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
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!**