PWSA
Prader-Willi Syndrome Association UK
Awareness... Support... Understanding

Annual Report 2013-2014

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 (PWS) is a rare, complex genetic disorder that affects both males and females from birth. The syndrome causes low muscle tone with resultant motor development delays, short stature if not treated with growth hormone and incomplete sexual development. Most have mild to moderate learning disabilities and will be emotionally and physically immature. Challenging behaviour in varying degrees can occur in both children and adults. The defining aspect of PWS is an overwhelming, untreatable appetite which develops in childhood and the constant feeling of extreme hunger cannot be satiated however much they eat. Without rigorous food management together with exercise regimes, life threatening obesity will usually develop. It is estimated that there are around 2,000 in the UK living with PWS. We work closely with the majority of those with PWS and the myriad of professionals from health, social services, residential and education, helping them to manage this very rare and complex syndrome.

Who are we?

PWSA UK has been providing specialist advice to those affected by PWS for over 30 years and our dedicated team offers:

- Telephone and email helpline offering support, information and advice
- Information, literature and publications for parents, carers and professionals
- A programme of family activities throughout the year and a parent volunteer network
- Training programmes, both accredited and non-accredited for professionals providing support for those with PWS, conferences, consultancy, attendance at multi-disciplinary clinics
- Campaigning
- Support for and opportunities to participate in research

Just remember ... we are only a phone call away.

7 Family Days

7 Christmas Parties

1 Family Weekend

188 Families

getting together

during 2013-14

Chairman's Report

With the 8th International PWS Organisation Conference successfully behind us, the Trustee Board and staff, with input from a number of our members, were able to refocus on the Association's core objectives and how to meet them at a Strategic Planning meeting held in September. The direction for the next few years and how to accomplish it has developed over recent months. Clarity around what the Association is there for has been an important factor and I hope that in the coming months our improved communication with you will be evident. Please let us have your feedback if you disagree!

Apart from a restructured Service Delivery team, we have prioritised our relationship with our wonderful band of volunteers, without whom so much support, entertainment, fundraising and quite frankly, common sense intervention, would not be possible. We have recruited a Volunteering Project Manager to nurture these vital relationships and to encourage others to join the volunteer team. As always our financial resources require careful management, especially as they are almost entirely reliant on the fundraising efforts of our members. I am very aware of the huge amount of effort it requires to raise funds and donations even in a benign environment, which has not been the case in recent years. As a result we strive to ensure that 90% of funds raised are ploughed back into services for our members.

The Association successfully applied to re-register as a Charitable Incorporated Organisation which was accepted by the Charity Commission and took effect on the 1 April 2014. Apart from the legal clarity this brings to a charity's status, we hope that this will encourage more of you to come forward as potential trustees.

My thanks to all our members, staff and volunteers for making this another successful year for the Association.

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

Our Work this Year

The financial year 2013 to 2014 has been an extremely eventful one for the Association. The International Conference dominated much of the previous year, and the first three months of this financial year saw us working long hours to ensure that it was delivered on time and on budget. We were absolutely delighted to welcome 552 delegates to the International Conference over the five days; professionals, families and people with PWS from 37 different countries. The PWS Family came together with a feeling of brotherhood that crossed all national boundaries and it was truly inspiring to have the privilege to host it.

We were sad to say goodbye to Tracy Withers in October, Kendra Rhodehouse in December and Karen Greig in March, but were delighted to be able to welcome Jackie Waters back full-time as our Support Team Manager and for Erin Deegan to become a full-time PWS Co-ordinator. Leanne Nicholson also joined us in December as our Fundraiser.

At Christmas we finally made the move from our old, damp premises to a slightly newer, smaller office which doesn't let the rain in. We are now housed in one office which has made communication easy and team morale good.

A vote was taken at our 2013 AGM to form a new Charitable Incorporated Organisation and our application was accepted by the Charity Commission in March 2014. This means that the members and trustees are now safeguarded from any financial liabilities the charity incurs, and the charity has a legal personality of its own, enabling it to conduct business in its own name, rather than the name of the trustees.

The website has been revamped to improve its security and navigation but also to ensure that it will size to the increasing use through mobiles and tablets. Immediate online accessibility to our resources is now the first choice for many of our members and we are committed to ensuring that all information and literature will be available through our website.

Immediate online accessibility to our resources is now the first choice for many

We have also undertaken a complete review of our information, literature and training and we are undertaking an ambitious plan for updating and creating new material for where we have identified gaps. To support this, our trustees have formed an Editorial Working Group to support and oversee all information provision.

A Service Delivery Working Group was reformed this year, reporting to our trustee board to support and oversee the support function of the Association. This group meets regularly with the support team to review our service provision and to agree the strategic direction of all our support functions. We have responded to 735 requests via our helpline supporting families with a wide variety of issues.

