

# PWSAI NEWSLETTER

Hi All

Welcome to our summer newsletter, yes I have been informed it is summer. I even checked the calendar -- it is summer!! We have a few new pieces for the newsletter, we have a new family writing about their first experience on attending the family support day in Nenagh in Tipperary, we have a new website and we are looking for content for that. Anthony Carr was at a conference in England on PWS and he has written a piece. Marguerite Hughes gives us an update on the new ideas and some of the workings of the Committee, Pauline Kerley tells us about her Fundraising Disco! and we have a few dates for your Diary! Do you want to see something in your newsletter just email me [annosmile1@hotmail.com](mailto:annosmile1@hotmail.com)



## PWSAI Website

PWSAI is currently updating and revamping its website. We are seeking to modernise the layout and content and to create a website that is useful lively and welcoming. If you have any suggestions for content or features that you would like to see included please send them to me at [webmaster@pwsai.ie](mailto:webmaster@pwsai.ie)

Thanks,

Brian

*We hope exams went well for all those that were doing them! And for all the parents who had to endure them! What's a few more grey hairs!! Best of luck with the results!!*



## **Aoife and us!** Our Áoife was born 4 weeks early

**weighing 5lbs 4oz**, we found out when she was a month old she had Prader-Willi Syndrome. The day of the diagnosis is still very vivid. I can remember dressing her up that morning in a lovely pink dress and matching coat that had been bought for her by her Granddad and she looked a picture. We only had her home a few days and were still excited about dressing her up. Afterwards I couldn't look at the outfit without sadness. It was like the before and after. I was not the same person that had dressed her up that morning. We went around for months accepting the hand we had been dealt in some ways but in other ways we were in denial about the reality of life with her condition. Despite this we decided from the very beginning we weren't going to accept what is the standard outcomes for a child with PWS. Áoife was dragged everywhere with us. She was at picnics and though she couldn't sit up herself we had her in a Bumbo seat so she sat on the picnic rug with everyone else and was just as much a part of things. There could have been a temptation because she was quiet baby to leave her alone but we didn't. She was brought swimming despite very poor head control and floppiness. She was in a play gym with towels stuffed and wrapped around her to give her support and a sense of the world from a different perspective. She was hung from door frames in a bouncy seat to get the feeling of being upright. Though God love her she was like a rag doll just flopping there. She has slept in a tent on more than one occasion and has been to many Irish dancing Feiseanna. She loves music and dancing and being outside. We decided we were going to carry on as normal and she was going to become part of everything as much as possible.

By chance we saw Oisín O'Neill and his parents on TV3 around the time we were deciding on Growth Hormone Therapy. I got in touch with his mother Ann and it was from then we started to not live in our bubble of denial and get out and about and talk to people and tell people about our little girl. We felt that every person we told and explained the condition too was another person educated. When we found out about a day for PWS families we decided we were going. There may only be one family member with PWS but really it's the whole family that has it. We arranged to go along to Nenagh for the PWS Family Day and face the realities of the condition. We hoped we would get information and strength from people who had more experience with this than us. In reverse, we hoped our story could possibly give insight to other families.

The first child we met was Mary Rose age 5 who is wonderful and so happy despite everything she has faced. After meeting her and her family and having a conversation we were immediately struck by their energy and enthusiasm. This is something we think of on the days when energy and positivity is in short supply. The first adult we met was Peter age 42 and he gave us great hope for the future.

On the morning of the meeting we went for a spin to Lough Derg. We were all feeling anxious about the meeting and not really knowing what to expect. When we got back to the hotel we met Jack standing beside his mother's car. He waved over to us and when I waved back he came over and introduced himself. He proceeded to help me unload all the bits and bobs I was holding for Aoife and chatted to her whilst we finished unloading the car. Meeting Jack at that moment set the tone for the whole day. It was go with the flow from there on. It broke the ice for us and we all were much more relaxed by the time we arrived in to the meeting.

