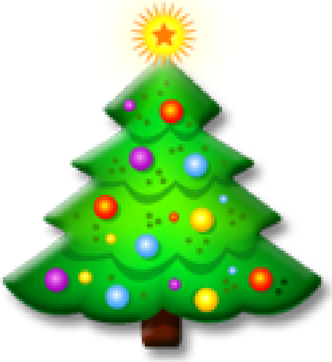
PWSAI CHRISTMAS NEWS LETTER



Hi all. Welcome to our Christmas newsletter! We have news on the working of the committee and what has been achieved and what to mark in the calendar for 2013 thanks for that report to Marguerite Hughes.

There is also a piece about sleep apnea and growth hormone by Elvie Larson who has a little boy George who has just celebrated his first birthday!

We also have a report from our new treasurer Sean

Also a piece about the workings of our fantastic new interactive website if you have not seen it you should check it out

We have a lovely piece from Conor Grassick about his brother Colin and PWS. We have a little bit on fundraising.

If you would like to put in a piece for next year's newsletter be it an article you read, some advice or even a recipe, let us know, you can contact me on

annosmile1@hotmail.com

Christmas wishes,
Christmas greetings,
Christmas joy and
happy meetings,!

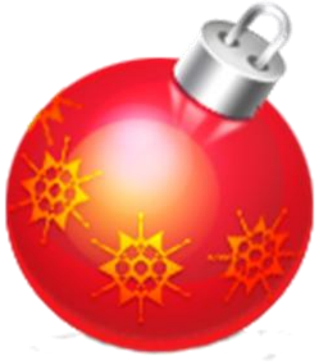
Hoping Christmas
dreams come true
bringing happiness for
you

And then throughout
the coming year, may
your road be always
bright and clear,

May love be close in all
you do and life is
always good to you!

A WORD FROM THE NEW TREASURER

I just want to introduce myself. My name is Sean Kelly. I have a 4 year old daughter, Aoife who has Prader Willi Syndrome and I have been involved in PWSAI since 2009. In October I took over from Lena Lawlor as Treasurer of PWSAI. Lena has been looking after the Associations finances for many years and has done a wonderful job of keeping our heads above water in good times and bad. Thankfully Lena is still involved in PWSAI and no doubt I will be seeking her advice from time to time over the coming months. Just to let you know how we have done so far in 2012, up to November 1st 2012 we received €4,758 from fundraising and donations. In the same period PWSAI spent €10,615 (e.g. Carmichael Centre costs, Phone bills, Printing Cost, Family Day Nenagh).PWSAI rely on fundraising as its only source of income. We are extremely grateful to all those who helped raise money in 2012. If anyone has any thoughts or ideas for fundraising in 2013 please do let us know. Finally I would like to wish you all a very happy Christmas and a peaceful new year.



Speaking of Fundraising!!

As you can see from Sean`s report, funds raised for our association was very low this year. I know fundraising is not for everyone and it may not be easy to find the time or the event. But no matter what you do, No matter how much is raised, it all counts. We have ordered 500 fundraising packs which include a T-shirt, a pen, sponsor card and a drinks bottle all inside a drawstring bag all items in the bag will have the PWSAI Logo on them as well as the bag itself! So let’s put them to use.

RUNNING!

The Ballycotton 10k, There is a 10 mile road race held near me in Ballycotton every year and would have approx. 2000 runners, they pick a charity every year and I wrote to them some time back and asked them to consider PWSAI for their nominated charity and I'm glad to say we have been chosen! So if you know any runners doing this race please ask them to encourage the runners to fill their sponsorship cards!!

