Annual Report

Fiscal year end 31.10.23

pwsai

PRADER WILLI SYNDROME ASSOCIATION IRELAND

www.pwsai.ie

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 31/10/2023 were:

Rory Tierney - Chairperson
Derek Corrigan - Vice Chairperson
Sean Kelly - Treasurer
Emma Walsh - Secretary
Don Tallon
Derek Corrigan
Ann McCrann
Yvonne Rochford
Jane Cox
Anthony Carr
Mary McEntee

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, Stephen McHugh, Kelley Owens, Annette Enright 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.

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.

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.

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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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COMMUNITY

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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.

ADVOCACY

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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.

INTEGRITY

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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.

RESPECT

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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 2024

Hi All,

PWSAI have had yet another great year in finally achieving 2 of our biggest projects over the last 10 years. In March we finally launch our national report and in September we officially opened the world first respite house for people with Prader Willi syndrome.
We also developed further our 'Whole of Life' strategy with the set up of AWSI our Adult Wellbeing & Social Inclusion subcommittee as well as strides in our SUAS group, Staying Connected focus and our fundraising strategy. The strength of our New Diagnosis committee continued and we had successes in Education and training.

National Report Launch
The highlight of the year for me was finally launching our Joint National Report in partnership with the HSE.
7 long years have gone into bringing this report to fruition and it was a very proud moment for us to officially launch this report with Minister Rodric O Gorman along with many senior HSE officials including Bernard O Reagan head of Operations for Disability services.
This report is for you. For your GP, your teachers, care providers, clinicians, and your community teams around the country. It acknowledges that's Prader Willi syndrome is real. Our lives are real and the complications and complexity of PWS are real. This report gives us a document developed in conjunction with the HSE which gives us strength and a voice.
The publication of the report brings us to the next phase in our journey; bringing the reports recommendations to life. Gary and the board have already started on this with the setup of implementation groups involving key HSE officials and an oversight group chaired by Bernard O Reagan.

Thank you to everyone involved in the generation of this report from the original round table discussions with the HSE in 2017, the fact finding trips to Denmark and Germany, the many meetings of the National Working Group, the writing and editing of the report and its further 29 revisions and edits, the socialisation through the department of health and other government departments, the process undertaken with the National Clinical Program for People with Disabilities, the gathering of so many wonderful photographs to ensure the report was personal and real, the many meetings developing the recommendations while ensuring that we did not allow for our key asks to be diluted and finally the journey to publication and launch. This has been a mammoth task and a hugely rewarding result.

Specific thanks to Jane Cox for the many hours of edit, detail and proofing she added over many different versions. We would not have the same high quality report today without Janes attention to detail and tenacity.

Special thanks also to Gary Brennan for keeping this report moving, always keeping it on the HSEs agenda, being our daily link to the HSE and for his determination and drive to ensure we got to publish and launch the report we deserve.

This report represents the next phase in our development, embracing a holistic life approach to support people with Prader Willi Syndrome and their families, across all stages of life. It serves as a powerful advocate for individuals with PWS and their families, empowering them to comprehend their needs and advocate for the highest standards of care and wellbeing, from service providers, while also highlighting areas for improvement in the future.

Respite & Residential

Another success this year was the official opening by Minister Anne Rabbitte of the world's first PWS specific respite house, aptly named Ait Shona, Happy Place.
Run by Resilience Healthcare, who already have 2 PWS specific residential houses in Ireland, Ait Shona located in Stradbally Co. Laois, will be available for both children and adults with a diagnoses of PWS, who will avail of the service at different allocated times.

At the opening in September Minister Rabbitte announced further funding to increase capacity nights in Ait Shona. This means that even more families will be able to avail of the service.
If you would like to make an expression of interest, would like more information, or have more questions, or would like a tour of the house itself please make contact with Gary who can arrange. We understand that changes are difficult, and planning and expectations are important to every person with PWS.

