PWSAI CHRISTMAS NEWS LETTER 2014

Hi all. Welcome to the 2014 Christmas newsletter!

We have all the news and pictures on the family support weekend which was held in Limerick in October last. We also have news from the conference held in Dublin in September.

The annual Family Support Event was in Limerick this year. The whole operation was organised by Tony and Pauline Kerley assisted by their daughter Emma, and a band of family and friends who left no stone unturned to give us all a great weekend! The Fabulous Castletroy Park Hotel was the venue and the weekend kicked off on the Friday night with a room organised with various activities to keep everyone happy. We all met and mingled and eased back into old friendships, Some took an early night and were all set for the jam packed day ahead. Saturday started with a cuppa and again the room was filled with activities for all, which included a chance to get your nails done professionally! Next door there was an iPad camp, which was ran by “Lets go Summer Camps” and Sarah was our very helpful iPad camp leader (we would like to thank them for giving us the use of the iPads free of charge). Added to that we had a Teddy bear mountain, where young and old were able to choose a Teddy, a dinosaur, a puppy or whatever took their fancy and have it stuffed. They also received a certificate of ownership of their very own keepsake from the weekend! There was also a magician, and some music, mostly ran by DJ Emma Kerley! And phew after all that everybody needed lunch! After lunch we had “The fantastic Race with a difference” which turned out to be a Pigeon race for which each child, teenager, and some adults were given a ticket which corresponded with a pigeon! The pigeons were left go in full flight and the race was on, all pigeons were tracked and the winner would be announced at the Gala dinner that night. There were a few free hours for families to enjoy the lovely walks nearby or use the pool in the hotel. Then it was time put on the glad rags and go to our now annual PWSAI Dinner dance. Again the hotel had the room looking fantastic and we were served a beautiful meal. There were certificates given to those fantastic people who cycled in the Galway cycle for PWSAI.

There was a slide show Titled “Me being me” which showed all our children, teenagers, and adults with PWS doing all the wonderful things they do best! And to finish, each person with PWS was given lovely hampers to take away, which had something for everyone. But not before the DJ came on and we danced the night away. And there were some great moves on show. Even after a late night for some we all still managed to get up for yet another surprise. It was the “Party Bus”, a double decker bus, which had been transformed into a mobile playground inside. There was also a bouncing castle and face paints and while all these activities were going on all weekend, all the parents were able to chat and offer support, advice, and laugh at and smile at, all the funny things only us as parents of a person with PWS get!

At 1pm it was time to go home and as everyone said their good byes the question was who would be doing it next year!!!!!!???

A huge thank you to Tony and Pauline Kerley and, of course, their family and friends who helped out at the weekend. Thanks to the Castletroy Park hotel whose staff were so helpful in every way. It was a great weekend and the highlight of many a family’s year!

PWSAI Conference 2014

On September 17th PWSAI's 2014 conference entitled "International Perspectives on PWS: A Lifespan Approach" took place in Dublin. Over 90 people attended including representatives from 30 families. It was particularly gratifying to welcome 6 families who had never previously attended a PWSAI event.

As those who were there for the full event will remember, it was a long and busy day! From 9.15am to 5.30pm one speaker after another, all internationally renowned in their fields, took to the floor. We had planned the conference with the explicit aim of ensuring that it would offer material of relevance to adults who have PWS as well and babies and children who have PWS. We believe that we succeeded in this regard and were delighted to observe so many families asking questions both in the formal question times and at the breaks. We were also very happy to receive so much positive feedback from the audience on the day.

The speakers too expressed their delight at the engagement of the audience and thanked PWSAI sincerely for inviting them to present.

For those of you who missed the event or would like to watch the presentations again please go to this link where you will see recordings of the speakers presenting on the day: http://pwsai.ie/annual-conference-2014/annual-conference-2014-presentations/

If you would like to see the presentations but don't have internet access, or would like to send a copy of the presentations to somebody who doesn't have internet access, please contact Ann on (087)9354914 to request a (free) DVD of the presentations.

Big thank you to Marguerite Hughes and Don Tallon in organising such a great conference and co-ordinating all the speakers for the conference it took a lot of work and I'm sure a few sleepless nights so a big………

Making Films

As you will know, one of the 5 projects that PWSAI has decided to spend Galway Cycle funding on is the production of training films about aspects of PWS. After several months of planning the practical elements of this work began in September, when we filmed three professionals talking about new diagnosis (Dr. Susanne Cassidy), growth hormone treatment (Dr. Charlotte Hoybye), and behaviour and mental health (Prof. Tony Holland).

In October we brought a film crew to the family weekend in Limerick to film families offering their perspectives on these subjects, as well as on dietary management.

In total 11 of the families who came to Limerick volunteered to participate in the films. I had the privilege of observing all the interviews being filmed as I was assisting the crew. I found the experience profoundly moving and inspiring. One after another families spoke of their fear and devastation at the initial diagnosis and went on to reveal how they had risen to the challenges that PWS presents. Of course, one of my favourite parts was listening to parents who, with obvious pride in their voices, described the many achievements and positive characteristics of their family members with PWS. Another high point was watching people with PWS willingly and confidently participate in the films.

None of the families who participated in the films stand to gain from their participation. Yet all were very eager to try and ensure that other parents whose children are diagnosed with PWS receive information that is more accurate and (in many cases) also more hopeful than the information they themselves had received.

