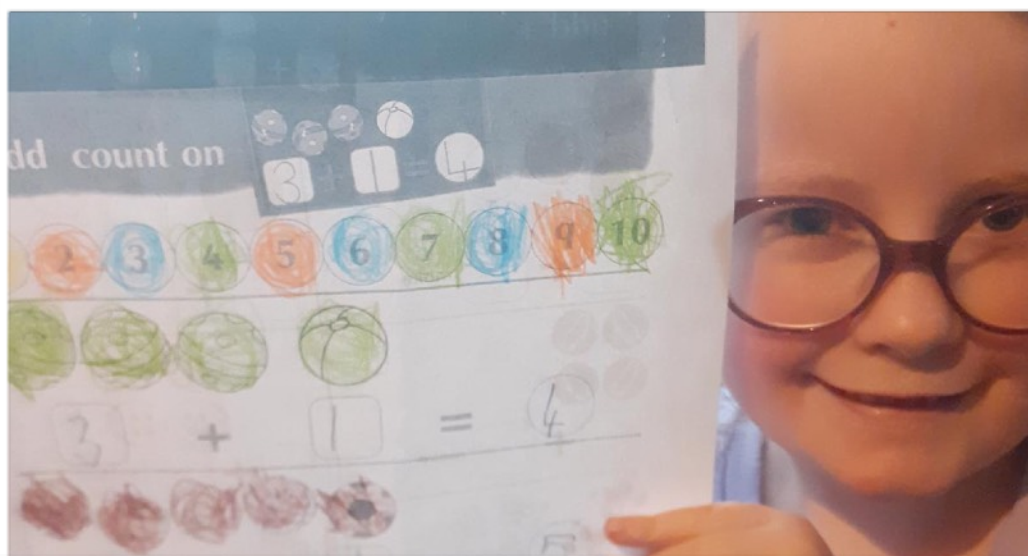


PWSAI Newsletter



Hi Lexie! Well done on all your fantastic learning! Gold Star for you!!

Hello

We hope you and your family are keeping well. Spring is in the air and fingers are crossed that restrictions will ease soon. Schools are now back on a phased basis and isn't that a welcome development for all!.....

There's lots to read in this edition of the PWSAI newsletter! Thank you to all the fantastic people with PWS who shared their photos.

SAVE THE DATES

1

**GO ORANGE FOR PWS
AWARENESS**

28th May 2021

Wear Orange today!

2

PWS 5K

Virtual

28th-30th May 2021

3

VIRTUAL CATCH UPS

Let Emma know if you
& your person with
PWS are interested!



Hi Adam!

We hear you're having great fun throwing stones into the river on your weekend outing!



Hi Finn!

Thank you for sending this photo of you and your cat! It made me smile!



Hi Henry!

Congratulations on cycling every single day in February!! A Virtual trophy for you!



Would you be
interested in a
Wellbeing Workshop
for Parents?
Let Emma know!

PWSAI Board updates

The Board of PWSAI continue to meet virtually during these tough times and there are many projects being worked on, albeit with some delays due to covid19.

We also have some new subcommittees set up on specific areas. You don't have to be on the board to join a sub-committee and maybe you think you could help out by joining one.

Currently we have 4 working sub-committees which are:

- International Conference
- Residential and Respite
- New Diagnosis
- Fundraising & Awareness

We also have plans to set up an Education sub-committee. These are the key working areas of our charity at the moment. So if you would like to get involved feel free to make contact with Emma or any member of the board.

It all counts!

We are always looking for new fundraising opportunities at PWSAI and here's your call to help! We've recently set up a new fundraising sub-committee in order to generate some funding for the International conference in Limerick in 2022. Most people shudder at the thought of wandering up and down a street shaking a bucket and shouting at strangers. But there are other ways! This is where we want to think outside the normal fundraising channels. We are looking for ideas and connected people in order to get some simple PWSAI fundraising streams set up.

Do you work in a company that may be willing to help out by giving their charity donations to PWSAI?

Do you know people in different companies that would choose PWSAI as a charity partner?

Do you have any income generation ideas?

Could you run or walk or cycle every day for a month?

Could you encourage your work colleagues to compete in a step challenge?

It all counts.

If you have any ideas or would be interesting in helping out contact Rory at the Fundraising committee on Rory.tierney@pwsai.ie



A MESSAGE FROM THE NEW DIAGNOSIS SUB COMMITTEE.

The PWSAI New Diagnosis Sub-committee is looking for help! This sub-committee was set up to create supports through mentoring for new parents. If you have a few minutes to help out, please fill in the below surveys, we would be very grateful.

1. Life as we know it - Answers will feature on our website in the section for New Parents. Please answer the questions like you are talking to a new parent of a baby diagnosed with PWS. Click [here](#)
2. Your child's diagnosis : The purpose of the survey is to gain a wider understanding of how the diagnosis was delivered and received plus the lasting effects. Our goal is to be able to compile a list of suggestions that could help new parents at the time of diagnosis. All information received and shared with new parents will be anonymous. Click [here](#)

PWSAI

Membership is now due: 2021 through to 2024. Membership is 15 euro for 3 years. you can sign up on the website or click [here](#). Thank you to everyone who has signed up so far.

