



FAMCARE Information Session: Managing Challenging Behaviour Summary

The Famcare Board of IPWSO was delighted to welcome a big group of parents and carers to its first online Family Meeting on the 22nd of April, 2023. To accommodate different time zones, the meeting took place at 2 different times, 9am and 5pm UK time.

We were pleased to welcome six wonderful speakers. Their presentations are now available, and we hope those of you who were not able to attend will be able to watch them and to share with others who might also find them useful.

"Thank you to all the speakers! Excellent and parent-focused presentations, we could learn a lot again. It is very important to educate families in time. With the right strategy, they adapt to challenges more easily. Thank you so much!"

~note from parent who attended.

Part 1: Listening up - what a PWS behavioural challenge could be.

Susanne Blichfeldt, MD. The Danish Prader-Willi Association, IPWSO Clinical and Scientific Advisory Board (CSAB), Denmark

[Prader-Willi syndrome - behavioural challenges in the first years and how to cope](#) (PDF)

(9am AND 5pm meetings)

Tony Holland, President of IPWSO, University of Cambridge, UK

[Behavioural challenges in older children and adults with Prader-Willi syndrome](#) (PDF)

(9am meeting)

Janice Forster MD, Developmental Neuropsychiatrist, Pittsburgh Partnership, USA

[Behavioural challenges in older children and adults with Prader-Willi syndrome](#) (PDF)

(5pm meeting)

Part 2: Preventing Challenging Family Life.

Yvonne Rochford, Parent, PWSAI Trustee, IPWSO Famcare Board Member, Ireland

[Preventing challenging behaviour in Prader-Willi syndrome \(PDF\)](#)

(9am AND 5pm meetings)

Karin Clarke, Parent, Chairperson PWS Support Group South Africa, IPWSO Trustee, South Africa

[Managing behaviour in Prader-Willi syndrome \(PDF\)](#)

(9am meeting)

Lynn Garrick, Parent, Chair of the IPWSO Professional Providers and Caregivers Board, Programme Director, AME Community Services, USA

[Preventing challenging family life with Prader-Willi syndrome \(PDF\)](#)

(5pm meeting)

Presentations were followed by Questions and Answers, and group discussion.

Meeting summary (9am meeting)

This short summary is taken from the meeting transcript. Moderator **Georgina Loughnan**, physiotherapist/healthy lifestyle clinician, Metabolism & Obesity Services, Royal Prince Alfred Hospital, Sydney, Australia, closed with an overview of what we heard at the meeting.

I'd just like to thank our wonderful speakers, Susanne, Tony, Yvonne and Karin. You've really given us a lot to think about. It's been fabulous, and I'd just like to do a quick summary.

From Susanne, we certainly learned that we need to start good habits and support very early in childhood and continue them. And from Tony, to emphasise the importance of knowledge and also understanding, and to always remember that, yes, the biology is significant, but also the environment has such a huge impact on their well-being and their behaviour, of course.

Yvonne emphasized how important it is to identify feelings and to speak about them, just as we do with other children, and bring humour into it and try and work on reducing rigidity. I think that's a really important thing that has not always been expressed, but I think it's very important.

And then Karin told us to validate feelings and identify them, and identify what you can do rather than what you'd consider. But most importantly, I would just say, share as much validated information about this with everybody who is involved in your child's life and know that they can have great lives and there can be great outcomes.

Meeting summary (5pm meeting)

This short summary is taken from the meeting transcript. Moderator **Susanne Blichfeldt, MD**. The Danish Prader-Willi Association, IPWSO Clinical and Scientific Advisory Board (CSAB), Denmark, closed with an overview of what we heard at the meeting.

Thank you all very much for joining us for this session on managing behaviour in family life. I just want to summarise that I presented about the very youngest children and their behaviour and how they can be different in behaviour and understanding compared to other children.

Then Yvonne talked about the young child, how to make strategies around transition and also about thinking differently, and having many systems or ways to handle situations and make it clear. I think it was good that your daughter she really knew when you said 1, 2, 3, for example, then she knew (what to expect) and also your dance about her flexibility was very good.

And then we had Janice's important presentation. You said that the food interest was around the same time when you first see the behaviour problems. And then the very important thing about food security and also about tantrums. You said it very often comes because of disappointments and all the stress related situations.

And then Lynne ended with a very personal story, it was a warm story, and I think for all families it was really something that we could all say, yes, we know this can be a situation. Your situation with five children is perhaps not the same for all families, but you were in the situation as a single mother and also with a job. And how much can we manage? It ends up that the family still thrives and you have a good relationship with your other children as well. You talked about having a game plan for everything in the family and the routine, about being consistent and do not give in to the behaviours. I think we all know the situations that you described and we are glad to know that we share the same situations.

Thank you to those of you who participated. We look forward to holding the next Family Meeting later in 2023 and will share details in the IPWSO Newsletter when it is announced.

If you use some of the advice from the presentations and discussions for your own family, we'd love to hear if helps. Please feel free to write to Shelly, scordner@ipwso.org to tell us how the Family Meeting has changed your day-to-day life with a loved one with PWS.

Ends. April 2023.