As editing is still ongoing, it will be some time before the films are ready to be released. However, from what I have seen so far I feel very sure that they will be a hugely valuable and inspiring resource for families. PWSAI is very grateful to all those who participated. Thank you!

Marguerite

Prader- Willi workshop

With some of the funds received from the Galway cycle we are setting up a workshop called “Living well with Prader-Willi Syndrome”, which will be run in early February 2015. This is aimed at children from birth to 12 years and will be dealing with every subject from speaking about PWS to family, friends and to the child with Prader-Willi, good habits on diet, exercise and communication, understanding and working with different behaviours, getting ready for school etc and any other topics parents may want discussed,

If you think this is something you would be interested in please contact me

Ann O Neill 0863912678 or email annosmile1@hotmail.com

School Help

Again due to GC funds we are trying to help families in any way we can. The more I learn about PWS the more it seems that having PWS and going to school can bring its own challenges.

Before I had my son Oisin, in my former life!! I worked in a school for children with special needs mainly severe to profound Autism and I learnt so much in that time, I was also trained in many aspects of dealing with added needs and challenging behaviour and it really has helped me and Oisin in finding school life pretty good, now there are a lot of things that I have had to put in place with the school and a lot of communication between us but so far fingers crossed everything is going well (Oisin is in 4th class, he goes to a main stream school with a shared SNA)

So are you having difficulty with your child in School ? Can we help?

If you would like to discuss anything with me or pick my brains as small and all as it is please give me a buzz. If I feel I can help I will or maybe we may know another parent who may be able to.

If I feel I can't help in your situation We have many contacts one being an Educational Psychologist who may be able to help, So if we can help we will, if we can't we might know someone who can!

Contact 0863912678 or annosmile1@hotmail.com

Baseline Study of Prader-Willi Syndrome in Ireland

Another of the 5 projects that PWSAI received funding for from Galway Cycle 2014 is a baseline survey of people with PWS in Ireland. We intend to fund research that will provide a detailed and current picture of how people with PWS live in Ireland today. This 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.

This project will involve considerable time and energy. We will seek to consult with families throughout this process and to keep them informed of developments. While we are currently at a very preliminary stage in investigating options we invite any families who would like to give us their view on this plan now to do so at any stage by emailing info@pwsai.ie or calling 087 9354914.

Of course, we are well aware that we will only be able to develop an accurate picture of living with PWS in Ireland and use this research as an effective service planning tool if we get the cooperation of a large majority of families. On this basis we will be strongly urging all families to participate in the research. People with PWS and their families will own the outcome of this work and will determine how successful it will be.

Other Research

We would like to draw your attention to two research studies for which participants are currently being sought.

1. Studying emotion control in people with PWS

Dr. Kate Woodcock and colleagues at Queen's University Belfast is currently seeking volunteers for a study on Emotion Control in PWS. If you can spare a couple of hours to participate (the study involves a phone interview with a parent and a face-to-face computer game for the person with PWS) please consider volunteering. More information about the study including links to two information videos can be found on the research page of the pwsai website: http://pwsai.ie/research/.

For more information or to join the study you can also contact Kate at k.woodcock@qub.ac.uk or by telephone at: 0044 28 9097 48862.

2. **MRI Study of Neural Endophenotypes in Prader-Willi Syndrome.**

The PWS Research Group at the University of Cambridge is carrying out a research study to find out more about the brain in PWS and is looking for participants with genetically-confirmed PWS, who are aged between 18 and 24 years old. The study would require participants and their carers to visit Cambridge, UK, where the person with PWS would be asked to do some games and have a brain scan. Expenses incurred by participants and their carers in going to Cambridge would be paid for by the research group. You can access a general description of the study, a participant information sheet, and a carer information sheet on the pwsai website at: http://pwsai.ie/research

For more information or to join the study you can also contact Katie Manning at kem60@medschl.cam.ac.uk or by telephone at: + 44 1223 746163

Putting the Fun into Fundraising!

Pictured here are our fantastic 4 after running the Cork city marathon in aid of PWSAI **Thanks to**

Diana Murphy, Trish Cantwell, Rebecca Cantwell, and Laura Downe

WE NEED YOU!!!

Are you a member of PWSAI??

Our current memberships will expire at the end of December 2014.

We are a fantastic association and while we have great support from many different people, we would love to have all of you who support us also become members. Joining is easy - from early 2015 onwards we'll have details of our new memberships available on our website, Facebook and in our next newsletter.

Situation Vacant

Would you like to take up the writing/ putting together of the newsletter! This newsletter!

It's time for a few fresh ideas and it could be you!!

A lot of content is given to you so it really is a case of putting it together and maybe adding a few ideas of your own.

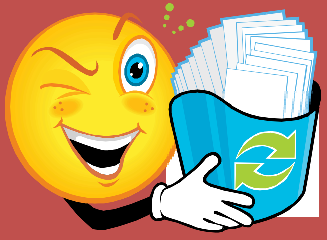
As my guys would say its easy peasy lemon squeezzy!

Come on a new year's resolution for someone maybe!

I'll be waiting ….. annosmile1@hotmail.com

Top tip! Are you trying to encourage your child to do something new or try harder at something, a tip is to get some one important to them to write them a letter, a coach or a teacher maybe (easier said than done I know) but Santa sometimes writes to mine telling them how impressed he is with a certain task they have decided to undertake or how well they are doing

It works every year!



Well that's it for another year

I hope 2015 is good to everyone and we all have a fun Christmas and a cheerful new year! I hope santa comes to ye all!!