European Reference Networks

EAP Winter Meeting, Rare Disease Working Group

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Risto Lapatto

European Reference Networks

- European Reference Networks are virtual networks involving healthcare providers across Europe. They aim to tackle complex or rare diseases and conditions that require highly specialised treatment and a concentration of knowledge and resources. There are 24 ERNs involving 25 European countries including Norway, over 300 hospitals with over 900 healthcare units and covering all major rare disease groups.

- **ERN BOND**: bone disorders
- **ERN CRANIO**: craniofacial anomalies and ear, nose and throat (ENT) disorders
- **Endo-ERN**: endocrine conditions
- **ERN EpiCARE**: epilepsies
- **ERKNet**: kidney diseases
- **ERN-RND**: neurological diseases
- **ERNICA**: inherited and congenital anomalies
- **ERN LUNG**: respiratory diseases
- **ERN Skin**: skin disorders
- **ERN EURACAN**: adult cancers (solid tumours)
- **ERN EuroBloodNet**: oncological and non-oncological hematological diseases
- **ERN eUROGEN**: urogenital diseases
- **ERN EURO-NMD**: neuromuscular diseases
- **ERN EYE**: eye diseases
- **ERN GENTURIS**: genetic tumour risk syndromes
- **ERN GUARD-HEART**: diseases of the heart
- **ERN ITHACA**: congenital malformations and rare intellectual disability
- **MetabERN**: hereditary metabolic disorders
- **ERN PaedCan**: paediatric cancer
- **ERN RARE-LIVER**: hepatological diseases
- **ERN ReCONNET**: connective tissue and musculoskeletal diseases
- **ERN RITA**: immunodeficiency, autoinflammatory and autoimmune diseases
- **ERN TRANSPLANT-CHILD**: conditions and complications linked to the transplantation in children
- **VASCERN**: rare multisystemic vascular diseases

ERNs in practise

- Working groups on certain diseases/disease groups
  - Data collection
  - Guidelines
  - Shared resources in, e.g., diagnostics
  - Consultations
  - Study design
- Members of ERN have national responsibility
  - To help other health care providers
  - To help patients to benefit from ERN knowledge
  - To collect national data

Call for New Members 2019

- > 800 applications
- Consortium, Full Member, Affiliated Member
- Approx. 1 member/10 Million people + additional affiliated members
- Small countries (< 2-3 Million) -> affiliated
- New members start in 2021

What You Can Do

- Identify ERN members in your country
- Make sure children are appropriately presented
- Demand information etc. from the member HCP to patients and HCPs
- If there are no members, find a way to benefit from ERN