We want this service to be not only a world's first, but a world class service and here we need your help. We see Ait Shona as an extension of the family home and Resilience are striving to tailor each stay to each individual's needs. I would ask that you provide as much feedback as possible directly to Resilience or through Gary so Resilience can continue to improve the service each time.
Nothing worthwhile is easily achieved, and this was very much the case for the last 10 years of this project. I am stuck for words to describe my gratitude to the R&R subcommittee on what they have achieved on this Respite service. I fear with the passing of time, and the many barriers and road blocks, they encountered that they too do not fully appreciate what they have achieved and delivered for people with PWS for many generations to come.

A huge thank you to Anthony Carr, Don Tallon, Jane Cox, Gary Brennan, Paul Wright, Donnacha Clancy and Annette Enright for years of dedication to this and in delivering to our families a world first PWS specific respite service which will improve the lives of people with PWS and more importantly the quality of life for their primary caregivers.

Following the opening of a second residential house Rose Lodge in summer 2023 Resilience Healthcare will open a further house in Fermoy Cork in early 2025. PWSAI would like to thank Resilience for their continued support and care of people with Prader Willi Syndrome and for working with us to deliver the service requirements of PWS that our people need every day.

Gary Brennan, Nation Development Manager

It gives me great comfort to know that when we are all going about our daily lives there is one man in the country that is constantly thinking and working on improving the lives of people with PWS in Ireland. Gary Brennan, our national development manager advocates on our behalf with the HSE, other government bodies, and other groups, as well as delivering a huge amount of PWS specific training sessions to care providers, schools and supporting families with advice and in accessing supports. Id like to thank Gary for his energy and dedication.

HSE National Disability Operations Community Services & Prader-Willi Syndrome Association of Ireland

A Report on the Joint National Pilot of the Health Service Executive and the Prader Willi Syndrome Association of Ireland

Staying Connected

We know that Prader Willi syndrome can be sometimes isolating and lonely for us as parents and for our people with PWS.

PWSAI has focused on improving this through our Staying Connected strategy, through the success of new diagnosis subcommittee chaired by Kelly Owens and the development of our new Adult Wellbeing & Social Inclusion subcommittee set up by Don Tallon.

New families are making contact with us quicker and we are agile in creating a support network when they are ready. The New Diagnosis subcommittee send welcome packs to all new diagnoses and are working with maternity hospitals to improve this further so we can ensure that all new parents can find us and access the right information when they are ready to do so.

Our new AWSI subcommittee looks to support the wellbeing of adults with Prader Willi Syndrome as well as looking at ways to better support their social inclusion.

I would like to thank Don Tallon for a very specific qualitative piece of research he conducted with parents last year to understand the needs and wishes of this cohort. Following this AWSI held a parents event in April to fully understand the common themes families were experiencing and to look at ways in which PWSAI could support these needs.

The first SUAS social event planned and hosted by our very own SUAS advocacy group supported by Emma, Anne McCrann and Gary took place in June and was a huge success. The group also had their first in person meeting earlier in the year.

We know that the voices of people with PWS are so important in developing supports and independence. 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.

These elements of Staying Connected and social inclusion will continue into next year with additional plans for similar social events for younger age groups.

PWSAI has also improved our reach across our social media platforms including more of a professional reach since the launch of our Report. The success and strength of our website continues with many professionals including teachers, SNAs and service providers using our website as their source of information for Prader Willi Syndrome in Ireland.

Our family weekend again has record numbers this year and this proves that we are better together. There is no other room in the world on that Saturday night that has a better knowledge and expertise on everything Prader Willi Syndrome. It is a fantastic source of information and a great way to make connections and support for the rest of the year.

From experience I know that there is always another parent who has gone through exactly what you are dealing with now so please make those connections and reach out.
We as parents are the experts. We are stronger together and our success is our togetherness.

