



Annual Report 2017

Prader Willi Syndrome Association Ireland

PWSAI

Fiscal year ended 31 October 2017

The PWSAI Vision

A world where persons with Prader Willi Syndrome (PWS), their families, and their carers are supported in all aspects of care, education, and well-being.

The PWSAI Mission

To raise awareness and understanding of PWS and to improve the choice and quality of care, education and support for persons with PWS.

The Origins of PWSAI

PWS was first described in 1956. Just over a quarter of a century later the first child was diagnosed with PWS in Ireland. The Prader-Willi Syndrome Association Ireland (PWSAI) was established in the late 1980s by a small number of parents whose children had been diagnosed with PWS. In 2002 PWSAI became a company limited by guarantee. In 2013 PWSAI amended its governing documents to enable it to start formally registering members.

PWSAI Today

PWSAI is structured as a company limited by guarantee and is run by a board of directors comprising parents of people who have PWS. PWSAI has no paid staff.

The following served as PWSAI directors during 2017:

- Anthony Carr (Chair)
- Sean Kelly (Treasurer)
- Emma Walsh (Secretary)
- Caitriona Dunne
- Lena Lawlor
- Rory Tierney
- Derek Corrigan
- Conor McHugh (Appointed 01-07-2017)
- Elaine Murphy (Resigned August 2017)



Irish Times Article

In addition to the directors, PWSAI was assisted by many other volunteers who provided administrative support, organised events, coordinated advocacy efforts, and fundraised. Particular thanks is owed to Don Tallon, Paul Wright, Donnchadh Clancy, Jane Cox, Elizabeth Flynn., Ann O'Neill and Marguerite Hughes.

Terenure 5 Mile



National Survey Launch

PWS Association Ireland AGM Meeting Sept 15th, 2018

We continue to make progress on advocating for all those with PWS in Ireland.

Following the Launch of the National Survey.

“A Population-Based profile of Prader-Willi Syndrome in Ireland”.

in 2017 it was critical that we build on the exposure and good will achieved during the research, publication and launch from academics, medical experts and politicians. It was agreed that the main focus of PWSAI should be to take a lifelong approach for the provision of services for those with PWS. From the research data, it was clear that there was a significant gap of understanding and knowledge shown by those given responsibility to develop and provide Respite and Residential Care in Ireland. As a result it was agreed that R&R Sub-committee would undertake the main Role in advocating for these services This initiative was launched with a R&R information meeting directly after the AGM on 18th June last year. We received continued support of the Main Committee, who were updated on regular bases as to progress.

Key points during the year:

A commitment was given to PWSAI at the survey launch by Minister for Health Simon Harris to arrange a preliminary meeting with the HSE which resulted in the first meeting on the 7th July 2017 with DR Cathal Morgan(Head of Operations Disability Services).At this meeting a commitment was given to set up a HSE/PWSAI Working Group made up of members from HSE and PWSAI with a leading expert in PWS as an independent advisor When we proposed Dr Tony Holland this was warmly accepted by the HSE.

In parallel PWSAI were arranging a fact finding visit to Germany by parents, due to the success of the visit to Denmark(May 2017) this was arranged for Sept 2017 and included representative from Resilience care who had shown great interest in developing PWS Specific services in Ireland.

PWSAI had a very successful Family weekend in Portlaoise on the last weekend of September organised by the Kealey's which was attended by Susanne Blichfeldt from Denmark who is a retired paediatrician and mother to Mikael. Susanne gave freely of her time and held a talk and discussion session on self help and hygiene related issues.

In Nov 2017 a meeting was held between PWSAI and Rehab care to get an understanding on there plans in relation to R&R Provision. This was a informative meeting, but we have not received any clear strategic direct from Rehab that involves PWS.

On Sat 11th Nov a very successful meeting was held in Portlaoise combining both travel parties that went on the fact finding meetings to Denmark and Germany. the purpose of this meeting was to share learnings and to combine the varied experiences from those involved.

On the 13th Dec a meeting to discuss the TOR's for the HSE/PWSAI WG was held. Dr Michael Byrne Principal Psychologist with the HSE was also present. The main discussion points were in relation to defining the scope of Health and Social care model for PWS. It was at this meeting that the HSE confirmed funding for a pilot program for PWS Specific services and that a whole life approach to care was the best way forward. It was agreed at this meeting to invite Prof. Tony Holland onto the WG as International Independent advisor.

The Inaugural meeting of the HSE/PWSAI WG took place on 21 Feb 2018. Although this meeting was very progressive and scoped out significant areas for service development it was not followed up as promptly by the HSE as we anticipated PWSAI would like to thank Minister for Health Simon Harris for his continued support along the way in assisting where requested .

