#### **Newsletter Content**





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### An interview with Gary Brennan, National Development Manager, Prader-Willi Syndrome Association of Ireland, on the International Prader-Willi Syndrome Organisation Conference 6-10 July 2022, Limerick, Ireland

#### How does it feel to be the host for the next international conference?

It is an honour! <u>PWSAI</u> was absolutely thrilled to be chosen to co-host <u>IPWSO 2022</u>. There were lots of worthy contenders and the bidding process required a great deal of careful consideration and investment of members' time. The International Conference is a key part of IPWSO's activities, and it gives PWSAI, as co-hosts, the opportunity to raise awareness of PWS on a national and global stage.

### How are you all preparing for the Conference?

In terms of the logistics, we're very lucky; the <u>University of Limerick</u> is an ideal venue with state-of-the-art conference facilities, great indoor and outdoor spaces, and the onsite campus accommodation is super - it's good for both families and individuals as there are apartments and single rooms. There are also excellent hotels nearby including the Castletroy Park Hotel and the Kilmurry Lodge and these are offering preferential rates to IPWSO 2022 delegates. <u>Limerick City</u> has a good range of accommodation options too.

Our focus now is on helping to develop the various strands of the Conference programme and securing the stellar line up of speakers, for which the International Conference has become so renowned. The Conference also attracts a very wide audience including people living with PWS, parents, academics, scientists, clinicians, researchers, PWS Associations and professional providers and caregivers. It is a unique event and such a great opportunity for meeting colleagues and friends, old and new, and developing new collaborations.

# How will Covid affect how you carry through the Conference or the planning of it?

There is no doubt COVID is a challenge. We'll all be working to ensure a safe environment for everyone and whilst decisions regarding the COVID-19 vaccination will be a personal/family matter, IPWSO and PWSAI are strongly advocating that all delegates are vaccinated before travelling. Opinion from experts is that people with PWS do very well after receiving the vaccination. Indeed, proof of vaccination when entering Ireland and on admission to venues and places of interest, continues to be a requirement. We and the University of Limerick will be working to <u>Irish government</u> and industry standards to keep us all safe during our Conference and we'll amend our guidance if necessary – keeping everyone safe has to be our number one priority.

At this point we are still very hopeful and are working on the basis of an in-person event - that's what people are telling us they want. Our theme for the Conference, *"We're all in this together"* reflects our ambition that we will all be together in July 2022, creating the potential for change and finding new ways to accelerate the work that needs to be done.

## Are there any new and exciting issues/topics that you hope to present?

It's hard to believe how much will be covered over the week – it is very exciting! The Clinical and Scientific Conference will look at lots of new and emerging research and benefits from input from invited speakers from relevant fields of science outside of PWS – so it is truly interdisciplinary in nature.

The Parents Conference will cover a wide range of topics including how to talk to your child about PWS, nutrition, exercise, management of behavioural challenges as well as providing opportunities to meet the speakers.

The Professional Providers and Caregivers Conference will explore independence, positive risk taking, wellbeing, the principles underlying models of restrictive practices, person-centred planning, and social media -the risks and benefits – to name but a few themes.

We're really excited about our programmes for people living with PWS including the Children's Programme and "SUAS", which means "**UP**" in the Irish language. This is our "Stepping **UP** Adults Symposium". We'll have morning workshops and afternoon activities – there is something to suit everyone, and Limerick has fabulous <u>attractions</u> right on its doorstep. Places are limited on both programmes so do <u>register soon</u> – the early bird rates close on 7 April 2022.

In a new development we have our one-day Interdisciplinary Conference on Saturday 9 July. This is designed to support competency development and knowledge sharing amongst educationalists and the allied health professionals - psychologists, social workers, mental health professionals, physiotherapists, nurses, dieticians, speech therapists, occupational therapists, and doctors. It is an important and necessary initiative; people living with PWS need everyone to take a holistic view of how the syndrome affects them and often these professionals do not have opportunities to hear directly from people with the syndrome nor the specialist scientific and clinical communities that have the expertise and know-how about current treatments and supports. So, the Interdisciplinary Conference will address lots of themes across the lifespan – education, diet, behaviour, clinical characteristics of PWS and changing perspectives on supporting people living with the syndrome. Please share the news about this event with your contacts.

As the programmes come together we'll be uploading information on the <u>website</u>.

## What about the social programme?

We've a special meeting planned for our Associations – it's an opportunity for them to reconnect, and new groups, in particular, welcome the support from those more established organisations.

We've also planned a great social programme with a gala dinner on Friday 8<sup>th</sup> and a "ceílí", a traditional Irish music and dancing evening, on Saturday 9<sup>th</sup> – so bring your dancing shoes!

It really is a gathering of our global PWS community and of course, none of it would be possible without the generous support of our <u>sponsors</u>, including Friends of IPWSO USA, Novo Nordisk, Radius, Resilience Professional Care Providers, Faílte Ireland, and the Hospital Saturday Fund – a huge thank you to each and every one of them!

## If someone wants to extend their stay in Ireland, what would you recommend they see and do?

Ireland has so much to offer! Visitors never fail to be impressed with the spectacular scenery. It's green place and that's because we get so much rain – so do bring suitable clothing! Limerick, as the venue for the Conference, is the gateway to the <u>Wild Atlantic</u> <u>Way</u>, which at 2,600 km in length is one of the longest defined coastal routes in the world. Behind every bend on this magical coastal road a new delight awaits. I'd recommend you do your homework and plan your trip as you'll either need to hire a car or book with a travel guide - check out the <u>IPWSO 2022 website</u> as a starting point.

We're counting down the days and hope to see you all there!

Further information on:

Travel and accommodation in Ireland Key Dates for IPWSO 2022 How to Register Platform and Poster Opportunities for the Clinical and Scientific Conference Platform and Poster Opportunities for the Professional Providers and Caregivers Conference Conference Programmes and Social Activities Sponsorship and Exhibitor Opportunities Discovering Ireland

Contact: Conference@ipwso.org