

PWSAI Summer Newsletter 2014



Welcome to the Summer edition of our newsletter and it is jam packed! It actually writes itself! We have a few different stories from our now famous Galway Cycle! We have news on the amazing fundraising by Lake Region Medical, the workings of our committee and upcoming dates for our diaries!

A very important date for your Diary!

PWSAI's 2014 AGM will take place on June 21st in the Ashling Hotel (this hotel is across the road from Heuston train station) at 10:30am.

All PWSAI members are warmly invited to attend. If you are not a member you can join online now at: www.pwsai.ie

Alternatively you can become a member of PWSAI by completing the registration form and paying the €15 membership fee on the day. If you are interested in becoming a director of PWSAI and would like to discuss this in advance please contact Anthony Carr (PWSAI Chair) on 087 9354914. PWSAI has an ambitious programme of activities planned for the year ahead. We would welcome help from anyone who is willing to lend a hand!

The Galway Cycle

While all cyclists cycled for Prader-Willi, we had a few who cycled because they knew someone special with PW. We had 3 dads of children with PWS, our chairperson Anthony Carr, Rory Tierney and Ray O Neill . Also cycling were godmother to Henry, Claire Keogh, auntie to Aoife, Mairead Kelly, and special friends of Mary Rose, Ronan, Sarah Jane and John. A huge round of applause please!!



As a child my family's menu consisted of two choices,



take it, or leave it!



The Galway Cycle



BE CAREFUL WHAT YOU HOPE FOR!

(A personal perspective on the Galway Cycle 2014 by Anthony Carr)

The journey all started when PWSAI made a presentation to the Galway Cycle Committee in John Hume lecture Theatre, NUIM. We were chosen to present in alphabetical order, as a result PWSAI were last on the night. While sitting there listening to the other worthwhile charities it was difficult not to see the merit in the other charities and how each of them would be deserving of the selection. Despite this my determination and resolve was increased, that PWSAI's unique and special story would be delivered and heard above the others.

The selection process required all presenters to leave the lecture theatre while the committee voted. At this stage it was real "X-Factor" style with anxious and nervous groups left waiting for the committee decision. It really felt like the decision was never going to come, but in reality it probably was no longer than 10 mins. Finally a door swung open and the committee chair announced that the charity selected for the Galway Cycle 2014 was PWSAI. I have to say that once I heard the letter "P", reality dawned on me. The PWSAI team were ecstatic with excitement as the announcement set in and we realised that this win was equivalent to winning the LOTTO!

During my short acceptance speech I committed that I would also take part in the cycle itself, as I thought that if in excess of 200 cyclists were going to put themselves through such personal levels of endurance then so would I. It's at this stage that the GC took on a secondary and completely different meaning to me. The question was, how was I hoping to achieve cycling 400km over 3 days, when I didn't even have a bicycle! I recalled on my way home that night a conversation I had with a good friend of mine over a few pints a year previously, as to ideas around fund raising. One of the crazy ideas I considered on the night was a cycle across the country from Dublin to Galway, but who would be crazy enough to do that!! As with most good idea's it came to nothing, that was until that faithful night in October 2013.

So the GC planning began, initially through monthly meetings with GC Committee in NUIM, ending with bi-weekly meetings as D-Day crept closer. The cycling training started in earnest in a gym in Phoenix, Arizona (above all places) while on work assignment, during Nov/Dec 2013. This continued after Christmas when I returned to Ireland and picked up my brand new bicycle. In mid February the open road training began in earnest, under the supervision of the GC Training team. The training experience in all weather conditions was a challenge, but the camaraderie and spirit was always up beat. The training Marshall's gave freely of their time

every Saturday and Sunday morning to prepare us for the mammoth challenge ahead. We gradually worked from 40km cycles up to 110km training sessions, finishing a week before the cycle weekend itself. It was during these weekends that I met numerous likeminded cyclists all with a common objective to cycle to Galway and back while raising as much money as we could along the way for our charity ...PWSAI. These cyclists reaffirmed in me something that I thought we as Irish people had lost and that was our overwhelming generosity and giving to worthy causes. *How wrong was I!!*

