# 2020

# ANNUAL REPORT

pwsai
PRADER WILLI SYNDROME
ASSOCIATION IRELAND

Fiscal year ended
31st October 2020

www.pwsai.ie

## Contents:

# About PWSAI

Prader Willi Syndrome (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 is governed by a Board of Trustees.

The Board of Trustees for the fiscal year ended 31/10/2020 were:

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

## VISION

A WORLD WHERE PERSONS WITH PRADER WILLI SYNDROME, THEIR FAMILIES, AND THEIR CARERS ARE SUPPORTED IN ALL ASPECTS OF CARE, EDUCATION, AND WELL-BEING

## MISSION

TO RAISE AWARENESS AND UNDERSTANDING OF PWS AND TO IMPROVE THE CHOICE AND QUALITY OF CARE, EDUCATION AND SUPPORT FOR PERSONS WITH PWS

## Our Objectives

- To improve the quality of life of people with PWS and provide a forum where their voices are heard
- To provide information and support to parents and families of people with PWS
- To increase awareness and understanding of the syndrome among the general public
- To improve access to appropriate, high quality social care supports for people with PWS
- To improve access to high quality mental health and clinical supports for people with PWS
- To improve the successful participation of people with PWSin education across the lifespan
- To support research into Prader-Willi Syndrome.

# Letter from Chairperson Anthony Carr

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PRADER WILLI SYNDROME
ASSOCIATION IRELAND

**PWS Association Ireland**

**AGM Meeting Sept 18th, 2021**

***We need you, so that we can move forward together!***

The last year and a half have been very challenging for everyone but more so for those having to care for a family member with PWS. The social lockdown that was imposed, although we understand was necessary, lead to loss of supports and services that families rely upon to function and cater for the needs of their family member. Irrespective of the age group involved the routine and structure that is so important for those with PWS was disrupted requiring a new norm with different challenges. Although we are learning to live in the Covid era we have a long way to go before we return to a resemblance of how things use to be. As a Board we were able to continue our work through virtual meetings on Teams and Zoom, which is a very convenient and efficient way of having meetings but it cannot replace having a face-to-face contact in person. It has also been necessary to use various social media communications platforms Facebook, Instagram, what's app, linked in etc to keep you informed as to what has been happening. Where we felt it appropriate, we also sent our targeted communications through mail on certain topics, as well as the PWSAI Newsletter.

Another casualty of Covid was the cancellation of our family weekend last year to the disappointment of everyone as this is the social opportunity of the year to meet up and for those with PWS to meet their friends. As you have probably read the family weekend is now rescheduled to go ahead on the weekend of 18-20th Feb 2022, in the Hillgrove Hotel Monaghan. Thanks to the McEntee Family for agreeing to follow through on their commitment to host. It's advised that anyone planning to attend make their reservation with the Hotel, as soon as possible, as the rooms which are held open for the event will only be kept for a limited time period. As an association we will adhere to government Covid Protocol guidelines as they pertain at that time.

As you are aware the HSE have been funding a 2-year pilot for, Gary Brennan as our National Development Manager. In May of this year following a successful review of the pilot between PWSAI and the HSE, the HSE agreed to make a permanent commitment to fund this position going forward. This is a great endorsement of the work carried out by Gary on behalf of PWSAI and the confidence placed in PWSAI by the HSE in our efforts to advocated for all with PWS.Some of you will have engaged with Gary already, for those who have not, PWSAI would encourage you to reach out to him, his contact details are readily available. Gary attended our last Family weekend in Killarney Oct 2019 and since then it has been his plan to organise regional meetings with members, so as to offer time to families to meet him individually and as groups. Unfortunately, due to Covid Protocol this has not been possible until now, so he is planning this Autumn/Winter to do just that. He will identify a number of venues around the country, where he will book facilities to allow him to meet groups or individual families. I would encourage as many families as possible, to take this opportunity to meet Gary as he is your support and will help in anyway, he can to assist your family with your individual needs. Details will be sent out once organised.

