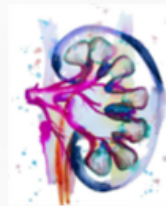




Fédération des associations des patients atteints d'une maladie rénale rare ou d'origine génétique

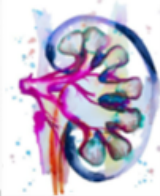


Newsletter

BUILDING LASTING RELATIONSHIPS WHILE SUPPORTING PATIENT COMMUNITIES



Progress begins
with people.
Every
breakthrough,
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with the passion
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collaboration of
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Welcome to
FEDERG
Magazine.



Newsletter



BUILDING LASTING RELATIONSHIPS WHILE SUPPORTING PATIENT COMMUNITIES

Progress begins with people. Every breakthrough, every milestone, and every success starts with the passion and collaboration of those who make it happen. Welcome to FEDERG Magazine.

During this second half of the year, our member associations have once again demonstrated the strength, dedication, and commitment that define our community. Through a wide range of initiatives, they have continued to support people living with a rare or genetic kidney disease and their families, ensuring that no one faces their journey alone.

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20th AIRG Spain Patient Day – Barcelona, October 2025

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AIRG FRANCE Patient Day – Paris, Dec 2025

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HIPOFAM Patient Day – Seville, October 2025

From patient-focused events that bring together healthcare professionals, researchers, and experts to share the latest innovations and advances, to awareness campaigns, educational activities, and community initiatives, our members continue to create opportunities for learning, connection, and hope.

In this edition, we are proud to showcase the inspiring work of our member associations and celebrate the impact they are making across our community.

AIRG-SPAIN PATIENT DAY – BARCELONA, OCTOBER 2025

Uniting for Hope: 20th AIRG-Spain Patient Day in Barcelona
Sharing Knowledge, Stories, and Strength in the Fight Against Rare Kidney Diseases



On 4 October 2025, Barcelona hosted the 20th AIRG-Spain Patient Day, an important annual meeting dedicated to genetic kidney diseases. The event took place at Casa Convalescència of the Universitat Autònoma de Barcelona, bringing together specialists, patients, and families for a day focused on knowledge, dialogue, and mutual support.

The meeting began at 9:00 a.m. with registration, followed by the official welcome from Marta Roger Pla, President of AIRG-Spain. In her opening remarks, she highlighted the importance of creating spaces where patients and professionals can meet, exchange experiences, and stay informed about the latest developments in research and care for rare kidney diseases.



Jose María Cacharrón, Alport patient,
Antonio Cabrera and Susana Carvajal Hipofam,
Manuel Arellano, Federación Alcer, Ignacio
García, Fundació Renal Jaume Arnó

Throughout the morning, leading specialists from major hospitals in Barcelona shared updates on several important conditions and clinical challenges. Among the presentations, Dr. Berta Cuyàs addressed autosomal dominant polycystic kidney disease with liver involvement, while Dr. Roser Torra presented the new clinical guidelines for Alport syndrome. Dr. Gema Ariceta also spoke about C3 glomerulopathy, providing insight into advances in diagnosis and management.

Other sessions explored key topics affecting patients living with rare kidney diseases, including cystinosis in adult patients, distal renal tubular acidosis, and the surgical management of polycystic kidney disease. These presentations offered both medical updates and practical perspectives for patients and families seeking to better understand their conditions.

AIRG-SPAIN PATIENT DAY - BARCELONA, OCTOBER 2025

The programme also included a session dedicated to social and legal issues that affect many people living with chronic kidney diseases. Manuel Arellano, First Vice-President of the Federación Nacional de Asociaciones ALCER, discussed the recognition of disability and incapacity in patients with genetic kidney diseases, highlighting the challenges many patients face when navigating administrative and social support systems.

STRENGTHENING EUROPEAN COLLABORATION

FEDERG had the opportunity to further strengthen its commitment to European collaboration by bringing together the voices of two AIRG leaders: Sandra Lawton, President of AIRG France, and Stéphanie Sénéchal, President of AIRG Switzerland. Joining the Patient Day celebration remotely, they shared messages of support, friendship, and solidarity, reinforcing the strong bonds that unite patient communities across Europe.

