

ERKNET European Reference for Rare Kidney Diseases

Report of the 1st E-PAG ERKNET Patients Meeting (Sunday 5th March 2017 AMSTERDAM)

A European Reference Network for Rare Kidney Disease - ERKnet - has been developed early 2016 under the leadership of Pr. Franz Schaeffer, University of Heidelberg. A proposal has been submitted to the EU Commission in June 2016.

The process of getting patients involved in ERKnet was initiated by FEDERG in 2015, and in 2016 spring, 2 members of FEDERG (Claudia Sproedt and Daniel Renault) were elected as E-PAG representatives for the kidney network. The E-Pag reps have contributed to the writing of some sections of the proposal as well as the reviewing of all.

The ERN board of Member States, has officially approved ERKnet in mid December 2016, thus the process of patient involvement needs now to be started.

This 1st E-PAG meeting of ERKnet in Amsterdam was attended by 25 participants. It had two concrete objectives:

1. Identify patient representatives for each subgroup and task force of the ERKnet and getting patients organised in subnetworks mirroring the framework of ERKnet (see appendix).
2. Initiate the preparation of patient contributions in view of the ERKnet official launching to be held 23rd and 24th May 2017 in Heidelberg.

Session 1 INFORMATION on the ERN, the EPag and the ERKnet

The first session of the meeting was aiming at providing the participants with the latest and most comprehensive information on the ERN and specifically on ERKnet. Three speakers:

Matt Johnson EURORDIS : *The ERN initiative: background, hopes and ways forward*

Daniel Renault E-PAG ERKnet: *Foreseen Patients contributions to the ERKNET: Governance – Healthcare pathways – Ethics – Protocol for transition – Research – Safety and quality – Monitoring*

Franz Schaeffer Coordinator ERKNET (Via Skype connection) *Overview of the ERKNET network and what it plans to do and the role of patients.*

“The voice of patients must count” if there is one sentence to take home, this is the one.

This sentence of Franz Schaeffer, summarizes the spirit in which ERKnet is about to start as far as patient's contributions are concerned. This is a strong motivation for patients to invest on the ERN, with the idea that our contributions will be heard and will contribute to the success of the ERN in influencing positively **healthcare pathways** for all European patients.

SESSION 2 Subgroups per type of renal pathology

The objective was first to initiate the process of identifying the important features from the patient's perspectives on "Healthcare pathways". Elements reported are only there to reflect the discussion. Further analysis and discussion through a subnetwork of patients should be performed.

The second and more important objective was to identify among the participants at least two volunteers as E-Pag subgroups for **this preliminary phase**. The preliminary phase will last till the end of May where ERKnet will be officially launched in Heidelberg. By that time the enlarged patient subgroups corresponding to the specific working group will decide as to who should be the representatives in the working group or task force.

So the mission of the **preliminary representatives** of the E-Pag subgroups is to first to contact all known patient's associations relevant to this working group, coordinate and conduct the initial steps of the consultation process.

Metabolic nephropathies (Cystinosis,...): early diagnosis, New born screening, X-disciplinary one day appointments, Psychological and social supports, relation with Pharmas, concern about interruptions of treatment linked to a disagreement on price after a trial, link with other metabolic diseases (Other ERN).

WHO: Claudia Sproedt + to be discussed in Cystinosis network Europe

Tubulopathies (Bartter & Gitelman, FPH..): Coverage of the mineral supplement for all (different forms, e.g. liquid or pills such as Slow-K, as not all forms go well with everyone), early diagnosis, personal code bracelet with health information, identify best practices and develop standard protocols, promote research, investigate long-term effects of minerals deficiency, QoL and social.

WHO: Susana Carvajal Arjona + WanMin Huang + Antonio Cabrera

Immune mediated glomerulopathies (Nephrotic Syndrome, ..): harmonization of information to patients, Need for developing a strategic vision for research on NS, Increase patient Voice in the research agenda, Need to include individuals experts-clinicians in the ERN, expand to other associations in in eastern countries as well as in Germany,

WHO: Marcel van Hest, Johanna Rohlfing and Evy van Kempen.

Hereditary glomerulopathies (ALPORT,..): Psychological support particularly during childhood, a questionnaire on pathways should be widely circulated in the Alport patient community to gather most concerns. The FEDERG Alport chapter is to be the platform for supporting the E-PAG rep in this working group.

WHO: Jacqueline van Kempen and Daniel Renault.

ADPKD: monitoring of the introduction of the new medicine TOLVAPTAN with different applications protocols in Europe, link with the ERN on transplantation, are Immunosuppressors tailored to PKD ?,

WHO: Cathriona Charles - Gerard Kuipers

Thrombotic microangiopathies (aHUS,..): Diagnosis to be more standardized, Great expertise on board, treatment and analysis

WHO: Marjolein Storm & Nacho Nunez.

