

Prader-Willi Syndrome

Hi everyone, welcome to the 3rd edition of our newsletter!



Again a lot has been happening since our last newsletter. We had our A.G.M and now have a new chairperson in Anthony Carr who has written a little piece for the newsletter, We have a great piece from Lena Lawlor who tells us all about Peter`s big birthday bash`s!! Thanks to Emma Harnett who is our member profile.

This as I have said is our 3rd newsletter and I must say I am quite enjoying the experience but I`m not sure ye are, as my poor e-mail inbox remains sadly empty again! 2 emails hit my inbox from the last newsletter. So thanks to those two ye know who ye are!! So do I dare dream

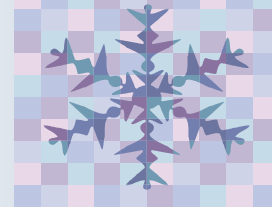
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Lawler who turned the fantastic 40 this year and celebrated in style read on to find out more.

Get well Wishes to Mary Rose who had a serious operation in September and recovered really well her mam and dad said she was a true trooper

We have decided we are going to have a committee ROAD SHOW!! We are going to take our committee meetings to different parts of the country if we are in your area we will let you know so you can come along and let us know what`s happening for you and what we as a committee can do to help. What do you think? Antony talks more about it in his master piece!

We talked at our last meeting about setting up our own Centre of excellence which is getting professionals educated on and about PWS and mixed with their knowledge create a group of professionals that are available to us to deal with each family`s



Christmas is coming and the stress is building up!

Can Santa please bring?

- *Money and time!*
- *A cooked moist turkey!*
- *Tasty Brussels sprouts!*
- *Happy content cranky free, children!*
- *And in-laws!!*
- *A wash up fairy!*
- *A huge surprise for mammy that she didn`t have to buy herself or hint at!*
- *A little bit of snow but still mild outside!*
- *Batteries!!*
We have everything else covered!!!

Individual problems. We are getting names together from each sector like speech and language therapist, dietician. Psychologist, Psychiatrist etc. If you have dealt with a professional and found them extremely knowledgeable or willing to listen or learn you can give us there name and we can add them to our list.

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Oisin Story.

We took part in an RTE radio one documentary it was a great experience, Showing Oisin`s life just as it is, the up`s and the down`s. It is still available to listen to or down load just go to www.rte.ie we would like to thank everyone who sent lovely messages and text`s much appreciated, not sure we will get over our ages being broadcast on national radio thou!! By our 6 year old daughter!

Fundraising



We are organizing new fundraising pack`s so if you have a fundraising event like a run or a marathon, a coffee morning whatever it may be you can contact us and you will receive a fundraising pack, which will include printed headed posters, with a space available on it to write about your event, printed t-shirts, new sponsorship card`s and information booklets

For 2012 we are setting out on looking for patron`s for our association, we have a few great names it is just a matter of getting them to lend their name and face to us, easy I know! Have you any ideas any footballer, soap star, rugby player, G.A.A Star, or someone you know, let me know.

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Oisin action man o Neill playing hurling!

Thought for the day!!!

One day a farmer's donkey fell into an abandoned well. The animal cried piteously for hours as the farmer tried to figure out what to do. Finally, he decided the animal was too old and the well needed to be covered up anyway; so it just wasn't worth it to him to try to retrieve the donkey.

He invited all his neighbors to come over and help him. They each grabbed a shovel and began to shovel dirt into the well. Realizing what was happening, the donkey at first cried and wailed horribly.

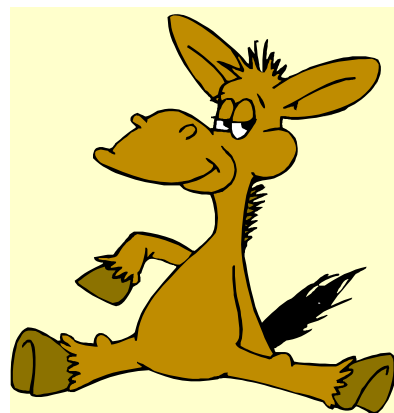
Then, a few shovel-full's later, he quieted down completely. The farmer peered down into the well, and was astounded by what he saw. With every shovel-full of dirt that hit his back, the donkey would shake it off and take a step up on the new layer of dirt.