Finally the cycle date arrived on 28th March 2014, when at 06.30, 212 cyclists with support crew left NUIM... What a sight!! Filled with a hearty breakfast we all set off. Weather was wet, but at least it wasn't windy. Things changed by the time we reached our first stop in Kinnegad as we were welcomed with a shower of hail stones. While in the process of dismounting from the bicycle I didn't disengage my cycle shoe from the pedal quick enough and fell over.....I was told on several occasions that it happens to everyone at least once, but I was hoping it wouldn't happen to me in such a public manner. At least I got the mishap out of the way early in the weekend.

A route across the midlands was mapped before us and following stops in Moate, Ballinasloe and Loughrea the last leg of the westward journey was all that was left to complete. A brief stop in Oranmore set us up for a short final cycle into Eyre Square. This was the first time I allowed myself to think that I had made it. *OH, how wrong was I!!* I got a puncture 1km further up the road and had to sit out the last few Km`s in the back of a Mechanic support van while the procession of cyclist made it to the finish line in Eyre Square.

The Saturday was filled with good humour, as we all spread out over Galway city centre wearing our bright blue GC Hoodies. There was no way that the general public could miss us. That evening in Monroe`s it was clear that everyone in attendance, while having a good time, were proud of the cycling endeavour and the personal achievement attached to it. There was also an air of anticipation while waiting for the announcement of the total money collected at that stage. What enriched the occasion was the number of PWS Families who were there to show their support, something which was noticed by the whole venue and gave a greater meaning to all those who had trained and fund raised for months to make the event a success for PWSAI.

Following a number of speeches the time had come to announce the running total. I had a figure of between €50-80k as an achievable figure. *OH, how wrong was I!!!* The running total at that stage was €110k... WOW (and still rising). The urge was great to celebrate, but the return trip loomed early Sunday morning and common sense prevailed. Following a few hour's sleep, made even shorter as the clock's changed that night to Summer time, cyclists started to merge on CIE depot, in Eyre Square. Just after 07.00 the chain of cyclists made their way out of Galway on what was a bright crisp morning. With the favourable weather on our side again steady progress was made as we cycled back towards Maynooth. My own progress was hampered by another puncture just as Athlone was in my sight. With the help of the support team and a puncture repaired I rejoined the pack again.

It was around Tyrellspass, while the pace setting van was trying to get the pack through a narrow section of the road, the pace picked up to a point where the extra effort started to burn the thigh muscles, pushing the pain threshold. Having overcome that and allowing myself to think of the next stop at Mother Hubbard's, yet again I got another puncture. I had at this stage gained a reputation, for staging my punctures so as to take a rest while repairs were being made. In my defence I'm not that ingenious. During the Mother Hubbard stop I felt that cyclists for the first time were allowing themselves think that they had made it. The closer Maynooth came the more irrelevant the pain and energy zapping effort became. The sight of Maynooth Cathedral spire and the sharp bend onto main street Maynooth left one with a feeling of personal achievement. This feeling flipped to one of how significant this was for PWSAI, once I caught the sight of the PWS contingency in the crowd while taking the last turn into the Square opposite Brady's Bar.

Throughout this whole experience I constantly switched from thoughts of how this was a personal challenge to one of how significant this event was for PWSAI. Most of the time both emotions were intertwined with one and other. When I allowed this to merge into the collective goodwill and positivity of everyone around me I knew I was privileged to experience a unique event in my lifetime. I finally would like to thank everyone who made this event such a phenomenal success.



This is a piece written by a marshal at the Galway cycle called Conor McHugh. I just asked him to write a piece about this year's cycle through his eyes!

She's been unusually quiet since Mother Hubards. It's the last stretch. There are 367 kilometres behind and 25 to go. And she's feeling as strong as ever she did during those 367 Kms. The smile is wide, the legs sing up and down. There's something going on in her happy head.

Within sight of the top of the last incline between Enfield and Kilcock, I reach for the button on my radio, press it and say "Right marshalls, when you reach the top of the incline, go then. Just go."

