pwsai
PRADER WILLI SYNDROME
ASSOCIATION IRELAND

2025

ANNUAL REPORT

www.pwsai.ie

Fiscal year ending 31.10.25

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 1986 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. PWSAI employed an adminstrator in 2025.



Family Weekend 2025

www.pwsai.ie

OUR BOARD OF TRUSTEES

The Board of Trustees for the fiscal year ended 31/10/2025 were:

Rory Tierney - Chairperson
Derek Corrigan - Vice Chairperson & Secretary
Yvonne Rochford- Treasurer
Don Tallon
Derek Corrigan
Ann McCrann
Sean Kelly
Anthony Carr
Mary McEntee
Emma Walsh (resigned June 2025)

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 Audrey O'Reilly, Paul Wright, Ann O'Neill, Marguerite Hughes, Stephen McHugh, Kelley Owens, 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.

The Board of Trustees thank Emma Walsh in her role as administrator for her dedication in the day-today running of PWSAI.

Go Orange for PWS Awareness 2025







Our 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.

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PRADER WILLI SYNDROME ASSOCIATION IRELAND

Our 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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PRADER WILLI SYNDROME ASSOCIATION IRELAND

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.



I 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.



R 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 RORY TIERNEY - AGM 2025

Prader-Willi Syndrome Association of Ireland
Annual General Meeting 2026 – Chairperson's Address

Dear Members,
Welcome to our Annual General Meeting for 2026.
I am delighted to have this opportunity to reflect on another year of progress, achievement and connection across the Prader-Willi Syndrome Association of Ireland (PWSAI).
As we look back on the past year, we have so much to be proud of. Our community continues to grow, not just in numbers, but in the strength of the connections between us. We are meeting more often, sharing more experiences and building relationships that make a real difference to the lives of people with Prader-Willi syndrome (PWS) and their families.

For a community like ours, that connection is everything. It reminds us that we are not alone, that we can learn from one another, and that together we can achieve far more than we ever could individually.

A Whole-of-Life Approach to PWS

Our strategy of taking a whole-of-life approach to Prader-Willi syndrome remains at the heart of everything we do. We continue to develop the pathways, services and supports that people with PWS need throughout their lives, from early childhood through adolescence and into adulthood.
I am pleased to report that our plans remain on track, and we have made meaningful progress in several important areas.

Respite and residential supports

Earlier this year, capacity at Áit Shona increased from 25 to 40 places, enabling 15 additional families to access much-needed respite. This is a significant development, offering more families the opportunity to rest, recharge and spend valuable time together, knowing their loved ones are receiving specialist care and support.
Respite is not simply a service. For families living with PWS, it can make an enormous difference to their well-being and their ability to sustain the demands of daily life.

Dietetics

We have continued to roll out our dietetics service, with the addition of two new dietitians based in Ireland. Families can now access support through online or face-to-face referrals, alongside our continued collaboration with Cate Fox in Australia.
This expansion strengthens the specialist support available to our families and helps us build a more accessible and sustainable service for the future.

Supporting the transition to adulthood

We are currently piloting a psychological assessment programme for five families navigating the transition from childhood to adulthood.
This is a pivotal stage in the lives of people with PWS. The move into adulthood brings new challenges, expectations and opportunities, and we want to ensure that people and their families have the right supports in place to navigate this transition successfully.
We look forward to seeing the outcomes of this pilot and, hopefully, expanding the programme to support future families approaching this important milestone.
Our ambition is simple: to give every person with PWS the strongest possible foundation for adult life, with the right supports, opportunities and pathways available when they need them.

LETTER FROM THE CHAIRPERSON
AGM 2025

Moving Forward: Listening to Our People

In February, our AWSI subcommittee hosted the Moving Forward seminar at the Aisling Hotel in Dublin. It was a tremendous success and an important step forward in our conversations about adulthood, independence, education and employment.
For me, the highlight of the entire day was hearing directly from our people with PWS. They shared their stories, introduced speakers and spoke honestly about what they want and need from educators, employers and the wider community.

