never happened to my knowledge anywhere in Central Australia before or the Northern Territory and possibly in many other places at that time.

The third thing – the really big thing for me – was the Alligators.¹ So let's talk about the Alligators because that really casts things forward in a different way and with an international perspective. Somehow we got contacted: and we're going: "Why are you the Alligators? We don't have alligators here in the Northern Territory. We have crocodiles so how do you work that out?" So they were the Alligators because they'd looked on a map of the Northern Territory and they'd seen the East Alligator River in Arnhem Land and they wanted to go there and paddle their canoes up there, and we thought: "Oh good on you, yeah right. They just don't know".

¹ 'Expedition Alligator' was a group of HIV-positive people from the UK who travelled to the Northern Territory and engaged in workshops with the Territory's AIDS Councils; see Nicholas Bates, 'Northern Identity', Burn, August 1993, pp10-11.

They were on about: "People with HIV are everywhere. We can do everything that you can do. We want to go on an adventure and we want to incorporate public education as part of our adventure". So we saw it as fantastic, and another way for us to start linking in to the community. These were ordinary people: they were gay men, they were injecting drug users, they were people who had contracted HIV from blood transfusions, they were all sorts of people. They had on board an expeditionary adventurer guy who was a bit of a jock and a bit of a good looking, and we go: "Oh, okay!" And they had on board a nurse educator person who'd done counselling and education around HIV/AIDS. This sort of motley crew of everyone from a part-time academic at Oxford University, through to injecting drug users from some of the poorest communities in the UK, and everything in between.

We organised social activities, education opportunities and media. We would have cracked the mainstream in Alice Springs, probably just the ABC and the *Centralian Advocate*. We cracked the gay media because I wrote articles for them, and we wrote about them and their experiences. So that broadened our horizons and made it an international thing, and we had links suddenly with these groups in the UK. It gave us the confidence to do our outreach, I think, a little bit better – some more ideas and it was another kind of anchor for us in those days.

So they're the three things: getting organised and setting up, establishing a dedicated office, and the Alligators. Di Lane I think was the chair or the president or whatever we called it in those days.

Expedition Alligator in front of ACOCA Office, Gap Rd, Alice Springs (Photo © Therese Ritchie, 1992)



Having the perspective of someone who was a community worker in the Aboriginal community largely in those days but who was also a lesbian.

In those days, we talked a lot about coalition politics – I don't know if people still use that term – but that was important to us for that same reason: you work with

whatever resources you have and if you've got mates who are dykes, yeah great, bring them in.

I left in early '92 so that period – I came back in mid-1990 – it was probably eighteen months that I was the co-ordinator and then I resigned and went back to Sydney. I just needed to get out of Alice as I'd been there too long. ♦



Peter Knibbs

NORTHERN TERRITORY AIDS COUNCIL

1989–2014

When I first started there, the only drug we had was AZT and, as we all know now, the virus became resistant to that very quickly ... We're only a small town, but a lot did die and it wasn't until the protease inhibitors were available that people stopped developing AIDS defining illnesses.

Peter Knibbs (2nd from right, white T-shirt) May Day Parade, 1990 (photo courtesy Dino Hodge)

I am Peter Knibbs and I first got involved with the AIDS Council of the Northern Territory in 1989 or 1990. I knew Dino Hodge personally, and he asked me to come to an annual general meeting for the AIDS Council. And then I got coerced into going onto the board of management, just a board member, I didn't have any official position. And I remember being overwhelmed by acronyms initially with people talking about ACON and PWLA and all the other acronyms that went with the industry back then. So, I don't think I contributed much initially, it was just a very steep learning curve.

Terry McClafferty was on the board then and Anthony Smith who had died a year or two ago. Steve McGreevy, yeah. There's a woman, Lori Ford, and Gordon Cameron – he was new to the board as well – so we supported each other in our floundering to come to terms with it all.

I was working at the hospital as a nurse in the orthopaedic ward, and I'd actually looked after Mark Wilson who had been the president of the AIDS Council at some stage.

And I think him and Lori were travelling to Alice Springs on AIDS Council business and had a car accident and he had a quite nasty fractured pelvis, so he was in hospital for quite a while. And that was back in the days when all health care providers were petrified of anybody with HIV; myself included probably, because I didn't know any better. And poor Mark was nursed in a single room and we used barrier nursing or reverse barrier nursing, I can't remember which one. So, every time you went into the room you had to put on a gown, a mask and gloves, so of course people avoided going in if they could, because they couldn't be bothered dressing up. And his meals were always left outside, because the kitchen domestic staff were scared to take it in, and his meals were all one paper plates with plastic knives and forks so they could all be thrown away afterwards. So usually when he got his meals they'd be cold. It would have been '88, '89, yeah. He had a fairly open wound that had to be dressed every day, which was quite a complex thing to do as well, so in retrospect that was a real eye opener.

I think the only saving grace was Peter Morgan, the ex-Queen Mother of Darwin. Peter was pretty out there. His mother came up to live with him from Melbourne and she was in the orthopaedic ward as well, having a knee operation. This is at the same time that Mark was in there. One minute Peter would be down fussing over mother and adjusting her bed jacket and being the good son, then he's down with Mark gossiping about all the gays in Darwin. So, I think that was good for Mark to have Peter around to provide that bit of familiarity. Being in a room by yourself where nobody wants to go in, it gets pretty isolating.

It took a while to change. I mean, when I started working with – well it wasn't Clinic 34 then – the then AIDS/STD unit, one of my first jobs was to do education sessions for the hospital staff on HIV and what it meant, and that type of thing. Jill Gorman who was the charge nurse of the medical ward, was very progressive and she was instrumental in changing a lot of those barriers around looking after people with HIV. Eventually it got to the stage that you wouldn't know somebody was HIV by the way they were managed in hospital from any other patient.

When I started with the AIDS/STD unit, Sue Dubow had been there quite a while and she was the stalwart of the program. She'd worked with Shirley Hendy and Nan Miller, and was basically instrumental in setting up the education programs. At that time the main emphasis was on public awareness and education, and the clinic only ran two sessions a week from outpatients in the hospital. So we weren't seeing a big caseload of people with HIV or people with STIs and things, it was mainly an educational role. I think that changed a lot once Frank Bowden took

over as the head of the unit, because he was an infection disease physician and had worked at Fairfield Hospital in Melbourne during the early days of the HIV epidemic. He was very clinically focussed, and that evolved into the clinic actually moving down to Block Four where our unit was based so that we could eventually see STI patients any time of the week, and the HIV clinic expanded as well. We got another doctor on board and we would've been seeing HIV clients probably three or four clinics a week then.

I think I first started in 1991 and then I left, I ran a café for twelve months and that wasn't a huge success. I was lucky enough to get my job back in the AIDS/STD program and I stayed there until I retired in 2014.

I guess to put it in a different perspective, when I first started there, the only drug we had was AZT and, as we all know now, the virus became resistant to that very quickly. We had one fella who had AIDS and was dying, and we were trying to get a new drug DDI for him. We eventually got it and it was in powder form and it tasted horrible. This guy had pinned so much hope on this new drug being a miracle worker for him, but now we know it was in the same class as AZT, so the virus would've been resistant to it as soon as he started taking it, and he went on to die.

I mean we're only a small town, but a lot did die and it wasn't until the protease inhibitors were available that people stopped developing AIDS defining illnesses.

I was the principal HIV nurse for the clinic and being a relatively small clinic, patients were able to ring up or just pop in if they needed something. And like all medical establishments, it's very difficult to go straight to the doctors, so I was the intermediary between the client and

the doctor. And it was a time of great change, and before we had the protease inhibitors people were getting very sick and up here being in the tropics, we were seeing conditions that you wouldn't see down south.

I remember one particular fella – who Bill McMahon would remember – and he had a condition called *nocardia* which caused all these revolting ulcers all over his body. It's a soil bacteria, so it's contracted through contact with soil. I think he and his wife had just recently arrived in Darwin and had nowhere to stay, and Bill McMahon arranged for them to stay in a room at the AIDS Council in Knuckey Street when it was there. So you developed these very close and intense relationships with people and their families as you help them recover from these fairly devastating illnesses. But, again this particular fella went on and died because we just didn't have the drugs to treat him then and his virus became resistant to the drugs that we did have.

There was another condition *penicillium marneffe*, which we saw in a guy who originally came from Burma, and that's something that is contracted through contact with rats, usually in bamboo groves. So, whether this fella had had this bacteria just living dormant for quite a while, but again that's something that people down south just never see.

What's called the Kirby Centre now, used to be the National Centre for HIV Epidemiology and Clinical Research. They maintained databases on new cases of HIV and people who are diagnosed with AIDS defining illnesses. So we would notify these cases to them. I mean these infections weren't unknown, I mean it's not like we discovered them, but they were rare in

Australia. I think Frank Bowden probably would have presented some cases at national conferences and wrote some up in medical journals.

The introduction of the protease inhibitors certainly did give hope, and there was a lot of hype and talking about the end of HIV and AIDS with the protease inhibitors. But that was short lived because there was quite severe side effects with those drugs. They affected metabolism of fat in the body, so people were getting redistribution of body fat, they were getting big pot bellies and losing fat from their faces and their arms and their legs, and developing diabetes and other things. So the shine went off those drugs once we realised those side effects came with them.

The other thing about them was that there was a huge pill burden with them, so people could be taking six tablets three times a day, and some had to be taken with food or on empty stomachs, and that type of thing. Compliance with medications has always been important with HIV because the drug obviously develops resistance and some clients just weren't suitable for these new regimes because they had other factors, like drug and alcohol issues or social issues that just make it difficult to take these medications regularly.

The AIDS Council had support workers like Bill McMahon who was there during this time. He was very good in trying to find suitable housing for people if they were homeless. The drug companies used to give us little alarm reminders that the people could have to remind them when to take their tablets, and nifty little pill boxes that they could take out if they're going out for dinner, so they could take their tablets with them, and that type of thing. But the people

that were going to take them were going to take them regardless, and the people with all the issues were going to fail no matter what you did.

There was also the leftover mentality from when AZT came out, because when it was first used the doses were too high and some of the side effects were pretty atrocious, and I wouldn't be surprised if people actually died from taking AZT. So there was a bit of a conspiracy theory still going around that the drugs are worse than the disease and, even with a lot of overwhelming evidence that newer

drugs did work and prolonged life and stopped people getting AIDS, there were some people that were still clinging onto these old concepts and just refused to go onto medication.

A lot of the men who had HIV who were Indigenous, a lot of them were bisexual and urban Aboriginal people, so reasonably well educated and fairly compliant with medications and that type of thing. But with other people, I quickly learnt that I had to work with people where they're at. There was one particular Aboriginal



Left: Lori Ford (red shirt) and Steve McGreevy.
Right: Terry McClafferty (green singlet), Peter Knibbs, unknown.
Photo courtesy Dino Hodge, circa 1988.

couple that Bill and I were involved with who had alcohol issues, family issues, separated from kids and that type of thing. It was the woman who was diagnosed first and there were quite a multitude of issues to deal with, but there was no point trying to deal with her medical issues when she was worried about her kids or about her partner bashing her up last night. So, quite often you had to put your medical priorities on the back burner while you dealt with their issues.

She was a prime example of putting somebody on medications when you shouldn't have. There was just no way she was going to manage that heavy pill burden and she ended up with multi-drug resistant virus, and eventually infected her partner, so he would've been infected with a drug resistant virus.

The philosophy was always compliance with medication, so that's been there from day one. And we were involved with a study called the Delta Study, which was looking at two agents compared to a placebo. That was one of the very first studies that showed that using a combination of drugs provided benefit to single treatment by itself. For a small clinic we had maybe half a dozen patients on the trial, and when the trial finished we found that most of them were on active drug, so they were getting two drugs which provided them individual benefit. It kept their virus lower and T cells higher and kept them well enough until we got the newer drugs coming out that proved even more effective for them.

My philosophy was you have to allow people to be human and everybody forgets to take drugs occasionally and it's not the end of the world. And even for patients that are

missing drugs more regularly, I think it's better to take a supportive approach than try and lecture people and tell them they're doing the wrong thing. Because in the end it's their responsibility to take their medications or not, and all we can do is just be supportive and help them as much as we can.

It's certainly a lot easier to have HIV now than it was twenty years ago, but there are still factors associated with it that don't change, and that's like telling new partners that you have HIV, which is as difficult now as it ever was. Some of my clients virtually became celibate after their diagnosis with HIV because they were just too afraid to infect other people. I think it's changing a little bit now. I think in terms of undetectable viral loads, people's risk of infecting others is very, very low, but there was still the message that you have to have safe sex every time. In some ways I think that was a little bit unreasonable and unrealistic.

Working up here was very different to the role that nurses do in bigger centres. When I took long service leave a nurse from Liverpool Hospital in Sydney came up and did my job for three months. She was amazed at how much we were allowed to do. Because we do testing all the time and it was not uncommon for me to be giving people a positive HIV result, and that was just something that nurses would never do in centres down south. So I think being a small centre our roles were a lot more diverse and we had a lot more responsibility than a lot of other places. Conversely, when you go to conferences and say you're from Darwin, people think, "Oh, ends of the earth. What would you know about HIV", and that thing. Whereas, I think working up here, we're probably some of the most experienced clinicians in Australia when it comes to HIV. ♦



Lori Ford

NORTHERN TERRITORY AIDS COUNCIL

1986-1989

We were not well supported by the NT government initially, and it became like a 24-hour-a-day effort - people lived and breathed it. It was like nothing else existed in our lives for a time, it seemed, because we were just working so hard ... It was a fascinating time, when there was such a high need and to see people of all walks of life coming together to achieve the same outcome. It was just brilliant really.

I first became involved in the AIDS Council around 1986. I had a work colleague by the name of Ian Lauchlan who suggested I come along for a while as they were really needing some help. We both worked in the welfare office in Casuarina at the time and he went on to become the CEO. Before Ian there was an acting CEO who was loaned to our organisation from the ACT by the name of John Westlund.

I was a committee member and when Ian left they had decided they really needed an educator counsellor more than a CEO. So I applied for the first educator counsellor position and was successful. I was there until about the end of 1989.

We were upstairs

We were not well supported by the NT government initially, and it became like a 24-hour-a-day effort – people lived and breathed it. It was like nothing else existed in our lives for a time, because we were just working so hard. Everybody that was involved was some kind of volunteer, whether they were working on special projects, committee issues or short-term projects. We had a lot of transient people and a lot of volunteers who would assist the AIDS Council when they were in town, which was great.

At that time, one of the key projects was establishing the needle exchange program. It was initially not really legal to set it up at that time, so Simon Nish, Ian and myself went to the police to try and get people onside to work with us, which was very successful. When I worked there I was employed as the Educator/Counsellor. We had an admin person who was on secondment from NT Health, Michael Breshnahan. Later we employed an admin worker, I think part-time, by the name of Niki Patmios, and she was a great help as well. We really did everything and anything that was needed to be done as we didn't have any funding for any kind of additional support.

A lot of counselling was done over the phone, as people were very fearful of being seen near the AIDS Council. Even bumping into me somewhere in the street was a concern, because they felt that if they were seen with me then people would just put two and two together.

During that time there was the establishment of the Friends group, which was the support group for people living with HIV. For a time they used to meet at my house because they needed somewhere to meet where people weren't going to be associating them with other people

who were known to have HIV. It was a very small group initially. It was a very difficult time with discrimination and it was a time people were also trying to find out "who might have AIDS, or who didn't have AIDS". I can remember one guy with HIV being in hospital who had a broken hip or a broken leg, so he couldn't move out of his bed. The cleaners wouldn't clean his room and meals were left outside on a tray, of which he couldn't access unless one of us physically went in and fed him. People just didn't really understand how they could get HIV. At that time, there was a car accident that someone was involved in, and the automotive people working for the insurance company didn't want to touch the car because they were frightened that they could catch it. That all sounds quite silly now, but in those days there was a lot of fear in the community.

We did a lot of education even as committee members because there was just so much to do. Some of the education I was involved in was with schools and with the Defence Force. They held military exercises in Darwin-Kangaroo '88 and Kangaroo '89, and we ran Safe Sex workshops in these tents at the Defence Force, which was quite a novel thing at that time. We did run a lot of Safe Sex workshops in the community. We used to go to the nightclubs and hand out pamphlets advertising Safe Sex workshops, and ran them at least monthly. We did a lot of education in schools, education to nursing staff, the police, defence, welfare groups, youth groups – but it was all very much one-off and ad hoc. It was when people wanted it or allowed you to come in to run AIDS education. In those days we didn't have a lot of funding, and so we were reliant on volunteers to help out a lot. There was a lot of advocacy for people, and we also established a group

for people that were friends or families of people living with HIV. It was very good for people to get together, because everybody was being so secretive at the time. I think the needle exchange was a major program that we took on, and it worked extremely well. We also worked a lot with Banyan House rehab service, and we had a lot of volunteers from Banyan House who were coming in as well.

I didn't have a lot of meetings with the government myself. I do remember Neal Blewett visiting, and he was very supportive. I don't think that the NT Government were particularly supportive. Funding was a major factor but we had a lot of committee members who really worked tirelessly to negotiate and really get the government onside. Ant Smith was heavily involved, Jenny Norris, Terry McClafferty and Dino Hodge all having meetings and trying to get the government onside. It was a tough time in those days.

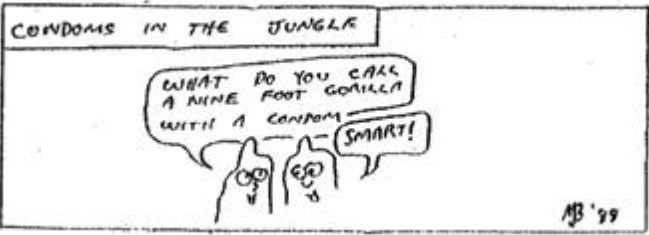
It was also a remarkable time to be involved with a community that were all pulling together when there was such a high need, and to see people of all walks of life coming together to achieve the same outcome. Stephen McGreevy was our vice president for a while and he was very supportive of staff in the Council. Mark Wilson and John Dunham were also heavily involved. Mark was part of the Darwin Gay Society, the president for a while. He was heavily involved and assisted with training. I think it was really good Sally Thomas agreed to be the Patron in that era. That did make a difference to our standing in the community.

There weren't initially a lot of sex industry workers involved. I think that happened afterwards. It was

initially mainly the gay community that were leading the way, but also a lot of heterosexual people because we couldn't get people on the committee and people were concerned about their jobs or how they would be perceived if they were involved.

I'd have to say there were some very difficult times, because you had all these different sub groups who all had their own issues. But it's like any group: you've got groups within groups and everything was highly emotive. We did have some very strong discussions at different times, but overall the work that was achieved in those early days was just amazing, and people were all ultimately there for the same cause. There were times where factions felt that other sub-interest groups were taking over. That's probably just a normal kind of group norming, storming, forming of any group with such emotive issues.

Initially there was an AIDS Action Group in Alice Springs. In the early days there was someone who was doing education; it might have been Megan. There was obviously issues at some point between the two groups – there always is in the NT between Darwin and Central Australia – with any group about who's getting the most funding. It seems like there's a lot more factions when you start getting funding. When you haven't got any funding you're just all fighting for the same cause. ♦





Megan Brooks

AIDS COUNCIL OF CENTRAL AUSTRALIA

1988-1990

Megan Brooks - Northern Territory Archives Service, Peter Strickland, Spur's Bar Visitors Books Vol 2, Nov 1991

An Elder from Hermannsburg came in one day and said, "We've had people coming into our community saying you have to use condoms because otherwise you'll catch AIDS. We have talked about it and we know that if you use condoms you can't get pregnant - and we think that they're just trying to stop us having children" - which is not an irrational interpretation at all. They had a high index of suspicion, because they suspected it could be another genocidal government policy directed at them.

My name is Megan Brooks. I worked at the Central Australian AIDS Action Council and then ACOCA from 1988 to 1990.

I was the only person there initially. The first office we opened was a shopfront called Safe Sex Worx, very '80s, with a big X. Some people thought it was a hairdressing salon, because we had big bottles of lube on the shelves, like shampoo. We sold condoms and lube and dams. Back then you had to order the dams from dental supply companies and, because they weren't made for sexual purposes, you just had to try to get the thinnest and least disgusting ones.

I was there on a day-to-day basis and did a lot of the grunt work, but of course lots of other people were involved. The board and all of the people who were involved in their voluntary capacities did huge amounts of work. So I was

lucky to be getting paid, but I have to say it wasn't enough money to live on and I had to have other jobs as well, working as a barmaid and in the disability sector.

The way I came into its orbit was that I knew John and his partner Paul. I'd been living in Alice Springs for a couple of years prior to him starting the AIDS Action Group, and he had cobbled together a bit of funding - which I presume came from Commonwealth sources - enough to employ someone.

John approached me about it and I asked, "Would you not want to have a gay man in this role?" and he said, "Look, we've talked about it and we think it might be best to have a woman, because gay men are going to be comfortable with a woman, and then women and heterosexual men hopefully will be comfortable with a woman too. So we

think given our limited resources having a woman in the role might be the best bet." I had a background in the community sector and that was my sort of field of work, and I suppose they thought that I might be interested in the position – which I really wanted to do.

The board had a pretty clear program of work they wanted to achieve. Also, with such a small organisation and so many people doing it on a voluntary basis, there's a big overlap between the voluntary and more community social stuff and the paid work. For example, there was a regular gay and lesbian dance night which many people helped organise. We also had a small amount of brokerage funds that assisted people with HIV who were in crisis, so we were able to help people out with some of their costs.



At that time when people were getting sick there were few services to assist them. People like Sarena Ruediger nursed people as they died at home. It was done with a lot of secrecy because people felt it was unsafe for it to be known that they had HIV or AIDS. I remember being in the hospital with my colleague Gavin Dale when he became sick and people coming in who didn't know he had HIV, standing in front of the yellow infection control sticker so that they wouldn't see it.

Actually, there was lots of subterfuge. My understanding is that some people's death certificates would say they died of cancer or heart failure. It wasn't recorded as AIDS-related on their death certificate for various reasons.

I'd do pre-test counselling with people because it wasn't straightforward in that era. I had a checklist sticky-taped to the desk so that I could remind myself of all the things to talk through. Because treatments in that era were so lousy and the disadvantages of being known to be HIV-positive were so profound, there were some good reasons not to be tested back then. People needed to stop and really think through what it meant to get tested.

I remember using diagrams of mosquitoes that showed that they couldn't transmit HIV. That was a big concern for people and maybe particularly in the Northern Territory, mozzies, but there was a really widespread fear of HIV transmission.

People would come and talk about things to do with sex and drugs, and for a lot of them it was focused on HIV. But once people knew that this place existed, some would just come and talk about sex. I remember a middle-aged woman weeping because she'd never had an orgasm, and she wanted me to help her with that. And this conservative

John Hobson and Megan Brooks circa 1992 (Photo, David Haigh)

heterosexual man who wanted to find out how to order sex toys. In that era before the internet, many people were in the dark about sex. So there was actually quite a lot of work that was just about sex.

When we set up the needle syringe program (in 1988), at first nobody came. We set it up in a walk-in storeroom. We got an article in the local newspaper saying, "It's okay to come to this place and get needles and the police will not be watching the building", and then people started to come in. People would rock up and walk to this cupboard take whatever they wanted, and off they'd go. I would never have thought that there was a lot of injecting drug use happening in Alice Springs before we set up the NSP.

I can remember when we worked in the Safe Sex Worx office, an Elder from Hermannsburg came and said, "I want to talk about AIDS", and I went, "With me?" because I was a woman. He said it didn't matter – I think because I was non-Aboriginal – but he'd been sent in by his community to find out more about this, because I believe there had been quite a lot of Commonwealth AIDS education happening in Aboriginal communities, much of which had not been understood particularly well. It wasn't done in a way that was making much sense to people.

So he said, "We've had these people coming into our community saying you have to use condoms because you'll catch AIDS. We have talked about it and we know that if you use condoms you can't get pregnant – and we think that they're trying to stop us from having children" – which is not an irrational interpretation at all. They had a really high index of suspicion, because they suspected it could be another genocidal government policy directed at them.

So one of the good things about having that shopfront set up was that people who came into Alice Springs would see it and go, "It's about sex", and all kinds of questions came your way.

I was the Central Australian rep for Scarlet Alliance, the sex workers organisation that still exists, because I had worked as a sex worker and was quite involved in sex worker issues. We'd have get-togethers with the sex workers, we would do spaghetti and education. We'd have slideshows of really disgusting STIs, because the medical slides show extreme versions of diseases that you'd never see on an actual body, because no-one would expose themselves to another person if they looked like that.

Sex workers would come in to buy their safe sex supplies. We'd talk about safe sex and occupational hazards. But they often needed to debrief about their work as well. They just needed to tell someone all the weird, crazy and sometimes distressing stuff that happened in their jobs – and it's pretty interesting!

One night this random drunk at the pub where I worked said, "I know you. You work at the AIDS Council, don't you?" And I went, "Yes, I do, that's my other job." And he goes "I know you've got AIDS." And I went "Really, how would you know that?" And he goes "I've been watching you and you've been losing weight." I thought, "Yeah, this is a really small town."

So, I was talking about things like the brokerage or some of the support services we offered to people, but if I saw them on the street we would pretend we'd never seen each other before in our lives. You had to be very, very discreet about everything. I'd go to the supermarket and would see

people – the woman who'd had been sobbing about being anorgasmic, or a person who's got HIV and there's all this stuff going on – you literally had to look through each other. It was social death to be seen on the street with me, because I was quite associated with that organisation and people who had something to hide really didn't want to be seen anywhere near me.

There was me initially, and then Gavin Dale came on as another employee. Gavin had come to Central Australia with his boyfriend to work at Yulara. He was a pastry chef, and I think he was still living at Yulara when I first met him. He came in wanting to buy condoms and lube and he only had a credit card. I remember laughing because we were such a small operation and we didn't have the

facilities for credit. It struck me as very cute. He started working at the AIDS Council, but became very sick. He died of AIDS in the beginning of 1991, by which time I had just moved back to Sydney. Gavin and his boyfriend had moved back there when Gavin became very unwell.

I think for me, the fact that my time at the AIDS Council and then leaving Alice Springs coincided with Gavin's death was significant. Gavin is the only person I've been with when they've died, it was an enormous privilege. But afterwards it was like, "Okay, now onwards", because it's very painful and of course he wasn't the only person to have died. There were a lot of funerals back then. A lot.

I would like to pay homage to Gavin. He was a gay man who'd been rejected by his family. He bore the brunt of homophobia, AIDSphobia and losing his life way too young, and in the midst of all that he worked with such grace for other people in the same situation. He was just amazing. He was a really beautiful man. I'd like his name to be remembered.

Also, I'd like to pay homage to John Hobson, who was an extraordinary force who made this all happen through sheer force of will and his incredible intellect. I really don't know how he did it. At the time, I just accepted that he did it but you look back on it and go, "Wow." He created gay community in that town. He created the AIDS Action

Group. He found people to come and help him. He got money and support. He played the politics. He did it all, really. That's how I see it.

In those early days people really needed to get their shit together and do something about this terrible disease, and John was absolutely one of those people. He lived and breathed the cause and he took it really, really seriously, probably to his own detriment at times. I'm sure that his life was a lot more stressful than it might have been. I'm glad that he had Paul and a really lovely home life to counter balance it. He worked all week in in his paid job, which he was also really committed to, and then just worked all the rest of his time to bring that organisation into being and keep it functioning. All credit to him I say. So I'd especially like to honour and acknowledge Gavin and John. ♦



Central Australian AIDS Conference 1990, Alice Springs (photo David Haigh)

Megan Brooks, Jim Buckell, John Hobson, Sarena Ruediger dressed as baby condoms - Henley on Todd Regatta, Alice Springs 1988 (photo, David Haigh)





Sarena Ruediger

AIDS COUNCIL OF CENTRAL AUSTRALIA, HIV/AIDS COORDINATOR, DEPT OF HEALTH

1988–1994

It was really the power of everybody coming together that made it at all possible to respond to what we were having to deal with... It was very urgent, it was essential to respond respectfully and it had to work. It was time to do a lot of things that was challenging for everyone, especially people who were at risk or already affected... there was lots to do, it required everybody to act... we managed to put on the first HIV/AIDS conference in Central Australia to bring everyone to attention, to take part. It couldn't just be a talkfest, it wasn't... We did a lot of really amazing stuff out bush... We had to break through the whole thing about, "It's not cultural. You can't talk about sex or any of those things out in Central Australia", and we blew all those myths apart.

Alexis Young, Sarena Ruediger, Kerri Leach 1993 (Photo, David Haigh)

My name is Sarena Ruediger. I timed my moving and living in Alice Springs with the beginning of the HIV/AIDS epidemic - an urgent, timely response was needed. What was critical to that was supporting the already significant efforts that had been going on by a small group of gay men, largely, to develop a really strong community response, and to set-up an AIDS Council.

That must have been about '86 to '88. I was working with the NT Health Department at that time. Neal Blewett, the Commonwealth Health Minister at the time had initiated and established a Commonwealth consultation process that contributed and informed the way to move forward. This created a supportive policy environment and mandate for us to work from. *A Time to Care, a Time to Act* as

I recall. My involvement, along with everyone involved, was helping to set that up and deliver. It was such a collective effort at the time with everybody being part of ACOCA. ACOCA was vital. I got to know and admired their commitment, passion and smarts. Even though we had to think on our feet really. My main role was working in the Health Department but I was an ordinary member on ACOCA from about 1988 to about 1994.

HIV/AIDS was new. It was the Grim Reaper time, so there was a lot of not knowing or misunderstanding about HIV/AIDS. People need to get accurate information and challenged about their values. We were starting to see people affected by the illness, mainly gay men were becoming sick. It was kind of urgent to do a lot of things



Malcolm Cole (photo David Haigh)

throughout central Australia. I remember at that time we needed to promote condoms. That was new business for most. We had to do a lot of PR work and we did a lot of education workshops. We worked with Congress really closely: we helped spray paint the Congress car, we worked on promotional material, and we worked on employing people to work with us. We worked on men's business and women's business. Frank Djana, Geoffery Tjungurai Barnes, Paul Rivalland were instrumental in Men's Business, while women's business I really remember Jennifer Thompson, Julie Turner, Susie Bryce, Family Planning mob, Pam Lofts and many others who made a big difference through their commitment and support.

Funny stories and adventures with condoms.

I remember one day going to somebody's house, he had an interesting toilet roll holder. It was a perfect sized penis, and I think Kerry Leitch spotted said, "Oh, that'd be great for us to use as a model for teaching purposes", - we only had bananas through Family Planning. Who was going to take safe sex seriously with only a plastic yellow banana? We tried out some other suggestion that someone had said to us from Darwin actually. I think Dino Hodge was around then. Alexa Young and Kerry Leitch did a dash to the sex shop in Darwin and bought a thousand wax candles. They were all good until they had an inappropriate droop in the hot sun on the way to Uluru and we received some feedback from the many remote clinics we had distributed to. Live and learn exercise. One of the gay boys was a potter and made us a thousand skin coloured and black clay penile models that stayed up. That was just amazing because we actually had a really, excuse the pun, useful tool to use.

at the same time and, from the Department, we couldn't have done anything well without the AIDS Council of Central Australia. We had to work together. We were like one big family.

We contributed to the response needed in Central Australia. We had to set up HIV testing and counselling services; there was a big avalanche of that going on as people became more aware. Those days, everybody was worried about HIV and AIDS affecting Aboriginal people and their communities, so we did a major response to that working with Congress, CAAMA, the Alukura and community leaders

We led on everything, really. We really had to start caring for people. At that time it was just shocking. People were very young. We had a number of gay men and we actually had a really beautiful young straight woman who had gone for a trip to Africa and come back. So we were dealing with setting up all of the things that needed to be set up to care for people - and that was just learning on your feet. We actually did care for all of those people, and we were busy at the same time dealing with people that were returning HIV-positive results and/or at risk, in linking them with the AIDS Council and trying to create some sort of supportive environment for them.

There was a lot of discrimination and not really understanding it. So the whole thing about infection control and about getting people to the best quality care that was available, which at the time were specialist services mainly in Sydney. While we had to do a lot of demystifying, those people living with HIV and AIDS were their own advocates along with ACOCA. We supported them and their families and their friends as best we could.

I remember one person who died and the mortuary and the funeral directors wouldn't take his body, which was pretty distressing. The doctors wanted to put patients in isolation and make it public that they had HIV and AIDS, so we did a big role in advocating for their privacy and discrimination and confidentiality issues around their HIV status and their sexuality. We had to work with the church and other powerful community groups and some of their responses, etc.

