VOLUME 1

SEPT-DEC 2024

FEDERG

NEWSLETTER

MEMBERS ACTIVITIES

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From left to right: Flavia Galletti, AIRP and PKD International, Dra Barbara Tanos-Lora Senior Lecturer in Biomedical sciences, Dr Alessandra Boletta Cystic Kidney Disorder leader researcher

AIRP on 6th Biennial European Cilia Research Meeting 24

This global event is the largest scientific gathering focused on cilia and flagella research, bringing together experts and patient advocates from around the world.

From left to right: Béatrice Fleury, Alain Essade, Stéphanie Sénéchal, Jeanine Besler (AIRG France), Elles Essade, Emmanuel Léchaire

AIRG Switzerland celebrated its 20th anniversary….And we literally “danced in the rain”!

It was simply an unforgettable evening, rich in exchanges and emotions, full of hope and resilience.

ASHUA Commemorates International aHUS Day

ASHUA commemorates International aHUS awareness Day by denouncing that, even in 2024, there are problems to save LIVES, by denying access to treatments authorized by the Ministry of Health and the Spanish Agency for Medicines and Health Products.

"Run to Save Lives", although it may seem like a slogan, is a warning to health professionals, because only a quick diagnosis of aHUS and the right treatment can save a person's life.

(follow page 8)

FEDERG

MEMBERS ACTIVITIES

NEWSLETTER

Decembre 2024

Susana Carvajal Arjona
FEDERG president

ILLUMINATING PATHWAYS TO IMPROVE UNDERSTANDING, HEALTH AND WELLBEING

FEDERG NEWS LETTER is a tribute to our former President, Tess Harris, who never stopped fighting for rare and genetic kidney diseases and empowered us all to keep moving forward.
Federg is a federation of 17 European Patient associations, each of which plays an extraordinary role at national level in supporting great communities of patients, research and information on genetic and rare kidney diseases.

01.

We want to give visibility to the associative and patient support work carried out by our member associations

02.

We promote research and dissemination of rare kidney diseases describing the needs for improving understanding, diagnosis and care .

The care of our kidneys is in our hands. Patients are an important active part in the well-being of kidney disease.

OUR SUCCESS IS GIVING VOICE TO THE NEEDS OF OUR PATIENTS

The articles are compiledby some of our member associations and contain testimonies of events that took place from September to December 2024. The exemplary member associations work and support for our patient communities is admirable. We thank all associations,

Airp inCilia, 2024.

This meeting was an invaluable opportunity to connect with European associations supporting patients affected by various ciliopathies, both renal and non-renal.

Renal ciliopathies are rare genetic disorders linked to primary cilium dysfunction, which negatively affects tissue development and function. In pediatric nephrology, disorders like nephronophthisis (NPH) and autosomal recessive polycystic kidney disease (ARPKD) contribute to 15% of childhood chronic kidney disease (CKD) cases, generally progressing rapidly to end-stage kidney disease in early life, which poses significant challenges for patients, families, and healthcare systems.

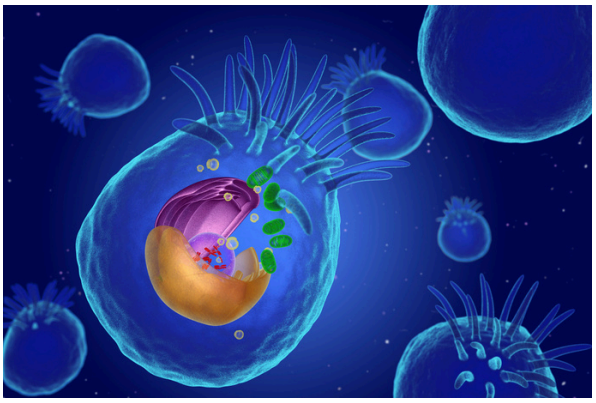
The event brought together a wide array of participants, including members of the TheRaCil consortium. This consortium, comprising clinicians, geneticists, biotech firms, and specialists in cilia biology, bioinformatics, data science, artificial intelligence, and patient advocacy (with PKD Charity UK as a partner), provided a collaborative platform to discuss goals and preliminary results. Sophie Saunier, TheRaCil coordinator, presented a plenary titled “Novel Therapeutic Approaches for Nephronophthisis and Renal Ciliopathies.” Additional presentations included Bernhard Schermer’s exploration of “Regulated Cell Death Pathways in Renal Ciliopathies” and a poster session featuring research by Lucie Menguy, Guillaume Rocha, Damelys Calderon (Imagine Institute), and Aurelius Roskothen-Shevchuk (UMC Utrecht).
The UK-based CILIAREN consortium, focused on improving diagnosis and management of renal ciliopathies and fostering innovation in therapies, also attended. Together with TheRaCil, CILIAREN hosted a working lunch, inviting patient representatives for an exchange of ideas, underscoring the mutual benefits of patient-researcher collaboration.

