

# 6th International Prader-Willi Syndrome Caregivers' Conference

21-23 May 2024, Berlin, Germany

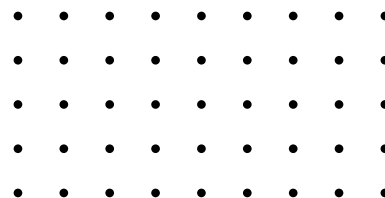
**In memory and honor to Pam Eisen**

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

**Dr. Norbert Hödebeck-Stuntebeck (Dipl.-Psych.)**



#PWSCARE24

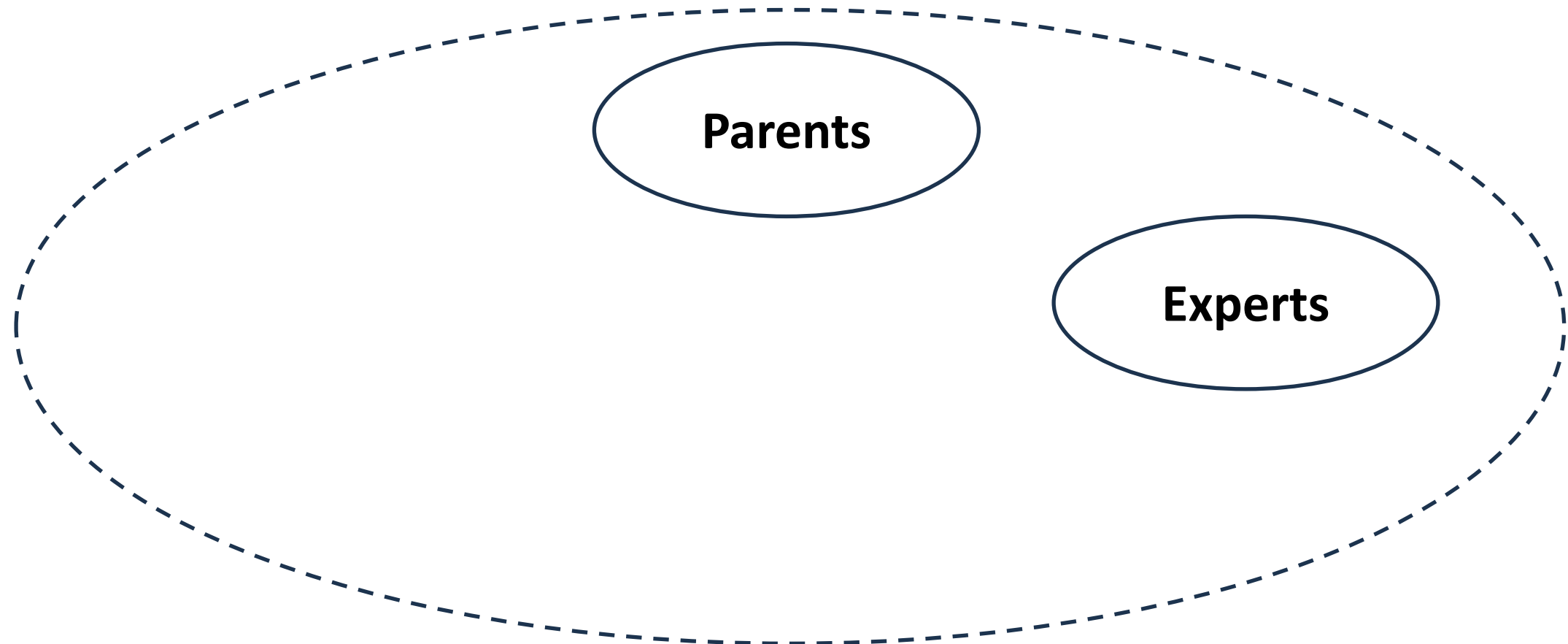


**There is no future without  
the past**

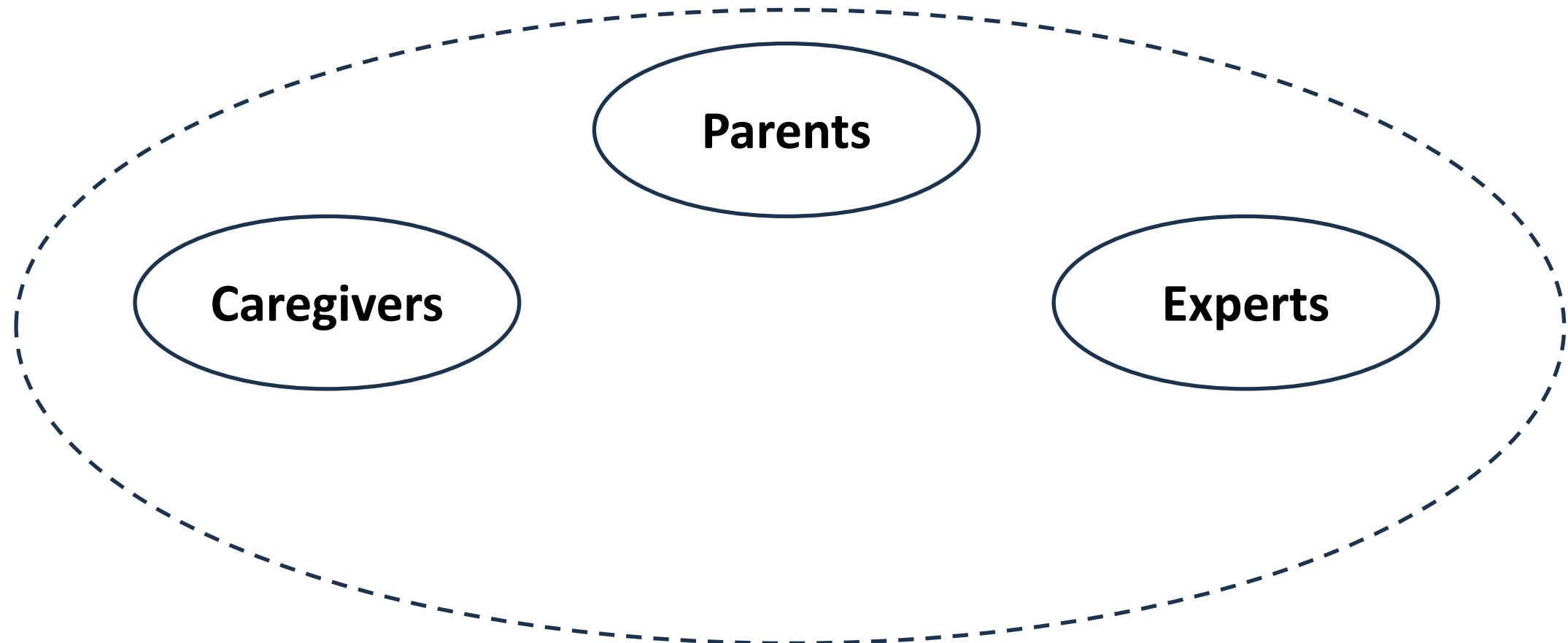


Pam Eisen,  
Former president of IPWSO, 2005

## International Prader-Willi-Syndrome Organisation (IPWSO) in 2005



## International Prader-Willi-Syndrome Organisation (IPWSO)



## **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 qualitative 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

**Seperate 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)

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**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)

