



# Mental Health services for adults with PWS

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# Agenda

- Introduction  
Who are we? How is our Outpatient Department designed?
- What have we learned over the past 9 years?  
Medication vs Environment, Time, Communication
- The ideal setup  
In an ideal health system

# Who are we?

Dr. Christian Eberlein

Psychiatrist

Dr. Maximilian Deest

Psychiatrist

Prof. Helge Frieling

Psychiatrist



**Outpatient Department for Mental  
Health in Rare Genetic Disorders**

- since 2014
- ca. 130 patients/year

# Outpatient Department for Mental Health in Rare Genetic Disorders

## Outpatients

PWS, age 12+, living mainly at home, one time consultation/regular treatment

## Specialized care units

5 dorms, visitation 4x/year

## Consultations of professionals

General Doctors, Psychotherapists

What have we  
learned?

# It takes time

- To see people
- To talk to patients
- But even more time to talk to parents
- To see a change

Time is rare for:

- Psychometric testing such as IQ tests
- Emergencies

What have we  
learned?

# Medication vs. Environment

- You do not treat the patient you treat the environment
- But you can support the patient with medication
- 90% of the problems in adulthood are a result of what started in the childhood and exaggerate at life time events

People with PWS and their families need a continuous support, especially at key points in their life

# The ideal setup

- **Multiprofessional Team**  
Psychiatrists, General Doctors, Psychologist, Social Worker
- **Treat the system**  
Also providing help for the parents and the siblings
- **Continuity**  
Starting in Childhood over the life span
- **Continuity**  
Starting in Childhood over the life span, but also in emergencies
- **TIME!**