



# PWSAI NEWSLETTER

## Hello!

Hello PWSAI families,

It's been a while since the last newsletter and although we've all been quietly taking ourselves through lockdown and beyond, the work at PWSAI HQ hasn't stopped.

Since our last physical meeting in early March the board has met twice in our new virtually sitting which is taking a bit of getting used to! There have also been many more sub committees and working groups continuing to carry on what is a very busy time in PWSAI.

Planning for the International conference, continued work on respite and residential care as well as the National Report and work on setting up regional hubs are all current projects we are working on.

We hope everyone has had a good summer and were able to make the most of how things currently are. It's been a long few months! Back to school is suddenly upon us and soon hopefully it'll feel like everything is back to normal.

If anyone needs advice or support please get in touch with Gary, Ann or Emma. Contact details are available below

Stay safe.

Gary Brennan, National Development Manager  
087 385 1387 [gary.brennan@pwsai.ie](mailto:gary.brennan@pwsai.ie)

Ann O'Neill, PWSAI Family Liaison  
087 252 2832

Emma Walsh, PWSAI Secretary  
[info@pwsai.ie](mailto:info@pwsai.ie)

## Dates for your diary

### PWSAI AGM 2020

26th September 2020 at 10.30am - via Zoom

Please email [info@pwsai.ie](mailto:info@pwsai.ie) for the link

### PWSAI Virtual Day!

Saturday 3rd September - Virtual PWSAI Online fun & celebrations.. via zoom. Please email [info@pwsai.ie](mailto:info@pwsai.ie) to join

## Join the PWSAI Families WhatsApp group

We are starting a WhatsApp group specifically for updates from PWSAI. This will be an admin controlled group which means only admins can post in the group. However, your number will be visible to all members.

To join, please get in touch at [info@pwsai.ie](mailto:info@pwsai.ie)  
Thanks, Emma - PWSAI Secretary

## Join the Board

It would be brilliant to have some fresh faces join the PWSAI board.

The amount of time needed is probably less than you think! The amount you'll learn is probably more than you think! And we're a very friendly group where all ideas and contributions are welcome.

If you'd like to join the board but can't make the AGM, get in touch with Emma at [info@pwsai.ie](mailto:info@pwsai.ie)

## The Virtual PWS 5Km 2020

2020 has been a difficult year for so many reasons but somehow we can all be really proud of what we have achieved because this year was the year the PWS5k broke its own records. An astounding €11239 was raised across the weekend of the 20th June as you all individually laced up your runners, took to the streets and raised a ton of money for PWSAI.

We had so many participants this year from Sydney to Navan and Cork to Donegal and everywhere in-between. And probably even a few still running their laps of the original course in Maynooth.

So far in 5 events, the PWS5k has raised over €25,000 in funding for PWSAI. A massive thank you to everyone who took part, raised money and created a lovely community weekend on Facebook with so many great photos and videos it really was an event to remember.

If anyone wishes to join the team in planning or helping out at next year's event feel free to drop an email to [pws5km@gmail.com](mailto:pws5km@gmail.com) or contact Rory or Emma.

The video is live on YouTube - Virtual PWS 5k 2020

## An Opportunity not to be missed!



The 11th International Prader Willi Syndrome Organisation conference takes place from the **6th-10th of July 2022** in the University of Limerick.

Following a presentation made by PWSAI at the IPWSO conference in Cuba last October Ireland was the chosen country for the next conference beating stiff competition from Thailand India and Malaysia.

This is a massive opportunity for PWSAI and all our members to showcase our organisation, our people, and our wonderful country.

Planning is in the early stages and we plan to bring many PWS experts from around the globe to Limerick to speak at the professional providers and caregivers conference, the clinical and scientific conference, as well as the parent and family program.

Estimated prices for the parent and family program is €200 per person (TBC) for the Saturday and Sunday sessions including a variety of speakers covering many topics across the spectrum of Prader Willi Syndrome. Accommodation is available on the UL campus from €59 pppn or in surrounding hotels from €100 pppn

There is also a gala dinner planned for the Friday night which is amazing opportunity to meet each other as well as other parents caregivers and experts across the international community.

