



PWSAI NEWSLETTER

May 2015 | contactnewsletter@pwsai.ie

Dates for your diary

Living Better with PWS Workshop - 10am 30th May 2015 - Aisling Hotel, Dublin.

PWSAI AGM - 11am 21st June 2015, Glenroyal Hotel, Maynooth.

PWS 5k - 2pm 21st June 2015, Maynooth University South Campus.

Thank you to our Fundraisers

Aileen (Team Henry) - 10k in London - May 9th

Sabrina, family & friends (Team Cian)- Hell & Back Hercules in Sligo- 16th May

Michaela & family (Team Lexie)- Women's Mini Marathon - 1st June

Hello Jim!

Jim's started playing football and making all his family very proud of him!



A letter from your Chairman

Hi,

I'd like to give you an update on Committee changes as well work going on in PWSAI.

It is with regret that I inform you that Ann Grassick has decided to leave the committee of PWSAI and her function of Liaison Officer/Admin, with immediate effect. Ann has been an active member of PWSAI for several years. In her role on the committee Ann worked tirelessly for the good of all in the PWS community. As Liaison Officer she also provided immense support to those who sought her advice in times of need. Her experience and commitment will be missed by all. On behalf of PWSAI and all that has sought her help and advice in the past, I would like to offer Ann our sincere thanks. As individuals and committee members we wish Ann all the best and hope she will continue to be involved in whatever capacity that may be in the future. Ann O'Neill has accepted to take on the role of Liaison Officer (Thank You!) while other functions will be taken up by other members of the committee. There will be a transition period while we sort out contact numbers/e-mail etc., but we will work to complete, as a priority, and will communicate any changes made.

Keep an eye on our web-site!! www.pwsai.ie

PWSAI Liaison Officer (Ann O'Neill) phone number is 0872522832 . This number will be active from Tuesday 12th May 2015.

There are a number of initiatives the committee are working on that we will need your help and involvement;

- Baseline Study on services/lack of services available

Hello Lexie!



Lexie is a year old. She is a very happy, always smiling, amazingly strong little girl. Lexie is our little angel that made our fantastic family complete. Lexie has three sisters Paige, Lauren and Emma. They love her so much and they keep her going and have brought her on so much. Lexie loves laughing at her sisters when they make funny faces and also loves to pull her daddy's glasses off his face.

She thinks that is funny and bursts into giggles. Lexie is able to hold her own head and gets better every day. She can sit on her own for about a minute supported by pillows and is also trying to turn over by herself. Lexie loves her baby massage that she gets every day. We are very blessed to have our beautiful blue eyed princess Lexie in our lives.

We as a family take every day at a time and enjoy every special moment with Lexie. We love helping her reach her goals and as a family we will help her reach all her goals.

to people of all ages with PWS.

- Respite/Residential needs survey.
- Contact Data Base review and update of all with PWS.

This information will allow us to target our work more effectively, so please get involved. All information provided will be kept confidential and subject to the Data Protection Policy.

On another point, I would like to encourage as many as possible to become members of PWSAI. A Charity is only as strong as its core membership and its ability to understand its needs. This is not for fund raising but to inform us as to what individuals needs are. Of course it would be great if people could find the interest in joining PWSAI Committee itself. As the more who get involved the more we can achieve!! Involvement doesn't necessarily mean having to attend meeting's etc., but if someone has an idea /project that they feel they would like to take on and need some support then contact a member of PWSAI.

Thanks for taking time to read this Newsletter!!

Regards,

Anthony Carr

Chairman PWSAI.

PWSAI Membership 2015-2017 Now Available!

Thank you very much to the many individuals and families who joined PWSAI since we started formally welcoming members back in 2013. As our first membership period (2013-2014) has now expired we are asking people to once again sign up as members.

Our current membership period runs from 2015 to 2017. The membership subscription for this period is €15 - i.e. only €5 per year!

Why join? Because by joining PWSAI you will strengthen its voice and mandate in seeking to raise awareness and understanding of PWS and to improve

PWSAI training Films

In our last newsletter we reported that we were in the middle of editing 4 films produced by PWSAI on new diagnosis, dietary management, behaviour and mental health, and growth hormone treatment. As many of you will already know, we released the films on YouTube in late December and they have already been watched over 3,400 times!

Huge thanks once again to the 11 families who participated in the films. Thanks also to the professionals who took part free of charge and the Galway Cycle whose funding enabled us to pay the film crew and make the films.

If you haven't yet seen the films you can watch them by clicking on the "New Films" button on the PWSAI homepage - www.pwsai.ie

Or you can look them up directly on YouTube by searching for "PWSAI".

Contact the newsletter

We'd love to hear from you!