As the farmer's neighbors continued to shovel dirt on top of the animal, he would shake it off and take a step up. Pretty soon,

the donkey stepped up over the edge of the well and trotted off, to the shock and astonishment of everyone.

The Moral: Life is going to shovel dirt on you, all kinds of dirt. The trick to getting out of the well is to stop wailing, and not let the dirt bury you, but to shake it off and take a step up. Each one of our troubles is a stepping-stone. We can get out of the deepest wells just by not stopping, never giving up! Shake it off and take a step up.

By the way, after he calmed down, the donkey kicked the crap out of the farmer who tried to bury him, which brings us to the second moral of this story: **When you try to cover your ass, you will always get your ass kicked.**



Hi to all Parents and Guardians of PWS Children and Adults.

My Wife Caroline and I have a lovely 4 year old Daughter, Lauren, who has PWS. We also have a Son James, who is 6 years old. Both of them having been born in January think Christmas goes on for a Month, with 2 parties to fit in immediately after Christmas.

I have been on the committee for over 2 years now, working with a Group of dedicated Volunteers, who give freely of their time in the support of all Associated with PWS. A lot of this work is done through networking with each other daily/weekly, as well as meetings to progress the Aims of the Association, as well as providing particle support where and when needed.

At this Year's PWSAI AGM, I was privileged to be nominated and duly accepted the Role of chairman of the Association.

The committee is made up of individuals, who bring a lot of Experience from their individual lives/Career's, as well as representing a wide Age group of PWS Children.

The Association has a wide spectrum of involvement with Professional bodies, Health Care Organizations, Support Specialists, Sister charities etc., to :

- Represent and Support PWS Children/Adults/Care rs/Parents on an on-going bases
- Arrange Annual Conference and Education/Support seminars yearly.
- Work on more long term Goals such as Residential care.
- Building up a Team of Experts, who's services can be used by all PWS Children.

We could not do this work without the continued support of all of you. To all who get involved and contribute in any way we offer our gratitude. Needless to say your continued support is needed, so as to continue the work of the association.

In an effort to make the Association accessible to everyone, we intend to have more of our meetings outside the Dublin region, in the coming year, so as to give people an opportunity

Christmas card time again.

- Christmas cards are an easy way for us to fundraise most of us send cards so make yours a PWS card contact Ann Grassick 0879354914 and place your order ASAP!
- If you're having a dish that requires rice like a curry, use graded, carrot instead of rice, when combined with the sauce it has the same texture as the rice and saves on the calories.
- Fruit Cake for Christmas
- 1kg mixed fruit
- 500ml fruit juice or cold tea
- 350g self raising flour
- Soak fruit in juice or tea overnight, stir in flour mix well, bake in bottom of oven @125 for 2-2 1/2 hrs.

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Leave a copy of our newsletter with family and friends, let them know what we are doing and you would never know what ideas they may have for us!

to meet and engage more frequently with the Committee.

We would encourage as many as possible to attend, and we would welcome any comments/suggestions/ideas people would have.

Details will follow in future newsletters.

Let's all work together to achieve a better future for our Children.

Anthony Carr

Chairman PWSAI



Check out this lovely link on pws on the Canadian website

<http://www.fpwr.ca/2011/announcements/top-10-myths-about-prader-willi-syndrome/>

I know money is scarce for all of us but for the spring party if it is at all possible the more that could stay over, the better, so many of us speak about the best being when the day is down that we sit back with a drink and chat! so start saving now!!

So that's it from us thanks to all contributors', can't wait to check my in box!!

Happy Christmas to all!



March 2011•••

We have decided to hold the spring Day this year, March is the date and venue we are currently looking at is maybe somewhere in Tipperary? It's going to be a day were we will have a disco for the kids, a games section board games cards, arts and crafts etc. so the mam's and dads can chat swap the stories, tips etc. All welcome brother's sister's nannie and granddad's but there is a snag, funds are low so we will be asking all family's to pay for their own lunch.

Accommodation will be available at a reduced price for those who wish to stay over; more details will follow in January

