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- ERKNet is one of 24 European Reference Networks (ERNs) established in 2017 by the European Union to improve medical care for patients with rare and complex diseases.
- Consortium of 38 expert nephrology centers (32 pediatric, 18 adult units) in 12 EU countries.
- Providing top multidisciplinary healthcare for more than 40,000 patients with rare kidney disorders.

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ERKNet ePAGs

- FEDERG
- AIRG Belgium
- AIRG France
- HIP OFAM
- PKD Charity
- PKD Familie Sichern e.V.
- SELBSTHILFGRUPPE FÜR KOMPLEMENTEBEDINGTE ERKRANKUNGEN
- NephEurope
- Cystinose Selbsthilfe e.V.
- Leben Eben!
- Nvn nierpatienten vereniging nederland

Patient Website

- Directory to ERKNet experts for individual rare diseases
- Diagnosis-finding tool
- Patient journeys
- List of patient organizations throughout Europe
- Repository of multilingual patient-oriented disease information

Patient Satisfaction

H-CARE SURVEY

Help patients share their experience of the care they receive for their rare or complex disease

Patient Information Materials

> 600 available disease-specific information documents and hyperlinks posted

Development of new multilingual information documents

contact@erknet.org  www.erknet.org / www.patients.erknet.org  @EuRefNetwork

This project has received funding from the European Union’s Health Programme (2014-2020).
ERKNet Objectives

- Advances the development of new therapies for patients with rare kidney disorders.
- Develops new guidelines for the diagnosis and treatment of rare kidney conditions.
- Offers top quality multidisciplinary healthcare for a wide range of rare kidney disorders.
- Offers virtual consultation services to physicians throughout Europe.
- Promotes best knowledge by organizing workshops and online webinars.
- Supports clinical research to improve diagnosis and risk prediction.
- Works closely with the patient community.

Objectives:
- To identify contemporaneous cohorts of patients with rare renal disease for clinical research.
- To monitor treatment performance and patient outcome in the participating centers.

Guideline Development

- Standardized evaluation of existing documents
- 40 endorsed guidelines
- Posted on website and implemented in ERKNet centers
- Gap analysis and prioritization of 7 new guideline topics
- Formation of writing committees, organization of evidence review and workshops

eConsultation Service

- CPMS is a free-of-charge online service provided by the European Commission to support physicians in diagnosing and treating patients with rare and complex kidney diseases
- Referring of challenging cases to European experts across national borders
- Regional tutor system

The ERKReg Registry

- ERKReg: The European Rare Kidney Disease Registry
- Objectives:
  - Center administration
  - Disease demographics
  - Natural history information
  - Genotype-phenotype information
  - To monitor treatment performance and patient outcome in the participating centers
  - Monitoring of guideline adherence, critical care and outcome indicators

Postgraduate Curriculum in Rare Kidney Diseases

- ERKNet Webinars
  - Online archive of past Webinars
  - Twice per month
  - Global attendance
  - Upcoming:
    - Case-based eLearning curriculum
    - Short-term exchange visit programs

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