Financial Summary

Statement of Financial Activities
(as at 31st March 2017)

Total Incoming Resources	373,774
Total Expended	383,097
Net Incoming Resources	-9,323

Balance Sheet

Tangible Fixed Assets	12,396
Net Current Assets	310,215
	322,611
Unrestricted General	131,710
Unrestricted Designated	180,984
Restricted Funds	9,917
	322,611

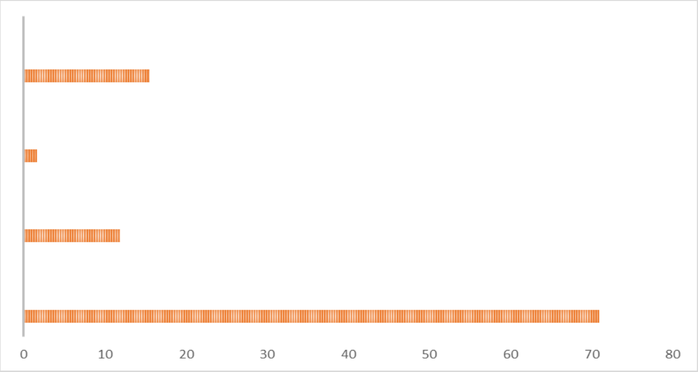
Income Sources

Charitable Trust : 15.5%

Literature and Promotional Goods : 1.6%

Earned Income : 11.9%

Fundraising : 71%



Expenditure

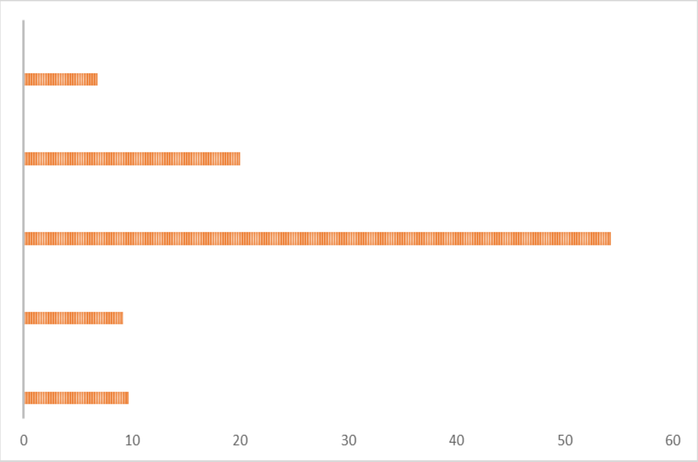
Familynet—6.8%

Info, Literature & Publications—20%

Support for Adults & Children—54.3%

Fundraising Costs—9.2%

Running Costs—9.7%



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PWSA UK

PRADER-WILLI SYNDROME
ASSOCIATION UK

pwsa.co.uk

Annual Report
2016—2017
Cure the Challenges of Life with Prader-Willi syndrome

William and HRH Princess Michael of Kent

This year our Familynet Project and fantastic Familynet volunteers have held:

- 20 family days
- 15 coffee meet-ups
- 5 social events
- 6 Christmas parties and 1 New Year Party

We also organised 2 very popular family week end breaks, one in Whitecross Bay and one in Hampshire

'Having all the PWS children and adults together is invaluable support for our daughter. It's the only time she is in the majority with her needs'

In 2016 we were very pleased to access a grant toward our Education Project from Jeans for Genes, as issues with education arise constantly on our helpline and facebook pages - usually prefaced with the comment 'They just don't get it.' Thanks to our Jeans for Genes grant, three 30 minute training videos for Nurseries, Primary and Secondary school teachers, full of information about how to support someone with PWS within the classroom are now live on our YouTube channel. All schools should now 'get it' and a video for colleges will be next.

We set up a focus group in 2016 to enable adults with PWS to input directly into the strategic direction of the Association and in particular, to the information that we provide. They have been working hard on our project to create a number of online animated videos for people with PWS, about PWS and Sexuality called 'Growing UP with PWS'. These short animated videos tackle concerns such as delayed or incomplete puberty, growing up and feelings, not everyone being able to have children, consent and staying safe online, and other sensitive issues. This project is due to be completed early 2018.

Income is always an issue for the Association. All charities find it hard to raise funds but each years seems to grow more difficult. Our ability to raise funds has a direct impact on the services we can provide and the cuts in funding that have affected us all over the last few years, has only increased the need for our services.

Thank you so much to all those of you who tirelessly donate, run, walk, swim, climb or do any of the other absolutely amazing things you do to raise funds for the Association.

You are all superstars and we couldn't keep going without you. Without your amazing support, we would not be able to continue; we would not be here for the new diagnoses each year and would not be here to help you combat the challenges of life with PWS.

Thank you to every one of you.

Our work this year

is always a juggle between responding immediately to families who need our help and support, and giving time to ensure that all our information is as up to date and relevant as possible. We are a small organisation with a small staff team but we have high ambitions — and if we don't aim high for our Prader-Willi syndrome community, who will?

One of our major projects this year has been to create a Care Pathway for children with PWS, which will set the standard for the medical care all children with PWS should receive in the UK. It will ensure that children seen outside the current PWS Multi-Disciplinary Clinics are able to access the same levels of care as those within the clinics, and also guide those consultants working with only one or two children with PWS.

