Prader Willi
Syndrome
Association
Ireland

pwsai
PRADER WILLI SYNDROME
ASSOCIATION IRELAND

www.pwsai.ie

# ANNUAL REPORT

## FISCAL YEAR END 31.10.22

# 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.

A National Development Manager was appointed to PWSAI in May 2019 to support PWSAI's objectives.

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# OUR BOARD OF TRUSTEES

The Board of Trustees for the fiscal year ended 31/10/2022 were:

Anthony Carr - Chairperson
Rory Tierney - Vice Chairperson
Sean Kelly - Treasurer
Emma Walsh - Secretary
Don Tallon
Derek Corrigan
Conor McHugh
Michelle Rousseau
Ann McCrann
Yvonne Rochford
Jane Cox

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, Caitriona Dunne , Stephen McHugh,  Annette Enright, Mary McEntee and Donnchadh Clancy.

The Board of Trustees extends their thank you to Gary Brennan, PWSAI National Development Manager for his commitment to improving the lives of all people with PWS and their families.

# VISION AND MISSION

## VISION

A world where people 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 Prader Willi Syndrome 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 PWS in education across the lifespan.

To support research into Prader-Willi Syndrome.

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# OUR VALUES

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C

## COMMUNITY

PWSAI identifies as a community of families with a common challenge and a common bond. We support and care for each other. We connect with families, professionals and researchers at home and abroad to share ideas and knowledge about how best to live with Prader-Willi syndrome.

A

## ADVOCACY

PWSAI aspires to make a positive difference to the lives of people in our community by providing an environment where individuals or groups can speak for themselves. We also advocate on behalf of those who cannot speak for themselves.

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## INTEGRITY

PWSAI commits to honesty, accountability and transparency in how we conduct all our affairs. We aspire to stand the test of scrutiny by all our stakeholders, and also members of the public, regulators and the media.

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## RESPECT

how we conduct our relationships with others. We treat everyone equally and in a professional manner; and seek to uphold the human rights and diversity of all stakeholders.

#CAIR

# LETTER FROM THE CHAIRPERSON

PWSAI
AGM Meeting October 24th 2023

Hi All,

It’s been another great year for PWSAI building on the huge success of the international conference in July 2022. We have developed strong links with our international partners and more importantly here at home the connections to policy makers, care providers and the HSE is stronger and the understanding of prader willi syndrome and the specific needs of prader willi syndrome is better.

On the back of the international conference last Autumn our board developed our new Strategic plan for our future. This plan was developed in order to maintain our 'Whole of Life' approach to PWS and also to use the strong connections from the conference to drive us forward. This plan created the streams for our subcommittees into 2023.

We continued our strong developments in Residential and Respite working with Resilience Healthcare who opened a further PWS specific residential house in Monasterevin during the summer with another site in Cork online to open later in 2024.

After a rigorous process involving PWSAI, HSE officials and a number of providers last winter Resilience Healthcare became the provider for our first ever PWS specific Respite house also to open in 2024 in Stradbally Co. Laois. This service will be for both children and adults, who will avail of the service at different allocated times. We all need to work together to make this service a success. We need to learn together in order to set up a world class respite service. The intention is for the service to be tailored to individual's needs, so you as carers have an opportunity to shape the service and develop how it works going forward.

I  would like to thank the R&R subcommittee for all their hard work to get Residential and Respite services to where they are today. We have come a long way in the last number of years but this is a long road and we have more to do. The idea is that all families will have options and supports available to them. It may not be for you today but in the future our vision is a world where specific Residential and Respite services are the norm and an option for all people with PWS in order to support families and carers at home.

Our National Report in conjunction with the HSE is nearing a conclusion. Again this has been a huge task with many frustrations and blockages along the way. We have remained consistent in our messaging and refused to back down on the elements of PWS that to us in our world are essential and neccesssary in keeping our children safe. Hopefully with no further delays we will be in a position to publish and launch our report in 2024. This will be a landmark moment for PWSAI give then the report will have been produced in collabaration with the HSE.

