

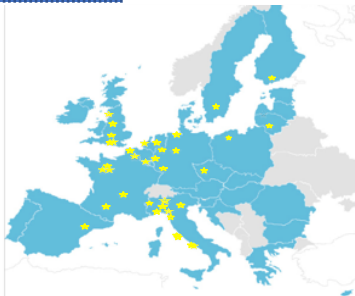


Vera Cornelius¹, Tanja Wlodkowski¹, Giulia Bassanese¹, Claudia Sproedt² and Franz Schaefer¹

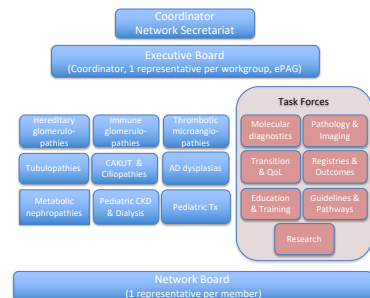
¹ Division of Pediatric Nephrology, Center for Pediatrics & Adolescent Medicine, University of Heidelberg

² Chair, ERKNet ePAG Board

About



- 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.



ERKNet ePAGs



FEDERG
Federation of European patient groups affected by Renal Genetic diseases

AIRG Belgique
Association pour l'Information et la Recherche sur les maladies Rénales Génétiques Asbl

AIRG France
Association pour l'Information et la Recherche sur les maladies Rénales Génétiques

hipofam
Asociación para la información y la investigación de la hipomagnesemia familiar



PKD International
Global alliance for polycystic kidney disease

PKD
Familiäre Zystennieren e.V.



Selbsthilfegruppe für komplementbedingte Erkrankungen
MKF und JMKF e.V.

NephcEurope
CARE & CURE FOR NEPHROTIC SYNDROME



Leben.eben!
Cystinose Selbsthilfe e.V.

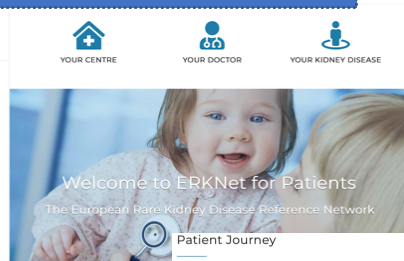
nvn
nierpatiënten vereniging nederland



Patient Website



- Home
- What is...
- Your Centre
- Your Doctor
- Your Kidney Disease
- Patient Journey
- Patient Organizations
- Patient Communities
- Research
- Events & Meetings
- ERKNet for Healthcare Professionals



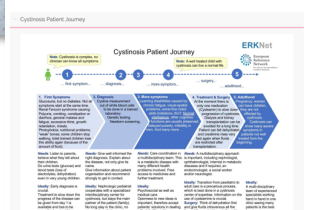
Rare Kidney diseases

You can find a disease either by typing part of its name or selecting the symptoms.

Enter disease name:

Select symptoms:

AK amyloidosis
Alagille syndrome
Alport syndrome
Alstrom Syndrome
Autosomal dominant polycystic kidney disease
Autosomal recessive infantile hypercalcaemia



- ✓ 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



WHAT IS THE H-CARE SURVEY?
The H-Care survey is part of the European Reference Networks (ERNs). These networks bring together experts from across the European Union to ensure that people living with rare and complex diseases are able to benefit from the best treatment and advice available for their condition. The H-Care survey has been set up for ERNs.

HOW CAN YOU SUPPORT THIS SURVEY?
Distribute leaflets to patients, care or family members of patients with a rare or complex disease and encourage them to participate in the survey.

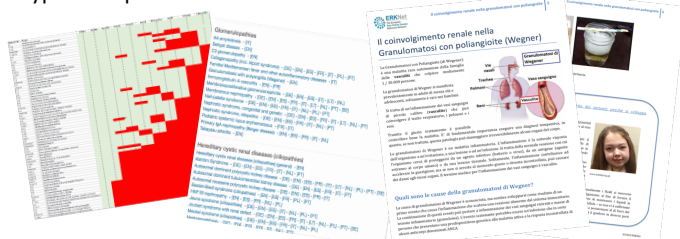
WHAT IS RARE BARRIERS VOICES?
This survey is conducted for Rare Barrier Voices (RBV), an online survey collecting together over 10,000 patients, carers and family members. The programme is run independently by EURODIS-Rare Disease Europe and is a non-profit initiative. All of the information shared will be used to improve the lives of people with rare or complex diseases and to support the research community.