Highlights from the Patient Meeting. The two-day CILIA2024 Patient Meeting, held at University College Dublin, provided a unique space for patients, scientists, and healthcare professionals to explore the latest in ciliopathy research.

Highlights from the Patient Meeting

The two-day CILIA2024 Patient Meeting, held at University College Dublin, provided a unique space for patients, scientists, and healthcare professionals to explore the latest in ciliopathy research. Set in the UCD Club and O'Reilly Conference Center, the event balanced structured sessions with informal networking, designed to strengthen connections and understanding among the ciliopathy community.
The formal opening, led by Helen May-Simera, featured experts including Chris O’Callaghan, Jane Farrar, Fiona Copeland, Mieke Van Haelst, Rachel Giles, Mark de Leeuw, Phil Beales, and John Sayer. A highlight was the “World Café” session, where patients rotated among discussion groups, giving them direct access to experts to ask questions and share personal insights.
Following the "World Café," a dynamic Q&A session, moderated by Ruxandra Bachmann and Barbara Tanos, delved into various topics with the panelists. Later, Bendert de Graaf led a session on clinical trials and translational research, covering the pathway from laboratory research to patient therapies. Talks on notable projects, including Rhythm (Mark de Leeuw), CILIAREN (John Sayer), and Axovia (Phil Beales), rounded out the day, followed by a networking reception and an informal session for young adults to discuss their unique experiences.

On the second day, a debrief from the "World Café" led into the formal opening of CILIA2024, with two key scientific sessions. The morning focused on therapeutic advancements for ciliopathies, while the afternoon examined underlying mechanisms of these disorders. A poster session followed, showcasing both research findings and patient perspectives, leading into a Patient-Scientist Exchange chaired by Helen May-Simera. This session provided insights from patient organizations, industry representatives, and researchers on collaborative research and ciliopathy databases.
A touching tribute was made to our late President Tess Harris, honoring her lifelong dedication to the ciliopathy community and to the patient world. Audrey Hughes, PKD Charity UK's Patient Involvement and Engagement Officer, closed this memorial moment with a heartfelt speech.
The meeting concluded with a final reception, celebrating the shared knowledge and strengthened bonds formed during this collaborative event.



One of the highlights of CILIA24 was the organization of a "lay poster session" dedicated entirely to the patient community. In a specially designated area, a large number of researchers showcased posters crafted specifically to present complex scientific concepts in accessible terms. It was inspiring to see the enthusiasm and dedication of these remarkably young and talented scientists, who eagerly explained their work with simplicity and clarity.
Images were carefully illustrated, and text was adapted to ensure understanding. I was particularly moved by one young researcher who had developed 3D crochet models of DNA strands and cells, demonstrating both healthy and mutation-affected cells. This hands-on approach was invaluable, especially for patients affected by ciliopathies which resulted in visual impairments. I would like to congratulate the organizers of CILIA24 for this idea. This thoughtful initiative highlighted their commitment to inclusivity and patient-centered communication, making the event not only informative but genuinely accessible to all patients.

The role of FEDERG in this process is especially significant. While gene therapies may not be interesting for other renal disease due to their diverse causes, they will certainly transform the approach to most genetic disorders.

For patient associations, attending scientific events like Cilia24 is invaluable. Such gatherings keep us informed of research progress, highlight promising developments, and provide insights into challenges facing new therapies

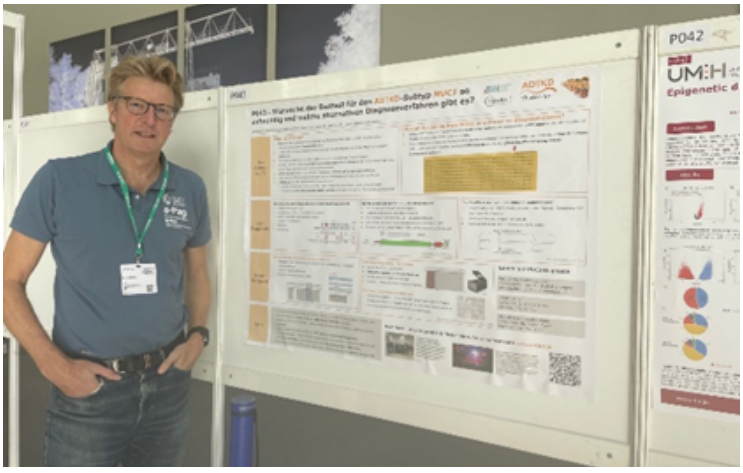
Personally, the chance to meet patient representatives across the ciliopathy spectrum was particularly enlightening. It was inspiring to learn about advancements like gene therapy for eye-related ciliopathies, already showing positive results.

