

6th International Prader-Willi Syndrome Caregivers' Conference

21-23 May 2024, Berlin, Germany

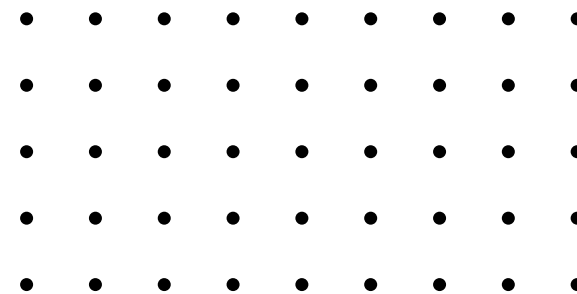
IPWSO's initiative to give people with PWS a voice

Svetlana Labun

EJF Hollerhaus gGmbH, Trustee IPWSO, Germany



#PWSCARE24



IPWSO's initiative to give people with PWS a voice

IPWSO People with PWS Committee

Founded in 2022

International experts supporting people with PWS to advocate for themselves to ensure their voice is heard.

Our members:

Svetlana Labun (Chair), Shelly Cordner, Norbert Hödebeck-Stuntebeck, Georgina Loughnan, Hubert Soyer, Kate Woodcock, Lantz Yap

IPWSO's initiative to give people with PWS a voice

IPWSO People with PWS Committee

- Supports individuals with PWS to advocate for themselves
- Ensures their voices are heard
- Works to establish platforms for expressing needs, wishes, and experiences
- Facilitates communication with PWS professionals
- Establishes mechanisms for the engagement of PWS individuals
- Develops a structure for collaboration with PWS individuals around the world
- Empowers PWS individuals to participate locally and with IPWSO
- Reporting to the board on committee activities

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Procedure

- Meetings every two months
- Discussions on addressing and involving people from different countries
- First step: Compiling experiences from different countries

Questions to address

- Suitable platform for PWS individuals
- Necessary support structures
- Meeting logistics: digital vs. in-person, group size, frequency
- Coordination: consolidating group results, national and international exchange
- Reaching potential participants with Prader-Willi syndrome
- This condensed slide captures the essence of your points effectively.

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Example: Australia

Our Way Of Life – Australia (OWLA)

- established since August 2021
- Led by Georgina Loughnan and James O'Brien
- virtual group of PWPWS
- Participants: primarily from NSW, ACT, Victoria; also includes K.Y. from Malaysia
- Age Range: 18 to 46 years
- Discussion Topics
e.g. Employment, Mental illness, Life during COVID lockdown, Advocacy for PWS, Bullying at school, Friendships and relationships.
- 2-day conference in December 2022, with presentations by individuals with PWS about their activities

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Example: Germany

Starting with regional groups 2023

- **Northern Germany**
Group Löhne
- **Berlin**
Group at Darßer Straße, an EJF facility
- **Southern Germany**
The group is in the process of being set up



Cologne, 2016

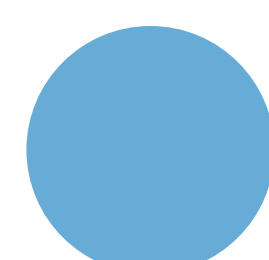


Nuremberg, 2019

Examples of successful engagement with PWS groups



Munich, 2018



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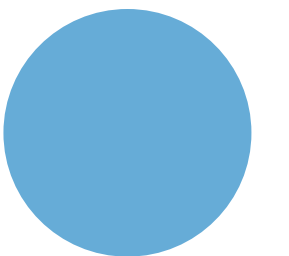
Our Future

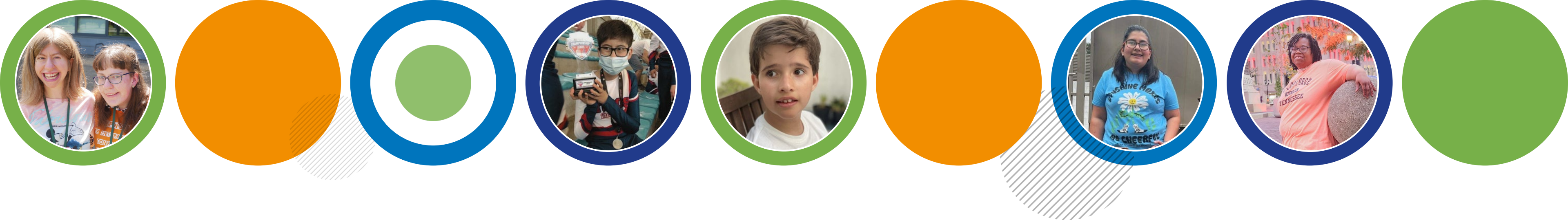
- Plan to publish a guide for setting up and running PWS working groups
- Encourage establishment of similar groups globally
- Foster networking and representation within IPWSO
- Guide may serve as encouragement for caregivers to initiate groups
- Committee welcomes inquiries and looks forward to exchanging ideas

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"Everyone has potential, absolutely everyone."

Walter Gunz





Thank you for your attention

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