LATEST NEWS AND UPDATES

Newsletter Early 2025 Late 2024

Latest Update from the world of FEDERG representation

FEDERG

REPRESENTATIONS

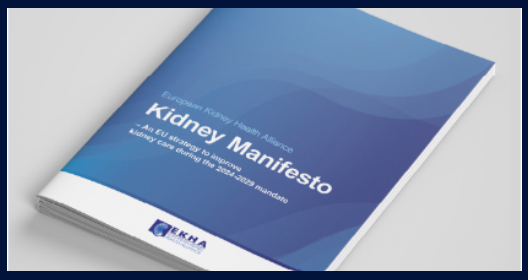
FEDERG REPRESENTATIONS

Newsletter Early 2025 Late 2024

LATEST NEWS AND UPDATES

Latest Update from the world of FEDERG representation

Highlights of Early 2025 Late 2024



FEDERG supports the EKHA manifesto and the European Kidney Forum in the European Parliament on January 2025

Early Detection, Better Outcomes: Advancing Kidney Disease Screening in the EU. EKHA launched the annual European Kidney Forum. This project seeks ways to help better understand the needs of large communities of patients affected by chronic kidney diseases.

Supporting the WHA Resolution on Rare Diseases

RDI is officially establishing a loose Coalition with patients groups, January 2025

This coalition will serve as a flexible and inclusive network of like-minded organizations and individuals committed to amplifying the impact of this critical resolution. Our shared efforts will focus on raising awareness, fostering advocacy, and mobilizing global and national support for its successful adoption and implementation.

Supporting the EKPF Manifesto, FEDERG in Annual Summit 2024 and General Assembly

Last October 2024, FEDERG attended the EKPF Annual Summit and General Assembly to reaffirm its commitment to joining forces and strengthening ties between patient communities. It was a very enriching meeting.

FEDERG

REPRESENTATIONS

LATEST NEWS AND UPDATES

ILLUMINATING PATHWAYS TO IMPROVE UNDERSTANDING, HEALTH, WELLBEING

I'm thrilled to present the very first issue of Federg Representation: Latest News and Updates! This edition highlights just a few of the most exciting and impactful events from late 2024 to early 2025. Federg is actively collaborating with a wide range of stakeholders to shape the future of healthcare, working on the changes that will transform care systems across Europe and beyond. Stay tuned for more amazing updates as we continue to drive progress together!

Federg is an incredible federation made up of 17 European Patient Associations, each doing extraordinary work at the national level! These associations are champions for their communities, providing vital support for patients, advancing research, and spreading awareness about genetic and rare kidney diseases. Together, we're making a huge impact and driving positive change across Europe!

1. Be an active part in decision-making regarding the care and treatment of rare genetic kidney diseases in Europe and in the world.

2. Advocating for rare and genetic kidney patient communities.

3. Addressing the unmet needs of patients for a holistic approach to care and treatment of rare, genetic kidney diseases.

A holistic model goes beyond treating the disease, it nurtures the entire individual, promoting healing through every part of their existence. This approach not only enhances clinical outcomes but fosters a renewed sense of purpose, hope, and dignity for patients with rare kidney disease.

FEDERG
REPRESENTATIONS

FEDERG supports the European Kidney Forum in the European Parliament on January 28, 2025

Early detection leads to better outcomes! That's the powerful message EKHA members delivered at the European Kidney Forum in the European Parliament on January 28, 2025. EKHA, a dynamic European Alliance of key stakeholders in the world of kidney diseases, is rallying behind this crucial demand to advance kidney disease screening across the EU.

As proud members of EKHA, FEDERG fully supports this initiative to improve early detection and save lives. Recent studies, like the GENSEN study from the Spanish Society of Nephrology, show that many individuals on dialysis or awaiting a transplant may not even know the cause behind their kidney failure. This is why early detection is critical!

FEDERG and the vast European communities of patients with genetic and rare kidney diseases, strongly believe that screening, early detection, and education are absolutely critical! These steps are essential to ensure that patients receive timely and effective treatment, giving them the best possible chance for a healthier future. We are committed to making this a reality!

A diagnosis must be accompanied by an accurate description of the disease in the clinical history of these patients.

That is why it is necessary to include the specialty of genetics in the multidisciplinary clinical health care service that treats these patients.

Why is so important?