My sincere thanks to Martha Jones, Richard Tallon, Danielle Cantwell, Bronagh Enright, Aoife Kelly and everyone else who contributed to making the day such a success.

The seminar may have created more questions than answers, but that is not a bad thing. In fact, it is often where the most important conversations begin.

We heard about the importance of purpose, meaningful opportunities and having a voice in decisions that affect our lives. We were reminded that our people have their own ambitions, views and aspirations, and that it is our responsibility to listen and help create pathways that allow those ambitions to develop.

This conversation must continue. We need to keep asking what our people want from life, what meaningful participation looks like for each individual, and what we can do to make those opportunities a reality.

The day also marked another first for PWSAI, with our first-ever TY work experience student supporting the event. Thank you to Annie Hughes for choosing PWSAI for her work experience. We were delighted to have you involved.

New Diagnosis and Early Support

Our New Diagnosis subcommittee has continued to develop its work supporting families in the early years following a diagnosis.
Through a range of online talks and information sessions, the subcommittee is helping families access knowledge, guidance and support at a time when they may have many questions and face considerable uncertainty.

SUAS SOCIALS 2025





LETTER FROM THE CHAIRPERSON
AGM 2025

We need to keep developing. We need to keep asking questions. We need to remain curious about what more we can do, what we can do better and how we can ensure that every person with PWS has the best possible opportunities throughout their life.

We cannot slow down.

We cannot rest on our laurels.

And we cannot stop.

We have benefited from 40 years of progress, determination and generosity. Now it is our responsibility to play our part, however big or small, so that the next generation inherits something even better.

Let us continue to build a community where families feel supported, where people with PWS are listened to, where opportunities are created rather than limited, and where no family feels they have to face this journey alone.

Let us ensure that the next 40 years bring even greater progress, stronger supports and brighter prospects for every person with PWS in Ireland.

Thank you for being part of PWSAI, for everything you have contributed so far, and for everything we will achieve together in the years ahead.

Thank you.

Rory Tierney



Frambu 2026



PWSAI Subcommittees – We Need Your Voice!

Our subcommittees meet online throughout the year, providing an opportunity to share your ideas, express your views and help shape the future of PWSAI.

Can you spare a couple of hours to help strengthen our community and make a difference to the lives of people with Prader-Willi syndrome and their families?

FUNRAISING & AWARENESS 2025

Special thanks to our marathon runners — Andrew, Alan, Martin, Ruiri, Roisin, Anna, Mick, Ben, Luke, Michael, Colin, Jemma and Conor — who raised over €40,000 between them.











Thank you to everyone who organised coffee mornings, Team Stella for their big raffle, Team Aoibh for our Family Weekend, Audrey and all our Bucket Collectors, the SUAS Committee, and everyone who took part in our PWS 5KM in May. Every effort counts, and we are so grateful.

Your hard work has strengthened our finances and helps us continue developing vital supports for our families.

Looking Ahead

We look forward to building on this year's progress and continuing to support our members and families.
Thank you to the PWSAI Board, staff, volunteers, committees and everyone who gives their time, energy and generosity to our charity.
You are all part of what makes PWSAI special.
Thank you for being part of our PWS family.
With appreciation,
PWSAI Treasurer





PWSAI FINANCIAL STATEMENT

For the financial year ended 31st October 2025

Treasurer: Yvonne Rochford

2025 has been a fantastic year for PWSAI, with expanded supports for our members and families and an outstanding year of fundraising.

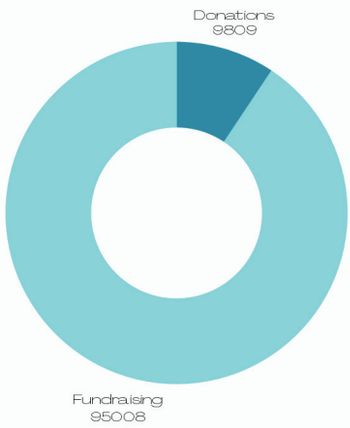
A huge thank you to our families, volunteers, fundraisers, donors and supporters. Your generosity helps us make a real difference to those living with Prader-Willi Syndrome (PWS).

