2025

NEWSLETTER

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Today's FEDERG representations Summary

The strength of this federation, bringing together 20 patient organizations, is in our unwavering presence and visibility for those living with rare and genetic kidney diseases. By standing together, we make sure that the voices of patients and their families are heard, their needs recognized, and their experiences acknowledged. Our role is not only to support but to actively participate in the conversations that shape diagnosis, treatment, and care, ensuring that this community is considered and represented at every opportunity. Through our collective effort, we strive to open doors for better care, improved treatments, and a future where no patient faces these challenges alone..

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Empowering Young Voices Beyond Medicine: FEDERG at Connect 4 Children – Shaping the Future of Paediatric Kidney Research

Susana Carvajal Arjona, Hipofam, Federg president, ERKNet ePAG Chair
Susie Gear, Alport UK, Alport Alliance
Elia Galli, a young patient living with Alport Syndrome and MD
Megan Hawkes, 18 years old patient living with Nephrotic Syndrome
Katie Brown, Young patient living with a rare form of Alport Syndrome

Connect 4 Children: placing young patients at the heart of paediatric clinical research

In April 2025, FEDERG representations had the privilege of taking part in an inspiring European meeting organised within the framework of Connect 4 Children, a programme dedicated to transforming the way paediatric clinical trials are designed and conducted across Europe.

The Multi-Stakeholder Meeting on Paediatric Chronic Kidney Disease, held on 28-29 April 2025 at the German Cancer Research Center in Heidelberg, brought together young patients, families, clinicians, researchers, industry representatives and patient organisations with a shared objective: to shape more inclusive, ethical and meaningful clinical research for children and adolescents living with chronic kidney disease.

It was a truly enriching experience. By exploring together the concept and design of clinical trials, participants created a unique space in which patients, experts and all those involved in medicine development could openly exchange ideas on how clinical studies should be shaped—especially for children. Throughout the meeting, the importance of adapting information to age, improving the overall patient experience, supporting families and ensuring that young people are involved from the earliest stages of research design was repeatedly highlighted.

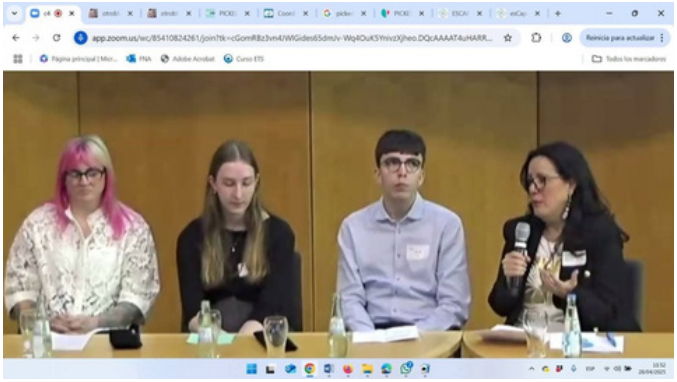
A central message of the meeting was clear: paediatric research cannot be built without the voices of those who live with rare and chronic diseases every day. Thanks to the strong involvement of the patient community and the support of organisations such as EURORDIS – Rare Diseases Europe, young patients were not only invited to participate, but were actively encouraged to contribute, challenge existing approaches and help redefine priorities for future studies.

The collaborative spirit that characterised the meeting was further strengthened by the engagement of patient representatives from FEDERG. Their contribution underlined the importance of cross-border cooperation to address common challenges such as limited trial availability, difficulties in patient recruitment and unequal access to innovation.

For FEDERG representations, this meeting was also an opportunity to reaffirm one of the federation's core objectives. FEDERG is committed to supporting and empowering young people living with rare kidney diseases, and to making visible that their needs extend far beyond clinical care alone. At a very early age, many young patients are already facing complex challenges related to education, social life, emotional wellbeing, personal development and the transition towards adult life with a chronic condition.