Fundraising remains a challenge for every charity. As part of our new corporate fundraising strategy this year Audrey O'Reilly joined the team and has built a strong plan with Derek to develop our fundraising. We continue to work on ways to access donors outside our PWS family bubble and have our first large bucket collection planned in Liffey Valley Shopping Centre on the 1st November which is a fantastic opportunity for us to fundraise and raise awareness of Prader Willi Syndrome.

Following the success of our Dublin Marathon partnership last year raising in excess of €13000 we have 5 more runners taking part this year and more places available for next year. This has proved a fantastic fundraising stream for us as well as raising the awareness of Prader Willi Syndrome and PWSAI.
I would like to thank Derek Corrigan and Audrey O'Reilly for the planning and implementation of our fund-raising this year. If you would like to take part in a fundraiser, support the team or have ideas on further revenue streams please contact Derek.

After 8 successful years the PWS5k has now raised an astounding €60,000 for PWSAI. What started out as a local 5k attracting 100 people in its first year has evolved into a virtual Orange Day celebration over an entire weekend at the end of May each year. A huge thank you to Emma for organising, reminding, coordinating, marketing and celebrating Orange Day and the PWS5k weekend, as well as getting schools and care providers involved and for making our National landmarks Go Orange last year.
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.

Jane Cox, PWSAI Board Trustee - 2024.
After many years supporting PWSAI Jane Cox has stepped down from the board. Jane has been a huge strength to PWSAI over many years and was the key instigator in linking Simon Harris to us in 2017 which was the kernel of what eventually became our National report.
Janes attention to detail, never letting anything go, ever, determination and drive, including all night editing sessions on our National report has improved our charity immensely and the lives of people with Prader Willi Syndrome for many years to come. I wish to thank Jane for her time, energy and in giving so much of herself to PWSAI.

The Board of Trustees
Our board, subcommittees and Gary our National development manager continue to make me proud of PWSAI every day. It is important to understand the amount of work, energy and time that these volunteers give to improving the lives of people with PWS as well as balancing carer duties of their own of which I am hugely grateful. PWSAI would not be what is it without them.
PWSAI is in a very strong place having successfully complete 2 of our long term goals this year. We have strong relationships and respect with the HSE, key government ministers and Resilience Healthcare and are always open to forming further links in order to progress our mission and objectives.
Finally most importantly, I want to acknowledge those of you living with PWS. You play such a pivotal, central and crucial role in PWSAI. You are always our greatest inspiration, motivation and purpose in what we do.

Thank you.

Rory Tierney

FUNRAISING & AWARENESS 2023

In 2023 we saw a team take on the Dublin Marathon for PWSAI for the first time. A huge thank you to all for the amazing fundraising, over €13000 raised - a special mention to Team Lulu and Jonny for the huge amount of fundraising in 2023.

GO ORANGE FOR PWS AWARENESS 2023

Every year more and more people are learning about PWS through our PWS Awareness day in May.

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

PWS 5K 2023

The PWS 5K took place with families all over Ireland taking part. Thank you to everyone who laced up their runners raising €7549 for PWSAI in 2023.

Thank you everyone who took part and supported PWS awareness and fundraising in 2023

Fundraising helps us with projects like the Welcome & Sensory Pack for new families!

Thank you Team Ethan & Team Martha for running the VHI Women's Mini Marathon for PWSAI