I flick my left hand, the chain moves into the big ring. I flick it twice on the right and take the strain in my legs. They should be tired, they should protest, but the turbo, lacking if I'm honest since Loughrea, kicks in. Before I know it, I'm bent forward over my handlebars and I'm at 40 kph.

As I pass the front, I see Ivor and Caoimhe and Alan rolling in beside me. The radio crackles and beeps in my ear as others relay our move. I feel a presence behind me, and look back. She is on my wheel, glued to it with intent. She has her ticket, she is on this train, because she has something to say and she's been writing the two-sentence speech in her head for the last hour.

In truth, we all have something to say. We do this every year. When we're within sniffing distance of Kilcock, with no hill left to nurse anyone up, the marshalls move to the front, and head in before everyone else in order to clap them all through the square.

It's the marshall's own small way of paying tribute to the hard work that got everyone to Galway, and home again. But it's also a special moment amongst ourselves. For the first time in 12 weeks, we're on a bike with no responsibility and no reason to look behind.

As we reach the turn off into the town we are two neat parallel lines of fluorescent yellow. Legs like pistons, breathing is faint, mind is clear, heart is strong, soul is light. Sometimes there is happy and relieved chatter. Sometimes I'm lost in my determination to get to the square and have my say.

I look to my left and she's there. Legs rotate smoothly, shoulders relaxed. Eyes are steel behind the glasses, face is wrapped in a pink scarf - Ninja Marshall has something to say.

Into Kilcock, down past the petrol station, barely pointing at the holes. No need to shout, 12 weeks of this - we all know where they are.

Into the square. Fling/prop the bikes up, arms tighten around you. Helmets clash, ear pieces fall out with all this urgent non verbal communication. Maybe you just say "well done", or "we did it!"

What you actually want to say is more of everything: "You poured your soul into these past 12 weeks; you stood beside me as I put my life on hold to dig the foundation, plaster the walls and tile the roofs of the dreams of hundreds of people who cycled, cheered, clapped their hands, rattled their buckets, told their stories, cried when they couldn't get another inch from their bodies, asked us for a nomination and changed their lives - you gave your heart, your tired legs, your dodgy knees, your good advice, your exhaustion, your puff when I could push no more, your blood and your sweat. And now as you try to stop yourself from giving your tears, I love you like a brother/sister."

But then, you know, for those inarticulate moments, a bear hug says all that, and a lot more besides.

Then the dam bursts and she says it. It comes gushing out imperfectly, garnished with the salt in her tears. "From the bottom of my heart," she says, pouring the words into the bottoms of ours, "I want to thank you for everything you've done for Henry. You don't know what a difference this will make to his life and the lives of all the children with Prader Willi and their families."

Dry eyes are in desperately short supply.

She is Claire Keogh and she is Henry's mother's best friend and his godmother. And in 2014 she was always the embodiment of the dual magic of the Galway Cycle - how it can change the lives of the people who take part in it, and the lives of those who benefit from it.

PWSAI came to us with low expectations in the sense that they didn't expect to get the nomination. To even get a chance to make the presentation was a big deal. But two things were in their favour - they had lots of friends in the Galway Cycle family through their

association with Emma and Rory - two extraordinarily brave people who invited us into their family's often time traumatic story for the benefit of all other future Prader Willi families - and their circle of friends.

And they also had the default position of the Galway Cycle family in their favour - we like to make a difference, a clear identifiable difference. And in PWSAI, it wasn't hard to see what that difference could be. I learned long ago never to underestimate the difference the Galway Cycle could make to a person's life, and what it could mean to them.

Hardened men have framed pictures hanging in their homes of the moment they arrived into Galway for the first time. Some have met their spouses, their best men, their best friends on a Galway Cycle weekend. All of us have met a little bit of what we like about ourselves.

Every year we make a difference to the lives of people involved in a cause that we supported. Sometimes it's the money, sometimes it's because we gave our favourite weekend of the year to them, and sometimes it's nothing more complicated or profound than that we let them share the stories of their troubled hearts with us. Either way, I'm reminded that cycling and the Galway Cycle reveals to us the better angels of our humanity.