During the meeting, FEDERG actively supported a group of brave young participants who powerfully expressed these realities and highlighted the specific needs of young people that are often overlooked in traditional research frameworks. Making these voices heard—and ensuring that psychosocial, educational and quality-of-life aspects are considered alongside medical outcomes—is a fundamental part of the federation's mission.

Empowering Young Voices Beyond Medicine: FEDERG at Connect 4 Children – Shaping the Future of Paediatric Kidney Research



Susana Carvajal Arjona, Hipofam, Federg president, ERKNet ePAG Chair
Elia Galli, a young patient living with Alport Syndrome and MD
Megan Hawkes, 18 years old patient living with Nephrotic Syndrome
Katie Brown, Young patient living with a rare form of Alport Syndrome

This process of empowerment and meaningful participation was made possible with the support of Alport UK, a member organisation of FEDERG, and Alport Alliance, both of which provided guidance and expertise to help young people take part safely, confidently and effectively in discussions with researchers and other stakeholders. Their contribution ensured that youth participation was not symbolic, but genuinely impactful.

Throughout the two days, the meeting demonstrated that, despite differences in healthcare systems and national contexts, the challenges faced by children and adolescents living with rare kidney diseases are remarkably similar across Europe. The discussions confirmed the urgent need to move towards a new model of paediatric clinical research—one in which patients' experiences and priorities are embedded from the earliest stages, transparency is strengthened and collaboration becomes the standard approach.

For FEDERG representations, participation in this Connect 4 Children meeting reinforces a long-term commitment: to continue promoting the active involvement of children, adolescents and young people in research, and to work alongside European and international partners to build clinical trials that are more human, more inclusive and truly aligned with the real needs of young patients and their families.

conect 4children

Multi-Stakeholder Meeting on paediatric Chronic Kidney Disease

28-29 April 2025

Lecture Hall (Hörsaal), German Cancer Research Center (DKFZ)
Address: Im Neuenheimer Feld 280, 69120 Heidelberg, Germany
& Videoconference (Zoom)

Programme

DAY 1 – 28 April 2025 (time CEST)

09:00 – 10:00 *Registration and Welcome Coffee*

10:00 – 10:15 **Welcome**
Gilles Vassal, *SIOP Europe*
Objectives of the meeting
Franz Schaefer, *Heidelberg University Hospital*

10:15 – 13:00 **Session I: Medical need for innovative therapies in paediatric CKD - setting the scene**
Chair: Julie R. Ingelfinger, Harvard Medical School

10:15 – 10:45 **Epidemiology and natural history of CKD in children**
Jerome Harambat, *Centre Hospitalier Universitaire de Bordeaux*

10:45 – 11:15 **Medical and therapeutic needs for paediatric CKD**
Rukshana Shroff, *Great Ormond Street Hospital*

11:15 – 12:00 **Patient perspective**
Introduction and Panel Discussion Chair
Susie Gear, *Alport UK*
Panelists
Elia Galli, *ePAG, a young patient living with Alport Syndrome and MD*
Susana Carvajal Arjona, *Hipofam, Federg, ERKNet ePAG - mother of a teenage son living with a rarer form of kidney disease*
Megan Hawkes, *18 years old patient living with Nephrotic Syndrome*
Katie Brown, *Young patient living with a rare form of Alport Syndrome*

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FEDERG ePAGs at the 9th ERKNet Annual Meeting – Strengthening Patient Expertise in Rare Kidney Diseases

From 19 to 21 May, FEDERG patient representatives as ERKNet ePAGs (European Patient Advocacy Group members) took part in the 9th Annual Meeting of the European Rare Kidney Disease Reference Network (ERKNet), held at the Irish College in Leuven, Belgium.
This important annual gathering brought together clinicians, researchers and patient representatives from across Europe, united by a shared commitment to improving the lives of people living with rare and genetic kidney diseases. The meeting once again demonstrated a core belief shared by all participants: unity is our greatest strength.

