



ERKNet European Patient Advocacy Group (ePAG)

Workshop Budapest, 18.05.2017
Claudia Sproedt, FEDERG

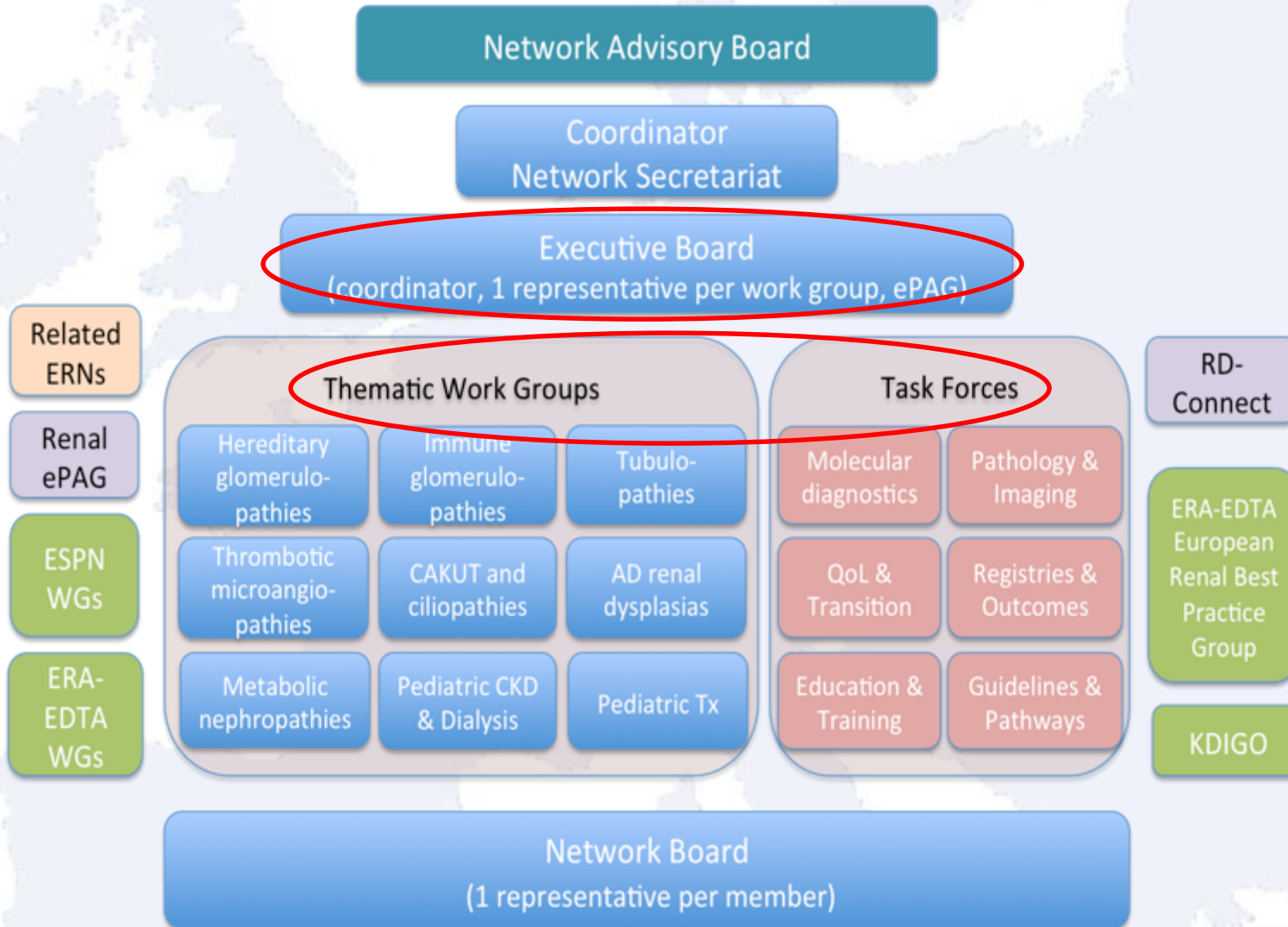


ERKNet – European Rare Kidney Network

How we got started

- In 2013 FEDERG was founded.
European Federation for Rare and Genetic Renal Diseases
- “Umbrella”-Organisation for European patient organisations helping patients with rare or genetic kidney diseases or kidney affecting diseases
- Franz Schaefer (coordinator of ERKNet) and Daniel Renault (chair of FEDERG) developed this ERNs main structure
- Jan. 2016 First meeting of interested Medical centers (8) and patient representatives (3)
- ERN application in 2016 and shortly later the Election of interim patient representatives.
- Progressively expanded (a work in progress; perfectible next years) with agreed Terms of Reference
- Now 36 professional partners and 35 patient organisations in the ePAG

ERKnet Governance Structure



ERKNet Governance Structure

Board / Committee	Chair	ePAG representative
Network Advisory Board	Franz Schaefer	Daniel Renault
Coordinator Network Secretariat	Franz Schaefer	
Network Executive Board	Franz Schaefer	Daniel Renault
Network Board	Franz Schaefer	Daniel Renault / Claudia Sproedt
Thematic workgroups	ePAG representative	
Hereditary glomerulopathies (ALPORT..)	TBD	ePAG rep (TBD)
Immuno glomerulopathies (Nephrotic Synd.)	TBD	ePAG rep (TBD)
Tubulopathies (Bartter & Gitelman,..)	TBD	ePAG rep (TBD)
Thrombotic microangiopathies (aHUS)	TBD	ePAG rep (TBD)
CAKUT and ciliopathies (ADPKD,..)	TBD	ePAG rep (TBD)
AD renal displasias	TBD	ePAG rep (TBD)
Metabolic nephropathies (Cystinosis,..)	TBD	ePAG rep (TBD)
Pediatric CKD & Dialysis	TBD	ePAG rep (TBD)
Pediatric Tx	TBD	ePAG rep (TBD)

Task Force Groups

Task Force Groups	Chair	ePAG representative
Molecular diagnostics	TBD	ePAG rep (TBD)
Pathology imaging	TBD	ePAG rep (TBD)
QoL and transition	TBD	ePAG rep (TBD)
Registries and outcomes	TBD	ePAG rep (TBD)
Education and training	TBD	ePAG rep (TBD)
Guidelines and pathways	TBD	ePAG rep (TBD)

Challenges to be met by ePAGs

- Our kick-off meeting will be held in Heidelberg on May 23-24.
Who will show up? Will it be difficult to get the workgroups set and what are the most important topics?
- There is excitement everywhere at the moment.
How long will it last? And who will do the lot of work after the first year?
- How can we find more partners – patient groups, medical centers, perhaps „lonesome riders“ in small countries.
- How do we share travel costs, hotel, and all other financial needs?
If there is some funding (by EU??), who will be responsible for organising all this?

Challenges to be met by ERNs as a whole

- How to get the workgroups working?
 - Electing the chairs
 - Calming the waves between competing clinics
 - Deciding which are the most important things to do right away
 - Not to forget that there are well informed patient representatives to work with, to share work and happy moments, to trust as partners, to ask for assistance, support, sometimes encouragement?!
- Registries and platforms
 - Do we all need different ones? Can we use existing ones?
 - If not: how can existing registries be linked?
- How do we organise the information platform – for patients and clinicians and everybody?
 - Who decides which patient representative is in charge (or: has the honour) to talk to patients having questions?
 - How do we teach all clinics that there exists a patients' advisor in the network?