

# Rett Centers and Clinics in Europe

- Country: Germany

- Do you have:

We have a Paediatric Neurology Clinic with Social Paediatric Center and for adults a Neurology consulting hours

- What kind of center:

A medical center in a hospital

# Rett Centers or Clinics

- How many girls and boys are seen each year?

Children: 60 – 70

Adults: 30

- Where and how is the diagnosis carried out?
- Pediatric Neurology and Dept. Genetics

# Rett Centers or Clinics

- What are the specialists, please list:
  - Paediatric Neurology,
  - Pediatric Cardiology
  - Neurology,
  - Orthopedic devices
  - Physical medicine and rehabilitation,
  - Gastroenterology,
  - Endocrinology,
  - Nutrition, swallow therapy,
  - Orthopedic surgery,
  - Medical genetics and genetic counselling,

# Rett Centers or Clinics

- What are the clinical exams carried out:
  - EEG, epilepsy monitoring,
  - Blood exams (e.g. anticonvulsant drug monitoring)
  - Cardiology, autonomic function monitoring,
  - Sleep monitoring,
  - Osteodensitometry,
  - Behavioural assessment
  - Communication counsel
  - Orthopedic counsel and devices
  - Pediatric radiology – scolioses observation and treatment,

# Rett Centers or Clinics

- What are the caregivers and health careproviders:
  - Physiotherapists,
  - Speech therapists,
  - Occupational therapists,
  - Educational therapists,
  - Psychologists,
  - Is there assistive technology? (i.e AAC alternative and augmentative communication technology, ...) ---
  - social worker

# Rett Centers or Clinics

- Is there a connection of the center with research labs? **Yes**
- Is there a social or advisory service for families? **Yes**
- How is the Center or Clinic financed:
  - Is there a Rett Association or Foundation involved in the financing and/or the decision making? **No**
  - Paid by health insurance system**
  - Do families have to pay for exams? (please give details) **No**