For FEDERG, participation in this meeting represents far more than attendance. FEDERG has been, and continues to be, one of the main providers of trained and experienced patient representatives for rare and genetic kidney diseases within the ERKNet community. This year's meeting also marked nearly nine consecutive years of close and structured collaboration between patients, caregivers and healthcare professionals. Year after year, expert patients and caregivers work side by side with leading clinicians and researchers along three fundamental pillars: diagnosis, treatment and research in rare kidney diseases. This long-term partnership has made it possible to integrate the lived experience of patients into highly technical and clinical processes, strengthening both scientific excellence and real-world relevance.
FEDERG members actively contribute by sharing in-depth knowledge of rare kidney diseases based on patient experience. Their contribution plays a key role in initiatives such as the development of clinical guidelines, the design of patient journeys and the completion of clinical work through the systematic identification of unmet patient needs. In particular, patient representatives support the design of guidance documents that reflect not only medical outcomes, but also the mental, emotional and psychosocial impact of rare kidney diseases on patients and their families.

ERKNet
The European Rare Kidney Disease Reference Network
for patients

Federg members:
David van Bennekom, Dent Disease, NvN, Netherlands,
Sébastian Honoré Cure Lowe foundation, Denmark

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During the meeting, FEDERG representatives highlighted complex and often underrepresented realities faced by people living with rare kidney diseases, including highly demanding treatment pathways such as kidney replacement therapy, dialysis and kidney transplantation, both in adult and paediatric settings. Long diagnostic delays, limited access to specialised care and the ongoing lack of effective treatments capable of stopping or significantly slowing disease progression remain major challenges for the community.

These are not abstract issues. They are real-life experiences that patient representatives bring to the table so that they can be considered in clinical decision-making, research priorities and policy discussions.

Through structured dialogue with clinicians and researchers, FEDERG representatives ensure that patient perspectives are embedded in areas such as guideline development, care pathway optimisation and future research strategies.

The presence of ePAGs within ERKNet continues to demonstrate how patient expertise can meaningfully complement medical and scientific knowledge. By working together with healthcare professionals, patient representatives help shape a more holistic approach to rare kidney diseases—one that acknowledges the complexity of living with a lifelong condition and the profound impact it has on education, work, family life and mental wellbeing.

The 9th ERKNet Annual Meeting was a powerful example of what can be achieved when medical excellence, scientific innovation and patient experience come together as equal partners. It showcased a truly unique collaborative model in which doctors, researchers and patients work as one team to address some of the most challenging aspects of rare and genetic kidney diseases.

For FEDERG, this meeting reaffirmed a long-standing commitment to strengthening patient representation at European level and to ensuring that the voices of people living with rare kidney diseases continue to shape diagnosis, treatment and research. The collective strength and shared expertise demonstrated in Leuven clearly showed that building better care and better research is only possible when all stakeholders work together, with patients at the very heart of the process.

Susana Carvajal Arjona ERKNet ePAG Chair
David van Bennekom ERKNet ePAG co-Chair

Pr Dr expert Franz Shaefer, ERKNet Coordinator

FEDERG members & ERKnet ePAGs: Susana Carvajal Arjona, Hipofam Spain,
Renée de Wildt, NvN Netrherlands,

FEDERG members & ERKNet ePAGs: Susana Carvajal Arjona,Hipofam, David van Bennekom, Den Disease, NvN,Netherlands, Christian Scheidler, ADTKD Germany, Flavia Galletti, Airp Italy & PKD International, Monika Reichegger Arge Niere Austria

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FEDERG in RDI Coalition: A Historic Moment for the Global Rare Disease Community
UNITED IN GENEVA: A Milestone at the 78th World Health Assembly

Geneva, May 21–24, 2025 — The rare disease community achieved a transformational milestone during the 78th World Health Assembly (WHA78) in Geneva, Switzerland, when the first-ever WHO Resolution on Rare Diseases was officially adopted by Member States. This landmark decision — “Rare diseases: a global health priority for equity and inclusion” — establishes rare diseases as a priority within global health policy and sets the stage for a 10-year World Health Action Plan to improve health systems and ensure inclusive access to care worldwide.