A Year of Achievement

This year saw expanded dietetic supports and SUAS programme and our Association represented at the IPWSO conference in Arizona, continued supports and welcome packs to Newly Diagnosed families and a record number of training sessions for members and care providers. Thank you to everyone who helped make this possible.

Income

PWSAI Income for 2025, total: 104817 excluding HSE funding.



An Outstanding Year for Fundraising

Together, we raised an incredible €105,000 in 2025 — €95,000 through fundraising and just under €10,000 in donations, compared with €41,609 in 2024. A massive thank you to our Fundraising Committee and everyone who played a part!

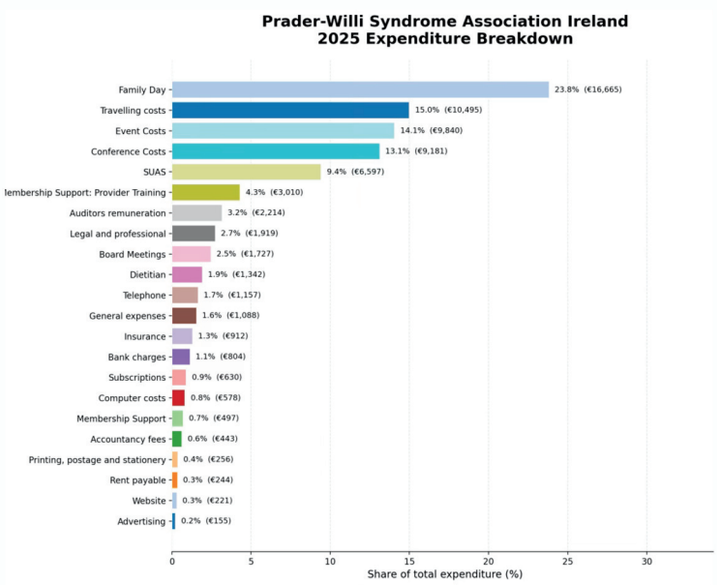
Financial Overview

Our 2025 expenditure totalled €69,975, excluding HSE funding, compared with €56,365 in 2024. This increase reflects our investment in member supports, programmes, training and SUAS socials.

We remain committed to managing our funds responsibly and ensuring they make the greatest possible difference. A breakdown of our 2025 income and expenditure is presented below, excluding HSE funding.

Expenditure

PWSAI Expenditure for 2025, excluding wage costs.





Bucket Collection September 2025

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The Future

New Diagnosis and Early Childhood Support

- To provide a clear pathway of support following diagnosis and throughout early childhood.
- To develop resources and practical supports for families.

Connection and Community

- To strengthen connections through regional hubs, peer support, meet-ups and the annual Family Weekend.
- To grow membership and encourage greater involvement.

Education, Awareness and Professional Training

- To raise awareness of PWS among the public, professionals and policymakers.
- To continue specialist training for educators and service providers through the National Development Manager.
- To share up-to-date information, practical management tools and research developments, including clinical trials and research opportunities.

Fundraising and Research

- To encourage fundraising to sustain and develop PWSAI services.
- To support PWS research initiatives in Ireland.

