11th INTERNATIONAL PRADER-WILLI SYNDROME ORGANISATION CONFERENCE

How to show your support for IPWSO 2022







WHAT IS IPWSO 2022?

Our 11th International Prader-Willi Syndrome Organisation Conference is a unique event that, once every 3 years, brings together people from all over the world and from many different backgrounds, to share knowledge, understanding and information about Prader-Willi Syndrome (PWS).

In 2022 our International Conference will be held at the University of Limerick, Limerick City, Ireland from 6 – 10 July 2022 and IPWSO and the Prader-Willi Syndrome Association of Ireland (PWSAI) have pleasure in inviting you to join us.

We're all in this together!

Our rallying call reflects this special gathering of clinicians, researchers, scientists, professional providers and caregivers, parents, adults, and children with PWS, health and allied professionals – dieticians, physiotherapists, psychiatrists, nurses, mental health professionals, clinical and educational psychologists, occupational therapists, social workers, speech therapists, doctors, and the educational sector – everyone who has a desire to support and improve the lives of all those affected by the syndrome.

It is now time for the global PWS community to come together, to reconnect – it is time to share knowledge and understanding, share research and expertise. It is time to give, and receive support, meet old friends and colleagues, and make new and meaningful connections – and have some fun too!

We're all in this together and it is time to get together in Ireland!

Can you help us spread the news?

Key Messages:

• Our rallying call: "We're all in this together!"

It is now time for the global PWS community to reconnect, time to share knowledge and understanding, share research and expertise – trusted information. It is time to give, and receive support, meet old friends and colleagues, make new and meaningful connections, and have some fun too! We're all in this together and it is time to get together in Ireland, where a "Céad Míle Fáilte" – a hundred thousand warm Irish welcomes - awaits you! Register Now!"

- This is a unique event for sharing information about PWS.
- This conference brings together people living with PWS together with experts on the syndrome – clinicians, scientists, researchers, families, professional caregivers, and allied professionals – a unique gathering of all those affected by PWS and those interested in improving the lives of people with the syndrome.
- This will be the first IPWSO conference to take place in Europe since 2013 and our members have chosen Ireland as the venue.
- We have a stellar line up of speakers across all programmes.
- If you are a scientist, researcher, clinician, professional caregiver, a person with PWS, a parent or family member, involved in a PWS Association, this conference will be of interest to you.
- This is an International Conference. By coming together and collaborating, we grow and strengthen the global PWS community. Together we help to reduce inequality by raising awareness of PWS and setting standards of good practice.
- Ireland is ready to receive and welcome delegates when it is safe to do so.

- <u>SUAS the symposium for adults with PWS:</u> "SUAS" means "UP" in Irish and this is our "Stepping UP Adults Symposium. This is a call to step UP and discuss the challenges that affect you! What do you want for your future? It's a chance to meet old friends and meet new people too and have lots of fun! We'll also have a programme for Children with PWS.
- Specific to Interdisciplinary Programme: Be part of this interactive educational meeting designed to bring together professionals who support adults and children with PWS, but who would not normally have such a unique opportunity to meet and consider the syndrome in a holistic manner. This Conference will be of interest to all those involved in primary, post primary and further education, clinical and educational psychologists, doctors, mental health professionals, nurses, social workers, dieticians, dentists, occupational therapists, speech therapists and physiotherapists – all the allied professionals in health and education who treat and support people living with PWS.
- Specific to Parents Programme: Increase your knowledge and understanding of the syndrome; share your experiences; it is a time to reflect; a time to develop new strategies and coping methods; a time to receive support and in return give support by sharing your experiences; a time to reconnect with old friends and meet new families. The conference will help you, your loved one with PWS, your family and other families in your country.
- Specific to Clinical and Scientific Programme: Share your expertise; learn about and help advance the research into this rare disorder; refine your ideas and get feedback on your work; discuss advancing medical technologies; make meaningful connections, be inspired; re-invigorate your practice and get to know others in your field. Help reduce inequality and set standards of good practice.
- <u>Specific to Professional Providers and Caregivers</u>: this is a unique opportunity for professional caregivers from across the globe to meet and discuss how best to support people living with PWS. Meet likeminded

people, compare models of support, explore best practice, learn from trusted sources about the syndrome - how it affects people with PWS - how best to support the wellbeing of people with PWS. Learn about personcentred planning, independent living, alternative housing, emerging technologies, and smart homes.

Toolkit Now Available:

Here's a sample of our materials in our marketing toolkit, freely available on our <u>website</u>. You can help show your support for IPWSO 2022 by:

 Downloading the IPWSO 2022 banners and logos and making them visible online. (Banner <u>Short Version</u>) (Banner - <u>Long Version</u>) (<u>Rectangle with</u> <u>Logo</u>).



• Add our IPWSO 2022 web signature to your emails.



- Share our key message for IPWSO 2022 "We're all in this together!" and specific reasons to attend for each audience, as detailed above.
- Follow us on -

Twitter: <u>https://www.twitter.com/ipwso</u> Facebook: LinkedIn: <u>https://www.linkedin.com/company/ipwso</u> Instagram: <u>https://www.instagram.com/ipwso/</u> YouTube: <u>https://www.youtube.com/channel/UCdaADGNib1thtelhtVWx0Gq</u>

- Use the official hashtag #IPWSO2022
- Download and share the Welcome song from the young people of Ireland to delegates of IPWSO 2022 which also provides an overview of the Conference.

https://ipwso.org/wp-content/uploads/2021/12/IPWSO-2022-Welcome-Song-V2.mp4 Download and use on your social media platforms: "Why I'll be there!" testimonials for the Parents Conference, Professionals attending the Clinical and Scientific Conference and for Professional Providers and Caregivers Conference.







Testimonials for Twitter, Facebook, and LinkedIn

- Download and spread the word about our Call for Abstracts for the Clinical and Scientific Conference and the Professional Providers and Caregivers Conference.
- Spread the word about our new Interdisciplinary Conference. (<u>Pdf for</u> <u>teachers</u>).

- Tell your story about the benefits of attending IPWSO Conferences check out Jackie Gill's story and share: (short video) <u>https://ipwso.org/wp-content/uploads/2022/01/Jackie_Gill.mp4</u>
- Post a blog or share a story in your newsletter: see this <u>interview</u> with Gary Brennan, National Development Manager, PWSAI, and co-hosts for IPWSO 2022.
- Drive people to our website: <u>https://ipwso.org/news-events/conference-2022/</u>
- Promote the location of our Conference by using #Keepdiscovering, #wildatlanticway, #fillyourheartwithireland.

Thank you for all your support!

The IPWSO 2022 Planning Committee