



Federation of European Associations of Patients affected by Renal Genetic Diseases.

PRESENTATION of FEDERG

FEDERG is a Federation of European associations of patients affected by Renal Genetic Diseases, officially registered under the Belgium Law (Royal arrêté WL 22/16254 22 May 2014) with a legal seat located at Cliniques Universitaires Saint-Luc, Service de Néphrologie, avenue Hippocrate, 10, 1200 – Bruxelles, legal district of Bruxelles.

- **FEDERG: an umbrella organization on renal genetic diseases in Europe**

The FEDERG's basic goal is to build at European level, an umbrella organization on Renal Genetic Diseases (RGD), with the objectives of being a voice of all patient concerns, facilitate the dissemination of knowledge, express solidarity among patients, ensure a fruitful relationship with professionals, weigh on the research agenda and on public health policy.

The motivations for a European federation are multifold:

- A better recognition and an increased weight compared to that of an association alone (research, public health decision, drugs, clinical trials, ..)
- An easier collaboration with nephrologists and other medical professionals
- A better chance to apply for European funding (They are more and more allocated to organizations and projects that cover several pathologies)
- High solidarity between associations and between countries.
- Effective cost sharing
- An increased ability to mobilize patients all over Europe.

In this endeavor, there are specific areas on which FEDERG wants to make a difference.

Driving the research agenda

By reaching a large number of associations, patient groups and families, FEDERG wants to be able to accelerate research on RGD, to promote cohorts and registries, to mobilize more efficiently patients for clinical trials, to participate in the advisory boards of clinical trials, to raise funds for research, to help set the research agenda on RGD by contributing to develop international research strategies, and emerge as a strong European partner when international collaboration is desirable.

A patient's voice and a legitimate stakeholder of public health decision and for quality of life

Decision about marketing and reimbursement of medical treatments are taken by European and national authorities. FEDERG wants to be recognized as a legitimate representative of patients when it comes to RGD.

Patients affected by RGD must fight not only to get a correct diagnosis and then a treatment when they exist, but also for getting a quality of life as similar as possible to that of anyone else. Life is impacted in many aspects: side effects of treatment, chronic fatigue, quasi impossibility to have a normal social life, difficulties at work, difficulties to get a mortgage, educational hurdles for youngsters. All this are at the periphery of the medical domain, but here again public decisions at European level might make a difference on patient's life. We want to voice the patients also for quality of life.

- **Share and solidarity for patients affected by Renal genetic diseases**

As most of the RGD are considered as rare diseases, patients with RGD are commonly concerned affected by this aspect (rareness): we share the rarity of our conditions.

There are however numerous rare diseases, hence Renal Genetic Diseases (RGD) collectively account for about 10 % of patients reaching ESRD in Europe. Besides autosomal-dominant polycystic kidney disease (ADPKD), which, with a prevalence of 1:1000 is by far the most frequent, there are approximately 40 rare and up to 200 extremely rare RGD, affecting all structures of the nephron. The economic burden of RGD is huge, since dialysis treatments of affected patients account for 0.2 % of national healthcare budgets and most orphan drugs are very expensive.

RGD may impact the quality of life and relationships of a whole family including reproductive/family planning matters. Although the clinical consequences of the kidney disease vary with each pathology, patients with RGD are sharing numerous aspects which are related to the medical course as well as life quality:

- Diagnosis, Treatments, ESRD dialysis and transplantation
- Genetic transmission, decision about pregnancy,
- Difficulties in growing as a child, teen ager and young adult.
- Social life, educational and working conditions.

At national level we share many aspects related to public health (treatment cost coverage, rare diseases policy, etc...).

As we share many aspects of our conditions, the sense of "Solidarity" is very strong among us. Solidarity is a key value for rare/orphan diseases: as patients affected by rare disease or as association of patients, we turn to society for more solidarity towards the ones suffering from these orphan diseases. In turn, our duty is to genuinely help each other, making solidarity within our groups of patients a reality. In RGD you have rare, less rare and extremely rare diseases. The spirit, on which such an umbrella organization as FEDERG is built, makes each member fighting not only for his disease but for all diseases.

Solidarity is the motto of FEDERG: Solidarity of patients towards each other, solidarity between associations and patient groups, and solidarity between countries.

- **FEDERG: goals, aims**

FEDERG is a non-governmental non-for-profit European federation of associations, groups and other organizations as well as individuals, who support children and adults living with renal genetic diseases.

Our overall aim is to:

Improve the health and quality of life of all those affected by renal genetic diseases, through advocacy, representation, engagement and collaboration.

Our specific aims are to:

- Be the voice of national patient groups (whether formally constituted or unincorporated associations of patients) at the highest institutional level of EU policy making and public health
- Lobby to remove inequalities of care and discrimination across the EU
- Enable and empower national patient groups to better support patients and families in their own countries
- Help researchers in their work to identify and study disease causes, therapies and improved treatments.

