



Annual Report 2018

Prader Willi Syndrome Association Ireland (PWSAI)

Fiscal year ended 31 October 2018

Chairman's Review 2018

PWS Association Ireland

AGM Meeting Sept 21st 2019

Reflection on the journey over the last 2 years!

The achievements made by PWSAI and in particular the R&R Sub-committee in 2019, are as a result of the strategy developed and work undertaken after the launch of the national survey in 2017. ("A Population-Based profile of Prader-Willi Syndrome in Ireland").

It's worth recalling and reminding ourselves that in 2017, we felt it important to build on the exposure and good will achieved during the research, publication and launch of the survey 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, 2017. The R&R Sub-committee received continued support throughout the last 2 years from the Main Committee.

On the 7th July 2017 we had the initial meeting 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 Dr Tony Holland as a leading international expert in PWS as an independent advisor. Fact finding visits were arranged to Germany and Denmark in May and Sept 2017, to which we invited Parents, HSE and Resilience care representatives. These visits were incredibly successful as it gave an insight into best practice of care for PWS , to decision makers in the HSE and Care providers.

The Inaugural meeting of the HSE/PWSAI WG took place on 21 Feb 2018.Only through continue feedback to the constituency office of Minister for Health Simon Harris and his personnel interest into the workings of this WG, that progress was made.

The HSE launched an online survey which was completed on 29th Aug 2018, by 42 families and lead to the Carer Experience of HSE service Provision workshop, which was held immediately after this AGM 15th Sept 2018.Monthly meetings followed through out the end of 2018 where the main work focussed on combining the outcome of the 2 WGs into one document.

Work from the Models of support group, lead to the proposal that the best way forward would be for PWS to employ a Development Officer dedicated to working on Advocating for all with PWS in Ireland and working to PWS Specific Objectives and timelines. This person would report to Chairperson of PWSAI and be funded by the HSE. The Role was advertised Mid Dec of 2018, through various social media channels and Irish Jobs.ie, with closing dates for applicants for 25th Jan 2019.After short listing to 8 candidates from 18 applicants,6 were interviewed, in week commencing 25th Feb 2019.Dermot O Donnell (Disability federation of Ireland) and Helen McDaid (HSE)assisted in this process. The position of Development Officer for PWSAI was offered to Gary Brennan, on March 11,2019 with him taking up the position on the 9th May 2019.

Returning to PWSAI /HSE WG it has to be said that progress was slow, early in 2019, due to lack of engagement from the HSE. This again required us to engage with the Minister for Health to stimulate the HSE into allocating time and committing to finalising a final Document. The final draft of this document is complete and awaits the approval from the HSE at our next meeting on 27th Sept

2019.

While we have been working on these initiatives from Sept 2017 Laura Keane (Resilience Care) has been building a business plan around a proposal to open a PWS Specific Residential house. The vision that Laura had and the clarity of purpose she set herself to make it happen is inspiring. It took a lot of hard work, personnel commitment and perseverance along the way. She remains focused despite disappointments and set backs along the way. This drive and tenacity has culminated in the announcement of the opening of our second PWS Specific home in Enniscorthy later this year.

We should not forget other important activities of PWSAI and the successful workshop on March 23rd, 2019 “living better with PWS”, which took place in Portlaoise. Delivered by PWSAI Liaison officer Ann O Neill.

We also have the possibility of partaking in a unique Soleno drug trial which potentially can suppress hyperphagia in PWS.

So looking back on the strategy set out in Sept 2017, and what has been achieved:

- First PWS Development Officer Recruited.
- Second PWS Specific Residential House opened.
- Joint HSE/PWSAI Document published, laying out the unique nature of PWS and a blue print for service provision in Ireland.
- Much wider and deeper understanding within the HSE of PWS.

I must acknowledge a few people whose hard work and commitment has made this happen;

Minister for Health Simon Harris, to him we offer our sincere gratitude for his support over the last 3 years.

All on the R&R Sub-committee and specifically:

Jane Cox,

Who offered her assistance to the R&R committee at a most timely and critical juncture.

- Tireless work as Member of HSE/PWSAI WG.
- Without whom the HSE/PWSAI Final Draft Document would not have been achieved.
- Also her input into the Job Description and advertisement of the Development Officer position.
- Finally her numerous trips to Minister Simon Harris constituency office when needed.

Don Tallon,

who works tirelessly across a wide spectrum of initiatives and has played a key role in PWSAI achievements over the last 2 years,

- Organising the fact finding trips to Denmark/Germany.
- Tireless work as Member of the HSE/PWSAI WG.
- Advisor to Care providers, resulting in 2nd PWS Residential home.
- Advocating for PWSAI participation in the Soleno Drug Trial.
- Continued support to the wider membership particularly in times of crisis.

