

A place for professional PWS caregivers worldwide to share practice-driven knowledge, information and support.

Caregivers' Forum



Vision

A world where people with PWS and their families receive the services and support they need to fulfil their potential and achieve their goals.

Mission

To unite the global PWS community to collectively find solutions to the challenges of the syndrome and to support and advocate for people with PWS and their families, PWS associations, and professionals who work with people with PWS.

Contents

- 4 About IPWSO
- 5 What is the Caregivers' Forum?
- 6 What topics will be discussed in the Forum?
- 7 Forum members
- 8 IPWSO / PPCB Forum leads
- 9 What is a Caregiver Delegate?
- 10 Meet the Delegates
- 14 Join the Caregivers' Forum



IPWSO was established in 1991. Since then, we have supported and connected national PWS associations, as well as people with PWS, their families and the professionals who work with them.

Forty-seven national PWS associations make up our current membership and we support individuals in over seventy other countries. While we are proud of our heritage and recognise that some people with PWS now achieve far better outcomes than were believed possible in the past, we are acutely aware that people with PWS and their families continue to face serious challenges, particularly in countries where knowledge is limited and treatments, services and support are difficult to access.

We believe that timely and consistent access to reliable information, as well as early diagnosis, informed medical care and therapeutic services, and access to social care and support are all necessary to enable people with PWS and their families to achieve the best possible outcomes.

In some countries, early diagnosis and good health have become common and a generation of adults with PWS is emerging for whom new models of care and support may be needed. In other countries, early diagnosis remains rare and life-threatening levels of obesity are routinely observed.

We operate in a challenging environment. However, we are committed to working for a world where all people with PWS and their families receive the services and support they need to fulfil their potential and achieve their goals.

About IPWSO





What is the Caregivers' Forum?

The Caregivers' Forum is a virtual space for professional PWS caregivers worldwide to share practice-driven knowledge, information and support.

IPWSO supports this caregiver community by facilitating:

- 3 Caregivers' Forum meetings annually
- 3 Forum newsletters following meetings
- A webpage for the Forum which includes latest news and shared resources
- Ad-hoc support for networking in your own country.

The Forum is by PWS Caregivers, for PWS Caregivers.

The spirit of the IPWSO PWS caregiver community has always been one of collaboration. Topics covered will be suggested by Forum Members and are likely to include important information on themes such as Ageing, Challenging Behaviour, Day to Day Care, Medical Care, Relationships and Sexuality, Research, Rights and Restrictions, Social Skills and much more. IPWSO regularly asks for feedback and ideas to help make our meetings and information as relevant as possible. As a Forum member, you will have the opportunity to let us know what issues are at the forefront of mind when you think of your work supporting people with PWS.

What topics will be discussed in the Forum?



Forum members

Anyone working in a professional role as a provider of care for people with PWS is welcome to be a part of the Forum. Members will have different roles and levels of involvement within the group.

PPCB members

The Professional Providers and Caregivers Board (PPCB) of IPWSO is an advisory board which is dedicated to sharing best practice, information, knowledge and techniques to those providing care to the global PWS community, in order that those living with PWS may live their lives to the highest quality.

Caregiver Delegates

Caregiver Delegates are the point of contact that IPWSO's Professional Provider Caregiver Board (PPCB) uses to distribute information about residential support. Caregiver Delegates are appointed by their country's PWS Association. Read more about them from Page 8.

Forum members

Anyone working in a professional role as a provider of care for people with PWS is welcome to be a part of the Forum. Signing up to the Forum mailing list ensures you receive invitations to meetings, newsletters and shared resources. We encourage all Forum members to share information from their country and to be active participants.



IPWSO / PPCB Forum leads

PPCB member Neil acts as Chair for the Forum. He was Caregiver Delegate for Australia before joining the PPC Board of IPWSO. Shelly supports all administration of the Forum.



Neil Gumley
Disability Professional,
The Orange Hive
Australia



Shelly Cordner
Project Manager,
IPWSO, UK



Pictured: PPCB Members at the 6th International PWS Caregivers' Conference, Berlin, Germany, 2024.



What is a Caregiver Delegate?

IPWSO's forty-seven members are constituted PWS Associations representing families around the world. Our member associations are subscribed members with voting rights. Each registered PWS Association appoints Parent and Professional Delegates to be their representatives. When applicable, a Caregiver Delegate is also appointed.

Caregiver Delegates are the point of contact that IPWSO's Professional Provider Caregiver Board (PPCB) uses to distribute information about residential support. Caregiver Delegates are appointed by their country's PWS Association. They do not have the right to vote, but may carry their country's Proxy vote and attend General Assemblies. A role description is available [here](#).

At present, IPWSO has 12 appointed Caregiver Delegates, in Australia, Austria, Denmark, Ireland, Japan, the Netherlands, New Zealand, Spain, Sweden, Switzerland, UK, and USA.

Meet the Delegates

When you join the Caregivers' Forum, we'll ask if you would like your email address to be shared with your Caregiver Delegate (if applicable in your country). They will be your main point of contact for networking and information sharing within your country.

If you are in a country that does not have a Caregiver Delegate appointed by the PWS association, we will support you through the forum, newsletters, and we're happy to respond via email to any queries you might have.



As the forum grows we hope to support many more associations to recruit their Caregiver Delegates and to grow the caregiver network in each country.

On the next few pages you can get to know some of our current Caregiver Delegates...

