



# PWSAI NEWSLETTER



December 2015 | [newsletter@pwsai.ie](mailto:newsletter@pwsai.ie)

## Dates for your diary

### Respite & Residential Information Day

Saturday 27th February 2016

Aisling Hotel, Parkgate St, Dublin.

### PWSAI Family Weekend -

14th-16th October 2016

Park View Hotel, Newtownmountkennedy, Co. Wicklow

## Hello Aoibh!



Aoibh from Dublin got a wonderful Christmas present of a tricycle last year, which she now cycles to school every day. I bet everyone in her family wants to borrow it!

Aoibh also goes horse-riding every week and is very busy in her new secondary school. Well done Aoibh! Hope you get some great Christmas presents this year too!

**Merry Christmas & Happy New Year to all our PWSAI members and their families, from the PWSAI Committee.**

## PWSAI FAMILYWEEKEND 2015

What a wonderful time was had by all at the PWSAI Family Weekend 2015. There was so much fun to be had from a pet farm to a fire truck, motorbikes and a clown, a magician, arts & crafts, nail painting, funny photos, a pigeon race and lots of dancing that continued late into the night. It was inspirational to see everyone's achievements over the last year with the PWSAI Awards. A huge thanks to Pauline, Tony and Emma Kerley and Ann O'Neill for another brilliant PWSAI Family Weekend.

**\*\*NEWS JUST IN!\*\***

The PWSAI Family Weekend 2016 is taking place on the 14th-16th October 2016 in the Park View Hotel, Newtownmountkennedy, Co. Wicklow.

We are really looking forward to seeing what Lena & Ann have planned for us. More details will be released soon but in the meantime if you need to contact Lena or Ann, here are their details: Lena Lawlor (087) 6388240 or Ann Wright (085)1457170.





## New Films Coming Soon!

With funding from the Galway Cycle 2014 PWSAI recently made two training films to add to those it produced in 2014. The first, on *Therapeutic Interventions*, is presented by a US physiotherapist who is the mother of a son with PWS and has vast experience working with children with PWS. The second, on *Managing Your Child's PWS Behaviour*, is presented by a renowned US psychologist and PWS researcher. These films are currently being edited and will be made available via PWSAI's website and Facebook page soon.



## PWSAI Liason Officer

Ann O'Neill is our PWSAI Liason Officer. If you need any advice or to be put in touch with other families, don't hesitate to contact Ann at 087 252 2832

## PWS (Prepare to Walk or Sprint) 5K 2015

The second annual PWS5K took place in late June and was another fantastic success!! Over 300 people took part in the event with many more families and friends supporting the event. It was wonderful to see so many PWSAI families from across the country, adding another date in the PWSAI calendar for a chat with friends, new and old.

The total amount raised on the day for PWSAI was €3718.31.

A big thanks to all involved including fundraisers, all who took part, the volunteers and supporters.

See you all in 2016 for another great event! A New year, a new start, get training now for PWS 5k!





## PWSAI Workshop 2015

The Living Better with Prader-Willi Syndrome workshop took place in early September, aimed at the parents of people with PWS under 12 years old. We would like to extend our thanks to Ann O'Neill for all her hard work. It was a huge success and everyone left a lot more knowledgeable.

It's another great way to meet like minded people for a chat and sharing ideas on living with PWS. The next workshop will take place in late spring/early summer. Keep an eye on emails/Facebook for a date. This is definitely not one to be missed!

## Conference Travel Grant Scheme

In order to increase knowledge about PWS in Ireland PWSAI has decided to offer two grants to parents/carers who wish to attend the 2016 International Prader-Willi Syndrome Organisation (IPWSO) conference. This conference is being hosted by the Foundation for Prader-Willi Research (FPWR) in Toronto, Canada from July 20th - 24th.

Each successful applicant will be awarded the costs of their economy class flights, accommodation and conference registration fees.

All applicants must be willing, if they are successful, to be publicly identified by PWSAI as having received a travel grant (e.g. on the PWSAI website and in its annual report).