We had the Commonwealth strategies and AFAO behind us. That was essential in supporting privacy and

confidentiality. We set the system up to protect that but even within the department, people wanted us to tell names because it was a notifiable disease. I remember being asked to disclose, because actually our team were the only ones that really knew their names. We never disclosed, so we had a little bit of a hoo-ha with certain individuals at the time.

I think we had it a bit easier, for some reason, in Central Australia than in Darwin. It was easier to have a faster collective effort and response in a smaller sized community. It was really the power of everybody coming together that made it possible to respond to the issues, so much better. The NT AIDS Council were doing a lot of advocacy work that made it easier for us too, like around setting up a needle exchange program - that was pretty challenging. Even addressing issues around legislation for sex workers and trying to create safe sex working environment for them was a really big one at the time because of the NT legislation - there was no official brothels. God, there was so many issues and solutions to find.

The Aboriginal response - I think the AIDS Council really helped with that because we managed to put on the first Summer of Safe Sex and the first HIV/AIDS conference in Central Australia, and that was a joint effort between ACOCA. In fact, they did a lot work in getting it all ready. That was in about 1991 and a lot of things came out of that. It was called The First Central Australian HIV/AIDS conference. It was held at Araluen. We had a full house - it seats 500 people, and we did it on six grand. I got the money for that to fund it and to employ Di Lynn through ACOCA for a time to coordinate it. We pulled in a lot of speakers. Fred Hollows came up - he was interesting

because he wanted to put gates into all the communities to stop people coming in with HIV. Malcolm Cole was instrumental in that conference because he was really the centre stage as an Aboriginal man deeply affected. He came up willingly and I think at that time he was probably starting to feel a bit unwell, yeah.

We were very, very sad. You're dealing with people dying, bravely, in front of you all the time. I wasn't part of the gay community but I was considered part of their family. It was a tough gig. We started to make quilts then.

We did a massive joint community education effort in Central Australia - The Summer of Safe Sex. Di Lynn did a great job organising it for ACOCA.

We made a massive giant condom. It must have been at least twelve foot long and about three foot wide. We took it in the Henley-on-Todd, the boat race held in Alice every year. We had all these baby condoms all dressed up around it, and we were throwing condoms out to the crowd. We did pretty well in the Henley-on-Todd; everyone else had boats and we had a giant condom with little legs out of the bottom of it.

I worked pretty closely with Tony Hand. He was fabulous. He did a lot of the beat work, a lot of the setting up of the needle exchange, just everything. Kerry Leitch was amazing because she'd worked with AFAO. So she had really good corporate governance skills, and she was a laugh a minute and just charmed everybody really. Alexa Young, who I worked with, was fabulous. She did a lot of all of the hospital work and nurse education, protocols around health care worker education and safety stuff. She really contributed to breaking down barriers and

enhancing quality work and tackling and dealing with conservatism and fear.

Don Dale was the NT Health Minister at the time - if he hadn't had given the go ahead, it would have been really problematic. We were surprised, it being a conservative government, that he gave the go ahead to the needle exchange program. Instantly. And he got the police on side. We - me, Tony, Kerry - had a meeting with Don Dale and the police to set up and get the needle exchange at ACOCA working. It was well used, discreet access, confidential and safe.

One person who I cared for really closely wasn't part of the gay community, as such. They were a very private couple. I became very close friends with him and his partner and helped them through their journey until he died in Alice Springs Hospital. I remember night after night being up there. We tried to keep him at home for as long as we could. I remember he said, "I just want to die watching Tony Barber's *Sale of the Century* with x." Blow me down, that's what happened. He sat up there and said, "Prop me up on these pillows and turn on the tele please, I'm watching *Sale of the Century*," and they were difficult words for him to get out. He just passed away watching *Sale of the Century*.

We did a lot of really amazing stuff out bush. There was an Aboriginal man, Frank Djana who passed away some time ago. He was profound in his ability to bring men along in Central Australia. And an Aboriginal woman, Kerry Arabena, who we did work with in Women's Business that got pretty down and dirty when we did it properly out bush. We had many laughs, and honest and open education opportunities with women. The NPY Women's Council

made great women's only business videos, that we used to great effect in every community with our portable telly on in private women's spaces. We developed women's resources, like streetwise comics with a local flavour, they helped in explaining a lot of important information for women. We had to break through the whole thing about, "It's not cultural. You can't talk about sex or any of those things out in Central Australia", and we blew those myths apart as best we could. We went on that journey with a lot of people too. I didn't do the men's stuff but I certainly did the women's stuff. That was really important at that time. I think we did it respectfully and properly according to law for women, and that was just another world really.

Paul Rivalland worked with Frank and Geoffrey, getting black coloured condoms that Aboriginal men wanted. Tony Leitch, an artist, worked with them in making a community storyboard to talk about important issues for men. It travelled to every community and the stories travelled with it. Dave Batty and Frances Kelly made films and promos, they were great, through CAAMA Radio and viewed on Imparja. The list goes on.

We had some great dance parties as well - setting up a gay and lesbian friendly venue for people to come together as a community. That was just a full-on initiative by ACOCA and by people there. They were great nights, even though I think we had to shift venue a couple of times. One got closed down because of the public backlash, and then it re-opened around the place and they were great. I remember Magda Szubanski came up, and Tiddas. We had good music and it brought everybody together - even if you were just passing through Alice. All welcome. ♦



Henley on Todd Regatta - 1988



HIV community storyboard with painting by Geoffery Tjungurai Barnes, Frank Djana and Tony Leitch 1990 (photo courtesy David Haigh)



Anthony Smith, Ian Lauchlan, Michael Bresnahan, Lori Ford, Dino Hodge, Jenny Norris, Terry McClafferty 1988 (photographer unknown)

Jenny Norris

NORTHERN TERRITORY AIDS COUNCIL

1988-1990

Because there was so much vitriole on the subject of HIV and we had people now in the NT who were being targeted as individuals, if we didn't work to support these people, why would anybody who was living with AIDS want to be involved with the organisation at all? I believe, for the AIDS Council to have just worked in a general advocacy and policy role would not have been sufficient given the amount of prejudice at the time. We think we would have missed game of the day.

My name is Jenny Norris and I was a board member – I think we called it a committee at the time – of the Northern Territory AIDS Council, which is what it was called in the '80s and early '90s. I was on the committee from 1988 to early 1990 when I had to go to Alice Springs to work for a prolonged period. Ian Lauchlan was the executive officer. He was just about to leave the Territory for Melbourne along with a couple of my friends, Cheryl Hall and Melissa Linderman, who were on the Committee. They persuaded me to stand because I had an interest. I had a number of friends down south who were HIV-positive and I was interested in the area generally.

I was elected Secretary and therefore was part of a small executive. The Chairperson at the time was Trevor Miller. The Vice-chairperson was his wife, Nan Miller, who was a stellar person. Nan worked in the Communicable Diseases area of Royal Darwin Hospital and she was an absolute

champion for the rights of people with HIV. Unfortunately Nan passed away a couple of years ago. Anthony Smith was on the committee in 1988, and Terry McClafferty, and we were looking to encourage more gay men to become involved at the time.

Whilst nationally and internationally HIV was not just a gay male problem, it had moved into the heterosexual population and, of course, therefore sex workers as well as drug users were target populations. In the Northern Territory, the main group that were at risk were actual gay males but we were particularly concerned about the potential for widespread infection if it was introduced into the Aboriginal community. We really wanted to get a lot more gay males involved in the committee and the workings of the organisation so that gay males generally could relate to the committee and the organisation generally. It was with that in mind that I encouraged

Dino Hodge to stand for committee, and another friend of mine of the day, Steven McGreevy, who was a senior Commonwealth public servant at the time. I was lucky to serve with both of these people and when I left the committee, a whole bunch of people were joining the committee, in particular John Dunham and Deb Gough – people whose names were quite well known at the time.

We made a decision fairly early in my time on the Committee after the vacancy created by Ian's departure, that we really needed a HIV counsellor to work with our target group. Due to our funding position we opted for a HIV counsellor rather than an executive officer. We thought that the board could probably share a lot of the executive office roles and that really we needed some workers to work with the people who were living with AIDS. So we took the decision at the time to recruit an HIV counsellor – Lori Ford – instead of an executive officer, and the committee shared the management functions. I was responsible for managing the staff in the organisation.

Dino was treasurer and Anthony Smith soon stepped up to be vice-chairperson and then was elected Chairperson in 1989. They took a larger role in dealing with the high level government and with media, as did Terry McClafferty, so we all shared a lot of functions around amongst the Executive group.

At the time we were a small organisation. We had three staff at one time but generally only two. The Northern Territory government didn't want to increase our funding so they lent us one of their administrative staff to work in our office and that was Michael Bresnahan. He worked firstly with Ian Lauchlan and later supported Lori. We kept

pressing the NT Government for funding but it came to a point where they said, "Well, you can't have our person and more money," so they took Michael back and this was part of the funding battle we had with them. By that time we had recruited another person with a welfare background – Niki Patmios. So at one stage, we actually had three staff but generally there was just two. For most of the time that I was on the board, it was Lori Ford and either Niki Patmios or Michael Bresnahan.

It was early days for the federal government's Needle Exchange Program and I believe that the Federal government actually started its needle exchange program in States and Territories and the Northern Territory AIDS Council became the place that operated the exchanges in the NT. It was one of the things that, whilst the Northern Territory government were reluctant to hand over the funding, they didn't philosophically or as the government of the day, want to get involved in. It was a very difficult thing for a government to run a needle exchange program as you can probably imagine. There was only one service that dealt with rehabilitation for people who were substance users, other than alcohol, and in fact the Northern Territory Government of the day said that we did not have any drug users in the Northern Territory. That's partly because their policy was to give them a bus ticket out of the state to another state where they could receive rehabilitation services. That was somewhat of joke at the time.

NTAC of course provided policy input, information services and worked with and supported people with HIV. We did peer education, there were newsletters, and we tried to work with the gay community generally but we also started to work with the sex workers. We provided

peer education and we had volunteers working the beats handing out condoms, et cetera. And we were the voice of the non-government sector that was involved in that particular area in the Northern Territory.

This is not to diminish the role of the Central Australian group, but the government wanted to deal with one organisation that had a Territory-wide role, not two separate organisations. At some point I recall they may have even had funding channelled through NTAC. We certainly led on policy and could lead on government liaison and challenging policy.

Some years after my time on NTAC there was a period in which the Central Australian AIDS Council, for some reason that totally escapes me, decided that they would expand their mandate and incorporate disability. That was an interesting development and, of course disability then, I think, did take away a bit of a focus. I believe there was probably funding to be had from that source and somebody who was working with them thought that was an opportunity.

So for a small organisation like NTAC what can you do? You pick your big issues and we seemed to have lots at the time. Funding challenges; working with people and their families, and trying to get more people who were isolated in the community to become engaged in the organisation; and of course peer education and the like; and tackling prejudice. We started to work with needle and syringe users and of course John [Dunham] came to work to be part of the committee, too. John was a haemophiliac and he'd contracted HIV from a blood transfusion before blood was tested. He brought a whole new dimension to the AIDS Council at the time.

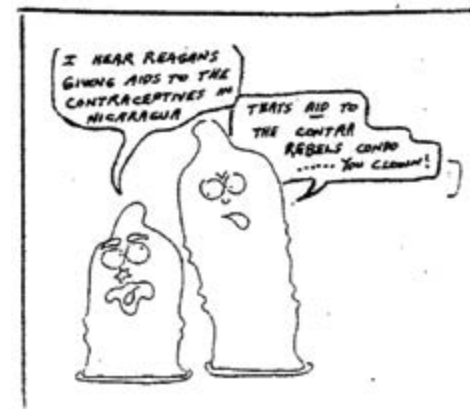
When I joined the Council our premises were in the Burns Philp Building – we were on the first level of Burns Philp House, which is on the corner of the Smith Street Mall and Knuckey Street. It was a very small space. We did need more space, so we sought and found premises in the Homecraft Arcade – quite a nice spacious premises on Cavanagh Street.

At the time the Environment Centre and their Green Turtle shop was on one corner of the horseshoe arcade. Opposite was a café. There was a telecommunications shop at the front on the other entrance to the arcade. The arcade also had a little beautician's shop, a laundrette and a dry cleaning place, a school uniform shop, and the Rasa Sayang restaurant at the back. There's still a restaurant at the back of that arcade now – it's called the Sari Rasa. NTAC rented the last premises at the back that faced the restaurant. We were in the centre of the premises. It was quite large. We then had room for meetings, for private discussions with people, and we had room for storing things like some needles and syringes.

The arcade had a second level and upstairs unfortunately was a real estate agent and he was the property manager. He was not the owner of the building. The property manager particularly didn't like the AIDS Council and didn't like homosexuals, didn't like people with HIV, didn't like anything about us and so he became quite difficult. The owner was a Chinese businessman. He didn't have any personal prejudices about it. No views. He was happy to lease to us but the real estate agent tried to force us out of the arcade. He used a range of tactics, including first telling us that he wasn't going to give us the lease. This consumed a lot of energy for the Committee – we had to approach the owner and he came and intervened.

The property manager also actively tried to set the other tenants against the Council by scaremongering. He told the café and the restaurant that we'd breathe on their customers and everyone would get HIV. I know this because these business people recounted this to me. He told the mother and daughter who ran the school uniform shop that drug addicts were going to come and leave syringes lying around and when kids came to pick up their uniforms, they'd pick up the syringes, and parents would no longer come to their shop. He tried to put the fear of God into the Filipino woman who ran the beautician shop. Part of my role was to work with the other tenants.

So first he tried to have the other tenants kind of push us out. When he didn't succeed there he turned off the air conditioning to the premises, which he could control from outside the office. Our staff were there working with no air conditioning and in difficult conditions generally, so it became a real campaign against the AIDS Council. As well making trouble equally in the media about the terrible things that were going to happen now that the AIDS Council was there.



At the time that I was on the committee, we had a pretty unreceptive Northern Territory population generally. They were easily rattled by

things. They weren't supportive in any way – neither were the politicians – of people with HIV. We had passed the Grim Reaper days and all that sort of publicity was out there – the shock factor. There was a lot of prejudice and we were getting bad press. It was at this time that we discussed appointing a patron. We needed a well-regarded person who was not afraid of adverse public comment to support us. Terry McClafferty suggested Sally Thomas. She thankfully agreed and is still with the organisation today.

Those were some of the first challenges – the big challenges we had. That took a little bit of time to resolve. But it even took a couple of days to get our air conditioning back on. One of the board members spoke with the owner and, because then the agent was supposed to be acting in his interests not against his interests, and he got all that reinstated. Begrudgingly, this man continued to cause us a bit of grief. So that was a big issue for us at the time.

We then also had to deal with the fact that the Northern Territory government thought that they could use the Federal funding they were channeling to us better themselves, and that they didn't want to fund us any more. We were then in battle with the Health Department, or particular people within the Health Department. A group of us had to meet with Marshall Perron, the Chief Minister, who happened to be Health Minister of the day as well. The CEO of Territory Health, Graeme Symonds, was there as well. That was a very difficult, challenging time. The previous Health Minister, Don Dale, who had retired due to illness had been very supportive. Marshall Perron on the other hand wasn't sympathetic and we only saw a break in that when the health portfolio moved on to Steve Hatton. He was a much more liberal thinker – he was better

Cartoon by Michael Bresnahan,
NTAC Newsletter 1988

about many things affecting the organisation. He actually came unannounced to a Council committee meeting. He just turned up and said, "Look, I don't know what's going on here but you'd better tell me the story". So he did meet with us and things changed.

I don't know where the organisation would have gone, or what would have happened to people like Kenny and Mark if we hadn't have had an HIV counsellor. I have to say that after the stories hit the media, people were very, very angry, they didn't trust anybody, they were really insecure. It took a long time to get their trust and be able to assist and support them in everything, from securing the accommodation to actually fight the battles with the Health Department.

Lori Ford was a substantial support to people living with AIDS and to some of the families. I think to this day that she's still in touch with Kenny's mum.

Because we had people now who were being targeted as individuals and if we didn't work with these people and support these people, why would anybody who had HIV want to be involved with the organisation at all? I believe for the AIDS Council to have just worked in a general advocacy role would not have been sufficient given the amount of prejudice at the time. We would have missed game of the day.

We'd gone from having a board that was really no people that were affected by AIDS to a tiny group that might be affected. So a lot of the people weren't really in the target group that we were trying to service, and we really needed to change the kind of emphasis on the committee to better reflect the people that we were trying to serve at

Old advertising NTAC Newsletter 1988



the time. After Nan left the Committee I was then the only woman there – it was a bit of a misogynous time, I can tell you. And it was quite tough. Lori found it quite tough, both from the client group side, she battled all through that. Because she was quite close to all the people that she was working with and she gained their trust and that they had somebody who they could rely on, that wasn't just a friend but somebody else that could help fight their battles. ♦



Dino Hodge

NORTHERN TERRITORY AIDS & HEPATITIS COUNCIL LIFE MEMBER

1989-1994, 2013-ONGOING

NTAC's staffing levels increased overnight from two to nine positions (six full-time and three part-time). The full flow of funding finally allowed NTAC to begin to deliver a range of services that a diversity of client groups were needing and expecting ... It was a pivotal moment in the Council's history.

The Northern Territory AIDS Council was born into a world of ignorance and bigotry, and baptised in a cauldron of fear and hatred. Little wonder, then, that the NT government failed to take seriously the widespread harm suffered by HIV-affected individuals and communities through blatant prejudice and discrimination. Worse still, the NT government persisted in denying the Council full funding.

Under its *National HIV/AIDS Strategy*, the federal government had committed monies to the AIDS Council to deliver services across a broad field of areas. The funding was routed via the NT government, which had agreed to contribute extra funding under matched grants, and then to disburse all of these monies to the NT AIDS Council. It was a lot of money, but the NT government gave NTAC just enough for two positions (one administrative and one service delivery) and an extremely limited operational grant.

During the three years since its incorporation in 1986, I observed that the Council's board struggled to establish sound management systems, while the staff were

overwhelmed with the services needed for People Living with AIDS (PLWA, as they were then termed), and for the diverse groups affected by the virus. The lack of proper funding, together with the extremely sensitive and pressing demands for service delivery, meant that NTAC's people burned out fast. One of the few who was a mainstay during those first years was Lori Ford, initially as a volunteer and board member, and then as a staff member.



Simon Nish, Mark Wilson (dark blue shirt, back), Sally Thomas unknown meeting circa 1988

Back: Sim Lee, Middle: Ian Lauchlan, Brad Weis, Front (reclining): Dino Hodge 1985 (photo courtesy Sim Lee)

It was in this context that my friend Jenny Norris, who was working as a manager with the federal health department, suggested I join the Council's board. Other board members included Dr Anthony Smith, NTAC's vice president and then working at Menzies School of Health Research; Deborah Gough, EO of Family Planning NT; and David Patterson, a lawyer with the NT Department of Law. I was working with the federal Human Rights Commission as assistant director of the NT office. It seemed to me that if anyone could get the Council up and running, it would be this group of people.

The most pressing priority in 1989 was to secure the funding being withheld by the NT government. Following some negotiation, a meeting was scheduled with Bruce March, the federal health department's Territory manager, Graeme Symonds, CEO of NT Health, and key NTAC board members. The sole agenda item was funding of NTAC. It was my role to "workshop" the meeting.

The *National HIV/AIDS Strategy* designated funding for specific areas of service delivery by AIDS Councils.



Using the *Strategy* as a guide, these commonwealth monies were itemised on a white board, and then the NT government's matched funding commitments were listed. Once all the funding allocations had been tallied, we analysed the monies that were actually disbursed by NT Health to NTAC. The substantial shortfall was the subject of pointed discussion. Graeme Symonds came to the party and the meeting concluded with a renewed commitment. NTAC's staffing levels increased overnight from two to nine positions (six full-time and three part-time).¹

The full flow of funding finally allowed NTAC to begin to deliver a range of services that a diversity of client groups were needing and expecting. And, vitally, the Council's board for the first time since its inception could now fully devolve administration and service delivery to paid staff, and instead devote itself to policy and governance. It was a pivotal moment in the Council's history.

HIV in those times was still largely regarded as the "gay plague". HIV-positive people were divided into two categories: infected gay men, and "innocent victims" whose lives had been destroyed as a consequence of gay men's depravity. Today it is hard to evoke the pervasive fear, disgust and hatred, but it was real.² It was, I suspect, this atmosphere that allowed the NT government to consider it acceptable to siphon-off money meant for HIV services. Such was the contempt for HIV-affected communities. Don't believe anyone who suggests otherwise.

A primary objective of NTAC when it was incorporated was "to fight discrimination against homosexual people resulting from the AIDS scare, and present their rights and liberties".³ Anthony Smith was a man of considerable ability, and his

NTAC Float for the Bougainvillea Parade 1988



Dino Hodge, Sim Lee Stonewall 'Splash of Pink' evening 1985 (photo courtesy Sim Lee)



election as president of NTAC at the AGM in September 1989 came as no surprise. One of his first actions was to write to the NT government about legislative issues raised in the *National HIV/AIDS Strategy*, and specifically about the need for anti-discrimination legislation. Steve Hatton, then Minister for Health and Community Services, replied that "the community has not indicated that such an initiative is considered a priority at this time".⁴

NTAC's board members were encouraged to make contributions relating to their individual fields of expertise, and so David Patterson had convened the law and policy working group with Anthony and myself as members. We reviewed the *National HIV/AIDS Strategy* and discussed it with work colleagues. To clarify our thinking and to contribute to the national debate, we prepared an article "HIV status, sexuality and discrimination in Australia: whose turn to (en)act?", for the *National AIDS Bulletin*.⁵

The International Covenant on Civil and Political Rights to which Australia was a signatory established the scope and impetus, we argued, for legislative protection against discrimination. Queensland, Tasmania and the Northern Territory were the only jurisdictions yet to introduce any form of anti-discrimination legislation. For some years the NT government had resisted calls by women's, ethnic and other interest groups for anti-discrimination legislation, explaining that attitudinal change was best achieved through education. We held that the Commonwealth could act should the NT government fail to introduce legislation.

NTAC's legal working group organised a Territory-wide "phone-in" during Human Rights Week in December 1989 to gather data on discrimination. The survey was to illustrate the lived experiences for a comprehensive report we were preparing. *HIV/AIDS, Discrimination and Law Reform in the Northern Territory* was tabled in February 1990 with both the NT and federal governments. We recommended anti-discrimination legislation and legislative reforms for intravenous drug use and the sex industry, and outlined policy reviews in employment, education and correctional services. Importantly, we called for equal recognition of same-sex relationships and equal age of consent as for heterosexual relationships.⁶

Ian Lauchlan, Condo the Clown, Simon Nish – Hot Gossip Hooker's Ball, December 1987

In July 1990, Chief Minister Marshall Perron announced the government would introduce anti-discrimination legislation.⁷ Perhaps the bitter and public stoush in mid-1989, when a commercial realtor attempted to deny NTAC rental premises, had helped generate a more receptive mindset.

Perron subsequently formally replied to NTAC's report that, "The complexity of the issues, and the number of agencies involved in the consideration of your submission, has resulted in considerable time and effort being expended in preparing a response."⁸ Word came back informally a couple of years later that the government continued to rely upon the report when formulating its responses to issues arising from HIV/AIDS.

The inclusion of HIV status and sexuality in the proposed anti-discrimination legislation was endorsed at all community consultations held by the government across the Territory. NTAC was further encouraged when it was invited to join a working party established by the government to summarise the issues identified at these consultations.⁹ The *Anti-Discrimination Act* received assent in December 1992, exactly three years after NTAC's 1989 discrimination "phone-in".

Working closely with NTAC's board, staff, clients and volunteers has been memorable. It was hard yakka and it was intense. I am proud of our achievements – and impressed with all that NTAC/ACOCA/NTAHC has continued to achieve, particularly the contributions nationally with Indigenous peoples. Most of all, it has been inspiring to be associated with so many caring, dedicated and community-minded people. ♦

Condo the Clown, Ian Lauchlan – Mardi Gras stand, NTAC Office Knuckey St, 1987

¹ "President Profile: moving into a new year", NTAC newsletter, circa February 1990, 2.

² Dino Hodge, *Did you meet any malagas?*, Little Gem, NT, 1993: see index: HIV – discrimination; also, "clippings of Northern Territory newspapers 1984-88", copies held by NTAHC and by Australian Lesbian and Gay Archives (ALGA).

³ "Legal Notices: Notice of Intention to Apply for the Incorporation of an Association", *Northern Territory News*, 5 November 1985, 31.

⁴ Steve Hatton to Anthony Smith, 17 December 1989, located at Northern Territory Archives Service (NTAS): Hodge, Dino, NTRS 3701, Personal Records 1977-1993, P0001/2, 'Discrimination'.

⁵ Dino Hodge, David Patterson and Anthony Smith, "HIV Status, Sexuality and Discrimination in Australia: whose turn to (en)act?", *National AIDS Bulletin*, vol 4, no 6, July 1990, 48-51.

⁶ Copy available at NTAS, Hodge records, 'Discrimination' and at ALGA.

⁷ Dino Hodge, 'One Little Jurisdiction', *National AIDS Bulletin*, vol 5, no 2, March 1991, 27-29.

⁸ Marshall Perron to David Patterson, 2 August 1990, NTAS, Hodge records, 'Discrimination'.

⁹ Hodge, 'One Little Jurisdiction'.





Marcus Schmidt

NORTHERN TERRITORY AIDS COUNCIL / NORTHERN TERRITORY AIDS & HEPATITIS COUNCIL
1988–2014

There was a significant body of work done by NTAC at the time to establish a needle syringe program in Palmerston ... So, safely injecting, having education programs for prisoners, getting information to prisoners on their pre-release program prior to release to community ... I think valuing that diversity and actually getting its voice in – I think that was important.

Marcus Schmidt and NTAHC Life member, Christine Wier 2002 (photographer unknown)

I arrived in Darwin in 1985, aged 20, and within weeks I met a person who had an 'AIDS' diagnosis. Whilst I was aware of this new illness, to my knowledge I had not previously known anyone who actually was infected with this lethal virus. As it happened, we became close friends until his death some six years later. HIV-positive people were a relative rarity in the Territory in 1985, although that was to change rapidly. They weren't called HIV-positive people then, they were called 'AIDS victims'. This was technically correct as although it wasn't understood at the time, the progression from contracting the HIV virus to developing Aquired Immune Deficiency Syndrome, and the multitude of life-threatening illness that resulted, was very rapid. So, 'AIDS victims' was a common term for those who contracted this terminal disease in those days. And, of course, that brings up a whole heap of other adjectives that were used to describe them.

I was aware of, but not directly involved in, the moves to establish NTAC in 1986. I was acquainted with Dino Hodge, Terry McClafferty, and Simon Nish – who, amongst others were all actively lobbying for services to combat the impact of AIDS in the NT. My memory of going to the NTAC office for the first time was when it was in Jape Plaza in about 1988. I recall meeting Iain Butterworth, employed there in a community liaison role. I also recall meeting the President, John Dunham around that time.

Jumping forward a little bit, and I'm guessing it was possibly around 1991, I was acquainted with Mark Wilson who, at the time, was the Vice President of NTAC. Mark was a NT government worker at Treasury. He had contracted HIV and was relatively public about his diagnosis. In those days a lot of people became public about it because somebody else made it public for them, and that may have been Mark's experience. I do recall he did take a public profile about having HIV. That was significant in

the context of Darwin at the time because he was a public servant, so he knew a lot of people and he was willing to do that. He also knew he had little time. People didn't have a lot of time in those days.

Mark asked me to consider going on the Board of NTAC. I explained that I didn't have any particular skills for a board position. I was a young bloke in Darwin. And to my shock, within a week of that conversation, Mark died.

Through people I knew, I become more involved in supporting people who were ill with AIDS. NTAC staff member Bill McMahon, who was the Care Support Coordinator, would identify people and what practical assistance they might need. So I would find myself being called to jobs where somebody needed their lawn mown, or some other practical assistance. Particularly at that time, there were heterosexual people or people who identified as heterosexual who had contracted HIV before much was known about the illness and its various modes of transmission. I met them and sometimes I got to know them a little, or a lot, and I got to know something of their lives.

Usually the person receiving the support was quite frail, so I got to meet the people close to them. Through that I met some wonderful people, who were often quite isolated in their experience of caring for a loved one who was dying from an incurable disease that was highly stigmatised and feared.

Occasionally I run into a family member now, some twenty-five or thirty years later, which is kind of sweet because we sort of know who each other is and what we did for each other, and what their life experience was at that point in time. Context wise again, HIV – or AIDS as it

was called – was quite a taboo illness and highly stigmatised. And so people whose family members had HIV/AIDS were often similarly stigmatised.

In the late 1980s a personal friend, Royce (Roy) Dunbar, moved to Darwin from Perth. After a period of time living in Darwin working at the Casino, Roy become the Executive Director of NTAC. Perhaps responding to the earlier recommendation of Mark Wilson, I joined the Board for a period of time. At that stage NTAC was located on Knuckey Street, at Winlow House. The President was Jan Stafford, and Roy Dunbar was the Executive Director at the time. I'd done maybe up to twelve months of attending meetings and trying to make sense of what was going on, but it wasn't where my skill set was at at the time. So I just didn't continue in it and, to me, I felt that I wasn't able to contribute effectively. I retained my volunteer activities however, and over time this evolved into more direct personal care as there was a big need for this.

NTAC assisted a UK group of HIV-positive people and their carers who visited NT on an event to educate people about the disease. From memory it was called 'Expedition Aligator'. I think this was about 1992 or '93. Billets for this group were sought and I was able to host a young woman and her carer from the UK for a few days. A straight girl in her early twenties, she had contracted HIV from a sexual encounter with a man she met whilst living with her family in Africa. The education tour – which took the group by bus to Tennant Creek and back to Darwin over a couple of weeks – was an attempt to bring the reality of 'AIDS' to the general community. It was very affecting meeting these people who had

travelled so far. We all knew they were on very limited time, and were all quite young. There was no effective treatment at the time.

Five years on from my arrival in Darwin in 1985, the personal impact of HIV/AIDS was utterly unavoidable. Numerous people in my immediate social group had been diagnosed as 'HIV+' and some had died. My closest friend, who lived interstate, died in 1991 and it seemed that the devastation of this virus was unstoppable.

Bill McMahon contacted me one day because somebody who I knew was unwell and needing care in his pensioner unit, as it was always the case by that stage. His friends and family had more or less withdrawn because of this person's relatively erratic behaviour. He had what we now know as AIDS-related dementia, but people didn't necessarily grasp that. So sometimes he was very disoriented and difficult. So people that were particularly close friends got a bit sick of him. And I knew this guy and Bill asked if I would help out. So I joined what evolved into a 24-hour care roster. The people that were providing the practical support and the day-to-day comfort were predominantly older women, carer volunteers from the Red Cross or similar services. And he was a gay guy in his late-thirties, quite dependent, pretty much bed-ridden, and his only real social connections were medical staff and well-meaning carers, but from way outside his social context. So what I found really rewarding was to rock up at his place, and at various times he may have been laying there pretending to be dead or whatever, and I'd go in and just go to his record collection and put on a record and then start doing the dishes and emptying the ashtray. After a little while I'd look across and I'd see his

finger was tapping and his toes were moving and he'd yell out to me something such as; "Oh she was good. I saw her at the Palais in 1972". So I got the full story of Diana Ross. And then I got the full education on Phoebe Snow or on Nina Simone or on which other person that he had a record of. And so I was getting educated through his record collection and he was reliving his glory days.

At other times dementia would visit. I found him one night sitting in bed with the telephone cord wrapped around him and he looked up and he said, "Thank God you're here". I said "Why?" He was very distressed and agitated. And he said, "Fucking room service. The amount of times I've stayed in this hotel and you'd think I could get some fucking room service". I said, "What was it that you – "Oh I want some fucking burger and chips". And I said, "Oh okay, maybe I can help you with that", and I unwrapped the cord and took the phone off him and he laid back in bed, and he looked over at the television and then on came Neighbours – and he said "I used to watch this all the time when I lived in Darwin". He just settled down and watched his TV while I went off and got him a burger. At that moment he had no comprehension that he was in his pensioner unit in Darwin, and not his favourite St Kilda Hotel, all along.

So in a way, it was really good to be a young person supporting other young people at this absolutely pivotal part of their life. They were dying.

