Breakout session 4: Care continuity: transition from childhood to adulthood

- One of the main criteria to participate in ERNs is to ensure pathways for the transition between peadiatric and adult healthcare for RD patients. This is still lacking for several disease groups at many hospitals. An exchange of experience and tools is of great importance.
- The transition of young adults with chronic diseases from peadiatric care to adult care is challenging
  - Peadiatric care: Like a family : protection, understanding, call backs, Few complications, Parental presence
  - Adult care: Fear of the unknown and of not being understood, Parents less present even if YP is still very dependent, Seeing « old » patients, with complications, Becoming aware of some limits : career, fertility…
- There is a risk of inadequate medical follow-up: Young adults drop-off leading to discontinuous treatment
- It is crucial to have early introduction and a structured transition where patients and their families are involved
  - Start early
  - Individualize – disease specific needs
  - Have a structure/plan
  - Involve the patient
  - Resources
- Transition area with transition culture and minimum criteria's (training program, psycho-social plan and transfer to adult network, evaluation plan)
- Establishing education and training programs for transition-specialized staff and continued work with Patient organisations
- Some clinical paediatric specialist work together with adult clinician, as team, at the hospital
- Continued research to evaluate outcomes of different transition strategies
- Need for standardized protocols including minimal set of requirements and a need for Transition management
- A suggestion: A working group within ERN focusing on transition
- Is there a beginning of a trend to keep young adults longer (22-25) at children's hospital if the outcome are better?