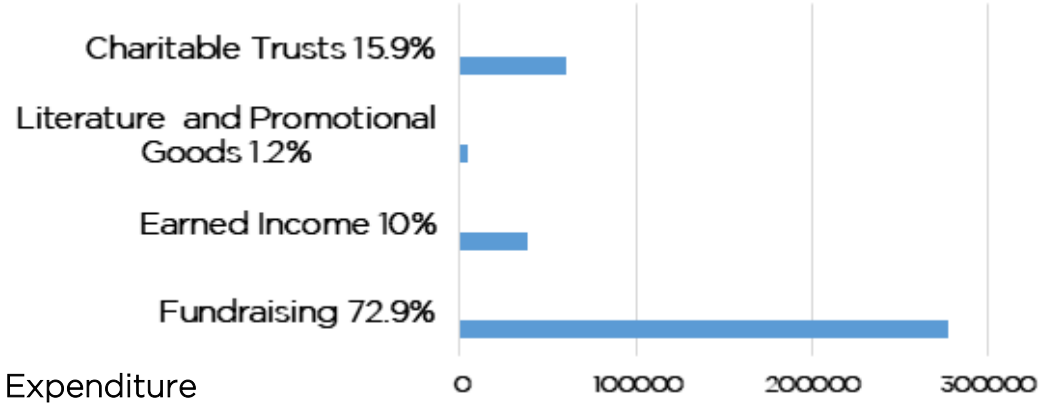
Financial Summary
Statement of Financial Activities
(as at 31st March 2018)

Total Incoming Resources £380,719
Total Expended £409,418
Net Incoming Resources (328,699)

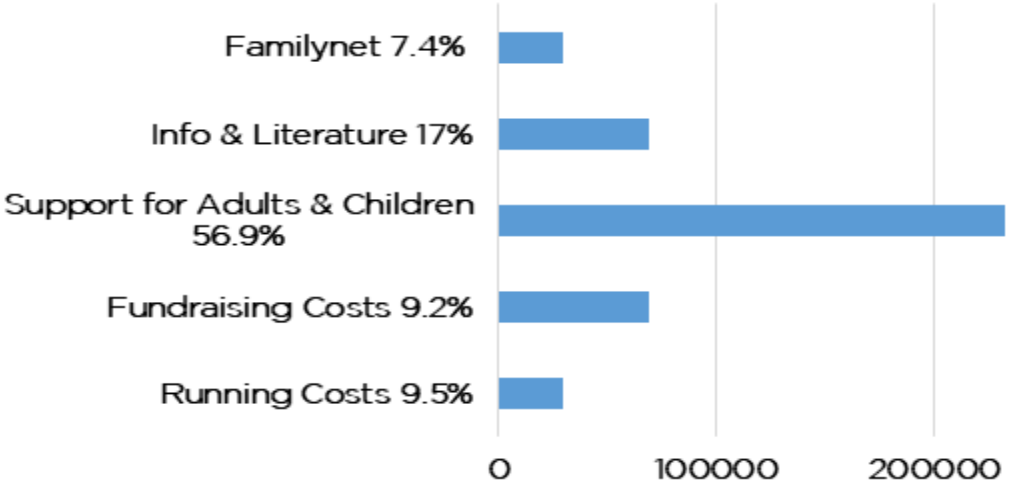
Balance Sheet
Tangible Assets £14,774
Net Current Assets £283,871

Unrestricted General £106,301
Unrestricted Designated £162,422
Restricted Funds £25,189

Income



Expenditure



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PWSA UK
PRADER-WILLI SYNDROME ASSOCIATION UK
pwsa.co.uk

Francis Booth and Rt Hon John Bercow MP
Speaker of the House of Commons

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

- 26 Familynet social events
- 15 coffee meet-ups
- 5 Christmas/New Year Parties

We also organized two very popular family weekends, one in Whitecross Bay, Cumbria and one at Sandy Balls 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'

This magazine is written primarily by Francis, one of the Focus Group members with input from others and has proved a great success.