In the earlier days of NTAC's establishment it seemed that the media, the government, anyone was looking for any excuse to find a problem with NTAC. Blood-borne virus (BBV) transmission was (and is) a highly stigmatised issue – and NTAC was firmly in that space. So heaven

forbid someone finds a syringe in the street or even worse still a child's playground. Or just over the road fifty metres from the needle exchange, they find a thousand of them or whatever. You know, of course, three days of NT News is basically taken up with hysteria. And this went on and on. It is against this social context that NTAC/NTAHC's achievements over time are so significant.

I had the opportunity to watch on as many talented and committed people contributed to NTAC/NTAHC over the years. I stress there were many!

Christine Weir arrived in Darwin from Adelaide in around 2001 and joined the Board around this time, as did Christine Fitzgerald, another person whom I knew and encouraged to join the Board. Christine Fitzgerald was significantly involved in the large body of work required to align NTAC with Hepatitis Australia, amongst other achievements.

Chris Weir, who was working with me in the prisons, identified the need to do two things through our prison system. One was to improve access for HIV-positive prisoners to medications and supplements. But also to challenge the prison's notions around blood-borne viruses (BBVs) in general. So, teaching safe injecting practices to people who would leave prison and use injecting drugs, having BBV education programs for prisoners, and getting information to prisoners about community services available on their pre-release program prior to release. So through that initiative we would bring in workers from NTAHC to educate prisoners and staff and through this, to support prisoners who had BBVs. Getting a supply of condoms into the prisons was a step

too far – and to my knowledge the provision of condoms has still not been achieved in NT prisons.

I've had nothing to do with what was achieved in this particular area – but there was a significant body of work done by NTAC at the time to establish a needle syringe program in Palmerston. Certainly there was a strong conservative view against this proposal by the Palmerston Council, and the government was reluctant to intervene. So there was a significant piece of work in getting that project approved. Petra Jackson was the worker involved, and Chris Day initially, then Frank Farmer, was the Executive Director when this was eventually achieved.

Frank Farmer arrived in the role of Executive Director and established a term of effective leadership and stability for the Council. Not that it had been particularly unstable, but there had been some machinations towards the end of Chris Day's time that had been unsettling for the agency. We've seen that occur from time to time. Frank came in and reset the agenda. He'd worked a long time at the WA AIDS Council. He was a very capable operator and guided NTAHC's development and expansion very effectively during his tenure.

Somewhere in the early to mid-2000s I re-joined the Board. I was at the official opening of the Alice Springs office when it was established at Railway Terrace under NTAHC. The Deputy Administrator conducted the opening and Jill Mead had recently taken up the Coordinator position. Jill and her team, including VJ Thorpe and others, did a great job of establishing the service in Alice Springs, particularly their work engaging with Indigenous people and service providers. They got it moving. You

know, to NTAHC's credit, it's still there, still in the same place, still operating; it's a fabulous little outfit actually. Whilst the majority of the Board meetings were Darwin based, the Board did convene in Alice Springs on occasions. We had planning days in Alice Springs.

Dawn Lawrie joined the Board as President and held the role for a considerable period. The AIDS Council had by now become NTAHC. The Board and the Executive Director had positioned it as a serious and relevant NGO with national linkages through the Hepatitis Australia and the ongoing AFAO affiliations. NTAHC's local profile became more generally accepted and positive in no small part due to the respect that both Dawn Lawrie and Frank Farmer earned through their respective contributions. Notably also was the ongoing official Patronage of (then) Supreme Court Justice Sally Thomas, who also consistently and quietly maintained/s a significant and often unseen contribution in supporting the aims and objectives of NTAHC and the diverse population it serves.

Frank Farmer resigned, having attained a position interstate. This triggered unforeseen movements at the Board. The President resigned to contest the vacant Executive Director position and was unsuccessful. A panel selected Barry Horwood as Executive Director. The Vice-President, Neil Ludvigsen acted as President for a short while. The Secretary was Damian Dempsey. And he left the Board and I'd been on the Board a while. John Carsen had been on the Board a while. I think Chris Weir was still on the Board. There was a lady in Alice Springs, Jodie Carr, Leanne Melling was also a long-term board member. Peter Tiffin was the Treasurer but was stepping down at the end of his term to relocate interstate. But the

President position was vacant and Bob Callaghan came onto the Board as President for just a few months before he resigned. This created a problem on the Board. We had Barry Horwood relatively new to the Executive Director role and we had no President-in-waiting, and things were flaying around a little bit. John Carsen and I both said "You take it" and John didn't want to and, frankly, neither did I. In a way, I'd become the accidental President at that time. There's a lot of responsibilities to take on that role. This was probably all within six months of Dawn Lawrie stepping down and Frank going.

It was a hard gig. Amongst the duties of President there is a responsibility to maintain effective relationships with the operational management team, primarily the Executive Director position which reports to the Executive Board; to chair regular Executive and Board meetings (all members are volunteering their time); and to also effectively represent the interests of the membership, consumers, and stakeholders of the organisation.

The foundation members of NTAC had, I remembered well, quite deliberately positioned NTAC as a 'broad-based community organisation' in its Constitution. I always had the view that collectively we had the aims and objectives as detailed in the Constitution to uphold; as President I took the view that as we are a small community locally, we couldn't split into three or more different organisations to respond to HIV, hepatitis, and other BBVs. All consumer groups needed to be heard.

My experience on the Board at NTAHC was that acceptance of diversity was not a given even though we all live under a rainbow. For a period we had a person on the Board who

was occasionally ‘on the nod’ at Board meetings. And I would get lobbied by other Board members to have them removed from the Board. And I was like well “No”, because when she’s with it, she’s really with it, you know”. That’s the reality of what we’ve got here, what we include and represent.

Going to the national meetings in my role as President was helpful personally because I was able to immediately get some support from some other Presidents, hear from the consumer organisations, and from staff of other agencies. So some of that was about where NTAHC can contribute to the national agenda; how do we, as the NT, raise our issues that are similar or different to what’s happening elsewhere. For example, the issues of the HIV sector is quite different viewed from ACON versus viewed from NTAHC – and how to actually articulate that.

A relatively short period of time after I was in the role of President it became apparent that NTAHC was not being administered effectively. I consulted with others and took action to ensure the ongoing viability of the organisation. We called for an audit and commenced negotiations with the primary funder, Territory Health, around the administrative challenges that we were facing. During that period Barry Horwood retired.

Colin Burden was a NTAHC program manager working in Darwin at the time. Colin stood up to act in the role of Executive Director. And this is, from the point of view of President, very challenging because of the change of management, the audit of all programs going on, the funders were cautious, and staff were feeling the strain.

The Executive Director position was advertised. Colin was

selected. Colin was an experienced medical administrator and he worked in the role for a little under two years. Colin knew he had limitations in his knowledge of broader policy issues specific to the BBV sector, and the Board knew that, but he also had many strengths. After where we’d been, he was a good appointment. The agency’s programs were operating well, funding was again secured, and staff were, in the main, satisfied and productive. I was preparing to step aside from the Board when Colin came to me to announce he was leaving the position and moving interstate!

We then went through another recruitment process and Alison Edwards was selected as Executive Director. Alison was very quickly across the brief, and was able to contribute very effectively and strategically at both the local and national level. She had good political connections at the Commonwealth and NT level, and with Indigenous people and organisations from her previous roles. Alison identified with the LGBTI community and was willing and able to engage the sex worker and IDU consumers and representative agencies. So she was able to calibrate the programs NTAHC delivered to link these directly to the consumer communities. I think her appointment was a hugely important and timely placement for NTAHC.

During my term as President, the Board agreed for NTAHC to become a founding member of the LGBTI Health Alliance, a national advocacy organisation. I considered this a very important initiative because this entity could lobby for broader health issues than BBV that impact LGBTI people – and that this may reduce the expectation on NTAHC to encompass these issues in addition to its

core business. Related to that – and it didn’t happen in my time, but it’s happened under Bill Paterson’s leadership; is the formation of the Territory Rainbow Alliance. Now, sure, no doubt it has its life force associated with NTAHC but it is a separate entity. You know, it has its own identity, but it’s important that the matters of relevance to the LGBTI and affiliated communities have an independent platform.

Notwithstanding my confidence in Alison’s capabilities in the role of Executive Director, she was unpopular with some, as, no doubt, was I! There was a period of agitation and disturbance which played out in part in procedural actions of the membership and with the support of some Board members which were, in my view, an unfortunate distraction at the time.

Some changes had occurred on the Board. Bill Paterson joined (from memory as Vice President). Trish Crossin (Senator Crossin at the time) was also elected, and Larissa Ellis joined from Alice Springs. Trish Crossin was assisting on the Constitution Review sub-committee of the Board. A review of governance was commissioned by the Board. This was a significant step for NTAHC as it began a process to broaden the understanding of the key elements of governance of the agency, and to provide advice on how to implement change in the governing structure and roles.

Now I was approaching the end of my second elected term as President, feeling quite exhausted after about five years in the position, which included three incumbent Executive Directors. I remember approaching Bill during my term as President to see if he would even consider it. And at the time he wasn’t considering that the presidency was for him. But it became for him. I stood down at the

end of my term. Bill Patterson became President. I recall it being a smooth transition to Bill.

I was aware that given the circumstances that led to my initial appointment as President, it was important that succession planning had occurred, and followed through. I remained on the Board, occupying an ordinary member position for a further twelve months. My observations of Bill in the role of President was that he was very good at it.

At some stage early in Bill’s term as President, Alison resigned. After Alison left Craig Cooper was appointed Executive Director. I was still on the Board at that time. The governance review report was finally delivered. Bill ended up taking that forward – implementing the various recommendations with the Board after my time. That was a good and necessary thing to do.

On reflection, it has been a privilege to support the work of NTAHC over the years, and to try and make a useful contribution where I can. I remember well the many, many people who were impacted by the devastation of the early years of the AIDS virus in the NT and elsewhere. Fortunately, this virus is now more effectively treated, as recently is Hepatitis C.

And always, to me, I always bring it back to that – what do we do about blood-borne viruses today? Who are the people that we need to be working with now? Yes, there’s all this other stuff out here that’s really great to get involved with, but when you’ve only got a few staff, and a relatively small amount of money, it’s important to bring in those minority voices, and to listen. I think valuing that diversity and actually getting its voice in – I think that is so important. I hope I was able to do that in a compassionate way. ♦



Bill McMahon

NORTHERN TERRITORY AIDS COUNCIL
1992–2001

One day the Drug Squad started stalking us out, and they were picking up people when they'd come to get needles and searching them. Anyway, Royce straightaway got on to the Police Commissioner and he had them pulled off and a meeting sorted out, and so we had good relationships with the police.

My name is Bill McMahon. I commenced employment with the Northern Territory AIDS Council in January 1992 and I finished, I think, late 2001. I did just about 10 years.

Royce Dunbar was running NTAC then. Royce was an excellent administrator and also a very good peoples person. He was a good team leader and the people I worked with worked very well together. Royce developed good community relations with the police and hospital etc. so I felt very comfortable working here. At first I thought it might've been a little bit hard but I found I was accepted well, and I accepted everyone else well, so we had a good basis. I found it very rewarding because I'd been working with St Vincent de Paul in a men's hostel out at Bhakita House, up near Nightcliff, and there seemed to be a continuum there. There were a lot of men working here and a lot of them were in, I guess, fairly poor circumstances due to their poor health. So I ended up with a client base at one stage of about thirty-three HIV-positive people.

We started off in Cavenagh Street, and then we moved to Manton Street, and then we moved down over in Knuckey Street. We were there for a couple of years, and then we were further down over in – there's a pile of streets we were in. Cavenagh Street, Knuckey Street, McMin Street, Manton Street and Woods Street. I haven't got the dates but I think I've got roughly the order.

While I was working here I became state president of St Vincent de Paul and I was also president of the Mental Health Association. At that stage I was also the chairman of the Housing Commission Appeals Tribunal, and my assistant was the Ombudsman at the time, Tony Fitzgerald who's since deceased. He was a great bloke too. But I found it exciting because I'd already had the community involvement and I felt I had something to offer these clients, who at that time were suffering terribly because the treatment was only AZT and people were dying, and there was a big stigma in the community. I felt that it was something worthwhile. I had a family with four children

Bill McMahon and partner Sue, late 90's (photo courtesy Bill McMahon)

and they were quite supportive. Sometimes people's accommodation was tough and I'd put them up for a while until the family started to object.

In those days it was a very, very secret business. Confidentiality was so important because we had married couples – the man had been bisexual – and we had women who had been drug users, and so it was very much emphasis on confidentiality.

One of the services we provided at the AIDS Council was transport. I had a vehicle available for use all the time and I used to run people to the hospital. We had a very good treatment doctor here, Frank Bowden, at the time. Frank was there most of my time here, and also there was Jan Savage and she was very good. Frank went on to become inaugural professor of medicine at Canberra University. He's very good in the treatment area or the infections and the balancing drugs, and the clients seemed to have a lot of faith in Frank.

There was also Peter Knibbs. Well, Peter was a saint! Peter and I worked very closely. Peter would ring me up and say to pick up so and so. We worked as a team, and I don't think in my time we never had many disputes in the organisation. We were able to work together – which I gather later they did have a lot of disputes.

I remember after I'd resigned I was called in to be the acting chairman for a while because there was some bloody stupid thing, mainly personality stuff, but in those ten years that I was here we seem to be lucky enough to have the leadership. The president when I came in was Faewyn Goyen.

In those days too we had a health minister called Stephen Dunham, and his brother John was one of the founders of the AIDS Council. And of course John was one of my clients. He was one of my first clients. It was interesting because I was very close to John's mother Maureen, in St Vincent de Paul, and Maureen had pushed me forward as the state president after her to take over. So here I am working for NTAC and I'm also state president of Vinnies and I can remember it would've been probably the '91 May Day March, the procession. I'm walking out the front for NTAC with a placard 'Safe Sex', and behind me is a mother superior of the Sisters of Perpetual Indulgence led by Dino Hodge. He had Terry McClafferty and a few of them dressed up.

What happened was Royce got a settlement and he took off to Cairns and set up a restaurant. Barry Horwood was next. He was a "let's do it" type of guy, but unfortunately that didn't translate over to making sure the finances were right – and so it was more like, "let's do it, and worry about the money later". I think that seemed to compound into kind of a crisis. That was sorted out which was great. I'd been away on holidays and I came back and it was all sort of sorted out.

Chris Day. They had the multiple therapies, you know, more drugs and people were getting better. Well, he just came to me one day and said, "Bill, I think you'll only be needed part-time now. Go part-time." So I went home and had a chat with my wife and I said, "Well, it seems to me if I'm working part-time I'm not needed now." So I just resigned straight-away and I was out of there. I thought Chris was a prick but I wasn't going to fight it. I could see he had some rationality there. What he was saying made sense and I thought "Well, I have to accept it and move on", so I moved

on. I accepted it. We didn't have any sort of meetings about it. I just resigned and I told the others I was going and it was all over.

I suppose most of the clients were probably lower socioeconomic people. I don't remember ever turning anyone away. Some of the addicts were a bit tough to deal with, but in those days – there seemed to be a lot of MS Contin around, the tablets. Heroin has never really got into here. It's always been MS Contin or the other one.

Royce had good communications with the police. I remember when we were down over at the back over here in Woods Street near the NT News building, one day the Drug Squad started stalking us out, and they were picking up people when they'd come to get needles and searching them. Anyway, Royce straightaway got on to the Police Commissioner and he had them pulled off and a meeting sorted out, and so we had good relationships with the police.

Also Royce had a good relationship regarding the beats, because I remember one very prominent citizen who got done. They were lodging charges and I remember him coming in to Royce and he was crying – and a few phone calls and that and it was all over. Everything was dropped. But what they've done since then, I notice now just driving around, all the toilets have been dragged down. Just past Pee Wee's at East Point there used to be a public toilet block and – it was a funny story – and anyway Sue, my wife, was driving with a lady called Wendy Hoy who's a very prominent kidney physician. She was doing research on Bathurst Island and she's world-renowned. So Sue was driving there with Wendy one day and she

spotted Barry outside the toilets, she stops and gives a toot and Barry comes over and he introduces her to Wendy. It's a big social thing and anyway next day Barry was quite embarrassed when he said to me, "Would the girls have known what I was up to?" I said, "No, of course they wouldn't."

In those days there was the real spectre of death with many clients. You could just see that rapid decline in their health. They were having all sorts of infections and rashes and ulcers, internal problems. And then often they'd become bedridden, and then there'd be home nursing and all that to deal with. Once they've built up resistance to the one drug there was nothing left. It was a slow, painful, terrible decline and it was often fairly rapid. I'd been a Catholic priest and I started doing funerals because the family or the partners wanted me to do them. I was doing funerals quite regularly.

One thing I remember vividly was a couple who rented a house in Stuart Park. The guy was quite wealthy and very prominent. He'd come from Queensland and he was dying. He was fucked and he was just waiting. He had a partner with him. He'd been to Downlands College as a boy, the boarding school, and he said he wanted to go to confession. He wanted to square things off as far as being Catholic went. I said, "Well, I'll line a priest up," so I lined up a priest. I thought it would be okay. Anyway, the next day I got a call from the priest saying he felt uncomfortable. He said they were actually holding hands and kissing and I said, "Well, what would you expect? They're lovers. They're in love." He said, "I just found it a bit hard to handle," so he went to the person and he said he didn't feel comfortable with them. And so I went to Bishop Ted Collins – nice

bloke, ex-policeman – and I said, "Ted, we need a gay priest or a gay-friendly priest here because we've got a lot of Catholic boys and Catholics who are dying and they want to sort things out with the church, and we haven't got any bridge there. I can help to a certain extent but they want a Catholic mass and I'm not getting into that. I've left that show behind."

Anyway, he rang me up about three days later. He said, "I think I've found the right guy for you. His name is Peter Woods." Anyway, Peter turned up about a week later. He's an MSC (Missionaries of Sacred Heart), and he was an openly-gay man and he'd written a couple of books in conjunction mainly with a lady whose son was gay. Anyway, Peter turned up and sort of mixed with the mob and he was again, as far as financial support, a help too, but also he could assist with funerals, just at the funeral parlour.

There were a lot of funerals. When I say a lot, I suppose the first year there probably would've been ten. I remember one guy – he wasn't actually involved, an Aboriginal guy and I never had any dealings with him – but he won Lotto, something like twelve million. I gather he had many friends and he was flying them all over the bloody world – these young Aboriginal boys from around Darwin, they're going everywhere. And he looked after everybody's family and that. When he died, he had this huge funeral. He had so many people attend his funeral. A lot of happy memories, a lot of sad ones too.

I remember visiting a guy at Royal Darwin Hospital, and I noticed a tray outside his room and there was a big sign on the door something like 'Infectious Diseases, Keep Out'. So I went in and said, "Have you eaten yet?", because the

tray looked like it was untouched. "No, I haven't eaten," he said. I went and brought the meal in and sat with him. After that I saw Frank Bowden and Peter Knibbs and said, "This is abominable." I had a talk with one of the cleaners and she said, "No, we can't go in there. It's very contagious," all this sort of shit, and they said, "Well, we're going to have to run an education program," – I mean, for the nursing staff. So they did that and of course one of our key helpers was Maureen Dunham. She went to visit John in hospital and he got the same treatment; and the brother Steve became the health minister. So it was good, they did an education program, and all that was about '92/'93.

In the early days we had these emaciated people getting around dying, and that created this public awareness and we got a lot of support. We had Sally Thomas as patron and she was good.



Charles Roberts (NTAC NSP) and Sue – late 90's (photo courtesy Bill McMahon)

In those days you were regarded like leprosy. Somehow or other, you were at fault. There was that fault business, I think. So you needed an atmosphere of mutual trust and confidentiality, and so that provided the need for the Friends group. I can't remember whether it was fortnightly but sometimes it would be weekly, depending on what was going on, and we used to get turn-outs. It seemed to go really right up till nearly the time I left, and people like Knibbsy could come along.

I remember there was a lady who was a psychologist and fairly well-up in the Health Department. She was sort of fairly well-advanced and she was going on a trip to Europe, and she had a Catholic background. There were an Italian order of nuns at Nightcliff. I took her along, introduced her to them and they organised for her to have a couple of weeks in Assisi. That was a transforming thing in her life, just being able to wander around Assisi. She came back and she died not long after, but she was happy.

I felt that it was important that people who knew they were dying were able to do any unfinished business. One of our keen members of Friends – it was quite sad – he finished himself off with just a plastic bag. That knocked everyone around, but yet no-one got too upset in the sense that we all accepted that it was his decision and that's the way he wanted to go and he'd had enough.

No-one would criticise if someone decided to go. We'd all offer support to keep people, to try and support people, but when they decided, well, that was their decision. It was just sad, but that was the way it was.

People died, some would come and some would go. I remember I found it very hard. We had a few married men

and women, that was very hard – they didn't want to mix; it was strange, but we supported them. But it's a bit like the Camus story, isn't it, *The Plague*: all of a sudden you wake up one day and it's all gone. It was a bit like that, wasn't it, and the medication came in, and so while it was there we were all caught up in it trying to cope the best we could.

John Spellman set up just over here – near where that bloody terrible looking building [Evolution Tower] is now – and he had this bar called Mississippi Queen. I remember quite a number of times people would wander into the AIDS Council and they'd be broke and homeless and they'd be HIV. Anyway, I had an arrangement with John and I'd just take them over to Mississippi Queen and I'd say to John, "This gentleman is in need of – ", you know. He'd say, "What in the bloody hell do you want me to do about it?" This is John. I said, "John, this man is very in need." I never said he's HIV, but I think John could get the message. He said, "Right, I've got a spare bed there," and he had these bloody caravans, he had about three classes of accommodation. I told him the bloke was broke and he said, "He might have to do some work," and the bloke said, "Yeah" – and they never had to do any work. And then I'd find them some proper accommodation elsewhere.

Spellman had a big dispenser with condoms on the bar. We always kept that topped up for him. We'd keep him in condoms and if anyone wanted the needles or anything, they knew they could just slip over there and we'd fix them up. So I regarded John as one of our good supporters. A lot of our guys thought he was an arsehole but he was like that with everyone, that gruffness. I found he had a good heart on him. That's what mattered. ♦



Tony Hand

AIDS COUNCIL OF CENTRAL AUSTRALIA

1991-2006

Because if someone had have walked in the door and said I'm HIV-positive, or I want to get tested, or what's safe sex, or you fucking dirty poofers or whatever - we had to deal with that and we actually did deal with it, just like everybody else did, with solidarity and strength.

Front: Di Lane, Tony Hand, Back Di Lyn, Sue Grant, Sarena Ruediger (photo courtesy Tony Hand)

For me, the AIDS Council, especially in the early days when it was ACOCA, was very fresh, very primary, very under-resourced but full of enthusiasm, dedication and a willingness to tackle a big scary issue and do whatever was necessary. I was asked by the coordinator at the time, Jim Buckell, if I would do the needle exchange one day a week as a peer educator. I went, great! Peer educator. That was in 1991 and back there was a potentiality and a growing concern that HIV would go bananas in Central Australia.

Anyway, Jim said to me "Tony, you're the only person I know who's injected drugs before, and would you be this person". So I went, "peer educator? Okay sure." I didn't actually know quite what that meant but I did know it was going to be a challenge. The Outreach program was funded initially for one day a week. There were the usual service visits you do in the beginning, the getting to know me thing. Bloody hell I had dreadlocks, what looked like jail tattoos and, oh my God, bare feet. Talk about look the part.

I was 26. I was from New Zealand and lived in very rural and remote parts of northern Western Australia, so I didn't really know much about AIDS at all, or HIV, it was just AIDS then.

The first taste I had of anything to do with the global reach of HIV/AIDS was the Big Tease that was happening in Perth around 89/90. Ricky Lee Jones, Whoopi Goldberg, and other famous people had drawn graphics and slogans on T-shirts, it was a huge AIDS awareness project and it was held at the Burswood Casino. Jim took me along to it; I then discovered that it was probably more of an issue than I was aware of. Jim had already a big experience with HIV because of a friend of his Eric Michaels, who came here from America and worked at the Central Land Council, he wrote the book *Unbecoming* documenting his experience of living with HIV.

I grew up in the shearing sheds, and never thought I'd be asked or have input into a primary health project like injecting drug user outreach in my life. Who'd of thought

that one day a week project would be the start of a career that would take me to places and allow me to do what I didn't even dream of back then. However I wouldn't have been able without the professionalism and dedication of the people who mentored and supported me like Jim, like Sarena Ruediger, Alexis Young, Di Lane and Kerri Leach.

Back then, in the early '90s, we were dealing with new things that everybody else in Sydney, Melbourne and all the other big centres had had a taste of already. There were three of us when I started at ACOCA with a board of seven or nine and community supporters.

The first coordinator of was Megan [Brooks]. She lives in Sydney now; it was then the Central Australian AIDS Action Group. I first met Megan when the Action Group was above a pharmacy in town, and it was a rat infested shit hole which smelled of ether that seeped from the camera repair guy's office down the hall, an alarming smell to greet people accessing to AIDS awareness information, condoms and lube. David Ben David was the next co-ordinator after Megan. The AIDS Action Group finally grew out of that home and we moved to across from where Malanka Lodge was, at the front of Gagliardi's on Todd Street. When Jim left as the coordinator, Di Lane took over. She did a fantastic job. I can't remember what year that was. After Di Lane a guy called Tony Cooper took over. We nicknamed ourselves Tony Cooper and the ACOCA nuts.

I remember the first time we visited the police – it was to talk about the needle exchange and to introduce myself as the outreach worker and just to answer any concerns that they might have had. Anyway, Sarena and I went to this meeting and there was this row of chairs in a semi-circle

and we had two chairs in front facing the semi-circle, we sat down and this group of cops walked in, sat down and looked us up and down. I went "Hi, my name is Tony and I'm from the AIDS Council, or from ACOCA, we'd like to talk to you about the needle exchange and how we've been going for a little while now and it's really great you guys aren't giving it any attention, you know it's about harm reduction", and all of that kind of stuff. They listened, looked at each other, said "no worries, thanks very much", got up and walked out. Sarena and I sat there; we looked at each other and said in unison "that went well?" We went back to ACOCA satisfied we got the message across, we think. Well, interestingly enough one of the people in that room is now a government advisor who I've had dealings with in my work for the NT Government.

ACOCA when I first started was very much connected with Clinic 34, which was CDC [Centre for Disease Control]. We had to be aligned with other services, and there was an educator called Sue Grant also played a big part in supporting the cause and the many campaigns we organised.

I will never forget when the Ankali Project came to town and we did the Ankali Workshop designed around friendship and mentoring support for someone dying of HIV/AIDS. Ankali was huge a milestone in terms of HIV support and bringing the issue of death and dying to the forefront of reality for a lot of us who had experienced what was happening in other centres. The significance of the workshop was not just for us at ACOCA, but for other people who were supporters of the issues. There were some positive people, some gay men, people who had already supported someone who had died and other

community members. It was a mixed bag of affected people and sentiments were high and raw. So, you could imagine the type of emotion and drama for those people sitting in the room listening to the facilitator talking about caring for someone to the end. Ankali was, if I remember correctly, based on the Elizabeth Kubler Ross philosophy of caring and supporting people through dying and death.

I suppose we were, as I said, sheltered from a lot of stuff that was going on in Sydney and Melbourne and other major centres but that didn't make it any easier.

People had died when we were around and my colleagues at the time had supported people at their most serious illness and death. Some people diagnosed as positive left town. Also, some people diagnosed as positive decided they would be treated at other places, rather than in Alice Springs for fear of stigmatisation. There was a small group who didn't identify at all and who could blame them, and those who totally identified, which in this environment took absolute guts man. We were educated enough to know back then that there was so many different way you could stigmatise and discriminate against someone without even knowing it. So, we were very conscious about what we were learning and how we were delivering our services, and we didn't take it for granted.

One thing we did have in abundance was skill and knowledge around empathy or competence around empathy and a willingness to really show it. Saying you were non-judgemental was one thing, demonstrating it was quite another. I suppose, we really just embrace it as it is and was. After all we didn't know where this disease was going to take us and for how long, we just knew we

had to be ready for anything. It was about health rights, okay? In health, those rights are everybody's rights.

I was lucky to have worked with some very experienced professionals in that time of ACOCA that provided me with a diverse skill set. My colleagues had experiences working with different minority groups, or marginalised groups and discrimination issues in the past. So, HIV/AIDS was just another one of those issues but it was urgent and unknown. In the early days we had lots of people from all over telling us about how we should be doing things, but they didn't live here or have our associations just as we didn't live where they were or have their experiences. What was important to us in Alice was the validation we got from those who understood the complexities of being in a town like Alice, that we were doing great with what we had, and that this horrible fucking thing was affecting us just as much as anybody.

Because if someone had have walked in the door and said I'm HIV-positive, or I want to get tested, or what's safe sex, or you fucking dirty poofers or whatever – we had to deal with that and we actually did deal with it, just like everybody else did with solidarity and strength.

The Summer of Safe Sex campaign was a massive event held at the Todd Tavern, the local red neck pub. The Painters and Dockers from Melbourne came up and played at the event. It was fantastic, very well attended by different members of the community. It was a big community event and very well organised.

We had World AIDS Days, Candlelight Vigils, all the events that promoted raising awareness nationally. I remember World AIDS day sausage sizzles in the Mall standing in

forty degree heat cooking endless sausages with onion and rapidly drying out bread. Holy crap my sweat (and a few tears) literally went into those BBQs. The Candle Light Vigils where there'd be eight to fifteen of us standing in the mall freezing our fucking tits off, shivering in icy winds, constantly relighting candles and remembering friends, lovers, brothers, sisters and people we knew who had died, standing as a community in reflection and mourning.

That whole ACOCA/AIDS thing permeated through our social lives, which was also part of the deal. Everywhere we went, we were the people who worked for the AIDS Council, even today. I'll never forget doing some education in another job role a few years ago for an organisation on an Aboriginal community west of Alice. I went to the local shop at lunch time where a group people were sitting out the front and one of group calls out, "Hey, I know you, your that AIDS fella." I hadn't worked for the AIDS Council for more than 10 years by then. Nice to know we had an impact!

When I got the job at ACOCA as the needle exchange project officer, I went to this international conference in Melbourne, and next minute I was the national secretary of AVIL (the Australian IV League). I worked with people like Marion Watson, David Herkt, Jude Burn and Annie Madden and some other really experienced people who taught me heaps, but it put Alice Springs on the national agenda for injecting drug user issues....hooray!

My first presentation about ACOCA and the needle exchange project was for government alcohol and drugs agency. It was probably '91. There was one person attending and I still know that person today. I had, you know, the dreadlocks then and homemade tattoos, hippie dress

code. But Margaret Borger was very patient with me and my little presentation. It was with transparencies back then, with an overhead projector. You took a transparency, put it on, did the spiel, took it off and put on another one. Well, we had to; there wasn't much choice back then. There was no such thing as data projectors and laptops were just new, USB ports and sticks were probably just forming in someone's imagination.

The gay men's community was small, the lesbian community was bigger. At one dance party we had twelve men and fifty women; slim pickings for us boys This hasn't changed much over the years. I'll never forget the time there was this little gay rally in the mall, and I mean little. Three men with a candle standing under the sails in the mall chanting "we're here, we're queer, and we're not saying sorry." A group of friends and me were on our way to attend and show our support. On hearing the chanting my friends and I started chanting "we're here, we're queer and we're not going shopping." If you were limited to K-Mart and one men's clothing store called Men's Land, which probably should have called No Men's Land, you'd protest too. This was probably about '93.

We did have these dance parties called Asylum. They were going when I arrived in '90 to when I left for Sydney in 95. They were pretty fucking wild and great fun. We actually had a 50th anniversary party of Asylum one year. Not fifty years, fifty dance parties because there was one a month. The anniversary was at a place called Honeymoon Gap and there were people from all over Australia who had previously lived in Alice. The dance parties were fantastic, a really organic community event. We used to set it up, drag a huge heavy dance floor from across town with

lights, extension cords and a box of records fund raised for. It wasn't ACOCA's, but the staff from ACOCA including board members, gays and lesbians and community supporters made them truly Alice Springs. ACOCA always had a presence though, whether it was with signage, posters or flyers, or condoms, you know what I mean? All of that health promotion stuff. We went from a pizza parlour to the bowling alley, to an underground sort of night club complete with fake palm trees and fairy lights. One of the best things was the look on the faces of the staff who worked at these places who could not believe what they were seeing. They never said a word to their credit, but you could imagine what they were thinking. Magda Szubanski apparently came to one of the dance parties, I wasn't there that night, damn it.

The parties were one thing, but we also had some pretty big events here in terms of conferences and events. One in particular was the first national Aboriginal HIV conference that happened here I think in '93, or '92. And that was a big deal. There were positive Aboriginal people, their supporters, an array of health professionals and service providers; it was a very significant event for the time.

