

# PWSAI Activity Report 2013

## *Chairperson's Review by Anthony Carr*

### **“much achieved but a lot more to do”**

The past year will be remembered as the year of the Galway Cycle and the positivity which was shared by all that participated in this incredible event. I feel that the financial windfall which has resulted is one which was unimaginable, even to the more optimistic among us. Equally as valuable is the awareness spread during the event and the unity of purpose that was shared by all who participate in the weekend. When combined with the Lake Regional Medical and Hospital Saturday Fund, total receipts will be in excess of 150k. It is only right that we take a moment and reflect positively on this achievement, but there is a substantial responsibility that comes with having this resource at our disposal. This undertaking has taken a lot of our time and commitment over the last year and it has proven worthwhile with such a return. Now PWSAI needs to ensure that this money is used for the betterment of all with PWS.

We have made a commitment to the GC as to some of the initiatives for which this money will be spent.

1. **Information Packs.** For families, educators and medical professionals
2. **Training Videos.** Produce training video`s with the participation of International/National experts. For the benefit of families and professionals
3. **Conferences.** To bring international experts to Ireland.
3. **Bursary Scheme.** Pursue relevant training for parents that will empower them to act as advisors for new parents.
4. **Research Fund.** Stimulate research into PWS in Ireland by offering one or more research grants. Baseline study of services available to people who have PWS countrywide

Combine this with the draft work plan documented for 2013/14, in which we highlighted other areas of focus for last year, namely:

#### Work plan 2013-2014

- Improve residential and respite options for people with PWS.
- Improve the levels of support we provide to individuals with PWS and their families
- Continue to maintain prudent management of finances
- Improve our Public Relations and Advocacy
- Improve governance in PWSAI
- Improve psychiatric and psychological supports available to people with PWS

At all times we need to be conscious of including all PWS members and age groups in our plans. That being said we represent such a diverse group, who have one thing in common, a defective gene 15. A considerable amount of work has been done during the year and for that I thank the committee members for all the hard work that has been put in. But there is yet a lot to do!

It is also encouraging to be invited to participate in research studies namely:

- Emotions and how they affect Behaviour—Kate Woodcock.

- Disomy (UPD) research into mental health ---Kate Manning and Tony Holland
- PWS EEG study--- Louise Gallagher /graduate research  
We should encourage as many as possible to participate in these initiatives as it's only through these that we achieve a greater understanding of how to manage and live with PWS

I look forward to:

- the upcoming conference and hearing the range of topics presented by a range of international experts as well as the presentation from Judith Meehan ,which is titled "Profile of a Prader-Willi Specific Clinic"

An Independent Charity Regulator has been set up, which is good news in my opinion for all charities and we need to ensure we continue to adhere to our Code of Governance, Financial Management and Data Protection Policies.

In my opinion we can only achieve these objectives with a collective effort. Roles and responsibilities of committee members needs to be clarified and aligned with these priorities. We need an agreement on what our priorities will be for the coming year. Then once agreed we need to put our collective energy following through on these. Where there is a difference of opinion we need to understand that it's healthy to have an open and honest discussion, but once there is a decision we all need to commit and move on. No one has personal or hidden agenda sand we all should realise that some of our objectives will target specific groups more than others. But as I mentioned before we need to ensure our overall strategy is to improve that lives of all age groups with PWS. We are all driven by a common goal to improve the life of everyone with PWS, as well as leaving a legacy for the next generation. Once a committee member agrees to taking ownership for any given task they need to follow through otherwise we will not be able to make progress.

Members will come and go from the committee for various reasons, some of them very personal and we should respect that. While on the committee we should treat each other with respect and be conscious that we all will be going through difficult times at one time or another. So we should show support and consideration at all times, while working to achieve set goal.

I have said it before that it's remarkable how such a small number of people driven by a common goal can achieve so much. But due to the large volume of work I feel we will need support from other PWSAI members, outside the committee. To that end I would encourage all PWSAI members to assist in whatever way they can. This does not necessitate joining the committee, but the preference would be to get other members to join.

Finally I'd again like to thank the committee again for their hard work and support during the last year. We should look forward to an equally productive 2014/15.