During the event, FEDERG President highlighted the importance of collaboration among European patient organisations in addressing the challenges of rare kidney diseases. By working together, these organisations are helping to advance rare disease policies, promote research, and advocate for improved diagnosis, treatment, and long-term care for people living with rare kidney diseases.

The meeting reflected a shared commitment to building a stronger European patient community—one that amplifies patients' voices, fosters cooperation, and drives meaningful progress for individuals and families affected by rare kidney diseases.



Dr Victor Pérez Vald'Hebron Hospital
Materno Infantil Nephrology Departement



Stefanie Sénéchal AIRG Suisse and
Sandra Lawton AIRG France



Susana Carvajal FEDERG

AIRG SUISSE & AIRG FRANCE

On October 4, 2025, during the APNP (Association of Pediatric Nephrology Professionals) Congress, AIRG Switzerland and AIRG France joined forces to highlight their shared commitment to supporting people affected by genetic kidney diseases. Although each organization operates in its own country, they work toward the same goals: providing reliable information to patients and families, advancing scientific research, and encouraging organ donation.

Throughout the year, both associations organize a wide range of initiatives, including patient and family meetings, participation in medical conferences, educational campaigns, awareness activities on organ donation, and fundraising efforts to support innovative research projects. Their work is carried out entirely by dedicated volunteers, many of whom are patients themselves or relatives of those living with rare kidney diseases.

Under the leadership of Stéphanie Sénéchal, AIRG Switzerland also serves as the patient representative within KOSEK, the Swiss Coordination for Rare Diseases, ensuring that the experiences and needs of patients are reflected in healthcare policies and decision-making.

Meanwhile, AIRG France, chaired by Sandra Lawton, continues to play an important role within ORKID, the French healthcare network dedicated to rare kidney diseases. Together with her team, she works to provide guidance and support to families while strengthening collaboration between patients, healthcare professionals, and researchers.

Their joint participation at the APNP Congress demonstrated the value of international cooperation and reinforced a simple but powerful message: together, we can achieve more. By working side by side, AIRG Switzerland and AIRG France are amplifying the voice of people living with genetic kidney diseases and advocating for better care, greater awareness, and continued research.



Stéphanie Sénéchal AIRG Suisse,
Sandra Lawton, AIRG France

AIRG Switzerland has also partnered with Swiss artist Sophie de Quay to produce the inspiring song "On danse sous la pluie" ("We Dance in the Rain"). Written by Stéphanie Sénéchal, the lyrics celebrate resilience, hope, and the determination of patients and their families to move forward despite the challenges of living with a rare kidney disease.

The project received significant media attention across Switzerland, with coverage in both regional and national media, as well as strong engagement on social media platforms. This visibility has helped raise public awareness of AIRG Switzerland's mission to support patients, promote organ donation, and encourage research into genetic kidney diseases.

Special thanks to Sandra Lawton and Stéphanie Sénéchal for sharing their inspiring work and their commitment to the rare kidney disease community. If you want, I can also make it sound more like a press release, a website news article, or a magazine feature.

HIPOFAM PATIENT DAY – SEVILLE, OCTOBER 2025

Held in October 2025, the HiPoFAM Patient Day brought together patients, families, healthcare professionals, researchers, and experts for a comprehensive and informative event dedicated to advancing knowledge on inherited renal hypomagnesaemias.

The meeting was honoured by the opening remarks of the Director of FEDER (the Spanish Federation for Rare Diseases), an organisation representing more than 440 rare disease patient associations across Spain. During the event, she expressed her interest in the progress being made in the field of renal hypomagnesaemias and reaffirmed the importance of supporting research and patient advocacy for rare diseases.

One of the highlights of the programme was the presentation by Julieta Torcha, researcher at the Vall d'Hebron Research Institute (VHIR), who shared the latest advances in the renal pathophysiology research project. She announced that the research has reached an encouraging stage, bringing scientists closer to identifying a therapy capable of slowing—or even halting—the progression of the disease towards kidney failure. This promising progress reflects the unwavering commitment of HiPoFAM, whose members continue to dedicate time, resources, and fundraising efforts to support research that offers hope for the future.