Anyway, so there was education and there was promotion of ACOCA through the dance parties and other occasions, of course. But of course it was going to be like that, we were the dance parties and we were ACOCA and we were the community. So you couldn't really escape the issues, ACOCA had a parallel to our lives.

An enormous amount of great work was achieved back then by everyone and I feel very privileged and honoured to have been a part of that early foundation laying.

I came back to Alice in 2000 and Sue Fielding was managing ACOCA at that time. Then a guy called Eric took over in about 2001/2 and it wasn't very long after that ACOCA started to lose its lustre and integrity and community support. Many rumours at the time tried to explain why it all went horribly pear-shaped and accusations were flying left and right. Employees left town in a hurry, Eric was never seen again. Holy crap, one minute ACOCA was doing fine, next minute it was a laughing stock and closed. Very sad.

I think about eighteen months went by before there was talk of the newly name Northern Territory AIDS & Hepatitis Council annexing what was ACOCA. Frank Farmer was instrumental supporting and driving the initiative, and Jill Meade was employed as the manager of NTAHC Alice Springs branch. I was employed in 2005 as the HIV/Hep C Support Officer then later in a community development role. Heaps of work was done to re-establish the service by the new staff team with support from Darwin and the community but there's nothing like the passing of time, a re-branding and a change of address to revitalise anything. There were many highlights from that time I could touch on but that's for others to tell. I left NTAHC in 2007 to deliver nationally accredited training for the NTG. Even though things have changed service wise, the dedication and commitment of the people who are part the amalgamated organisation continues to provide quality care and support to HIV and Hep C affected communities and people across the NT. May the bright star of responsive and decisive community action shine on. ♦



Phil Walcott

AIDS COUNCIL OF CENTRAL AUSTRALIA

1993–2001

The candlelight vigils would be in May and sometimes we'd walk up and down the mall, just silent vigil stuff, and then there'd be some readings, and there'd be a bit of an after party thing. The cohort of the gay and lesbian community was really quite strong back then.

I arrived on the 26th of August 1993 to start with the AIDS Council – the AIDS Council of Central Australia, it was known as. ACOCA was its acronym. So it was down on Todd Street, further down past the mall, and is currently The Medicine Tree and Gagliardi's was next door. We were a tenant of Mr Gagliardi. He'd roll in at 9:10 on a Wednesday morning to collect the rent. Tony Cooper was the coordinator at the time. Tony and his partner Mel. Tony Hand was working as the needle exchange person, and he was good friends with a friend I'd made in Sydney by the name of Jim Buckell. They were actually partners at one point in time. Paola Nadich was the women's educator. Barbara Crowley was our bookkeeper, and Jana Obst was the social worker. So yeah, just a little band of people.

I got very friendly with John Cross who was the HIV educator at Central Australian Aboriginal Congress. We did a lot of work together, intercultural stuff. Looked at things like beat programs and trying to target M-S-M rather than G-A-Y, because they seemed to be more at

risk because they weren't identifying. That kind of stuff. John and I, we'd go to Tennant Creek. We just did some outreach kind of stuff there.

I got contracted to Congress for five weeks to help John set up Anwernekenhe conference out at Hamilton Downs. Paola was the president, I think at the time. It was exciting and I was just really delighted for John, because it'd been a passion of his since he was very young. He had this dream of bringing gay Aboriginal men together and being recognised for being gay and Aboriginal.

My former partner Alan got to come up, because he'd been involved in another one prior to that. Not Anwernekenhe but he'd come to Alice Springs for an AIDS conference at some point before I got here. It was just very exciting, because out at Hamilton Downs there was nothing. There was a generator and you had to run computers off. So by the time that people from the Commonwealth come up on the Thursday, we actually had documentation from workshops that we'd generated.

Phil Walcott - Northern Territory Archives Service, Peter Strickland, Spur's Bar Visitors Books, 1983 - 2005, Volume 2, 18/01/94

First National Aboriginal & Torres Strait Islander Gay men & Transgender Sexual Health Conference

ANWERNEKENHE



ANWERNEKENHE

Hamilton Downs
Northern Territory, Australia

October 31 - November 4, 1994

It was great. We brought together all these people from all over Australia. John and I put in a report. We got \$35,000 in Government grants. Nothing from the Northern Territory, mind you, but we got I think 25 thousand from Queensland and 10 from New South Wales or something like that. You know how you send off submissions, cross your fingers?

It was John's dream, and he cried when we were finishing up. I can just remember – and he just needed to be by himself. But he realised his dream and I was just so delighted for that to have happened. It was the first time in the world that a group of Aboriginal men and Sistagirls had come together to talk about HIV and AIDS. The conference subsequently generated national policy on HIV and Aboriginal and Torres Strait Islander people. And the dream is still going. We just had Anwernekenhe number 6 in Alice Springs, November 2015.

I left the organisation in November of '94 and went to work at the Health Department. There was a bit of continuing connection. John became quite ill with depression, not very long into my time there. It was kind of – he was your friend, and you're also

working with him a professional level, but it was obvious by then that boundaries in Alice Springs get a little bit skewed from time to time. You still respect, and you have to respect confidentiality certainly, and people's rights to privacy, but you just know people socially and then sometimes you just have to work with them on a professional capacity, so you've just got to draw that you know. Unfortunately, John completed a suicide in about May of '95.

I subsequently became a board member again, after a period of time. There was a lot of stuff that hit the dumper, because there was a guy called Eric that was appointed as the coordinator, and then he called himself the managing director or the chief executive officer, and he ended up paying himself twice whatever. That was the demise of ACOCA.

ACOCA was dissolved, reluctantly, because it was running separately from the Darwin office. It was receiving its own funding for a period of time. Then Frank Farmer from Darwin NTAC came down and paid some visits, got a bit of community consultation together and said, "Well, do you think Alice Springs is ready to run its own? It would be a subsidiary of Darwin," and yeah, sure, okay. So that's where all that sprang.

I'd attend the candlelight vigils from time to time, some of the fundraisers. Kalika Murti Suich who is a yoga therapist and social worker from the town would sometimes lead from a yogi kind of perspective. She'd have blessings and stuff for the vigils. The candlelight vigils would be in May and sometimes we'd walk up and down the mall, just silent vigil stuff,

and then there'd be some readings, and there'd be a bit of an after party thing. The gay and lesbian community was really quite strong back then. It was a bit enclaved because it hadn't received quite the same recognition as it does now, where now it's all a bit like, "Yeah, so what?" Everyone's got a gay neighbour or gay grandmother or lesbian aunty, so it's not any sort of big deal. But back then it was.

The biggest concern when I was here was that HIV would get into the Aboriginal communities, and given the high rates of STIs, that it could really decimate. There was a lot of MSM sex going on in the river, and a lot of people being pretty promiscuous.

Well, they worked in with Michael Howard who was working for the HIV Unit at the hospital, and Condo Man was adapted to here. This was the later '90s, I guess. Because it was gradual introduction stuff. But fortunately, through a variety of programs and just getting people to adopt safer sex practices and that sort of thing, it didn't get in to that, it didn't decimate. Prior to me coming here, on my trip overseas, I'd gone to South Africa and it was just rampant, absolutely. I'd go along to things in Johannesburg, like health clinic meetings, and the denial level was just huge in black South Africa: "No, it's a whitefella disease. We're not going to get it."

In 2001, Kalika and I set up *Alice IS Wonderland*, which is the dance parties. I'd already set up *The Rainbow Connection* – the first gay and lesbian B&B. Off that, she and I developed the *Alice IS Wonderland* stuff. Well, there was ten weeks' worth of stuff in the newspaper. We had condoms, gloves, all sorts of educative material was available there for

people to use on the night. We'd hold them out at the racecourse, the Gap View Hotel, the Memorial Club, wherever. We'd move it around to keep it a bit interesting for people. *Alice IS Wonderland* was designed to just the bring the community together in a jovial kind of fun way.

The culture of town was homophobic and fear-ridden. We were getting letters in the paper from the Christians, the born agains, Potter's House and a few of those sort of organisations, that the mosquitoes in town were going to bite us people who all had AIDS and fly out to the ponds and lay eggs, and it all was going to come through the water system and it was going to infect everybody in town.

Then all the other conspiracies that would come through, the green monkey story because media thrive on conflict. They just love it. Anything that brings up conflict, though, they'll bond with it, and just spread its fear needlessly into people. Certainly it was one of those things you had to just try and have some sense of credible evidence. Again, it was all about evidence-based stuff.

When I was at ACOCA, we tried men's groups, and mixed men and women. So anyway, you just go on and just did it, because it's what you do. But it was an exciting time to get to know Alice Springs and the country and stuff, and I was living in a group home.

Well, changes over time when ACOCA just became part of NTAC. But ACOCA reached an end and then NTAC decided to – Alice Springs as an outpost again.

Prominent achievements? Certainly Anwernekenhe, being involved in that. Some of the men's projects, and just helping to elevate awareness as an educative process

through the school system, and sporting clubs, and whatever groups that people were moving. I guess I was probably only there about fourteen months as a member of staff. The community action at the time was hostile, building into tolerance and then becoming acceptance these days. Because I think that's probably where it's morphed into. We'd got the beat program in Alice Springs and Tennant Creek. John and I would go up about every two months. Going in the pubs and toilets, and service stations, and just getting paraphernalia out there around. The old Cover Yourself posters. There's still one in the airport at Alice Springs. Well, it's pretty old. Yeah, that was more of an education awareness type program.

I'd often get phone calls at *The Rainbow Connection* for people who'd want a bit of sex. "Is there anyone there? Any workers?" Because we've had occasionally had sex workers in town who would advertise through the local press. Male workers, yeah. But I'd have people who would come into town who weren't necessarily staying at our place, but just wanted to know what the local sex scene was like. I don't know. "How long you here?" "One night." "Can't you go without it one night? Be okay. It won't fall off. It'll be all right." Anyway. So from what started off as a bit of a focused reason for being here, it just rippled away into what it's become, and I've just had a whole bunch of really nice experiences living here. ♦



Jim, Paul, John, Craig & Crystal – Hot as Hell prize-winning float, Sydney Gay & Lesbian Mardi Gras 1988



Paola Nadich - Northern Territory Archives Service, Peter Strickland, Spur's Bar Visitors Books, 1983 - 2005, Volume 3, 16/02/02

Paola Nadich

AIDS COUNCIL OF CENTRAL AUSTRALIA

1993-2010

I remember being in an ad with my son - who was probably about five or six - and a photo was taken of his hand in my hand together, and then there was this whole hoo-hah because I had on a very masculine watch at the time, so people assumed it was a male's hand, and then there was a bit of hoo-hah about having a man and a child.

Interviewed by Panos Couros on 24 February, 2016

PN I would say the early '90s I first got involved with the AIDS Council of Central Australia, when it was in Todd Street at Gagliardi's. That was for a few years, and then I left Alice Springs and I came back to work there in '99 because I had a job as a youth harm reduction officer, and did that probably for a couple of years. On and off, after that until about 2010. Since then, I've not had much involvement.

PC Okay, so there are a lot of stories in all of those periods, so the first time you were with Phil and Tony?

PN I was volunteering then around that time, and then I think Phil turned up a bit after that. There was one period there for maybe about a year I was even chair because nobody else would do it.

PC You did quite a few different roles there?

PN Yeah, I've done a fair bit through the needle and syringe program as youth harm reduction worker, I did a bit around sexual health stuff as a women's educator, working really closely with Clinic 34 and [Central Australian Aboriginal] Congress.

PC And how was that work in the community?

PN Look, I think it was okay. When we did do community stuff, I allowed myself to be directed by Indigenous workers and followed their lead. In some ways it was quite difficult because for a lot of people English was their second, third, fourth language. Sex wasn't really talked about, but you did the best you could.

PC So did you mainly work with Aboriginal people?

PN No, it was pretty mixed, it was across the board. And a lot of stuff also with health workers like nurses and just other organisations.

PC Were you personally affected by HIV and AIDS in any way?

PN Not HIV, I've got Hep C. I've known close friends who are HIV-positive, and I guess it was going through that. Probably the very first person who I met who was HIV-positive was when I was about seventeen at my aunty and uncle's dinner table. They were very straight, middle class people in Adelaide and their connection with this was around football, but they were very nonjudgmental and accepting people at the same time.

PC When you were with the Council the first time, what sort of programs were being run?

PN There was a support worker, there was a needle and syringe program. I guess I remember the people more than the programs, so there were people like Di Lane, Di Lyn. I remember being in an ad with my son – who was probably about five or six – and a photo was taken of his hand in my hand together, and then there was this whole hoo-hah because I had on a very masculine watch at the time, so people assumed it was a male's hand, and then there was a bit of hoo-hah about having a man and a child.

PC I've heard of Di Lyn and Di Lane...

PN Di Lyn and Di Lane, Sarena Ruediger. Tony and I have been friends for a very long time, and because I got involved through knowing that he was involved. Alice Springs is a bit like that – it's not what you know, it's who you know, and sometimes you don't even need to know anyone, you just need to have the right personal attitudes.

There was that thing of, "It's not in the Indigenous community, but when it does get in there, it's going to go like wildfire." And my understanding is we're still saying that, which I think is quite interesting.

There was a lot of support for the gay community. And then a few more years later, diverse funding to the queer community, generally. The AIDS Council used to be quite strong in that, advocating for and supporting and providing a safe space and organising events.

PC Can you tell me about some of the events that come to your mind?

PN There were a few girls around at the time, and we were quite strong in supporting them, and tried to do monthly dances and get performances happening. There was a really young drag performer from Darwin who came down a couple of times, I can't remember her name. Really skinny, tall, quite amazing.

PC From the Tiwi Islands?

PN No, she wasn't actually Indigenous, it was a non-Indigenous person, Grey. I think that was a really good time. We did things like interviews with CAAMA Radio for one of the World AIDS Day weeks. We got CAAMA to broadcast from the mall, we did an all-day broadcast. People like James Ward were around, and I think even in the earlier days, Dr James Ward was around.

PC Okay, what was his role?

PN I think he was doing research at the time, so he was quite closely associated with the Council. Who else? Jim Buckell, I think it was Jim and somebody else who

got ACOCA happening in the first place. So they were quite good days when Central Australia had its own AIDS Council that wasn't attached to the Darwin AIDS Council.

PC Were you here when ACOCA fell apart?

PN It fell apart, yeah, I was around. There seems to have been lots of people going "It should be this and it should be like this". And it's across the board in organisations, really, and I'd imagine Darwin as well, where people come from somewhere else and go, "We should do it like they do it", and then change everything, try and do that, and then it doesn't work and then they leave. Then I think the locals get a little bit disillusioned and get a bit burnt out from being the only ones doing it, so then they fall away as well, so then you've got nobody. Then you've got the department. But I think the department were always a bit "Why do we need two AIDS Councils in the NT?"

PC There was a bit of a scandal that happened, wasn't there, where there was someone called Eric. The fraud squad got involved?

PN Yeah, was it that bad? Yeah, right.

PN I think he was ex -military. I remember that his house burnt down.

PC Yes, that's when ACOCA fell apart.

PN I was involved with the Territory Users Forum, and Charles Roberts was around then, yeah. And Charles Roberts used to be a really strong drug user advocate who was quite loud. So we still had contact with NTAC

around that stuff, so when Frank Farmer came down to find a place and to get that all happening, I was in contact with Frank and we sort of did, myself and another person, Jodie Hill Carr, I can't remember her name, I asked if we thought this was a good place. So I guess in some ways, it was the drug user advocacy that kept their fingers in the connections, really. And then it became a bit more focused around the Hep C program and then NTAHC became the AIDS and Hepatitis Council.

PC And how did you feel about the integration? Did it work in the beginning?

PN I think it was a bit mixed, but I think there was also an understanding that something had to happen and if that's the way it was going to go, then so be it. And Frank [Farmer] was quite good in how he went about it. And I think this place – it's good to see that it's still here and it's still happening here and even since then there have been really sort of highs and lows here.

PC Any highs that you remember?

PN Well, me, of course! But I guess for me, it was that time that I was here and we did have a pretty strong Indigenous connection and I did have the sister girls coming here and hanging here quite a bit. I had a couple of young Indigenous workers who were trying to mentor into being educators. And I guess for some of those people, it started them on that journey of knowing that they could have a voice – because they were quite smart young people. And they've all dispersed now.

Yeah, a young HIV man who I supported who finally passed away, Tristan. That was a pretty sad time because he ended up living in Melbourne in the hospital there away from everyone, away from his family. I think in some ways, he wanted it like that and in other ways, that was sort of difficult for him. That was around the time when the movie that was filmed in Central Australia, *Sampson and Delilah* came out.

Then there was also really low times around that time as well because things were always changing at the Top End – new directors, all again with different ideas of how things should happen down here, or really not even supporting down here at all. Yeah, it got to the point where I was actually made redundant, which is probably why I've nothing to do with the whole service for quite a few years because I wasn't very happy with the whole process.

PC So would you say there was a lack of understanding, where there was a miscommunication?

PN Yeah, I think so. And not really I guess necessarily including the community in that vision. And there's been a little bit of forgetting about the old people who put lots and lots of hard work in to this area and this field for a long time. And yes I think you've still got to nurture those people – like Tony Hand, for example.

PC What do you think your personal achievements were?

PN Probably the stuff around the Sistergirl support, and I worked fairly hard on advocating for drug users as well. I think that whole community were very comfortable with coming here, and that was a bit

of a double-edged sword.

Frank was, I think for a lot of us, there was quite a love-hate relationship with him, but I think he did a lot of good work for NTAHC and he provided some sort of consistency because he was there for quite a few years. And he was quite supportive across all the programs – and I think that's maybe one of the challenges for NTAHC is there are so many different groups in a way that had to be supported and nurtured and that if you're not the right person, then it can easily just swallow you up and spit you out.

It's good that NTAHC's still going and it's good that it's still got a place in Alice Springs. Maybe one of the highlights, I had a couple of women's, not retreats, but a couple of communities had a few days women's programs where it was not just about sexual health, there were sort of things like dietary stuff and diabetes stuff, but we all worked together to deliver those.

PC And that's all part of the holistic approach to health?

PN Yeah, that's right, I think so too.

PC And can you think of one favourite moment?

PN One favourite moment? I think that I was quite proud of the broadcast with CAAMA in the mall and that was just before I left. I thought that was really successful and that had a good thing. That was probably 2009. So we had an all-day broadcast and just kept bringing up issues for HIV and people like James Ward being interviewed. There were a few other people, but I can't remember who they were.

I guess I'm a little bit surprised these days where it doesn't seem to be quite so much support for the queer community and even though it's not completely tied in with HIV and Hep C, I guess it's just that supporting the...

PC Because you say that about here – Darwin NTAHC works with the Pride Committee really closely.

PN Well NTAHC down here used to drive the whole Pride stuff and that doesn't happen anymore.

PC But do you think that's also a product of Pride actually coming in its own thing?

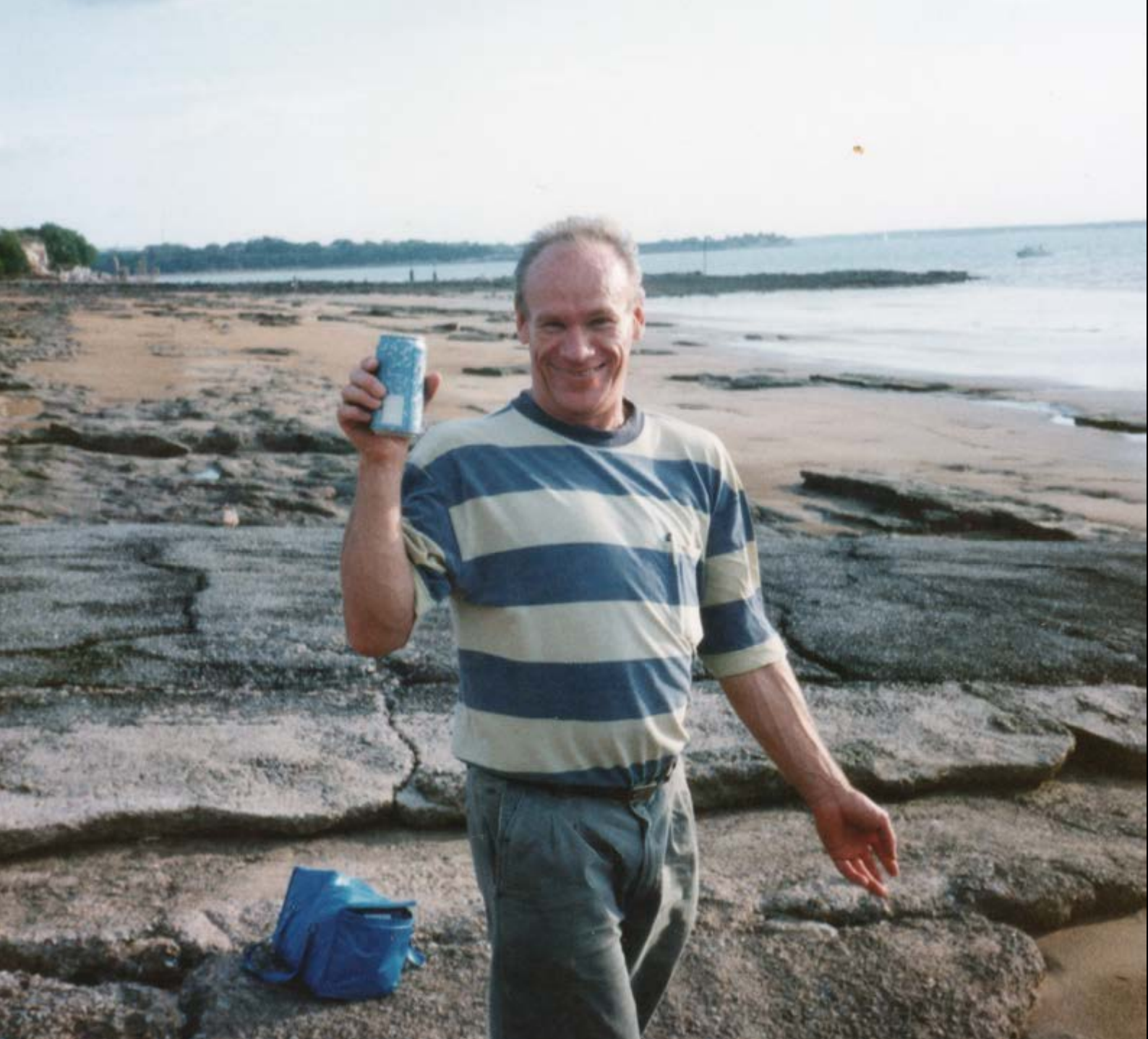
PN Possibly, possibly, yeah. And whether that's a good thing or a bad thing, we don't really know. Whether that came out of, there were actually a couple of people here who just went, "We don't care if we're not being supported, we're doing it, anyway, we'll do it ourselves".

PC Okay. Do you have any more to say?

PN No, that's fine, that's good for me. ♦

Paola Nadich, 2016 (photo Panos Courous)





Paul

NORTHERN TERRITORY AIDS COUNCIL / NORTHERN TERRITORY AIDS & HEPATITIS COUNCIL
1995–2012

I'm still here. I'm going strong. I'm absolutely compliant and enjoy my job. I work full-time as an alcohol and drug and gambling counsellor. I always look forward to engaging with NTAHC events and staff, and I just want to make it totally, totally, totally welcoming.

My name's Paul and I've been involved with Northern Territory AIDS and Hepatitis Council (NTAHC) and the Northern Territory AIDS Council (NTAC) over many years, since about 1995 when I came back to Darwin. As an HIV+ person, I was involved with the support group, Friends NT.

Friends NT was a support group for people trying to understand what was going on. At that time, people really didn't understand what to expect. Trying to get support because you felt so isolated with the community, being able to talk about that part of yourself. I was very conscious of that because of the stigma, the possible discrimination that I had faced over the years prior to that, so it was a relief having a group.

With NTAC relocating from Carey Street to Manton Street, I got involved as a volunteer with NTAC and doing various jobs and positive speaking. I was asked whether I would like to be the Co-ordinator of the Friends NT group and I thought, "Well, I can do that." I was at NTAC usually five days out of five. It was a good experience. It gave me a lot of insight into the

complexities of what was going on for a range of different people. Because I only saw the world from through my eyes, it allowed me to see so much more. Working through that group was on a fortnightly basis between people getting their Centrelink payment, so it was in their off week when they were probably not able to afford much, and so we used to put on a few beers. We were very conscious of the type of foods. NTAC provided us with money to put on those events, and we even bought a barbecue so that we could have more variety.

That happened for quite a while at the downstairs area at NTAC in Manton Street. On a nice evening, we'd even have the barbecue under the big tree at the back, and it was just lovely. But it progressed to the point where we realised having it at the same place every time, that we needed to generate some other interest. So over time, there were quite a few community people who put up their own homes as a venue so that we could sit down and have a really lovely dinner and engage different guest speakers on topics that the group recognised they wanted a bit of help with. It just flourished from there.

Paul, 1997 (Photo David Taylor)

Apart from that, I was also HIV+ rep on the Board for quite a number of years. One of the benefits of volunteering was that I actually ended up with a full-time job at Danila Dilba because of the volunteer work that I was doing – not only with NTAC but with Family Planning and Danila Dilba at that time. And I remained on the Board as an ordinary member for quite a time.

There were discussions around the drugs. I was on AZT for quite a while, even earlier than coming back to the Territory, but there was D4T, DDI, 3TCs. They created wasting. It's something you live with and go on from. I used to do lots of education with high schools and assist Jan Holt as a public speaker. I must have talked to thousands of high school students over the years, which was rewarding.

Compliance has always been a big thing for me. Understanding some of the lifestyle changes that I needed to do and quitting smoking was a very big thing. I just went cold turkey with that. Alcohol and recreational drugs, well, that dwindled to the point where it just doesn't happen for the last twenty years. I know that I need to do a certain amount of exercise. I need to eat proper food, so changing the diet was very, very important.

*Eat, Indulge, Connect*¹ was a very good thing to come up from NTAHC. The way that the girls used to engage with us was just beautiful, because it wasn't just showing us the foods but it was why those foods, and where they fit within a person's diet, and boosting energy levels and helping the immune system. Ollie the chef

was very engaging and wanted to make sure that we really understood the information. It was such a friendly atmosphere for us and some of the staff from NTAHC in how we got together. It was something we really looked forward to, and I do miss it as it was.

The other person who I really liked to engage with was Jenny McDonald. My connection with Jenny goes way back to Fairfield Hospital in Victoria where I used to talk to her around the various topics in understanding HIV and nutrition. When NTAHC engaged her to come to Darwin and I realised who it was, I just jumped at that opportunity, and many times after then too, to engage with her because she was a very knowledgeable person around HIV and nutrition. We used to go to Clinic 34 mainly to engage with her but she did do some workshops and forums.



Mim O'Flynn, Jenny McDonald 2011

¹ *Eat, Indulge, Connect* is a support program dealing with nutrition and cooking, and run for HIV-positive people from 2010–current. Conceived by Alex Galeazzi and co-produced by Alex, Lana (Pocock) Richardson and Panos Courous.

I remember it was a particular NAPWHA forum that came to Darwin and I was asked to facilitate that. I felt quite honoured because Jo Watson from NAPWHA and Jenny McDonald were there. I've been to so much. I've sat on ASHM forums with GPs as a HIV+ person to do a case study. I've represented NTAC and NTAHC at AFAO meetings – and one of the key things was when they were looking at formalising the national strategies, of which there's five now.

NTAC gave me the opportunity while I was the Friends NT co-ordinator to visit interstate organisations, including PLWHA and other AIDS Councils. It was quite an insight to what was going on, and I got to talk as a guest speaker, too. I remember vividly my first positive speaking engagement when I went down to the the PLWHA. Phillip Metcalfe – lovely gentleman – gave me the opportunity to work with an Aboriginal man, Colin Ross. And he said, "We'll go off and do public speaking." We went to Redfern High School and I thought, "I'm an observer here", and sat down and listened to Colin. Then he said, "And we've got Paul from Darwin and he's going to now talk to you," and I just got up and did it. I felt like the duck on a pond – all smooth on the top but my feet were going like crazy underneath. And that was my introduction to positive speaking. I was an Accredited Speaking Member (ASM) with the National Speakers' Association of Australia to help me upskill speaking as well.

In the early days, on radio 104.1 FM there was a Wednesday night program "Sexuality Reality". We used to go on there

² *Walking on Water*, Lake Alexander, 1999, Tracks Dance Company.
³ *Love vs Gravity*, Darwin Entertainment Centre, 2000, Tracks Dance Company.

as a panel with NTAC ED Barry Horwood and a few other people from the community. We used to talk as a group – people used to call in and ask questions – and we'd comment and talk about it from our own perspectives.

I also had the opportunity to work with David McMicken, one of the artistic directors of Tracks Dance Company. He put together some plays and events. The one that is more memorable is the candlelight vigil.² There was an effigy that we towed across Lake Alexander and it was set on fire. It was just really great.



Another time where there was a play at the Entertainment Centre around what it was like to be dealing with HIV.³ My role was sitting on the ground and I had this bell that I had to ding, and every ding I had to take a handful of tablets, which was just lollies anyway but

the point was there. For the audience, it was an insight into what it was like to be living as a HIV+ person, and each individual person that was on the stage was interacting a different story.

I'd been living with HIV since the late '80s and there was a thing that goes around with people, that ten years, twelve years, and then "That's it, you're probably going to die of AIDS". I psychologically was ready to die until Bill McMahon said to me, "Hey, this is not who you are. Remember that." And he said, "I've accessed this training that you can do, too, being a Certificate IV Workplace Training and Assessor." So I thought, "You know, I've been doing training for so much of my life, especially when I used to teach Kung Fu for many years in Adelaide, and that's exactly what I want to do." And from doing that, and then getting a full-time job from the volunteer work, and making sense of who I was and making changes in my life – I realised that I had some goals and one of those goals was to go to uni and do a degree, which I have completed. I've done various other diplomas and certificates. So it was like, "Life goes on. Don't wait to die." So that was the turning point for me and it was a credit to NTAHC and the the team they had within the organisation that uplifted me and gave me purpose back.

One of the most significant times – if I've got to pick something out – was standing side by side with Crystal Johnson and facilitating a session within the Sistergirl retreat and putting our arms around each other. It was such a lovely time. And then the other time where we facilitated together the transgender workshop 101, because that went for a good length of time. It was about being with her and listening to her story, it was just so lovely.

Another special moment for me was in 2001 at a World AIDS Day dinner, I was presented with two awards by the NT Minister of Health, the Honourable Jane Agaard. The first award was for 'HIV/AIDS Community Education', and the second was for 'Services to Indigenous Communities'. It was an absolute pleasure to receive those awards and the comments that came from community members on the night were very uplifting.

I remember going to Nhulunbuy working with Chiquita Peel and, as a volunteer of NTAC, I was invited to talk to a strong women's group. As a guy, I had to be very wary on what I was talking about but the ladies gave their permission to talk about whatever I wanted to talk about. Nothing was taboo. I must have spoken for easily two hours on all sorts of things, and with Chiquita alongside me, I felt so comfortable and it was a really good session. I remember one lady just bursting out in tears. It was like, "Wow, I didn't realise it was such an impact on anybody." Afterwards, as a group, they performed a healing with me and that sits in my heart even today, that they would do all of that.

In fact, in all the years that I've had the absolute pleasure to work with Aboriginal people within remote communities, I have been blessed by many types of engagements and from that I learnt to value my friendship towards my own mother. It taught me that much and that's how much I value that.

As a positive ending note, I'm still here. I'm going strong. I'm absolutely compliant and enjoy my job. I work full-time as an alcohol and drug and gambling counsellor. I always look forward to engaging with NTAHC events and staff, and I just want to make it totally, totally, totally welcoming. ♦

Paul and Jan Holt, Candlelight Vigil, Lake Alexander, May 2011 (Photo Panos Courros)





David Taylor

NORTHERN TERRITORY AIDS COUNCIL / NORTHERN TERRITORY AIDS & HEPATITIS COUNCIL
1995–2001

So there's always that question, well how does this disease affect you? Are you affected by the disease? I don't have it in my blood stream, but it's in my soul because all or most of my soul mates and friends, so many of them are infected by the disease, I am affected by it.

I'm David Taylor – aka Daisy or Daisy May or the Dowager Dame Daisy May, it depends on what level you're going up – but my real name, as I was born, was David Taylor.

I was involved in the AIDS Council from the mid-90s until the year 2001. I volunteered, I went on the board, I was treasurer, vice president and then President and then I resigned 2001.

