

ERKNet

European Patients Advocacy Group (ePAG)

Terms of Reference (ToR)

based on the General Rules for Patient Engagement
approved by the ePAG Steering Committee, 9.06.2021

[Insert date of approval by ERN Board]

1. Introduction

The ePAG of ERKNet is formed of representatives of patient organisations within the scope of ERKNet. The ePAG structure mirrors the subgrouping of rare renal diseases and the task forces of ERKNet. The ePAG will work collaboratively with ERKNet Healthcare Providers (HCPs) (full, associate, and collaborative members) based on the operational criteria to be fulfilled to be an ERN and an HCP.

2. Composition of the ERKNet ePAG (Group)

To elaborate and express the voice of patients in the ERKNet, it is created an "European Patients Advocacy Group" (ePAG), dedicated to rare renal diseases.

ePAG members are national or international patient organisations based in the European Union. Patient organisations based outside the European Union (EU), in Europe at large or based in other countries relevant to ERKNet, will progressively be included, on a case-by-case basis, in conjunction with the collaboration of ERNs with HCPs beyond the EU.

Each patient organisation wanting to become a member of ERKNet nominates one or more persons as their representative(s). These ePAG advocates should be aware of the "General Rules for Patient Engagement" and the Terms of Reference. They have to be endorsed by their patient organisation and approved by the ERKNet ePAG group and chair and the ERKNet coordinator.

ePAG advocates are active in the ERN governance structure including the Network Advisory Board, the Executive Board, Work groups and Task forces.

3. The ePAG Chair and Co-Chair

The ERKNet ePAG advocates elect one ePAG chair and one co-chair (one vote per each patient organisation being a full member of the ePAG). The ePAG chair (or co-chair) are based in the European Union and have the mandate of managing the ePAG towards elaborating a structured voice of the European patients affected by rare renal diseases. They coordinate the work of the ePAG advocates, lead through discussion and organise meetings on a regular base. They will liaise with their affiliated patient organisations to ensure true and equitable representation of the patient voice in ERKNet.

The ePAG chair (or co-chair) is a full member of the ERKNet board and he/she participates in the decision-making process. They have an official permanent mandate to represent EURORDIS and the affiliated patient organisations. The ePAG chair (or co-chair) ensure rare renal disease patient organisations are consulted by ERKNet for disease-specific discussions, projects, and activities.

The ePAG chair (or co-chair) represents ERKNet in ePAG meetings, committees or workgroups organised by the Board of Member States or EURORDIS (e.g. Steering Committee, Workgroups for Registries or Guidelines, AMEQUIS) to make sure the voice of patient organisations in ERKNet is heard. These mandates can be split between chairs and work group leads.

The term of office is two years. Re-election is possible. In case the chair resigns earlier, either the co-chair is taking this function or a new chair has to be elected. A new co-chair election is also needed to fulfil co-chair vacancy in case the co-chair becomes the chair.

The chair will facilitate the flow of all ERKNet information within the ePAG (group).

4. ePAG Work Groups and Task Forces

To shape the contributions of the patient community towards the goals of ERKNet, a corresponding ePAG work group of patients for each ERKNet work group and for the task forces is created. An ePAG work group gathers representatives of patient organisations or representatives of informal groups concerned by the specific theme.

Members not belonging to an association are welcome to join the ePAG work groups as individuals or representatives of an informal group as long as there are no patient organisations in their country representing their pathology in the ePAG. Membership of individuals is purposely offered to further expand the network of patients to countries where patients are less organised in associations.

5. ePAG Working Group Lead

Each ePAG work group is represented by a lead elected by members of the ePAG work group or task force, regardless of their number (one vote per association). ePAG leads are elected for a three-year term.

The lead must be a member of a patient organisation that is a full member of the ERKNet ePAG. He/she must commit to speak for all patients living with conditions covered by the work group. He/she has to represent patient organisations within the respective ERKNet work group and circulate information to the members.

It is up to the work group lead to ask patient representatives from outside ERKNet to become partners when it comes to special questions or tasks (like guidelines e.g.) and insider knowledge is needed.

For practical reasons one person can only be a lead of a single working group. It is recommended to elect a co-lead just in case the lead is not available or the work load increases.

6. ePAG Core Team

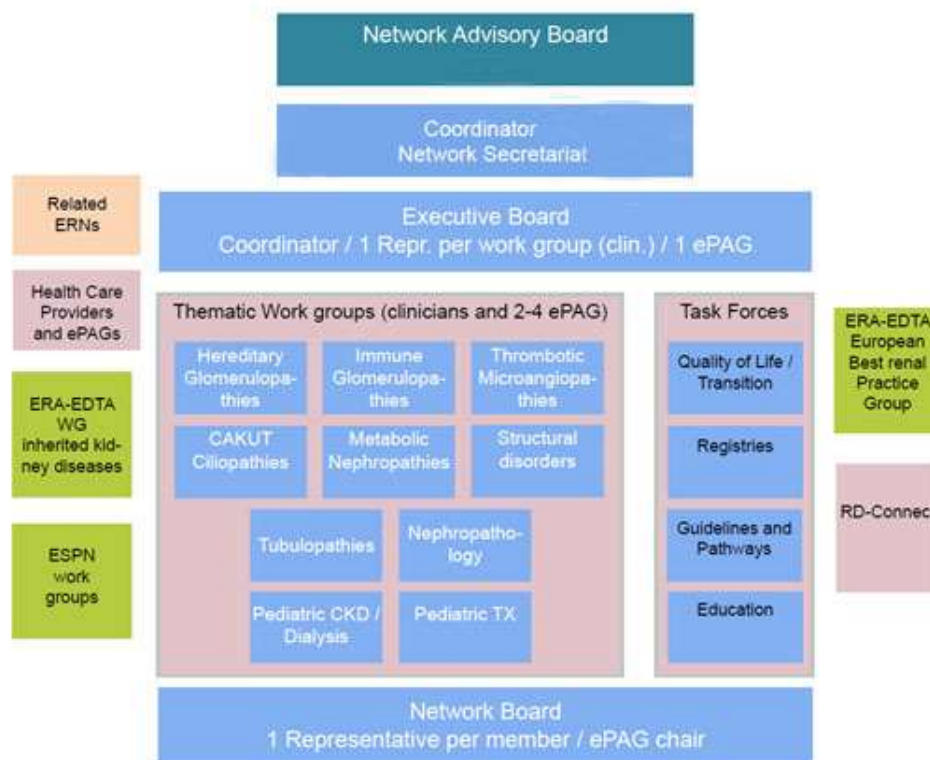
ePAG Chair / Co-Chair and the leads of the working groups compose the ePAG core team, i.e. the executive body of the ePAG. The ePAG core team will meet regularly electronically and on a face-to-face meeting occasionally. The ePAG core team should meet at the annual meeting of ERKNet.