There won't be a PWSAI family weekend in 2022 so this is a fantastic opportunity to meet up and talk everything PWS with people who really know and care!

Having such a massive conference in Ireland is a once in a lifetime opportunity for a small charity like ours and we intend to make it the best ever!

Having travelled to IPWSO conferences in Cambridge and Toronto as well as FPWR conference in Las Vegas it turns out attending conferences is an expensive business but I have to say the wealth of knowledge, networking and friends I have made have made it all worth while. All the speakers are around throughout the day during coffee breaks and lunch and it is not an opportunity to be missed to be able to discuss your own specific questions and needs with world experts in PWS.

Now it's in Limerick Ireland and for all Irish families with people with PWS it really is an opportunity not to be missed. Never again will the world of PWS be on our doorstep.

Further updates to come as planning gets underway in 2021 so start saving and let's make Limerick 2022 the year to showcase our wonderful organisation and community in Ireland.

## **PWSAI AGM 2020**

Due to Covid19 restrictions, the PWSAI AGM will be held via Zoom on the 26th September 2020 at 10.30am.

All PWSAI members are warmly invited to attend.

Contact [info@pwsai.ie](mailto:info@pwsai.ie) for the link to join our virtual AGM.

## **PWS Awareness Day 2020**

Thank you to everyone who went orange for PWS Awareness Day 2020! See our Facebook page for all the photos!



## Impact of Covid-19 on people with PWS Survey

The Impact 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)



The current COVID-19 pandemic and restrictions has had broad impacts on daily living and access to mental health and disability services for people with Prader-Willi Syndrome. We currently do not know what effects this will have on their immediate needs or over the intermediate term. To evaluate the impact of the pandemic and restrictions on the mental health, behaviour and well-being of vulnerable populations, an international collaborative group has developed an online survey called The Coronavirus Health Impact Survey (CRISIS) for use with typically developing youth and youth with neurodevelopmental disabilities.

The neurodevelopmental research group at Trinity College have further adapted this survey, CRISIS-AFAR-PWS, to address the needs of young people and adults with PWS. Your survey responses will give us an idea of what we can do to best support and plan services for people with PWS for the future.

Email [info@pwsai.ie](mailto:info@pwsai.ie) for the link to the survey

## PWSAI Online Family Day 2020

We are all very sad that we won't be together at the PWSAI Family weekend this year. Thank you to the McEntee family for staying on as hosts for 2021! However, we still want to celebrate our incredible VIPs who just happen to have PWS.

Save the date: Saturday 3rd October 2020, as we join together virtually via Zoom.

### ReCreate Workshop

We have organised ReCreate to do an online make and create workshop "Create your own Creature". This workshop will engage PWSAI families on a journey of reuse and creation by investigating materials from the ReCreate warehouse to make their very own special creature. The workshop will take place via the platform Zoom and materials will be supplied to everyone taking part. (Participants will need to supply their own scissor, glue and tape). There are limited places, so don't delay in getting booked in.

The specially selected box of materials will encourage families to play with the reuse materials to create their very own creature. The facilitator (Jo) will take the families on a process led creative journey and give the them creative tips, suggestions and plenty of support and encouragement!

**To book your place, please contact Emma at [info@pwsai.ie](mailto:info@pwsai.ie) before 10th September 2020.** The time of the workshop is to be confirmed.

### Celebratory slide show - Saturday 3rd Oct at 7pm

Put on your fancy clothes and join us via zoom for our annual celebratory slideshow!

To take part in the celebratory slideshow via Zoom, please send a photo/video of your person with PWS and the reason they make you so proud of them.

Please email the photo/video before the 25th September to Emma at [info@pwsai.ie](mailto:info@pwsai.ie)







## National Working Group on Prader-Willi Syndrome – Report Imminent!

Through the intervention of Minister Simon Harris, a National Working Group was set up to look at the needs of people with PWS and their families, and at what should be done to improve service provision, especially in the areas of Respite, Residential and Mental Health.