Regards,

Anthony

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## **Treasurer's Report by Sean Kelly**

### ***Fundraising***

2013 was a good year in terms of fundraising for PWSAI with €13,315 received from fundraising/donations. This compares with €4,458 in 2012. I would like to thank everyone involved in fundraising for the great work and effort they put into raising so much money in 2013.

### Expenditure

Expenditure was €21,977 in 2013, which was an increase of €10K on 2012. The increase was mainly due to €5,550 spent on fundraising packs and €2,500 in preparation for the Galway Cycle. As can be seen from the increase in money raised the fundraising packs were a great success. We still have 40% of the packs left.

In 2013 PWSAI held both a conference and a family day. A registration fee of €20 was charged for the conference which helped to offset the costs. We also received sponsorship of €3,000 from Pfizer for the conference.

The cost of the family day was reduced by sponsorship and donations received at the event. As can be seen from the table below PWSAI was able to run both the conference and family day at no cost to the association.

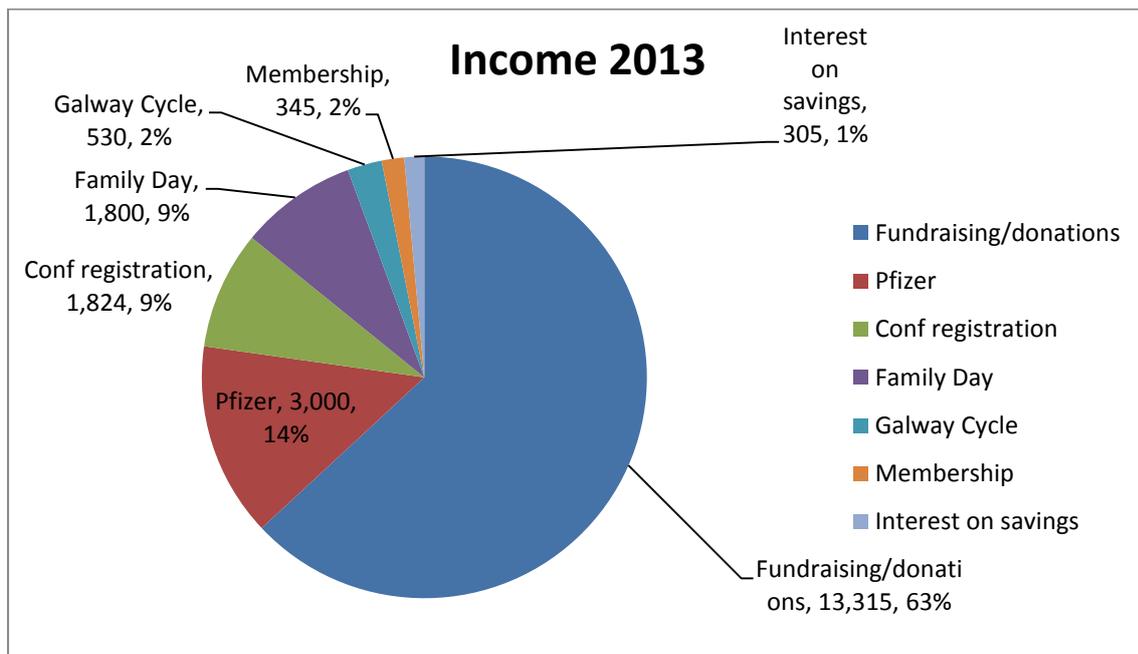
	Conference	Family Day	Pfizer	Total
<b>Costs</b>	€3,304	€2,600		€5,904
<b>Income</b>	€1,824	€1,800	€3,000	€6,624
<b>Total</b>	-€1,480	-€800	€3,000	€720