I am doing the Cork Marathon next year! Now there I have put it in print so I now must follow through. Ahhhhhhhhhhhh!! I am doing 26 miles for PWSAI. The Cork city Marathon is on the June bank holiday weekend, it is a great marathon really because you can do the 26 miles as an individual as I have decided to do, or get people to do the 26 miles as a team and do it on a relay basis the teams can be as little as 2 or a max of 5! I am going to drag as many people as I know and as many as I don't, to help me complete the miles. I have started my training and I'm up to about 23 miles a week yes a week not a day but have to start somewhere! I aint no Sonia O Sullivan, actually her granny could probably do better than me but any way I just think Oisin faces difficult stuff every day and does it most of the time with a Smile, so I can surely drag myself around 26 miles even if it takes me all day be warned it just might!! Don't think because it is in cork that's it is only local runners the cork city marathon has runners from all over the country

So here`s what you cud do

- Dust off your own runners and do it
- Or get a team together and do it! If 5 of you did it the most anyone need rum is about 5 miles?
- If you know any runners ask them to do it for PWSAI
- Organise a team to run it and you get the sponsorship for them! Tell people about our website and the option to donate safely online
- Take a sponsorship card in my name and ask for peoples support if everyone you know gave you a euro?

Membership Survey Update

In the last newsletter we announced that PWSAI would be conducting a survey to gather your views about the committee's proposal to formalise how PWSAI organises its membership. Since then representatives from 38 families have completed these surveys. Thank you all very much for doing this! For those who are interested in finding out exactly what feedback we received, we are attaching a detailed analysis of the responses. The committee considered each comment received (without knowing who they came from) and prepared replies to them which are included in the attached.

In general we received strong support for our proposal to formalise membership and charge a small annual membership subscription. Respondents also supported our plans to ensure maximum transparency and accountability in PWSAI and to encourage greater member participation. Following on from this feedback we will go ahead with our plans to formally register members. This will not happen immediately because we need to complete one change to our Memorandum and Articles of Association first and also need to ensure that we have robust data protection procedures in place before seeking personal details from families. However we hope to have our membership system up and running and lots of families signed up well before our AGM in May 2013. We will keep you posted on this!

PWSAI's 2013 Conference

Plans are advancing for next year's conference, which is scheduled to take place in Dublin on **19 April 2013** and to focus on Behaviour and Mental Health in PWS. We are delighted to report that we already have three excellent speakers lined up for this conference. These are:

- Professor Tony Holland, a Cambridge-based psychiatrist and internationally-renowned PWS researcher, with whose work many of you will already be familiar;
- Professor Chris Oliver, a Birmingham-based neurodevelopmental psychologist whose research interests include behavioural phenotypes in a range of genetic syndromes including Prader-Willi syndrome.
- Anna Arstein-Kerslake, a disability rights researcher based at the Centre for Disability Law in NUI, Galway whose current work focuses on reforming legal capacity law and introducing supported decision-making.

We will provide more details on the conference on our website as soon as they are confirmed and are encouraging all families to invite all those who they think would be interested to attend.

Committee Update

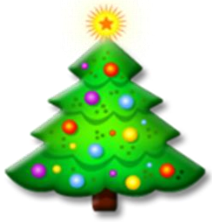
We have decided to include a brief paragraph on the work of the PWSAI Committee in every newsletter from now on in an effort to increase our transparency and, hopefully, to entice others to join us on the Committee!

So, what have we been doing since the Summer Newsletter? We have met twice (in September and November) and hope to meet again in December. These are some of the main tasks that we have been working on:

- April 2013 Conference. In addition to lining up speakers we have been liaising with a possible funder, contacting various medical professionals whose input we are eager to obtain, and organising logistical details including booking a venue.
- Membership Restructuring. As already described in this newsletter, we have been surveying the views of members and making the necessary preparations to formally begin registering members during 2013.
- Governance Code. A comprehensive code of practice for good governance of community, voluntary and charitable organisations in

Ireland was launched in June 2012. PWSAI is currently working its way through the action points for this code and aims to be fully compliant by mid-2013.

