



PWSAI NEWSLETTER

Dates for your diary

PWSAI AGM

19th June 2016 @ 10.30am

Glenroyal Hotel,
Maynooth

PWS 5km

19th June 2016 @ 2pm

Maynooth University,
South Campus

Register online
www.pws5km.com

PWSAI Family Weekend

14th-16th October 2016

Park View Hotel,
Newtownmountkennedy,
Co. Wicklow

Hello Aoife!

Aoife (age 6) is busy training for the PWS 5km in Maynooth!

We can't wait to see you at the finish line with your family Aoife!



Hello!

We hope you and your family are keeping well. I'm writing this in the beautiful sunny weather which I hope lasts all summer.... It's lovely to be able to go for a walk without bringing the umbrella!

We hope to issue a newsletter 2 to 3 times a year but you can stay up to date with all the news from PWSAI by.....

- Emailing info@pwsai.ie to be added to the mailing list. Also add info@pwsai.ie to your contact list, so the emails don't go into spam.
- Texting Ann O'Neill, the PWSAI Liason officer, to be added to our group text list. Contact Ann PWSAI Liason Officer on 087 252 2832
- Checking Facebook, Twitter and the PWSAI website www.pwsai.ie

PWSAI AGM

The PWSAI AGM is on the 19th June 2016 at 10.30am in the Glenroyal Hotel in Maynooth, Co. Kildare.

All PWSAI members are warmly invited to attend.

We hope to see you there!

**PWSAI Liason Officer
Ann O'Neill**

**If you need any advice or to be put in touch with other families, don't hesitate to contact
Ann at 087 252 2832**

PWSAI Workshop 2016

The Living Better with Prader-Willi Syndrome workshop will take place in September (date and location to be confirmed), aimed at the parents of people with PWS under 12 years old.

It's a great way to meet like minded people for a chat and sharing ideas on living with PWS.

Keep an eye on emails/ Facebook/text list for a date.

Films

Since the last newsletter in December, two more films commissioned by PWSAI have been released.

- Managing your child's PWS behaviour- Elizabeth Roof
- Therapeutic Interventions for the young child with PWS- Janice Agarwal

You can find these videos on the PWSAI website or on youtube.

Thank you to the Galway Cycle 2014 for funding all the educational videos.

Join the PWSAI Committee



This picture shows the PWSAI committee (minus the secretary who was taking the picture!) at their recent meeting.

After many years of service, some of this group will be stepping down from the committee at the PWSAI AGM on June 19th. We would be delighted to hear from anyone who is interested in joining the team.

The amount of time needed is probably less than you think! The amount you'll learn is probably more than you think! And we're a very friendly group where all ideas and contributions are welcome. Come on, you know you want to..

PWSAI FAMILY WEEKEND 2016

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

Phone 01 2015600 to book your room.

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.



Hello Emma!

What a beautiful photo of Emma and Dad Tony from Limerick. Looks like you were having a lovely day out. We look forward to seeing you both soon!



Thank you to Fields!

Fields have chosen PWSAI as their charity partner for 2016. They had a very successful table quiz last month raising €3200 for PWSAI. Thank you to all the staff and friends of Fields for their generosity.



Fundraisers

Good luck and thanks to Edel and Jayne Harrison who are doing some fantastic fundraising for PWSAI in conjunction with Loreto School, Spawell Road, Wexford, and St. Patrick's National School, Crossabeg, Co. Wexford. They are also helping to raise awareness of PWS throughout Wexford and beyond.

A painting by the very artistic Jayne



PWS (Prepare to Walk or Sprint) 5K 2016

We're busy preparing to make the 2016 PWS 5km even bigger and better than before. While you patiently wait for 19th June to come around, lace up those runners and get out and have some fun being active.

PWS 5km is for all ages and all abilities. Our motto is 'Come and be active with your family and friends!'. Spread the word. We can't wait to see you there.

You can register online at www.pws5km.com

€10 for adults, €25 for a family.

There will be face painting, fun along the route and refreshments on the day.

National PWS Survey Update

61 families have now completed the Population-Based Profile of Prader-Willi Syndrome in Ireland survey, which was commissioned by PWSAI and is being conducted by researchers in TCD and Tallaght Hospital.

Thank you very much to everyone who participated!

Analysis of the results has already begun. The full results

Hello Emma & David!



Beautiful smiles from beautiful people, brother and sister David and Emma from Cork.

International Conference

Toronto, hosted by FPWR and IPWSO from the 20th-24th July 2016.

We're looking forward to hearing lots of updates from the IPWSO conference.

Hello Henry!

Henry (age 3) training for the PWS 5km! He's looking forward to seeing lots of his friends on the day!



will be described in a report that is due to be completed by the end of June. PWSAI will be requesting a meeting with Minister Simon Harris and his officials after that date to advocate for improved services.

If you have not yet signed up for this research please do so TODAY to ensure that your family's needs are described and reported to the Minister. For example, if you think your family would benefit from respite, residential care, or any other services please complete the survey to ensure that your needs are reported.

If you already have a survey please return it immediately to

Sarah Feighan,
Dept. of Psychiatry
Trinity Centre for Health Sciences
St James's Hospital,
James's Street
Dublin 8.

If you have not already received a survey please contact Sarah now to request one on 01 8962315 or feighans@tcd.ie

It will not be possible include any surveys received after June 10 so if you want to tell your family's story of living with PWS please do not delay.

We look forward to contacting you with the final report after June.

We'd love to hear from you!

Email us at info@pwsai.ie

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

Keep
in touch

*Wishing everyone a lovely summer
& we hope to see you soon!!*