

Hello!

We hope all our members, families and friends are having a fantastic 2018 so far.

In this PWSAI newsletter, you'll find information on PWSAI membership, the 2018 Family Weekend and a summary of the recent PWS conference in the USA.

To stay up to date with everything from PWSAI, please add [info@pwsai.ie](mailto:info@pwsai.ie) to your contacts. We also regularly update Facebook and twitter.

## **PWSAI Membership 2018-2020**

It's that time again, PWSAI membership renewal and sign up. As per previous years, the cost for membership will be €15 for the three years.

You'll find attached the PWSAI membership form which can be returned by post or emailed. Payment can be made by cheque or online at [www.idonate.ie](http://www.idonate.ie) - search for Prader Willi Syndrome Association Ireland.

We hope you continue to support PWSAI by becoming a member.

## **Facebook groups for parents/carers of people with PWS**

PWSAI currently do not have any specific Facebook groups. However, there are many in the UK and USA which offer advice & support.

Many of these groups are split into specific age groups. If you'd like to be added to any of these groups, please get in touch via our Facebook page.

## **PWSAI Family Weekend 2018**

We are excited to announce that the 2018 PWSAI Family Weekend will be in the Nuremore Hotel and Country Club in Carrickmacross, Co.Monaghan from October 12th to 14th 2018. A huge thank you to the MacRuairi family for organising the next PWSAI family weekend.

Below you will find the room rates and contact details for the hotel.

The rate is €135 per double or twin room per night including breakfast. The family rate is an additional rate of €25 per child per night.

- €135 per double/twin per night
- €160 for family room with 2 adults and 1 child per night
- €185 for a family with 2 adults and 2 children per night
- €210 for a family with 2 adults and 3 children per night
- €235 for a family with 2 adults and 4 children per night

To proceed with making a reservation please call the hotel direct on 0429661438 and they will happy to assist you with your bookings. Credit card details will be required for confirmation only. No deposit is taken from the card. The cancellation policy is 48 hours prior to arrival.

Once you have booked with the hotel, please let us know that you are attending by email [info@pwsai.ie](mailto:info@pwsai.ie) or text 087 252 2832

### **PWSAI contact details:**

Ann O'Neill (PWSAI Liason) 087 252 2832

Emma Walsh (PWSAI Secretary) [info@pwsai.ie](mailto:info@pwsai.ie) or via the PWSAI Facebook page.

**Rory Tierney, dad to Henry wrote this lovely piece on why the PWSAI Family Weekend is the highlight of the year in their house.**

It's like the night before Christmas. The Thursday night before the PWSAI family weekend. Bags are packed and details discussed. A lot of details and a lot of discussions. But that's all part of the fun. Part of the game.

The meticulous planning so that nothing can go wrong. Nothing happens that we don't know about. The way its been planned. Not that that ever really works fully. But we try. And next year we'll try and probably fail again. Always learning.

We dampen expectations in the hope of avoiding disappointment. It's another part of the game. The names that have come up week after week after week. The anticipation. The excitement. The dreams. The imaginations on how things will happen. The questions. And also the unanswerable questions.

Will they be there? When will they be there? How will they get there? What will they say? What will I say? What will you say? Why are they coming? Do they know I'm coming? Are they excited? Will they be excited to see me? Do they like swimming? Will they swim with me? Why will they swim with me?

But we try. We try to answer every question without committing. Avoiding topics to avoid upset. Like mini unqualified politicians.

Unable to plan what will happen in many different cars in many different minds in many different situations in many different parts of the country. We try to control it all. It's that simple.

But it is exciting because we all know what we're all thinking. The knowing glances. The understanding support. The fantastic moment of distraction and the little wink. The nod of thanks that so many others will never understand.

Together this weekend we are comfortable. No fear of what others might think like other social situations No avoidance of any topics. Everything is on the table and we want to talk about it. There'll be no dancing around egos this weekend. There may be dancing. We're all in this together. We want to vent. We want to laugh. We're allowed. We want to understand more and learn more. We want to feel free. The burdens of everyday life gone for the weekend. Our children safe in everyone else company.

Our most positive feature is our unity. Our understanding. Our safety. And that's why it's so great to mingle with these people.

We've come together for a reason. We didn't choose it but it's here. It chose us. But we chose to embrace it. To challenge it. To beat it. Each separately day to day in our own ways. But together this weekend as one giant social network.

The best weekend of the year.



**Laura, we heard you started  
playschool. We hope you  
are having the best time!**

**In November 2017, Marguerite Hughes and Sarah Feighan attended the PWS Association USA Conference. They're both written summaries of their experiences.**

### **The Prader-Willi Syndrome Association USA Conference, November 15th -18th - Marguerite Hughes**

The largest PWS conference in the world took place in Florida recently with over 700 participants (people with PWS, parents, professionals and caregivers). It was a pleasure to be there, mostly because of the conference itself, but also because of the "respite" opportunity afforded by having an entire week on my own in 26 degrees sunshine!