Advocacy and Service Development

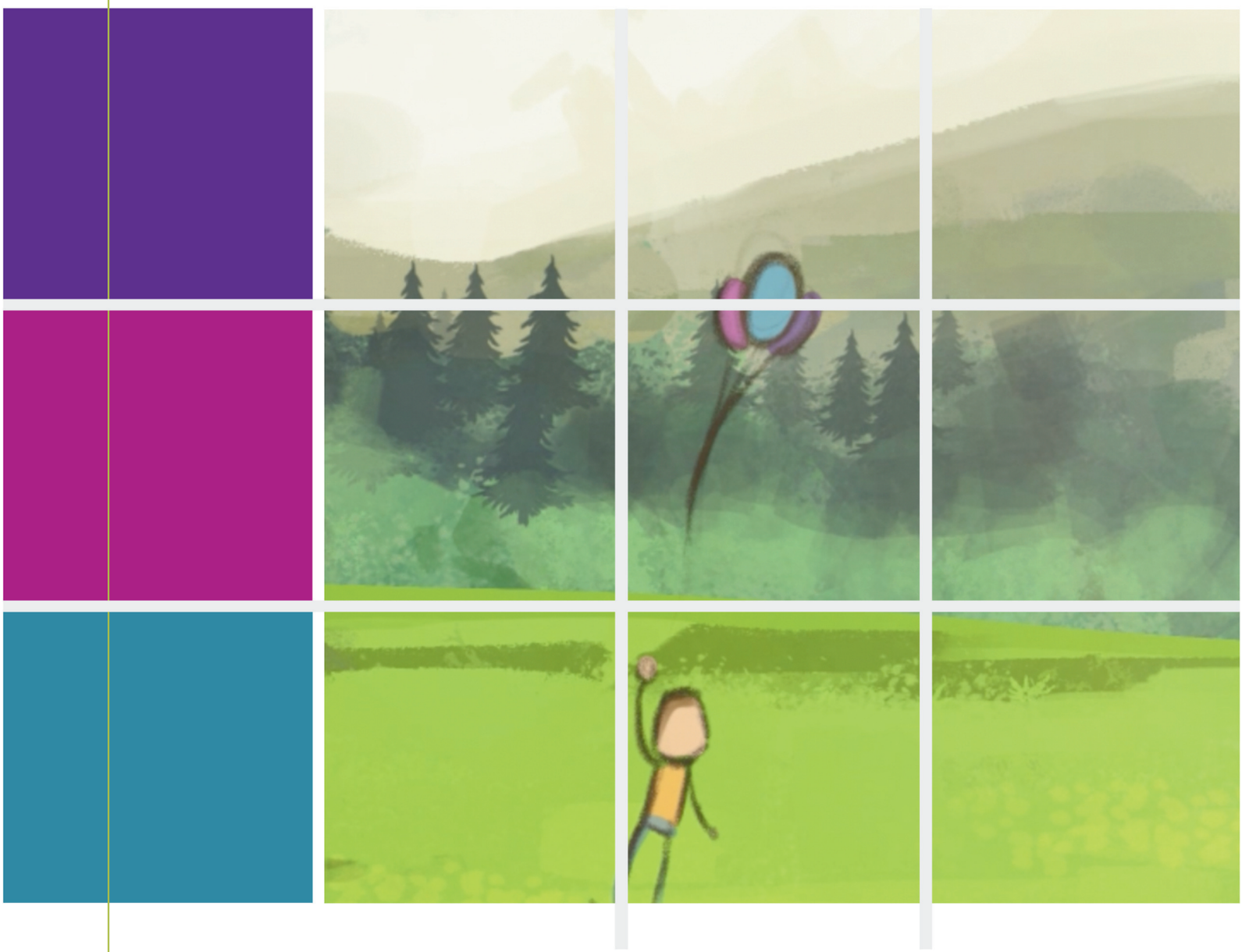
- To advocate for appropriate respite, residential and community-based services.
- To progress the recommendations of the National PWS Report.
- To strengthen regional advocacy and address gaps in services.

Planning for the Future

- To support lifelong wellbeing, healthy ageing and transitions at every stage of life.
- To promote future planning and continuity of care and support into adulthood and beyond.

Governance and Organisational Development

- To strengthen membership and ensure the voices of people with PWS, families and carers inform our work.
- To review and maintain compliance with the Charities Regulator's Charities Governance Code.
- To support subcommittees in progressing PWSAI's mission.



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