



# Parallel Session 6

## Patient – Clinician partnership

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# Disclosure statement

We have no actual or potential conflict of interest in relation to this program/presentation



# Patients: keys to the ERNs

- ERN result of the will of patients
  - National plans also
  - Sustainability, inclusion in health system
- Patients added value:
  - Different perspective: you understand when you become a patient. ERN for patients
    - Medical aspects
    - Other aspects
  - Knowledge of the disease
    - New diseases
  - Role as
    - All actors in the ERN (quality of the ERN)
    - Representative: their disease / patients perspective
  - Team effort
    - Special skills from the patients (lawyer ethics...)
    - Dissemination



# Backgrounder

- Challenges
  - Speak english
  - Communication skills
  - Role as
    - All actors in the ERN (quality of the ERN)
    - Representative: their disease / patients perspective
  - Technical language, technical aspects
  - Limited time available
  - Not feel as second zone citizen within ERN
  - Limited resources
- Solutions
  - Eurordis, ERN help
  - Included in all aspects

- Exemples

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