All applicants must also be willing to prepare a brief report on their experience at the conference within 6 months of the end of the conference.

The scheme is open to any parents/carers of someone with PWS who are based in Ireland except people who are directly affiliated with FPWR or IPWSO. Only one travel grant will be awarded per family.

Priority will be given to applicants who have a track record of supporting people with PWS in Ireland and demonstrate a willingness to continue to support others.

The closing date for the receipt of applications is January 15, 2016.

All applications will be considered and voted on by the PWSAI directors whose decision will be final. Successful applicants will be informed by the end of February 2016.

To apply please provide the information requested below by email to [info@pwsai.ie](mailto:info@pwsai.ie) or by post to PWSAI, Carmichael Centre, Carmichael House, North Brunswick Street, Dublin 7.

### Conference Travel Grant Scheme – Applicant Details:

Name:

Email Address:

Telephone Number:

Street Address:

**Your past and current activities supporting people with PWS:** Briefly describe your previous and current activities supporting people with Prader-Willi syndrome.

**Purpose of Grant:** How will you use the knowledge you gain at the 2016 IPWSO conference to benefit people with PWS and their families in Ireland? Be as specific as possible in your answer.





## International News

1. A series of excellent presentations made at the Asia Pacific PWS Conference held in Melbourne earlier this year are now available to view free of charge on YouTube. These include presentations on food security, living with an adult with PWS, oxytocin research, the use of psychiatric medication and growth hormone. You can watch all of these presentations here: [https://www.youtube.com/channel/UCNoz8gMUCB3E\\_AdUDSIvyKg/videos](https://www.youtube.com/channel/UCNoz8gMUCB3E_AdUDSIvyKg/videos)

2. Two wonderful films by Dr. Janice Forster on behaviour management in PWS were recorded in New Zealand earlier this year and can be viewed at: <http://www.pws.org.nz/dr-janice-forster-presentation-wellington-nz-201/>

3. For those of you who live with an adult with PWS, the latest IPWSO publication, Strength in Boundaries, may be of interest. It can be accessed here: [http://media.wix.com/ugd/a71d4c\\_e512389e05b64f53a11e6f9f0d742ce7.pdf](http://media.wix.com/ugd/a71d4c_e512389e05b64f53a11e6f9f0d742ce7.pdf)



## PWSAI has a vacancy to fill!

After almost 5 years in the role, PWSAI's current Company Secretary will be stepping down in 2016. PWSAI is legally required to find a new Company Secretary to take over this role.

### So, why should *YOU* consider becoming the new Company Secretary?

1. By becoming Company Secretary you will learn more about PWSAI and PWS. This information could be helpful to you and your family.
2. The Company Secretary works as part of a team that aims to help everyone with PWS in Ireland. By becoming Company Secretary you will work to help others.

### What does the role involve?

The Company Secretary is responsible for duties including maintaining the register of members and the register of directors, ensuring that minutes of meetings are kept, ensuring that statutory forms are filed correctly and on time, providing members with notice of meetings and complying with any duties imposed by the Companies Act.

### What qualifications does a Company Secretary need?

No specific qualifications are required to become Company Secretary although, ideally, the candidate would have some knowledge of charity governance issues. Attention to detail, a high standard of written English, and a willingness to keep abreast of changes in charity regulation are all important.

### How much time does the role take?

The core duties of the Company Secretary rarely take longer than an hour a week. However, like all PWSAI directors, the Company Secretary may choose to become involved in PWSAI activities in addition to the core Company Secretary duties.

### Is the Company Secretary paid?

Like all PWSAI directors, the Company Secretary is not paid. However, expenses incurred in the course of fulfilling the role (e.g. postage, printing and travel to meetings) will be reimbursed by PWSAI.

### Would you like to find out more?

If you would like an informal conversation about the role of the Company Secretary please call the current Company Secretary (Marguerite Hughes) on 087 9621681 at any stage.