As you may recall from my review letter last year, the HSE and PWSAI had completed a comprehensive National report which we had been working on with the HSE from July 2017.A commitment was given to us by the HSE that the report would be reviewed by the Disability Board of HSE on 28th Sept 2020 and they would get back to us. (This was the week after the 2020 AGM.) Despite our best efforts we were unable to get feedback from the HSE or a plan on when we would publish the report. We were also assured that a submission had been included in the funding estimates for 2021, for a PWS specific respite service, but were not kept up to date on any progress. Through persistent lobbying of politicians and continued pressure on the HSE, PWSAI were afforded a meeting with the Minister for Disabilities Anne Rabbitte and Minister for Mental Health Mary Butler in Feb this year. Also in attendance were the members of the HSE whom we had worked with to compile the report. The outcome of that meeting was that we were not successful on getting funding for the Pilot Respite service in 2021 and that PWSAI would now be working with Prof Mac Maclachlan who is National Clinical Lead and Chair of National Clinical Program for People with Disabilities (NCPPD). There was a feeling it has to be said "of here we go again". But the NCPPD has taken the National Report and are working with PWSAI to work through the identified priorities from its recommendations. The provision of PWS appropriate respite service is still the number one priority and we can confirm that an agreed funding sum has been included in the estimates for 2022.The letter you would have received from PWSAI to lobby your local politician is to ensure the Minister for Disabilities is kept reminded of the need for PWS respite service and to encourage her to approve the spend in full.

Once the Respite pilot gets started (we remain optimistic) PWSAI would encourage all our members to actively engage with the association to help plan and co-ordinate the services so that all age groups, needs, and genders are accommodated. We need to maximise the use of the available bed nights for the benefit of our members. The service will be community based and offer families and those with PWS respite, prolonging the length of time the family unit can stay together, while facilitating an easier transition to residential care to those who need it.

# Letter from Chairperson continued...

The Resilience Residential home (Lemongrove) in Enniscorthy continues to provide PWS care, tailored to the needs to PWS. There is further development on site to increase the capacity of the residence by 3 more places. Resilience as a care provider are also interested in providing the Respite Care services which is likely to be located in the Midlands region and also further PWS Residential services in the Munster region. If you need contact details for Resilience Care don't hesitate to contact us. (location of the respite will be announced when funding has been approved, we remain optimistic that the funding will be approved, but keep reminding your local politician)

Also, in July 2022 Ireland will host the IPWSO International Conference, in University of Limerick. This is truly a once in a lifetime opportunity for a small country like Ireland to show how to host such a prestigious event. It will more importantly put us on the national stage and help to spread awareness of PWS. For you our members it will give you access to International Medical Experts, Researchers and Clinicians in a convenient location. Our aim is to ensure that the event is planned in such a way, so all who wish to attend can avail of this opportunity and we will keep you informed through newsletter and social media as plans progress. Planning has already started but will gain momentum from now through to the event itself. What we will need are volunteers to help with co-ordinating and facilitate the event, so please come forward if you feel you can help in anyway. Early Bird registration will be opening soon so keep an eye on PWSAI updates on social media.

Fundraising efforts continue which while generating revenue they also spread awareness among the general public.Thanks to all who, organised and took part in these events. Tesco fundraiser by Louis and Henry, Louise Corrigan fundraiser, Go Orange for PWS Awareness goes from strength to strength (great support from families sharing orange images via our PWSAI social media), Virtual PWS 5K raising 11,239 euro (incredible support from families) and Emma for organising Virtual PWSAI celebration due to cancellation of the Family weekend 2020.