I got involved when I moved from Perth and because I was in business in Perth – I didn't really have a real good sense of gay community, and what I found was the AIDS Council actually was the centre of the gay community for Darwin in a lot of ways. In Darwin in the mid-90s, there wasn't a Throb Nightclub. There was a club that would open spasmodically on a Saturday night only. That was below the Don Hotel, which is now the bottle shop of the Cavenagh, and of course Spellman's Mississippi Queen was there. Spellman's was the rail car bar and the restaurant.

I was asked to join the board because I was in business and so they wanted somebody with the business mind to complement the board. I really enjoyed myself. I met some amazing people. I had seen first-hand some friends that had passed away with AIDS-related illnesses in Perth, so it was close to my heart, and I have friends that are HIV positive. I am not positive but I've got many friends that are. So there's always that question *How does this disease affect you?* I don't have it in my blood stream, but it's in my soul because all or most of my soul mates and friends, so many of them are infected by the disease, I am affected by it. From one point for me, and I've actually had serious debates and arguments with some of my friends, is this notion that you don't know what it's like. I guess part of me is upset by that because maybe no I don't know – but I'm standing beside you, I am helping you, I'm in the hospital when you when you're not well, and I stand and nurture you and look after you and try to get you to recover. Of course I'm affected by the bloody disease because it's a part of who we are generally as a community, okay?

Mark Halton and David Taylor, 1996 (Photo courtesy David Taylor)

The era 1995 to 2001 saw Barry Horwood come in as the ED for the first time, because I believe he did return to Darwin and was the ED for a little bit, later on. I feel under Barry's guidance that was a most amazing time. We had lost a really good educator in David Pratt, or DJ Space Ace as he might be known, and Jan Holt replaced him as the educator and she's still involved in AIDS and STI prevention. She still cares and this is going twenty years on, which is quite remarkable really. But Barry Horwood came in and he is a gentleman of senior years, well past his retirement, and a gentleman that came out a little late in life, but my God, what an incredible, wicked, wild sense of humour the man had. He had an acid tongue and it would strip paint. He was just amazing, he really was. But what he did for the AIDS Council, he actually pulled it in as a more cohesive unit. He employed, and he will say, he employed a beautiful blonde young man called Jed Masters - a remarkable human being who has worked in Aboriginal communities in Central Australia, whose father was a doctor. This kind and compassionate man was sent over to the Tiwi Islands and it was because we heard there was trouble in the area. So Jed went over and he connected very, very quickly with the sister girls on the Tiwi Island. We'd found money, God only knows, but we found money, we got the girls over to set up some dance parties, we did some social stuff, 1996/97, around there.

The AIDS Council building was in Manton Street. Underneath the elevated house we created some space and we did dress-up parties and we had talks. What we surreptitiously did was we would bring in the people from Clinic 34 and we'd have a little testing clinic going on upstairs and we just did it - that it was a natural thing.



Miss Marsha Majora and the Dowager Dame Daisy May (right). Aviation Institute circa 2000 (photo courtesy of David Taylor)

So I was involved with going around op shops and finding dresses so these girls can just have some fun and play. Someone else would bring some music. Someone else will do something else. We'd throw on a barbecue and we'd really look after the girls. But in [doing] so, get them into a routine and get them educated about the use of condoms and what is safe sex and what is not. To me, that was ground-breaking work to enter into a community that had had this third gender for many, many, many generations that nobody wanted to talk about. It was just taboo, don't talk about it, et cetera. This is where I first met my niece, Crystal Johnson, who has gone on to be a national voice for the rights of sister girls all over Australia.

The biggest significant issue for the AIDS Council then was funding. We had - and we were I guess in a way, we were lucky, very lucky to have a Minister for Health who was Stephen Dunham, whose brother, John Dunham who contracted HIV and subsequently passed away. John was married to Karen - she's one of the owners of Throb Nightclub. It was very good to have Stephen as Health Minister at the helm as he had a personal connection to the disease.

At the time we were having significant rises in sero-conversions, and wanting to get out and do outreach, et cetera. More positive people here meant we were stretched. The needle exchange was actually going through the roof. It was almost crippling us and we simply weren't getting enough money to provide needles and safe injecting equipment here in the Territory. Unfortunately Barry Horwood resigned and left Darwin. The staff and board had to pick up the peices. This would have been 2000.

So as I say, [Barry] did remarkable things, but sometimes he would say, "Well let's do it and we will worry about the money later". Well later actually came, and I was left holding that little baby. But needless to say we were still doing great things around the community. We would throw dance parties. Again, remember that there was no club at this stage because Throb didn't turn up until later. So we had four or five years of creating our own fun. We would find places like the Bowls Club, the Aviation Institute, and other places and we would put on our own party.



Simon Kurt and Barry Horwood, 1994 (photo courtesy of David Taylor)

They would say, "Oh, we need a banner" - usually that was made at my house for the big craft works. Or, "Oh we need rainbow flags, measuring twelve by four metres - okay well let's go over to Daisy's place and he's got a sewing machine, we'll make one". We did! We made hundreds of flags and I think some of them are still around, which is really nice to see. So that was our community spirit that you don't get in a nightclub. A commercial enterprise says they're a voice of the community or whatever, but in the end it is still a for-profit, commercial enterprise and it's not community driven. Anyway we had fun. We did crazy, wild, wonderful stuff. We had picnics at East Point. It was nice to be able to use the AIDS Council as that driver - and a lot of the stuff we did, did not cost the AIDS Council any money, but it was good to have them as the backup or whatever you want to call it.

There was always safe sex packs. There was always one or two or three people from the AIDS Council that were there that helped to drive it. All of our dance parties, it would usually be the staff of the AIDS Council that would sit at the door and take the money and be accountable, so to speak. Then the community drove the music and the entertainment.

It was actually an interesting point in Darwin, where kids, youth, were having trouble coming out. So just remember it's twenty years ago, it wasn't as easy for people to come out as it perhaps is today. So my place ended up where if a kid was bashed or bruised or the brother beat him up or the father kicked him out or the mother didn't like poofters, they would invariably end up at Auntie Daisy's house. Sometimes there might be up to ten or twelve kids on mattresses on the floor, just knowing that they've got

a safe space that they can catch their breath before they go and attack the world again. So we ended up as the unofficial safe house if you like. That's what you did. But we couldn't say anything. I might be jailed now for this, I don't know, but I know that every single one of those young people love and respect me today and that's okay. Someone says, "Oh, have you got any children?" "Yes, about 120 or 130, yes. I do." So yes, this place on the weekends would be full.

Once Barry Horwood had resigned and was heading off to greener pastures, the position of ED was advertised and a gentleman called Chris Day got the job. So in comes Chris Day.

I'm going to be very, very clear and concise about this because if Chris Day does see this I want him to really hear it and he will know that it is the truth as I saw it. I found him to be a nasty, horrid bully. He was considered a brilliant financier. I stayed on the board despite him. This man would turn up in tiny little hotpants and a black fishnet top and try to be the manager, the CEO of a not for profit organisation and expect people to respect him? I really don't know what he was thinking. The man didn't have anything nice to say about anybody. He certainly didn't seem to give a rat's arse about the people that were suffering with the illness.

From the start there was a beautiful, beautiful, wonderful man who I still talk to today, he's long retired, named Bill McMahon. Bill was the care and support worker. Bill is a staunch Roman Catholic, heterosexual, father and grandfather, but the most caring, beautiful man I know. He was adored by his clients.

He was involved in the board of St Vincent De Paul and so part of that Care and Support. He would also have his connections to make sure that someone had furniture, a new bed, clean sheets, all those practical things. Bill never used his religious beliefs, but he certainly used the teachings of Christ to work with people, and he was a forgiving, kind, open man. I remember him saying "You wouldn't believe some of the stories I've heard, they would curl your toenails, they were just - what people tell me, and this is because I'm not gay". Yeah, well that's obvious Bill, you're not. But Bill had a thing and it was so good because at that stage we're talking about drugs that are not quite working. So we've still got people in and out of hospital

The side-effects of AZT and others and trial drugs that were going on, sometimes the side-effects were even worse. So there were people sick from the drugs that are trying to make you better, and it was Bill's job to pick up those shattered pieces and assist where could. Well, Bill had this great thing of using the car, and he called it his "cone of silence". So he would transport people to and from appointments and he would try never to have two clients in the car at the same time. He said, "That's where I did my counselling". Two people in the car, that's it, there was no place really private at the tiny little place in Manton Street, even if you had a private office, you can hear what's going on through the paper-thin walls because it was just an old Darwin prefab. So Bill used the car and I thought that was the cleverest thing. One of the first things that Chris Day did when he came in is he took Bill's car away from him and didn't replace it, and made him use a pooled car. Now to me that's like saying - well you can't have an office any more.

He just took a dislike to Bill. I reckon he wanted a gay person in that role. He didn't obviously want an older straight guy, an older straight guy that was as compassionate as I've ever seen anyone, but he didn't want that. Chris Day was working on the next lot of recurrent funding and that's great. I was giving assistance where I could as the Treasurer. So it was in 2001, I can't remember, probably mid-year some time, Chris Day had been there for about six [months]. It was a board meeting, and I got the letter to say that we'd got the \$156,000 that was going to get the AIDS Council out of the poo. It was just before the meeting and Chris Day comes out with a tray of grapes and looks me in the eye and says, "Would you like a grape? They're a bit sour, you might like them". I knew then I had to go. So I read out that we'd received the money and I felt I'd left the Council in financially good hands. He managed to destroy that place. He destroyed and broke the soul and the spirit of the place. Now we've got a very beautifully functioning, wonderful, lovely AIDS Council, which I'm slowly but surely getting more involved with again. But I had to leave for my own sanity, I had to leave.

Well what he did was, he sold Bill's car, he sold Barry's old car, he got himself a nice fancy one, that was the first thing he did. He then got a grant and he built this magnificent bar underneath the house at Manton Street and within months convinced the board that they had to move. So Chris Day really divided that place I believe, in that some people didn't want to move from Manton Street, believed that the extra money could be used in services rather than a fancy new building. Now the fancy new building is actually where the AIDS Council is today. So I do understand that you need to look at progress and that sort of thing, but at that time I didn't think that the

Council was stable enough to warrant that move. In fact, there were protests, the police were called.

There were groups of people within the community, and within the positive community, that did not want - and especially the needle and syringe using population - didn't want to go out onto Woods Street because it's a lot more open and it's a busier area, whereas Manton Street was a nice tucked away off-street. You wouldn't know that the AIDS Council was there because there were no signs out the front.

What probably for me was the most enjoyable little bit of working alongside the AIDS Council was when I did a series of cooking classes over a few years for people living with HIV. That was very important back then because people didn't like to come out as being positive. But it was about me researching what good, healthy, clean food is about and being able to translate that into something that's easy to do and delicious. I really enjoyed those nights where we'd have six to ten people in the back room. I'd cook up, we'd eat, we'd talk about food, but then it became about life - and everything else - and I think that was really good in that there was this beautiful level of trust.

I'm now slowly getting involved with the Council again, now that my dear friend Daniel Alderman and other caring people are working there, and there seems to be a soul returning to the organisation. I'm happy to see this happen. ♦



Gary Lee

NORTHERN TERRITORY AIDS & HEPATITIS COUNCIL LIFE MEMBER

1995–ONGOING

I made the AIDS Council so safe, and welcoming, and a place where they'd get information, anything like that, anything; we'd be there to help them. And it was known that at the AIDS Council there was a lot of blackfellas that hang around there and all the sisters and it was great.

My name is Gary Lee, a Larrakia man from Darwin. I began working at the AIDS Council in 1995. I was employed by Danila Dilba and my position was placed at the AIDS Council, just down the street, and I was the first Aboriginal Torres Strait Islander Peer Group Educator.

It was my job to to invite Aboriginal Torres Strait Islander sistergirls, gay boys, to the AIDS Council. By the next couple of weeks I set up a program of one or two days a week at the AIDS Council. We had a lot of sistergirls and gay boys, a mixture, and they'd come and then we'd do things from that beginning.

We had self-esteem workshops and we also did safe-sex messages, so it was a mixture of everything, whatever they felt most important. I think at the time it was safe-sex and also for homophobia. We had a thing on homophobia, but it wasn't such a big issue – not as big as the other issues. It turned out a lot of things came out, like a bit of violence, you know, lots of those issues which are still around in a way.

But the best thing was that the girls – we used to call them the 'girls' because they would come – mainly the Tiwi ones and some from Daly River, and we'd organise different things. Otherwise they could come down, they could read the latest magazines at the AIDS Council or other books or even just a big place to be there because a lot of boys were coming into town and at that time they were – I wouldn't say it was homophobia but it was. A lot of them were, I shouldn't say suffering, but they were being abused in a way. You know, this one would have this white malaga, this one and this one.

The irony was that these boys, they had quite nice malagas around they would come and see. But then when I asked them about this person and were they good to him, it all boiled down to they were just there for sex. And that's okay because for some of them, that's all they wanted. But I think they actually had that thing where they thought they would meet the malaga of their life and they had that beautiful romantic dream.

Gary Lee 2016 (photo Panos Courros)

I didn't put them off that dream but I had to talk about the reality. When I was talking about these men there, doesn't matter what colour they are, some will be very abusive and they knew it and they still saw this person. So I had to deal with that sort of thing.

'Malaga' is actually a name, it's a Gurindji name and malaga means 'man', it actually means 'boss man' which when the early Retta Dixon – not the Retta Dixon Home, the other one [Kahlin Compound]– they used to refer to the boss man as malaga. It's actually not a Larrakia word but it's a word that became socially accepted in Darwin. You know, "I've got a 'malaga", so it was kind of 'boyfriend'.

During that period one of the boys who was from Daly River, beautiful boy, his behaviour was a bit different and he got HIV and he was only very young. I think he's still there. And he was the first one but when he found out that he had HIV he stopped coming, and then one time I saw him in town and I asked him how is he? And he was very bitter. He was told by the doctor to go on this medication and then he became like a recluse. And then I met two or three other boys and unfortunately they're all gone now through various things, not necessarily going through the HIV, it was through violence and this awful stuff. So at first there was no one but then later there was positive HIV people.

At first people, like the Tiwi girls, they knew that HIV was 'the one' and when the other boys, especially this one from Daly River had come out with it that he's got HIV and there wasn't anything negative about that person, nobody – there was none of that at all, never. It was just like, "Poor fella". But there was no personal thing from the

Aboriginal community, from the gay community, so I don't know if he got that. But back on his community, where he still is as far as I know, I don't know if he faces discrimination or anything. And around that same time he just stopped coming and he doesn't.

I remember there were a lot of fun times because I felt that I've got to make this a happy thing, and we would do things like organise every year a retreat. All the girls would come, so that was great and they were lovely times. But the message of safe-sex, even though they knew about that – and since that time when I found out two other boys became positive and I didn't know about – I felt that the message is not getting through really, and it doesn't. And I didn't blame the boys because nice malaga came, they go together and he didn't want to use condoms, so they didn't. Just like that, so that was sad. But other times, it was mainly a lot of fun.

On the weekends, even though I stopped work for the week, I didn't stop working because I'd go round the beats and I'd be dropping off condoms. That's how it was in those days. But I'd go to the beats and I'd give condoms out to people. But the sistergirls, I really didn't see them much at the beats, especially down at Fannie Bay beat, which is the biggest.

When I was first employed by Danila Dilba and placed into the AIDS Council, that was at the time of the very first Anwernekenhe Conference. I didn't go to that because I had to go to India for work, but I said I would send Maurice [O'Riordan, my partner]. So he went and he worked his arse off. And that first conference there in Alice Springs, that they said that every AIDS Council

should be linked to local Aboriginal Health Services, Medical Services – and they applied to Danila Dilba straightaway after that conference. They moved straight-away and they've had a good relationship between Danila Dilba and the AIDS Council, which there still is, and they formed this position straight-away that year. And I applied for it and I got it, so that's my entrée, through the AIDS Council and Danila Dilba.

I used to do a lot of work with Steve Sparks and he was very, very good. He'd do the white side, I'd do the black side, sort of thing. On the weekends, we'd do those condom runs, because that was the only way they'd get free condoms at that time. We'd go down to Vestey's Beach beat and you'd know everybody there and you'd say, "Here, here!" It was lovely; it was kind of like a social thing but a safe thing. We'd say, "Well, you can come around and be a slut but be a slut with these." And also at that time the Hibiscus toilets was a beat, if you can imagine at that time. Yeah. And the sistergirls used to say, "There's plenty malagas there." And I'd say, "Are you sure?" That's what gave me the idea. I approached Pat [Anderson, EO of Danila Dilba] asking, "Can I write this thing about all these malaga to malaga [men to men]?" I said I would just go and do and find out, and I researched and wrote the report *Malaga to Malaga*.

I'd like to think that I helped reveal the mystery of the AIDS Council to sistergirls. When I said to them, "You've got to come to the AIDS Council." They said, "Oh." You know, their reaction, "Why would we want to go there?" And I said, "Well, what do you know about the AIDS Council?", and they'd reply, "Oh, it's really tough." But they loved me, you see, they loved me, I could tell you. And I said, "Well, I'm

working there for the first time and they are so helpful." And they said, "Alright, we'll come there then." So, when they came to the AIDS Council and there was Steve and I sitting there and we had everything: there were resources, videos, anything, and they could run amok, basically. And it was great. So I made the AIDS Council so safe and welcoming, and a place where they'd get information, we'd be there to help them. And it was known that at the AIDS Council there was a lot of blackfellas that hang around there and all the sisters and it was great. That's one of the legacies, I think.

Crystal was one of the first ones I met, so she helped a lot, and they just loved me. So, when I see them, they run up and kiss me like I'm an old aunty and I think, "That's okay, you can call me that." You know, they do. And they're very respectful. I would meet some sistergirl that I've never seen and ask, "Which one are you?", and they answer "I'm so-and-so, you know, when I was a little girl?" And I was "Oh!" It's beautiful to have that.

I'm lucky because I came from Darwin, I lived my history and my home and that was behind me, and so it made it a little bit easier. Other people would say, "You're Larrakia" and I'd say, "Yes, I know", and then I would pull that sort of rank.

I started my career through the AIDS Council. Because I have to tell you that working at Danila Dilba was okay, it was very good, but it was working at the AIDS Council I think that for me, freed me up. It was very, very, good working for the AIDS Council. And for the Aboriginal and Torres Strait Islander issues, it was the best thing when the AIDS Council hired me. It was beautiful. ♦



Crystal Johnson

NORTHERN TERRITORY AIDS COUNCIL / NORTHERN TERRITORY AIDS & HEPATITIS COUNCIL
1998-ONGOING

That World AIDS Day, we had sports and then people were talking about HIV during their school hours. Then after that all the old people came and for the opening day, they actually sang and danced for the dead, you know, and I explained to the old people and it was the first time in history. That was like early 2001.

A Hi, my name is Crystal Love Johnson and I'm 46 years of age. I started with the AIDS Council from 1998. What really got me kick-started was I came to an event – they did drag shows and had functions, Pride Party and all that. I had a good friend, Gary Lee, who got me into talking about the AIDS Council, and we came into the office. The old office used to be at Bishop Street. In those days there was nothing on Indigenous people, about trans and gay, lesbian, bisexual, trans people or intersex people. It was so hard to talk about these sorts of things. Gary introduced me to a lot of things in my community that I didn't know about, who I was as a trans woman/sistergirl. Working up through the years with the AIDS Council, we did a lot in our communities.

Q What were some of those things that you did?

A We ran retreats with sistergirls. The first one I've been to was in 1999, in Lake Bennett. We did HIV,

same-sex, and also we did beauty and wellbeing, how to look after yourself.

Q Was that the first retreat?

A Yeah. It was the first retreat with Michael. Being with those girls and Alexis – he was there as well – he worked for and did a little bit of emotional and social wellbeing.

It actually did empower me a lot to talk about issues, like: where trans people and sistergirls and brotherboys could find safe haven in their own community? How can we change that community and better ourselves? How can we find a place where we can call home without running away? How can we find networks and find peace within ourselves and our own community? Because coming from an Indigenous background and Indigenous culture, they don't accept trans, gay, bisexual or transgendered people, brotherboys, intersexuals, and it's really, really hard.

Crystal Johnson (photographer unknown)

So these retreats actually gave us the power to be who we are for three days. It actually makes you feel good and it actually empowered you. It did, it empowered me a lot to be where I am today, and to be the voice of my gay community, Aboriginal community here in the Northern Territory.

Q And so have things changed in the community because of these?

A It actually did. When people used to come back on their community, some of the sistergirls used to say, "Oh, I don't care. I can wear a dress", and they'd go talking to people about a retreat, showing them what we can do and how we can do it and working at a change. People in the Aboriginal community see that within us, they see this spirit and how vibrant, alive they are in that community. That was a good thing. It actually helped a lot of our people.

Q This is in Bathurst, on Tiwi?

A Yeah, Tiwi Island. Tiwi Island was the first forefront of the sistergirls staying at this retreat.

Q Jan Holt told me that in those early days, they would throw a dance party and they would make the sistergirl meetings the same time as the dance party?

A Oh holding that meeting to the dance party, oh my god! Everybody was just talking, "Look at the high heel shoes" because they were thinking more about that dance party and looking pretty. To that day, it brought happiness to their face, being who they are and showcasing at their drag shows. Like when I do drag – I'm a female impersonator – and I do teaching the girls

makeup and putting on good shoes, you know, you don't have to look like a drag queen to do drag shows. You can be who you are and a lot of people expressed themselves in many different ways. The dance parties were just like, "Oh my god, you could be who you are", you know.

Being a community, it actually changed most of the people's ideas, like men in dresses dancing to ladies songs. These days they've got Lady GaGa and everybody's twerking and all that, that didn't happen in our days. We made it happen in our communities, get up there and dancing with all the women in big discos, and we'd have our own. And that actually inspired them to go out and be themselves in discos instead of worrying about, "Oh, what shall I wear?" and "How shall I present myself in my community?".

Q So this is all really because of how NTAHC supported you?

A Yeah. NTAHC was a lifeline for all of us and also for me. Without the Northern Territory AIDS and Hepatitis Council, we wouldn't be where we are today. And the future depends on the community and also to other sistergirls who are coming out now.

Q Do you know where a lot of these sistergirls are? Are you in touch with them now?

A I do. I'm in touch with them on Facebook and Diva's Chat, Twitter. For me, I can see the AIDS Council going further. With this being the AIDS Council that they had tended to develop more and actually be stronger in what they do.

Q What about HIV and the community, how has that affected you and how's that affected your community?

A The Northern Territory AIDS and Hepatitis Council used to come out to our communities to organise. For World AIDS Day on Tiwi Island we did candlelight vigils and also this one Thai lady made these big glowing things where you actually put candles in them and it lights up like a lantern. That World AIDS Day, we had sports and then people were talking about HIV during their school hours. Then after that, all the old people came and for the opening day, they actually sang and danced for the dead, you know, and I explained to the old people and it was the first time in history. That was like early 2001. The first one they had was early '99, the World AIDS Day.

When we had that big mass in 2000, I couldn't believe the whole school came, the whole community came, and the priest was talking about HIV in several countries and Australia, how people live with it and it's about the stigma that they have. A lot of people in our community then, we said prayers, then we had Holy Communion. That was actually the first big mass that I was in, in my community. Being there and seeing it was so amazing.

Then we did the same in 2001. First Father was having a mass during the day and then we had one at school. That's all year round now: this year, last year and the Father talks about HIV on December the 1st, and then you say a little prayer for all the people who are living with it and also to find a cure. Then we have quite a big one on Sunday to remember the people that all died. It's been going ever since.

Q Do you think a ceremony like that, with possibly, education and things with it, has that changed the way that people practise sex?

A Community-wise, yes people talk about it, but living in a remote community, it's still the same. People still don't believe in condoms, people still believe in skin. When you're having sex with someone, there's always the man who will be dominant. Our community didn't change because you can talk about HIV, but you still can't change the thinking of Indigenous people in our communities.

Q So it's just been luck that HIV hasn't spread like crazy?

A Yeah. It's different with Ice, but HIV – yeah.

Q And of course in Central Australia the Aboriginal communities have the highest STIs –

A That's in all of the Northern Territory – yeah.

Q So were you involved in any sistergirl activities in Alice Springs?

A I worked on a couple of projects, but not much. We're just in the Top End, but I've started doing it for the last four years with Starlady, working with the AIDS Council doing translation of posters. I did a couple early in 2002 – just like running projects, you know, and helping out with the AIDS Council, and talking about getting our sistergirls to come to the retreats and like more or less advertising the retreat.

Q And have you got any stories that you remember?

A I remember one story: we all went to Adelaide and I think Damian Murray was there with us, and Tarquin.

After the retreat we went to a conference, we got invited to do a song and a dance. And what happened was that our drinks of all the Tiwi Island girls got spiked. That was hard. Lucky that I wasn't drinking then, I had to take one sistergirl back home and it was just so bad. Everybody's drink was spiked and I was worried. I got up and started knocking on everyone's doors. We went and missed the flights and everybody's IDs were missing. Everybody went on international flights, like travelling all around Australia, and then we all met in Darwin. It was the craziest time that we ever had. That was early 2004.

Another one was my niece was in Cairns, it was early 1999 during the dry season. We all went to Magnetic Island with the first transgender sistergirls retreat over there. What happened was that Lay, my niece, she was so rotten and then she would start taking a fit, I don't know what happened. And then after that I had to go on a little golf buggy to one of the Qantas planes to get her luggage. And shamed, though, I had this biggest, humungous dress. It was flowing like the Marilyn Munro dress. I was still in drag, mind you, and I was all, 'Oh my god!', makeup hanging out and my wigs were just coming out. Everybody was all staring at me, taking photos, you know, "The black fella's in a Marilyn Munro dress". I said, "Oh my god, shame job!" I went in and got her bags. They got the ambulance and I was shamed, I was there in my dress crying my tears out, you know, with her luggage. We were flying back to Darwin then, and that was with Jed Masters.

When Jed first worked with the Northern Territory AIDS and Hepatitis Council, I respected him as a brother

and that's when the kinship started, you know, like family. He felt uncomfortable, but he learned about trans people and gay people and our people. He actually helped us do a lot of things very wisely, because he's been straight and we've been trans and gay. He was an Aboriginal Project Officer. He wasn't Aboriginal, he was a white European. Straight white man. Straight off the block. [laughter] I mean not that block, but you know.

There were other women as well, there was Alysse and there was another two straight women. I forgot their names now. There were mostly gay people who actually helped the Northern Territory AIDS and Hepatitis, there was Tarquin – God bless – there was Stanley Versace, there was Bruce Forrester. We did a lot of sexual health work with Bathurst Island Health and also with helping out with the AIDS Council. Gary [Lee] and – who else – Steve Sparks.

Steve was the second Aboriginal Project Officer. He was a very, very helpful man with sistergirls and with gay men. He would try and help sistergirls to start programs, and young gay men, and also for trans people. He did a lot for our community and he was good at his work, but you know, the heart wasn't there in the right place. But when you work for an organisation, you feel good in what you do and sometimes he would not feel good with the other workers, the other previous Aboriginal Project Officers, they didn't feel good about themselves, they didn't have an identity as being Aboriginal or have a sense of where they belong and, you know, ownership of the program. I said to all of them, "At the end of the day, if you're not Aboriginal or non-Aboriginal," I said, "the program will fill you and you will fill it up later. It's like filling up a glass

of water and where there's no water in the glass, but when you fill it up slowly, it will get full and then you will know what is the true meaning of a work placement and working with Indigenous people."

I would like to see the project grow and to be better. I know that it is hard because of funding and, being a non-profit organisation, it's hard to see where the money goes and what the project can do. Projects can grow and actually be more better. You know, it needs more funding because looking at this project, we were the only communities before anywhere else – here in Darwin – that we did retreats for trans and gay people. We were the first and that's been going on for a long time, but it's stopped now. Before I die, I'd like to see the project reborn again and make it bigger and better.

How can we help our Indigenous population? Well guess what, the Northern Territory AIDS and Hepatitis Council did it. Bathurst Island was smack bang right in the middle, but guess what, it changed our community a lot. For the past nineteen or twenty-odd years, my community changed from where I am today. Sistergirls was a name that nobody would bring out, or brotherboys. Tiwi Island was the first, but the AIDS Council helped us along the way with these projects that they did. So you know, we have to start realising that it is not the money – though of course we need the money – we need people's heart and drive and we need our people to realise that the AIDS Council can do a lot and they have the power to do it. And if they can't do it, well you know what, at the end of the day, you have to succeed at what you do. ♦

Sistagirl retreat, Mt Bundy 2006 (photographer unknown)





Jan Holt

NORTHERN TERRITORY AIDS COUNCIL

1997-2000

We had quite a few volunteers back then because the front desk was all volunteers, NSP was volunteers, and I established a men's line during that time ... We had a big thank you dinner at the Darwin Bowls Club. It was like a bit of a party, and the drag queens came along. It was so successful that we actually initiated having monthly gay and lesbian dance parties.

I was working at NTAC from 1997 to 2000. I was the volunteer coordinator/education coordinator. We were based in Manton Street then. It was an old house and when I went to have my office there, my office actually was my bedroom in that house prior to the cyclone. It was bizarre, yeah! The director was Barry Horwood when I first joined, and I think Barry was there for two years, and then Chris Day came on as the executive director.

I think working with Barry, he was very much into community development. This was prior to Throb [nightclub], and there was actually a gay nightclub that operated on the weekends and I think it was called Juicy's, so there wasn't a place for people to come together as a community. Barry was really very good at bringing that community together. It started out that we had quite a few volunteers back then because the front desk was all volunteers, NSP was volunteers, and I established a men's line during that time. There was a big training group and all the guys came and got their training.

Barry was really good, he had a background of working in VAC [Victorian AIDS Council] and also at a positive living centre, so he wasn't new to the area. He was very much into really acknowledging and thanking volunteers, so we used to have a lot of dinners and barbecues and what have you.

And then Chris Day came on and I think he was also from the Victorian AIDS Council, and I left within about a year of that.

One thing that Barry did, and I mean, I'm not a nightclub person myself, but we had a big thank you dinner at the Darwin Bowls Club. It was like a bit of a party, and the drag queens came along. It was so successful that we actually initiated having monthly gay and lesbian dance parties. I was charged with organising that and it was so easy to do, because it was not there for profit, it was there for community development.

We started off at the Darwin Bowls Club, and then we moved to the Aviation Institute. They were hugely popular.

Jan Holt, 2000 (photographer unknown)

They were on the last Saturday of every month and people were coming up from Katherine to come to it. It was gold coin entry, and we would just get DJ Bitch and she would just hire the sound equipment, the drag queens would come, we'd just fling up a few banners. It was real grassroots stuff but we were getting three or four hundred people there each time. And it was also really good because if you had anything to tell people, you could tell them, or if we needed some volunteers and it was really good for that.

But when Barry left, Chris Day thought that he would have it as a fundraiser, so we were sort of at loggerheads with that, because he wanted \$15 to come in the door, and I said, "You must have concessions." And I remember, I used to do the door with Damien Dempsey – he would normally be the door person – and Chris would actually have me check people's concession card. So when Chris Day then wanted to make it into fundraising, and we moved it to Browns Mart, what we had to do was to stock the bar, we had to staff the bar, and it was the first and only time we ever had any violence, and there was some violence at that one, and it took a hell of a lot more to actually organise. So I don't think it really went anywhere. It might've had a couple of more. I think I left soon after that.

But what actually happened at the old Manton Street (which was an elevated house), underneath was the NSP, and we had quite a lot of space under there, so the money that we did raise from those few fundraising dance parties went towards kitting out the underneath part into a bar. We would have drinks after work every Friday. Spellman got his knickers in a knot about that because we didn't consult with him, because his

bar was just one street over, and he thought that we were going to be in competition because he still had the Train Bar and the Mississippi Queen.

It was my last day working at NTAC when this bar opened, and everybody had gone to do some training, and there was myself and two volunteers in the NSP, and Spellman storms in, "Who's in charge here?", and I went, "Oh me", and he hands me this thing. He'd gone to the Licensing Commission. Because we were calling it the Mardi Bar, he'd gone and he'd registered a business name in the name of the Mardi Bar, so we could not call it that. And I think it operated two times, and then the Licensing Committee said, "You cannot operate this", because there was no provision for wheelchair access to a toilet. So I think we actually invested quite a lot of money in to putting that bar in to place, only to have it close.

Prior to the bar being opened, we used to sit in the back garden of a Friday after work with some wine and a carton of beer and there was an honesty box and you'd throw your money in there.

