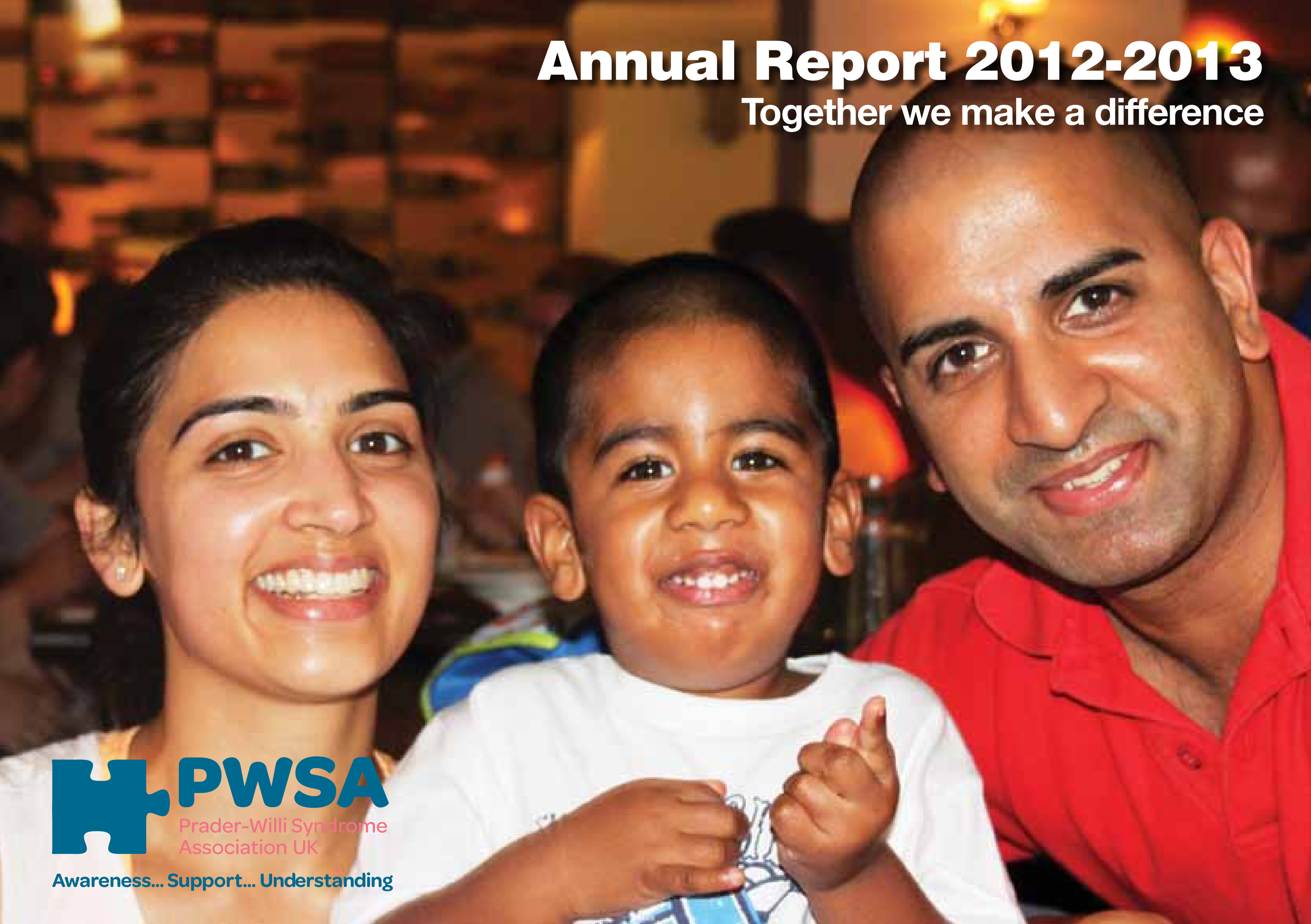


Annual Report 2012-2013

Together we make a difference

PWSA
Prader-Willi Syndrome
Association UK

Awareness... Support... Understanding

Everything we do is about valuing and supporting individuals with Prader-Willi Syndrome, their families and carers.

What is Prader-Willi Syndrome?

Prader-Willi Syndrome (PWS) is a rare, complex genetic disorder that affects both males and females from birth. The syndrome causes low muscle tone with resultant motor development delays, short stature, if not treated with growth hormone, and incomplete sexual development. Most have mild to severe learning disabilities and will be emotionally and physically immature. Challenging behaviour can occur in both children and adults. The over-arching aspect of PWS is an overwhelming, untreatable appetite which develops in childhood—the feeling of hunger cannot be removed however much they eat. Without rigorous food management together with exercise programmes, life threatening obesity will usually develop. It is estimated that there are around 2,000 in the UK living with PWS. We work closely with the majority of those with PWS and the myriad of professionals from health, social services, residential and education, helping them to manage this very rare and complex syndrome.

Who are we?