PWSAI Board have completed our Code of Governance to ensure we are in compliance with the Charities Regulators act. The code sets out the standards that charities should meet to manage and control their activities. This work will facilitate the better administration and management of PWSAI, by putting in place systems and processes which focus on advancing the charitable purpose as well as ensuring that we manage in an effective, efficient, accountable and transparent way. The code will also help us meet our legal duties under charity law. In time the charities regulator will publicly display whether or not charities comply with the Governance Code, which will become part of our entry on the Register of Charities. Where compliance with the code is indicated on the Register of Charities, it will give confidence to all stakeholders that PWSAI has an effective governance system and process in place. Thanks to Rory for taking ownership and seeing it through to completion and also the Board for working to the spirit of the code and holding us each other accountable to it.

The present Board of Directors for PWSAI are Emma Walsh Tierney, Jane Cox, Michelle Meadows Rousseau, Yvonne Rochford, Ann McCrann, Rory Tierney, Don Tallon, Sean Kelly, Conor McHugh and Derek Corrigan. Gary Brennan as National Development Manager reports to the Board.The members of the Board of Directors are also members of our sub-committees of which we have:

- New Diagnosis
- Education
- Finance & Fundraising
- Respite & Residential (Paul Wright and Donnchadh Clancy also members)
- IPWSO Conference

I would like to thank them all for the hard work over the last 12 months and encourage anyone who feels they have something to offer to contact us. It doesn't require a person to be a board member to be active on one of the sub-committees, we also have people who help us on an adhoc bases and some that are not members of the Board or sub-committee but work in support of PWSAI throughout the year. Thanks to Ann O`Neill and Caitriona Jones in particular for their ongoing support.

This year at the AGM there will be a New Vice-Chairperson position up for election. The intent of this position is for a co-ordinated transfer of roles and responsibilities between the Chairperson and incumbent Vice- Chairperson. The elected Vice Chairperson will succeed me as Chairperson when I step down at the AGM in 2022.It is important that the key roles in the Board change hands on an agreed term as it ensures the Board gains the benefit of new ideas, talent and leadership.

Reaching out to us doesn't require anything more than a phone call or e-mail and there is no further commitment expected from you. The year ahead will be one of the busiest yet for PWSAI and you our members, but we can't do it alone we need your engagement, so we can move forward together.

Regards,

Anthony Carr Chairperson PWSAI

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# Key Milestones

## 2020

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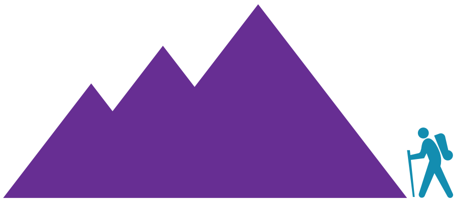
|---|---|
| **November 2019** | PWSAI win bid to host the International PWS conference in July 2022 |
| **December 2019** | PWSAI awarded Shannon Region Ambassador award for their successful bid to host IPWSO conference |
| **February 2020** | Respite & Residential sub committee continue to work with HSE advocating for services for families |
| **March 2020** | Global pandemic. PWSAI Trustee and sub committee meetings move to online platforms. |
| **April 2020** | PWSAI deliver PWS medical alert booklets to all families in Ireland |
| **May 2020** | PWSAI families support Go Orange Day for PWS Awareness |
| **June 2020** | PWSAI families support a virtual PWS 5K rising over 11,000 euro for PWSAI! |
| **July 2020** | PWSAI Trustees begin Governance training |
| **September 2020** | Three new board trustees join PWSAI. PWSAI launch WhatsApp group for PWSAI Updates |
| **October 2020** | PWSAI host a virtual Celebration for families |

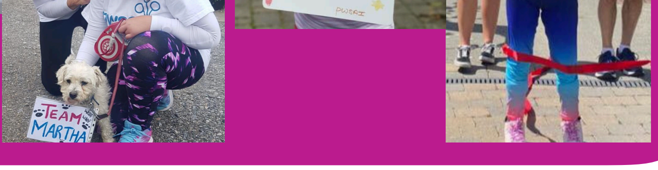
# 2020 Fundraising & Awareness



Laura's Auntie Louise Corrigan climbed Kilimanjaro in aid of the Prader-Willi Syndrome Association Ireland raising €3000.
THANK YOU!