# LETTER FROM THE CHAIRPERSON

We continue to see the spread and success of the international conference last year with our National Development Manager Gary Brennan delivering a huge amount of PWS specific training sessions to care providers, schools and supporting families with advice and in accessing supports. PWSAI has improved our reach in supporting families through new diagnosis and also from new families we connected with at the conference, as well as the success and strength of our website and social media presence. This was hugely evident in our most recent family weekend with a whooping 48 families attending, many for the first time. This shows that we are stronger together and our success is our togetherness.

Another step from the international conference was the development of our own PWSAI advocacy group headed up by Gary Brennan. We know that the voices of people with PWS is so important in developing supports and independence. The group met in September and are due to meet again later this year. I would like to thank Richard Tallon, Martha Jones, Kevin Duffy, Jane McEntee, Finn McRuairi, Dannielle Cantwell, Mark Wright and Niall Flynn for giving their time and voice in order to better the lives of people with PWS.

Fundraising is always a challenging part of any charity and this year we challenged ourselves to improve our revenue streams by simplifying our fundraising and looking for donors outside of our PWS bubble. As part of this we have a strong corporate donor plan to be launched before Christmas. We also have 5 people running the Dublin Marathon all in aid of PWSAI. While some have a connection to PWS others have no connection at all and we are immensely greatful to these people for choosing us. To date they have collectively raised over €10000.

A huge thank you to all the other fundraisers including the PWS5k, now in its 7th year and a special mention to Tanya Hernandez and Emma Ryan for their recent fundraisers. Our strategy and projects would not be possible without the confidence that the funds are strong so we can operate at our best and more importantly that funding is never an issue in us delivering our goals.
My sincere thanks go to our fundraisers, members and families for your ongoing generosity, attention and care.

I am enormously proud of our board and sub committees. We are small but we fight big. We reach who we need to reach. Nothing worth fighting for comes easy. It may take time but we are resilient and we keep coming back. Our achievements always seem frustratingly slow but we are seeing the fruits of many labourious years from many previous boards and committees.

Thank you to our National development manager Gary Brennan – your hard work, your incredible commitment and your consistent dedication and conviction are immense.

And more importantly, I want to acknowledge those of you living with PWS. You play such a pivotal, central and crucial role in PWSAI. You are our greatest inspiration, motivation and purpose.

Thank you. Rory Tierney

# FUNRAISING & AWARENESS 2022

A huge thanks to the families who took to the airwaves, the tv screen and newspapers to raise awareness of PWS- Marguerite Hughes, Ann O'Neill, Emma Walsh, Rory Tierney, Margie Walsh, Paul Wright, Jackie McHugh, Anne and Martha Jones.




**Global conference aims to help families affected by Prader-Willi**

By MAEVE QUIGLEY

IT'S a rare genetic disorder that results in a range of physical, behavioural and mental health issues and is estimated to affect approximately 120 people in Ireland. Next month the University of Limerick will host hundreds of delegates from around the world who will share knowledge and advance understanding of Prader-Willi syndrome (PWS).

Taking place from July 6-10, it is the first conference to be organised in Europe by the International Prader-Willi Syndrome Organisation (IPWSO) since 2013.

Prader-Willi syndrome — named after Swiss doctors who first identified the condition — happens by chance, the result of an absence of certain genes. It is quite rare and it's thought that around five babies are newly-diagnosed with PWS each year.

Babies with PWS are often described as "floppy" due to their low muscle tone. Initially, this can result in feeding difficulties, a failure to thrive and impacted growth.

However, as people with PWS grow older, strength and muscle tone are improved through physiotherapy and other supports.

While major motor milestones are delayed, they are generally achieved, again with support from various health professionals such as occupational therapists and speech and language therapists.

PWS is associated with learn-

drome Association Ireland, says this will be of benefit to those living with the condition at home and abroad.

'People with Prader-Willi syndrome think about food all the time and live in a constant state of food-related anxiety,' he says. 'There is no cure or treatment for this brain disorder which prevents them from feeling full. It is a lifelong condition and people with Prader-Willi do not

appropriate and timely access to care and support, people with PWS can still go on to live fulfilling lives.

With help, and a range of appropriate supports, people with PWS can expect to accomplish many of the things their peers do — complete school, achieve in their leisure activities, even move away from their family home.

They do, however, need a sig-

## GO ORANGE FOR PWS AWARENESS 2022

Every year more and more people are learning about PWS.

Go Orange Day is a worldwide event that PWSAI is delighted to support.