The next meeting of the HSE/PWSAI WG took place 11 June at which it was agreed to have 2 work streams:

Scoping

Models of support

Members of each group were selected and working TOR's for each group with the oversight of both feeding back to the HSE/PWSAI WG. These 2 groups have been working through meetings and conference calls to progress their objectives and will feedback to the HSE Steering committee on 24th Sept.

Work of the scoping group lead to the recommendation that a Qualitative Survey was required to get clear insight into what it was to live with PWS and what services were and were not available across the different age groups. This HSE online survey was completed on 29th Aug, by 42 families and has lead to the Carer Experience of HSE service Provision workshop, which will be held immediately after this AGM.

Work from the Models of support lead to the proposal that the best way forward would be for PWS to employ a PWS Development Officer dedicated to working on Advocating for all with PWS in Ireland and working to PWS Specific Objectives and timelines. This person will report to Chairperson of PWSAI and funded by HSE . The Job description and Person specification for the Role has been agreed and awaiting Approval before we go to advertising and interviewing candidates.

Taking a look back at my chairmans letter for the 2017 AGM and placing it alongside the letter of 2018 it is truly amazing how far we have come as an association and how much we have achieved in the last few years. As I always say unless we can see substantial changes/progress in service provision for all with PWS we have achieved nothing but I feel we need to take time and reflect on all the hard work that has brought us this far. This as always could not have come through without the hard work of the R&R Sub-committee with the support of the main committee as and when called on. There will come a time soon when these hardworking committee members and others ,will get due credit for their hard work and commitment. Mentioning them individually in this letter would be an inadequate recognition of all their hard work. I will choose a more appropriate way and time to give them the true praise for all their hard work.

I'm humbled to work with such dedicated individuals!!!!!!!

Regards

Anthony Carr

Chairman PWSAI

PWSAI's Work During 2017

- We offered one-to-one support and advice by telephone, Facebook and email.
- We disseminated relevant information by means of our website, newsletters, Facebook and Twitter.
- The PWSAI Family Weekend was another fantastic gathering of families with children/adults with PWS. In 2017 it was organised by Kealy family and took place in Portlaoise. It had a great turn out, with over 30 families attending.
- The R&R subcommittee made links with HSE representatives to further knowledge of PWS. Representatives from the R&R committee travelled to Denmark and Germany on fact finding trips to learn more about the R&R services offered in their countries.
- In June 2017 PWSAI held an R&R information meeting to gain a better understanding of services.
- In March 2017, the National PWS Survey was launched by Minister Simon Harris. This resulted in nationwide coverage of PWS, from an article in the Irish Times, to speaking with Matt Cooper on Todayfm and other local radio stations.
- In April 2017, copies of the National PWS Survey was delivered to all families in Ireland.
- In Feb 2017, Ann O'Neill hosted another workshop for families of children age 0-12 with PWS. This workshop focuses on living better with PWS.
- PWSAI continued to do the work necessary to meet its legal requirements including reporting to the Companies Registration Office and the Charities Regulatory Authority.

Plans for the Future 2018 and beyond

During 2018 PWSAI will continue to work on the ongoing projects that received funding from the Galway Cycle as well as other projects that have been identified as necessary by PWSAI's committee and members. The National Survey further highlighted the need for respite and residential services for people with PWS.

There has been a strong focus on working towards respite and residential services for people with PWS and increasing awareness of PWS throughout the medical and disability services.

PWSAI will continue to work on creating additional resources for families and professionals working with people with PWS. PWSAI will continue to provide opportunities for people with PWS and their families to meet and learn from one another.

All of PWSAI's work relies on the willingness of suitably qualified volunteers to give of their time.

Fundraising & Awareness Spreading

PWSAI were lucky to be the chosen charity for the Terenure 5 mile in May 2017. This raised 6000 euro for PWSAI. Thank you to the Jones family. The PWS 5K took place in June 2017 and raised over 4000 euro. This brings the total raised by the PWS 5K to over 14,000 euro.

There were many fundraisers by families and we thank each of you.

A special mention to the McHugh family, the Cox family, the Kerley family and to Andrea Egan and Elisha Doyle for sharing their personal stories on radio and in the newspaper.

PWSAI is very grateful to all the individuals and organisations who donated money, participated in or organised fundraisers, or raised awareness of PWS during 2017.

2017 Treasurer's Report

Income for the year was €20,053. This was made up of €16,000 raised through fundraising and €3,300 through donations.