PWSA UK has been providing specialist advice to those affected by PWS for over 30 years and our dedicated team offers:

- Telephone and email helpline offering support, information and advice
- Information, literature and publications for parents, carers and professionals
- A programme of family activities throughout the year and a parent volunteer network
- Training programmes, both accredited and non-accredited for professionals providing support for those with PWS, conferences, consultancy, attendance at multi-disciplinary clinics
- Campaigning
- Support for and opportunities to participate in research

> ***"It is great to know that PWSA UK are only a phone call away and can give us the support we need"***

552 delegates from 37 countries.

We learnt a lot, networked a great deal and made many new friends as well as reconnecting with old ones.

PWSA Annual Report 2012-13

Chairman's Report

Despite not taking place until after the end of this financial year, the IPWSO International Conference dominated our activities throughout this one, as the bulk of the planning, programming and organisation of it needed to be completed by March. We have a small staff. Thus it was no mean feat not only to organise and hold the conference but at the same time keep up our level of service to our Members. As indicated elsewhere in this report, this too was achieved. I wholeheartedly thank our staff and volunteers for their contribution and achievements in such a busy year.

In July, therefore, we had the honour of hosting the 8th International PWS Organisation Conference jointly with the University of Cambridge at Fitzwilliam College. The event was a great success and we welcomed over the five days 552 delegates both professional and people with PWS and their families from 37 different countries. In total 79 people with PWS attended. We learnt a lot, networked a great deal and made many new friends as well as reconnecting with some old ones. The feeling of brotherhood was overwhelming and humbling and will remain with me for a long time. For further information and extracts from the conference please visit our website or the conference edition of our newsletter.

Now that this major event is over, we are focusing with renewed energy on the direction of the Association over the next few years, taking account of the economic environment we find ourselves in. The sustainability of the Association's finances remains a key preoccupation in being able to continue first class delivery of information and support to our Members, especially to those with PWS. We intend to be creative and do more with less, use technology to its full potential to communicate and deliver services and support and harness our team of committed volunteers as effectively as possible. Research brings hope and we will support the very best there is as proactively as possible. The Trustees and Staff are already preparing plans for the next phase and these will be disseminated via our Newsletter or Instant News when fully formed.

My thanks for another successful year go to all who so selflessly support us, the Trustees and other volunteers, and of course our dedicated Staff.

> *"The feeling of brotherhood was overwhelming and humbling and will remain with me for a long time"*

Our work this year

A report from Susan Passmore, CEO

The economic climate has continued to be a difficult one for the Association during this financial year, as it has for us all. The strategic review in 2011 and consequent restructure of the staff team, together with a very busy fundraising year and rigorous control of our expenses, has enabled us to maintain a balanced budget for 2012 – 2013. Our long term financial stability is a key priority to ensure that we will be here to support those living with PWS for generations to come.

The internet and social media are changing the way in which charities engage and offer their services. Social media has become a vital tool for communication to many, and it is important that we move with the times and embrace all that the internet has to offer. The new website, launched in 2011, remains constantly under review and offers instant access to information. It received 142,000 hits this year and receives between 2,500 and 3,500 unique visitors each month. Our Facebook page has over 1,200 followers and Twitter remains popular with over 400 regular followers. There are also several closed Facebook Groups run by, and for, PWS parents which enable parents to exchange views, experiences and ask for tips from each other. The Association is very pleased to be a member of several of these groups.

Communication via our helpline, emails and meetings continue to be the principal focus of the staff team who dealt with 907 requests for support during this year from 794 individuals. These can be broken down into 464 calls to our helpline, 345 emails requesting support, 17 meetings, 25 letters and staff and trustees attended 24 multidisciplinary clinics in Brighton, Chelsea and Westminster, Birmingham and Glasgow supporting 56 families.

We continue to review the information and publications that we have available and this year have begun compiling the ‘PWS Journey’ which will have individual sections containing information relevant for the age groups of birth-2, 2-5, 5-10, 10-13, 13-18, 18-25, 25-40 and 40+. All other publications and information will be reviewed over the next year to ensure that all information we have available is as up to date as possible.

Our social events have mostly been volunteer led this year with support from the office and we

907 requests for support

464 telephone calls

24 multi-disciplinary clinics

16 family activity events

have welcomed people with PWS and their families at 8 family days, 6 Christmas parties, a theatre outing and a family weekend break. In March we held another charity show featuring our Celebrity Patron Jo Brand and Friends. This was once again a warm and wonderful evening as well as raising much needed funds.

The Association introduced a subscription membership this financial year. Membership is free to all people with PWS and to all families during their first year of contact with the Association.

The Association took part in the government consultation on Personal Independence Payments this year. We registered our concern about the ability of the assessors to adequately assess the complex needs of those with PWS, or any rare syndrome at one face to face meeting. We also registered our concerns about the particular difficulties experienced by those with PWS that will not be apparent within the generalised categories of the activities section.