Particularly insightful was the exchange with another non renal ciliopathy group who shared their experience with a Phase 1 clinical trial launched in March 2023. Although open for nearly a year, patient enrollment remains low due to hesitations surrounding genetic therapies, with patients wary of being the first to test this new type of drug. The concern that this trial may fail due to insufficient participation highlights the need for patient associations to play an active role in educating, supporting recruitment, and mainly addressing patient concerns.
This experience brought home the realization that similar trials may soon emerge for renal ciliopathies. As potential therapies come to the fore, our role in explaining study parameters, fostering informed choices, and offering support will be crucial. The role of **FEDERG** in this process is especially significant. While gene therapies may not be interesting for other renal disease due to their diverse causes, they will certainly they will certainly transform the approach to most genetic disorders.
In order to support patients effectively, it is essential that we work together, sharing information and resources to keep our community informed. Explaining these complex topics in patient-friendly terms is no easy feat, and we cannot accomplish it alone. Our partnerships with scientific networks like ERA and ERKNet are more crucial than ever, as we need to learn how to navigate the nuances of these new therapies and guide our community through informed decision-making.

The learning curve is steep, but our duty is to stay ahead, advocating for patients and ensuring they are well-prepared for the evolving landscape of treatment options.

Flavia Galletti
AIRP Patient representative
PKD International president.

Poster: MUC1 gene test, diagnosis ADTKD at DGFN Berlin, September, 27, 2024.



The poster addresses the specific issues related to the MUC1 gene test. It describes why the diagnosis of this ADTKD-subtype is so difficult and which new methods are developed to improve MUC1 gene testing.
Gene testing in general is of utmost importance with respect to ADTKD as the disease cannot be detected by blood, biopsy or blood probes.
Most ADTKD variants such as UMOD can be diagnosed by Next Generating Sequencing (NGS) panel testing which are nowadays quite common in diagnostic laboratories.

Unfortunately, ADTKD-MUC1, one of the most common ADTKD subtypes, cannot be tested using NGS as the MUC1 gene defect occurs in the so called VNTR region of the MUC1 gene which cannot be read by NGS in general.

Therefore, other methods must be applied for the ADTKD-MUC1 gene test, the current gold standard is the so-called Snapshot method. However, this method is time-consuming as it requires a high number of manual procedures, which in many countries cannot be adequately invoiced. Therefore, only a limited number of labs do perform the Snapshot test in Europe, which is a very unsatisfying situation from the patient's point of view.
A new MUC1 diagnose method called VNTyper has been developed in France, however this method is only applicable in an academic environment so far. Dr. Bernt Popp from BIH has improved VNTyper by speeding it up, however further efforts are still required to make this new test applicable for common gene test laboratories.
This research is of utmost importance for ADTKD treatment as patient identification is of utmost importance to set-up clinical trials in future.

Meeting with Silvana Bazua, October 9th 2024

Silvana is a post-doc at the Broad Institute in Bosten, Massachusetts, USA. She is member of Anne Grekas team which is the most advanced research team worldwide addressing ADTKD research.

Silvana´s research interests are ADTKD bio-marker (urinal preferred) and the renal protein cargo system.

Presentation on internal workshop at Berlin-Institute-of-Health@Charité (BIH) , October 14th 2024

We were asked to give a presentation at an internal workshop at the BIH, the research an-institute of Charité.
At BIH, many researchers with less patient contact are working, e.g. computer scientists, geneticists, and biochemists.That's why were asked to give a presentation on ADTKD with the perspective of a patient's organization.
In the presentation we presented our family story with ADTKD and gave insight into a living with dialyses based on the experiences of our daughter.
Figures about survivals rates and the quality of life for patients with long-term dialysis have been presented. The figures show that long-term dialysis patients have a lower survival rate than cancer patients.
Christian Scheidler
ADTKD Cure

Hipofam Day, Valencia 28, 2024.

Outcomes of the Familial Hypomagnesemia project led by Drs Gema Ariceta and Ana Messeguer at Vall d'Hebron Institut of Research.

