6th International Prader-Willi Syndrome Caregivers’ Conference

21-23 May 2024, Berlin, Germany

In memory and honor to Pam Eisen

„The future of assistance and care of people with PWS“

Dr. Norbert Hödebeck-Stuntebeck (Dipl.-Psych.)
There is no future without the past
Pam Eisen,
Former president of IPWSO, 2005
International Prader-Willi-Syndrome Organisation (IPWSO) in 2005
International Prader-Willi-Syndrome Organisation (IPWSO)

- Parents
- Caregivers
- Experts
From 2005 to today

Many people in the room where a part of this wonderful and intensive way
The first two caregivers conferences in Herne, Germany,

visible basic and the qualitativ content for all the following work of the caregivers in IPWSO

2008 2009
IPWSO conference Taiwan 2010,

Formation of Professional Provider Caregiver Board of IPWSO (PPCB)
In the following years we do

Separate caregivers conferences each over three days

2012 Caregivers conference in Wildbad Kreuth, Germany

2018 Caregivers conference in Munich, Germany
Local conferences in

2014, local caregivers conference in Jerusalem, Israel

2015, local caregivers conference as a part of the national US PWS Conference, Orlando, USA

2017, local caregivers conference in Santiago de Chile, Chile
Caregivers conferences as part of the IPWSO conferences

2013, IPWSO conference Cambridge, UK
2016, IPWSO conference Toronto, Canada
2019, IPWSO conference Havanna, Cuba
2022, IPWSO conference Limmerick, Ireland
The Present
The present situation of PPCB (evaluation)

Caregivers conference as part of the IPWSO conferences (presentations)
  Very stable with a high quality

Separate caregivers conferences every three year Workshops and presentations
  Very stable with a high quality

Caregivers delegates
  longer starting period – a very big potential for sharing knowledge in many parts of the world

“Best practice guidelines”
  good basic, but 15 years old, wait for an updated
The present situation of PPCB (evaluation)

**PWS-specific training programs for caregivers**
- only locally used, not coordinated and not mandatory for all PWS services (Quality of care)

**Exchange between staff of different PWS group homes/services in a country**
- Implemented only in very few countries

**Various diagnostic procedures** that are very suitable for PWS
- no psychological binding/coordinated diagnostics

**Early intervention**
- no coordinated/consistent early intervention focused on PWS
International Prader-Willi-Syndrome Organisation (IPWSO)
The Future
The future of care of people with PWS - Recommendations

1. Changing in the philosophy of care

- From structure to frame
- From excluding to including
- From determination by others to selfdetermination
- From „No“ to „Yes“
- Support the increasing of positive skills and not minimizing mistakes

By accepting the individual characters and competences of each person with PWS
2. Changing the focus: From Weight to Behavior

The main problems in the countries where caregivers are working become more and more the challenging behavior and less the weight situation

Searching for answers about why does he or she does this behavior?
3. Research

Research must be more focused on all-day care
What are the best methods of:
  - Prevention
  - Handling crisis situations
  - Reflecting challenging behaviour

Brians Hughes research was a good start in this – but all members of this study knows that there is much to do.
The future of care of people with PWS - Recommendations

4. PWS Training program for caregivers

With the goals of:

- Understanding the syndrome
- Behavior management
- Weight management
- Physical exercise
- Kommunikation

„Quality is the basis“

Standardized and available for all countries.
5. Diagnostic instruments to understand the behaviour of people with PWS

Standardized methods available for all countries.
The future of care of people with PWS - Recommendations

6. PWS Training program for people with PWS

With the goals of:
- Understanding the syndrome
- Behavior management
- Weight management
- Physical exercise
- Kommunikation

Standardized and available for all countries.

„If I know what I have, I have the chance to decide what I want to do.“

Increasing of meaningfulness – increasing of self-efficacy – increasing of positive feelings

With the goal of increasing the subjective perceived well-being
7. Implementing a Program-Director in IPWSO

With the tasks of:

- developing and coordinating methods and tools and to
- make them available for all countries which have a need for this
- Train the trainers
- Coordinates the IPWSO PWS behavior consultant (oder caregivers delegates)
- Develope „Continental groups“
“I am sure, Pam loves to see what happens with her idea, developed at a balcony in Sarasota nearly twenty years ago (2005).”