We'd be delighted to receive photos of your achievements and we'd love to hear from parents & carers who have great advice to share.

the choice and quality of care, education and support for people with PWS In Ireland.

You can find out more about PWSAI membership and sign up online by clicking the "Join" button on the PWSAI homepage - www.pwsai.ie

Or you can print the membership form that appears at the end of this newsletter and return it with a cheque made out to Prader Willi Syndrome Association Ireland to:

Prader Willi Syndrome Association Ireland
Carmichael Centre
Carmichael House
North Brunswick Street
Dublin 7

Baseline Study of Prader-Willi Syndrome in Ireland

In our last newsletter we reported that PWSAI was seeking to commission research on a baseline survey of people with PWS in Ireland. This research will provide a detailed and current picture of how people with PWS live in Ireland today. It may cover issues such as the services and supports being received by people with PWS and their families, the perceived needs of people with PWS and their families, as well as the numbers, geographical distribution, ages, and living circumstances of people with PWS.

Why do we want this information? We believe that PWSAI can better advocate for improved services and better identify needs if we have an accurate picture of the population of people with PWS.

For example, as part of our current advocacy efforts in relation to residential and respite care, we have recently been asked for this information.

Since the last newsletter we have continued on our work on this project and are currently in discussions with academics and medical personnel regarding setting up a pilot. We will continue to keep you posted on the progress of this work.

Workshop

The "Living better with Prader-Willi Syndrome" workshop will take place in the Ashling Hotel Dublin on Saturday May 30th from 10am till 4pm. The workshop is funded by the monies raised by the Galway Cycle 2014 and is free to all participants.

This is aimed at parents, carers, grandparents, aunts and uncles of children with PWS aged from birth to 12yrs. The workshop will enable open discussion and advice on many subject ranging from speaking about Prader-Willi, Diet, Hyperphagia to Education.

Places are limited so book early.

To book your place or for any queries please contact

-Ann O Neill
0863912678 (personal number)

-Liaison Officer (Ann O'Neill) phone number is 0872522832 . This number will be active from Tuesday 12th May 2015.

annosmile1@hotmail.com

PWSAI Family Weekend

It's a weekend we all look forward to, so keep an eye out on for a 'save the date' coming very soon!

PWSAI AGM

PWSAI's 2015 AGM will take place at 11am on June 21st in the Glenroyal Hotel in Maynooth.

All PWSAI members are warmly invited to attend.

If you are not a member you can join online now at: www.pwsai.ie

Alternatively you can become a member of PWSAI by completing the registration form and paying the €15 membership fee on the day.

We hope to see you there!

Your Association Needs You!

PWSAI has a long and proud history. Thanks to the voluntary work of many parents over the last 25+ years it has hosted events, sought to improve services, sought to provide support, sought to offer resources and much more.

To enable PWSAI to do even more than it has in the past we need more people to become directors of PWSAI this year.

What do we need people to do?

1. We need people to get involved in our ongoing projects, which include:

- Advocating for improved respite and residential services
- Creating information packs
- Making educational films
- Conducting a baseline survey
- Running peer support workshops
- Planning a conference to take place in 2016
- Family weekends

2. We need people to assist with the administration of PWSAI. This covers areas such as financial management, governance and ensuring compliance

Hello Mary Rose!

Greetings from Dungarvan, Co Waterford. Mary Rose turned 8 years old in January this year and when we think back over the last 8 years we are bursting with pride for all the achievements she has made and all the challenges she has overcome.



Despite every obstacle put in her path she is extremely happy in mainstream NS in 1st class (With the aid of her adoring SNA), she is involved in Swimming, Drama & Hip Hop clubs weekly, she has regular birthday parties to attend, she loves gadgets & books like her big brother Billy (who she has wrapped around her little finger) and is really enjoying the beautiful weather recently. Last Sunday she did her biggest walk ever and completed a 2 mile walk in reasonably hilly terrain in a local amenity called Colligan Woods. (She did sleep very well that night!)

7-8 years ago we never thought this reasonably normal lifestyle would be possible...she makes Kieran, Billy & I smile every day.

with the requirements of the new Charities Regulatory Authority.

3. We need people to assist with providing support to families. This covers areas such as being available to talk to families, writing for the newsletter, updating our Facebook page and website, and replying to emails.

4. Most of all we need people from all backgrounds who are willing to bring their ideas and experience to PWSAI and to commit some time to PWSAI (even half an hour a week) for a period of one year or more.

Please consider donating some of your time by becoming a director. If you would like to find out more about what would be involved please ring Anthony on 087 9444169.

International News

Starting from this issue we have decided to draw your attention to some interesting things relating to PWS that are happening internationally.