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## **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

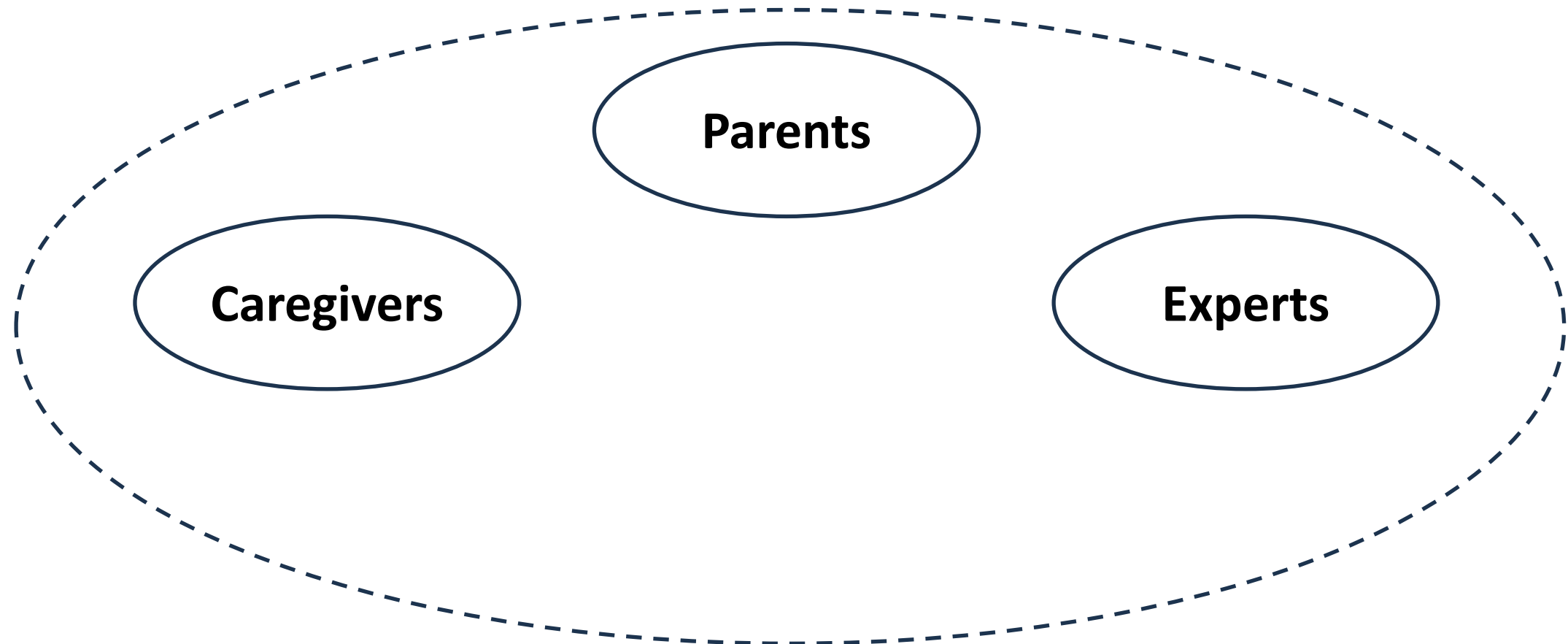
## **Various diagnostic procedures that are very suitable for PWS**

no psychological binding/coordinated diagnostics

## **Early intervention**

no coordinated/consistent early intervention focused on PWS

## International Prader-Willi-Syndrome Organisation (IPWSO)



# The Future



## 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.

## 4. PWS Training program for caregivers

With the goals of:

- Understanding the syndrome
- Behavior management
- Weightmanagement
- 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.

## 6. PWS Training program for people with PWS

With the goals of:

- Understanding the syndrome
- Behavior management
- Weightmanagement
- 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)
- Develop „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).”