This momentous achievement reflects collective advocacy, global solidarity, and unwavering determination by patient organisations, researchers, federations, and civil society partners who have tirelessly championed the rights, dignity, and needs of people living with rare diseases.

A Decade of Progress and Possibility

In the lead-up to the WHA78 resolution, organisations around the world joined forces to elevate rare diseases onto the global health agenda. On May 21, 2025, in conjunction with the Assembly, Rare Diseases International (RDI) and partners — including FEDERG-AISBL — hosted a side event titled “Momentum & Milestones in Rare Diseases: 10 Years of Progress, 10 Years of Possibility”. The event brought together representatives of patient organisations from every region of the world to celebrate the progress achieved over the past decade, share lived experiences, and commit to collaborative action in support of the newly adopted WHO resolution and forthcoming World Health Action Plan.

This coalition recognised that early diagnosis, expert clinical support, referral to centres of expertise, and access to appropriate, affordable treatment are essential pillars of care for people living with rare diseases — yet remain persistently uneven around the world.

FEDERG representatives: Stéphanie Sénéchal, AIRG- Suisse
Susana Carvajal Arjona, Hipofam & Federg president

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What the Resolution Means

The WHA78 resolution represents an unprecedented policy breakthrough for the rare disease community and for global health equity:

- Global Recognition: For the first time in WHO history, rare diseases are formally recognised as a global health priority, demanding inclusion in national health planning and policy.
- Early Diagnosis and Referral: Member States are encouraged to strengthen diagnostic pathways and ensure referral mechanisms connect patients with centres of expertise.
- Universal Health Coverage: The resolution calls for integration of rare disease care into universal health coverage schemes to guarantee equitable access to care, treatments, and support services.
- Global Action Plan: WHO has been tasked to develop a comprehensive 10-year global action plan, with measurable targets that will guide international progress toward equitable, inclusive health systems for people with rare diseases.

This collective achievement was made possible through a global coalition of advocacy groups, federations, and supportive Member States that stood together to elevate the voices of people living with rare conditions — a testament to what can be accomplished when communities unite behind a shared vision for health equity.

FEDERG representatives: Stéphanie Sénéchal, AIRG- Suisse
Susana Carvajal Arjona, Hipofam & Federg president,
Feder España president (Spanish Rare Disease federation) : Juan Carrión

During this high-level global gathering in Geneva, AIRG Suisse, a proud and active member of FEDERG, warmly hosted the FEDERG delegation in Switzerland and accompanied Susana Carvajal, President of FEDERG, throughout this major international event.
In addition, FEDERG had the opportunity to meet and further strengthen strategic alliances with the Federación Española de Enfermedades Raras (FEDER), represented at the event by its President, Juan Carrión.
In addition, FEDERG had the opportunity to meet and further strengthen strategic alliances with the Federación Española de Enfermedades Raras (FEDER), represented at the event by its President, Juan Carrión.
This exchange reinforced the shared commitment of both federations to advance patient-centred policies, promote cross-border collaboration, and jointly support the implementation of the new global agenda for rare diseases.

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FEDERG members at the 62nd ERA Congress – Vienna, Austria, June 4–7

Patient Representatives Supporting Europe's Most Important Nephrology Congress
The 62nd European Renal Association (ERA) Congress, held in Vienna, Austria from 4–7 June 2025, stood out as one of the most influential global gatherings in nephrology — bringing together experts in clinical care, research, and patient advocacy under the theme "Game Changers in Nephrology." With over 10,000 participants, more than 2,800 scientific abstracts, and a comprehensive programme spanning chronic kidney disease, dialysis, transplantation, genetics and critical care, the congress served as a pivotal forum for advancing kidney health and innovation worldwide.

