

1. Meeting of people with Prader-Willi-Syndrome for the “development of future offers for people with Prader-Willi-Syndrome”

Starting point

The invitation to the first meeting of people with Prader-Willi-Syndrome to "develop future offers for people with Prader-Willi-Syndrome" was issued by the International Prader-Willi Syndrome Organization (IPWSO) based in Cambridge, England.

The event was implemented on site by Dr. Norbert Hödebeck-Stuntebeck (PWS-InterNational) as a member of the Professional Provider Caregiver Board, an advisory board of the IPWSO.

It is the goal of the IPWSO to establish representation of people with PWS on all of its committees. So far, parents, professional caregivers, doctors and scientists are mainly represented on the IPWSO committees.

In order not to decide how to integrate people with PWS, a committee was set up in the IPWSO to pursue this path “with people with PWS instead of about people with PWS”. Norbert Hödebeck-Stuntebeck is a member of this committee.

Structure

Four meetings are initially planned:

- September 19, 2023
- November 14, 2023
- January 30, 2024
- March 19, 2024

Each time from 2 p.m. to 4 p.m. , located in the city of Löhne, Germany.

As the sessions progress, the content, goals and results increasingly focus on the ideas and interests of the participants.

In the first meeting, Norbert Hödebeck-Stuntebeck presented the basic idea of the IPWSO initiative.

The exchange with the group begins by asking the question:

“Which topics will be relevant for people with PWS in the future?”

Based on the answers to this question, the second step will address the question:

“How can people with PWS represent these results in the IPWSO themselves?”

Similar groups operate in other countries as part of the IPWSO initiative. The aim is to bring together the results from the groups in the different countries. This can be done through online sessions.

Contents of the first meeting

1st session PWS for PWS

Location: Löhne in Westphalia

Date: September 19, 2023

Participants:

Seven participants with PWS, adults, 4 women, 3 men, from three locations in Germany and Norbert Hödebeck-Stuntebeck

Welcome and Introduction

Norbert Hödebeck-Stuntebeck welcomed all participants on behalf of the International PWS Organization.

He presented the purpose of the meeting. "In the future, people with PWS should be able to represent themselves in the International PWS Organization."

Until now that wasn't the case.

But the IPWSO now wants to change that.

The IPWSO would like to hear from people with PWS:

- How should the IPWSO involve people with PWS in its work?
- How do people with PWS want to represent themselves in the IPWSO?

The aim of the group is to make suggestions to the IPWSO on how they want to represent themselves in the IPWSO in the future, how they want to speak for themselves.

Overview of housing offers for people with PWS in Germany

In order to get an overview of how many PWS housing offers there are currently in Germany and where they are located, Norbert Hödebeck-Stuntebeck showed a map of Germany with the places where there are specialized housing offers for people with PWS. Some offers were

known to the participants, other information was new to them. The number of around 500 specialized PWS residential places throughout Germany came as a surprise to most people.

Advocacy

The long-term goal of the group was already stated in the introduction that people with PWS should speak for themselves and other people with PWS in the IPWSO.

The participants expressed that not all people with PWS in the IPWSO can or want to speak for themselves, but that some representatives can or have to do this for them. This means that some represent the interests of others.

The participants put together the contexts or their own experiences from which they already know interest groups:

- home advisory board,
- workshop council,
- Residents' Advisory Board,
- City Council for the Disabled.

Some participants already have experience representing others.

Work assignment/goals of the group

The participants agreed that they would undertake the following tasks for further collaboration in this group:

- You want to act as an advocate for other people with PWS.
- You want to develop results on the question: "Which offers will be helpful and necessary for people with PWS in the future?"
- You want to exchange your results on the question with other groups in the world.
- You want to bring and represent these results at the IPWSO.

Content and topics

The next question was what specific topics or wishes for change the participants had. The following questions were asked:

- Which topics are important for people with PWS?
- What is already good but needs to be expanded?
- What is bad and should be changed?

The basic idea is pursued:

"If I know what I want, I can work for it.

To stimulate the collection of topics, Norbert Hödebeck-Stuntebeck presented a list of general topics: Living - Work - Leisure - Relationships - Money - Independence.

At the meeting, this list was supplemented by the participants with the following demands:

- Being able to decide for yourself where you live
- More housing options for people with PWS
- Privacy should be secured “being able to be alone sometimes without anyone watching”
- Listen to the radio in peace
- Be able to get a job opportunity in the general labor market.
- To experience an appreciation for your work.
- Equality, “not being labeled”, getting more opportunities
- To be able to live without violence, to be able to live in an environment in which there are no constant crises.
- More free time for people with disabilities, especially for PWS
- Improve entry options into outdoor pools or into train carriages so that you can use them better
- Having the opportunity to live with your partner together.

The list should also be supplemented or changed by the participants in all further meetings. This (changing) list represents the topics that the group wants to address in future sessions.

Leisure time

The group decided to deal as the first topic with the topic of leisure.

The questions were:

1. What should change in the leisure area for people with PWS?
2. How can this be done?
3. What can you do?

The following points were collected as results of the first question.

Collection of results:

- There should generally be more leisure activities for people with PWS
- There should be more holiday offers. These must be tailored to the needs of people with PWS
- It must be ensured that the employees who are necessary for support are paid
- When it comes to leisure activities or holiday offers, the providers must be informed about the topic of food for people with PWS
- The leisure activities must be barrier-free so that many people with PWS can use them
- When traveling by train, there must be guaranteed assistance when changing trains. You have to be able to ask people where you have to go or get help getting in and out

- There must be enough time to change trains
- The food offerings in the cinema must change, otherwise it will be too difficult for people with PWS to resist the offers
- People with PWS also have to learn to change something, for example in their own food

It was agreed to continue working on this point in the next meeting and to develop answers to the next questions on the topic of leisure time and then to work on the other topics.

Summary and closing comments

Norbert Hödebeck-Stuntebeck once again provided information about the further dates for the group

Comments from the participants about this first meeting:

“It was very nice to meet other people with PWS and to exchange ideas with them and work on something together.”

“I want to come back”

“I think it's good to exchange ideas with others. This way you get to know what other people's interests are.”

“I think it's good to be integrated into the IPWSO”

“I find it very instructive to sit with the others and hear from them.”

“I think it's good to exchange ideas with others in the world.”

"It was good"

All participants expressed their desire to be present at the next meetings.

Norbert Hödebeck-Stuntebeck reported that the annual meeting of the PWS Association Germany e.V. will take place shortly.

Individual participants who will be taking part in the conference were interested in presenting the results of the first session as part of the PWS annual conference.

Mr. Hödebeck-Stuntebeck will contact the PWS Association Germany e.V. in this regard.

Gez.

25.09.2023

Dr. Norbert Hödebeck-Stuntebeck