

PWSAI Newsletter

APRIL 2017

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Hello!

There's a lot of news from PWSAI.

We launched the PWSAI National Survey on the 9th March 2017. It was a great success with Minister Simon Harris launching the survey and many medical professionals and service providers in attendance. This survey would not have happened if it weren't for a team of committed people- thank you to the researchers and committee members who made this survey such a success. We'd especially like to thank all the families that spoke on the day; *Anne Jones, Donnchadh Clancy, Elisha Doyle, Ann O'Neill and Rory Tierney*. It's a very hard thing to do to stand up in-front of a crowd and share your personal story. Thank you from all of us. The survey and executive summary can be found online at www.pwsai.ie

Ann O'Neill is the 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

Dates for your Diary

Add info@pwsai.ie to your email contact list so
you don't miss out on PWSAI news.

TERENURE 5 MILE

We're very fortunate to be the chosen charity for this years Terenure 5 mile. It takes place on 14th May 2017 and is suitable for everyone. Hurry though, it sold out last year!!

NEW RESEARCH

Prof Lousie Gallagher with researchers Sarah Feighan & Hyun-Ju Kang of Trinity College are looking for participants for a qualitative case study to explore parents' hopes, barriers, and concerns about transition from secondary school to adulthood.

If you are a PWSAI parent of an adolescent with PWS, you will find a letter enclosed detailing the study and how to take part.

1

TERENURE 5 MILE

14th May

www.terenure5mile.com

2

PWSAI AGM

Sunday 18th June
10am, The Glenroyal
Hotel, Maynooth

3

PWS 5KM

Sunday 18th June
2pm, Maynooth

www.pws5km.com

4

PWSAI FAMILY WEEKEND

29th September
The Heritage Hotel,
Portlaoise

PWSAI Family Weekend 2017, 29th September, The Heritage Hotel, Portlaoise

Thank you to Margaret Kealy & family for organising the PWSAI Family weekend 2017. We're all really looking forward to it!! Thank you to all the fundraisers who make the PWSAI Family Weekend possible!



Saturday 30th September

- ▶ Activities in the morning
- ▶ Lunch will be provided by PWSAI
- ▶ Afternoon free time
- ▶ Our annual dinner dance will take place Saturday evening!

Book your room directly with the hotel

- ▶ €298 for two nights B&B
- ▶ Hotel has a swimming pool and is located in the centre of Portlaoise town
- ▶ www.theheritagehotel.com or 057 86 78 588

RSVP to Emma

- ▶ Email info@pwsai.ie or text 087 252 2832
- ▶ Please include number of family members attending and any dietary requirements
- ▶ Also, please email photos of your person with PWS and tell us about them achievements and proud moments since last year.

PWS5K 2017



The PWS 5Km is back for its 4th year and we're hoping it'll be bigger and better than previous years!

The PWS 5km committee have spent many hours ensuring that this is different to any other run or walk. The fantastic grounds of St Patricks college Maynooth give the PWS 5km a unique and spectacular backdrop.

As previous patrons will know there is lots of fun and surprises on the route to keep things exciting and interesting for younguns and adults alike. And this year we'll be adding even more to make this fun run even more fun!

It's also a looped event meaning that anyone can take part at any level and take part as a runner jogger or walker and even if you don't fancy the full distance, one loop of exercise is better than no loop!

This is a fun run suited to all ages groups and abilities. *Come and be active with your family & friends!* **Register at www.pws5km.com**

We are also looking for some marshall support on the day so if you'd like to help out please contact us on 0857265160 or pws5km@gmail.com

Dear Members,

Just a quick update on what`s going on. PWSAI have had a truly remarkable year so far!!

As you are aware the official launch of our National Survey, "A Population Based Profile of Prader-Willi Syndrome in Ireland" was officiated by Minister for Health-Simon Harris, Thursday, March 9, 2017. The Minister must be commended for following through on his commitments since we first met with him at Family support day last October 2016. The Launch event was strongly supported by a wide spectrum of interested parties, Politicians, Medical/Health Professionals, Care Providers, Educational Bodies and PWSAI members. The feedback from those in attendance was very complimentary and encouraging.

The Minister made a commitment at the launch that he would set up a meeting between himself, PWSAI R&R Sub-committee and the HSE, so we could articulate the unmet needs of our members particularly in relation to Respite and Residential Care and Psychiatric services. He duly arranged this meeting, which was held on Tuesday 4th April, with the Minister, Marion Meany (Head of Operations and service Improvement, Disability services) and PWSAI R&R. This was a very productive meeting for PWSAI as the Minister clearly understood our needs and requested that the HSE arrange a working group with ourselves and other interested parties.

The main points the Minister made were:

- He stated that the HSE needed to understand our needs and the responsibility was clearly left with Marion to work with PWSAI to do that.
- He saw the survey as a document which highlights immediate needs but also a road map for continued service provision.
- He wanted costings prepared and submitted by the HSE in the book of estimates later this year for Budget 2018, as a start. You can take it that PWS is now a line item on the HSE Budget proposals going forward.

PWSAI will continue to use the survey to promote our needs and develop further initiatives. We do need your continued support to work at a local level to spread awareness and Advocate for services. We will be calling on your help to assist with ongoing projects.

I would encourage as many as possible to attend the AGM on 18th June, Glenroyal Hotel, Maynooth and the PWS 5K walk/run afterwards. This meeting allows us an opportunity to discuss ongoing initiatives with as wide a membership as possible and get your inputs and feedback. So please attend if you can at all, we would be delighted to see you.

Regards, Anthony Carr - PWSAI Chairman