Familial Hypomagnesemia with Nephrocalcinosis and Hipercalciuria, HFHNC is a recessive genetic disease, considered ultra-rare because there is 1 patient in 1 million, is characterized by mutations in the genes Claudina 16 and 19 and by an increase in the urinary excretion of Calcium and Magnesium accompanied by hypercalciuria and polyuria and frequent urinary infections. It is a multi-organ disease that can affect vision in some cases, but its main effect is the progression to kidney failure.
The characteristic mutation in Spain and France are patients who have the mutation in the gene p.G20D in Claudin 19 and present a great phenotypic variability, in other words that the presentation of the disease and its symptoms are very different between patients, even between siblings.
The suspicion of other factors that are generating this variability is what led the team to investigate what happens in these patients. There is no specific treatment to preserve renal function nor biomarkers to predict its progression to renal failure.

The HFHNC project at the Vall d'Hebron Institute has 2 main objectives:
1- Identify the pathophysiological mechanisms underlying the progression of HFHNC and the phenotypic variability observed in patients.
2- Identify drugs using artificial intelligence for the treatment of HFHNC and its associated symptoms.

How? The VHIR team uses:
1.- The study of wole exome sequencing,
2.- The study of the intestinal microbiota and
3.- The analysis of urinary miRNAs.

For this study, all Hipofam patients provide urine, fecal and blood samples to be analyzed. The role and collaboration of patient associations is crucial for its success.
What are the main objectives?
The HFHNC research team has found and listed 19 phenotypic risk variants that are associated with faster progression.
The importance of obtaining a panel of phenotypic variants is crucial because it allows patients to be classified according to the risk of renal progression and to offer them personalized therapeutic options.

The Patient Day is always a good opportunity to talk about the results carried out at the Vall d'Hebron Research Institute with the help of our pre-doctoral researcher Julieta Torchia.

Two brothers with the same disease, but with different progression, were studied through blood samples and the discovery of the previously identified variants was confirmed: the protective variants in the brother with mild progression and the risk variants in the brother with rapid progression.
Using stem cells from these two brothers, an organoid will be created in which the progression of the disease will be studied, and drugs will be tested.
In parallel, the Vall d'Hebron Research Institute is also studying the influence of the intestinal microbiota in relation to these phenotypic variants.
The studies led the team to identify significant changes in the composition of the bacteria (Beta Diversity).
The VHIR team is seeking to develop other therapeutic strategies that improve the progression of the disease based on the observation of changes in the composition and activity of the intestinal microbiota of patients with HFHNC.
Regarding the observation of the third methodology, urinary Micro RNAs, 18 miRNAs were identified that are related to the rapid progression of the disease. This will allow them to be used as treatment and as biomarkers to improve the progression of the disease.
Data obtained from a cohort of 55 Spanish patients, and they are establishing a collaboration with Polish patients from the Medical University of Lublin. The collaboration of patients beyond our borders is important to obtain better results given that it is an ultra-rare disease.

For this study, all Hipofam patients provide urine, fecal and blood samples to be analyzed. The role and collaboration of patient associations is crucial for its success.

Regarding the selection of the drugs used, they were based on data obtained by AI, thanks to the characterization of the molecular composition of HFHNC through clinical data of the patients. This characterization led to a mathematical model and the identification of proteins affected by miRNAs that could function as therapeutic targets and the proposal of repositioning drugs, i.e. drugs that are already on the market. Six drugs were proposed that have been tested with cell lines to see their efficacy, of which 2 are promising for reversing the phenotype of the disease, although they are in the preliminary phase.
By 2025, these drugs will be used in mice and organoids to see their effect in a systemic and personalized way for each patient

These studies have managed to obtain recognized awards such as the best oral communication in the AENP Spanish Association of Pediatric Nephrology and in the ESPN, European Society of Paediatric Nephrology.

Therefore:

- The results obtained in the exome, mi RNAs and intestinal microbiota are promising to provide patients with more appropriate and personalized therapeutic options.
- The drugs identified by AI have shown promising results to reverse the phenotype of the disease in the cellular model.
- The testing of drugs in animal models and organoids will allow determining their effect in a systemic way and in a personalized way for each type of patient.

Susana Carvajal Arjona
Hipofam representative
ERKNet ePAG Chair
FEDERG president

ASHUA commemorates International aHUS awareness Day

by denouncing that, even in 2024, there are problems to save LIVES, by denying access to treatments authorized by the Ministry of Health and the Spanish Agency for Medicines and Health Products.