The first thing that struck me about the conference was its sheer size. For those few days PWS seemed common as every time I left my hotel room I bumped into people with the syndrome. In fact, at the conference itself there were probably more people with PWS than live in all of Ireland! Across the US there are estimated to be 10,000 - 20,000 people with PWS.

I attended the caregivers program, parts of the scientific program and the parents program. There was lots to learn. I heard about the ongoing hyperphagia drug trials (at least 3 companies are currently conducting Phase 2 trials of hyperphagia drugs) and new research into oxytocin. I heard about new vagus nerve stimulation research that has found both improvements in behaviour and social functioning and weight loss among people with PWS.

I attended excellent talks about orthopaedic issues in PWS and the use of psychiatric medications. I was reminded that there is no "magic" diet for people with PWS and that obesity-related problems remain the leading cause of premature death among people with PWS.

I heard discussions of difficulties with social care in the US and was interested to note just how similar the problems discussed were to those experienced in Ireland - e.g. large residential "congregated" settings and sheltered employment workshops are being closed down.

I heard too about the high levels of depression and anxiety among parents of people with PWS and the need to recognise these symptoms and seek help.

Finally, I heard inspiring presentations by adults with PWS, including one who had recently completed a law degree.

I left feeling both relaxed and hopeful. It felt good to be reminded that there are many amazing people working tirelessly around the world to expand opportunities for people with PWS and help manage its challenges.

Sarah Feighan

The PWS USA conference was an amazing opportunity to see what is happening in Prader-Willi research at a global level. Thanks to PWSAI, I was lucky enough to attend both the scientific conference which was held over one day and the general conference which was held over two days. At the scientific conference, there was research presented by experts from all over the world who had extended experience of working with young and old people with Prader-Willi Syndrome. Getting to hear these presenters talk and to meet them was an incredible experience for someone like myself who had just spent their first year learning about the syndrome.

PWS is a rare disease and one of the fundamental challenges of developing new treatments for rare diseases is that there is relatively little known about the pathophysiology or the natural history of the disease. This is why it was fantastic to listen to the first presentation of the day from Dr. Merlin Butler from the University of Kansas who presented the first set of results from an eight-year longitudinal study of individuals with PWS. This is the largest and longest study to date with 355 patients with PWS taking part. Further analysis are underway at the moment to look at access to services, treatments and clinical outcomes so it will be very exciting to see that data when it is published. This type of longitudinal research will be instrumental in providing researchers with a better understanding of PWS which will then lead to better treatments.

There was a number of different clinical trial studies presented across the day. One that stood out in particular was for young infants with PWS. Dr. Jennifer Miller's group at the University of Florida are looking at how intranasal oxytocin spray affects suck and swallow competency in young infants with PWS. They are hoping that this treatment has the potential to eliminate the need for gastrostomy tubes and nasogastric tubes for feedings. Anecdotal evidence from Dr. Miller and parents at the conference suggested that it has been helping so that is another very interesting study to keep an eye out for in the future.

An emerging area of interest for researchers is the brain-gut-microbe axis. This refers to the communication between the brain and the gut and how it can be influenced by the gastrointestinal microbiota. Emerging evidence has shown that changes in gut microbes can lead to obesity. It was exciting to see Dr. Andrea Haqq's team at the University of Alberta just started a study looking at the gut microbial composition of individuals with PWS compared to matched controls. If there are significant differences, this may mean there may be the potential to design therapies aimed at reversing gut dysbiosis (a microbial imbalance) which could help improve metabolism and lower inflammation and obesity in individuals with PWS. Hopefully we will be hearing the results of this study at the next conference.

Overall, the scientific conference highlights how active the Prader-Willi research community is and how many different projects are underway at the moment to try understand the syndrome better as well as improve treatments and outcomes for people with PWS. When working on the research study with PWSAI last year, myself and my supervisor, Prof. Gallagher, were stunned with the willingness of the PWS community to take part in research. I am really looking forward to continue working in the area of PWS research in Ireland and hope that at next PWS-USA conference, we will be able to show what research we have achieved in Ireland.

**Henry Tierney wants to send a special THANK YOU message to Oisin O'Neill and all his brothers and sisters and to Noah Lane's brother Finn, for their brilliant videos they sent him to tell him how much fun yard time is in school! He loves going out for yard time now!**



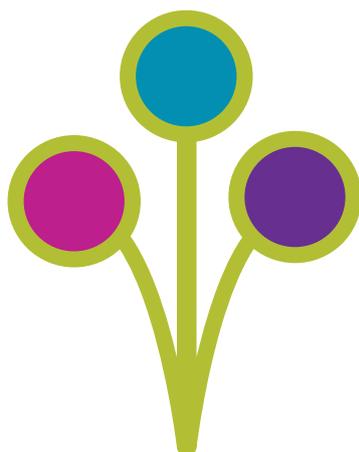
Have you received a copy of the findings  
from the Carers' Respite survey?  
If not, please send me an email and I'll forward it to you.  
[info@pwsai.ie](mailto:info@pwsai.ie)

Financial Wellbeing <https://www.financialwellbeing.ie>

Financial Wellbeing host workshops around the country on setting up trust funds, special needs bank account, hospital passports and entitlements, amongst many other services . Some of our parents recently attended a workshop and found it very helpful.