1. Early treatment is key! By providing patients with timely access to doctors, hospitals, and specialized care, we can prevent the development of additional diseases, protect other organs from deteriorating, and reduce the risk of other health complications that may arise from inadequate care especially for hereditary conditions that often affect multiple organ systems.

.

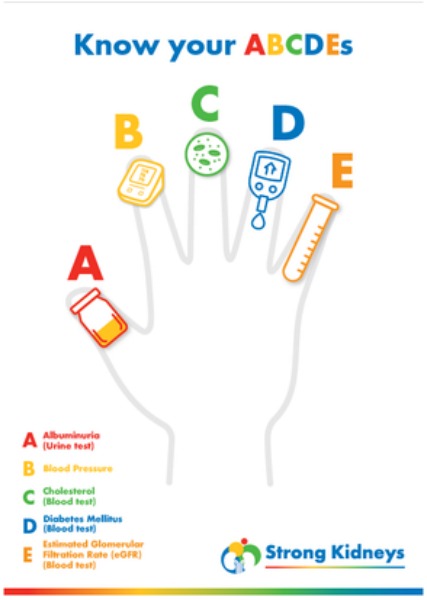
2. Let's uncover hidden cases of kidney disease! Hereditary and rare diseases may be behind these missed diagnoses. Along with diagnosis, let's promote genetic testing for patients and their families. By reaching out to the families of people with undiagnosed kidney failure, we can identify more people who may be living with kidney disease without even knowing it. Early detection is key to saving lives!

3. By acting now, we give young patients a brighter, healthier future and the opportunity to live longer, healthier lives! The earlier a kidney disease is detected, the sooner appropriate treatment is given, the later renal replacement therapy is required, and the longer a person's life expectancy is. With the right treatments, there is a possibility delay kidney failure and this is especially necessary for young kidney patients.

Federg took a special role in the EKHA Network event leading up to the European Kidney Forum, where we showcased the impactful initiatives of our members. We reaffirmed our commitment to support the EKFand the EKHA Manifesto: an inspiring report aimed at addressing the needs of patients for kidney disease care. The event also provided an important opportunity to reflect on EKHA's progress in 2024 and chart a bold path forward into 2025.

This year's European Kidney Forum, titled "Early Detection, Better Outcomes: Advancing Kidney Disease Screening in the EU", highlighted the critical need for timely detection and screening of kidney disease.

The event featured contributions from healthcare professionals, patient advocates, and policymakers.This event, moderated by Tamsin Rose, aimed to spotlight the role of early detection in preventing the progression of kidney diseases, improving patient outcomes, and strengthening healthcare systems.



The discussions focused on the integration of kidney disease prevention into the EU's broader health policies and strategies, particularly in relation to the links between other noncommunicable diseases (cardiovascular diseases, diabetes) and chronic kidney disease (CKD).

The Forum gathered insights from European Union policymakers, healthcare professionals, patient advocates, and others to consider the great value that EU action can bring in addressing kidney diseases. This hybrid meeting took place in the European Parliament in Brussels, Belgium, and was co-hosted by Members of the European Parliament (MEPs) Tomislav Sokol, András Kulja, and Hilde Vautmans.

The ABCDE model as a best practice for the EU

Professor Alberto Ortiz (Chair of the Registry and Renal Science; Chair-elect, European Renal Association) discussed the "ABCDE" method of kidney disease prevention, which translates to Albuminuria, High Blood Pressure, High Cholesterol, Diabetes and Estimated Kidney Function. These five key points are essential aspects in detecting and testing (for) CKD.

FEDERG REPRESENTATIONS

The Forum gathered insights from European Union policymakers, healthcare professionals, patient advocates, and others to consider the great value that EU action can bring in addressing kidney disease.

FEDERG members are active in supporting kidney disease inclusion policies. *"Early Detection, Better Outcomes: Advancing Kidney Disease Screening in the EU"* was the motto of the European Kidney Forum 2025. It was a great opportunity to underline the need of better care, better screening for the detection of kidney disease, especially the most neglected ones, which are the rare ones.

At FEDERG, we believe that early detection of kidney disease ensures well-being and an improvement in the quality of life of patients, as well as better life expectancy. It is especially important for us to be the voice of patients with hereditary kidney diseases and to support them as members of EKHA. Families, patients, and their caregivers face a series of barriers to early diagnosis and suffer the health consequences of late detection of kidney disease. It is important to delay kidney failure, transplantation or dialysis, as long as possible, in order to offer patients a longer life expectancy.