SESSION 3 Transversal per Taskforce

Transplantation and Dialysis: map down what is common to all kidney diseases and what is specific to R/G renal diseases, Help patients making a choice for dialysis independent from the technology available by the clinicians, clarify criteria that lead to pre-empted transplantation, survey on ESRD, list of living donors, promote multi-countries transplantations (cross-over), focus on teen-age rejection due to non adherence.

WHO Transplantation: Evy van Kempen+ Laura Parise

WHO Dialysis: Francisco Montfort + Laura Parise,

Registries: Shared Governance between patient's organisations and healthcare professionals, Sharing the financing while insuring independency of private interests, ensuring ethics, ensuring feedback from researchers, service oriented management, investigating how patients could enter the data themselves, investigating bridges between existing databases, censuring previous studies,

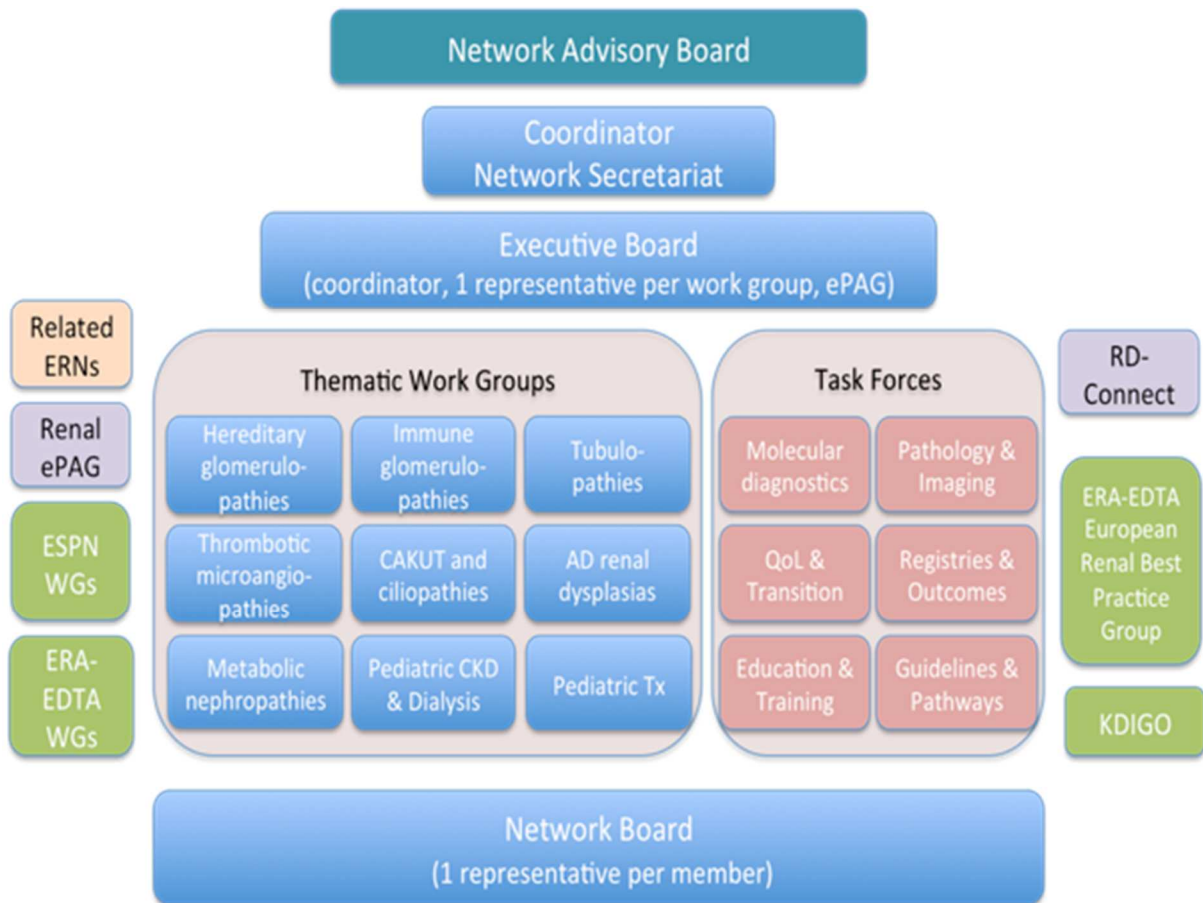
WHO Marjolein Storm and Marcel van Hest

Quality of Life and Transition: Concerns the patients and families, sensing the best practices, mutual recognition patients/professionals to improve dialogue. Giving a patient a sense of control of his/her situation will improve the psychological wellbeing and therefore a greater chance for a swift recovery. Psychological support, aiming to a holistic view. Support in transition phase by multi-disciplinary team.

WHO: Brenda de Coninck & Rita Pieters



Group photo of the participants to the 1st E-PAG of ERKNet



ERKNet structure with Work Groups and Task Forces