"Run to Save Lives", although it may seem like a slogan, is a warning to health professionals, because only a quick diagnosis of aHUS and the right treatment can save a person's life.

aHUS is one of the 7000 rare diseases identified, only 10% of them have an effective treatment, and aHUS patients are very lucky to have life-saving treatments since 2011, but the ASHUA association demands more, because without research and without a rapid diagnosis, we will continue to lose organs and lives. With the follow-up carried out by ASHUA, it can be seen that, in 2024, that is, 13 years after the appearance of the first drug for this rare disease, there are still patients who lose their kidney function due to the inefficiency of some doctors, or perhaps due to pressure from public administrations to reduce health spending.And how much is a person's life worth?
24.09.2024. The Atypical Hemolytic Uremic Syndrome Association (ASHUA) commemorates today, September 24, the International Day of the Disease of Atypical Hemolytic Uremic Syndrome (aHUS) along with many other associations from other countries. This day 24 is confirmed as an icon for patients, health professionals, and it is hoped that also for public administrations, because it must be remembered that aHUS can be defeated, and research is the key to prevent patients from dying.

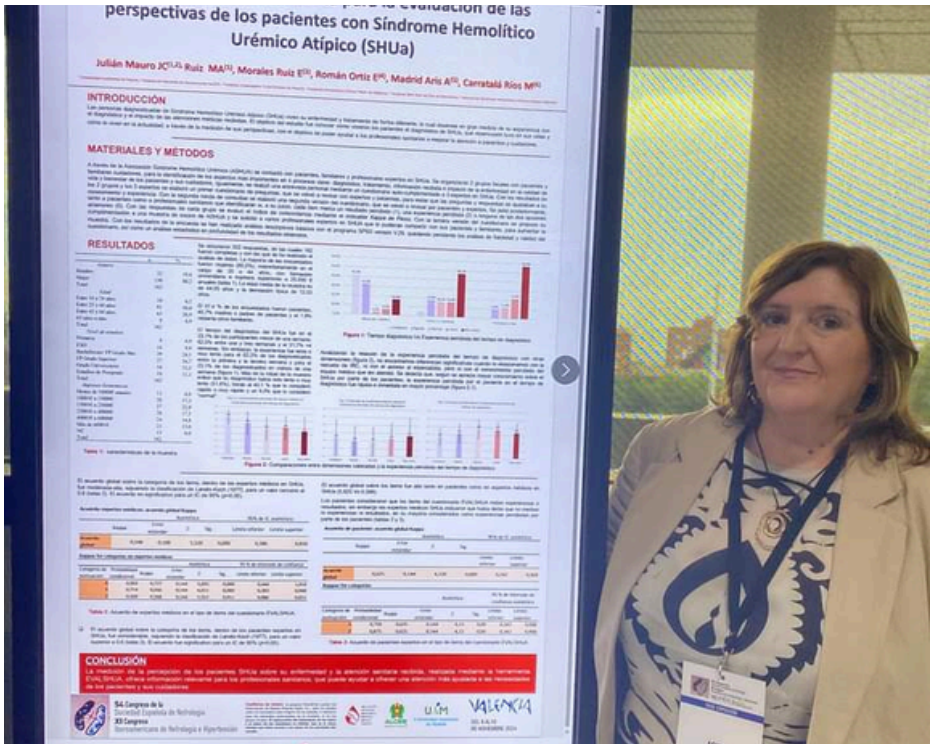
In 2010, the EMA (European Medicines Agency) authorised the first drug for this ultra-rat and potentially fatal disease,

In 2010, the EMA (European Medicines Agency) authorised the first drug for this ultra-rat and potentially fatal disease, and the Spanish Ministry of Health incorporated it into the National Health System so that the autonomous communities (CC AA) could immediately begin administering it to patients. It took several years for all the ACs to administer it to all patients and exactly 4 years passed, that is, for 4 years patients were discriminated against simply for living in an AA CC that did not do its job, putting the lives of many patients at risk.

Today, in 2024, the ASHUA association is still more active than ever, helping patients and families, collaborating with doctors and researchers, but undoubtedly taking a very important step with the collaboration of the Spanish Society for Healthcare Quality (SECA) with which the Standards for the Certification of Care for Patients with Atypical Hemolytic Uremic Syndrome have been created.for both adult and pediatric patients (quality standards for the management of aHUS). In collaboration with expert nephrologists from all over Spain, these rules must provide clarity on how to act with a patient at risk of death. The two QualiSHUa standards are already available, and the certification of health centres, services or units is one of the most widely used strategies to ensure quality. Certification systems, to which we are accustomed in the health sector, began in 1919, in the United States by the Joint Commission International (JCI).

Undoubtedly, another important activity initiated by the association is the ASHUA Observatory, created in 2018, and which aims to be a "thermometer" to know the status of aHUS patients and to be a voice of alert to health professionals and the administrations of the Autonomous Communities because the life of the aHUS collective may be in danger.