PWS 5K 28th-30th May 2021



Due to the current situation and uncertainty on group gatherings the PWS 5K is going virtual again this year.

Given the huge success of last years remote running and walking and the great excitement it generated for all our families across social media we just couldn't go without this year! But there will be some changes!

This year the event will take place on the last weekend of May to give all your school friends a chance to join up and take part so spread the word!

Also apart from just signing up to run you can also set up your own 5k fundraising page and ask your friends to sponsor you! We at PWS5k HQ know what a big deal it really is for someone with PWS to run or walk 5k so go out there and make people sponsor your efforts!!

You can do your run or walk at a time that suits you anytime through the weekend so it's time to get thinking and training, the big launch will be coming soon!!

www.pws5km.com

Age specific PWS Groups.

We have launched these groups on facebook. They offer great parent-parent support and advice for your child in your age group. If you'd like to be added please get in touch with Emma.

PWSAI Updates WhatsApp Group

Have you joined? We share news and relevant information here, so if you'd like to join, please let Emma know. This is an admin controlled group so only key information is shared.

Hello PWSAI Families,

It has been a difficult twelve months for everyone but there is a glimmer of hope that we are close to a return to some sort of normality and the opportunity to meet up with family and friends.

Here in PWSAI land, 2020 brought about a considerable change in how we communicate with our stakeholders. The PWSAI family event moved online as did all of our awareness training options and meetings.

At this stage all of our families should have received copies of the Medical Alert Booklets in the post. This booklet is a valuable resource that can be handed out to your GP, service provider and other family members as well as giving a copy to your person with PWS to carry with them. The booklet contains necessary advice for any medical professionals that you come into contact with.

For families that are having difficulties accessing services, we have produced a Pathway to Services document that will take you through the steps of the application process i.e., who to contact, how to complete the assessment form etc.

In 2021, the various sub-committees in PWSAI are working on a number of projects to support our people with PWS and their families. The publication of our national report, in collaboration with the HSE on the current state of service provision for people with PWS in Ireland is nearing completion and will direct PWSAI strategy for the coming years.

An exciting opportunity for siblings to participate in research on their experiences of growing up with a brother or sister with PWS is due to commence at the beginning of March. The information on how to participate is included in this newsletter.

PWSAI have been invited to participate in the Disability Participation and Consultation Network. The group, working in collaboration with the Minister for Disabilities, and led by Inclusion Ireland, the Disability Federation of Ireland and Aslam will represent the views of people with disabilities and ensure that those views are included in any policy decisions concerning them. PWSAI will have a voice within this network to support the wishes and needs of people with PWS nationally that will influence decisions made on their behalf.

PWSAI are currently working on a project to develop and 'Our way of life' advocacy group for adults with PWS. Individuals engaging with the advocacy group will have a greater sense of ownership and control over their relationships and activities, with a 'shift in power' where advocates influence services and structures within their lives through collaboration with the board of PWSAI. It is envisaged that our group will join a wide network of PWS advocacy groups around the world.

And finally, during 2021, myself and the board will work in tandem with IPWSO to deliver a successful IPWSO Global Conference in 2022 in Limerick. The conference will bring a number of experts from around the world to Limerick and importantly give all our PWSAI people with PWS and their families an opportunity to come together to learn, teach and support each other and families from around the world. We will be organising information sessions in the coming months, keep an eye on the website for updates.

If you require information or supports on any PWS related topic, please contact me at gary.brennan@pwsai.ie.

We're all in this together,

Gary.



PWSAI Living Better with PWS workshop

Ann O'Neill has kindly agreed to run the PWSAI Living Better with PWS workshop for 0-12 year olds virtually in 2021. This is a great opportunity for new parent and a great refresher for people who have attended before. Date to be confirmed but please email Emma to let her know if you're interested.

Virtual Catch ups:

We are organising virtual catch ups- The first will be for people over 16 with PWS. Please let Emma know if your person with PWS would be interested.



Wear Orange on May 28th for PWS Awareness Day & don't forget to share your photos for our social media.

Family weekend 2021

Sadly, this year we will be unable to host the PWSAI Family weekend due to the Covid19 pandemic. We hope to host the weekend in early 2022. Thank you again to the McEntee family for all the organising, planning and rescheduling. Once we have further plans we will update everyone. We plan to organise Virtual Catch Ups for 2021, so please let Emma know if you'd be interested in joining. And of course we will have a virtual family get together in October!