Bastian Bühler

Head of the Individual Housing Department, Stiftung Arkadis, Switzerland



Bastian Bühler originally trained as an electronics technician, and made a significant career shift after completing his apprenticeship. He felt compelled to explore the field of social work further and thus pursued higher education in this domain. In 2013, Bastian earned a Bachelor of Arts degree in Social Work. Throughout and following his studies he worked for the Arkadis Foundation, gaining valuable experience in the social services sector.

Since 2018, Bastian has worked as a team leader in the residential group for people with Prader-Willi syndrome. From July, 2024, he has taken on the role of Head of the Individual Housing Department. Another notable achievement in his career within the Prader-Willi syndrome field was his election to the board of the Prader-Willi Syndrome Association Switzerland. Additionally, Bastian proudly serves as the Caregiver Delegate for Switzerland, advocating for the needs and rights of individuals with Prader-Willi syndrome and their families.

Meet the Delegates

Myles Kelly

Project Manager, PWSA UK, UK



Myles has been privileged to work with and support adults with PWS since 1986. Working for a national care provider, he saw the number of people supported grow from 3 in 1986 to almost 100 when he departed in 2022. As part of the team, Myles played a central role in developing, maintaining and improving the standards of PWS care and support, as well as keeping abreast of the latest news and insights from around the PWS world, by attending national and international conferences and training events. In all that time, he knew that he would simply never stop learning about PWS, no matter how many conferences attended nor how much he read.

His role at PWSA UK from September 2022, sees him assessing how we can influence residential settings for adults with PWS to ensure they receive the best possible standards of care and quality of life, which will be hugely important to individuals and families across our community. Working for and with PWSA UK is the icing on his professional cake!

Mark Lister, B.S., BCaBA

Behaviour Analyst The Arc of Alachua County USA



Mark has 35 years of experience working with individuals with PWS, designing and managing, both residential and behaviour management programs. He was one of the founders of the Arc of Alachua County's PWS residential program. Currently the Arc is serving 65 individuals with PWS and was the first program to use applied behavior analysis (ABA) to ameliorate problem behaviour and teach life skills necessary to live successfully with PWS. Mark is also interested in the medical management of individuals with PWS.

When Mark first started working with individuals with PWS, people were just beginning to be diagnosed, usually well into adulthood. At that time there was no model as to how to best serve and support these individuals. Since that time, tremendous strides have been made in the medical and environmental supports for people with PWS. The young adults that we are now serving have vastly improved life outcomes as a result of early diagnosis, advanced medical care, and improved school and adult programs. That said, there is still more work to be done, and Mark is looking forward to working with the PWS medical and service providers to continuously improve the services available to people with PWS and their families.

Meet the Delegates

Mariam Muritala

Residential Service Manager, Rehab Group, Ireland



Mariam Muritala is a Residential Service Manager. She's an advocate for vulnerable people and has a passion for mentorship. She works with a multidisciplinary team to provide intervention and supports required for families to access resources/services required to enhance their health and wellbeing.

She has worked within the health and social care sector across various health organisations such as St. James's hospital, Cheeverstown, Rehabcare and St. John of God's for almost two decades.

She has supported many struggling families to work and live independently in the mainstream to fulfil their potential.

She holds two Masters, MSc degree in Systems Thinking in Practice (The Open University in UK) and, MSc in Strategy and Innovation (Maynooth University). She holds a BSc Honours degree in Health and Social Care (Open University, UK) and also Diplomas in Social Studies, Psychology and Childcare.

Mariam also has a passion for business, she's an entrepreneur, a Business Strategist successful in real estate and health and wellness products. During her leisure time, she plays lawn tennis, swims and love listening to music.

Fred Nicolai

Chairman Prader-Willi Stichting, Netherlands



Fred Nicolai is stepfather of Iris who is 31 years old and lives with PWS. Fred is father of Mart (30), Jos (26) and Karst (22). In 2013, he and his wife, Mirjam, started the Prader-Willi Huis (Home) in the countryside in the north of the Netherlands. It turned out to be the beginning of an adventure that resembled a roller coaster ride. Today they have nearly 35 caregivers and 29 PWS clients living and working in four locations.

Since 2019 Fred is the chairperson of the Dutch Prader-Willi Foundation. His main motivation is: united cooperation to achieve appropriate care for all people – young and old - with PWS.

Meet the Delegates

Jannik Sayoudi

Head of Institution, Residence "OXEN", Denmark



My name is Jannik, and I am the appointed Caregiver delegate of the Danish national Prader-Willi Syndrome association, where I am a board member. I am also a member of the Professional council, where we advise on PWS-related issues for both families and Prader-Willi Institutions. In Denmark we have 2 centers for rare diseases which support the 140 registered people with PWS that we know of.

Day to day, I work as manager of an institution with both housing and working facilities for people with PWS. The institution houses 10 people with PWS and was founded in 1986. I have 10 years of experience working with this exact target group, and my educational background is Pedagogue (Bachelor in Social Education) and Diploma in neuropedagogy. I also recently finished my Diploma of leadership.





Join the Caregivers' Forum

Register to join the Forum:

www.ipwso.org/news-events/caregivers-forum

Share the details with your colleagues

All Forum members are welcome at any or all of the 3 annual Forum meetings

Receive 3 caregiver specific newsletters annually

Network with the caregiver community on both national and global levels.



Questions?
Email IPWSO Project Manager, Shelly Cordner
scordner@ipwso.org



www.ipwso.org



twitter.com/ipwso



facebook.com/ipwso



instagram.com/ipwso



Salisbury House, Station Road, Cambridge CB1 2LA, UK