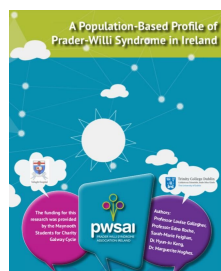
On behalf of PWSAI I would like to thank all those who fundraised for the association throughout 2017. Walkers Solicitors, Presentation College Tuam, Oisin O'Neill, Niamh Ryan, Hayden Hussey, Hickey Pharmacy, Fields Jewellers and all at Bray Garda Station.

Thanks to Rory and Emma and all those involved in organising the Maynooth 5K in 2017 which once again was a great success. Last but not least I would like to thank the organisers of the Terenure 5 Mile run for choosing PWSAI as their charity for 2017. This event was a brilliant chance to raise awareness of PWS and also raised over €6000.

Thanks to all those who made donations throughout 2017 including SE Logistics, Courts Service and Intel. Total received was €3,300



Family Weekend 2017

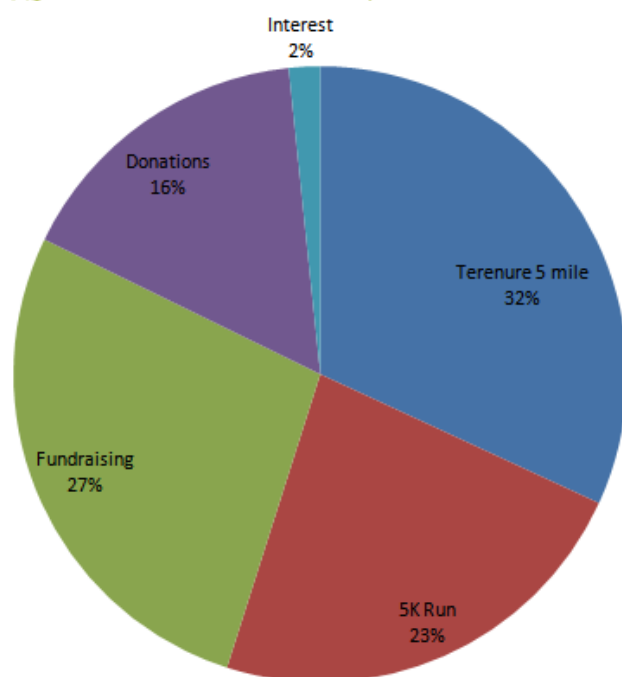


National Survey



Fact Finding Trip

2017 Treasurer's Report Income



Terenure 5 Mile	€6,205
5K Run	€4,479
Fundraising	€5,911
Donations	€3,138
Interest	€ 320
Total	€20,053

2017 Treasurer's Report Expenditure

Expenditure

Expenditure in 2017 was €29,734. The main items were

Survey launch €7,057.

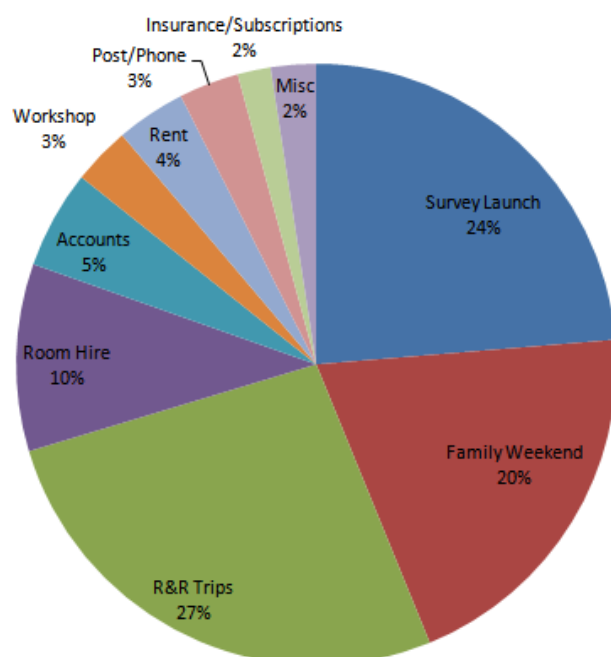
Family weekend €6,000

R&R Fact Finding Trips €7,900

Meeting Room Hire €3,000



Hickeys Pharmacy



Survey Launch	€7,057
Family Weekend	€6,000
R&R Trips	€7,900
Accountant Fees	€1,577
Room Hire	€3,000
Workshop	€ 924
Rent	€ 1,116
Post/Phone	€ 963
Insur/Subscrip	€ 530
Miscellaneous	€787
Total	€29,794

Prader Willi Syndrome Association Ireland

Carmichael Centre
Carmichael House
North Brunswick Street
Dublin 7
IRELAND

www.pwsai.ie

Telephone: (087) 2522832

Email: info@pwsai.ie

Charity Number: CHY15171

Registered Charity Number: 20051693 CHY

Companies Registration Number: 364058

