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
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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
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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
Examples of successful engagement with PWS groups

Cologne, 2016

Nuremberg, 2019

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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