Annual Report 2015—2016

Cure the Challenges of Life with Prader-Willi syndrome

PWSA
Prader-Willi Syndrome Association UK

Financial Summary

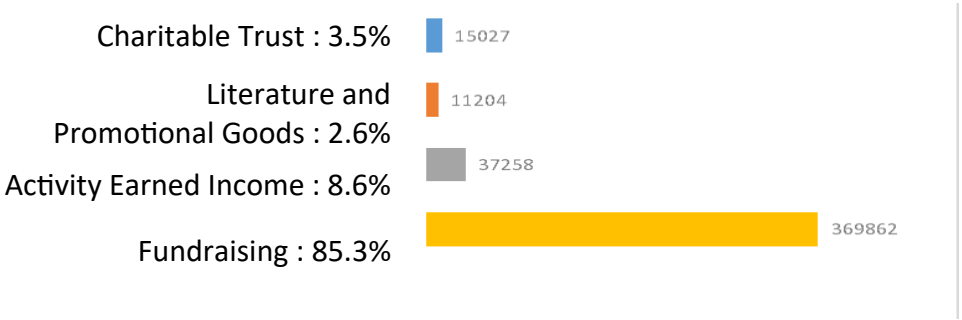
Statement of Financial Activities (as at 31st March 2016)

Total Incoming Resources	432,862
Total Expended	386,027
Net Incoming Resources	46,835

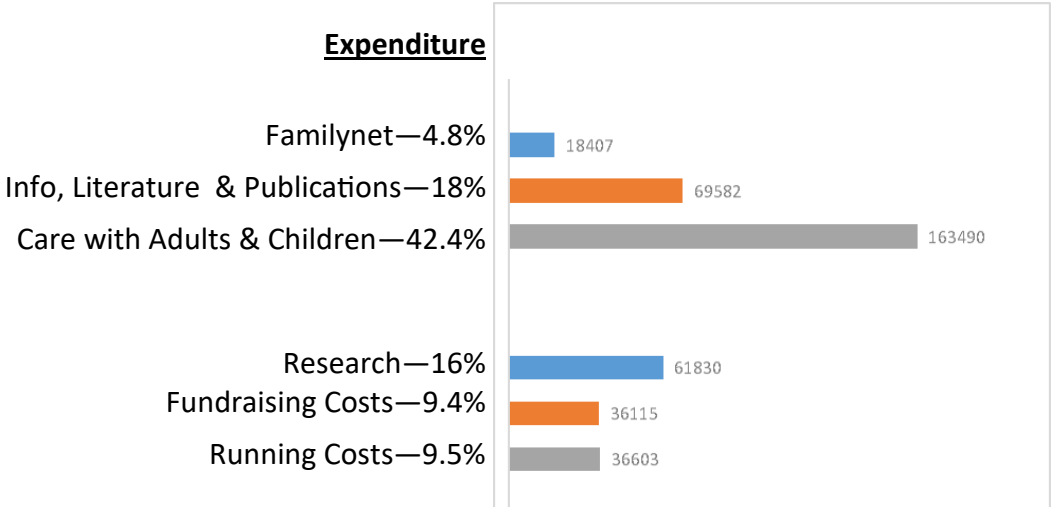
Balance Sheet

Tangible Fixed Assets	5,921
Net Current Assets	330,939
	336,860
Unrestricted General	138,921
Unrestricted Designated	195,752
Restricted Funds	2,187
	336,860

Income Sources



Expenditure



PWSA UK
Suite 4.4, Litchurch Plaza, Litchurch Lane, Derby DE24 8AA
Telephone: 01332 365676
Registered Charity Number: 1155846

This year, through our Familynet Project, we have held:

- **16 family days**
- **12 coffee meet-ups**
- **6 Christmas parties**
- **1 New Year Party**

We also organised 2 family week end breaks, one in Dumfries and one in Hampshire .

I've met people willing to share their experiences with us, offered to lend a hand or shoulder to cry on. I've connected with people around the world facing the same challenges. I've been surrounded by family and friends willing to share it all with us.

We were very pleased to access a grant toward our Education Project from Jeans for Genes. This project will enable us to put four training videos onto Youtube to teach Nursery, Primary, Senior and College staff about supporting pupils with PWS. Issues with education arise constantly on our helpline, usually prefaced with the comment 'They just don't get it.' The training videos should enable every educational setting to 'get it'.