Paul Wright and Donnchadh Clancy for active participation in the HSE/PWSAI WG`s and R&R Sub committee.

Marguerite Hughes ,who is prepared constantly to give her support and advise on any initiative we undertake as well as passing on her knowledge and experience from her position on the board of IPWSO.

Emma for her constant support as secretary to PWSAI and her responsiveness when requested for assistance.

Sean for the meticulous manner in which the finances of PWSAI are managed and reported out on.

To the remainder of PWSAI Main committee who have the confidence in the R&R Sub-committee to go about its' work.

Nothing worthwhile was ever achieved without hard work and commitment. The evidence of this can be seen in the progress achieved over specifically the last 3 years. With the support of the Development Officer role we need to set ambitious targets for ourselves over the next few years.

The committee needs to attract new members, so it remains energised and relevant to all age groups. The association needs to function on a principle of good governance and be seen to do so. Lets keep the momentum going!

Thank You all!

Regards,

Anthony Carr

Chairman PWSAI

Plans for the Future 2019 and beyond

To continue to advocate for respite and residential services for people with PWS.

To continue to support those with PWS and their carers.

To spread awareness of PWS, to share up to date information about PWS from day-to-day living with PWS tools, to information on research such as clinical trials and research opportunities.

To support the hosting of the annual PWSAI family weekend.

To support PWS research initiatives in Ireland.

To encourage and support fundraising for PWSAI.



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.

The following served as PWSAI directors during 2018:

- Anthony Carr (Chair)
 - Sean Kelly (Treasurer)
 - Emma Walsh (Secretary)
 - Derek Corrigan
 - Lena Lawlor
 - Caitriona Dunne
 - Rory Tierney
 - Conor McHugh
- 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, Ann O'Neill, Marguerite Hughes, Jane Cox, Donnchadh Clancy and Elizabeth Flynn.

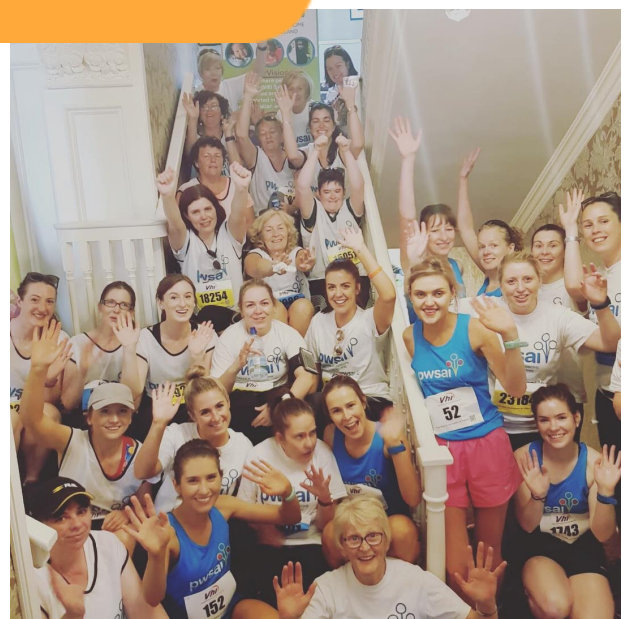


going orange for PWS Awareness Day 2018

PWSAI's Work During 2018

- We offered one-to-one support and advice by telephone, Facebook and email.
- We spread information on PWS via email, newsletters, facebook and twitter. Information included research opportunities, advice, news from International PWS organisations such as PWS UK, FPWR, IPWSO and PWS USA
- The PWSAI Family weekend took place in Carrickmacross in October 2018. Thank you to the McRuairi family.
- In December 2018, we promoted our search for a PWSAI Development Officer in connection with the HSE.
- The PWSAI Respite and Residential committee continued to have meetings with the HSE about increasing the knowledge of PWS in the country and advocating for respite and residential services.
- Delegates from PWSAI went to the IPWSO Caregivers conference and the FPWR conference.
- A focus group was held in September 2018 for parents/carers of people with PWS to feedback to the HSE, following the completion of a survey on Carer Satisfaction in August 2018.
- Membership of PWSAI needed to be renewed from Feb 2018, this was communicated via email, newsletter and social media.
- PWSAI turned 30 years in November 2018. We celebrated this at the PWSAI Family weekend in October 2018.
- PWSAI continued to do the work necessary to meet its legal requirements including reporting to the Companies Registration Office and the Charities Regulatory Authority.

Mini Marathon 2018



Fundraising & Awareness Spreading

PWSAI was fortunate to be a recipient of funds from the Hospital Saturday fund in 2018. A donation of 2300 was given to PWSAI.