To keep up to date with news from Financial Wellbeing, sign up to their newsletter found on their website.

**We'd like to send a HUGE THANK YOU  
to all the recent donations and  
fundraisers for PWSAI!!**



**pwsai**

PRADER WILLI SYNDROME  
ASSOCIATION IRELAND

## **Prader Willi Syndrome Association Ireland (PWSAI) Membership Application Form (2018 - 2020)**



### **Why Join PWSAI?**

By joining PWSAI you will strengthen its voice and mandate in seeking to raise awareness and understanding of PWS and to improve the choice and quality of care, education and support for persons with PWS in Ireland.

By joining PWSAI you will ensure that you can influence the priorities of PWSAI.

By joining PWSAI you will be connected with others who have PWS, who have family members or friends with PWS or who have a professional interest in PWS.

By joining PWSAI you will ensure that you receive regular newsletters and other correspondence from PWSAI.

By joining PWSAI you will ensure that you are invited to PWSAI events.

By joining PWSAI you will be contributing towards the financial costs involved in running the association.

### **To join PWSAI you can either:**

1. Complete this application form and return by email to [info@pwsai.ie](mailto:info@pwsai.ie) and pay for your membership subscription online at [https://www.idonate.ie/642\\_prader-willi-syndrome-association-of-ireland.html](https://www.idonate.ie/642_prader-willi-syndrome-association-of-ireland.html) OR
2. Complete this application form and post it with payment by cheque to Prader Willi Syndrome Association Ireland, Carmichael Centre, Carmichael House, North Brunswick Street, Dublin 7.  
Cheques should be made out to Prader Willi Syndrome Association Ireland.

### **Data Protection**

Other than to fulfil its legal obligations, PWSAI will not disclose the information you have provided to any third parties without your consent. By joining PWSAI you are consenting to PWSAI retaining the information you provide. For more details on how PWSAI will use and protect the information you provide see our Privacy Statement at [www.pwsai.ie](http://www.pwsai.ie) or request a copy using the contact information provided on [www.pwsai.ie](http://www.pwsai.ie)

## **PWSAI Membership Application Form**

### **Types of Membership**

PWSAI offers Individual Membership (with one vote) to all adults aged over 18 with PWS. PWSAI offers Family Membership (with one vote) to all families in which there is a person with PWS. PWSAI offers Associate Membership to all other interested parties - e.g. professionals with an interest in PWS or relatives or friends of people with PWS.

Please tick the type of membership for which you are applying:

- |                                        |     |                          |
|----------------------------------------|-----|--------------------------|
| Family (3 years - 2015 - 2017)         | €15 | <input type="checkbox"/> |
| Adult with PWS (3 years - 2015 - 2017) | €15 | <input type="checkbox"/> |
| Associate (3 years - 2015 - 2017)      | €15 | <input type="checkbox"/> |

### Donations

PWSAI aims to maintain very low subscription fees to ensure that as many people as possible can join. However, PWSAI also encourages any members who can afford to make an additional donation towards the running of the association to do so. If you would like to make a donation to PWSAI please indicate the amount here \_\_\_\_\_

### Your details

Title \_\_\_\_\_ First Name/s \_\_\_\_\_  
Surname \_\_\_\_\_  
Address \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
Email \_\_\_\_\_  
Telephone \_\_\_\_\_

### PWSAI Correspondence

Please indicate how you would like to receive your newsletters and other correspondence from PWSAI (we encourage people to use email where possible to minimise costs).

Email  Post

### Details of Individual with PWS to whom you are connected

Name of Individual with PWS \_\_\_\_\_  
Date of Birth \_\_\_\_\_ Male/Female \_\_\_\_\_  
Your Relationship    Yourself     Parent/Guardian   
to this person      Grandparent     Sibling   
                         Other Relative     Friend   
Professional (Job Title & Organisation) \_\_\_\_\_  
\_\_\_\_\_

## Supporting Others

If you are willing for your contact details to be passed on to other families/individuals who are seeking information about PWS please tick the relevant boxes below.

I give permission for you to pass on my telephone number

street address  email address  name and age of person with PWS with whom I am connected

## Involvement in PWSAI

If you would like to get more involved in PWSAI please tick the relevant boxes below and someone from PWSAI will contact you to discuss.

Fundraising  Joining the Committee

Writing for the Newsletter  Organising a PWSAI Event

Conducting Research  Other \_\_\_\_\_

## Payment

To pay for your membership subscription and make any additional donation if desired please either complete your membership application and return by email to [info@pwsai.ie](mailto:info@pwsai.ie) and pay online at [www.idonate.ie](http://www.idonate.ie) (search for Prader Willi Syndrome Association Ireland) OR post a cheque (made payable to Prader Willi Syndrome Association Ireland) to

Prader Willi Syndrome Association Ireland, Carmichael Centre, Carmichael House, North Brunswick Street, Dublin

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