The ePAG core team together with the ERKNet coordinator should organise an all ePAG meeting on a regular base.

7. ePAG Linguistic Correspondent

To facilitate the participation of patients and families that are not fluent in English, the ePAG will nominate members as liaison person for one particular European language to help filling language gaps and give members not fluent in English the possibility to make their voice heard in discussions. At start it is ambitioned to cover the following languages: Dutch, French, German, Italian, and Spanish. It is anticipated to enlarge to other languages in tune with the growth of the network.

ERKNet Structure



ERKNet ePAG structure and names (as of July 2021)

ERN Board	ePAG advocates	Patient Organization	Role
ERKNet Network Board	Claudia Sproedt or Susana Carvajal Arjona	Cystinose-Selbsthilfe e.V.; Hipofam	ePAG Chair ePAG Co-Chair
ERKNet Executive Board	Claudia Sproedt or Susana Carvajal Arjona	Cystinose-Selbsthilfe e.V.; Hipofam	ePAG Chair ePAG Co-Chair

The nominated ERKNet ePAG work group leads and members represent the voice of the patients within ERKNet and they contribute actively to the regular activities and meetings.

ERN Work groups	ePAG	Patient Organisation	
Hereditary Glomerulopathies	Johanna Rohlfing	Nephie e.V. / Idiopathisches Nephrotisches Syndrom	Lead
	Heidi Zealey	Alport UK	Co-Lead
	Marieke van Meel	NephCeurope	

ERN Work groups	ePAG	Patient Organisation	
	Karlheinz Steinecker	AIRG France	
	Evy van Kempen	Nierpatiënten Vereniging Nederland (Dutch Kidney Patients Association)	
Immune Glomerulopathies	Marieke van Meel	NephCeurope	Lead
	Johanna Rohlfing	Nephie e.V. / Idiopathisches Nephrotisches Syndrom	Co-Lead
	Evy van Kempen	Nierpatiënten Vereniging Nederland (Dutch Kidney Patients Association)	
Thrombotic Micro-Angiopathies	Alena Lass	aHus und MPNG Selbsthilfegruppe für komplementbedingte Erkrankungen	
	Francisco Monfort	Asociación Síndrome Hemolítico Urémico Atípico (ASHUA)	
	Evy van Kempen	Nierpatiënten Vereniging Nederland (Dutch Kidney Patients Association)	
CAKUT Ciliopathies	Renée de Wildt	Nierpatiënten Vereniging Nederland (Dutch Kidney Patients Association)	
	Tess Harris	PKD UK	
	Marjolein Bos	Dutch and Flemish Cystinosis Group	

ERN Work groups	ePAG	Patient Organisation	
Metabolic Nephropathies	Marjolein Bos	Dutch and Flemish Cystinosis Group	Lead
	Claudia Sproedt	Cystinose-Selbsthilfe e.V.	Co-Lead
Structural disorders	Uwe Korst	PKD Familiäre Zystenniere e.V.	
	Michel Schenkel	FEDERG	
	Flavia Galletti	Associazione Italiana Rene Policistico Onlus	
	TessHarris	PKD UK	
	Karlheinz Steinecker	AIRG France	
Tubulopathies	Susana Carvajal Arjona	Hipofam	Lead
	Virginia Guillon	GitelBart Association	
	Etienne Cosyns	AIRG Belgium	
	Renée de Wildt	Nierpatiënten Vereniging Nederland (Dutch Kidney Patients Association)	
	Antonio Cabrera	Hipofam	
Pediatric CKD / Dialysis	Evy van Kempen	Nierpatiënten Vereniging Nederland (Dutch Kidney Patients Association)	
	Manuel Arellano	ALCER	
Pediatric TX	Evy van Kempen	Nierpatiënten Vereniging Nederland (Dutch Kidney Patients Association)	
	Marieke van Meel	NephCeurope	
	Manuel Arellano	ALCER	

ERN Work groups	ePAG	Patient Organisation	
Nephropathology	Virginia Guillon	GITELBART Association	
	Susie Gear	Alport UK	
	Heidi Zealey	Alport UK	

ERN Task Forces	ePAG	Patient Organisation	Role
Quality of Life / Transition	Marjolein Bos	Dutch and Flemish Cystinosis Group	
	Claudia Sproedt	Cystinose-Selbsthilfe e.V.	
Registries	Tess Harris	PKD UK	
	Michel Schenkel	FEDERG	
Guidelines and Pathways	Tess Harris	PKD UK	
	Claudia Sproedt	Cystinose-Selbsthilfe e.V.	
Education & Training	Susana Carvajal Arjona	Hipofam	