Why Patient Associations at ERA Matter

Traditionally, scientific congresses focus on clinical data, trial results, and emerging therapies. While these are absolutely essential, involving patient associations ensures that research and care strategies are grounded in real-world needs — from early diagnosis and access to treatments to quality of life and long-term outcomes.
At ERA25, patient leaders brought this perspective to the forefront:

Daniel Gallego Ekpf president, Alcer Federation president
Susie Gear: federg member, Alport Uk & Alport Alliance
Juan Carlos julián: federg member, Alcer Federation, EKPF manager
Flavia Galletti: federg member, AIRP Italy &Pkd International

- Dani Gallego, President of the European Kidney Patients Federation (EKPF), participated as a voice for patients with rare and chronic kidney diseases, emphasising the importance of collaboration between patient communities and medical professionals.
- Susie Gear, is a very valuable representative of FEDERG with extensive experience representing patients and their families with Alport UK and the Alport Alliance, contributed insights from the rare kidney disease community — particularly in discussions where patient experiences can influence clinical trial design and endpoint relevance.

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FEDERG at the 62nd ERA Congress – Vienna, Austria, June 4–7

- Juan Carlos Julián, from the ALCER Federation Spain and EKPF Manager, and FEDERG Board member, highlighted challenges such as delayed diagnosis and the need to broaden genetic testing, especially for hereditary kidney conditions.
- Flavia galletti, is a highly valued member of the ePAG of ERKNet and a very experienced representative of FEDERG. She brings the voice of patients from AIRP Italy and PKD International, actively representing people living with polycystic kidney disease and contributing to scientific sessions on biomarkers, predictive clinical models, and updated clinical guideline
- Marta Roger , from AIRG Spain, also took part in the congress, playing an active role in representing Spanish patients living with different genetic and rare kidney diseases. Through her participation, she ensured that the diversity of patient needs and experiences across multiple inherited renal conditions was clearly reflected in scientific and policy discussions.She is also another highly valued and experienced member of FEDERG, contributing to stronger and more inclusive patient representation at European level.

Their presence reinforced that patients are not just recipients of care but partners in shaping care, research priorities, and healthcare policies — a shift that reflects the evolving landscape of patient-centred medicine.

FEDERG members:
Flavia Galletti: AIRP, Italy & PKD International
Christian Scheidler, ADTK. Germany
Monika Reichegger, Arge Niere Austria

FEDERG members: Marta Roger AIRG España,
Flavia Galletti: AIRP, Italy & PKD International

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FEDERG at the 57th ESPN Annual Meeting – Athens, Greece, June 15–18

Participation throughout the 57th Congress of the European Society for Paediatric Nephrology (ESPN)

Patient representatives from FEDERG-AISBL, the European federation of associations for people living with rare and genetic kidney diseases, had the honour of participating throughout all days of the 57th ESPN Congress. Our presence across the full programme reflected a strong and sustained commitment to collaboration with paediatric nephrologists, researchers and healthcare professionals, ensuring that the patient and family perspective was continuously represented with professional exchanges and networking activities during the entire congress.

The 57th Annual Congress of the European Society for Paediatric Nephrology (ESPN) — held in Athens, Greece, from October 15–18, 2025 — brought together leading clinicians, researchers, healthcare professionals, and patient advocates from across Europe and beyond. As the premier scientific meeting focused on paediatric kidney health, research, diagnosis, treatment and management, the event plays a central role in shaping the future of care for children with kidney diseases. ESPN's mission is to promote research, education, and collaboration across the field of paediatric nephrology for the benefit of young patients and their families.

FEDERG representatives:
Stéphanie Sénéchal, AIRG- Suisse
Susana Carvajal Arjona, Hipofam & Federg president,
Sandra Lawton, AIRG France

What made this year's congress especially meaningful was the warm and inclusive welcome extended to patient representatives — a reflection of ESPN's growing commitment to partnership with patient organisations in shaping clinical care and research agendas. Patient voices are increasingly recognised as essential, particularly in the development of clinical guidelines, shared decision-making, and improving outcomes for children affected by rare and genetic kidney diseases

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FEDERG at the 57th ESPN Annual Meeting – Athens, Greece, June 15–18

A Stand of Visibility, Outreach and Collaboration

For the second time, FEDERG, the European federation of patient associations for rare and genetic kidney diseases, had the honour of hosting an information stand at the congress, made possible through the collaboration and inclusion of ESPN organisers. This dedicated space served as a hub for sharing resources, raising awareness, directly engaging with conference attendees, and highlighting the lived experiences of families across Europe coping with hereditary kidney conditions. By placing patient voices front and centre, the stand helped bridge the gap between scientific advances and real-world patient needs.