- Submission on Domiciliary Care Allowance. The system of Domiciliary Care Allowance is currently being reviewed and submissions were invited from interested parties as part of this process. PWSAI made a detailed submission strongly calling for this payment to be maintained at its current level for all children with PWS. A full copy of PWSAI's submission is available on our website.
- Patrons. We have begun approaching high-profile individuals to request that they serve as patrons of PWSAI. We will update you as soon as we have good news on this front. And, if you know any celebrities who you think could help raise the profile of PWSAI please tell us!
- PWSAI's online presence. As already described, we are now on Facebook and Twitter and are continuing to update our website.



PWSAI Online...

Recently, PWSAI has been expanding its presence on the internet, especially in social media. We want PWSAI to provide information to as many people as possible -- families with PWS, relatives, friends, neighbours, educators, clinicians, and decision-makers. Nowadays, this means that we need to be seen and heard where all types of people are watching and listening, so as well as our direct newsletters and emails, we are now present on Facebook and Twitter, as well as on our new updated website.

Of course, not everyone knows what these services actually are, so here is a quick description of each.

Facebook is a 'social networking service' where, after registering, users create a personal profile, provide information and updates about themselves, and connect this profile with those of their friends so that everyone can stay up-to-date with each other. It is the most popular such service in the world, with over 1 billion users. PWSAI now has its own Facebook page. You can access it at: http://goo.gl/uBYKE. One way that people can support the page and make it useful is to 'Like' it...and to get other people to 'Like' it too! So, please spread the word...!

Twitter is a 'micro-blogging' site where people can post very brief updates or comments (no more than 140 characters or letters in length) called 'tweets' (you need to sign up to Twitter to post tweets of your own). Anyone who chooses to follow a particular person or organisation will get to see all their tweets. A very popular form of tweet is to tell people about an interesting article or service elsewhere on the internet and to include an internet link to it, so that people who see the tweet can click on the link and go see it for themselves. Over half a billion people use Twitter, and PWSAI has now joined this enormous flock of tweeters! If you are on Twitter, please follow '@PWSAI' (and please encourage other people and organisations to do so). Even if you are not a Twitter user you can still view our tweets by going to: http://twitter.com/pwsai.

Our website has been overhauled and is now packed with new features and content. As always, you can access it at http://www.pwsai.ie. As well as containing news and updates, we are also using the website as a place to store information about Prader-Willi Syndrome, and about PWSAI itself. It is also connected with our Facebook and Twitter activities. Also, a very important feature is that we can use the website to receive charitable donations via the iDonate.ie secure payments system. People can click on the 'Donate' button on the website and donate to PWSAI using their credit cards. People can also use the system to fundraise on behalf of PWSAI. Go to the website and click on the relevant links to get more information.

Finally, another benefit of these activities is that people around the world can contact PWSAI directly by posting a comment on our Facebook site or by sending us a tweet using Twitter. As always, however, you can contact PWSAI online by email -- quickly becoming the 'old fashioned' option!!! -- at info@pwsai.ie (or for queries about our online services, webmaster@pwsai.ie). See you on the internet!

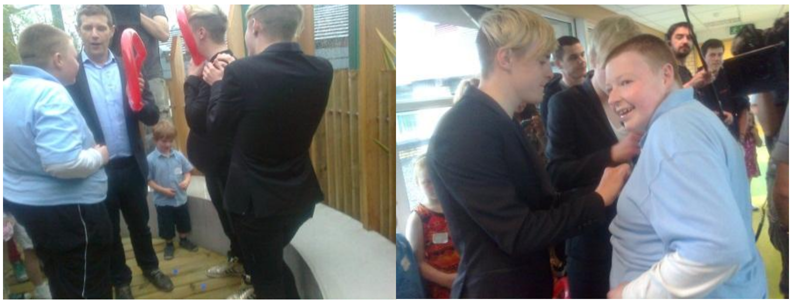
Sleep Apnea and growth hormone written by Elvie Larson about her son George who is now one.