PWSAI FINANCIAL STATEMENT

2023 Treasurer's Report (1st Nov 2022 to 31st October 2023)

Treasurer: Yvonne Rochford

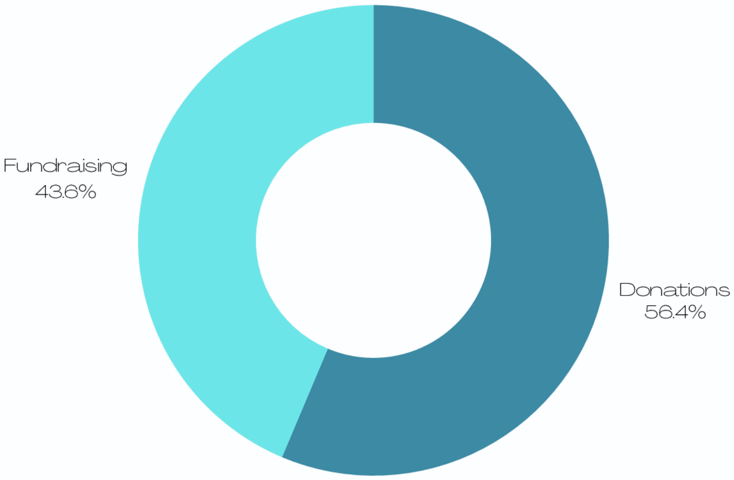
2023 has been a busy and successful year for PWSAI, with PWS Awareness month in May and the Family weekend in October. A huge thank you to all the people who have worked with us throughout the year to make this possible. Without the support of our members, friends and family we could not have achieved all the wins we saw in 2023.

A huge thank you to our fundraisers, who walked for us, ran for us, and helped us raise €25,900. Also to those families who made generous donations, thank you. Together you helped us raise a total of €46,000 in 2023, (excluding HSE funding). Through this generosity we have been able to expand our support, one example being the sending of Sensory Packs to welcome families of newly diagnosed children. We also started work to increase the number of social gatherings between our people with PWS. And of course we have been able to continue to provide training and advocacy, to support our loved ones with PWS.

Thank you to all who took part in 2023 and all who helped keep PWSAI in a good place financially. Balance in the bank as at 31st Oct 2023, €242,535.

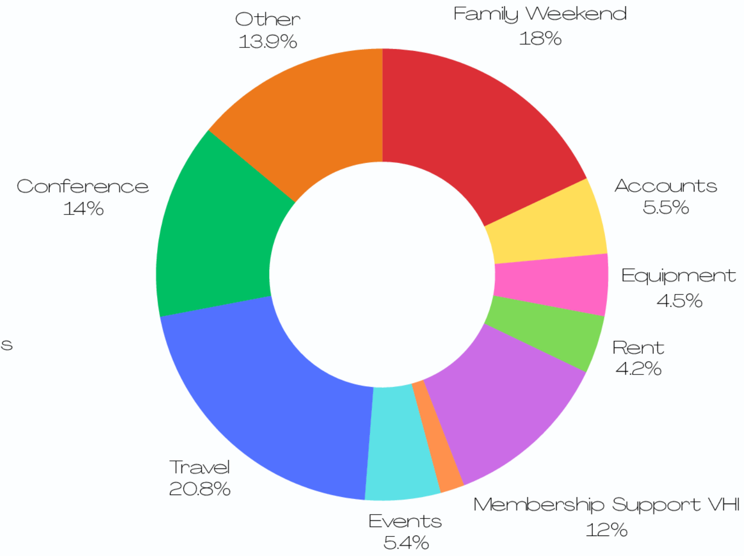
A breakdown of our Income and Expenditure for 2023 is below:

Income



Total income for the year €45922
(excluding HSE funding)

Expenditure



Expenditure for the year was €45149

Finally I would like to thank our previous Treasurer Sean Kelly for all the support he offered during the handover period in November 2023, and to the board and all involved in keeping PWSAI focused and moving forward.