In June 2018, a group took part in the VHI Women's Mini Marathon raising a total of 6500 for PWSAI.

PWSAI membership for the term 2018-2020 was launched.

A special thank you to all the parents/carers who filled in the HSE Carer Satisfaction survey and attended the focus group, as this has raised the awareness of living with PWS with the HSE.

PWSAI is very grateful to all the individuals and organisations who donated money, participated in or organised fundraisers, or raised awareness of PWS during 2018



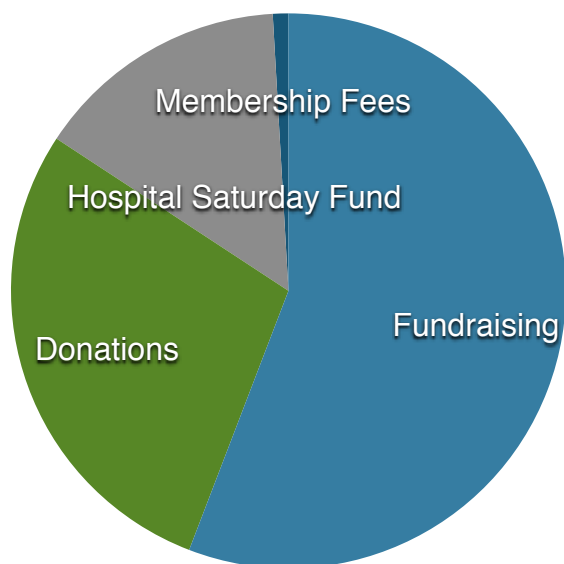
Jane Cox receiving a
cheque from the
Garda Tour de Force
Fundraiser

2018 Treasurer's Report

1st November 2017- 31st October 2018

Income

Income for the year was €15,484. On behalf of PWSAI I would like to thank all those who fundraised and made donations to PWSAI throughout 2018. A special word of thanks to those who took part in the Women's Mini Marathon raising over €6,500 in the process. Thanks also to those involved in the Garda Tour de Force and Deenside Wheelers for their fundraising efforts on behalf of PWSAI.



- Fundraising
- Donations
- Hospital Saturday Fund
- Membership Fees

Fundraising	8644
Donations	4400
HOSPITAL SATURDAY FUND	2300
MEMBERSHIP FEES	140
TOTAL	15484

PWSAI Family Weekend 2018

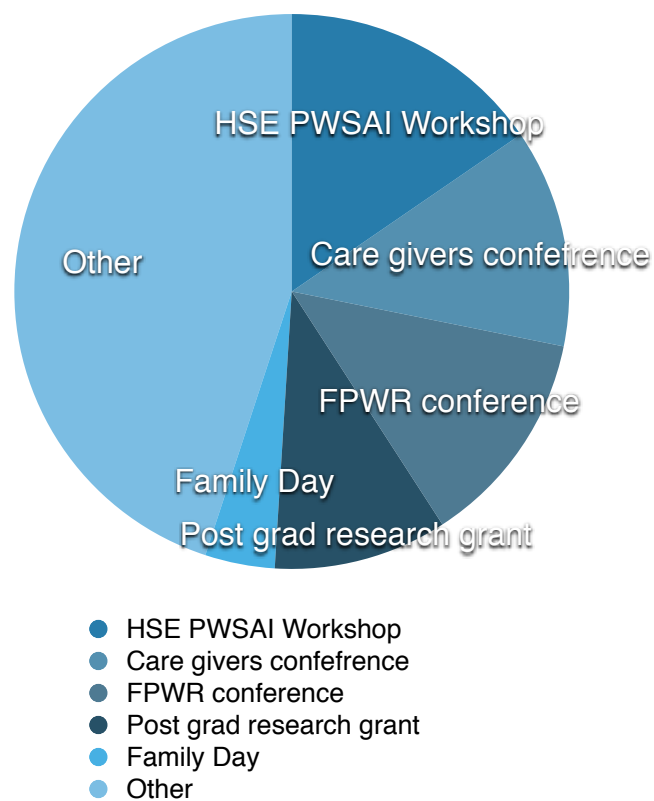


2015 Treasurer's Report Expenditure

Expenditure

Expenditure in 2018 was €13,751. A breakdown is given below.

HSE/PWSAI Workshop costs	2122
HSE/PWSAI Care givers conference	1752
FPWR FACT FINDING	1745
ACCOUNTANT FEES	1577
POST GRAD RESEARCH GRANT	1391
ROOM HIRE	1339
HSE MEETING EXPENSES	1034
FAMILY DAY	559
CARMICHAEL CENTRE RENT	541
PHONE	423
Print postage stationary	315
R&R Expenses	313
Insurance	308
Subscriptions	226
Bank charges	106
TOTAL	13751



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