The Association continues to fund research where possible and in this year have funded projects:

- Towards interventions for temper outbursts in PWS
- The effect of the IC mutation on 5-HT2c receptor variant in PWS-IC mice and their potential contribution to hyperphagia
- The bone phenotype in PWS-IC mice
- The role of locally expressed GOAT in the activity of Grehlin

The Vagus Nerve Project, headed by Professor Tony Holland, has now led to a further research project entitled “MRI study of neural endophenotypes in Prader-Willi syndrome” which the Association will be supporting in 2013/14. In addition, the Association continues to promote and provide opportunities for families to take part in a wide variety of research projects.

Much staff time this financial year has been taken up in planning and generally organising the International Conference. This has been a huge undertaking for our small staff team, but every member of staff has risen to the challenge and a very successful International Conference took place in July 2013.

We have achieved a great deal this year in difficult circumstances and look forward to the coming year ahead with great enthusiasm, passion and dedication to helping all those affected by PWS.

> ***“I was really grateful for your advice, the literature was very informative and I also passed the information onto school”***

Many thanks to

all our wonderful

supporters.

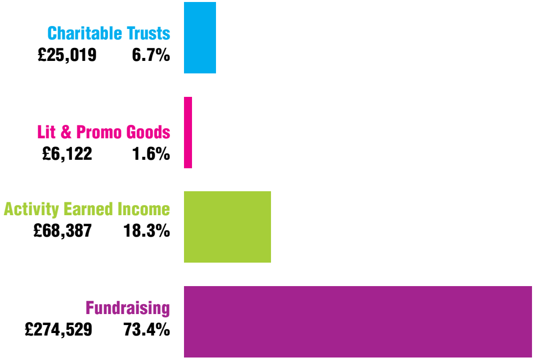
Simply put – we

couldn't do it

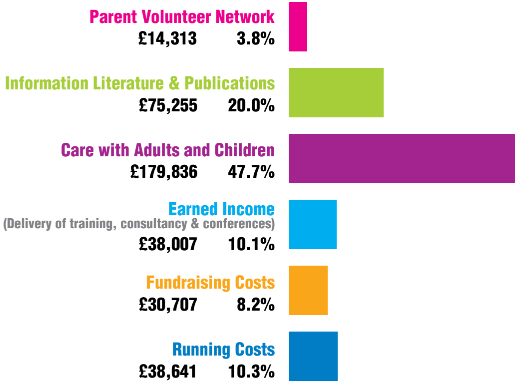
without you.

Financial overview

Income Sources



Expenditure



Financial Summary

Statement of Financial Activities

Year ended 31st March 2013	£
Total incoming resources	315,256
Total incoming expended	276,797
Net incoming resources for the year	38,459

Balance Sheet

Year ended 31st March 2013	£
Tangible fixed assets	3,713
Net current assets	271,358
	275,071
Unrestricted - General funds	38,359
Unrestricted - Designated funds	174,877
Restricted funds	61,835
	275,071

The statement of financial activities and balance sheet are extracted from the full statutory accounts which have been duly audited and are available upon request from Head Office.

The Association's policy is to accumulate a general reserve and a designated reserve to support specific purposes over coming years. The Trustees have agreed that unrestricted reserves should not fall below three months' operating costs which is the minimum recommendation of the Charity Commission.

> ***"Hats off to you – your work at PWSA UK is very important – thank you"***

A financially stable and sustainable Association.

First class information provision.

Extend our regional reach.

Long term growth.

Looking forward to the year 2013 / 14.....

A key long term priority remains to ensure a financially stable and sustainable Association. We will be holding a Strategic Planning Away Day in September 2013 where trustees and staff will come together to decide our priorities and goals for the next two years. The prime subjects for discussion will be our information provision, our regional reach and our long term growth. Instant accessibility of our information is paramount and we will be looking to make it in a format that is usable and suitable for all situations and across all media.

Our goals for 2013 – 14 will be:

- To deliver a successful and memorable IPWSO conference within budget
- To maintain a balanced budget and rigorous expenditure control to ensure maximum value for money
- To continue to review our service delivery to ensure we provide the best and most appropriate service possible for all affected by PWS
- To continue to review and update our information resources and the ways in which we make them available
- To look for opportunities to increase our volunteer network and to develop a strategy for volunteer support groups
- To promote, fund and provide opportunities for people to take part in research

Despite the difficult economic climate, we have been able to maintain financial stability in 2012 - 13. We are indebted to all our wonderful supporters who continue so tirelessly to fundraise for the Association in a great variety of ways. Your dedication provides essential support for those affected by PWS and ensures that the Association can continue to champion their rights. Supporters, staff, volunteers, trustees, people with PWS, parents and carers, professionals and members – together we are strong and can strive towards a world where PWS is not a barrier to a healthy and successful life.

"Our 6 week old grand-daughter has just been diagnosed with PWS so our family and friends are grateful for your info. I am sure we will be referring to it often"

Everything we do is about valuing and supporting individuals with Prader-Willi Syndrome, their families and carers.

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