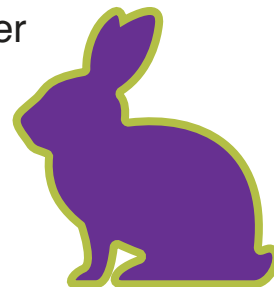


International conference virtual information evening

Excitement is really building for the International PWS conference that will be held in Limerick in July 2022. The IPWSO board are putting together a really fantastic range of speakers as well as plenty of time for catching up with friends new and old. After the 2020 we've had it'll be great to get together in Limerick for lots of information from the experts but also some good old fashioned catching up! We will be hosting an information evening soon, so keep an eye out for the date.

Easter is on it's way... here's an idea!

Everyone loves an Easter egg hunt! Rather than using real eggs, fill plastic eggs with clues that will lead to an easter basket filled with items such as: Art & Crafts, Playdoh, colouring book, word search book, a Football, Books, Dvds, Jigsaws, Bubbles.. the list is endless.



Have a happy & safe Easter

From Tanya,
Mum to Lulu

I had been thinking about fundraising ideas for a while but thought our options were very limited due to Covid, lockdown and the 5kms restrictions. Everyday online I was seeing so many wonderful people with PWS and their families getting up, getting out and exercising.

All of these people gave me a "light bulb" moment and the motivation I needed to follow in their footsteps. So, the 5km became a daily target rather than a restriction. I was hoping to raise a few euro to support PWSAI towards the cost of the IPWSO conference in Ireland next year. Having the conference in Ireland is a HUGE deal for us personally and for so many other families with loved ones who have PWS. The generosity with the donations was incredible especially when times are tough for so many right now. I'm so grateful to every single person who donated! It also gave me something to focus on throughout February and believe it or not I began to really enjoy getting out there every day and clocking up the kms, even in the rain and snow!

Thank you so much to everyone who donated and let's look forward to the IPWSO conference next year. 🧡



PWSAI Everyday Challenge

A shoutout to Michelle, mum to Jamie, who has taken on the PWSAI Everyday challenge for the month of March. Michelle who was inspired by Tanya, has also committed to doing 5k a day for PWSAI. Rumour has it Jenny, mum to Laura, has signed up for the PWSAI Everyday Challenge for April.

Is there something you could do everyday for the PWSAI Everyday Challenge?

Running? Walking? Swimming? Cycling? Yoga.... the list is endless. Who'd like to take the baton from Jenny for May? Get in touch with rory.tierney@pwsai.ie Thank you!



If you are a brother or sister of a person with PWS in Ireland and are aged 18+, you are invited to participate in an online survey to explore your experience of being a sibling to an individual with Prader-Willi Syndrome.

There has been little research conducted into what life is like for siblings of a person with PWS in Ireland. PWSAI are currently reviewing how we might better support siblings into the future.

PWSAI and the HSE are delighted to support a research piece by Ms. Saoirse Kavanagh as part of her Msc. in Applied Psychology with Trinity College Dublin. The survey is completely confidential. Once the survey data is collected there will be an option for participants to take part in a workshop to discuss their responses in more detail.

To participate in the survey please click on the link:

<https://www.surveymonkey.com/r/PWS-Sibling-Research>

For further information please contact:

Gary Brennan

National Development Manager

Email: gary.brennan@pwsai.ie

Phone: 087 385 1387

That's all for now. As always, if we can be of any help, please never hesitate to get in touch. Thank you to everyone who contributed to this edition of the PWSAI Newsletter.

Hopefully see you at a virtual PWSAI event in 2021.

Take care,

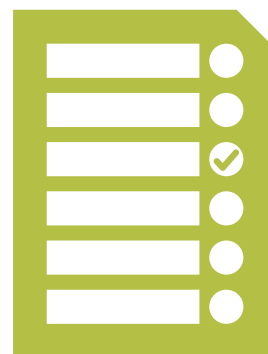
Emma

PWSAI Secretary info@pwsai.ie or
emma.walsh-tierney@pwsai.ie



**There was a lot to remember to do in this newsletter,
so I added a To Do list:**

- ☐ Save the Dates
 - ☐ PWS Awareness Day 28th May- Wear Orange!
 - ☐ PWS 5K 28th- 30th May
- ☐ I'd like to help with current projects - get in touch with Emma or a Board member
- ☐ Share your fundraising idea with Rory
- ☐ Survey 1 from New Diagnosis Sub-committee
- ☐ Survey 2 from New Diagnosis Sub-committee
- ☐ Ask Emma to add you to
 - ☐ PWSAI Facebook group for your child's age group
 - ☐ PWSAI WhatsApp group for updates for parents/carers.
 - ☐ PWSAI Virtual Meet up list for people with PWS.
- ☐ Sign up to PWSAI membership
- ☐ Take part in the PWSAI Everyday Challenge -get in touch with Rory
- ☐ Let Emma know if you'd be interested in a Wellbeing workshop for parents.
- ☐ Fill in Sibling Survey if you are a brother/sister of a person with PWS and are age 18+
- ☐ Email Emma re: Living Better with PWS workshop (0-12 years)
- ☐ _____
- ☐ _____
- ☐ _____



Prader Willi Syndrome Association Ireland

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