Financial Summary

Statement of Financial Activities
(as at 31st March 2019)

Total Income £485,676

Total Expended £437,143

Balance of General Reserves
£124,706

Unrestricted Designated
£190,318

Income

Donations and Legacies	£356,591
Charitable Activities	£123,069
Other trading activities	£5,651
Investment Income	£365

Expenditure

Raising Funds	£23,329
General	£6,643
Charitable Activities	407,171

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PWSA UK
PRADER-WILLI SYNDROME ASSOCIATION UK
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The 2018 National Conference
PWS Programme—Circus Skills

This year our Familynet Project and our fantastic Familynet volunteers have held 15 Family Social Events.

We also organized two very popular family weekends, one Sundrum Castle in South Ayrshire and one at Sandy Balls in Hampshire.

Heads of Ayr, Sundrum Castle 2018

"it is so important for us to attend the Familynet events as we meet up with people who understand the difficult times with the syndrome, no one looks down their noses at you when your child is kicking off, we are not judged when we are amongst friends"

We were delighted to access a grant from AVIVA this year to create our first easy read guide for young people and adults with PWS. This is called 'Healthy Futures' and is being written with the help and support of our OWL Focus Group of adults with PWS. The Healthy Futures packs will be distributed to everyone with PWS in the UK over the age of 16.

In November we attended a meeting at Portcullis House with MP Tom Pursglove, Prof Tony Holland and Dr Tony Goldstone, parents and representatives from Consensus about the particular needs of adults with PWS, and the importance to their health of accessing residential care if their weight is unmanageable. In 2019 we requested a meeting with Baroness Blackwood, Parliamentary Under Secretary of State at the Department of Health and Social Care, but she felt unable to meet us.

2018 will always be remembered by our staff team as the year of GDPR. The new laws have placed stringent requirements on all organisations and we, like all charities have had to comply. You can be assured that we will always treat your data with care and respect and we never pass it onto third parties.

Income is always at the forefront of our minds and our aim is always to do more, with less. The income that we raise directly impacts the services that we can provide so it is increasingly important for us to make our fundraising as effective as possible. We are incredibly grateful to all those who tirelessly donate, run, walk, swim, climb, sell 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. Each one of you ensures that we will be here, supporting our community today, tomorrow and for as long as you need us.

Thank you to every one of you,

Susan Passmore

Our work this year . . .

Sometimes it is difficult to know where to start when talking about our work and the services we offer. We are a small team who offer a wide variety of services, but supporting families to negotiate the complexities of PWS, and of the educational and social care systems, remain at the heart of everything we do.

In this financial year we received 549 queries to our helpline which took 1,469 telephone calls, emails, skypes, and meetings to resolve. These queries can range from completing DLA Forms, fighting Local Authorities for appropriate EHCPs, trying to access residential care, to new parents who have just received a diagnosis, parents struggling with difficult behaviours, with diet, and with general life with PWS. Our team works to resolve issues, mediates with a wide range of professionals, educates those who don't understand and supports families with information, advice and understanding.

We continue to ensure PWS Specialist Clinics are attended by PWSA UK staff or volunteers. We were delighted to start attending the new specialist clinic at Royal Stoke University Hospital, and will shortly be attending the new clinic at Edinburgh. We also anticipate a PWS Specialist Clinic opening in Leeds shortly. It is wonderful to see the increase in clinics specialising in PWS.

Last year, our trustees began to discuss our need to start campaigning about the issues that most affect families' lives. The need to lobby the decision makers about what needs to happen to make sure that our community gets the support it needs. Just as we began to gather support from other genetic disorder charities about the failure of the SEN system, the government announced an Inquiry into Special Educational Needs and Disability and the implementation of the 2014 changes to the SEND system.

We quickly mobilised a survey to provide the statistical evidence, and some of you contributed very heart rending stories about your struggles with the education system and we submitted formal written evidence in June 2018. The Education Committee has called many groups and government ministers to answer their questions and we are now waiting for the Government to respond to their report.

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 challenging behaviour. 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, WhatsApp 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, support for researchers and opportunities to take part in research

Our achievements in 2018—2019

Members

PWSA UK is a membership organisation and membership is through an small annual subscription and free to all those with PWS over 18. We currently have:
674 Members,

Research

In 2018 we finished our 'Britain and PWS' survey. The results of this survey are providing interesting evidence of the true position of PWS families within the UK and the results will help direct our strategy for campaigning. The Association continues to work closely with researchers by helping to source participants to take part in their research projects. This year we have worked with Professor Tony Holland, Suzannah Lester, Justin Chung under the supervision of Dr Kate Woodcock, postdoctoral researcher Nanda de Knegt from VU University in Amsterdam, the Netherlands, and Lauren Rice, a Postdoctoral Research Associate at the University of Sydney, Australia.
Additionally, Robin Chung, our Chair of the Research Working Group has been working closely with Soleno Therapeutics' Phase 3 Destiny trial and Millendo Therapeutics Phase 2b/3 Zephyr trial. We worked closely with both companies through their Ethics submissions and Robin attended the Ethics Committee meetings. These are both extremely exciting trials and are the first drugs trials we have been able to bring to the UK.

Social Media

Social Media continues to be an important means of communication for our families providing them with instant contact with a strong, supportive community. Our closed Facebook Group, PWSA UK Community Hub has 474 members, our Facebook page 4,063 followers and our Twitter Feed 1,244 followers. Patsy's fortnightly Facebook Lives attract an average audience of 200. Our weekly Instant News goes to 1,677 people.

Familynet

This year we held 15 Familynet social events. We also held two very well attended family week end breaks; one to the always popular Sandy Balls and for the fist time, a great week end at Sundrum Castle, in South Ayrshire. These week ends can be invaluable to families, knowing that they can relax in each others company, within a safe and supportive environment

Information and Publications

Information and publications on our website continue to be the backbone of much of our services, and this year our Your PWS Journeys have been completely updated. We have also a new publication 'Information for Police' for when someone with PWS comes into contact with the police, and our eleven animations about Growing Up with PWS are complete and available through our website.

Training

We delivered 20 training courses this year to individuals working for Residential Care or Supported Living Providers, and 1 accredited AIM award course.

Residential and Supported Living

We have held three Residential Care and Supported Living Providers' Forums this year. One in July was on the subject of Mental Capacity and open to parents, as well as providers.

Conferences

We held our biennial National Conference, in Derby in November 2018, attended by 425 people with PWS, their families and carers. The Saturday was, as usual, for parents of children under 16 and our headline speaker was Dr Jennifer Miller, from the USA. Sadly, with days to go, Dr Miller had to pull out of travelling, but with the wonders of modern technology she joined us through Skype. Dr Miller spoke about the latest developments in research and ran two workshops about Supplements and their benefits. Sunday was, as usual, for parents and carers of those 16+ with headline speeches from Prof. Tony Holland and Prof. Tony Goldstone. The programme for those with PWS and their siblings were very popular, featuring drumming, dancing and Magical Mayhem!

Conferences and workshops continue to be important events for parents; not only as an opportunity to hear from the experts, but also an opportunity to network with other parents, to gain peer support and to share experiences.