

The European Rare Kidney Disease Registry

Governance Structure

ERKReg Board

The ERKReg Registry is governed by a Registry Board (“ERKReg Board”), which is composed of 11 members:

- **The Chair**
 - ERKNet coordinator, who is the custodian and responsible for data protection

- **5 members of ERKNet**
 - 2 congenital abnormalities (adult & pediatric)
 - 1 glomerulopathies + TMA
 - 1 tubulopathies and metabolic nephropathies
 - 1 ped CKD/Dialysis and Tx
 - term: 3 years, one-time extension

Criteria for vacant positions:

 - active ERKReg participation
 - scientific interest, experience with cohorts and industry interactions
 - motivation statement required
 - application review and election by all working group chairs

- **2 representatives of the associated sub-registries**
 - Elected by all subregistry leads
 - term: 3 years, one-time extension

- **1 Board member of the ERA Workgroup Genes&Kidneys or Immunonephrology**
 - chosen by the ERA WG
 - watcher function
 - term: 3 years, one-time extension

- **1 member of the ESPN Working Group for inherited renal disorders (WGIRD)**
 - chosen by the ESPN WG
 - watcher function
 - term: 3 years, one-time extension

- **1 representative of the European Patient Advocacy Group (ePAG) for rare renal diseases**
 - chosen by and among the ePAGs
 - term: 3 years, one-time extension

The current composition of the ERKReg Board is published at the ERKReg website:
<https://www.erknet.org/patients-registry/registry-governance>

Data Access Committee

The data access committee is composed of different members, depending on the type of data requested.

For global and non-specific requests

- ERKReg Board without representatives of ERA and ESPN
- 3 largest contributing centres related to the population of interest. The respective centre leads, or a delegated person will be considered.
- A double majority is needed for approval

For disease/disease-group specific requests

- 1 ERKReg Board chair
- 1 ERKReg Board member for the disease/disease group of interest
- 1 ePAG for the disease/disease group of interest
- 3 chairs of the respective ERKNet working group
- 3 largest contributing centres related to the population of interest. The respective centre leads, or a delegated person will be considered.

- For subregistry related data: subregistry leads

- A double majority is needed for approval. For subregistry related data, subregistry leads will have the power to veto.