1. Prader-Willi World

A PWS mobile phone application, called Prader-Willi World, has recently been launched by IPWSO. It is free and suitable for all Android smart phones and other Android devices (an iOS version may be made available later). The aim of the app is to ensure that parents and carers of people with Prader-Willi syndrome will always have key medical information ("medical alerts") with them at all times. So, if you unexpectedly end up in a hospital you will have medical information about PWS with you. The app also includes other features such as a tool for recording height and weight, a means of connecting with other families, a section for recording notes, and lots of other information. You can download the app from the Google Play Store by searching for "Prader-Willi World".

PWS 5km

COME AND BE ACTIVE WITH YOUR FAMILY.

The second annual PWS5K takes place on Sunday 21st June at 2pm in the grounds of Maynooth University.

Last year was a fantastic event raising funds for PWSAI and also awareness for the rare syndrome we all know so well.



So why not join us for a day of run, fun and hopefully sun! All levels are catered for, whether it's a personal best time your looking for or a casual walk with friends through the beautiful campus. What better way to spend a summers afternoon!

Registration is open so check out our Facebook or new website due to launch this weekend www.pws5km.com

2. Beloranib and Other Clinical Trials

There is a lot of talk about the investigational drug, Beloranib, in PWS circles currently. So, what's it all about? The pharmaceutical company, Zafgen, is currently conducting Phase III testing of Beloranib in overweight and obese teenagers and adults with PWS. Zafgen are testing to see if Beloranib will change the way the body metabolises fat and whether it can reduce fat mass and decrease hyperphagia. There are currently 14 Beloranib study sites in the US with the possibility of testing also being extended to Europe. It will be very interesting to discover the results!

The Beloranib trial is only one of many trials of relevance to PWS taking place around the world. If you are interested in keeping up to date with others, a good place to start is by typing "Prader-Willi" into the listing at this link: <https://clinicaltrials.gov/>

3. Are you the parent of an adult with PWS who is living at home?

If so, you may be interested in the series of FamCare articles produced by IPWSO. To date, easy to read articles have been prepared on the following topics:

- Coping with Change
- Skinpicking
- Basics of a Healthy Adult Life
- Confabulation (story-telling)
- Health Checklist
- Managing a Meltdown
- "I want the same"

These articles can all be downloaded free of charge at: <http://www.ipwso.org/#!/famcare/canb>

If you don't have internet access and would like to read these articles please contact PWSAI and we will print and send them to you free of charge.

Miles to go before I sleep

In September 2014, the Average Joes (8 regular attendees from the Galway cycle) took on the Race Around Ireland, Europe's toughest endurance race. The Race Around Ireland is a non-stop 2,200 km bicycle race that circumnavigates the island of Ireland.

After 75 hours and one minute, they won the 2014 race. But that's not all they did.



They also used the race to generate to spread the word about PWS. And then, as if that wasn't enough they wrote a book with all proceeds going to PWSAI!

"Miles to go before I sleep" can be purchased from www.lulu.com

The guys will also be doing a presentation of the funds raised by the book to PWSAI at the PWS 5k in June! So there's another reason to come!

A big thank you to these 8 amazing guys and their brilliant support crews for what they are doing for our small charity.

4. International Conferences

A major Asia-Pacific conference on PWS has just concluded in Melbourne. <http://www.pwsconference.org/index.htm>

The PWSA (USA) national conference will be taking place from November 3rd to 7th 2015 in Florida. This is a major conference that includes a Professional Providers and Caregivers' conference. You can find out more at: <http://www.pwsausa.org/conference/conference-1>

The FPWR (USA) 2015 conference, which showcases current research, takes place in Texas from September 25th to 27th. You can find out more at: <http://www.fpwr.org/events/2015-fpwr-conference/>

Finally, the next IPWSO conference (the biggest PWS conference of them all!) will take place in Toronto from July 20th - 24th, 2016. It is being hosted by FPWR Canada who are running a competition for which the prize is a free trip to the conference (travel, accommodation and conference registration up to a maximum of Can\$2,500 - approximately €1,900). To be in with a chance to win all you have to do is raise Can\$500 or more (approximately €380) for either PWSAI or IPWSO during 2015.

PWSAI would like to offer its sincere condolences to the family, friends and colleagues of Aidan Lynam who died tragically. Aidan was an employee of Down Syndrome Ireland and one of the motorcycle marshals who helped keep everyone safe during the Galway Cycle each year. PWSAI benefited greatly from Aidan's generosity both during and after the Galway Cycle 2014.





Prader Willi Syndrome Association Ireland (PWSAI) Membership Application Form (2015 - 2017)

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 online and pay for your membership subscription online at www.pwsai.ie 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 or request a copy using the contact information provided on www.pwsai.ie

Type to enter text 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

Adult with PWS (3 years - 2015 - 2017) €15

Associate (3 years - 2015 - 2017) €15

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