ASHUA has worked very hard to position the association and aHUS patients at the top of healthcare, politics and society. As Francisco Monfort (president of the association) explains: "In 2012 we created the association after spending 5 years of our life inside a very dark tunnel with our son about to die and once this phase was over, thanks to the selfless help of many people and research, our son received a kidney transplant, leaving aHUS in the background and returning to normal life. It was our obligation to share the help received and our hard experience with other patients because what the doctors announced to us in 2006 could be changed, since without research 90% of patients died."



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ASHUA was declared of Public Utility in 2015, and is part of the ALCER National Federation. It has developed a QR wristband for patients to be quickly identified anywhere in the world in the event of a medical emergency. It has recently created the ASHUA Observatory that allows doctors to monitor the management of the disease, to know the quality of life and to identify needs to act in time.

Francisco Monfort, the representative of ASHUA, tells us that the association has also had to cross borders and learn to work at the European level, and that is why since 2014, ASHUA is a founding member of the European Federation of Genetic Kidney Diseases FEDERG, which is also part of the new European ERN Reference Units. and in particular gives a voice to patients in the ERKNET (The European Rare Kidney Disease Reference Network).

Francisco Monfort
ASHUA president

It is difficult to summarize and describe the work and collaboration in a press release. The association has united a large aHUS family, and this ultra-rare disease has been given visibility and voice among doctors, politicians and other patient associations.
But there is still a lot of work to be done. Research is the fundamental axis to better understand the disease and expand knowledge in the field of genetics, since only about 50% of the genetic defects that cause the onset of this pathology are known.

aHUS affects about 1,200 people in Spain and is one of the few rare diseases, of the 7,000 that exist, that has an effective drug to stop its evolution. According to studies by the ASHUA Observatory, this ultra-rare disease mostly affects children and women, specifically 70% of cases appear before the age of 15 and 66% affect women, many of whom fall ill after pregnancy. The same studies reveal that only 5% of cases occur in people over 50 years of age. Finally, the ASHUA Observatory also shows the concern of patients who demand more Research and more Information.

AIRG Suisse held a celebration for 20 years

It was simply an unforgettable evening, rich in exchanges and emotions, full of hope and resilience.

From left to right: Olivier Bonny, Jean-Pierre Venetz, Thérèse Sayarath, Hassib Chehade, Anne Cherpillod

Let us recall that in 2004, nephrologists, pediatricians from French-speaking Switzerland and patients founded the AIRG Suisse association with a common goal of informing patients suffering from genetic kidney diseases as well as their families, friends and colleagues and to support research. Until later, the association is now better known and it is with great pleasure that the committee chose to celebrate this anniversary in the enchanting setting of the Château de la Sarraz, in the canton of Vaud.
The evening began with a speech by the president Stéphanie Sénéchal, herself suffering from autosomal dominant polycystic liver disease (ADPKD 1). At the head of the association for more than 11 years, she highlighted the efforts made during these two decades to support patients with genetic kidney diseases and to advance research in this field still little known to the general public.
She then invited on stage the speakers of the scientific round table: Olivier Bonny, president of the scientific committee and professor of adult nephrology and head physician of the nephrology department of Fribourg, Professor Hassib Chehade, member of the committee as scientific coordinator of the CHUV and pediatric nephrologist CHUV, doctor Jean-Pierre Venetz, assistant doctor transplantation CHUV, doctor Anne Cherpillod, nephrologist for adults in Lausanne.

The round table began with the poignant testimony of Thérèse Sayarath, a multi-talented Franco-Asian artist (musician, stylist, activist, model).

She recounted how, about ten years ago, she suffered from burnout and, almost simultaneously, discovered that she had a hereditary disease, polycystic liver disease, like her mother. While she left her job to devote herself to her dream of becoming a singer, her illness quickly caught up with her. The cysts began to invade her kidneys and liver, and her body changed. Her liver reached a weight of 6.5 kg, increasing the volume of her abdomen. Out of breath on stage, she finally had no choice but to accept a transplant, performed in November 2022. Today, Thérèse lives with someone else's liver and, with precise and accurate words, she shared with us an intimate part of her journey. Very moved to share this story in front of an understanding and caring audience, she expressed what this moment meant to her.

Suddenly, little voices chanted Thérèse's name, who then began her concert with her magnificent title "Sirène". It was a moment suspended in time... Time, a recurring theme in her songs: the time we don't have, the time we don't take, and this precious time that sometimes seems so long, especially when waiting - a nod to her song dedicated to waiting for a transplant. She spoke about the disease, personified as Maladiva, and her fear of death in “No Right Times.” Overwhelmed with emotion, Thérèse shed a few tears, reminding us how complex and sincere each patient’s journey is, and that each new step represents a victory. After the tears, we smiled and danced to lighter songs criticizing the music industry, before ending by jumping and celebrating life to her latest track, “No Rules.”