The means of achieving these aims are to:

- Raise awareness of the impact of renal genetic diseases within the European institutions and represent patients in public health negotiation, in policy setting (insurability, financial coverage of medical treatments, associated social services, ethic issues) and at the European Medicines Agency (EMA)
- Promote, support and stimulate the sharing of knowledge and understanding of renal genetic diseases, nationally and across the EU
- Foster the formation and development of national patient groups or associations, where patients are not or less organized
- Support existing patient groups and associations by sharing information and best practice
- Provide information to help national groups to communicate with or lobby their national health organisations to promote the interests of their patients and encourage an integrated approach to their health and social care
- Provide information that will benefit patients who do not have a condition/disease-specific support group and those in hard-to-reach geographical/ethnic communities, including signposting them to reliable, quality patient information
- Promote collaboration between members, European institutions, European societies of professionals, international organizations
- Champion and drive an EU-wide research agenda

- Promote and contribute to the development of European registries
- Promote and/or participate in national and transnational laboratory, transitional and clinical research into renal genetic diseases
- Invite and encourage patient involvement in research and clinical trials
- Organise conferences, symposia, workshop and similar, and support the publication and/or dissemination of information and best practice
- Co-operate with other alliances, voluntary organisations and statutory bodies to further the interests of people with renal genetic diseases

- **FEDERG membership**

FEDERG is a non-governmental non-for-profit European federation of associations of patients that needs to be open to all patient groups and associations as long as they are concerned with one or more renal genetic diseases. The federation should be open also to non European organizations, either associations from outside the EURO 27 or international organizations.

At the same time FEDERG should be well legally framed for being a legitimate official partner on patient side in Europe.

The members of FEDERG are of two types:

- **Full members** are umbrella organisations, that is European single pathology organizations or national umbrella organisations, or national organisations of European Union focussed on one pathology.
- **Associate members** are associations, patients groups, individuals or informal groups devoted to renal genetic diseases which are not of European legal status.

Membership is acquired by sending a letter of application to the Board, which sovereign appreciates how to proceed with this request. Membership is maintained by the regular payment of fees.

- **FEDERG structure**

The agreed upon goal of FEDERG is “to Improve the health and quality of life of all those affected by renal genetic diseases, through advocacy, representation, engagement and collaboration at Europe level”.

It is our assumption that, the most important way to achieve that goal, is to genuinely strengthen collaboration of patient’s group on renal genetic diseases throughout Europe (and beyond).

FEDERG EUROPEAN integration

Governing bodies : BOD –AG

Scientific Committee

Transversal subgroups

Other Renal Genetic Diseases

Pathology chapter

Pathology chapter

NATIONAL Collaboration of RGD associations

By strengthening collaboration on the RGDs at national level: it is critical that national associations could engage themselves into a genuine collaboration by sharing information, holding meetings in common, participating to common fund raising campaign.

By favoring the development of European pathology chapters, gathering all national groups centered on a single pathology. This should be done for pathologies for which several associations are member of FEDERG. This strengthening process for some pathology should not be made at the expenses of other diseases left aside. In fact the presence of several AIRG national organizations from Europe is the guaranty that all renal genetic diseases are on board and that all pathologies should ultimately consider developing a European chapter.

By creating transversal subgroups, on aspect of RGD that are transversal to many diseases as per needed.

By realizing full integration at Europe level: clustering the previous elements into a consistent approach and offering a real European platform of patients organization affected by renal genetic diseases.

Tentative list of core and project funded activities of FEDERG

Core activity: Represent and voice RGD

- Participate as a patients group, in European professional societies, rare diseases' committee, European Medicine Agency and on in the agencies involved in setting the European research agenda on rare diseases.
- Contribute to the dissemination of public health policy in countries of Europe
- Help national associations voicing for equal access to treatments.
- Website: an information platform for RGD in Europe

Activity 1 INFORMATION: Information on Renal Genetic Diseases

- Update, translate existing RGD booklets in several languages
- Participate to the dissemination of information to patients via professionals in national and international events
- Strengthen the transversal knowledge on treatment and on best practices on all what we have in common with regards to: Compliance, transplant, family and social, quality of life "growing and living with RGD", genetic diagnosis, genetic advising, gene therapy.

Activity 2 PATHOLOGY : Support to pathology chapters

- Help associations' representatives (members) in organizing a pathology chapter, within FEDERG
- Support participation of patients without national associations

Activity 3 NATIONAL GROUPS: Fostering and Empowering RGD national patient groups

- Help patients and associations getting together at national levels (alliance, informal groups)
- Help creating umbrella national associations on RGD

Activity 4 RESEARCH: Research Agenda

- Participate as patients' organization to European projects
- Help developing research strategy
- Mobilize patients for clinical trials and establishment of registry
- Help mobilizing funds for rare renal diseases

Activity 5 INTERNATIONAL: International cooperation

- Liaise with major patient groups worldwide

- Cooperate with patients groups from neighboring countries
- Represent Europe patient groups in international meetings (patients and nephrologists)