As I'm sure most parents are aware, the endocrinologist will typically insist on a sleep study being carried out prior to prescribing Growth Hormone to ascertain whether or not the child suffers from sleep apnea. Fortunately, in George's case we had been pressing for the last 6months to get him started on GH ASAP which was the only reason, to our dismay, that we found out that he suffered from obstructive sleep apnea. This would have remained undetected had we not decided, as many parents I'm sure do, to go down the GH route as George did not display any of the typical symptoms i.e. snoring, excessive weight, laboured breathing, waking at night etc. When we asked the respiratory consultant why this study is not carried out as a matter of course with PWS infants in view of the prevalence of sleep apnea in these infants, his inference was that the system simply couldn't cope. My own cynical view, for what it's worth, is that the cost of hiring an oximeter to do a home sleep study along with the cepap to treat it is expensive and is costs that are ultimately born by the State as most PWS children would be entitled to a long-term illness card. Needless to say, the waiting list for the hospital sleep lab studies are out the door. That said, the long-term impact of undiagnosed sleep apnea over a 5-10 year period can result in an IQ deficit of 10 points or more, not to mention the lost time and energy that the child will suffer as a result of daytime napping to make up for lost sleep at night which, God knows, is something that a PWS child can do without!

We ourselves noted a marked difference in George's energy levels and daytime alertness as soon as he started on CPAP although finding a mask to fit him and getting him to tolerate it was, to say the least a challenge involving a lot of sleepless nights! We understand that private sleep labs are popping up all over the place in the States but as I understand it, there is only the one here with a long waiting list. The oximeter was certainly a satisfactory alternative for us to detect George's sleep apnea. Nobody told us until we pressed the consultant for GH and we hope therefore that sharing this information with other new parents of PWS babies, or indeed parents of older children, may help them get the help that George certainly needed.

Colin meets the stars

Colin took part in the Dermot Bannon, Room to Improve, programme to design a garden for the children, in Tallaght Hospital.



He was invited back to the opening this summer and surprise, surprise some special guests appeared!!The episode will be shown week beginning 21 December 2012

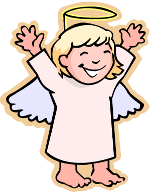
Hi All, My name is Conor Grassick and I am the 19 years old. My Brother Colin aged 15 has Prader-Willi Syndrome. Growing up I knew there was something wrong with Colin, but it wasn't until recently that I really understood what was wrong. Life is very busy with Colin and it is like all plans are centred around him. This used to annoy me when I was younger but now I can appreciate how important it is to plan our days to avoid any problems.

I think this syndrome is difficult and feel sorry sometimes because it seems that Colin is always in trouble. I can clearly see how important it is to be able to handle his behaviour correctly. You can never get angry with him even though you really want to sometimes. You have to deal with him in a firm but nice way.

I have ADHD and find it very hard sometimes not to be angry with him, but Mam helps me work it out. Our house seems mad but we are really happy. I always wonder what Colin would be like if he didn't have this syndrome controlling him Colin is the funniest person I have ever met and his comments to people in public are sometimes very funny. He is also very clever and keeps himself up to date by watching the news every day. He has a hit list for example James Reilly, Bertie Ahern and many more; he would go out of his way to meet them.

I have helped out with the Conference's and Awareness Days and really enjoy them. I look forward to meeting up with everybody and realise that talking to other families really helps me a lot. Colin and Dara Meyler talk to each other on the phone every day, the conversations are very funny but they both really miss each other if a few days has gone by without chatting. This I think would be a good idea if other teenagers were able to chat on a regular basis , and have friends who are the same and have the same pr I passed my leaving cert in June last and am doing a Special Needs course in college and hope to progress into Social Care . I am doing this course because it is really something I enjoy and most of all I hope to be a better help to my Mam.

I love my Brother and would not change him for the world.



What a better way to finish our newsletter I hope you have a lovely Christmas and every good wish for 2013

Ann O Neill