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ERKReg The European Rare Kidney Disease Registry

Newsletter April 2022

About ERKReg

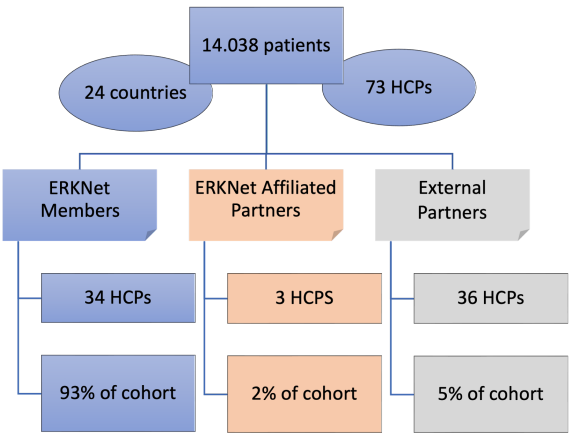
The European Rare Kidney Disease Registry "ERKReg" is **the largest and only patient registry for all rare kidney diseases**.

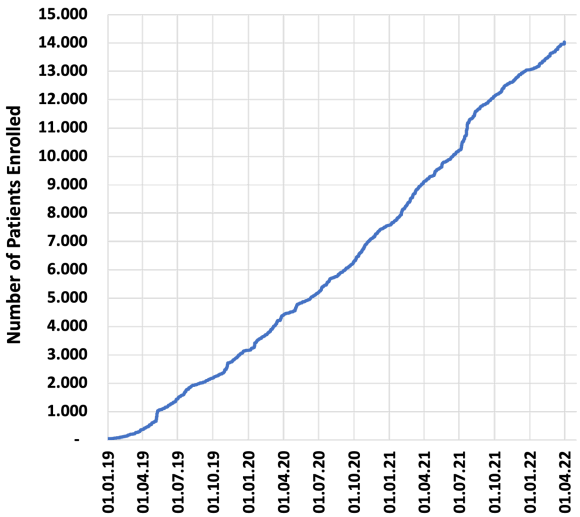
ERKReg collects basic demographic data as well as disease-specific information on treatment and disease progression and indicators of quality of care.

Aims of ERKReg

The ERKReg Registry is intended to facilitate the **identification of patient cohorts** for clinical trials. The monitoring of performance indicators should contribute to the **harmonisation and optimisation of the diagnosis and treatment** of rare kidney diseases in the long term. In addition, the collected data can be used to answer **research-specific questions**.

Data inclusion by 1st April 2022

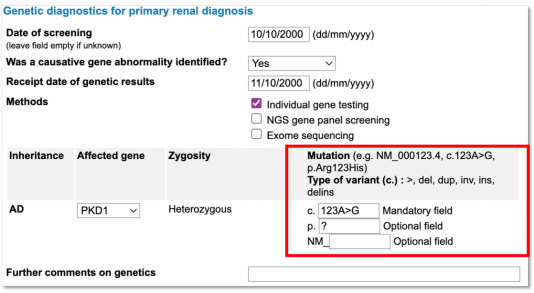




New data items and features

For patients with proven causative gene mutation

Harmonization of genetic data



Genetic data entry will now follow the HGVS (Human Genome Variation Society) nomenclature.
It is mandatory to indicate the DNA sequence change (c.), whereas the amino-acid change (p.) and the DNA reference sequence number (NM_) are optional. Centre queries will be sent out to correct data that were previously entered in the wrong format.

For patients with Cystinosis

Collecting medication history

For patients with Cystinosis (Orphacode: 213), treatment with Cystagon or Procysbi can be recorded in the medication database. Upon saving a visit update, a notification reminds you for completing the data.

For patients with Fabry disease

Collecting medication history and NEW key performance indicator (KPI)

For adult patients with Fabry disease (Orphacode: 324), treatment with Repaglal or Fabrazyme can be recorded in the medication database. Upon saving a visit update, a notification reminds you for completing the data. In addition, a new key performance indicator has been added: % adult male Fabry disease patients receiving enzyme replacement therapy.

Important: If you spot any technical issue, please let us know!

Include your patients to the sub-registries

We encourage all ERKReg sites to additional add their patients to the disease-specific sub-registries!

- ERKReg also serves as a platform for **disease-specific subregistries**. The participation in certain sub-registries is optional. Upon approval an extended case report form is collected for the respective patients.
- Three sub-registries are active:
  - ERKNet/ESPN dRTA sub-registry
  - ERKNet/ESPN pediatric SLE sub-registry
  - Eurocys registry for cystinuria
- Sub-registries currently in programming stage:
  - Sub-registry for Bartter syndrome patients
  - Sub-registry for MPGN patients

Find more information about the sub-registries

SAVE THE DATE – Next ERKReg User Day | 8th June 2022

We are planning to organize the **Third ERKReg User Day.** It will be held virtually on 8 June 2022 from 2:00-4:30 PM (CET). This meeting will be held for those **local team members who are in charge of entering patients** into the ERKReg database. We will present information on on new registry features and encourage the exchange of user experience.

Please register for the meeting at: **https://forms.gle/znS1PLAg4rS3VApbA**

Contact

The ERKReg registry is open to all interested nephrology services around the globe.

If you are interested in participating the ERKReg registry, please get in touch with the ERKReg project management:

ERKReg access and training /legal documentations/informed consent forms

Tanja Wlodkowski:

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IT support

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Visit the ERKReg website

Read the ERKReg publication

Find useful documents

ERKNet - The European Rare Kidney Diseases Reference Network

contact@erknet.org

Follow us on Twitter @EuRefNetwok

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