On the way into Galway, as I was counting down the kilometres, I saw a man in a blue jacket cycling along the inside beside one of the most experienced of us, Fergus.

I could see that his tyres were soft enough and it was pulling on his reserves. I called over to him and suggested he pull over and get the mechanics to give him a blast of air. In a lovely east Cork lilt he replied with equal parts friendliness and determination: "I've a wife and five children inside in Eyre Square waiting for me, and one of them has Prader Willi. And I'm not getting off this bike!"

Fergus gives me his reassuring look and says in his gentle way "Sure we'll keep an eye on him." I speak into my radio to tell the other marshalls that there's a man back here that we're pushing all the way into Galway if we have to. Because sometimes as the song says, we get to carry each other!

A selfie of the Marshalls!



PICS OF THE WEEKEND!

Here are some of the pictures from the weekend it truly was one I will never forget and will always be thankful for, For once I was in a place where so many people knew about prader willi, where prader willi was NOT a unknown syndrome, it was a weekend where people of all ages were shouting from the rooftops about needing support for prader willi and it at times was over whelming!

A sincere thanks to all cyclists, all Marshalls, all collectors, all supporters, the PWSAI committee, everyone and anyone who helped in this fantastic weekend and made it an unforgettable experience!



PWSAI Conference - 17 September, 2014.

The 2014 PWSAI conference entitled, "International Perspectives on Prader-Willi Syndrome: A Lifespan Approach" will take place in Bewleys Hotel Dublin Airport on September 17th 2014. We are delighted to announce that the following prestigious international speakers on PWS have already agreed to present:

Dr. Hubert Soyer (Germany) "Overview of Supported Living for Adults with PWS in Germany";

Dr. Susanne Blichfeldt (Denmark) "Healthcare for Adults with PWS and Evolution and Development of Adult Services in Denmark";

Georgina Loughnan (Australia) " Family Care and Physical Therapy for People with PWS";

Dr. June-Anne Gold (UK & USA) "Genetics of PWS";

Prof. Tony Holland (UK) "PWS from a Research Perspective: How are New Interventions Developed?";

Dr. Suzanne Cassidy (USA) "Overview of Health Issues for Children with PWS"

Janalee Heinemann (USA) "Overview of Current PWS Research"

We believe that this conference will offer a wealth of information in relation to supporting both children and adults with PWS and are delighted to have attracted such an expert panel of speakers. Topics of particular relevance to adults with PWS will dominate the morning sessions while the afternoon sessions will focus more on children's issues. This will enable people to attend for only part of the day if they wish.

Funding received from the Galway Cycle means that we will be only be charging €15 per person for attendance at the event. This will include lunch and other refreshments.

PWSAI also plans to make available a small travel fund to assist families from outside Dublin who would like to attend the conference, but could not afford to do so without financial support. We will provide further details in relation to this when the conference registration system is finalised.

We expect to set up the online conference registration system in June and will make families aware of this via Facebook, email and post. For those who do not have internet access it will also be possible to register by phone from June onwards.

Early booking is really advisable as there is limited space and we expect it to fill up fast.



Middletown Centre for Autism

The Middletown Centre for Autism offers free parent training courses throughout Ireland on topics including social communication, positive behaviour strategies, anxiety management and visual strategies. While these are specifically geared towards parenting children with autism and the trainers are only trained in relation to autism, many of the courses may also be relevant for parenting children with PWS. The Middletown Centre for Autism confirmed to PWSAI recently that all parents of children with PWS are welcome to attend these courses free of charge. If you are interested you can see the full list of courses and book online at: https://www.middletownautism.com/training-for-parents/?order_by=date

If you do not have internet access and would like us to post you the information please get in touch.

LAKE REGION MEDICAL FUNDRAISE FOR PWSAI AND RAISE A WHOPPING €19,000!!!!!!