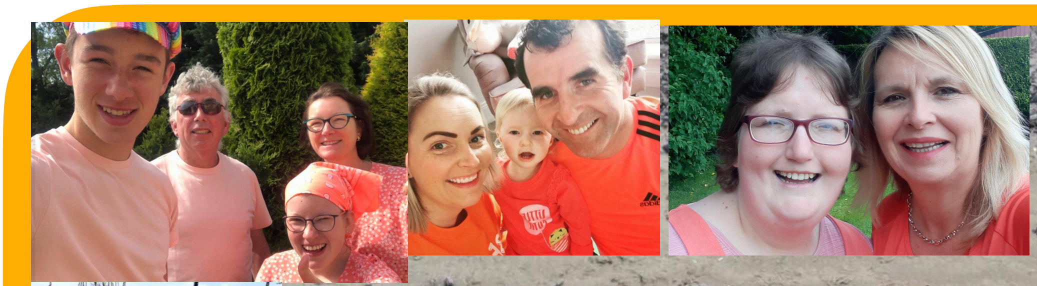
Louis and Henry, both from Galway collected a cheque for €317 euro from the Tesco Galway Blue token fund! Thank you!

The Virtual PWS 5K 2020 raised over 11,000 euro!



Thank you everyone who took part and supported PWS awareness and fundraising in 2020

## Go Orange Day for PWS Awareness 2020



# PWSAI during 2020

We offered one-to-one support and advice by telephone, Facebook and email.

A Whatsapp group was launched for updates

PWSAI thanks all who fundraised for PWSAI and supported PWS Awareness during 2020

The Board of Trustees are committed to meet the governance guidelines set out by the CRA . Governance training started in July 2020

PWSAI hosted virtual events during 2020 to stay connected with our families. A special thank you to the McEntee family who have had to reschedule the family weekend.

We spread information on PWS via email, newsletters, facebook and twitter. Information included research opportunities, advice, news from International PWS organisations.

PWSAI continued to do the work necessary to meet its legal requirements including reporting to the Companies Registration Office

PWSAI cancelled all physical meetings in 2020 in line with government advice.

PWSAI shared information from international PWS organisations that would be of interest to families.

PWSAI supported the International PWS Awareness day by going orange for PWS

# Financial Statement

## Treasurer Sean Kelly

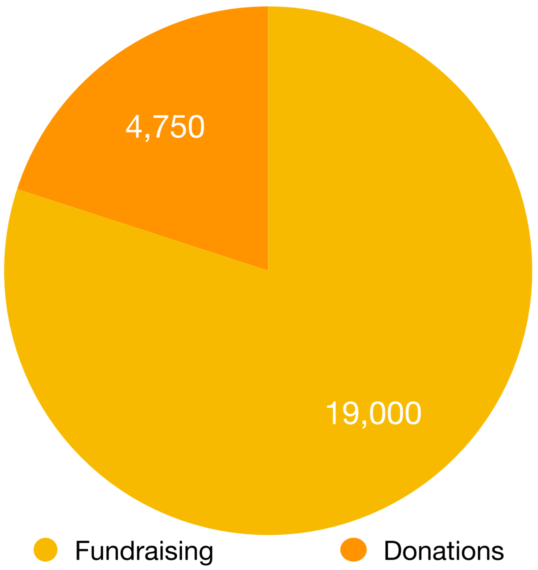
## 1st November 2019 to 31st October 2020

Despite the pandemic 2020 was another successful fundraising year for PWSAI with €19,000 raised. Thanks to everyone who organised and supported our fundraising events throughout the year. The virtual 5k was a huge success raising €11,239