First SUAS meeting

The Future

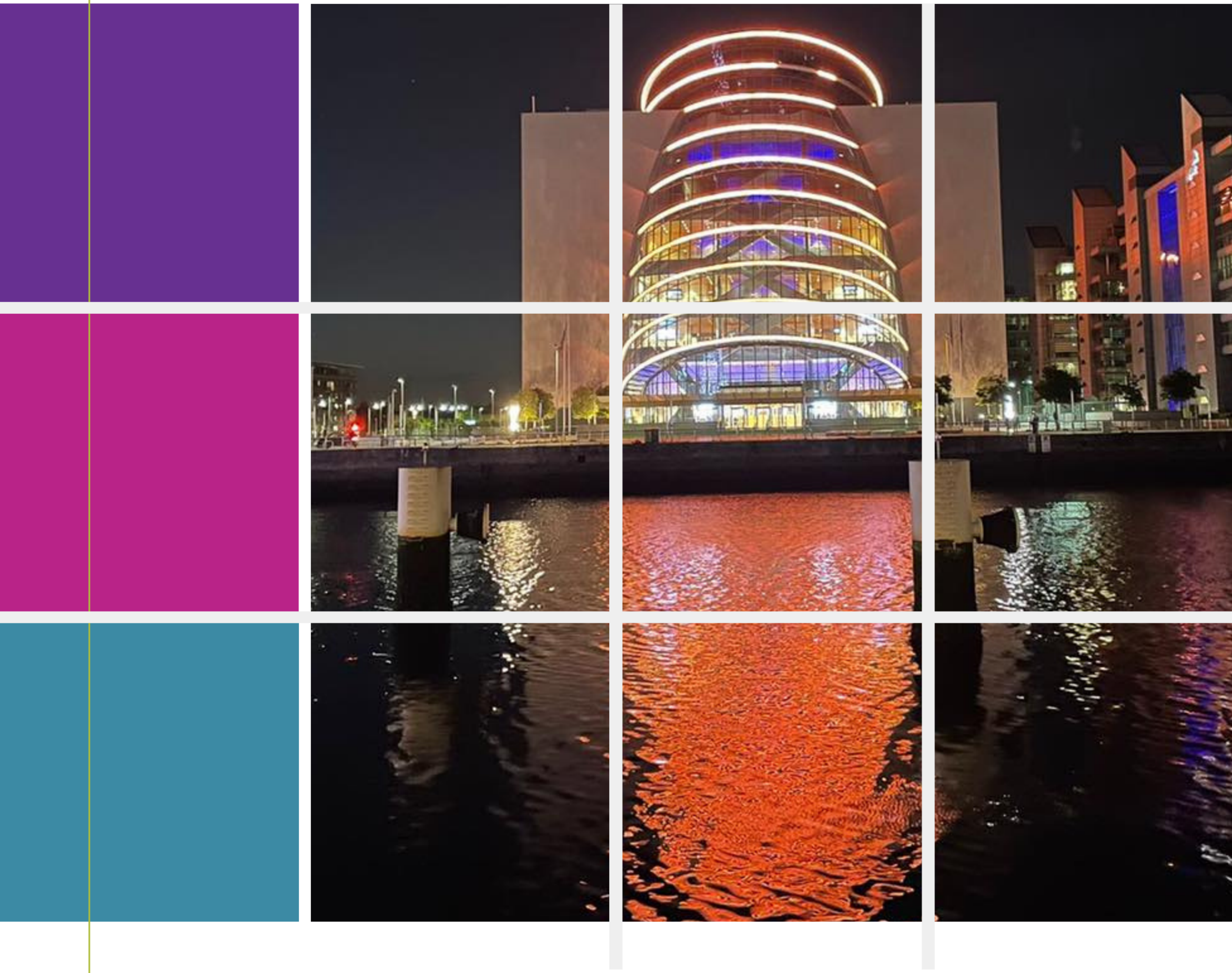
- To continue to support those with PWS and their carers.
- To provide a pathway from diagnosis.
- To support healthy ageing and wellbeing in PWS

- To support PWS research initiatives in Ireland.
- To encourage and support fundraising for PWSAI.
- To continue to advocate for respite and residential services for people with PWS.
- To action the recommendations in the National Report

- To launch regional hubs in key area to mobilise members and to advocate for and support additional services.
- To support the hosting of the annual PWSAI family weekend. & other meet ups throughout the year

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