Patient Advocates as Partners in Pediatric Nephrology

Attending the congress as patient representatives was a profoundly meaningful experience. Carrying the voices of 20 patient associations, the delegation represented families and individuals across diverse communities living with genetic and rare kidney diseases. Their presence helped ensure that discussions around research, care pathways, and clinical priorities remained grounded in the day-to-day realities faced by patients and their support networks

FEDERG representatives: Sandra Lawton AIRG France
Stéphanie Sénéchal, AIRG- Suisse
Susana Carvajal Arjona, Hipofam & Federg president,
Swith Pr Dr expert Jerôme Harambat

All of us are united under FEDERG-AISBL, and at the same time each of us represents a distinct national community of people living with rare and genetic kidney diseases across different European countries. Through FEDERG, we come together to act on behalf of 20 patient associations, standing united in bringing the patient and family perspective to the forefront of paediatric nephrology.

Those mobilising this vital perspective were:

- Sandra Lawton, representing AIRG France
- Stéphanie Sénéchal, representing AIRG Switzerland
- Susie Gear, representing Alport UK and Alport Alliance
- Susana Carvajal A., proudly representing HIPOFAM and AIRG Spain, alongside her role within FEDERG.

FEDERG representatives: Susie Gear, Alport Uk & Alport Alliance
Susana Carvajal Arjona, Hipofam & Federg president,
With Dr Laura Masella Division of Nephrology at the Bambino Gesù Children's Hospital in Rome, Rachel Lennon, Professor of Nephrology at the University of Manchester

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FEDERG at the 57th ESPN Annual Meeting – Athens, Greece, June 15–18

FEDERG representatives: Susie Gear, Alport Uk & Alport Alliance

The participation and presence of patient associations in pediatric nephrology congresses is essential, as it enables direct dialogue between specialists and those who live daily with kidney diseases in children. These associations provide a unique perspective on the needs, experiences, and challenges faced by patients and their families, enriching scientific discussions with real-life testimonies and priorities. Moreover, their inclusion promotes the humanization of medical care, supports education about the disease, and strengthens collaboration in research and health policy, ensuring that decisions and advances in pediatric nephrology align with the well-being and quality of life of patients.

FEDERG representatives: Stéphanie Sénéchal AIRG Suisse, Sandra Lawton AIRG France, Susana Carvajal Arjona, Hipofam & Federg president, with Senior clinician expert Aurélia Bertholet-Thomas Orkid Filière Santé.

FEDERG representatives: Sandra Lawton AIRG France Stéphanie Sénéchal AIRG Suisse, Susana Carvajal Arjona, Hipofam & Federg president, with Dr Lise Allard et équipe médicale du CHU Bordeaux.

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FEDERG at the 57th ESPN Annual Meeting – Athens, Greece, June 15–18

A Stand of Visibility, Outreach and Collaboration

Susana Carvajal Arjona, Hipofam & Federg president, with Pr Dr Stella Stabouli ESPN Board directors professor of Pediatrics-Pediatric Nephrology First Pediatric Department Aristotle University Thessaloniki, Pr Dr expert Franz Shaefer, Heidelberg Hopsital University, ERKNet Coordinator an ERkNet project managers: Stefanie Habërle, Vanessa Merck