European Union policymakers, healthcare professionals, patient advocates and other stakeholder at European Kidney Forum (EKF)

Susana Carvajal, Federg president.

Susie Gear, Federg member, Alport Uk, Alport Alliance.

Previous EKF Networking meeting, Federg presentation.

REPRESENTATIONS

FEDERG at the RDI Membership Meeting 2024 in Barcelona.

RDI has formally united with its member patient groups, including FEDERG, as part of a powerful informal "Coalition", resolutely backing the World Health Assembly WHA Resolution on Rare Diseases.

RDI Membership Meeting 2024, Working Groups

The Rare Diseases International (RDI) Membership Meeting took place in Barcelona, Spain from October 21–22, 2024. The meeting included sessions on current RDI activities, member introductions, and meaningful engagement with people living with rare diseases (PLWRD).
At the RDI Membership Meeting, FEDERG participated in working groups with other Patients Organisations worldwide where we emphasized the need for comprehensive and holistic care for people with rare diseases and their families.
By coming together as a united voice, RDI members worked to ensure rare diseases are recognized as a global health priority, paving the way for meaningful policy integration and improved lives for people living with a rare disease worldwide

FEDERG at World Orphan Drugs. Europe Congress 2024 in Barcelona.

This event was followed by the World Orphan Drug, Europe Congress from October 23 to 25 at the Fira de Barcelona. This impressive Congress brings together stakeholders in the rare disease field to discuss advancements, challenges, and future strategies.

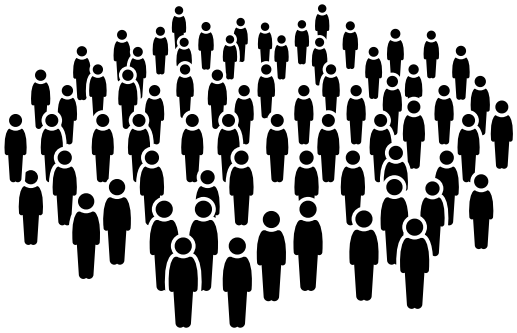
Federg had the opportunity to collaborate and learn alongside other patient associations and stakeholders from around the world, as part of an international team working to describe patient needs to improve healthcare and improve social understanding.

Alexandra Heumber Perry RDI Chief Executive Officer
Daniel de Vicente,Member of the Board of Directors of FEDER, Spain at the World Orphan Drugs, Europe Congress 2024.

REPRESENTATIONS

10 February 2025 marked an important turning point for the World Health Assembly (WHA) Resolution on Rare Diseases and the global rare disease community. The #Resolution4Rare has been officially recommended for adoption at the 78th WHA by the 156th WHO Executive Board.

Despite considerable progress, people living with undiagnosed diseases and their families continue to face significant global challenges: delay in diagnosis, difficulties in accessing and care treatments, stigma, financial burdens, social exclusion.
A health-specific framework for coordinated action with other stakeholders and Members States is needed to solidify commitment and translate this commitment and actions to overcome the barriers to accessing diagnosis, care and treatments for people living with rare diseases.



What is WHA Resolution?

A (WHA) World Health Assembly Resolution on Rare Diseases will aim to address challenges through a comprehensive global framework that includes raising awareness, improving diagnosis, enhancing access to care and treatment, and fostering research and development of therapies.

This is a major milestone in the global movement to improve the lives of the 300 million people living with a rare disease worldwide.

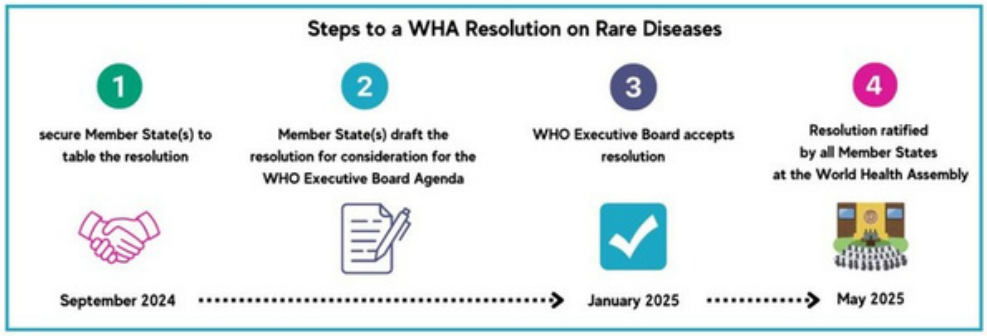
FEDERG, as part of the RDI, expresses its sincere thanks to the WHO for advancing this resolution, as well as to the more than 200 members of the Coalition and the entire global rare disease community for their unwavering support.