We met and played with children who had PWS and their brothers and sisters. We acknowledged and celebrated their many achievements with a slideshow. The children were happy, excited and having a great time. They weren't focused on the negativities. We spoke to parents who had been through the mill and had children who had suffered hugely. But they were there and smiling and getting on with it. Not focused on how tough times had been but that today was a good day and tomorrow will take care of itself. In the afternoon there was a disco and the children absolutely loved it. Their energy put their parents to shame.

I felt going to that meeting helped us greatly as a family. We faced reality and talked about it without glossing over things or trying to pretend everything was fine. We found the hyperphagia that the doctors talked so much about wasn't this terrifying thing. We found out other problems are much worse but people cope and get on with it and have a life. We wouldn't change our Aoife or her PWS. I don't know where Aoife begins and PWS ends but without this awful thing, she would be different and I love her just the way she is. She is the best thing that ever happened to our family. I know we worried and cried and grieved but I wouldn't give her back. Being with her gives us comfort when we are sad and she makes good times even more special. She makes us people we didn't think we could be. A broken heart just makes room for more love. She has cemented our whole family together and strengthened ties with our extended family.

That evening when the kids had gone to bed all the Mammies and Daddies had a bit of time to chat and get to know each other. Every single parent we met that weekend without exception was genuine, helpful, kind people. I don't know if they were this way before PWS or because of it. They have struggled and continue to struggle on a daily basis but get joy from their children. There was some great wit flying around, banter and more than a little singing. It showed us there is life after a Prader Willi Syndrome diagnosis.

The next morning, the kids were in fine spirits but the parents were a little quieter. On the trip home we talked about what we had seen and heard and decided we were the better for it. It was seeing Óisín and his family on TV purely by chance set into motion our first real steps on a journey of really accepting and living with PWS.



**Aoife enjoying her first PWS support day, with Jack showing Aoife how it's done!**



Anthony Carr pictured with Minister Phil Hogan accepting a donation from Intel in recognition of his hours of work with **PWSAI!**

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### **Conference in Birmingham**

Anthony Carr attended the [Conference in Birmingham-12/06/12: Behaviour & Mental Health in Prader Willi Syndrome.](#)

After the introduction by the new Chief Executive of the PWSA(UK), Susan Passmore, the morning session was made up of 2 lectures –

One from Professor Tony Holland(Cambridge University) on “The physical and psychological issues affecting behaviour and mental health in PWS”, and the other from Professor Chris Oliver (Birmingham University) and his team of post graduates on “Managing challenging behaviours in children and young people”– both of which were highly interesting and informative and I have been promised copies of the power point presentations from both, which when I receive I can forward to anyone who`s interested.

The afternoon was split into two workshops, one for people interested in children/teenagers and the others those interested in adults with PWS. At the workshops there were presentations from residential care providers, as well as people working with Adults in residential care. There was then an open forum for questions and answer session. The panel answered questions but the floor also shared their individual experiences, and how they handled specific situations. The panel was made up from experts in the field, Professor Holland, a representative from Gretton Homes, Voyage and from New Directions (Care

Providers). This was a useful and again, informative session during which there were many questions from parents with teenage children with Prader Willi Syndrome.

This was then followed with a further lecture from Professor Holland followed by Dr Sarah Bernard and finally Professor Oliver.

Topics included:

- Diagnosis and treatment of mental health issues in PWS.
- Assessment and management of children and people with PWS
- Research on Skin Picking.

The conference was well attended with 110 people, including Presenters, Parents/Guardians, Care Providers, and PWS UK Committee members.

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## **Residential and respite information**

Myself and Maria Meyler have been working for some time, looking for further suitable residential care. In addition they have been looking to add suitable respite provision to the services available for our older children / adults. To make any further progress, we need to talk to parents to establish what services parents need , who would consider the need for PWS specific residential / respite care and how urgent is that need. We have also become very involved, because of where we are at in our lives, with managing challenging behaviour and trying to find professionals who are willing to help us. Through contact with parents , we are now more aware that myself and Maria are not alone and that many of us are dealing with sons and daughters who have very high anxiety levels and whose very challenging behaviour can be very difficult, very disruptive and often times very distressing for both them and us . So we have been looking at the services available (or lack thereof) to help us to manage the anxiety and the behaviour. We are keen to try to improve both the information available but also to improve the services. In particular, the Association needs to be aware of professionals such as psychiatrists, psychologists and behaviour therapists, in particular, who have worked successfully with persons with PWS or who have carried out research into PWS.

