PATIENT WEBSITE

Find your Doctor

For each rare kidney disease renowned ERKNet experts are listed with contact information.

Find your Centre

The patient website shows an interactive map to find an ERKNet expert centre in your country.

Find your Disease

The patient website provides information documents (brochures, websites, patient communities) on many rare kidney disases in most European languages.

Find Patient Journeys

Experience reports from patients with rare kidney diseases to guide other patients through the different steps of the diagnosis and disease management.

Find your Patient Community

The patient website provides links to different patient organisations and communities in different countries to connect between patients.

Find more information here

Visit https://patients.erknet.org or scan the QR code

512 MILLION PEOPLE LIVING IN THE EU

30 MILLION WITH RARE DISEASES

2 MILLION AFFECTED BY RARE KIDNEY CONDITIONS

ERKNet
The European Rare Kidney Disease Reference Network

72 CENTRES

24 EU COUNTRIES

70,000 PATIENTS

ERKNet
The European Rare Kidney Disease Reference Network

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Visit our website and subscribe to our newsletter at **www.erknet.org**
Follow us on Twitter: **@EuRefNetwork**

ERKNet
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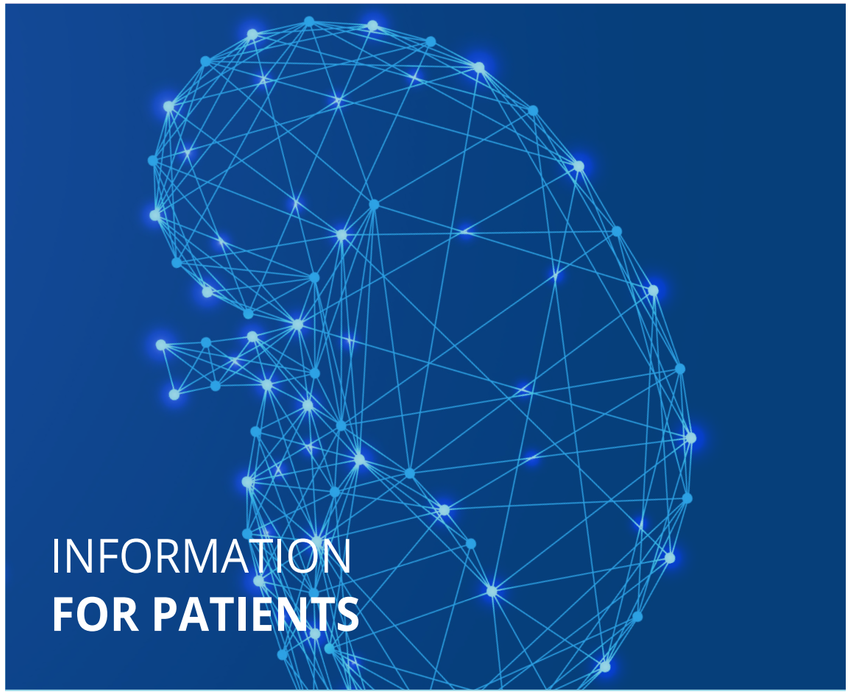


INFORMATION FOR PATIENTS

Co-funded by the European Union

European Reference Network

WHAT ARE EUROPEAN REFERENCE NETWORKS?

The European Reference Networks are virtual networks that unite healthcare providers with top expertise for the management of rare diseases across Europe.

The 24 networks aim to generate and disseminate knowledge on rare and complex diseases, and to provide the best possible care to patients in all European countries.

WHAT IS ERKNet?

ERKNet is the European Reference Network for Rare Kidney Diseases. It is formed by expert centres throughout Europe that provide healthcare to more than 70,000 patients with rare diseases of the kidneys. ERKNet provides expertise on more than 300 individual kidney diseases.

ACTIVITIES OF ERKNet

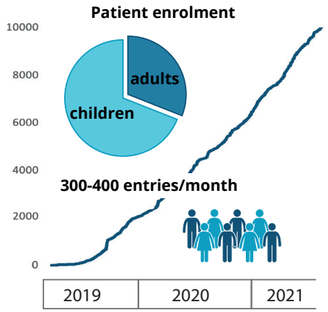
THE EUROPEAN RARE KIDNEY DISEASE REGISTRY

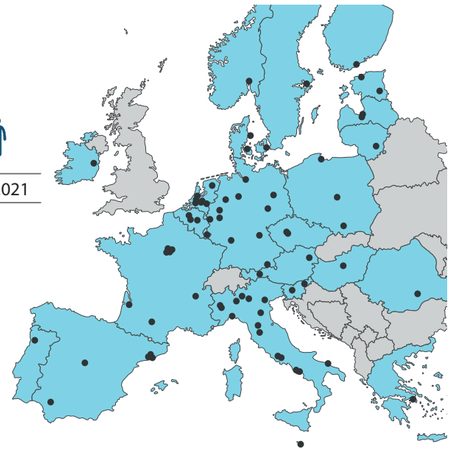
ERKReg is the first and largest Europe-wide registry for all rare kidney diseases.

ERKReg collects prospective information from all patients with rare kidney diseases within the network who agree to have their de-identified data recorded.

The registry helps clinicians, researchers and pharmaceutical industry to generate more knowledge about rare kidney diseases and focus their research and drug development to improve the quality of life of our patients. The registry also aims to help patient organizations, health authorities and policy makers in optimizing the support for patients with rare kidney disorders.

ERKReg is currently receiving patient data from more than 70 hospitals in 24 countries.





AIMS OF THE REGISTRY

Demographic Analysis

The ERKReg registry collects data from 24 countries and allows to analyse the frequency and characteristics of more than 300 rare kidney diseases in different regions of Europe.

Natural Disease History

Patient information is collected once a year by the medical teams to follow the clinical course over time. This will help to identify risk factors for complications and disease progression.

New Therapies

ERKReg data facilitates multicentre research projects to explore novel treatment strategies and new drugs that can improve the patient's wellbeing and quality of life.

The registry allows to find patients with a particular disease for which a new treatment is being developed. The registry team brokers the matching of patients with upcoming clinical trial opportunities.

In this way, the registry supports the rapid access of our patients to new therapies.

Benchmarking

The expert centres participating in ERKReg continuously follow the performance of their patient management according to key quality indicators of diagnostic and therapeutic interventions.

ERKReg provides performance statistics for each centre and the entire registry. This allows the centres to compare the quality of their management with that of the overall ERKNet community.

In this way, we support the excellence and continuous improvement of care in all ERKNet centres throughout Europe.