

Caregivers' Forum

Meeting Notes | Thursday 26 September 2024, 2pm UK time

Meeting 01.

Attended

From IPWSO: Shelly Cordner (UK), Nora McNairney (UK)

From IPWSO's PPC Board: Neil Gumley (Australia), Norbert Hödebeck-Stuntebeck (Germany)

Caregiver Delegates: Bastian Bühler (Switzerland), Kim Herivel (Australia), Myles Kelly (UK), Mark Lister (USA), Lynsey Moorehouse (Ireland), Jannik Sayoudi (Denmark), Janine Sinner (Austria),

Other Forum Members attending the meeting represented Australia, Austria, Belgium, Czech Republic, Denmark, India, Qatar, Romania, Spain, UK, USA

23 people in total attended.

Please note in accordance with [IPWSO's Privacy Policy](#) we do not release the Zoom recording of the meeting, or list the names of general Forum Members without their express permission. PPCB and Caregiver Delegates have given advance permission to have their names listed in the Forum.

Members should contact Shelly Cordner scordner@ipwso.org in the first instance if they wish to connect with specific Forum Members over email.

Agenda

2pm: Welcome to the Forum

Shelly and Neil gave a short presentation which included background to IPWSO, PPCB, Caregiver Delegates and the Caregivers' Forum. A PDF of the presentation is available [here](#).

Neil spoke about his journey working with IPWSO and the benefits of becoming involved with a global PWS caregiver community. He's gone from feeling like they were figuring things out on their own at the start, to now feeling supported and well-informed about working with people with PWS.

Medical Professionals and Families have spaces to share ideas and knowledge, such as IPWSO [Family Meetings](#) and [International Conferences](#). It is exciting to now have this dedicated space for Caregivers to connect.

(For information on all of IPWSO's in-person and online events visit: <https://ipwso.org/news-events/>)

It was emphasised that the Forum is "For Caregivers, by Caregivers" and Members are encouraged to share their own ideas and opinions on how the meetings and communications can work best for them.

2:10: Mark Lister, Caregiver Delegate, USA

Mark's presentation was on how caregivers across the US currently work together, and his aspirations to support this network in his role as Caregiver Delegate.

- Up until now USA haven't had opportunity to use the Caregiver Delegate role.
- There is a group of leaders in the US, Patrice Carrol, Lynn Garrick and Marguerite Rupnow who have been champions doing everything.
- There was a [Providers Conference](#) held in August in Savannah, Georgia. It was surprising to see the number of new providers coming into the field. They have very big programmes but are new to the PWS community.
- Providing structure to communicate and bring them on will be so important.
- Also nurturing the new generation of leaders.
- Mark's hope is that the delegate role will support that more.
- It will be important to get details from IPWSO 2025 International Conference back to people across the USA. This will require more than 1 person – needs to have a plan in place. People sitting in the conferences and engaged should be the ambassadors for this.
- Flow of information should be bi-directional.
- What are successes and failures?
- Generate resources, and provide information for areas where they're struggling.

So, Mark's role will be to go out and make contact with US providers and Forum Members and build relationships and find out the best ways to share information.

Also, and hoping this isn't overly optimistic, but hopes the Forum could be a form of emotional support for the providers. At a conference you may not get much new information, but you come back re-energised, motivated, and a better provider. Emotional support, sharing, building relationships, and knowing you're not alone is so important.

The flip side is, we're all very busy. Just staffing group homes is a daily priority. Hopefully the Forum doesn't get pushed aside as it's important.

Neil asks about the structure in the USA – how do they match up with PWSA | USA? Interested to see how they connect.

Mark says PWSA | USA, FPWR and IPWSO are all quite big in the US. There is a lot of cross-pollination. Many people are involved with or well known within more than one organisation. It is incumbent on the providers to get involved. Mark is hoping to draw in those who are not as involved. Find out how the newer ones are doing.

When Mark and his colleagues started their programme, they felt they were on their own. They had to figure it out day by day. It would be a shame for others to have to do that.