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, we now have four 30 minute training presentations for Nursery, Primary, Secondary and College teachers, full of information about how to support and differentiate for someone with PWS within the classroom, accessible to all on our YouTube channel. All schools should now 'get it' and if your children's school or college has not accessed the presentation, I would strongly recommend that you direct them to it.

One of our volunteers, Sue Newton created a PWS Calendar in 2017 which was very well received. We were delighted to be invited, together with Sue and her family, to Kensington Palace to present a copy to HRH Princess Michael of Kent. We were also delighted to visit Speaker's House with Francis, to present a copy to John Bercow, Speaker of the House of Commons.

Income is always an issue for the Association. All charities find it hard to raise funds but small, rare disease charities find it especially 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?

Our trustees have been discussing the challenges most affecting our PWS families and our need to start lobbying to address them. Campaigning will give us the platform to start the big conversations with the decision makers in society. The platform to tell people how PWS affects families and what needs to happen to make sure that our community gets the right support, in the right place, at the right time. Trustees have identified a number of different campaign topics that are important for the Association to champion, ranging from better provision for SEND, better support and opportunities for adults, all healthcare professionals using best practice guidelines, a greater awareness of PWS to specialist clinics available to all.

Our OWL Focus Group of ten adults with PWS inputs directly into the strategic direction of the Association and in particular, to the information that we provide. The group has been working hard on our project to create a number of online animations for people with PWS, about PWS and Sexuality called 'Growing UP with PWS'. These short animations tackle issues 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 now complete and ten animations are live on our website.

The Group also initiated the creation of a new quarterly magazine for adults with PWS which they named Wise OWL Feathers.

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
- Familynet: 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 2017—2018

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 683 Members:
184 Individual Members, 167 Household Members, 286 people living with PWS Members, 33 Life Members, 10 Corporate Members and 3 Non UK Members. Members receive our quarterly News magazine, together with hard copies of our Your PWS Journey. Most importantly, our members are helping to support the work of and invest in the sustainability of our Association.

Research

We have concentrated our research endeavors recently into our 'Britain and PWS' survey. 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 are four different surveys; 0-5, 6-17, 18+ and a survey for adults with PWS to complete, giving their own individual perceptions of the challenges of the syndrome. This is the first time we have surveyed adults with PWS and the results will be hugely beneficial. The Association continues to support researchers by helping to source participants to take part in their 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 3,485 followers, and Twitter account with 2,138 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 constantly working to increase our social media interaction. Our weekly Instant News goes to 1,597 people.

Familynet

This year we held 26 Familynet social events, 15 coffee meet-ups and 5 Christmas/New Year Parties. We also organized 2 very popular family week end breaks where families had the opportunity to relax in each other's 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 have continued to increase the information that we have available and are about to begin an update of our flagship Your PWS Journey publication.

Training

We delivered 18 training courses this year to individuals working for Residential Care or Supported Living Providers, and 2 accredited AIM award courses.

Residential and Supported Living

Our Residential Care and Supported Living Providers' Forum meets three times each year to share best practice, promote peer learning, collaborative working and improve outcomes for people with PWS in their care.

Conferences

This year we have held two one day conferences. One, in July 2017 was on Behaviour Management for adults and attracted over 60 delegates. The headline speaker was Prof Tony Holland who spoke about 'The underlying reasons for behavioural challenges in PWS'
The second, in October 2017, was on Positive Approaches to Behaviour and Diet in children which attracted over 50 delegates. The speakers for this conference were Dr Linda Gourash from the Pittsburg Partnership in the USA and Chris Smith from the Royal Alexandra Hospital in Brighton.

Conferences and workshops continue to be important events for parents as not only an opportunity to hear from the experts, but also an opportunity to meet other parents and to share experiences.