From left to right: Simon Jaccard & Sophie Loretan: Sophie de Quay

A song on the theme of resilience

As the President so rightly pointed out: a birthday without a gift is not really a birthday. That's when Sophie de Quay came on stage and Simon played the first notes of "Danser sous la pluie", a song written by the President a few months earlier on the theme of resilience and composed by Sophie de Quay. Between slam and rhythmic singing, we all applauded and danced, touched by the depth of the lyrics, resonating in each of us.

https://www.youtube.com/watch?v=ttFxyeCWW-c

And let's never forget this quote from Alfred Wiesbauer: "it's only when patients get involved that things move"!
Finally, despite the difficulties that we, the patients, encounter - as well as our caregivers - if I had only one recommendation to better live through these trials, it would be as much as possible, dance in the rain!

Stéphanie Sénéchal
President AIRG Switzerland

After that, it's finally time to pop the champagne and blow out the candles of a magnificent Black Forest cake.

At the Château de la Sarraz, we were all happy and grateful to be there...

The concert continued and we continued to "build bridges" between patients, doctors, researchers and industrialists. At the Château de la Sarraz, we were all happy and grateful to be there...
Then the sound cut out, the guests gradually left, and the lights went out. A feeling of sadness came over us at the thought of this moment ending, but our hearts were filled with joy at having lived this moment out of time.
A huge thank you to all the people who worked to make this party an unforgettable moment.

AIRG-France Members Day

A day focused on women with kidney disease.

AIRG France Day 2024 took place on October 12, at the Faculté des Sciences Médicales et Paramédicales of the Aix-Marseille University, la Timone. Pr Dr Jérôme Harambat president Scientific Board, Ms Sandra Lawton AIRG-France president, Pr Philippe Brunet, AP-HM Hôpital de la Conception Marseille, opened this Patient Day focused on women with kidney disease. It was very informative for everyone to learn from doctors.

Firts, Dr. Giorgina Piccoli informed us about the differences in the progression of rare diseases and their distribution according to sex. There were very interesting comments that attracted the interest of the audience : women live longer than men, is it a matter of luck or is it that men are less well treated? She spoke about the increasing rate of causes of mortality due to kidney disease. She stressed that women have a higher risk of urinary tract infection, pyelonephritis, the treatment can be changed between men and women but in men, especially in adults, the treatment is longer and the risk of scarring is greater. She also pointed out that autoimmune diseases like Systemic lupus erythematosus, are more frequent in women however, men have a more severe form. She wanted to emphasize that, Kidney diseases are different, frequency and severity may not correspond. Men and women are not equal when it comes to kidney disease, this is a hypothesis that needs to be studied further.

Then, Pregnancy and chronic kidney disease was the topic that was developed by Dr Vigneau from CHU de Rennes. The general message is that despite the risks of pregnancy with kidney disease, on dialysis or with a transplant, women with kidney disease who decide to become pregnant should be supported and accompanied . Pregnancy is a period of significant kidney risk, especially due to preeclampsia, and complications associated with blood pressure. In dialysis, fertility decreases and pregnancy is very complicated. With transplant, there is a fetal risk from immunosuppressants, a complicated obstetric risk and risk or loss of the transplant. Clinical support for programming and pregnancy planning must be provided in these cases.
Dr. Vigneau also highlighted that the pregnancy is also an opportunity to detect chronic kidney diseases. Proteinuria and problems associated with blood pressure should be key to planning a pregnancy in these patients, studying case by case, the type and state of kidney disease.

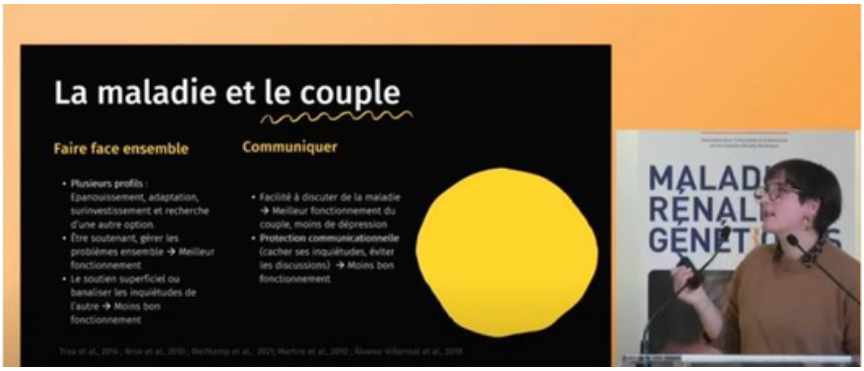
AIRG France particularly thanked Tess Harris for her work in developing the KDIGO guidelines for autosomal polycystic kidney disease