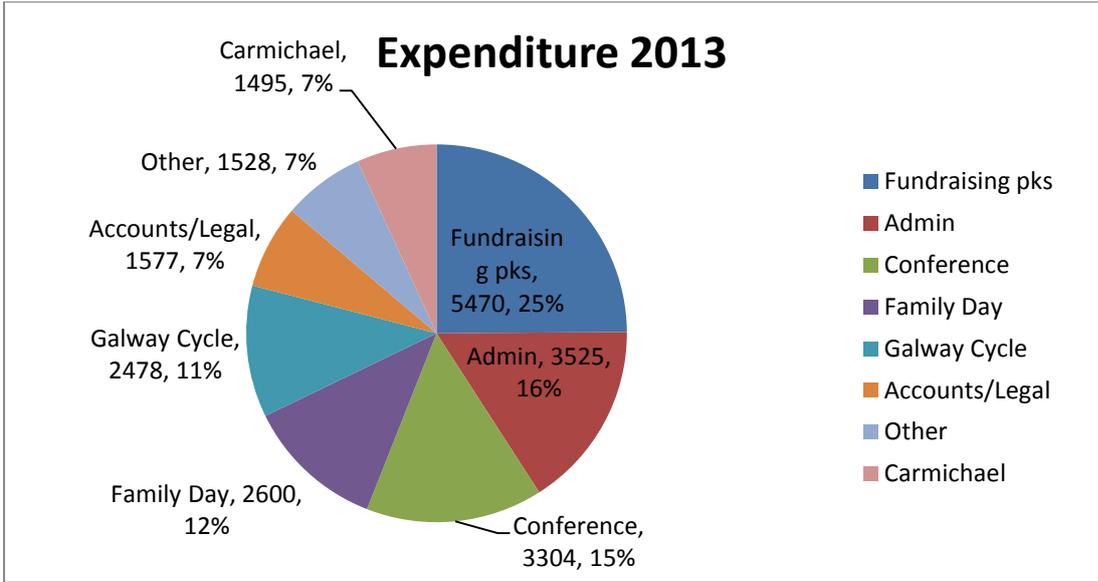
### Income

Total income for the year was €21,119 and total expenditure was €21,977 meaning a deficit of €858. However, if monies spent in preparation for the Galway Cycle are excluded then we actually had a surplus of €1,090 for the year.

Income	€21,119
Expenditure	€21,997
Balance	-€858

A breakdown of the income and expenditure follows.





<b>Fundraising Packs</b>	5470
<b>Admin</b>	3525
<b>Conference</b>	
Hotel	2274
Flights & accommodation for speakers	781
Conference information packs	249
<b>Family Day</b>	2600
<b>Galway Cycle</b>	2478
<b>Accounts/Legal</b>	
Accounts	962
Memo and articles advice	615
<b>Other</b>	
Meeting room hire	676
Insurance	248
Bank fees	126
The Wheel	120
IPWSO	100
Norton Anti-Virus	85
Vodafone	59
Genetic and Rare Disorders Association	50
Stationery	50
Misc.	14
<b>Carmichael Centre</b>	
Rent	825
Photocopying	340
Tickets	150
Postage	180
<b>Total</b>	<b>€21,977</b>

## ***Secretary's Report by Marguerite Hughes***

2013 was a year of rapid expansion for PWSAI and one that had many memorable highlights. While the Chairperson's report outlines the main events and achievements of the year, this report will identify key activities in relation to PWSAI's governance work and its communications with members and others.

### ***PWSAI Governance***

Following consultation with potential members in 2012, PWSAI amended its Memorandum and Articles of Association to enable it to start formally registering members in early 2013. By the end of 2013 PWSAI had signed up 24 paying members from 22 families in which there is a person with PWS.

Although the pace of this work was significantly slower than anticipated, PWSAI continued to work through the provisions of the Governance Code for the Community and Voluntary Sector and had completed approximately 75% of this work by December 2013. PWSAI remains committed to implementing the Code in full.

In addition to the AGM, which was held in June, the PWSAI Committee held 4 committee meetings during 2013.

### ***Communications***

PWSAI continued to offer individual support and information to families and professionals by phone, email, via Facebook and in person throughout 2013.

PWSAI issued 2 newsletters by email and post during 2013.

PWSAI continued to develop its website and to issue regular tweets to its followers throughout 2013.

PWSAI's following on Facebook expanded significantly during 2013 - it had 69 Facebook followers on January 1st 2013 and 470 on December 31st 2013.

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