We would like to express our deepest gratitude to the European Society for Paediatric Nephrology (ESPN) and its leadership — particularly Prof. Francesco Emma, President of ESPN, and Prof. Stella Stabouli, — for welcoming the members and representatives of our federation so warmly and inclusively at the congress. Their support and openness have been invaluable in facilitating meaningful collaboration and dialogue between clinicians, researchers, patient organizations, and families affected by pediatric kidney disease. We also wish to thank Prof. Franz Schaefer, Coordinator of the European Reference Network for Rare Kidney Diseases (ERKNet), and his dedicated team for their ongoing support, invaluable insights, and partnership in advancing patient-centered initiatives. The commitment from both ESPN and ERKNet has greatly enriched our experience and strengthened our shared mission to improve care and outcomes for children with kidney disease

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FEDERG at the World Orphan Drugs Congress – Amsterdam, Netherlands, October 27–29

World Orphan Drug Congress Europe 2025: Amsterdam Becomes a Global Hub for Rare Disease Innovation — and FEDERG Makes Its Mark

From October 27 to 29, 2025, Amsterdam's RAI Congress Centre hosted the World Orphan Drug Congress Europe, the largest and most established event of its kind focused on orphan drug development and rare diseases. Bringing together over 2 000 delegates, 250+ expert speakers and more than 130 exhibitors, the Congress provides an unparalleled platform for cross-sector dialogue on everything from regulatory policy and market access to cutting-edge gene therapies and patient advocacy.

FEDERG members:
David van Bennekom, Dent Disease, Netherlands, NvN
Honoré Sébastian, Cure Lowe Foundation, Denmark

FEDERG at the Forefront: Learning, Connecting and Advancing the Patient Voice

Among the many organisations present at the Congress, the FEDERG stood out for its active engagement and strategic presence. FEDERG's attendance underscored the federation's commitment to tapping into this vital space for learning about the latest scientific, regulatory and patient-centred developments, as well as for building valuable contacts across the rare disease ecosystem. For patient advocacy groups, events like the World Orphan Drug Congress offer a rare blend of expert insight and partnership potential — enabling organisations such as FEDERG to strengthen their advocacy, inform future strategies and represent patients with rare kidney conditions on a broader European and international stage.

Representing FEDERG at the Congress were David van Bennekom, attending in his capacities with Dent Disease and NvN, and Sebastian Honoré, representing Cure Lowe. Their presence was instrumental in fostering dialogue with industry, researchers and fellow patient advocates, and in raising awareness of the unique needs and priorities of people affected by rare and genetic kidney diseases.
Their active participation in workshops, sessions and networking activities helped reinforce FEDERG's determination to learn from global leaders, exchange ideas with key stakeholders and build collaborations that could benefit patients here in Europe.

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FEDERG at the EKPF Annual Summit and General Assembly 2025 – Milan, Italy, November 4–5, 2025

FEDERG strengthens the voice of patients with rare and genetic kidney diseases at the EKPF Annual Summit 2025

he EKPF Annual Summit – Bringing Kidney Patient Communities Together once again brought together patient associations from across Europe with a shared goal: to exchange experiences, present new initiatives and explore the latest innovations in chronic kidney disease care.

Organised by the European Kidney Patients' Federation (EKPF), the Summit is recognised as a unique European forum where patient communities connect, collaborate and build common strategies to improve kidney health and quality of life for people living with kidney disease.

FEDERG's participation: giving visibility to rare and genetic kidney diseases

The presence of FEDERG, the Federation of European Associations of Patients affected by rare and genetic kidney diseases, was especially meaningful at this year's Summit.

As a full member of EKPF, FEDERG actively contributed to the exchange of experiences and perspectives, highlighting the specific challenges faced by people living with rare and inherited kidney conditions. These challenges often include delayed diagnosis, limited therapeutic options, reduced access to specialised centres and the need for stronger European research networks.

Through its participation, FEDERG reaffirmed its commitment to ensuring that patients with rare and genetic kidney diseases are fully represented within the broader kidney community and that their voices are included in European discussions on innovation, policy and patient-centred care.

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FEDERG at the EKPF Annual Summit and General Assembly 2025 – Milan, Italy, November 4–5, 2025

FEDERG members:
Giulia Nutile, Asal Italy, Susana Carvajal A. Hipofam, with patients representatives from NvN Netherlands and Slovenia CKD.