2:25: Open Forum Discussion

- Myles says that it's important to talk more about the ageing process. It is a topic which is often raised by caregivers lately.
 - Thinks Lynn Garrick and Barb Dorn are going to repeat their presentation in ageing. (Information on this research into Ageing is available at this link. <https://www.pwsausa.org/aging-research-in-prader-willi-syndrome/> scroll to the bottom to view the 2-Part presentation.)
 - Myles also wants more people from the UK to be a part of the Forum. There are 3 big providers in the UK. Plans to market it more through PWSA UK. Service managers should be involved.
 - Hopes that Forum can provide continuous learning, continuous information. Some presentations can be inaccessible for some, the science should be presented in a way that's easy to understand.
 - There is also a UK hospital that supports 70 adults with PWS and there are great insights to be had from them. Get a few GPs to speak?

- There was a comment that would be helpful to know who to reach out to in different countries.

Note: Countries which have assigned Caregiver Delegates are [listed on IPWSO's website](#). Anyone can email Shelly, scordner@ipwso.org to be put in touch directly with their country's delegate.

- There was a question on the impact of changes in a group home. Sometimes people with PWS are living together in the same home for 40+ years – what is the impact when someone dies or moves?
- Myles says he has worked with adults with PWS since 1986 – in his experience they rarely express the grief in the ways we might expect. They didn't see the grief that we would all associate with losing someone.
- Lynsey shared that Resilience Care in Ireland have made huge investments in further developing services for people with PWS. Their current care homes support 10 adults and they each have their own apartments within the home and keys.
 - More recently they have opened a respite service. For a lot of families residential isn't an option right now. Mainstream respite care wasn't able to support as needed.
 - So, people with PWS are supported for a week outside of the family home. They are able to accept people as young as 6, no cut off. Youngest has been 11 – oldest 44. They alternate weeks between over and under 18s groups.
 - There was a comment that this would be good practice to understand what it is like living in a residential home. Often it is difficult to learn to live with new people.
 - This is government funded in Ireland, and it was a long process to advocate for it and get it approved.
 - Once the project is more established, we hope to hear about the respite care in more detail as part of the Forum. <https://resilience.ie/prader-willi-syndrome/>

- There was discussion on what hierarchical levels should be involved in the Forum. Including managers of providers in this group is important, as that will trickle down within organisations. The more people who do the all day care that can be involved, the more ideas will come up. Should be a mix of people at all levels, managers, nurses, psychologists, etc.
- Norbert highlights that 20-30 years ago we didn't talk too much about ageing so this is a hot topic. But there are so many other issues surrounding behaviour and emotions. His wish is that we do a lot to support young people now to develop self-competencies and social competencies. The Forum is a perfect group for this. Preparing young people with PWS to grow up well is the next step in the caregivers' world.
- Jannick suggests it would be interesting if once a year Members could share with each other in this Forum how many PWS homes and people with PWS living in PWS homes are in different countries. Denmark has 7 group homes.
- Interaction Disability Services in Sydney, Australia has 4 PWS homes with a total of 10 PWS participants across the 4 homes at this stage, and is planning to grow. One home has 3 people with PWS who have lived together for more than 30 years.

Note: Shelly will think about a short survey to member countries to ask about the number residential homes and the people they support.

3:05: 2025 International Conference

The upcoming 2025 International Conference was discussed as a key topic. **Dates are June 25 & 26 for the PPC Programme.**

Full conference website is here: <https://pwsausaevents.cventevents.com/event/04353c7a-d6b1-45f9-9d6f-48acda9cd07e/websitePage:eb489ae5-9c8c-4e7c-8b79-ac5b06a5e510>

We would like Forum Members to please consider submitting an abstract to present as part of the programme. It's important to represent the caregiver community globally.

Topics suggested are broad and you are also not limited to only those listed. The full programme will not be set until we're reviewed abstract submissions. DEADLINE IS 5 NOVEMBER.

Abstract process: <https://ipwso.org/news-events/conference-2025/#Abstracts>

- Myles asks about livestreaming. Nora says we may pre-record some presentations. This would only be possible through sponsorship, such as from pharmaceutical companies, providers and others.
- Mark says it is well worth the trip if you're planning to stay on and visit the American Southwest. Grand Canyon, Sedona Rock Formations and lots of amazing desert landscapes to see.

3:25: Close and Thank you

For detail on upcoming IPWSO events visit: <https://ipwso.org/news-events/>