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Patient Information Materials

> 600 available disease-specific information documents and hyperlinks posted

Development of new multilingual information documents



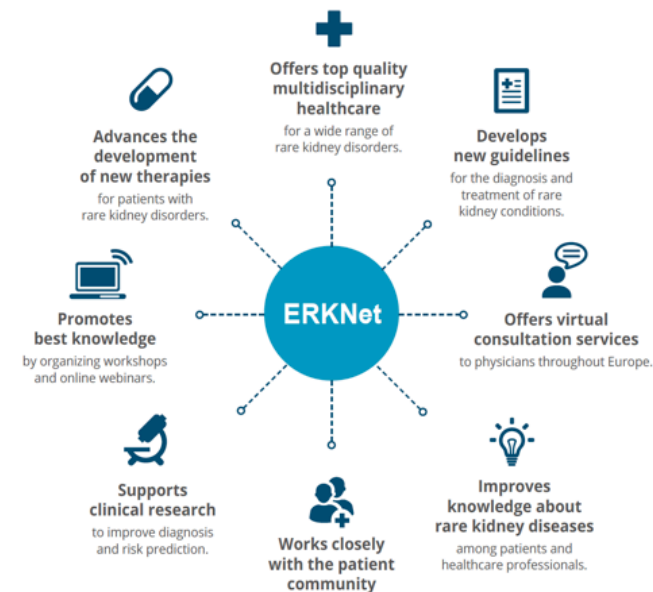


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ERKNet Objectives



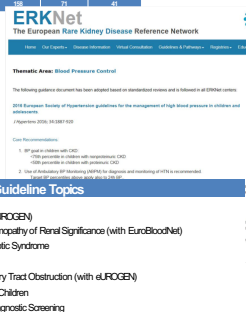
eConsultation Service

- 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



Guideline Development

| | Data elements | Guidelines for evaluation | Data elements |
|-------------------|---------------|---------------------------|---------------|
| Patients CKD | 65 | 26 | 12 |
| QAP | 25 | 5 | 2 |
| Metabolic NP | 18 | 15 | 10 |
| Adrenal disorders | 21 | 5 | 5 |
| Neurology NP | 5 | 5 | 4 |
| Protein 30 | 8 | 8 | 2 |
| TMA | 5 | 2 | 2 |
| CKRT | 3 | 3 | 3 |
| Thrombotic | 3 | 1 | 1 |
| Total | 175 | 71 | 63 |



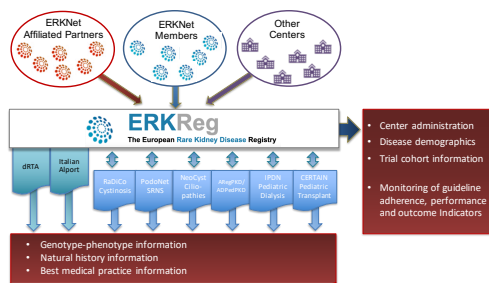
Standardized evaluation of existing documents

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

The ERKReg Registry



Objectives:

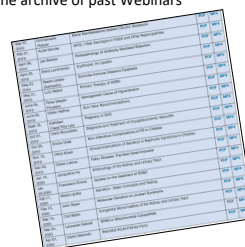
- ✓ To identify contemporaneous cohorts of patients with rare renal disease for clinical research
- ✓ To monitor treatment performance and patient outcome in the participating centers

Postgraduate Curriculum in Rare Kidney Diseases

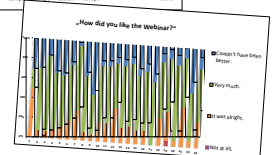
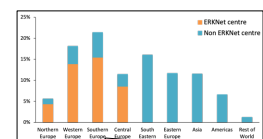
ERKNet Webinars

Twice per month

Online archive of past Webinars



Global attendance



Upcoming:

- ✓ Case-based eLearning curriculum
- ✓ Short-term exchange visit programs