EKPF members

A collaborative and inspiring European meeting
The Summit was marked by a strong spirit of cooperation and solidarity among patient organisations. Participants shared best practices, discussed emerging projects and explored new opportunities to work together to improve care pathways, patient empowerment and advocacy at European level.
Attendees were warmly welcomed by Giuseppe Vanacore from ANED Italy, together with Dani Gallego, President of EKPF. Their messages underlined the importance of unity among patient communities and the need to continue building a strong, credible and influential European patient movement in kidney health.
Building a stronger future for kidney patients in Europe.

The EKPF Annual Summit once again demonstrated the power of collaboration between patient organisations to drive positive change in renal health. By actively taking part in this important European forum, FEDERG continues to strengthen the representation of rare and genetic kidney diseases and to contribute to a more inclusive, innovative and patient-driven European kidney community.
Through dialogue, partnership and shared commitment, FEDERG and EKPF are working together to build a stronger collective voice for all kidney patients across Europe.

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FEDERG at D'Genes XVIII International Congress on Rare Diseases 2025

The XVIII International Congress on Rare Diseases, organised by D'Genes in collaboration with UCAM (Catholic University of San Antonio of Murcia), brought together patients, caregivers, clinicians, researchers and advocates in Murcia on 20–21 November 2025 to address the latest advances and challenges in rare disease care. The event featured a dynamic programme covering early diagnosis, research, therapeutic developments and the humanisation of care for people living with rare diseases.

Main Themes and Panels

Across the two-day Congress, a series of sessions and roundtable discussions explored critical topics including:

- Access to orphan and innovative medicines: examining current bottlenecks, regulatory challenges and future directions.
- Advances in early diagnosis: highlighting the vital role of genetic and clinical tools to shorten the diagnostic odyssey for rare conditions.
- Research as a gateway to hope: presentations on cutting-edge studies and collaborations shaping the rare disease research landscape.
- Improvements in treatments and quality of life: discussions about therapeutic options, supportive care and multidisciplinary approaches.
- Comprehensive care and humanisation: emphasizing holistic, patient-centred care models that address not only clinical needs but psychosocial wellbeing.

Participants also heard expert presentations on resources for social and health support, oral communications from researchers and families, and testimonies from those living with rare diseases.

During the XVIII International Congress on Rare Diseases organised by D'Genes, the awareness campaign "Unmask Rare Diseases" delivered a powerful and symbolic message. At the start of the event, all participants wore a mask, which they removed together once the sessions began, representing the urgent need to make rare diseases visible, to break social and healthcare barriers, and to bring the real faces and stories of patients and families to the forefront of public and institutional attention.

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FEDERG at D'Genes XVIII International Congress on Rare Diseases 2025

FEDERG's Impactful Contribution
A highlight of the Congress was the participation of FEDERG, represented by its President, Susana Carvajal Arjona. In her intervention, she brought vital attention to pediatric transplant and renal failure in the context of rare diseases, drawing on her expertise as a leader in rare kidney disease advocacy and as a coordinator of patient representatives within European nephrology networks.

Her remarks underscored how kidney transplant can be both a life-saving opportunity and a complex challenge for children with rare renal conditions, especially when faced with multi-organ complications or limited access to specialised care. By spotlighting pediatric renal failure, she helped weave kidney health into the broader rare disease dialogue — emphasising not only scientific progress but also the real-world impact on patients and families.

Bridging Science, Care and Community

The Congress demonstrated the value of bringing diverse voices together — from clinicians and researchers to patient advocates and families — to share knowledge, experiences and strategies. Across sessions, there was a consistent focus on collaboration, early intervention and the humanisation of care, making it a meaningful platform for advancing rare disease understanding and support.

By contributing her expertise and perspective, FEDERG's President not only raised awareness about kidney-related rare conditions but also strengthened the voice of affected communities in the ongoing effort to improve diagnosis, treatment and quality of life for individuals with rare diseases across Europe.