The dance parties were held '99 to maybe 2000. I remember it was when the war had broken out in Timor and Darwin was overrun with UN personnel, and some of the gay people from the UN used to come. This one American guy said to me, "I've been to all these fabulous dance parties in New York City. This is even more fabulous", and I think it was because it was so casual, and people were so friendly. You know what Darwin's like.

We did have a very tiny SWOP program happening then, very different to what's happening now, mainly through

the provision of condoms and lube and what have you, but it's far more sophisticated now. So there was Tracey, I can't remember her surname, so there was myself, Charles, and Bill McMahon is the other one. Bill's a very big key player in the history of NTAC, he was the care and support person. Bill was an interesting character.

Jed Masters instigated the Sister Girls program. He made contact with a lot of the girls from the Tiwi Islands, and he started the retreats. He would have a retreat in line with when a dance party was happening, because the Sister Girls often just didn't have that safe space to be who they were. So what would happen, they'd come off the retreat, and then they'd all glam up and perform, and I remember Crystal, that was the first time she ever performed, and she was very, very nervous. I remember her coming up to me saying, "I'm just so nervous", and I just said, "Just be yourself", and she said that really helped her. I can't remember what she performed, but she looked gorgeous.

Jed and I used to share the office, which was a bedroom in Manton Street (that I actually lived in just after Cyclone Tracy). He really struggled at first on how to work with Sister Girls, how to engage them, and sexuality is always a sensitive topic in Indigenous circles but he did a brilliant job.

There was another woman there, Petra. She worked on the NSP, too, or the needle exchange as we used to call that. One of the issues back then was we were really lobbying to get the NSP in Palmerston open, and there was huge community backlash and it took forever. It took like nearly two years of negotiations, so that was a very big issue, but because there were only seven of

us who worked there, we were a very small organisation. People felt really comfortable coming there, and even if it was just to come and pick up the *Sydney Star Observer* or *Lesbians on the Loose*. They always felt really comfortable and you'd often have Sister Girls running around in the kitchen, on the telephones, out the back, because we had a nice space out the back with a big garden and chairs, and it was kind of old Darwin style. But the NSP was very much a big thing, and at the same time, I think, AIDS Council of Central Australia was quite separate, and I think there were issues there.

We had, for a short time, a guy employed to run the beats, but yeah, I think it's really hard. Having worked in WA AIDS Council, we had two guys there who worked for a very long time on the beats, and that was their job, and they became well known. Whereas we were kind of relying a little bit on volunteers, and you need to have those volunteers who are peer educators. So it would run okay for a while, but being after hours, night-time work was really challenging, yeah.

The care and support, the SWOP, and I was involved with education also. It was really funny because I used to have to go to the AFAO gay men's education strategic thing, and I'd be the only woman there. That was kind of daunting, with all those big boys from AFAO. And it was really hard, too, because they'd do some national campaigns. I remember a few and it just didn't look like our guys here, and I'd go, "Look, this is all right for you guys in big cities and what have you, but you bring it back here and it doesn't speak to the guys" and I felt like I was the devil's advocate sometimes.

And of course the men's line. The men's line was really good in that there were about twenty guys who went through the course and it operated Saturday, Sunday and Monday. But all the guys were trained up to be able to answer it, and there were new guys coming to town wanting to know "Where's the beats? Where can I hook up?", that sort of thing, in the pre-Grindr days and all that. Sometimes there'd be concerns about sexual health and where to go, "Where's the sexual health clinic?". That really worked well for about two years. I think what had happened now, we were starting to get into the more technical age, and it became a little bit obsolete.

We actually worked well, not only with CDC [Centre for Disease Control], but also with Family Planning Association, and we had monthly meetings. We used to call it "show and tell." So we would always collaborate around World AIDS Day and Valentine's Day, and just a lot of sharing of information.

The other thing that I used to organise was candlelight vigils. Prior to me starting in the position, they'd been held in a number of places, but Lake Alexander became a bit of a sacred space there for a while. We would have it there for the three years I was there, and have it at the lake. David McMicken would sometimes light up a big structure and we had the candles and we had different things. Sometimes we had a string quartet or people speaking or a choir. It's the same across Australia, fewer and fewer people were coming to vigils, and then I think it took a different turn and now I know these days,

you've had premiere movies and different events, because you have to somehow engage people in a different way.

Candlelight vigils were pretty special to me, because I organised the first one in Perth, and it was quite large, and I was really afraid nobody would turn up, because we had it in the grounds of the church, which was right next to Royal Perth Hospital. This is in the days of when people were really sick and were dying, and the immunology ward used to be on the top floor. When we were having the ceremony, the lights would flicker on and off so people who couldn't come down because they were too ill, were flicking the lights to say that we're with you. Yeah, and then we planted some roses there and then it took the form that we used to walk from the church and we walked down to the big square in the middle of the city. And then it became bigger and bigger and we used to have people from the ABC MC-ing it and what have you.

I was very touched because when I left WAC, and I came home to Darwin, they invited me back for the first year as their guest speaker because I'd worked seven years in managing the support and care program. So yeah, vigils have always had a bit of a place in my heart and I probably haven't been to a couple for a while, but on that day I always light candles in my own place.

The other thing that we used to do was when Tracks Dance were putting on performances, they'd try and find people who we knew in the AIDS Council. I remember Minky [David McMicken] did the *Bodies of Light*, which was a very touching piece and a lot of our male volunteers actually performed in that.

During my time there, there was also an HIV-positive support group. Bill McMahon organised that, and it was very informal. They met, I think, monthly. I've actually hosted a few at my house. It was a social thing, and there

was quite a number of people would come along, both for support and a bit of social outlet. It was called *Friends*, and staff were always encouraged to attend, as staff were for all events, and nearly all the staff would always come. ♦



Jed Masters and others at Manton St premises, 1997 (Photo David Taylor)



Sue Fielding

AIDS COUNCIL OF CENTRAL AUSTRALIA

1998–2000

One of the big challenges I found was connecting with the Aboriginal community. There was a sense of there being separate health services, and almost no representation of that community in the AIDS Council ... One of the happiest moments I had was when we established a good connection with an Aboriginal health worker ... It was quite a breakthrough moment ... because the Aboriginal community was quite difficult to engage with ... because of people's impressions and assumptions that HIV was a gay disease, and that kind of thing.

I was the manager of ACOCA for two years from 1998 to 2000. I had been in Alice for about five years when I took this job. I had come from Sydney. In the time that I was in Sydney, I was quite affected by HIV/AIDS amongst my friendship group, but also I was involved with Ankali as an emotional support volunteer. I felt like I was somehow knitted into the community and that it was very much a part of what was going on in Sydney at that time.

When I came up to Alice, the profile of ACOCA was not particularly high. One of the things that I wanted to do when I took the job was to raise the profile of not just the organisation but the issue that it was dealing with. That was a real challenge. What I found was that there just wasn't a lot of conversation going on about HIV in the health sector, and almost a sense of secrecy. There was no talk of HIV in Aboriginal communities – it was kept

quiet. It was a bit like stepping back in time. So I felt that our role, really, was to bring the conversation up into a whole range of areas, and that's what we tried to do.

One of the significant issues for ACOCA at that time was to not be subsumed by the NT AIDS Council in Darwin. That was very important to the Board and the local people, people living with HIV, and me, actually. We fought and succeeded to maintain our independence, and consequently it meant that we had to do what we could with fairly small amount of resources.

We had a youth worker at one time who was trying to engage the community about a needle and syringe exchange operating, and education being offered through that. What I was trying to do was, as I said before, put HIV into the community conversation

Sue Fielding, 1999 (Photographer unknown)

through inter-agency networks. I felt that there was quite a lot of denial, really. People would go, "Do we have HIV in Central Australia?" And so it was trying to let people know that yes, we do, and ask what does it mean for you? and get those conversations going.

One of the big issues was connecting with the Aboriginal community. There was a sense of there being separate

health services, and almost no representation of that community in the AIDS Council. I'm sure that's changed a lot now, but back in those days we did make good connections through the Central Australian Aboriginal Congress health service, which was great.

There was some great people involved. Phil Walcott was involved on the Board. The person that I would say



Sue Fielding, 2012 (Photo Sally Hodson)

was a standout for me was a guy called Tim. He was incredibly supportive of me. It wasn't always easy being a woman manager. Even though I'm a lesbian, and the AIDS Council at that time was very much coming out of the gay and lesbian community, it was still a fairly male-dominated and gay male-dominated area. Of course, Alice being Alice, I found that the Board was great and very supportive, so that was okay.

ACOCA had a good relationship with Clinic 34. That was one of the positive, strong connections that we had. We had Board members from Clinic 34, and we had regular meetings with them, so there was great dialogue.

The needle and syringe exchange program was a big part of ACOCA's activities, and so maintaining an open door for those clients was really important. A number of ACOCA clients were living with HIV, and they would come by often. It was a very welcoming and social environment and people dropped in a lot. We were on Gap Road, opposite the Melanka Lodge, right next door to the Gagliardi building.

We were out and about as much as we could. Any opportunity to get out there and connect with people took place largely around education, letting people know we were there, what we did, advocating for people living with HIV, and just promoting continued provision of services for people with HIV and Hep C.

At the time I worked there, we did not want to join with NTAC. We wanted to remain a separate organisation because of the significant differences between our communities, and the fear of missing out on a fair share of resources – that they will be mostly held up in the Top End. So it was this sense of holding on to that, and

we succeeded for the time that I was there. I think there have definitely been benefits in amalgamating the two organisations later on down the track. There wasn't any negativity between us, and NTAC wasn't trying to take over; the suggestion was put forward by the funding body. I used to go up to Darwin and the NTAC manager would come down to Alice for meetings with us.

After I left ACOCA, I maintained contact with people because they were friends, and I saw them around town, but I didn't really have a close continuing involvement in ACOCA. The person employed by the Board after me, a guy called Eric Michaels, came up from South Australia. I do believe he wasn't that well, but I also understand that the organisation fell into disarray in this period. I'm not exactly sure of the details of that.

One of the happiest moments I had was when we established a good connection with an Aboriginal health worker who came in one day to find out more about what we did, and we started working together on disseminating information about safe sex practices for Aboriginal men. That was his interest as a male health worker. It was a breakthrough moment. I count that as one of the most positive things that happened while I was there, because the Aboriginal community was quite difficult to engage because of people's impressions and assumptions that HIV was a gay disease, and that kind of thing.

My memory of ACOCA is that it was a really positive sort of environment. People were very committed and worked hard to get out there with information and engage people. The Board was great. ♦



Shayne Kilford

NORTHERN TERRITORY AIDS COUNCIL / NORTHERN TERRITORY AIDS & HEPATITIS COUNCIL
1999-ONGOING

We've lost a lot of clients over the years. Overdose; they've left the Territory; they've gone on to treatment; some of them have come off treatment and come back and see us. Yeah, so it's a bit of a revolving door. There are a few hangers on. It's always got a bit of a changing face. We're always seeing news clients.

I've been involved with the AIDS Council since 1999. I came up here in 1988, on the 6th of January. When I found the AIDS Council, life started to happen from there. NTAC was in Manton Street then. I had friends who were HIV-positive.

Around about 2001 or 2002, I met a nice guy and he was positive. I just really enjoyed the community feeling of the gay and lesbian community, and found that I was accepted for who I was and that people weren't discriminatory. I could be who I was and, well, I found out that I am a bisexual man rather than being a gay man, and it was good finally to come out as not being straight.

I got involved with the SWOP Project because I did a bit of sex work. Through Kitty Gee, who was the SWOP officer, I started doing some work in the NSP as a volunteer. This was until the early 2000s. There was a lot of work involved but they were only funding a half-time project. Most of the work was out of hours even though the job required somebody to work 9:00 to 5:00. Kitty was always working after hours and working more hours than she

could do, so she really depended on volunteers to help with the NSP. Because half her monies was coming from NSP, she relied on volunteers to cover that so that she could concentrate on the sex work part.

The NSP was really strange back then. Everybody had a number and it was any number that they could remember. We'd write down that number just to gather some stats on what was going on. Maybe half a dozen of them remembered the number the next time they came. The rest of them had to make up new ones.

It depended on who was running the NSP at the time as to what changes were made. We used to have a big bench where we would serve behind and give people their equipment and what have you, which was pretty restrictive. Now we've got just an office desk and chairs to sit down and it's a lot more open. And we've got our equipment on the wall so if people know what they need they just go and grab it. Yeah, it's a lot better now.

Shayne Kilford, 2005 Palmerston NSP (Photographer unknown)

We've lost a lot of clients over the years. Overdose; they've left the Territory; they've gone on to treatment; some of them have come off treatment and come back and see us. Yeah, so it's a bit of a revolving door. There are a few hangers on. It's always got a bit of a changing face. We're always seeing new clients.



We were in Knuckey Street to start off with, which was just a tiny little place. People used to come up and get fit packs or something along the likes, and that was back in 1985, I believe. I'm not sure where they moved to after that, but that was their beginning.

I was co-ordinator of the NSP around 2005/06. So that was good and a step up the ladder for me. That was a pretty tormentous time, really, trying to organise six staff and get them to do work. The staff didn't get on with each other; they didn't want to work; they weren't motivated. So I sat them down one time and said, "Okay, what are your grievances. Let's list them and work through them." They came up with twenty grievances. I managed to work through most of them.

The guy who was manager of NTAC at the time didn't want to have anything to do with the grievances of the NSP. If there was a problem it was fix it yourself, so I tried very hard to fix problems myself. I mean, it was just a matter of them getting together airing their grievances – and when we met again there weren't so many grievances – just getting them to talk out their problems so that they could work together a bit better and actually do some work.

It was around then that we started doing a monthly theme with the NSP to engage with our clientele a bit more. So that was my achievement. We did "Everything about your NSP", we called it. We did things from steroids to blood-borne viruses, and the law, legalities, overdose awareness, safer injecting. You name it, and we thought it up and did it. So that was good fun. It still is to a certain degree. We do it roughly every quarter. And we've got days of significance. So we've

NSP Peer Generated Monthly Themes, 2012 (This page and opposite)

got the condom day, Hep C awareness day, overdose awareness day, International drug users day – and we do something on each of those days as well.

Yeah, up until Frank Farmer left everything was pretty good. The gay and lesbian community seemed to want more than they were entitled to – and Frank was a good ED despite what people have said about him – and he was quite prepared to offer monies and assistance and what have you but, yeah, the gay and lesbian community seemed to think that they ran NTAHC and not the ED. They basically wanted NTAHC to run Pride Day and things like that, whereas Frank was like, "It's your day, you run it and we'll auspice it and go from there." He didn't want his staff spending all their time working on stuff for the community when the community could work together and do it themselves. So that made some bad blood and it sort of carried on from there. People in the community got the Board involved in the organisation's problems where it wasn't the Board that needed to sort out problems. If they had problems with the organisation they needed to talk to the organisation not the Board. Unfortunately it accumulated into a bit of a slanging match and people gathering together to re-elect a positive board. So that was fun and games. But since that it's been pretty smooth going.

It was all pretty standard while Frank was here. Everything was smooth and flowed along really well. Frank made appearances here and there, organised an AIDS day ball, assisted with Pride meetings and auspiced the money for Pride. It was sad to see him go after only a few years.

Colin Burton [took over]. He decided that all of the money coming in from our funders, et cetera, should be put in



one bucket and then you just draw out of the bucket as you need it. No budget, no accounting unless it was bodgey accounting to show that he was doing the right thing when he wasn't. Fortunately for him the accountant bodgied the books to make him look good. I think he left before people found out. The finance guy quit and he left and locked the computer so that nobody could get in and see the bodgey bookwork that he'd done. That made things difficult for us to carry on with a new finance guy.

But yeah, the next ED found that. Oh, it's hard to keep up with the number of EDs I've seen. Yeah, so we had very little money and didn't know why, and then it was found during Alison's term that the last ED had bodgied the books and spent all the money. So she had to put up with that and when she put in for funding unfortunately she didn't get all the funding that she wanted. In fact she got less, so all the promises that she was making she couldn't fulfil and ended up leaving a short time after that. She made a good effort at it but yeah, being badgered by the Board and that didn't help, so, yeah. ♦



Daniel Alderman

NORTHERN TERRITORY AIDS COUNCIL / NORTHERN TERRITORY AIDS & HEPATITIS COUNCIL
2000-ONGOING

It took a number of years to negotiate Liaison Officers with the police – from meeting in the back of dark cafés and them not wanting to be known – to the fact that we had the Commissioner of Police sitting at the table with us to negotiate those projects.

I first got involved in July or August of 2000 when I started working as the youth and beats officer for a period of maybe four or five months. The Council was located at 8 Manton Street. The building doesn't exist anymore. It got pulled down a couple of months ago.

So I did outreach to the beats: Casuarina Beach during the day and outreach of a night twice a week. And we ran a youth group for young people, young gay men mainly.

I guess during the course of that period of employment I ended up in a hospital and very sick at the end of that, but during the course of that time in my first involvement and over the next couple years being a volunteer, I did some research into homophobia-based violence. That helped lead to the first GLLO [Gay and Lesbian Liaison Officers] project with the police force. So that was part of working at NTAHC as well, throughout that period. That was done with myself and my partner but it was also done as partly my part-time work and partly my volunteer work at NTAHC. It took a number of years to negotiate Liaison

Officers with the police – from meeting in the back of dark cafés and them not wanting to be known – to the fact that we had the Commissioner of Police sitting at the table with us to negotiate those projects.

A lot of gay and lesbian people don't feel necessarily comfortable accessing police or don't report violence or domestic violence or homophobia, so there's been successful piloting projects around the country where it's been shown that if people have somebody within the police force that's an identified person that they can speak to, then they're more inclined to speak to that person and report incidences.

Michael Scott was my boss. Chris Day was the ED. He was a bit of a character. And a priest was the Reverend Brother Des Cox or something like that. I don't know his surname. He had his Ministry or his church or whatever out at Humpty Doo. Neil Ludvigsen was vice president, I believe. David Taylor, being Daisy May, had previously been involved in the organisation and that was maybe a

Daniel Alderman, 2000 (photo David McMicken)

year or two before I arrived in town. That was that period over 2000. I was sick in hospital with an AIDS-defining illness and the executive director at the time came to me and asked me to resign from my job because they couldn't afford to pay me. So that wasn't necessarily a very pleasant time, just before Christmas. But I became involved again about eighteen months after that I suppose.

Before I moved to Darwin – I lived in Sydney and I became involved with organisations in Sydney through my work, through social research and HIV, and that first started in 1991. So by that point I'd been positive for five years and I started working in the field, became president of the Positive Living Centre in Sydney, had presented papers at conferences on being positive, or research that we'd done, and I worked on a number of national projects. I really enjoyed it and I wanted to be able to give back: I wanted to work in the field, particularly around providing a space for youth to feel comfortable. So as we know we have the highest rates of suicide amongst young gay people so – those sorts of social justice issues were really important to me.

I guess at that point in 2000 the main issue was funding. We'd get called into the office on a Friday and we'd be told, "We don't know if we'd have any money to pay you next week". So that was always an ongoing issue for that first four or five months that I worked here. Obviously it's in a much better, stable position today, but it was an ongoing issue for maybe three or four years. So after I left in 2000 I came back as a volunteer and I did stuff as a volunteer for Pride and I did stuff as a volunteer for the organisation. And then I started employment again in 2003.

It became the AIDS and Hepatitis Council throughout that second course of my employment. So I started in the

March of 2003 I think, and Frank Farmer was the executive director. And I think the president at the time was Dawn Lawrie. I think that's correct.

I feel that Frank did a tremendous job in sailing the organisation into a very stable and financial position and organised the incorporation of the organisation to take on Hepatitis. I think that that was a good thing. He'd had foresight because sooner or later, you know, the services that were going to be required in that area moreso than HIV, at the time for the Territory. Maybe not for other jurisdictions but – it was bit of a tumultuous time as well.

[We ran the] NSP, Sex Worker Outreach Program, Youth Program, Youth and Beats Program – so they were half-time each. In 2003 we had an Indigenous program that consisted primarily of Sister Girl retreats. So it's different to what it is today. And there was a person that did Care and Support. But they were based in another position. But in 2003 there was a designated Care and Support Officer by that point.

I think the SWOP Program was much better resourced than it is today, so it doesn't employ somebody full-time today though the capacity is almost point eight most probably. But it used to be full-time. The outreach program's focus has changed to be a broader focus on sexual health for Indigenous people, which I think is a good idea, instead of focussing on one particular section of the community. And the overall scope of the organisation has changed definitely. So the quality of our communication and of our events is much better. It's certainly setting a benchmark compared to what it was ten or twelve years ago.

Daniel Alderman & David McMicken, 2016 (Photo Mon Atkins)

Look, you know, I was in the office. It was an old, dilapidated elevated house with holes in it and the executive director at the time wanted to put a bar downstairs. Well that was a smart move wasn't it? John Spellman was around the corner a block away and run a licenced bar, so he was furious. So that got him offside, which was a main community player in the community. So there was a fair bit of vitriol at the time. Plus – I'm not sure what happened before I came on-board – but there was a bit of community backlash about particular people that had been treated in a bad way. So you always got a sense that people were, you know – but you'd have a dance party and 100 people would turn up. So it was really hard to work out what was going on.

But for that first few years that I was involved, the NTAHC used to run their own dance parties as fundraisers. And they might do that three or four times a year. And that was about providing a safe space for gay and lesbian people to come together to have a good night together. I suppose it didn't last too long from 2000. Maybe finished by the time 2005 or something came around. Throb had already opened so there was major competition. People weren't attending and the numbers started to dwindle. But it was about providing a safe space. They were in different locations but mainly they were run at the Aviation Institute in the time that I was involved, which is the club down near the airport.

Well, there was safe sex materials around, condoms and lube and stuff. And it certainly gave you the opportunity to have conversations with other people. It wasn't really the environment to do that in but to provide people with condoms, it was the main vehicle at that point.

The only other thing that I can think of is they had a ball which was at the Hilton, it's called now, and it used to be called the – I don't know what it used to be called. They've changed names so many times. And that was under Frank Farmer's time, up in the hotel.

We had quite a few [Candlelight Vigils] at Lake Alexander. And the youth group that I ran here when I was here in 2003 made lanterns and did a whole procession of lanterns and stuff throughout that time. I don't think I went to any other vigils anywhere else, always there.

I really liked Bill McMahon. He'd been the Care and Support officer during the '90s and he became president for a very short period of time through a very tumultuous period, and he just had that total compassion and understanding for people.

I think the organisation has done a tremendous job in being around for thirty years. And like all organisations and like individuals everybody changes, and so I think it's done a tremendous job at adapting to the times, really. ♦





Salus

(WORK NAME USED BY A SEX WORKER)

NORTHERN TERRITORY AIDS COUNCIL / NORTHERN TERRITORY AIDS & HEPATITIS COUNCIL

2000-ONGOING

"Nothing About Us Without Us"- the issues were and still are stigma and discrimination, access and equity to services, and the criminalisation of sex work.

My work name is Salus, I'm really happy to be able to speak about NTAHC as an organisation, in particular, the SWOP NT program – and also my interest in the NSP as well.

I first set foot in NTAC NSP in 2000. I was already aware of some sex worker history from NT that had crossed over into the national sex worker rights movement. There was once a co-convenor of Scarlet Alliance in the mid-80s who also was behind organising sex workers in the NT, (LeeC). There was a group that (LeeC) facilitated to form which was basically around union rights for sex workers and it was known as PANTHER – the Prostitutes Association of the Northern Territory for Health, Education and Referral – It was located in the NT Union offices on Wood Street. Around about the same time that PANTHER had formed, there was another really important component forming – and that was in sex workers overlapping in the response to rights based approaches to reduce stigma and discrimination, and support all of our communities to become a part of NTAC to respond to what was known as the AIDS epidemic.

With the formation of PANTHER, Lee and other sex workers became very engaged in NTAC, and PANTHER by default fell

under the first lot of funding with NTAC as well. PANTHER continued and then later in '90s and early 2000, a group called SAINT formed, which was the Sex Industry Advisory peer group for the NT sex workers. SAINT, although incorporated autonomously as a group under NTAC did start to move a little bit more away from strategic kind of union-based work and into more health promotion. In 2000 to 2001, SWOP (Sex Workers Outreach Program) NT formed, and by the end of 2001 it was cemented as a peer-based program.

By the end of 2001, SWOP NT had proven to Scarlet Alliance that the project now of NTAC, was peer led and peer run. So between 2001 and 2002 I knew a bit about SWOP as they had just been accepted to become a member of Scarlet Alliance, just as PANTHER and SAINT had achieved before.

This snippet of history brings me to when I first popped up here in NT, which was 2000. At that point in time, I was still a sex worker and I was still a sex worker who injected drugs as well. So I rocked into the NSP and was like, you know, I'm pretty out and proud on both levels. I'm a bit of a "Junkie Whore" and I'd like to be involved. "Junkie Whore"

Lizzie and Salus, 2006 May Day March, Darwin (Photo Alan Patten)

is a term I used then endearingly as that was my life and many people use those terms to shame us, so taking those terms on in ownership, throws it back. And for whatever reason at the time, a lot of my previous activism down south didn't come to fruition really here until about 2006, when I returned from South East Asia. Executive Director, Barry Horwood was at NTAC at the time and I quickly took a position on the Board for a period.

I had popped in and out of Darwin around 2004 a couple of times touching base with SWOP projects. A SWOP officer during this period (AT) and another delegate from NSP (LS) come over to East Timor and they did a small activity scope for their programs within NTAC. At the time (AT) was also the president of Scarlet Alliance and the SWOP NT officer. (AT) was also in her role from Scarlet Alliance able to offer support in an area I was working on with sex workers there. I think NTAC has always had a little bit of involvement with East Timor, so there was a crossover, when Frank Farmer an Executive Director of NTAC/NTAHC 2004 was in the role.

Returning to 2006 – 2007, I remained on NTAHC board of management. In November 2007 the SWOP NT position became available for a short period of time, there was talk from some Board members at the time to consider opening up the position for a "Non Peer", because in the past SWOP officer positions had at times been vacant for a few months previously. I was on the NTAHC Board - we could not put a non-peer in place, and of course, myself and a lot of other workers were like: "no way! no way, it's got to be peer led and peer focused, we will lose our membership with Scarlet Alliance as well!"

I think that's why peer-based programs like some NSP's and the SWOP programs have maintained a really strong focus on policy and on lived experiences of populations to lead that policy development. It's really best practice now around the world as well. Those shifts I think for drug users, particularly injecting drug users, and also for all sex workers who are linguistically and sexually diverse, and all different genders as well. To come together.

The issues for sex workers many years ago was around legalisation, having a special legislation that no one was criminalised under. Now it's about decriminalisation because any legal setting, by default, criminalises some part of the population – and we all know that criminalisation for sex workers is pretty detrimental to good public health outcomes.

My first involvement in the sex worker rights movement was after I'd started first working opportunisticly. But it was in the '80s in Brisbane, I didn't know the term sex worker but in hindsight opportunisticly or not, there was a pattern, it became purposely. In the mid-80s, I was in the ACT and I was fortunate to be around one of the Scarlet Alliance convenors at the time, (SM), They helped me work safely in my first brothel. I worked as an outreach officer at Workers In Sex Employment (WISE in the ACT), I volunteered my time also as an elected Chairperson at WISE. The Scarlet Alliance office was housed within the WISE office at the time as (SM) was both the Convenor of SA and the Executive Officer of WISE. WISE had a NSP within, the organisation was perfect for building my understanding of "Nothing About Us Without Us", the issues were then and still are, stigma and discrimination, access and equity to services and the criminalisation of

sex work. There were policies forming around that and although those issues are still the same, there was very strong solidarity with drug users, with gay men, the LGBTIQ community in general. A lot of sex workers identify as queer. We had a queer workers' union at that point in time (QEWU) The Queer Esoteric Workers Union, based in Sydney with (AM) another previous SWOP NT officer at the helm, this was the period of strength of activism rising out of stigma and discrimination, bursting through the academics papers on us all who had never on a daily level themselves lived the life of knowing how it felt to be shamed. There were a lot of very militant activists. Act Up started as well. So we had all of these really strong groups everywhere across the country. I think our friends dying of an AIDS-related illness, who had been living with HIV and who had been dying very quickly, within five years sometimes, that was the really big difference. We nursed our friends, friends whose own blood families had rejected them. We at times had time to plan beautiful passing ceremonies as our friends knew the timeline to their death back then.

Collectively everyone was really wild and angry but at the same time very motivated and really wanted to do reform. Like, we'd keep everyone safe ultimately, and try and get rid of this terrible stigma and discrimination and virus that was killing our friends. And I think that's changed. Even though the stigma and discrimination is still there, I think all of the communities that we've just talked about are not known as the "vectors of disease" anymore. I think it's much more widely-known as best practice to listen to peers, endorsing peer-led intervention today.

The policy development that came and still comes from peers over that period of anger, we still contribute to now, is known as best practice around the world. Harm Reduction, and the decriminalisation of sex work, drug use, same sex couples, or of people living with HIV for example.

PANTHER was a very militant sex worker rights organisation. It was an education and referral organisation, but it was very focused on union rights for the sex workers – and it probably, along with the very beginning of the formation of Scarlet Alliance, had a very different focus to what SWOP NT does today because funding puts in place different challenges. So when I got here in 2000, I found that although we'd gone leaps and bounds in access and equity down south, to say that an organisation like NTAC was accessible for large populations such as sex workers and drug users was dependant on who was working within. Certainly there was less availability at that time for myself to be involved as an activist in NTAC. It was more about the way the department was looking at what the outcomes should be for programs. And also it's an indicator of the amount of peers that are involved in programs too. So there wasn't, at that point in time, peer meetings to go to, because NTAC unbeknown to them, but known to Scarlet Alliance had employed (K) who was not a peer, but then at other times there was the ability to be involved as all other SWOP NT officers were peers. Funny really in reflection, it's not hard when we all get together to spot a non sex worker in a sex worker only meeting or other group of whores who is not, it only takes about 10 minutes and they are exposed as fake. That's because non sex workers will never know the

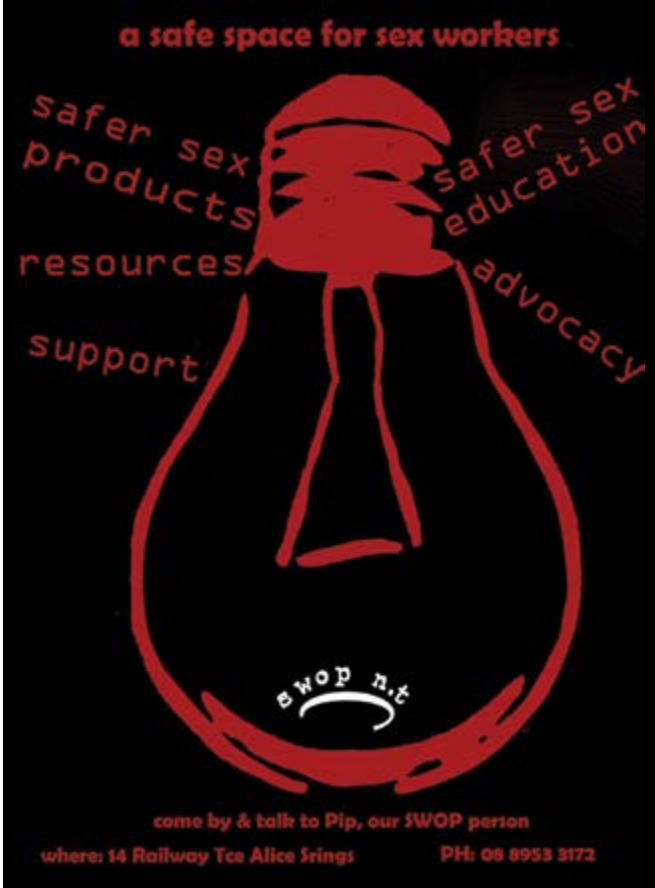
issues, the same as people who have never lived the life of a gay man, a sistergirl, transwomen and men, as a person living with HIV or (PWID) for people who inject drugs and understanding having a daily dependancy on injecting illicit drugs, etc.

