



PWSAI NEWSLETTER



What's Happening in 2017

Survey Launch

**Living Well with PWS
Workshop (under 12s)**

PWS 5K

PWSAI Family Weekend

All dates to be confirmed

**PWS (Prepare to
Walk or Sprint) 5K
2016**

It rained and rained and rained some more but that didn't dampen the spirits of all who took part. An incredible €4801 was raised!! A huge thank you to all who supported it from the participants, to the volunteers and sponsors. See you all at PWS 5K 2017!!

Kate Woodstock Research

Dr. Kate Woodstock has been in touch about a new research project and is looking for participants. Please see the attached letter.

Letter from the Chairman - Anthony Carr

Dear Members,

I just thought it would be good to give you an update on ongoing PWSAI committee work, in relation to meetings with both the Minister for Health and Minister for Disabilities, as well as the Survey Launch. As you maybe aware PWSAI had a meeting with the Minister for Health, Simon Harris on the 15th Oct during this year's Family Support day, in Wicklow. We also had a meeting with the Minister for Disabilities, Finian McGrath on the 15th Nov in Leinster House. During these meetings we gave a detailed overview of:

- PWSAI as an association and our members
- Outline PWS as a rare and challenging condition and its impact on the families with PWS members.
- Unmet needs and services required to assist families with PWS.
- PWSAI Survey and Launch.

As well as the topics outlined above and the awareness for PWS at the highest level in our Government, these meetings allowed us to stress the need for PWS to be recognised as a condition that requires PWS specific resources and supports. Minister Harris gave freely of his time and listened intently with great interest to what we had to say. He has committed to working with us and has since followed up with correspondence, to highlight his intent. Minister McGrath also clearly understood the unique and complex nature of Managing the condition through all age groups. Since the latter meeting only took place, so recently we have no further update, but we do have a commitment that his Department will work with us.

PWSAI also met Prof Edna Roche and Prof James Gibney in Tallaght Hospital on Friday 18th Nov, to inform them of our meetings with the Ministers and request their assistance in supporting our work. The challenges encountered by PWSAI and Tallaght Hospital, in our effort to improve and increase services were discussed, as was the progress made



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

Thank you to Emma Ryan & friends

Aoife Ryan's big sister Emma and her TY classmates choose Prader-Willi Syndrome for their YSI project last year. They raised just over 300e but the main focus was awareness which they did through a shoutout on South East Radio and an interview on KCLR FM with Edward Hayden. They also ran many information days in the school by giving facts over the intercom etc and giving out leaflets around our town.



in increasing services in Tallaght, for all age groups. Both parties agreed to continue to support each other with our common objectives.

I know that there is more work to be done before we see tangible results, but we as a committee will continue with our efforts to make a difference.

On the subject of the Survey, I would first of all thank all the families who participated, as the finished document gives all of us, as an Association, something to be proud of. We intend to have a formal Launch of the Survey early in 2017 and we will be working with a Professional PR company to assist us. The Minister for Health has indicated that he would be willing to officiate at the launch. We will keep you all informed as we arrange details around the launch and future progress with the Government Departments.

For now, on behalf of PWSAI, I would like to wish you all a Very Happy Christmas and Peaceful New Year.

PWSAI FAMILY WEEKEND 2016

A huge thanks to Lena, Ann and their families for a fantastic weekend in Wicklow. We all had such a fun time and it was great to see so many families there. From the fun in the hotel playing bingo and games, to the fun on the farm and the Garda Escort, not forgetting the lovely dinner dance, it was a weekend packed with memories that will be treasured.

See more photos at www.pwsai.ie



*Have a Wonderful Christmas
& a Happy New Year*