The PWS Multi-Disciplinary Paediatric Health Oversight is now complete, and was launched at the Society for Endocrinology Conference in November. It is now available to all on our website and we are encouraging all parents to make sure that their endocrinologists have read it.

We then need to embark on a Health Oversight for adults. We are very aware that this will be a very complex undertaking, but one that is desperately needed.

Our trustees have been discussing the challenges most affecting our PWS families and our need to start lobbying to address them. We have begun with a Charter for Education which sets out the needs of children and young people with PWS within educational settings. It is a clear charter for providing our children and young people with the right support, in the right place, at the right time. We plan to start lobbying councillors, MPs and Local Authorities to sign up to our PWS Charter for Education. This is not an easy ask but if we stand together and keep lobbying as many decision makers as we can, we will make a difference. If you would like to join our campaigning, please email me on spassmore@pwsa.co.uk.

What is Prader-Willi Syndrome?

Prader-Willi syndrome (PWS) is a rare, complex genetic disorder that affects both males and females from birth and throughout their lives. It causes low muscle tone with consequent motor developmental delays, a mild to moderate learning difficulty, incomplete sexual development, and emotional and social immaturity, leading to temper tantrums. During childhood, an overwhelming and insatiable chronic appetite usually develops which, without rigorous food management and exercise regimes, leads to food seeking, stealing and life threatening obesity. PWS occurs randomly in about 1:20,000 births and it is estimated that there are about 2,000 living with PWS in the UK.

PWSA UK is the only charity in the UK working with those with PWS, their families and carers, together with the wide range of professionals from health and social care, education and residential helping them to manage this complex syndrome and cure the challenges of life with PWS.

and we are only a phone call away . . .

PWSA UK provides:

- A telephone, email and facebook helpline for those in crisis or needing help, mediation, information and support
- An information hub providing everything you need to know about PWS in an accessible, engaging and relevant form
- Our Familynet project, providing a regional network of peer support groups, with a programme of family events within safe environments
- Training courses for professionals working with those with PWS. AIM accredited courses, workshops and conferences
- Research, funding for research throughout the world and opportunities to take part in research

Our achievements in 2016—2017

Members

Membership of PWSA UK is through an small annual subscription and we offer free membership to all those over 18 years with PWS.
We currently have 797 Members:
245 Individual Members, 192 Household Members, 254 people living with PWS Members, 42 Life Members, 55 New Diagnosis Members, 5 Corporate Members and 4 Non UK Members. Members receive our quarterly News magazine, together with copies of our flagship publication Your PWS Journey. Most importantly, our members are helping to support the work of and invest in the future of our Association.

Research

We have concentrated our research endeavors this year into our 'Britain and PWS' survey and launched the first 0-5 years section this summer. This survey will reveal a snapshot of the true position of PWS families within the UK and provide the important evidence we need to lobby for better services. There will be three further sections, 6-17, 18+ and a survey for adults with PWS to complete giving their own individual perceptions of the challenges of the syndrome. The Association also continues to provide as many opportunities as possible for people living with PWS and their families to take part in research projects and we have created a register of people who want to be contacted about research opportunities.

Social Media

We have a Facebook page with 2,927 likes, and Twitter account with 2,768 Twitter followers. We are also members of a further 6 parent led Facebook pages and respond with advice, information and support where appropriate. Social Media is an increasingly important means of communication for our families and the Association is improving and increasing our social media interaction. Our weekly Instant News goes to 1,597 people.

Familynet

This year we held 20 family days, 15 coffee meet-ups, 5 social events, 6 Christmas parties and 1 New Year Party. We also organized 2 very popular family week ends, where families had the opportunity to relax in each others' company, knowing that behaviors would be unsurprising, understood and supported.

Information and Publications

Information and publications on our website continue to be the backbone of much of our services, ensuring that families can access the information they need, when they need it—and it is all fully downloadable. We were extremely fortunate to be able to rebrand this year, thanks to a wonderful free offer by one of our parents who created our glorious pink and purple pallet together with our new feather logo. We are incredibly grateful to the generosity of the fantastic Cubo for their wonderful designs and ongoing creative support!

Training

We delivered 23 training courses this year to 260 individuals working for Residential Care or Supported Living Providers, and 3 accredited AIM award courses to 32 participants.

Residential and Supported Living

Our Residential Care and Supported Living Providers' Forum meets three times a year to share best practice, promote peer learning, collaborative working and improve outcomes for people with PWS in their care. One forum this year was on the topic of Supported Living and attracted 44 attendees.

PWSA UK Conference

A second National Conference was held on 19th and 20th November 2016 at The Hayes Conference Centre, Swannick Derbyshire. We welcomed 153 adults on Saturday and 156 adults on Sunday to hear a wide range of speakers and take part in a variety of workshops. We welcomed 44 under 5s into our crèche and 29 six to sixteen year olds into our Alternative Programme. The conference offers a wonderful opportunity to heart the latest information and management techniques in PWS, but it also provides an un-paralled environment to mix and network within our PWS community. The next PWS Conference will be on 13th and 14th October 2018.