2006 – 2009 there was a small group called Ho-Down that had formed – a Sex Worker Reference Group (SWRG) that still exists today, that directs SWOP NT really and raises contemporary issues so that we're really on the pulse with policy development and also to address better health promotion and human rights strategies. Ho-Down was a very interesting group that marched in 2006 May Day with a banner that said "My Body, My Buisness" a slogan taken from SA SIN a South Australian Sex Worker program also housed within an AIDS Council at the time. This was the first time that sex workers had marched in representation as workers in a May Day march for nine years, only PANTHER had previously marched with other workers for sex workers rights. During our march in 2006, we handed out little envelopes with "sex workers are safe sex experts" within envelopes condoms and lube sachets and workers rights messages, with stats around peer education being best practice with sex workers, and in Australia because of that diligence in peer education and peer-led health promotion, sex workers have maintained very, very low rates of HIV. In Australia it has been for pretty low about twenty years now, but we should not be complacent as our sex worker organisations from across every state in Australia are currently underfunded, peer education, skill sharing is the key to prevention. We need to dilligently concentrate on keeping that health promotion going though, not be complacent. I think that NTAHC is very

strong on health promotion with its projects, NTAHC needs more money too as a whole.

There's that old saying "unless you're living the life, you don't really know the issues". Certainly at NTAHC there's a crossover in lots of programs with people who access services, and there are those who crossover at different times as peers with staff who work in the programs. Certainly, I've crossed over into the NSP program, for sure. But I think the fight really has always needed to be maintained and funding is a very good example. There's been times where SWOP NT has been fully funded at five days a week in Darwin and one day a week in Alice Springs, and then there's other times where it's gone down to three days in Darwin only. Now I am back in SWOP NT again, currently, it's funded at four days, with an extra day just as a pilot to see how we go till June 16. I think unless our sex worker community really fights hard and shows evidence that we need this funding and we can do really good work with it, not much is going to change. We need to make change, and with adequate resourcing we can, what we do now is important and well done, but its not enough, even at five days a week to service and try to access sex workers across the whole of the NT, everyone knows that is impossible and less possible where we are now with funding, to support and have strong engagement in our SWOP NT programming.

The Sex Worker Reference Group (SWRG) is still fairly strong, even though there are transient sex workers in and out of that group as well, it's open to every single sex worker who is a past or current that has worked in the Northern Territory. So for that reason, sometimes there's new members there. At our SWRG meetings there are also



SWOP poster 2011

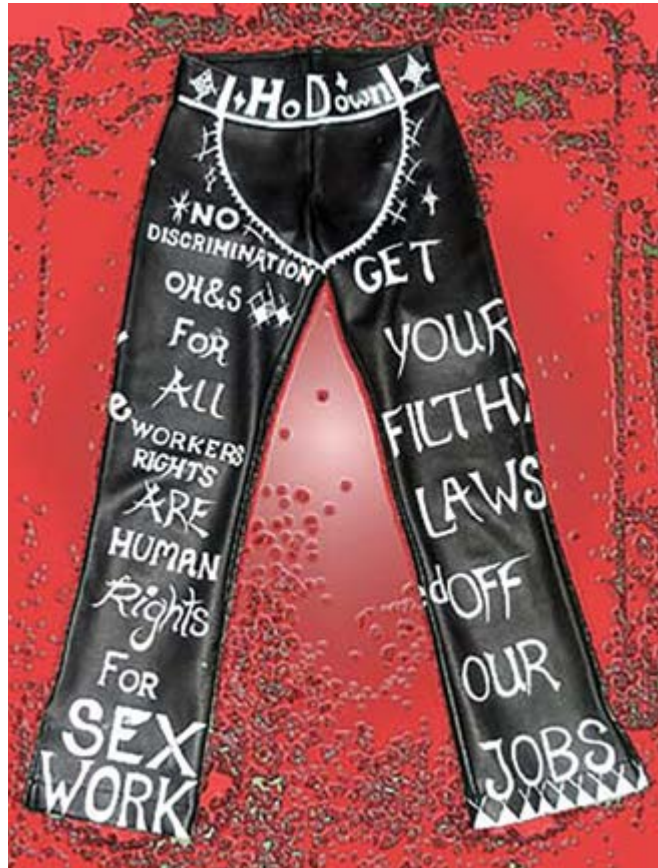
old established members who maintain presence, and at times original members will come back when they are visiting Darwin and attend. Just recently there was one person who was involved from 2003 and stayed fairly solid until about 2010 who has recently returned again.

So there's different periods of time where workers have energy to put in and out of the program on a variety of levels. The SWRG group participants work really hard, if

there's a decision to be made in NTAHC for SWOP, SWOP says "no, we need to go back to the reference group and we'll check about what needs to be the content". We don't make decisions blind in SWOP NT and we are proud of that core peer leadership principal from PANTHER and from Scarlet Alliances fruition, which still continues on today.

Recently what we've started doing, which we haven't done for a number of years, is submission work on law reform. We've completed two law reform submissions to save decriminalisation in New South Wales and to implement decriminalisation in South Australia. The Sex Workers Reference Group (SWRG) wrote most of the submissions with SWOP NT officers, as an example of good peer-based policy and leadership. NTAHC is very keen to have really solid, strong, peer-based policy and leadership with different programs, and so SWOP NT has been looking at all of the complexities of doing that. That again is further voluntry work for the reference group participants. But to do that, the group needs to work on long-term policy evaluation to make sure it works well. So that's a good example. Its always ongoing.

I mentioned (LeeC). There's many people that have gone in and out of the sex worker rights movement as well who no longer want to be known as a sex workers. I can think of other very significant people who worked in the SWOP NT program who I would love to pay homage to that have worked as sex workers, but it's not really my place anymore because they have moved in different directions, or have been uncontactable to endorse their names within this document. I have worked with sex workers in South East Asia, participated in Scarlet Alliance programs abroad as staff. Another SWOP NT officer before myself had



been the International Spokesperson for Scarlet Alliance, another was Scarlet Alliance representatives on AFAO board, a different person again was the Scarlet Alliance representative on AFAO HIV Educators Forum, There has been so much expertise over the years of input into the sex worker programs in the NT

I think that NTAHC gives people, anybody, a space to go into to remain anonymous to access our services. Alice

Springs, Katherine or Nhulunbuy sex workers, because of the stigma and discrimination across the Northern Territory, it is not so easy to cover the work. When sex workers travel through places like Darwin, interstate, into sex worker organisations, also in Sydney and Melbourne - sex workers meet other workers. SWOP NT supports workers regionally over the phone as best we can as possible without meeting face to face because we are unable to, we have to be very careful in checking settings of confidentiality, for example the space the worker is speaking within. We ensure we maintain links as best as possible for travelling workers and FIFO workers.

Organisations like Scarlet Alliance are really good for maintaining those links because there is now individual membership too. Many years ago, Scarlet didn't have that. Scarlet Alliance only had organisational membership. Now there is individual membership for sex workers, it's enabled a lot more workers to talk to each other on a national level. The internet helps too. We didn't have the internet before in the way that we do now.

Communication in very remote areas is tricky, there can be somebody working by themselves but now they're able to access through looking on the internet sex worker support from organisations like Scarlet Alliance or other organisations like SWOP programs, such as the one in Darwin information, then within the hour, there can be a worker on the end of the phone, and I think that's pretty magic these days. For instance, two weeks ago we did from scratch how to put a condom on over the phone, how to check a client over the phone, how to use all the equipment, and they had the safe sex pack from our office in front of them and then we also were saying "okay, so

Ho-Down slogan chaps for May Day 2006

can you see the way the condom rolls?, can you see what the rolled edge down does, you know, can you get a friend to practice on, bring them back tomorrow?". So we get on the phone again and we talk about how to check the client and lots of giggles, but it all works.

On a political level, I think I'd like to just use the opportunity to think about the wisdom of NTAHC's programs and the people that work within them and the people that access our programs, that volunteer their time and think about all of the amazing activism that has happened and the creativity around that activism. I think the resources that have been produced, and are still being produced, are in line with peer-led decisions. They've been peer focused tested and they work. And I think having peer-led programs works because having someone who has injected illicit drugs knows the complications around, for instance, how difficult it is to try and access equipment, safer injecting equipment at night and or understands the issues of why its important to get fairly good quality illicit drugs that aren't going to harm your system as much as really heavily cut drugs. And at the same time, try and balance getting to work at a 9.00 am to keep at work till 5.00 pm day job. Or shift work. Sex work can fall into similar hours for hospitality staff, the hours of operation for pharmacotherapies is limited so therefore inhibits people choosing if they wish to not use illicit drugs and utilize the substitution programs.

If there was decriminalisation of drugs, that would give better access to a known quality of drug in a way that the drug using community thought would would work, then people would be able to work and live better. There is a lot of myth busting to do, certainly people who inject illicit

drugs do work and there's an assumption that they don't. There's an assumption that sex workers who inject drugs aren't responsible as workers, either. I mean, sex work is work. And there's people that may not pay taxes and there's people that may not want to go through all of the different areas that they probably need to as sex workers. There sex workers who are investors and there are also sex workers who get by daily struggling to make ends meet. But all sex workers weigh up the options, there's not actually access and equity for workers either, so its not surprising that some sex workers will not disclose sex work as a job publically because the same workplace benefits are not yet acessable. Certainly Centrelink, at different points in time, have not recognised sex work as work. There is still a long way to go to change that mindset, its work and nothing else. The decriminalisation of sex work is the way to go "Sex Work is Work" So I think I'll just leave it with that. ♦



The Alice Springs SWOP story as told by Pip can be found on the digital timeline at www.ntahc.org.au/historyproject

Sharyn Marshall (NTAHC Program Manager) and Pip (SWOP), Alice Springs Dec 2011 (Photographer unknown)



Dawn Lawrie

NORTHERN TERRITORY AIDS COUNCIL / NORTHERN TERRITORY AIDS & HEPATITIS COUNCIL
2001-2005

Now during Frank's tenure we became NTAHC. We took on Hepatitis. There was some concern that maybe we were going too fast or too far but I felt that with Frank's background and his capacity we could do it and we should do it, and we did.

I am Dawn Lawrie. I'll give a bit of background because it is relevant to why I started with NTAHC or NTAC as it was then.

I was the regional director for the Human Rights Commission for six years and then I was administrator of Cocos Keeling Islands overseas for a couple of years. When I came back I got the position of the first Northern Territory Anti-discrimination Commissioner. So I had a very high profile. I'd had twelve years in politics before that as an independent member and sponsored a lot of social reform bills. Nobody else was going to do them so I did them, including establishing the parole board for Northern Territory. They didn't have one before I put my legislation through. And making sure that women were eligible to go on juries, which they weren't before.

So I was working at Danila Dilba as the executive director of the clinical services and a gentleman I knew asked if people from NTAC could take me for lunch, so I sort of smiled and said there's no such thing as a free lunch but yes of course. The story they told me was that there was open warfare within NTAC and that the treasurer

had called the police on the executive director to lock him out of the premises. It was turbulent and very destructive, and they asked at the peak of that if I would take on the position of president, to be a unifying force. I thought about it and said yes. Firstly, because I believed in everything that NTAC did.

I knew these people and they were delightful people. Anything I could do to help I would, and one of the things that I brought to it besides my huge experience in management was also a very real knowledge of problems people faced and the discriminatory attitudes of people, as you could imagine given my previous roles.

The other thing is, which is interesting, I was not a member of any of the groups affiliated with NTAC, wasn't gay or lesbian, didn't have haemophilia, I wasn't a drug addict; I was just me. So that was good because there was war within the organisation as well with the competing interests each vying for a piece of the pie. It was really quite destructive and unhelpful.

It was more gay and lesbian, not against, but fighting with the injecting drug users, and there was a third group, the sex workers. So everyone had the right idea for their particular interest but there was no harmony.

I was well known right across the broad church of NTAC, so there was no opposition to my coming in as president. The other one of the very good things that happened was one of my first duties with other members of the board was to interview for the executive director. The ED had resigned and the previous board had more or less pulled back. Most of them had.

So, I was very fortunate we chose Frank Farmer, and he was an absolute joy and delight to work with. He was so straight, trustworthy, across all of the issues, didn't play games. He was just a fine and really lovely person to have as ED. The board and Frank got on really, really well. He was seen as a fair-minded, competent manager and it was well known he had the trust of the board, so things settled right down which allowed us to get on with our jobs. As part of my role Frank would take me to the national conferences which I've got to say I found confronting at times, facing issues head on that really did confront me. One of the things which I will never forget is there was a doctor addressing us on sexually transmitted diseases and they had a graph for Australia, of the kinds of STDs and the number. He pulled out a separate graph for the Northern Territory because it was so bad it wouldn't fit on the other, and I found that horrifying.

They used to show these, I can only say lurid photographs of various parts of people's anatomy. I mean I had great management skills and great sympathy for all the

various people needing assistance but I had never really confronted anything like this, right in my face. Frank was quite protective of me and made sure that that I felt as comfortable as could possibly be. So, I didn't feel alone and it was a really interesting but rather confronting time.

Now during Frank's tenure we became NTAHC. We took on Hepatitis. There was some concern that maybe we were going too fast or too far but I felt that with Frank's background and his capacity we could do it and we should do it, and we did.

Now the other thing, something else about Frank I was going to tell you. When I came in, in those tumultuous times, the Northern Territory Government was threatening to withdraw funding. Because Darwin is a small place, they all knew about the tumult and of course it was a good excuse for them to say, "Get your house in order, we're defunding you". Fortunately it didn't happen before Frank arrived, and Frank and I would go and see the people in the Department of Health, Stephen Skov and others, talk about the plan we had for the future which we were able give to them, and all of a sudden instead of being mad outcasts we were seen as reasonable people with a vision and with a plan to back it up, and things got better and we got the funding.

So it was actually a very productive time and I thoroughly enjoyed it. But it was because I had such a good executive officer working for the board. The board was unified. He was great. We could take on extra projects. Because we felt happy and secure, that was filtering through. There was still partisan demands from the components. They all wanted all of the money, which

is a bit of an exaggeration, but we had to provide that balance between what programs we could feasibly fund, and we had not only the money to do it but the people to deliver it, and what we couldn't.

I still look back on that four years with great joy. I learnt a lot. I remain a firm and committed member of NTAHC. And I appreciate everything they do, it's great. I just hope it's as good as it was when Frank was there.

Now there's always been a divide in the Territory between Darwin and Alice. So we would go down and we had a lot of work to do to convince them that we had their interests at heart and it wasn't a Darwin takeover. It wasn't easy either. We encountered some hostility. Alice Springs is popularly known as the lesbian capital of Australia, and we had to overcome a little bit of mistrust from that community, that we would continue to support the aims and objectives of NTAHC, which was really what they were being funded to do. And I think by the time I left it was in far better shape, that's not difficult because it was in very poor shape when we started.

The board members were great. Always very supportive, I just didn't have to worry. It was one of the best boards I've worked with. There were a couple of people employed in the organisation who were mischievous. They still had all the interests of NTAHC at heart, but give them an inch and they'd grab a mile. But that's understandable. They had a particular focus and frankly they couldn't see anything other than their pet project or their focus. But you get that. The way is to manage it and make sure that they're not destructive to other people who are also committed and driven. So it has always been a balancing

act. And then we got a grant from the NT Government for the sister girl projects over on the Tiwi Islands, which bought in another dimension.

One continuing battle was making sure that the funding bodies remained onside, and we could produce the plans and the statistics to show that we were working according to the funding guidelines and that we were having outcomes. This was at a time, of course, when more people were dying. Things have improved dramatically since. And also, I mentioned there was a bit of controversy when Frank put forward the idea of taking on the Hepatitis program. There was some resentment from other cliques, if you like, within NTAHC who thought it would harm them. We had to convince them that it was all part of the same human entity and the need for support, advice, preventative programs, the whole thing. Going into prisons was started, from memory. I was talking to somebody very recently (who will have to remain nameless), who said that the rate of STDs among prisoners is still off the chart, which is very depressing, particularly for me, syphilis. I mean this is 2016 and we're still talking about syphilis and babies being born syphilitic.

You only need a couple of disaffected workers who think that their particular program is being not given its full share of daylight or you get people in the community who think that all people connected with the AIDS Council are coming to invade their homes and steal their daughters and rape their male children and, oh my god, they're very sad individuals but they are still out there. So I'm always very happy as a person well-known in the community. I've just finished my tenure as the chair of

the Northern Territory Placenames Committee. I'm always very happy to talk about the AIDS Council to give it the imprimatur of standing, and I still find that it amuses me, but I also find it a bit confronting that people have this peculiar idea that, as I say, NTAHC.

I guess the only thing I will say as a wrap-up is I still firmly support the aims and objectives of NTAHC. I think that maybe they could raise consciousness with politicians and those who hold the purse strings but the desperate need as a health and community issue which, as you say, it's getting worse, and that's horrific because it was bloody awful when I was there.

I would like to see Aboriginal Health Workers who are accredited – they get an accreditation as part of their training – be trained on these issues. But so that the people are based in the communities, and you could bring them in once every six months for a quick seminar, a refresher, remind them they're still loved and appreciated and out they go again. So they're trained Aboriginal Health Workers doing a whole variety of health work stuff, including preventative medicine of course which is very good but also have this additional training. When I was with Danila Dilba, what I found was that some Aboriginal Health Workers are no different to any other part of the community. One, for example, loved working with feet and the problems that go with diabetes, so I got him extra training and he became the foot man. Another one was very keen on eyes, so keen that I actually got him in when they were doing eye surgery at the hospital as part of the team.

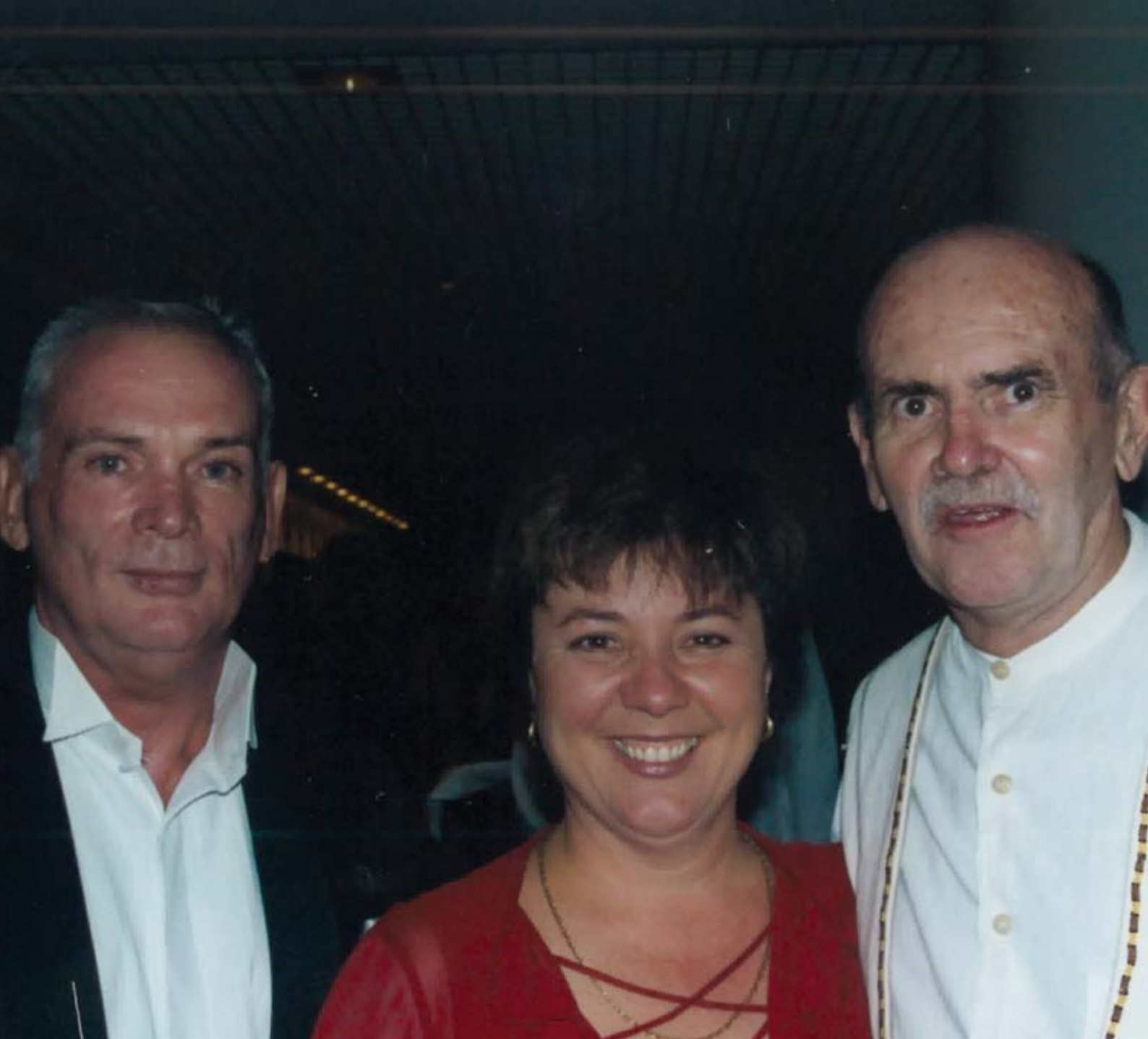
So you can do those things if you are a good manager and you recognise potential in somebody, train them up because that's a benefit for the community. That's not a cost, that's a benefit. And I don't think that is utilised enough right across NT government and the Department of Health. Not everyone's the same and if you see, it doesn't matter whether it's a health worker or an enrolled nurse or a certified nurse or a doctor – they will all, well there will be people who say I have a particular interest in whatever, give them the extra training. It's a benefit. Cost analysis would show that. That's it. ♦



Unknown, Dawn Lawrie, Frank Farmer, World AIDS Day 2005



Valentines Gay, NTAC Dance Party, Fanny Bay Bowls Club 1998 (Photo David Taylor)



Frank Farmer

NORTHERN TERRITORY AIDS COUNCIL / NORTHERN TERRITORY AIDS & HEPATITIS COUNCIL
2001–2005

In other states and territories, the ownership of AIDS Councils by the gay community was diminishing over time. They had achieved what they wanted to achieve with the establishment of AIDS Councils around the country – ensuring that there were dedicated services for people living with HIV, people affected by HIV, and the gay community generally. And, as most people would be aware, AIDS Councils were very political organisations. While I thought that that was diminishing elsewhere, there was no question the people who swirled around the AIDS Council in the Northern Territory had quite a bit of ownership over it – and it meant that they could be quite vocal at times.

My name is Frank Farmer, I was the Executive Director of the Northern Territory AIDS & Hepatitis Council from November 2001 to December 2005. I was working for the West Australian AIDS Council as the Community Education Manager. I got involved in the sector because I am living with HIV and I wanted to participate in the response and make a contribution. I put my hand up for the job in the Northern Territory a couple of years before combination therapies had become available. It took me a couple of years to gain confidence that I wasn't going to die as predicted, and that I felt that I had the opportunity to spread my wings, so to speak, and move out of Western Australia and Perth.

I was encouraged by Kitty Gee, who was working at NTAHC at the time in the NSP and as the Sex Worker

Project Officer. I applied for the job and I was successful. Prior to going to NTAHC, I made an assessment that it was about the same size as the department which I'd been managing in Western Australia, however, it didn't work out like that because within a short period of time of me being there, the Board decided to take up hepatitis.

There was no hepatitis organisation in the Northern Territory at the time and in order to address that, the Northern Territory AIDS Council decided to become the Northern Territory AIDS & Hepatitis Council. So we made an application to Hepatitis Australia to seek their permission for this to happen and they granted permission. Therefore we changed the name, and we introduced hepatitis to the organisation.

Frank Farmer, Julie McCrossin, Neil Ludvigson. World AIDS Day Ball, December 2001

From memory, when I went there, there was a Gay Men's Project Officer, an NSP, and there was a part-time Sex Worker Project. There was a support services position and there was an Aboriginal and Torres Strait Islander Project – which was focused largely on transgender people, most of whom lived on the Tiwi Islands but some were in other communities around the coast. So the organisation was quite small and the taking up of hepatitis in itself didn't immediately expand the organisation. There were no new funds for hepatitis so the organisation took it on knowing that we weren't going to receive additional funding to support that move. However, given that NTAHC was operating a Needle and Syringe Program, and the biggest and only needle and syringe program in Darwin, it was appropriate that we did take up hepatitis because we were actually engaging with most of the injecting drug users who were living in Darwin and therefore, people most at risk of hepatitis C.

One thing that I haven't mentioned is that within weeks of me getting to the Territory, the Palmerston Needle and Syringe Program opened. Now I shouldn't and didn't take any credit for that because all of the groundwork was done prior to me getting there, all the research was done to secure the opportunity, but the organisation had problems finding a site. They couldn't find an appropriate site in Palmerston, and within three weeks of me getting there, I was in the Health Minister's office, and the Health Minister decided that the government would help us out in finding a location, which they did.

Also after I got there was the World AIDS Day ball, which had also been organised before I got there. So that was my first public event, and an announcement was made

by the government to support us which really was made by the Health Minister – and it made the Health Minister and the government look good, and as the new kid in charge, it made me look good as well.

My understanding is that the organisation had gone through a difficult time, and Chris Day, who had been there for a couple of years before me, was responsible for refinancing the organisation. I never met Chris, but I did have a couple of conversations with him prior to me going up the Territory. I didn't have a handover as such, and my understanding was that he was a good financier and he had restored the finances of the organisation and put it back on to really solid footing.

When I first got there, I did go down to Alice Springs and I introduced myself to the AIDS Council of Central Australia. We mouthed all the right words about working in collaboration, working in partnership, et cetera, and those announcements were made in good faith, though in practical terms we had very little to do with each other. It was certainly operating in a very limited capacity when I went down and for the first year or so that I was there I guess. But it folded, it completely shut its doors. It was de-funded and the government, rather than to prop it up yet again, put the services out to tender.

So what happened was NTAHC tendered for it and we secured it. That was the first time in the history of the Territory that the two services were united as one, in a true sense of the word.

Anyway, we got the contract and I went down to Alice Springs and I looked at a number of premises and consulted with a range of people, and eventually

decided on the old railway house, which is still where the service is located.

Then we put up an application to the council, and I was advised that some people had put in objections to the opening of a needle and syringe program in that location, which was hardly surprising. But I realised that there was going to be hearing by the local council, so I thought I'd better get down there and speak to it in person. I flew down for the hearing and fortunately none of the people who had put in written complaints or concerns came to the meeting, so I had the floor to myself. I spoke for less than five minutes and council approved it.

Potentially it could've been incredibly problematic, but it went through without a hitch. We then recruited a small number of staff, including a Regional Manager, and that really marked the expansion of the organisation. We obviously picked up additional funding for that service. The organisation had the capacity for the first time to have an Executive Director and regional managers for the Top End and Central Australia, and those regional managers – even though Central Australia was a much smaller operation – the two regional managers were given equal status because the regional manager in Central Australia had additional representation responsibilities, but they did it as equals.

Yes, so Jill Meade took over Central Australia. Jill was a very colourful character and I liked her and we got on extremely well. I think she really represented the organisation well during the time that she was there.

There was a candlelight vigil that was held every year in Darwin. The people in the community that had a vested

interest were very committed to the candlelight vigil. Whilst in other states and territories, the interest in the candlelight vigils diminished, it was definitely sustained in the Northern Territory. Usually it was a very small affair around Lake Alexander at East Point Reserve.

Every year, World AIDS Day was marked by a World AIDS Day Ball, which was always put together by a committee drawn from the community. We worked together across the year to plan the World AIDS Day Balls, with varying success. Not every year was a screaming success and they never made any money. We never made a cent, though we didn't lose money by the same token, but there was an awful lot of work that went in for the result and it was probably the one event that provided the biggest profile for the organisation. Other than that, in terms of community engagement, it was mainly through education at schools and through other service providers, by providing education and personal perspectives as requested.

And, of course, we had a relationship with the user group, which was TUF [Territory Users Forum]. Difficult? Yeah, tough. A challenging relationship to manage as they were sort of a bristly group – which is as they should be. One of the leading lights was Gary Meyerhoff. Gary and I knew each other because he had come from Western Australia. He emerged in the Territory. He used to be one of the leaders of TUF, so Gary and I actually got on very well, he was actually a lovely guy. That relationship served a purpose and it was largely constructive, but of course, we had the NSP, and I think that's something that they, as a user group, always wanted but there was no question that were going to get it.

With the opening of Alice Springs, that meant that the Northern Territory AIDS & Hepatitis Council operated the three needle and syringe programs in the Territory, so that was quite a big responsibility. They were well run, were well patronised [and] the clients were very respectful of the service. They understood that the service was a legitimate health service that was there for them, and they were always respectful of that.

The community had quite a deal of ownership over the Council. As most people would be aware, AIDS Councils were very political organisations which meant that people could be quite vocal and critical at times, and sometimes that meant being critical of me. It wasn't uncommon for people to bail me up at social events, and tell me what they thought was wrong with the AIDS Council and what I should be doing differently or better, which was a pretty big catalyst for me to stop going out.

Overall it was a period of stability and growth for the organisation, and certainly in terms of growth, it was probably unparalleled in the organisation's history.

One of the important factors in that stability was the Board, and during the time that I was there, I consistently had good boards who were very supportive. And I had, for the entire time that I was there, the same chairperson in Dawn Lawrie, who I had a very good relationship with. She provided leadership to the Board, and she kept the Board working within its proper parameters. That is, the Board did not interfere with the operational management of the organisation – which can so often happen with small community-based organisations – the Board stuck to its job of looking

after governance and policy, and Dawn was very, very good at ensuring that the Board did its job.

I can't remember all the staff over the time I was there but here are some of my recollections. Deborah Wheatcroft was employed for most of the time as a support officer, and she did an amazing job. She and I got on very well, then I promoted her to do the Top End Regional Manager position and our relationship went completely belly-up. I did make the odd mistake. Daniel Alderman worked for a time there as the peer educator for gay men.

There was Kitty Gee, who I mentioned earlier, she was jointly managing the NSP and the Sex Worker Outreach Project and she did a great job in understanding and communication with her client base. She wasn't there for the entire time when I was there, she was only there for probably the first twelve months, and her husband relocated back to Western Australia, but she was good value. She got on extremely well with the sex worker community and she was excellent with the injecting drug user community. She was just the right personality for the job and she understood the issues. Shayne Killford was a constant, reliable volunteer and eventually became a paid staff member.

During the time I was there, there were at least three Aboriginal workers in the Aboriginal and Torres Strait Islander Program. Crystal Johnson was a constant presence. She was never an employee, but she was an important part of the project and always there with the organisation. I had a good relationship with Crystal.

There was another guy Braiden Abala. He was the project officer – not for the Aboriginal project, but for gay men

when I first went there, prior to Daniel taking up the position. Braiden was really good at the job but he left to do a master's in Cambodia. He was away for a year and then he came back and he was employed in the later part of my stay there, and he was terrific.

I think that the expansion of the service by taking up two disease bases and services in Central Australia was successfully managed, because there was a prolonged period of stability which enabled that to be managed, and I think that's what I see as my legacy. ♦

Nicole Cridland and Frank Farmer- World AIDS Day Ball, 2004 (photographer unknown)





Kirsten Thompson

CLINIC 34 / NORTHERN TERRITORY AIDS & HEPATITIS COUNCIL

2010 - 2014

At that time, the hep treatment program was just expanding with the different drugs that were coming through, and there were so many more people coming out of the woodwork who were actually getting tested, because there was publicity around the place.

I am Kirsten Thompson. My involvement with Clinic 34 in Darwin was from 2010 to 2012, and then I worked with NTAHC from 2012 to 2014. I'm still sending clients over there from here, which is Family Planning.

I became the Hep C CNC in mid-2010. Prior to that, I'd been working a little bit with NTAHC with HIV clients. Once I'd started on the Hep C side of things there was much more involvement, especially with new diagnoses. It was absolutely fantastic. You'd tell someone they're positive, get straight on the phone, and one of the NTAHC staff would come over, or we'd take someone over there, or arrange for a meet and greet, and then the NTAHC mob would take it from there and supply the care.

I was clinically involved, and didn't have the ability to look at housing situations and relationship issues and all that sort of stuff. At that time, the hep treatment program was just expanding with the different drugs that were coming through, and there were so many more people coming out of the woodwork who were actually getting tested, because

there was publicity around the place. People in their forties and fifties were finally finding out why they've been feeling a bit crappy for the past few years. So that's why it was so good to have a place like NTAHC to call up and say, "Right, I'm overrun at the moment. Let's see what we can do for these people who have just found out."

During my time, the process was pretty damn smooth. I can't speak for prior to me but after me, because I worked for NTAHC then, it was pretty smooth. It was great.

I can't speak about it from the general community because I was so heavily involved, and my view is very skewed towards the hep-positive people, but through educational activities that I've been involved in with different places that I've worked, there is still, to this day, such a stigma surrounding it.

Now the new treatments have arrived things are looking even better. The PBS listing came through on 1 March, and the process of telemedicine will accelerate their dispensation.