We have setup a new focus group for adults with PWS, to enable them to input directly into the strategic direction of the Association and in particular, to the information that we provide. The first meeting saw the five founder members decide that it should be called the OWL—Our Way of Life—Focus Group and the next meeting will see a further three join the committee. A strong input from people living with PWS is essential to ensure that they are always at the heart of everything we do.

We have also accessed a grant to help us create a number of online videos for people with PWS, about PWS and sexuality. We are planning to tackle issues such as delayed or incomplete puberty, growing up and feelings, not everyone being able to have children, consent and staying safe, and many more issues. This project is in its early stages but will help tackle some sensitive issues.

Income is always an issue for the Association. All charities find it hard to raise funds but months since the end of this financial year have been particularly 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 those of you who tirelessly donate, run, walk, swim, climb or do any of the amazing things you do to raise funds for the Association. You are all superstars and we couldn't keep going without you. Without your support, we would not be able to continue and would not be here to help you combat the challenges of life with PWS.

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 set our sights high and are determined to provide the best service.

We have reviewed our vision and mission this year and following numerous consultations with families and professionals alike are delighted to have as our vision for the future: 'Cure the challenges of life with Prader-Willi syndrome. To help us achieve this, we have set two exciting new mission statements:

1. Every person living with or affected by Prader-Willi Syndrome is offered the same good quality care, opportunity and support within society by 2025
2. Researchers and Doctors have the resources to improve the quality of life with Prader-Willi Syndrome, and ultimately find a cure by 2050

These may seem high ambitions, but ones we feel we are the critical issues we should be tackling — and if we don't aim high, who will?

One of our trustees Dr Robin Chung, is leading a project with our PWS Clinics towards achieving our first mission. They are writing a Care Pathway for children with PWS, which will be a standard for the medical care all children with PWS should receive. It will ensure that children seen outside the PWS 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. Once this Care Pathway is complete, the working group will look at a Care Pathway for adults. We are very aware that this will be a very complex undertaking, but one that is desperately needed.

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, 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
- Funding for research throughout the world and opportunities to take part in research

Our achievements in 2015—2016

Members

We currently have 683 Members:
204 Individual Members, 186 Household Members, 175 people living with PWS Members, 27 Life Members, 72 New Diagnosis Members, 3 Corporate Members and 3 Non UK Members.

Research

The Association continues to fund research where we can and this year have awarded £31,227 to Professor Tony Holland and his team to provide additional support to a proof of concept study of Vagus Nerve Stimulation (VNS) to treat the problem behaviours characteristic of people with Prader Willi Syndrome (PWS). This study of behaviours follows a study of the effect of VNS on the eating behaviour of people with Prader-Willi Syndrome. Although the results from the effect of VNS on eating behaviours were disappointing, reported changes in social behaviour of the participants led to this current study.

In March 2016 we also granted £30,000 towards Professor Marc Lalande's project to switch on the silenced set of genes from the maternal chromosome 15. In Prader-Willi syndrome (PWS), there is no intact copy of the paternal chromosome 15 so patients only have the switched off copies that come from the mother's chromosome 15. Prof Lalande's laboratory has identified an important new component of the 'switch off' mechanism, a protein called zinc finger ZNF274.

Professor Lalande's approach would allow turning on the maternal PWS genes without destroying ZNF274 at its other binding sites in the human genome and, hopefully, offer a more efficient and safer route for potential therapy in PWS.

The Association continues to provide as many opportunities as possible for people living with PWS and their families to take part in research projects.

Social Media

We have a Facebook page with 2,469 likes, and Twitter account with 847 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.

Information and Publications

We have undergone a major review of, and have now updated all our information and publications, and our flagship new resource, Your PWS Journey provides *'Everything you need to know about Prader-Willi syndrome'* in one place. Copies are sent out to Subscribed Members of the Association and the information is also on the website . We have upgraded our website to make it clearly navigable and all our information is now easy to find and fully downloadable to all. We are constantly extending our range of information and have this year produced information specifically for social workers, GPs, commissioners, residential care staff and more are in the pipeline.

Training

We delivered 23 training courses this year to 322 individuals working for Residential Care or Supported Living Providers.

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 Mental Health and attracted 78 attendees.

Familynet

This year we held 16 family days, 12 coffee meet-ups, 6 Christmas parties, 1 New Year Party and 2 family week end breaks. We also organized 2 family week ends, where families had the opportunity to relax in each others' company, knowing that behaviors would be unsurprising, understood and supported.