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POUR SOUTENIR LA RECHERCHE SUR
LA POLYKYSTOSE RENALE
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Polycystic Kidney Disease



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a brighter future for people living with alport syndrome



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BELGIUM



FEDERG

*Federation of European associations
of patients affected
by Renal Genetic diseases*

Why join FEDERG?

FEDERG aims to work across Europe for inherited renal diseases to:



- Facilitate access to information and care, enabling and empowering national patient groups



- Represent patient groups in the development of public health policies



- Develop the research agenda for treatment and cure through international collaboration.

Together we are strong, alone we are rare

Alone in our country, we are rare, isolated. National groups and associations need to get together to become strong.

A step towards international cooperation

Once organized and strong at Europe level it is easy for a federation to collaborate with other alliances to create a world wide alliance.

FEDERG is organized by disease area

FEDERG is a Federation for each renal genetic disease as well as for all renal genetic diseases at European level,

Here is a new opportunity to break down the barrier of knowledge, to share information in all languages.

FEDERG will provide information that directs you to the best information on each renal genetic disease through an internet portal.

Europe is the political space impacting our life as patient.

Decisions at European level on policy for rare diseases, on health and social services, on cross-boundaries access to rare treatment, on medicines development and authorization, are impacting our lives.

Europe is also a key player in financing research programs for rare diseases.

Only a European federation is entitled to represent patients in the European institutions

This is why our first step for international cooperation is to create FEDERG with the goal to represent the European patients affected by Renal Genetic Diseases, probably more than a million.

FEDERG is a European voice for the common features of health and life (genetic, dialysis, transplant, pediatric,..).

FEDERG plays a role on the European and International research agenda.

FEDERG can help the research community getting mobilized for European projects

Europe is a key funder for research projects on rare diseases.

FEDERG can be a critical actor in creating disease registries and biobanks, they are the two pillars to develop effective research projects and attract public and private funding (pharmaceutical companies).