By coming together with other Patients Assciations as a united voice, we ensure rare diseases are recognized as a global health priority, paving the way for meaningful policy integration and improved lives for people living with a rare disease worldwide.

The Resoution represents a crucial first step toward ensuring the adoption of the WHA Resolution on Rare Diseases and the Global Action Plan (GAP) at the 78th World Health Assembly (WHA) which will take place in Geneva on May 21 at the United Nations.

FEDERG
REPRESENTATIONS

WHAT IS THE PROCESS?



🎯 Our Goals for Rare Disease Advocacy & Universal Health Coverage (UHC)

1. 🌍 Promote Universal Health Coverage (UHC)
2. Ensure that all people have access to the health services they need—when and where they need them.
3. 👨‍👧 Support Families & Caregivers
4. Develop essential social and healthcare measures for individuals with rare diseases and those who support them.
5. 🤝 Strengthen Global Collaboration
6. Boost the efforts of Member States and all stakeholders working toward inclusive, effective health systems.
7. 📢 Raise Awareness
8. Shine a spotlight on the challenges faced by those living with rare diseases around the world.
9. 🔬 Enhance Diagnostics
10. Improve early detection and accurate diagnosis of rare diseases through better tools and training.
11. 💡 Accelerate Research & Innovation
12. Encourage the development of new therapies and treatment options tailored to rare conditions.
13. 🏥 Guarantee Access to Care
14. Ensure all individuals with rare diseases receive affordable, effective, and comprehensive healthcare—free from financial hardship.

RDI WORLD HEALTH ASSEMBLY SIDE EVENT

FEDERG
REPRESENTATIONS

FEDERG in EKPF Annual Summit 2024.
Federg supports the EKPF Manifesto and praises the 10 recommendations for fighting for the rights of people with chronic kidney disease.

Federg, a member of the EKPF, attended its Annual Summit 2024, held in Berlin on October 14, 2024. This was an excellent gathering of the Federation of Chronic Kidney Diseases, where FEDERG, as a hereditary disease group, was present. It was an opportunity to learn about topics of common interest such as anemia in chronic kidney disease, primary hyperoxaluria and its challenges, ongoing projects for patients with IgAN, the quality of life of patients with CKD, and the EKPF Manifesto, among others.

The Annual EKPF Summit 2024 emphasized the significance of collaborations, and it was truly inspiring to witness the expert contributions of our partners. It also provided a valuable opportunity to connect with patient organizations from Eastern Europe and gain insight into their unique challenges. New EKPF members from Poland, Serbia, and Hungary shared the outstanding work they are doing to support patients across their countries.

And children are important too. The EKPF promotes Krew Camp EKPF

The Kidney Recreation and Educational Week, set to take place from July 6th to 12th in Óbidos, Portugal, is being organized in partnership with APIR.

EKPF KREW CAMP

It is worth mentioning finally that on March 11 and 12, the EKPF participated in the meeting in Madrid with the partners of the KitNewCare project, who are analyzing options for better sustainability of kidney replacement therapies. KitNewCare is an EU-funded project under the Horizon Europe initiative, where EKPF is responsible for the Patient and Public Involvement Program.

The manifesto is a dynamic document that serves as a call to action.

The manifesto is a living document that acts as a call to action. It brings together healthcare professionals, patients, and citizens to emphasize the needs of individuals with chronic kidney disease in order to ensure they have a good quality of life. Through ten key principles, it outlines their vision for the future of people with CKD: Voice, treatment, participation, safety, independence, quality of life, research, innovation, mental health, and environmental sustainability.

EKPF Manifesto

This document is absolutely vital! It goes beyond just clinical treatment, addressing the full spectrum of care, including holistic and social support. The EKPF Annual Meeting also highlighted the urgent need for legal protection for living donors. It's not just about ensuring sick leave coverage – it's about making sure that those considering becoming living donors are fully informed about the risks and consequences. The ultimate goal is to enhance donor care and guarantee fair and equal access to transplants around the world!