Kirsten Thompson, 2013 (Photo Panos Courros)

Telemedicine is where the GP himself then gets on the phone to a consultant, and says, blah, blah, ABC about this person, we can email through all their test results and their records, what do you recommend? Do you agree with what I'm saying, and if so, then they can sign off and start the person on the treatment. So that's all in the pipeline at the moment. I know of three GPs personally who I've been speaking with about the need for a protocol written through Infectious Diseases as to how this telemedicine is going to occur, what the protocol is going to be – and then we'll have doctors that are able to prescribe.

This is very exciting, and these new treatments are now just twelve-week courses (as different from 24 or 48 week courses of very harsh combination therapies of the not so distant past). And even those with cirrhosis are now looking at treating so it's even better. We can now foresee a world in the future where we might have eradicated Hep C – in four or five generation's time, maybe.

However, the cost of the drugs is astronomical, which is going to be a big factor. I think with the government putting it on PBS, that's fantastic, but I do think there's going to be a bit of a kickback where there are other sections of health that aren't going to be getting this sort of money and people are going to start complaining about that.

When I finished at Clinic 34, I moved to the 'dark side' over to NTAHC. I left the clinical and came over to do care and support and education, and it was a real eye-opener. It was just a completely different perspective in the client care area. I was handing out drugs and looking after symptoms and that sort of thing at Clinic 34, and

any problems I'd contact a doctor saying, "this one's not working, this one's having side effects, this one's bloods have dropped this much", and then over at NTAHC it was: this person hasn't eaten for three days, I need to get some food in to them so that then their bloods might go better, because probably it's the starvation – and the homelessness and the relationship issues and domestic violence and things like that which effect the person. So it was a steep learning curve, but it was great.

I always wanted the two to work as one, and since I left Clinic 34 the hep C program was actually removed from the Sexual Health Unit, and moved in to the Liver Clinic at Royal Darwin Hospital which, in my personal opinion, just made it a lot less personalised. It's Outpatients Department: you wait for six hours to see someone because something else has happened. So I personally believe it should be treatment, and care and support, all in the one area.

My time at NTAHC was lots of fun, a great team, a nice and relaxed atmosphere, but when it came to the crunch, on the whole, most people were extremely professional, which is what you need in that sort of thing.

When I first moved to NTAHC there was a lot of in-fighting and cliqueiness – and that's from my perspective, from Clinic 34. The people I worked closely with, the care and support team – Lana Pocock (now Richardson) and Panos Couros – were doing their job perfectly, but you'd get involved in different aspects, or different parts of the organisation of NTAHC, and it'd be this section's not talking to this section's not talking to that section, it was just very cliquey.

I think there was a bit of a broom swept through by Craig Cooper, the new ED. He was brilliant. I think it was a very needed thing, and I think having someone coming in from the outside to do it and not a local was needed, because that person was already in cliques, and you sometimes just need that out-of-perspective, just to come in and say, "Hey, I know we drink together, but you've actually got to do the job here, too."

The programs NTAHC was delivering were, obviously, care and support, and it was very strong. The NSP is always a very-needed harm minimisation program. Sometimes a little dysfunctional, but it gets done.

Events, yeah, a lot of them stick out in my mind, but one in particular was the World Hepatitis Day down at the waterfront in 2013, which just involved members of the public coming down and we were able to just spurt a little bit of information in to each person's face. I thought that was the best program, and the best event that has ever been because it involved everyone. The Parliament House Hep B forum in 2014 was great, very focused, but was only for people in the industry. I love the World AIDS Day ones at the Precinct and the Christchurch Cathedral – they were out in the open and just grabbed people as they went past, and it was perfect. The same with the Youth Week event done by a young volunteer, Rennon Schafer, that also grabbed people as they went past.

I think to me, that works better, that's just my opinion. The focus on the industry is great, but it's still the same people every time and we're preaching to the converted. We need to get out there and go "NTAHC, NTAHC, rah, rah", but do it in a public forum in a safe way – like those three events, they were brilliant and Alex Galeazzi just does a fantastic job with them.

Also the health promotion graphics and Andy Ewings's ability to understand what I'm trying to say and put it in to pictures and words on a piece of paper or on a screen are second-to-none. I'm not artistic in any way, shape or form, and he just takes my dribble and makes it into something usable and presentable. There was that one that I remember, I was still working at Clinic 34, and it was the Strong Blood campaign – loved it.



I think the Sister Girl work was also really good. I have to throw that one in. I really enjoyed doing work with those girls. After a couple of years I still only got through to about four of them, but you take every little win you can, and not to expect something to be done for you because it's been done before. You've actually got to get out and do it yourself, and lay the groundwork again. I think that was a major point. A number of the girls do have hep C, a couple of them do have HIV. So it's really good to be able to connect on a few different levels because these sisters had not discussed their blood-borne virus issues with other people, very rarely, and for them to be able to come to the one-stop shop was great. ♦



Bill Paterson

NORTHERN TERRITORY AIDS & HEPATITIS COUNCIL
2011–2015

You know, it's like how are policy decisions influenced by the body positive? What are you doing about that? What are your consultative processes? What are your processes for engaging people who traditionally don't have a voice?

My name is Bill Paterson. I was President of NTAHC from 2011 to 2015. I started on the board as the HIV-positive representative, that was a couple of months before I became president at the AGM that followed. So I came onto the board in June, and then there was some upheaval in both the governance and operations of the organisation. I was asked to nominate for the position of president and I did.

The organisation was in a very troubled state at that time. There had been a special general meeting called of the members to declare a vote of no confidence in the board, which was interesting because there was no constitutional basis to declare a motion of confidence in the board. During my presidency, we did a constitution review and inserted the ability for the members to declare a motion of no confidence in the board.

My understanding of the problems were that there was a significant section of the membership – which was very small at the time, so you didn't need very many people for it to be significant – who were unhappy with the way

the organisation had been managed from an operational perspective, and how that situation had been managed from a governance perspective. And also the view that the board had reached a stalemate position, unable to function and move the organisation on. Elements of the membership had made significant representation to the Minister of Health seeking the defunding of the organisation. Also to the department responsible for managing the funding, which was Centre for Disease Control with the Department of Health, to have the organisation defunded or at least called to account for the way that it was operating.

And there had been significant representation to the patron, Sally Thomas, who had recently moved into the position as Administrator of the Northern Territory, (the equivalent of a Governor). She had been patron of the organisation since its inception. She's an amazing woman with social justice credentials as long as your arm, and she's stuck behind the organisation through thick and thin and really had a clear understanding of the role of patron. A very wise woman.

Trish Crossin & Bill Paterson, World Hepatitis Day 2012, MAGNT, Darwin (Photo Panos Couros)

What was very interesting about that special general meeting was that they took it upon themselves to declare a motion of no confidence in the board and therefore it would be a given that the board was cleared. Then they promptly appointed who they thought should be on the board from the people present in the room and some who were not. I don't deny that there was certainly problems with the governance and the operations with the organisation but this was a personal attack on individuals rather than on the Board as a whole.

As a president, from a governance perspective, that this had been allowed to transpire and driven from an operational issue, was shocking because a community-based organisation is not owned by its board or by its employees. It is owned by its community and if you have allowed the membership to get to such a point that a small group of people can have such an influence, it is a judgement on the way that the organisation conducts itself and had been allowed to develop. So from a presidential point of view, it was a shocking state of affairs for an organisation to be that way.

You know, it was a functional organisation, it had good funding, it acquitted, it had good systems and all of those sorts of things. But the personalities involved, each and every single one of them, displayed appalling disregard for each other and for the HIV-positive community that they were funded to serve.

Anyway, the meeting was told that they had no constitutional grounds for declaring a motion of no confidence in the board. Therefore we retained the board that had been elected at the previous AGM,

with the note that this was very soon before an AGM so people could nominate to join the board at that AGM and the membership could vote accordingly.

I had nominated as president because I had been asked by Marcus Schmidt, who was then vice president I think, and Sue from the education department who was secretary, and Trish Crossin who was an ordinary member of the board, if I would stand as president. Why they asked me that, I don't know. The assumption that I made was that I was a new face on the block, that I was an out and proud HIV-positive person which gives me enormous cache in an AIDS Council, and that I had previous presidential experience and community-based organisation experience in Sydney with multiple organisations, some of which had been in terrible strife and I had steered them out of that. So I had demonstrated my understanding of governance principles and how community-based organisations worked, particularly in the HIV sector, and they had recognised that. That's the assumption that I made.

What I really got was, "Well, none of us can stand. How about you Bill?" I thought it's a bit of a poison chalice, however it was the right time in my life and I stepped up to the mark. There was another man who had been put forward for president by some members who called the SGM. He used to run a bus line or something, or a transport company, and he turned up to this meeting and he was awful.

The Board were responding to the upheaval by attempting to bring peace, saying, "Well, we accept that there's problems with our membership." We'd in fact funded Matrix on Board – who are an NGO support organisation –

to undertake a governance review of the organisation, and to advise us on what has happened and how we might prevent that in the future. We were going into elections which would allow the membership an opportunity to elect who they wish onto the board. There was no constitutional basis for the decision that they came to at the special general meeting, so, "No we weren't going to clear the board but we will do these other things." The actions were all very conciliatory.

This guy started shouting and yelling and spat on me. It was absolutely horrendous. Jamie Broadford from the department was there, and I was the only positive person in the room and I'm the one that got spat on – you know? So, he's going on about how they need to get the AIDS taken out of the title because it's disgusting and the front door needs to be closed and moved around to the back alley. And of course for people like me who are empowered and resilient, the whole idea that people need to sneak down an alley to get into a Council that wouldn't name itself an AIDS Council was an anathema. It's like, "Where are you living? Are you living in the '70s or the '80s?" So of course that was where he was living – he thought it was a disgusting thing and people got it from disgusting behaviours and the organisation should conduct itself accordingly.

But what it showed to the people who were judging how we were managing this, was that we're up against this kind of rabid misunderstanding of the issues and a disinclination to really care about the positive people in this. It's all about personality politics. And he was asked to leave the meeting. So then we went to election and that guy – I can't even remember his name – withdrew his nomination for president.

As I was now president elect I could act in a kind of presidential way, which was good because the organisation was in crisis. The executive director was not coming into work, there was great concern amongst the staff about the viability of their jobs, and all of that needed to be managed. In fact, I was coming in with a kind of managerial brief to steer the organisation to a more stable footing. What I was trying to do with the organisation was moving it from a personality-driven to a process-driven model.

Many times in the history of the organisation these sorts of issues have arisen. The reason that they arise is because community-based organisations, by their very nature, emerge from the personalities that are around at the time to drive what they think should happen. But what is necessary to move forward is that the personality-driven nature of it needs to be dampened down, and a structural and process-driven framework established to meet the various needs and address the risks to the ongoing function of the organisation.

The primary responsibility of the president is to the membership or the body positive through the influence of the membership. In this instance, my primary responsibility was to the staff who were in a state of despair and confusion about what the future might be. And then we had a new board and, of course, a new president always has a honeymoon period. So during that period I allowed the executive director to resign, and went through our recruitment process where I actively recruited somebody who I knew had structure and process at the core of their practice.

Craig Cooper came up to the Northern Territory to follow his husband, so he didn't come up for the NTAHC job. He was working at Life without Barriers. I actively recruited him. And at the same time, I started imposing structure and process on the board with the development of working groups and formal board induction with external training about governance issues. It became clear with those very personality-driven people on the board that it was not going to work. As president, I was going to preside over a board where if there was going to be any personality politics played, it was going to be mine to drive this structure and process-driven agenda through. I was surprised at how successful that was.

A president and a CEO in step with each other are a formidable force in an organisation. Craig and I had had discussions about how we were going to manage the steering of this organisation to a secure foothold in funding, operations and governance. It was going to be "the Bill and Craig show" at least for the first six months, and then we would start to dampen down our personalities to let process and structure rule. So that was a very interesting induction to NTAHC.

Sally Thomas is an icon of social justice and stability. She had been sidelined as the patron for quite some years, so we reactivated that role. Part of it was a bit Machiavellian, because she was now the Administrator of the Northern Territory and she made Government House available to us as one of her three favourite organisations – which gave us cache of course. I instituted that all new presidents will go and meet the patron, and all the new executive directors will always be taken and introduced to the patron. The patron will be invited to all functions with

a brief about whether the patron has a key role or a secondary role. Re-energising the relationship with the patron really was about her role. After these meetings she'd send little hand-written notes – and they'd be in this spidery handwriting, "I think the organisation is in good hands, Bill." The Administrator of the Northern Territory is a busy person, and I just felt very honoured with that.



World Hepatitis Day 2013, Darwin Waterfront
(event coordinator Alex Galeazzi)

One big highlight for me, in terms of speaking to people who we don't normally speak to, was an event for Hepatitis Day that we did at the Waterfront. That was just inspired. We were all very nervous because we were going to troop down to a public place and set up our BBQ with a singing drag queen and a folk singer, and there was a whole bunch of people who are part of our crowd who came along. We were doing this on a weekend afternoon down on the Waterfront to a public crowd of maybe over 1000 people. It was a cracker of an event, just a cracker. Of course, the predominant people who came through that event were backpackers who were coming through Darwin on their way to or from south-east Asia. Who do you need to speak

to about Hepatitis and HIV risk in the Top End? One of the major groups are the travelling populations that are moving to and from high prevalence countries. It was inspired. Also, it established a really good relationship with, I think, the Lions Club because they're the ones who are the boss of the Waterfront and the BBQ and all of that sort of thing. And it was just a cracker of an event, and very different in terms of who we speak to and the way that we manage our profile. For me, that was a highlight just because it was so different from anything that had come before.

In terms of governance, constitutional reform, rewriting the constitution – that was pretty much single-handedly done by Trish Crossin. She was a Senator at that time. She wrote it in plain language and – because all jurisdictions have a model constitution – based it on the model but in plain language so it's easy to understand. I thought that was a really good piece of work. And the other highlight governance wise was the development of the sub-committee or working group structure for the work of the board.

The blood-borne virus epidemics keep changing, so what's necessary to do in response keeps changing as well. New treatments and new therapies, new models of reponse, all of that sort of stuff. One of my regrets about my time in the organisation – and I left NTAHC because I left the Northern Territory for personal and professional reasons, I didn't leave because I was fed up with NTAHC – was that I really wanted to see more primacy given to the voice of the people living with blood-borne viruses. For various reasons that never really eventuated, mostly because people with blood-borne viruses don't want to step forward in an environment like the Northern Territory perhaps they're

afraid of people knowing and concerned about what people may think about them. I assume that's why.

I work in a national representation and advocacy organisation now, and I know that the meaningful involvement of people with HIV/AIDS and the greater involvement of people with HIV/AIDS as a policy platform has a multilayered implication for any organisation. It's not just about delivering services and asking people if they like the services that they're having delivered to them. You know, it's like how are policy decisions influenced by the body positive? What are you doing about that? What are your consultative processes? What are your processes for engaging people who traditionally don't have a voice? You know, people with mental illness? Aboriginal and Torres Strait Islanders with HIV, those who identify as gay as well as those who are not gay? Aboriginal and Torres Strait Islander women who are living in the Todd River and can't negotiate their sexual safety? I think that's the future of creating legitimacy and currency with your constituent population. ♦



Kim Gates, Peter Kay, Bill Paterson, Craig Cooper,
NTAHC AGM 2013



Kim Gates

NORTHERN TERRITORY AIDS & HEPATITIS COUNCIL EXECUTIVE DIRECTOR
2012-ONGOING

Stigma and discrimination, I think, always has been, always will be one of the big issues ... STIs are through the roof in the Northern Territory. We have the highest rate of STIs and Hepatitis B in the country, and extremely high rates of gonorrhoea and chlamydia in Aboriginal communities. We're currently seeing a really big increase in syphilis ... We realise that Aboriginal people are not using condoms, not practising safe-sex, so that puts them at a bigger risk for HIV and other blood-borne viruses.

Kim Gates, World AIDS Day 2013 (Photo Panos Crouos)

My name is Kim Gates, and I've been employed at NTAHC since November 2012. My involvement with NTAHC goes back a little bit further than that because prior to working here I worked in the Department of Health and Ageing. I was the Assistant Director there and for quite a few years I was responsible for the team that contract managed NTAHC. So, I had contact with the staff through that contract management. I used to come over and visit occasionally, and get to know what the programs were doing and what the service was all about. So I have been in touch with NTAHC probably since about 2008, 2009.

I started as the Deputy Director. I was actually head-hunted for that position by the Executive Director at the time, Craig Cooper. When he first came to town and was on the NTAHC board he was new to the Northern Territory, and I was put in touch with Craig by a colleague who

recommended that he might want to utilise me to get the lay of the land, as far as the political landscape in the Northern Territory, because I'd been here a long time. We would meet for coffee every now and again and talk about some of the issues the AIDS Council was encountering and some strategies to go forward.

Over that time, I guess, we formed a relationship and he then encouraged me to apply for the position of Deputy. I said no a few times but then there was a change of the NT government and there was a change of the political direction around where funding should go, which morally didn't sit with me very well. So I decided that maybe my time in the bureaucracy had finished. When they actually advertised the position I threw my hat in the ring and put an application in. I was selected for an interview and was successful.

I started early November 2012. Obviously, after that Craig was my Executive Director for a couple of years and he was teaching me about the sector and what I needed to know, grooming me in a way. When he left he encouraged me to apply for his position. It was only after a very short time in the sector, about eighteen months, and I wasn't sure I was quite ready. It was a little bit scary at the time but I did it and I hit the ground running.

When I first came to NTAHC, I just remember the staff, you could tell they were all watching me because no one really knew who I was here. And there was, "Who's she? What is she doing here? What's her background?" You know. I got straight in the deep end because the Executive Director wasn't available to talk at the World Aids Day 2012 event which we had at the Christ Church Cathedral in Darwin. It was on the lawns there and it was really beautiful, and I had to give a speech.

I found that really challenging because I wrote the speech, a personal speech, about my experiences from the '80s and the friends that I lost to HIV, and it was something I hadn't really put pen to paper about for a long time and hadn't thought about for a long time. Reading it was even more challenging but I just remember afterwards the staff that were there coming up and going, "Now we know, now we get you." And it just – now I'm going to get upset – and it really just formed a bond with the staff that were questioning me in who I was. And from that moment on I was accepted and just went forward.

So, the key issues now, still the same old ones. Stigma and discrimination, I think, is right up there; always has been, always will be as one of the big issues. But I think getting

up with the latest treatments and latest prevention strategies, such as PEP and PrEP. And the NT's a little bit behind the rest of the country with some of those things mainly, I guess, because of small population size and our low numbers of HIV, but that doesn't mean that we shouldn't get access to some of these strategies.

I sit on the AFAO board, which has been a really good learning experience for me because I have actually got to know more about the national perspective and what's happening in other jurisdictions. So, there I'm able to identify what works or might not work in the Northern Territory and then say, "Yes, we want this" or "We don't want that", and then can start advocating for that. And I can use, through our membership with AFAO and NAPWHA, Scarlet, AIVL, etcetera, their expertise to help advocate through the NT government strategies that we want in the Northern Territory – using their evidence base.

The NT is a more unique situation. WA's a little bit the same, but I think we have very unique notifications in the fact that our HIV notifications are not predominantly gay men, as it is in most other jurisdictions. So, having a high percentage of heterosexual, a lot of people coming from refugee or migrant backgrounds, it is different and we bring a level of expertise to the perspective and talk about our experiences.

I don't know that we run any different programs; I just think that we target them in a different way. So obviously the needs of gay men might be different to the needs of heterosexual women, and we obviously are a peer-base service – we like to engage with peers and have our programs delivered by peers. Picking the

right people to deliver the programs is the key element to the success of our programs.

We have Care and Support, obviously – which is the main reason that the AIDS Council was actually formed in the first place – providing care and support for people with blood-borne viruses and some really concentrated case management, but also a lot of referrals and just general support not just to people living with viruses but also people who are affected by, at risk of, or family members. It's quite a broad program. We also have the Aboriginal Sexual Health Program which is there to not only educate Aboriginal people around STIs and blood-borne viruses but as well to engage with the Aboriginal community and to encourage them to get tested and sometimes do the more intensive case management support.

In Aboriginal communities there's so much going on for people and, when it comes to their health, there's a lot more acute care is required. There's a lot of people with chronic health conditions and so when they front-up at the clinic, sexual health or blood-borne virus testing is way down on the list of priorities. I think that's no fault of the clinic staff, that's what they have to deal with on a daily basis. And so they have to deal with issues as they come in the door. I think Aboriginal people don't really understand that there are illnesses out there that don't have any symptoms, and because you look well and you feel well, so you don't worry about going to the clinic. So, having a test for something that you may or may not have just doesn't seem important and just doesn't come into their realm.

Aboriginal people have, obviously, a very different lifestyle, very different diets, and so it can result in a lot of different

chronic conditions. There's a lot of diabetes which leads to renal issues, and heart conditions. But there's also the other issues that happen in communities, so alcohol and drug abuse, and family violence. So there's also a lot of people presenting at the clinic for some of those things that fall out of that.

STIs are through the roof in the Northern Territory. We have the highest rate of STIs and Hepatitis B in the country, and extremely high rates of gonorrhoea and chlamydia in Aboriginal communities. We're currently seeing a really big increase in syphilis and that's led to a couple of cases of congenital syphilis in young babies, which is really quite sad. We realise that Aboriginal people are not using condoms, not practising safe-sex, and that puts them at a bigger risk for HIV and other blood-borne viruses.

I think I'm the first Executive Director that identifies as Aboriginal. I'm led to believe that there are a couple of former EDs who have believed that they have some Aboriginal heritage but they hadn't been able to confirm that and so they didn't identify as Aboriginal. I didn't really grow up within an Aboriginal environment; I grew up the way most people grow up in a singular family environment in the suburbs. But throughout my life I've actually realised that I don't know as much about my Aboriginal identity as I want to, so I've actually gone out and tried to increase my knowledge. Over the years, I think I've certainly gained a much better understanding of the situations that Aboriginal people live in, whether it be in town or in remote communities, and I've been to a lot of remote communities. And through that understanding, I think, I can transfer that to my work and I can actually apply that to the workplace and what we need to do around strategies for Aboriginal people.

One of the things I'm encouraging all the programs to do is much more engagement with their peers to get involvement in the program themselves, like in the development of programs and how it's delivered and what it should look like. SWOP are probably leading the way with that. They have a reference group, and basically all the decisions that SWOP make for sex workers, the reference group are engaged and involved in that decision making process. So you don't have the one or two workers within the SWOP program making a decision for the whole community. And that's really the principle that we want to see happening across the board.

Certainly at the moment SWOP has achieved a level of autonomy more so than any of the others. I think other staff still feel they have to ask permission to do things and get reinforcement, and I'm trying to encourage staff to be more autonomous in some of their decision making because they're making some really good decisions but the fact that they feel they need that reinforcement, there's obviously some confidence issues.

At NTAHC, it's a little hard to sometimes engage peers in programs, particularly in the needle syringe program, obviously because people are probably participating in activity that's considered illegal. It creates barriers for people in engaging in the service, so we're just trying to find strategies and ways to engage rather than necessarily face-to-face, so we use platforms like social media and surveys and other events, and trying to get feedback at events to encourage people to have that involvement.

One of the relationships that's been strained on and off over the years is probably the perception of NTAHC

as an LGBTI service, and in fact we're not. We're not funded for that, although we do deliver services to people from within the community because they're identified as the primary populations at risk of having HIV and other blood-borne viruses. But having said that, we also offer some other services over and above what we're funded to do because there's a community expectation and, at the end of the day, there are no other LGBTI services in the Northern Territory.

We have relationships with Darwin Pride and Alice Pride, and we actually auspice them both and support them with their festivals each year. We have a reach into the community, as far as sending out newsletters and things like that, and hopefully we have a reasonable relationship. I'm not sure that we've done any evaluation on what that relationship currently looks like, or maybe that's something we need to do in the future.

We have a couple of signature events which are World AIDS Day and the Candlelight Vigil each year, and World Hepatitis Day. They're three events that we recognise each and every year without fail and through one way or another. We've had different types of events and I think that's our biggest challenge now, is how to come up with something bigger and better than the previous ones because we've set a bit of a standard around our events. Our Event Coordinator Alex Galeazzi can be thanked for that – he's done a wonderful job.

Our events now certainly have a regular audience and every time we also see a few new people. And we're also broadening our audience-base in Alice Springs, which is really good to be able to re-engage with that community.

Alex Galeazzi, Sally Thomas, Kim Gates – Candlelight Vigil, Lake Alexander, Darwin May 2015 (Photo Panos Courros)

Obviously it's very difficult to manage a remote site, and I think anyone in any sector would agree. When you've got a satellite site, it's very hard to make sure that staff feel included and they don't feel left out. It is challenging and I wouldn't say that we've been expert at that, and I don't think we still are and I don't know that anyone is.

When we have events now we always try to have one at the same time in Alice Springs and have it of similar capacity, so that people don't feel that they're like the poor cousins; that they're getting the same events, the same opportunities as what happens in Darwin. It's also quite difficult to manage that considering we've only got a small number of staff in Alice Springs office, but I think there's quite a few board members from Alice Springs who have brought on a whole lot of support from the community as well, so it's nice to see. We've actually got more volunteers in our Alice Springs office than we have in Darwin, so that's a testament, I think, to the hard work of the staff and the board there. So, I'd say that the partnership is healthy and I think it's healing. I think we could still do it better, but I think it's really quite good at the moment but it could be better.

Our events are also directed at the more general community, and we do that by having them in very public spaces and engaging the general community. We get involved in other events as well – so just this week we've been involved in Harmony Day with Darwin City Council and the Malak monthly dinners at Darwin Community Arts. We actually go out and get ourselves involved in the greater community. So, we've gone to things like the Adelaide River Country Music Muster, an audience that we

wouldn't traditionally engage with but we go out as a way of trying to broaden our reach into the bigger community.

Looking to the future, it's certainly a changing landscape with what's happening the HIV sector with changes in medications and treatments and prevention strategies, and we see new drugs in the Hepatitis sector which could possibly see the eradication of Hep C in the next five to ten years. It would be nice to say we're doing ourselves out of a job, that maybe there won't be a need for NTAHC into the future; I'm not sure that's our reality but it's nice thought. But, I guess, until we get on top of Hep B and there's still always going to be something for us to do. So, it's about diversifying what we do. At the moment, for example, we've got new Hep C treatments, so we're spending more time now educating people around the medications and the treatments and how to go about getting them. We're still doing the work, we're just doing it in a different way. ♦





L-R: Eric (volunteer), David Aanundsen (Aboriginal Sexual Health Coordinator), Fanny Waterfall (Aboriginal Sexual Health Officer), Jyoti Jadeja (Program Manager) Kanible Kitty (performer) Kiran Bheda (NSP Officer) Georgie (Silver Rainbow trainer) Film screening 2015, Alice Springs

David Aanundsen

NORTHERN TERRITORY AIDS & HEPATITIS COUNCIL ALICE SPRINGS

2014-ONGOING

STIs are still remaining high and there's a syphilis outbreak happening across the NT

I am David Aanundsen from Alice Springs NTAHC. I started around April/May of 2014, and I work in Aboriginal Sexual Health. I used to work in a similar role at ACON in Sydney so for me it's the second AIDS Council doing similar roles, but they do vary because the Northern Territory's different to New South Wales and as well the time periods have changed.

I see some clients from time to time but the client loads are not very high for Aboriginal HIV within Alice Springs, and some clients I see are more hepatitis related than HIV. Recently we did have a newly-diagnosed Aboriginal person with HIV.

The Aboriginal Sexual Health role includes education, health promotion and client work, but being in a smaller office as in Alice, you work on all the programs. One of the things I do through the project is Chair the Central Australia Sexual Health Network, so we bring all the sexual health services together to know what we all do and improve referral between services, which is quite handy.

The difference between other places and Northern Territory is that for a lot of Aboriginal people – and particularly where I work in Alice Springs, and in Darwin – English is

their second language and some can't read or write or don't speak English. Sometimes you've got that little bit of a difficult barrier. We try to overcome these circumstances by aligning ourselves with other workers from the community, so I work in partnership with Congress Health service. I've got those Congress workers that can help me out where I need or just other Aboriginal workers that I know. And because I've been in the NT for nearly eight years now, I've got enough contacts to know who can support me when it comes to language.

Darren Braun who works in the program in Darwin has been doing some work in Katherine and a bit further south. I have some education activities, events come up, clients, running committees, meetings. Sometimes there's deadlines with a lot of things that sometimes can prevent you going out to remote communities. I'm planning a trip in April to go out again. Places we're trying to target are those communities with higher STIs.

And then the other thing I do too is the Silver Rainbow LGBTI Aged Care Inclusive training, so I'm involved with that. Alice Springs are the main areas that we are currently targeting because I guess that's where the aged care

services are based. Some services could come in for training, so we could notify some of the outer regions and then if they wanted to come in for the training they could.

Congress services some outer regions, so part of it when we do the sexual health network is that some of those workers come in. So if we don't make it out ourselves, it's also about linking in with other services and people who do go out as well. And yes, they might be able to provide them some resources but also a lot of Aboriginal people do come from the remote communities into Alice Springs, and so some people from remote are seen in Alice Springs.

Some of the education has changed a bit over the last couple of months, but previously I was doing education in the prison and drug and alcohol rehab. And the Aboriginal Men's Centre in Congress. A lot of men who are living homeless come into Congress and just shave and shower and are fed some breakfast, and so I'll go and meet those guys. So even though I'm in Alice I'm seeing a lot of remote people. And when I was going to the prison, the majority of the guys were from remote so you're capturing them in Alice as well.

Some of the education materials I've had to adapt and change. I can't do standard PowerPoint educations with them because sometimes, if some can't read or write, or speak English and if it doesn't have any pictures it actually won't mean anything, and even for me speaking in English. So I've changed my education materials to being more visual. I'll take a whole lot of things out and put them on the ground, and then we all sit around in a group and go through one by one, you know, what is it, how can you be safe with the assistance of people who speak language.

It's a bit of fun too. Some of the guys have had the education a little bit and then the dental dams, when you get newcomers asking "what's this?", the others start laughing because they did it last time. So I like doing that and I'm finding that seems to be more engaging. I'm discussing what it is and how can you be safe. I just throw a question at them, and then they can grab the item and look at it and it's all very visual and touch and feel, unlike a PowerPoint and them only looking.

Well, some of the Elders didn't get the education themselves, but at the same time some of the Elders do see the importance because they're having to deal with the issues of high STIs in their communities. We've had some recent cases of infant deaths related to syphilis, and syphilis is out of control at the moment in Aboriginal populations of Central Australia. Congress recently wanted me to come in and talk to some of their Elders. These were some of the homeless guys of the community and they were quite keen to know more about STIs. Congress are not doing that education, although they're doing it in some of the schools but they've had to change and adapt what they're doing. But for Elders, I guess they're concerned about all those sorts of things and not having information or any education on it as well.

A new thing now is the uptake of syringes by young Aboriginal people, so that's something else that's a bit more new, as well as with the crystal meth sort of thing coming in. There's now more uptake in that area. It was the Goanna Report that was done recently and that's the evidence that's been gathered so far.

Aboriginal people are not really getting sexual health

education in schools, especially remote as much. So what would be good if some of our programs could be expanded a bit so there were bigger teams to go out – so you had a remote team and a central team, and males and females. These projects could do quite a lot but the funding restricts actually what you can do as well. With more workers, we can go out and do a lot more education in remote communities. So like myself, three staff in Alice Springs covering all the whole office and programs and running everything, sometimes it can restrict what you do.

I am careful cultural-wise because I'm a man and sometimes may end up educating both boys and girls together. When I'm in those situations, then I just go round the edges and give them some basic details and encourage them to get tested if they haven't been tested. I'll say it's a good chance if you haven't been tested, go and get a test. It has been good with some of the education, too, because it's been an opportunity to take them to Clinic 34 and actually have a test rather than just get education alone.

Funding wise, we're not too sure what's going on at the moment, and that's Australia-wide with all the Aboriginal sexual health areas. But the odd thing with the Northern Territory is that it's got some of the highest rates of STIs in Australia. More needs to be put into it because having less funding restricts really what we can do, and I think putting more funding in then we could address a lot more and do more remote work, but you do need the resources and vehicles and all sorts of things to get out remote. But, yeah, STIs certainly are not going down and there's a current syphilis outbreak going on, and we have had a new case of HIV in Alice Springs, and injecting is, I think,

on the increase in Aboriginal community as well. Particularly with things increasing, I think it's an ongoing issue and particularly now. ♦



Gary Lee & David Aanundsen, Anwerkenhe Conference, Alice Springs Nov 2015 (Photographer unknown)