The programme also featured Dr Gema Ariceta and Susana Carvajal, European Patient Advocate (ePAG), who presented the work carried out within the European Reference Network for Rare Kidney Diseases (ERKNet). They highlighted a collaborative European initiative aimed at identifying the unmet needs of people living with electrolyte disorders associated with rare kidney diseases.



Hipofam community



Isabel Motero FEDER Borad director,
Antonio Cabrera Hipofam president



Susana Carvajal Hipofam , ERKNet ePAG Chair, FEDERG president, Dra Gema Ariceta Irola, Vall de Hebrón Head of Pediatric Nephrology Departement ERKNet expert doctor,

HIPOFAM PATIENT DAY: ADVANCING KNOWLEDGE, RESEARCH, AND ADVOCACY

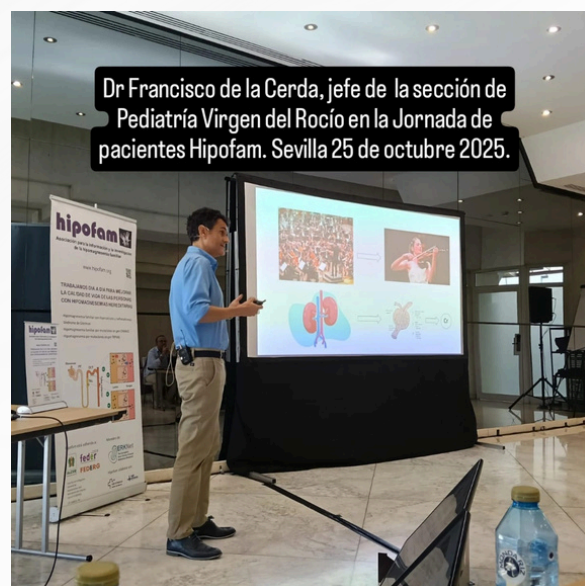
Drawing on input from expert centres across Europe together with European patient advocates, the project identified significant inequalities in access to electrolyte supplements between healthcare systems. For these patients, electrolyte supplementation is not simply supportive care—it is an essential, life-long treatment. Yet access and reimbursement vary considerably from one country to another, leaving many patients without equitable access to the therapies they need.

The initiative resulted in a scientific publication and a clear call to action, urging healthcare authorities to recognise these treatments as essential medicines and to address existing disparities across Europe. The speakers also emphasised the urgent need for child-friendly formulations, ensuring that children with rare kidney diseases have access to medicines adapted to their specific needs.

The HiPoFAM Patient Day once again demonstrated the value of bringing together science, clinical expertise, and the patient community to share knowledge, inspire hope, and strengthen advocacy for everyone affected by rare renal diseases.

One of the most moving moments of the Patient Day was the presentation by Dr Francisco de la Cerda, whose thoughtful reflections deeply resonated with patients and families.

Drawing on his extensive clinical experience, Dr de la Cerda spoke about the pivotal moment when kidney failure is diagnosed and renal replacement therapy becomes necessary. He emphasised that the way this life-changing information is communicated by healthcare professionals can have a profound and lasting impact on patients and their families.



Dr Francisco de la Cerda,
Hospital Virgen del Rocío Sevilla

He highlighted that this is not only a crucial time for making informed decisions about dialysis or kidney transplantation, but also a defining moment that can influence long-term treatment adherence, emotional wellbeing, and the confidence with which families face the future. With compassionate communication, clear information, and appropriate support, much of the fear, uncertainty, and stress that often accompany the transition to renal replacement therapy can be significantly reduced.

Dr de la Cerda also underlined the importance of continuous guidance and multidisciplinary support throughout this journey. Sharing the experience of the kidney transplant team at Virgen del Rocío University Hospital in Seville, he illustrated how a patient-centred approach—built on empathy, education, and close collaboration with families—can transform what is often perceived as a traumatic experience into one in which patients feel informed, supported, and empowered.