FEDERG
REPRESENTATIONS

Impact on Rare Diseases, More than you can imagine.

FEDERG supports patient representatives in commemorating World Rare Disease Day at the Eurordis "More than You Can Imagine" event at the European Parliament.

FEDERG supported Belgian rare kidney disease patient advocate, Karsten Wyngaert, at the "Eurordis new European Parliament Intergroup on Cancer and Rare Diseases". This was hosted by MEPs Stine Bosse, Adam Jarubas and Tilly Metz. The event, 'Impact of rare diseases. More than you can Imagine" aimed to foster a deeper understanding of the challenges faced by people living with rare diseases and their families.

Moderated by Enrique Terol, Health Counsellor of the Permanent Representation of Spain to the EU, the discussions stressed that while challenges persist, solutions already exist – what's needed now is political will and decisive action.

The event, co-hosted by MEPs Stine Bosse, Adam Jarubas and Tilly Metz highlighted the urgent need for improved EU policies, focused funding, and enhanced cross-border cooperation to address delays in diagnosis, treatment gaps, and social inequalities impacting the rare disease community. Amid global economic and political instability, speakers emphasized that failing to take action on rare diseases would result in higher costs—not only for patients and their families but also for healthcare systems and national economies.

Avril Daly, President of EURORDIS, emphasized the importance of working with the new European Commission to ensure rare diseases remain a top priority on the political agenda. She stressed the value of efficiency and collaboration, noting: "We can achieve more cost-effectively and intelligently; by thinking collectively – and that's why it's crucial to have people in the room who can collaborate and find solutions."

Virginie Bros-Facer, Chief Executive Officer of EURORDIS, delivered a powerful appeal for political action. "We have the data. We have the expertise. Now, we need the action

Karsten Vanden Wyngaert, from Ghent University Hospital and ERKNet, argued that comprehensive, multidisciplinary care should be the norm rather than the exception. He highlighted the importance of including social workers, educators, and mental health professionals in rare disease care pathways.

MEP Tilly Metz (Greens, Luxembourg) called for a more robust EU disability strategy, emphasizing the need for better recognition and standardization of disability assessments across Member States. "Accessing a timely and adequate disability assessment remains a significant challenge," she stated, urging policymakers to address this in the upcoming post-2025 Disability Strategy.

MEP Stine Bosse stressed that rare diseases require stronger European cooperation, as national-level approaches are often impractical. In smaller countries like Denmark, some rare diseases appear only once every five or ten years, making cross-border access to specialised care essential.

Sebastian Honoré, founder of the Cure Lowe Foundation, gave a deeply personal account of his son's battle with Lowe Syndrome, an ultra-rare disease with no treatment – not due to a lack of science, but because of economic barriers. "We are at the cusp of a breakthrough," he said, highlighting advances in understanding the disease.

FEDERG
REPRESENTATIONS

Festa del Ronyo, Kidney Festival, Recinto Modernista Barcelona

AIRG-E. Asociación Información Enfermedades Renales Genéticas , Hipofam , and Federg-Aisbl , Dra Roser Torra, Dr Mónica Furlano together under the slogan "Take care of your kidneys," celebrated World Kidney Day with the Kidney Festival at the San Pau Art Nouveau Complex in Barcelona, organized by the Puigvert Foundation, on Saturday, March 15, 2025

On March 15, from 10:00 a.m. to 1:45 p.m., the Puigvert Foundation hosted World Kidney Day at the Sant Pau Art Nouveau Complex. This family event aimed to raise awareness about the importance of kidney stones and kidney health. Dr. Torra emphasized that the kidneys are vital organs that not only filter our body's blood but also play a key role in regulating blood pressure, hormone secretion, and maintaining water and mineral balance. Despite their importance, she said, many people are unaware of their significance for overall health.

The event emphasized that chronic kidney disease has become a *"silent epidemic"* affecting millions of people worldwide, many of whom are unaware of their condition.

Doctors and other stakeholders emphasized the importance of understanding that taking care of our kidneys means taking care of our overall health. Simple daily habits, such as staying active, eating a balanced diet, taking medication correctly, and managing risk factors such as blood pressure, can significantly contribute to better kidney health and a better quality of life
The Puigvert Foundation, a leading center of excellence, FEDERG, AIRG-E, and Hipofam joined a day of fun and informative activities focused on improving kidney health.