PWSA
Prader-Willi Syndrome
Association UK

Annual Report 2014-2015

Together we make a difference

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 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 development 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, compulsive 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 approximately 2,000 people living with PWS in the UK.

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

Just remember we are only a phone call away

PWSA UK offers:

- Telephone, email and Facebook helpline for those in crisis or needing help, information, advice and support
- An information hub, providing everything you need to know about PWS in an accessible, engaging and relevant form, day workshops and our biannual National Conference
- Familynet project, providing a programme of family activities throughout the UK, offering peer support, social opportunities within safe environments
- Training courses for professionals working with people with PWS, AIM accredited awards for carers from support-ed living and residential care, workshops and conferences
- Funding for and opportunities for people to take part in research

Our achievements in 2014-15

17 in-house training courses + 10 learners on an AIM Awards Course

13 family days across the country with 446 people attending

288 people attended 8 Christmas parties throughout the UK

2 family weekends attended by a total of 40 families

First annual sponsored walk attended by 18 people

3 Residential/Supported Living Forums attended by over 100 care professionals

Your PWS Journey – 8 comprehensive guides from birth to 40+ for families and carers living with PWS
kindly funded by Priory Educational services, Craegmoor and Gretton homes

Our achievements in 2014-15

Our amazing fundraisers have taken part in the Virgin Money London Marathon, The Vitality British 10k London, Prudential Ride London 100, boxing, parachute jumps, Zip wires, Up at the O2, fetes, balls, swims, dragon boat races, ...shaves, in fact you name it our supporters did it.

Major new Familynet project developing regional groups to bring PWS families together

New literature produced including “Our Babies” and “Let’s talk about PWS” kindly funded by the Derbyshire Division Red Cross of Constantine

New diagnosis video on our website

Instant News sent to over 2,000 people weekly

Quarterly Newsletter/News in Brief sent out to over 1800 supporters

800 Twitter followers and 2300 Facebook Likes

Susan Passmore – CEO

"My daughter felt part of something, not apart. She was like other people, not unlike them".

Our work this year...

has, as always, been a balance between the need to respond to calls for help, the need to give time to updating all our information and literature to better inform families, and to making time to train residential care homes, supported living providers and schools to ensure they have the skills to care for people with PWS appropriately. We are a small team, often stretched, but with an absolute determination to provide 'everything you need to know about Prader-Willi Syndrome'.

We have reviewed all our PWS Literature and completed a major update of all our information. We have finished our latest major publication 'Your PWS Journey' which comprises of eight sections, each providing age relevant information with everything you need in one place. This is available free to all subscribed members in hard copy and as individuals with PWS increase in age, the next age section will be sent out.

In August 2014 we appointed Sharon McCall as Volunteering Project Manager to manage our exciting new Familynet Project. Sharon has already set up volunteer led Regional Groups in many parts of the country organising regular family events, coffee mornings, and Christmas parties. Peer support is an invaluable resource to new and experienced PWS families alike and we plan to increase the number of regional groups and their activities during this coming year.

In this financial year the old unincorporated charity was closed and the assets transferred to the new Charitable Incorporated Organisation. This transfer of assets has been recorded in our accounts as income of £270,087, showing a one off marked increase in income!

Our first annual conference for some years was held in November 2014 and over 337 parents and professionals and

125 people with PWS and siblings came together for two days of talks, work-shops, discussions and entertainment. The feedback was overwhelmingly in favour of regular conferences, so our next conference is already booked for 19/20th November 2016 – save the date in your diary!

We awarded a research grant of £3,000 to Dr Tim Wells of Cardiff University to create a novel model of ghrelin-null colony Prader-Willi Syndrome as part of his investigations into the effect of ghrelin on food hoarding, metabolism and skeletal growth and integrity.

Our President Tony Holland was awarded a CBE in the New Year's Honours List and we were very pleased to have been part of the application. We were also delighted when Tony accepted our invitation to become Patron of our new Prader-Willi Syndrome Association UK. As the Association looks forward, our first big project is to ensure that our new and updated information is available to all through our website, and this should be fully completed by January 2016