HIPOFAM PATIENT DAY: ADVANCING KNOWLEDGE, RESEARCH, AND ADVOCACY



Susana Carvajal, Hipofam
 Dr Julieta Torcha, Hipofam researcher
 Vall d'Hebron Institut de Research, VHIR

Behind every scientific breakthrough is a team committed not only to research, but also to the people it aims to serve. Julieta Torcha, researcher at the Vall d'Hebron Research Institute (VHIR), exemplifies this commitment through her work on familial hypomagnesaemia with nephrocalcinosis and hypercalciuria.

Her research focuses on analysing samples from patients and their family members to better understand the mechanisms underlying the disease and to identify therapeutic targets that could lead to treatments capable of slowing—or ultimately preventing—the progression to kidney failure. This work represents an important step towards addressing one of the greatest unmet needs of patients living with these rare kidney disorders. Equally valued by the patient community is Julieta's remarkable ability to communicate complex scientific concepts in a clear, accessible, and engaging way. Together with Dr Cristina Martínez, she has built a close and trusting relationship with patients and families, translating research progress into language that everyone can understand. Their commitment to open dialogue and patient engagement helps bridge the gap between the laboratory and the patient community, ensuring that research is not only advancing science but also empowering those living with the disease.

AIRG FRANCE PATIENT DAY PARIS- DECEMBER 2025

AIRG-FRANCE ANNUAL PATIENT DAY: LOOKING TO THE FUTURE OF RARE KIDNEY DISEASES



Dr Guillaume Dorval ADTKD



The AIRG-France Annual Patient Day, held in Paris in December 2025, brought together patients, families, clinicians, researchers and patient advocates for a day dedicated to one of the most important challenges in rare kidney diseases: achieving earlier diagnosis while preparing for the future of precision nephrology.

This year's programme highlighted the growing importance of genetic screening as a key step towards shortening the diagnostic journey for people living with inherited kidney diseases. Experts presented new initiatives aimed at improving access to genetic testing and integrating genomic medicine into routine clinical care, helping more families receive an accurate diagnosis and appropriate follow-up at an earlier stage.

Among the scientific highlights was the presentation by Dr Guillaume Dorval (AP-HP), who shared the latest developments in Autosomal Dominant Tubulointerstitial Kidney Disease (ADTKD). His work focuses on improving the molecular diagnosis of hereditary kidney diseases through advanced genetic approaches, helping to identify disease-causing variants that may otherwise remain undetected. These advances are expected to improve diagnostic accuracy, enable more personalised care, and create new opportunities for research and future therapies.

Another major topic was the growing role of artificial intelligence (AI) in nephrology. Speakers explored how AI is beginning to transform kidney care by supporting clinicians in interpreting complex clinical and genetic data, identifying patients at risk of disease progression, and ultimately contributing to earlier diagnosis and more personalised treatment strategies. While AI will never replace clinical expertise, it is increasingly becoming a valuable tool to support decision-making and improve patient care.

AIRG FRANCE PATIENT DAY PARIS- DECEMBER 2025



Susana Carvajal Federg president, karlheinz Steinecker
Airg France member and ERKNet ePAG and Sandra
Lawton AIRG France president



Withh Alport french patients

The meeting reflected AIRG-France's continued commitment to bringing together cutting-edge science and the patient community. By fostering dialogue between researchers, healthcare professionals and families, the event reinforced a shared vision: accelerating diagnosis, advancing research and ensuring that innovation translates into tangible benefits for people living with rare genetic kidney diseases.

Representatives from FEDERG were pleased to attend the AIRG-France Patient Day in support of the event and to further strengthen the close collaboration between European patient organisations. The meeting provided an invaluable opportunity to exchange experiences, learn from the challenges faced by people living with rare kidney diseases, and reinforce the shared commitment to improving patient care and advocacy across Europe.

The event also offered the opportunity to meet with European patient representatives who continue to work together to advance research, influence health policies, and ensure that the patient voice remains at the centre of decision-making.

In the afternoon, the programme featured a series of highly interactive workshops focused on patient support and empowerment, which were particularly well received by attendees. Among the most appreciated sessions were those dedicated to supporting patients and families at the time of diagnosis and during treatment decision-making. These discussions highlighted the importance of listening to patients' experiences, recognising their preferences, and promoting shared decision-making between healthcare professionals and patients as a cornerstone of person-centred care.