This year we have held 7 volunteer led family days, 7 Christmas parties and one family weekend. We have run 21 training courses, and 24 learners have completed our accredited AIM Award. We were very pleased to hold an extremely successful Child Development Day in London, organised by one of our volunteers.

The Association continues to fund research where we can and the Vagus Nerve Project, headed by Professor Tony Holland, has led to a further research project entitled ‘MRI study of neural endophenotypes in Prader-Willi syndrome’. The funding originally donated by PWSA UK to the Vagus Nerve Project was not all used and is now being directed to part fund this further project until April 2015. The Association has also granted £13,735.50 this year for a project headed by Prof Chris Oliver entitled “Skin picking in Prader-Willi syndrome: development and evaluation of a mobile app to record behaviour”.

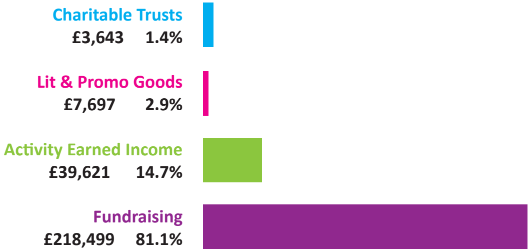
Our staff team have worked extremely hard this year, often in very trying circumstances and I am very grateful for their continued passion and dedication. The Association is also absolutely indebted to all our wonderfully brilliant fundraisers who jump out of aeroplanes, enter tough mudder competitions, run races, organise sponsored walks, coffee mornings, sales, dances and all manner of creative ways to raise money to keep the Association afloat. Every penny you raise makes a real difference and by working together we are all supporting the PWS Family in the UK.

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

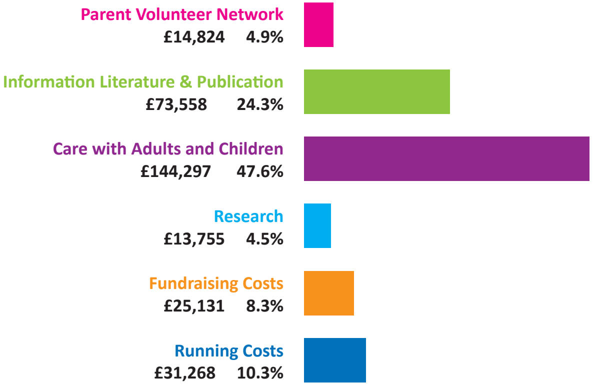
Many thanks to all our wonderful supporters – we couldn't do it without you

Financial Overview

Income Sources



Expenditure



Financial Summary
Statement of financial activities
(As at 31st march 2014)

Total incoming	466,224
Total expended	471,209
Net outgoing resources	(4,985)

Balance sheet

Tangible fixed assets	7,785
Net current assets	262,301
	270,086

Unrestricted – general	90,869
Unrestricted – designated	160,833
Restricted funds	18,384
	270,086

The statement of financial activities and balance sheet are extracted from the full statutory accounts which have been duly audited and are available upon request from Head Office.

The Association's policy is to accumulate a general reserve and a designated reserve to support specific purposes over coming years. The Trustees have agreed that unrestricted reserves should not fall below three months' operating costs which is the minimum recommendation of the Charity Commission.

You do a marvellous job and your information helped me greatly

Achieve growth

Be the number one

knowledge and

information hub

for PWS in the UK

To achieve

regional reach

Looking forward to the year 2014-15

In September 2013 we held a Strategic Planning Away Day with Trustees, Staff and some parents, to debate and plan the way forward for the Association and to establish our strategic objectives 2014 - 2016. These are:

- To achieve growth
- To be the number one knowledge and information hub for PWS in the UK
- To provide the best possible support to those living with PWS and their families and carers
- To achieve regional reach
- To be the voice for those affected by PWS
- To support and promote research into the management and alleviation of PWS

Looking forward to 2014 - 15, our newest development will be to work towards our objective of regional reach, through the establishment of regional peer support groups. We are calling this project ‘PWS Familynet’ and are currently applying for funding to drive this forward. In August 2014 we employed a Volunteering Project Manager who has extensive experience of establishing regional groups and supporting their development. Our Volunteering Project Manager will have responsibility for developing and delivering our PWS Familynet, but we will be looking for you, our members to design the project with us and to help ensure that we are delivering what you want.

Despite the difficult economic climate, we have been able to maintain financial stability in 2013 - 14. We are indebted to all our wonderful supporters who continue so tirelessly to fundraise for the Association in a great variety of ways. Your dedication provides essential support for those affected by PWS and ensures that the Association can continue to champion their rights. Supporters, staff, volunteers, trustees, people with PWS, parents and carers, professionals and members – together we are strong and can strive towards a world where PWS is not a barrier to a healthy and successful life.

Provide the best possible support to those living with PWS

Be the voice for those affected by PWS

Support and promote research

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

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