Lake Region Medical choose a different charity each year to support. In 2013 PWSAI was lucky enough to be one of the charities chosen. We wrote a letter to the company giving some information on the condition and Brendan brought it into the event organiser. A number of other charities were also put forward. Finally they were whittled down to two national charities and 2 local charities. All employees in the company had a chance to vote on their charity of choice. Brendan went around the company drumming up support and trying to get people to vote for us as the national charity of choice. We also emailed and texted people we knew who were on other shifts or who had family members or friend on other shifts. When the ballot was counted everyone was very excited to discover PWSAI was to be the national charity and the Neo Natel Unit in Waterford Regional Hospital was to be the local charity. Any funds raised were to be divided between the two charities. Most people in the company had never heard of PWS and didn't know that their colleague had a child with the condition. The Lake Region Staff and Management always throw themselves into any fundraising efforts and have been hugely supportive to local charities in New Ross such as the Community Hospital. However, knowing Brendan had a little girl with this condition made it very personal for people and they worked really hard at coming up with fundraising ideas. There was an operation transformation, some staff members did fun

runs for the organisation, there were books sales and cake sales. Jonny Evans from Manchester United donated a signed jersey which was raffled. There was a also a car draw. A hugely successful fashion show was organised, in fact the amount raised at this year's fashion show broke records. The models were all Lake Region Employees and they did a great job strutting their stuff up and down the catwalk, amid a lot of cat calls. The MC for the night was the Continuous Improvement Manager. Following all the modelling and announcing a disco started and all the workers let their hair down in the name of charity.

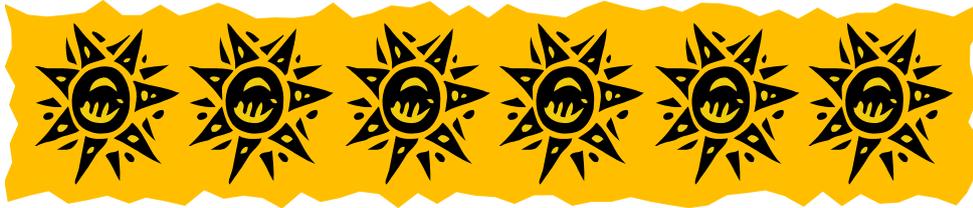
I recently met with the Charity committee and the Managing Director for the presentation of the cheque. Mr. Harris, the MD was very interested in the condition and asked loads of questions. He is interested in having something put in the staff magazine from time to time about the condition and maybe some photos from our Family Days. He asked what we hoped to do with the money and I said our wish was for the fund to go towards Family Days as these events provide so much support and information for families. For our special people it provides an occasion where their achievements can be celebrated amongst people who truly understand that walking is an achievement, cycling a bike an achievement and scoring a goal for your hurling team is an achievement. It provides time and space for families who are all struggling with one challenge or another to come together and talk and be really understood.
Written by Michelle Ryan

Huge thank you to all involved especially Michelle, Brendan and family!



A picture of the staff at Lake View Medical presenting a cheque of €19,000 to Michelle and Aoife stealing the show as always!

This year's Family Support day!!!



This year's family support day is being organised by Pauline and Tony Kerley and I am sure their daughter Emma has a huge say in it as well.

The date is drum roll please the weekend of 3rd 4th 5th of October 2014.

The location is the Castletroy Park Hotel in Limerick.

Pauline has loads already in place, we will have a mini iPad camp and a few surprise activities and the now annual PWS dinner dance is going to continue so make sure to bring the glad rags!

Please book direct with the hotel and mention that you are part of the Prader-Willi syndrome group. The price for the room per night B+B is €85. This is a max price but will be reduced according to the amount of people that book. So if you're interested get booking!!

Please also inform Pauline when you have booked as to how many of you are going and the ages of the children that are attending. This is very important in organising the weekend activities later in the year and Pauline will need some details and maybe some pics of you and your family for our achievement awards!

paulineflynnkerley@hotmail.com or phone 0874138619

A more detailed agenda will follow in time so remember to book early and contact Pauline as soon as possible as she is eager to get started and there is a lot to organise to make the weekend another one to remember.

So that's another news letter. Hope to see ye at all the various event coming up. Make sure to mark them in your calendar and if you want anything in our next newsletter pls contact me annosmile1@hotmail.com or 0863912678.