## PWS 5K 2022

The PWS 5K took place virtually with families all over Ireland taking part. Thank you to everyone who laced up their runners raising €6565 for PWSAI

Thank you everyone who took part and supported PWS awareness and fundraising in 2022

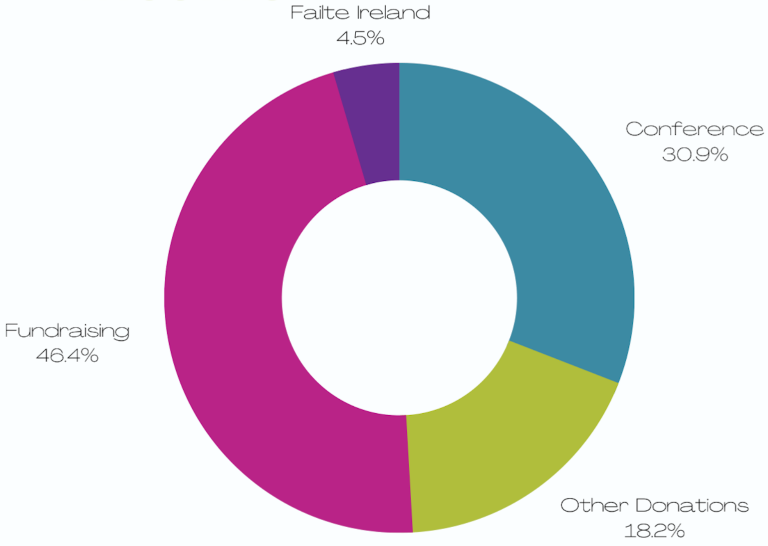
# PWSAI FINANCIAL STATEMENT

## 2022 Treasurer's Report (1st Nov 2021 to 31st Oct 2022)

2022 was another busy year for PWSAI with the IPWSO Conference in July and the Family Day in September. A huge thanks to all our fundraisers who were brilliant as usual raising over €25,500. We also received some very generous donations. Total income for the year was €55,000

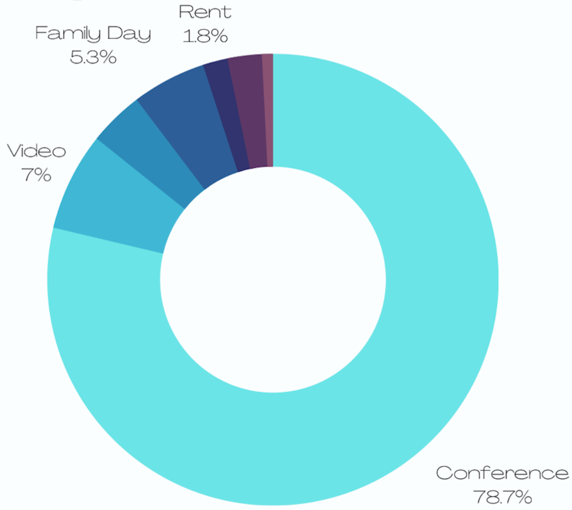
The IPWSO conference was a huge success thanks to the incredible work of everyone involved. A breakdown of the costs involved is given below.

## Income



Total €55,000
(excluding HSE funding)

## Expenditure



Expenditure for the year was €105,000

Conference Costs Breakdown

| IPWSO | 40,000 |
|---|---|
| Reg & Accommodation | 27000 |
| PR | 8500 |
| Merchandise & Leaflets | 3000 |
| Other | 1500 |

Today is my last AGM as Treasurer of PWSAI. I would like to thank everyone involved in the association for their help and support during the last 11 years. A special word of thanks to our amazing fundraisers whose continued hard work puts PWSAI in a good place financially.

Bank balance at 31st Oct 2022 was €231,794.

Finally I would like to thank Yvonne for taking on the role of Treasurer and wish her the best of luck in the job..

**The Board of PWSAI extends our sincere thanks to Sean for his commitment to the role of Treasurer for the past 11 years.**

# THE FUTURE

- To continue to advocate for respite and residential services for people with PWS.
- To continue to support those with PWS and their carers.
- To provide a pathway from diagnosis.
- To support healthy ageing and wellbeing in PWS
- 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 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 review the CRA standard in governance code.
- To support the projects of subcommittees to further our mission

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