The National Working Group is a collaboration between the HSE and PWSAI. The Group is chaired by Dr Cathal Morgan, Head of Disability Operations, HSE. The Group appointed Prof Tony Holland as expert external adviser. (Prof Tony Holland is President of IPWSO and Professor Emeritus of the Psychiatry of Intellectual Disability, Cambridge University.) Other members of the Group include a number of professionals from the National Disability Office, HSE, and members of PWSAI. Gary Brennan, our Development Manager, is also a member - Gary's appointment and the funding of his position were a direct result of the work of the Group.

The work of the Group is finally edging towards completion and a draft Report awaits final sign off by the HSE. Needless to say Covid-19 did its bit to help delay publication!

The report will make detailed comprehensive recommendations for Social Care supports (Respite, Residential and Day Services), Acute and Mental Health Services, Educational settings etc. It aims to be a blueprint for effective, appropriate services and supports for individuals and their families in Ireland across the lifespan. We have been very fortunate that many institutions such as Tallaght Hospital, TCD, a range of Social Care Providers at home and abroad, the NCSE, to name but a few, have been willing to assist the Group. We hope the Report will be an attractive and useful document for all our members and, indeed, for anyone working to support individuals with PWS. We also hope it will be of great help to Gary as he advocates for us all.

PWSAI has invested huge time and effort into this important project. Countless numbers of you have contributed towards this work, whether by filling out lengthy questionnaires, visiting PWS facilities abroad, being a member of the Group or one of its workstreams, attending the family focus day in the Red Cow hotel, chatting and brainstorming together at family weekends and information days over the years etc., etc.

We will be coming for more help!! For photos for the report, for attendance at the launch, for lobbying of our politicians so that money is found to implement the recommendations, etc. The work of PWSAI is never done til we are sure that the needs of our precious family members with PWS are met, and that whole families are supported.

## Regional Hubs

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Ireland is a small country but in our PWS bubble probably not small enough. Getting together really is fun but with so much going on in everyone's life this just doesn't happen often enough. The family weekend no matter where it is is still a long drive for someone and there'll always be someone who just can't make the one chance a year we get to get together for an entire weekend. Apart from that weekend, it's only the 5k run and the AGM and even they can't suit everyone all the time.

Therefore we believe that there is opportunity to try to develop two regional groups. An opportunity to meet up with others in your locality with a vision to improve needs and supports in specific key areas.

Initial meetings started in early March spearheaded by Don Tallon and Gary Brennan with a view to start a group in the Munster area and Waterford with the support of Ann and Ray O'Neill. There were plans in place to hold a group meeting for families from the area in order to garner support for a substantial National Respite Centre for adults and children and to ascertain the need for other supports in the area including Residential and other family supports. Unfortunately Covid19 restrictions have since slowed momentum.

We will need lobbying at political level if we are to achieve the objectives set out in our PWSAI / HSE joint document and we want to get as many families on board as possible to support those efforts.

The second regional group proposed is one within the border county area and Sligo. We hope to hold this meeting prior to Christmas in a hotel subject to social distancing rules prevailing. We are strongly of the view that these initial meetings need to be face to face in order to get maximum buy in.

Further details will follow as plans are put in place on this exciting new venture for us. Communications will be through social media, email and the new WhatsApp group. Please contact Emma to be added to this group for key important updates.

This really is a fantastic venture for our small charity and together we can make this happen. Hopefully we can make a success of these first regional pilot groups with a view to roll out more across the country in the future.

**We'd love to hear from you!**

**Email us at [info@pwsai.ie](mailto:info@pwsai.ie)**

The PWSAI Newsletter HQ would love to hear from you. If you have any advice to share or great achievements to be proud of, please get in touch!

***See you at the Virtual PWSAI Family Day 2020.... the countdown is on!  
Stay safe!***