At this point we would like to invite you to meet with us and other parents of children over 12 years. The purpose of the meeting is to share information, to establish the needs of parents and to work together to get better services for our children. We would urge you to attend because we are unable to progress this without your commitment at this time. We will finalise a date and venue as soon as we can establish how many would be willing to attend. Please call me on 087-9354914/01-8370863 or e-mail me at [anngrassick@hotmail.com](mailto:anngrassick@hotmail.com) and let me know if you are interested in attending.

Thanks,

Ann Grassick

## PWSAI Membership ... what do you think?

As some of you know, I joined the Committee of PWSAI in late 2011. One of the projects that we have been considering since is formalising PWSAI's membership – in other words, asking people to sign up as members on an annual basis. While this might not sound very important, I think that having a formal membership could make it easier for PWSAI to find out more about and act upon the wishes of those with PWS and their families. In addition, I believe that organising membership in this way could enhance our credibility and legitimacy as a national association and give us a formal mandate to pursue the objectives that are identified by the members.

Of course, while I am personally in favour of PWSAI operating as a formal membership organisation, I believe that this would only be appropriate if it was what the majority of potential members (i.e. you) want. As a way of finding out more about you want, I will be sending a very brief questionnaire to all of you within the next few weeks. Even though I know that lots of people do not like questionnaires, I would be very grateful if you could take a couple of minutes to fill it out and return it. If anybody wants to get in touch in relation to this my contact details will be included with the questionnaire and I would be very happy to hear from you.

Many thanks for now!

Marguerite

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## Fundraising

Hello to everyone;

We, the Kerley Family, Pauline Tony and Emma had a fundraising event in early May of this year for P.W.S.A.I.

We had a “Bucket” collection in our local Parkway shopping centre. Then we had an eighties Disco night in our local pub called the Horse and Hound. We had a great night it was well attended and both our family's also turned out As you can see from the photographs Emma was the DJ's sound check assistant!

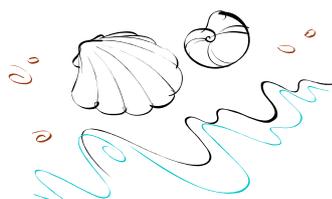
We had a great fun with the spot prizes as both the Kerleys and the Flynns had great competition over the spot prizes with the Flynns coming out on top!

We raised €2,000! We would like to thank everyone for their support, including the Flynn`s, The Kerleys my great friend Lorraine and her mother Marie. Please god we may even make it an annual event!



[Emma doing a sound check!](#)

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## Dates for your diary

Three significant upcoming events that the Committee of PWSAI would like to make you aware of are as follows:

1. Residential and Respite Information Meeting to be held in Dublin on October 13<sup>th</sup> 2012. All families that have previously expressed an interest in securing residential or respite placements will be sent invitations and more information as soon as the venue and time are confirmed. If you don't receive an invitation by the end of September but are interested in attending please contact Ann Grassick.(more details below)
  2. PWSAI Conference 2013. PWSAI is hoping to host a conference with a focus on behaviour and mental health issues among those with PWS. We have provisionally scheduled this for April 12<sup>th</sup> or 19<sup>th</sup> 2013.
  3. PWSAI AGM. We have provisionally scheduled PWSAI's 2013 AGM for May 18<sup>th</sup> or 25<sup>th</sup>.
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Thanks to everyone who contributed this time, Anybody with tips Advice, some fundraiser you did, something to get off your chest or something you would like to share with our pws community, please send it on to me [annosmile1@hotmail.com](mailto:annosmile1@hotmail.com) and we can put it on our next newsletter,

Till next time

Thanks

Ann O Neill