## International News continued...

4. Clinical Trials. In the last PWSAI newsletter we described how the pharmaceutical company Zafgen was conducting Phase 3 clinical trials of a drug called Beloranib in the USA. Zafgen believes that Beloranib may play an important role in addressing the hyperphagia and obesity associated with Prader-Willi syndrome. Sadly, two adults with PWS who were participating in Beloranib trials have since died. The cause of death in one case was respiratory failure due to pulmonary emboli. At the time of writing the cause of death in the second case had not been made public. Although it is not known if these deaths were caused by treatment with Beloranib, a complete clinical hold has now been placed on the Beloranib trials. It is expected that preliminary results from these clinical trials will be available in the first quarter of 2016.

Beloranib has received particular attention in the PWS community worldwide as its trial is more advanced (i.e. a Phase 3 trial) than others. However, many more clinical trials including several Phase 2 trials are also currently underway.



## Respite & Residential Information Day

### SAVE THE DATE

PWSAI RESIDENTIAL AND RESPITE CARE

INFORMATION & DISCUSSION FORUM

Saturday 27<sup>th</sup> February 2016

Venue: Ashling Hotel. Parkgate Street Dublin 8

11.00 to 16.00

In the context of a “whole of life” approach to the treatment of Prader-Willi syndrome, the Residential and Respite (R+R) Sub-Committee of PWSAI recently held a one hour meeting with Minister Leo Varadkar TD and Minister for Health and Children and his officials to highlight the substantial backlog of unmet need in the area of Respite and Adult Care for those with the syndrome who require such supports.

Separately our Chairperson Anthony Carr along with Laura Keane (Director of Health and Social Care services Rehabcare) and Kevin Clancy (General Manager RehabCare Developments and Contracts) held a meeting with three senior national officials of the HSE to discuss life and health requirements of those with Prader-Willi syndrome, and the on-going and emerging requirements for service support.

We wish to invite all parents/guardians of persons with the syndrome aged 10 or over to attend our information and discussion forum to inform you of the submissions that were made and to agree by consensus a plan for the development of Respite and Residential Services going forward for those with the syndrome. Please register your interest to attend by email to: [info@pwsai.ie](mailto:info@pwsai.ie)

An Agenda for the meeting will be emailed and sent by post to parents/guardians of all concerned in early January. We would ask as many of you as possible to attend on the day.

Anthony Carr, Donnchadh Clancy, Don Tallon & Paul Wright.

Respite & Residential Sub Committee





## Christmas Tips

PWS USA recently put together some tips for staying safe during the Christmas season. Here is just a selection but more can be found at <http://pwsausa.org/2015-holiday-tips/>

- If you will be with relatives, carefully plan ahead of time and communicate the importance of food control with all involved. Make sure all attending know the "rules of engagement" and agree to cooperate.
- See that someone at all times is clearly in charge of your child with PWS. Clearly define when you are "changing guards". As Dr Linda Gourash states, "When everyone is in charge - no one is in charge."
- If your child is old enough, rehearse the "rules" before the special day and come to a mutual agreement on what your child will be allowed to eat.
- It is okay to request that Grandma and other relatives tuck away tempting items during your visit and to discreetly check with you prior to offering your child a treat.
- Make sure you know what everyone is bringing, so there are no surprises on what the choices will be.
- Go over with the hostess or your family the plan to contain accessibility to food. This will help prevent your child from sitting near bowls of food, rolls, or condiments. Many people do not consider how many calories children can consume with the extras - sugar, butter, ketchup, etc.
- After eating when people are just visiting make sure food is put away or, if left out, someone is responsible for guarding it.

## Thank you to our Fundraisers

Trish Cantwell, who along with Diana Murphy and Laura Downey, participated in the Evening Echo Women's Mini Marathon and Michael Moloney who participated in a half marathon in Cork for PWSAI.

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

[newsletter@pwsai.ie](mailto:newsletter@pwsai.ie)

The PWSAI Newsletter HQ would love to hear from you in 2016. If you have any advice to share or great achievements to be proud of, please get in touch!

**We wish you a very  
Merry Christmas  
&  
a Happy New Year!!**