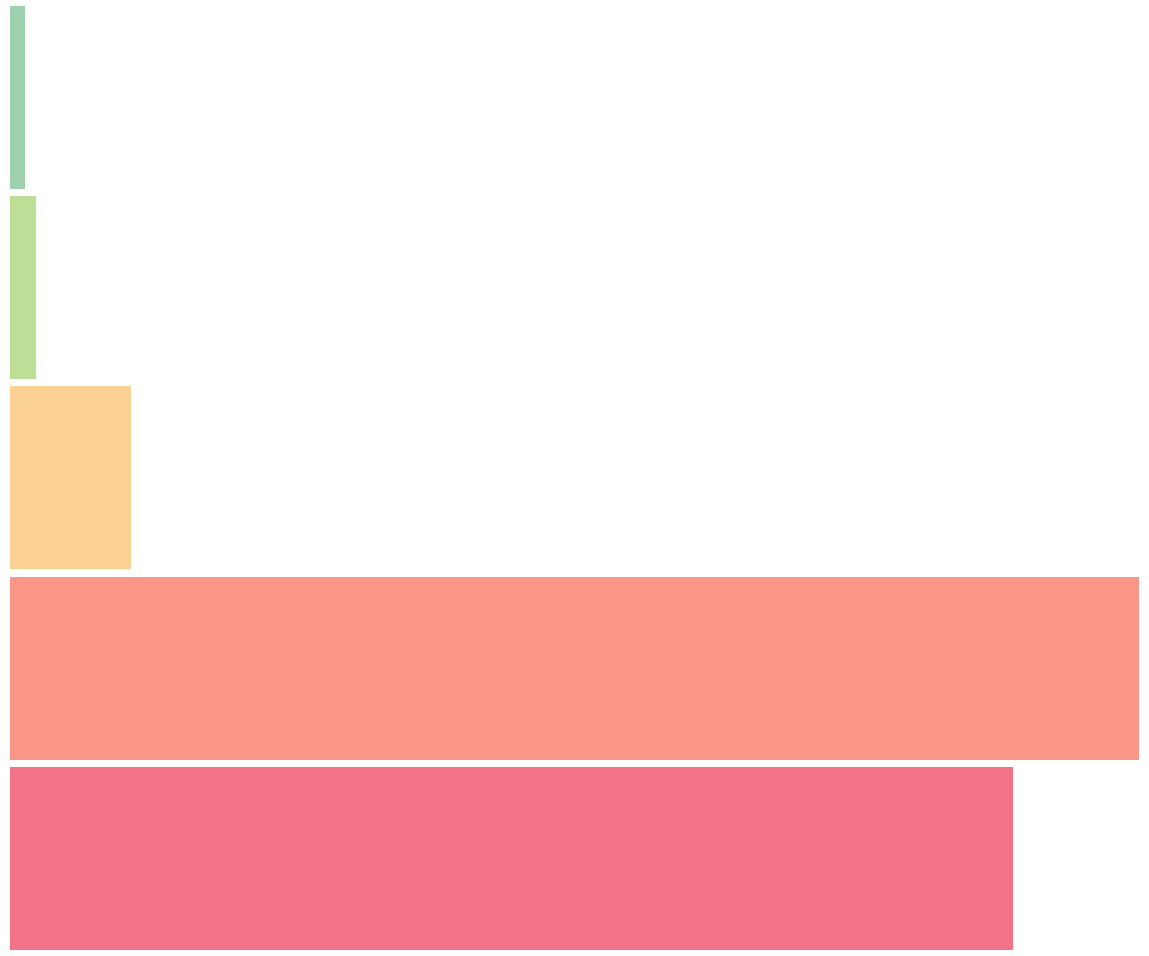
As part of our long term planning we will be reviewing the Association's vision and mission, and will consult as many of you as possible in this process. We aim to begin campaigning on all issues PWS and in 2016 will be identifying key areas to target. We want to take the issues that are of greatest importance to our people living with PWS, our families and professionals and bring them to the attention of the decision makers with a clear plan of what the issues are and what needs to be done to resolve them. Research is always of great importance to parents and professionals alike and we plan to increase our commitment to research to help move the worldwide research agenda forward. We will in-crease our fundraising to ensure that we can maintain our vital services to support families today, whilst investing in tomorrow.

As always, we are only able to continue to offer these vital services with the wonderful and dedicated fundraising of our supporters and invaluable help of our volunteers. Thank you to everyone who has supported the Association in any way; to our staff who work with passion and commitment and to our trustees who give endless time to building an Association to be proud of. We are small but our achievements are huge and we do this by working together for our PWS family.

> *"We would not have known, at times, which way to turn without your help".*

“Many thanks to our wonderful supporters – we couldn’t do it without you!”

Income sources



Charitable Trusts
£4,100 – **1%**

Lit and Promo Goods
£7,100 – **2%**

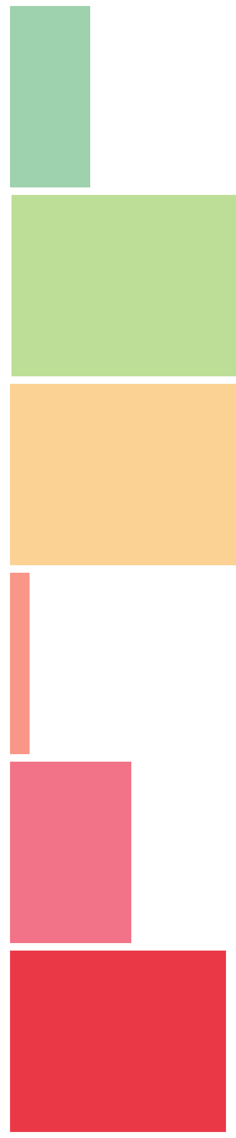
Activity earned income
£38,383 —**11%**

Fundraising
£304,007 – **86%**

Assets transferred from unincorporated charity
£270,087

total
£623,676

Expenditures



Familynet Project
£16,682 – **5%**

Info, Literature & Publications
£83,112 – **25%**

Care with Adults and Children
£176,380 — **52.8%**

Research
£3,000 – **0.9%**

Fundraising Costs
£270,087 — **6.3%**

Running Costs
£33,365 — **10%**

total
£333.651

Financial Summary

Statement of financial activities
(as at 31st March 2015)

Total incoming	£623,676
Total expended	£333,651
Net outgoing resources	£290,025

Balance Sheet

Tangible fixed assets	£5,961
Net current fixed assets	£284,064
	£290,035

Unrestricted general	£70,130
Unrestricted designated	£193,407
Restricted funds	£26,488
	£290,025

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

The people and quotes in this publication are all taken from those we support.

Photographs and quotes do not always represent the individuals shown and any names have been changed.

PWSA UK
Suite 4.4 Litchurch Plaza, Litchurch Lane,
Derby DE24 8AA
T: 01332 365676
E: admin@pwsa.co.uk
Registered Charity: 1155846