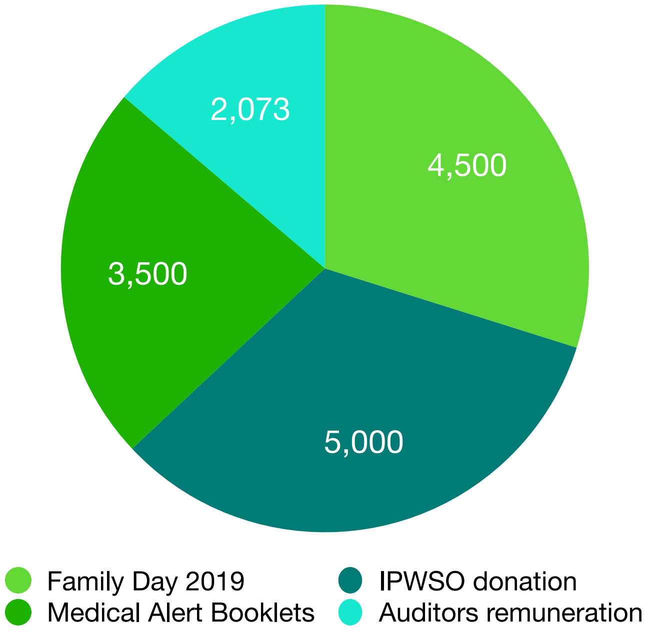
Donations received for the year came to €4,750

Details of Income and Expenditure are

**Income total €23,750**



Expenditure total €26,500



Overall the association is in a good financial position. Bank balance at 31st Oct 2020 was €231,000.

PWSAI
Virtual Celebration Day
October 2020

# Planning for 2021 & 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.

To plan for the 11th IPWSO conference that will be taking place in July 2022 in Limerick.

To launch regional hubs in key area to mobilise members and advocate and support additional services.

To host workshops on living better with PWS through different age groups

To continue to provide training through the National Development Manager for service providers and educators.

To encourage membership to increase our collective voice

To complete the CRA standard in governance code

To form subcommittees on key elements of the strategic plan in order to further our mission statement.

WE'RE ALL IN THIS TOGETHER

11TH INTERNATIONAL PRADER-WILLI SYNDROME ORGANISATION CONFERENCE

Limerick, Ireland
6 - 10 July 2022

Parallel sessions for:

- Researchers and clinicians
- Allied health professionals
- Care providers
- Adults with PWS
- Families

Plus activities for children with PWS

Register your interest at
www.ipwso.org/2022

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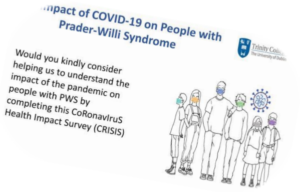
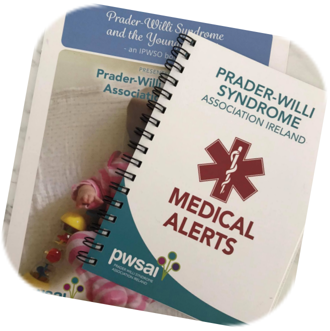
IPWSO
INTERNATIONAL PRADER-WILLI SYNDROME ORGANISATION

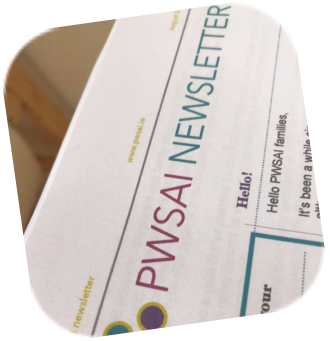


mpact of COVID-19 on People with Prader-Willi Syndrome

Would you kindly consider helping us to understand the impact of the pandemic on people with PWS by completing this CoRonavIruS Health Impact Survey (CRISIS)

Trinity College
The University of Dublin





Prader Willi Syndrome Association Ireland

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