Dr Emilie Cornec le Gall spoke about the specifics of autosomal polycystic kidney disease in women. She recommends consulting the KDIGO guidelines on polycystic kidney disease, the result of 2 years of work by researchers, expert nephrologists, pathologists and patient representatives. She thanked the work of Tess Harris, former president of FEDERG who passed away last March and and who collaborated by pointing out the needs of patients with PKD.

Blood pressure is a public health problem in France.

Women are more likely to develop complications related to blood pressure than the general population, an observation that has drawn the attention of experts who are interested in women and especially women with kidney disease, stressed Dr. Sébastian Rubin of CHU Bordeaux.
Women have many more cardiovascular complications than men and are exposed to social and occupational risks that make them more fragile. Cases of hypertension are increasing in France and it is a major public health problem.

The Biomedicine Agency with Professor Michel Tsimaratos about transplants in France and donors. He placed great emphasis on the importance of promoting organ donation and raising awareness among the population



Round tables were held to discuss topics such as puberty, fertility, sexuality,

In the afternoon, round tables were held to discuss topics such as puberty, fertility, sexuality, contraception, the impact on couples' lives, and the consequences in the relationship. Topics related to patient well-being were discussed. Adaptations to CKD were discussed, as well as the need to disseminate information about the different rare diseases in order to offer adequate support for each case. Emphasis was placed on vaccination and the adaptation of contraceptive treatments. The social sphere and the family and loving environment are also part of the psychological care of a renal patient. A patient is not isolated and his or her environment adapts to the disease.

AIRG- France

37th Spanish National Congress of kidney patients. Alcer Federation in Salamanca.

"The aim is to bring knowledge and advances in nephrology closer to people with kidney disease, their caregivers, family members and professionals," said its president, Dani Gallego.

The Spanish National Congress of Renal Patients took place from October 25 to 27, 2024 at the Palacio de Fonseca in Salamanca.
The congress brought together patients, caregivers, healthcare professionals, and researchers to share insights, promote innovation, and discuss key topics in nephrology

Program Highlights

The program opened with a focus on Chronic Kidney Disease, which was described as a major global epidemic. Discussions emphasized the risk groups such us obesity, diabetes and pharmacovigilance, which are critical to addressing the growing burden of CKD.
The spotlight then turned to Pediatric Nephrology, highlighting its significance in managing genetic kidney disease and the interest it has aroused in nephrology research. Advances in understanding these conditions, driven by the dedicated efforts of researchers and expert doctors make genetic kidney diseases better known, although there is still much to be done. .
Expert nurses provided valuable insights into the daily lives of patients and families, detailing impact on families and young patients were revealed.

Caregiver Support and Dialysis Advances

The study of the quality of life of caregivers and the importance of talking about them was also discussed. Innovations in home hemodialysis were highlighted, along with the challenges and success factors of both hemodialysis and peritoneal dialysis as critical treatments.
Topics such as the nutritional approach in hemodialysis, the improvement of the patient experience, and the challenges of transplantation in hypersensitized patients were also presented, underlining the need for comprehensive and personalized care strategies.
Next, it was the turn to talk about the European Network of IgA patients, the testimony of a patient with ANCA vasculitis and a patient with Purito caused by CKD. The participation and involvement of patients is important to un

.

Commitment to Innovation and Care

The ALCER National Federation reaffirmed its dedication to innovation and improving the quality of life for people with kidney disease. The congress showcased projects like "Advancing Together in Kidney Disease and Its Association with Diabetes" and the PreventCKD Project, which focus on improving prevention strategies and fostering advancements in therapies across Europe.
Sunday's session delved into nephrology nursing, consultation care for advanced CKD, and nephro-geriatrics. The discussions underscored the importance of vaccination and early prevention of CKD to enhance patient outcomes.

The ALCER National Federation reinforces its commitment to innovation and the quality of life of people with kidney disease at its Annual Congress.

Recognitions and Collaboration

During the event, 2024 tributes and recognitions celebrated the contributions of individuals and organizations advancing nephrology care. The congress concluded with a reinforcement of collaboration among professionals, patients, and families, emphasizing the pillars of education, prevention, and mutual support as essential to improving the quality of life for kidney patients.

New legislation on social protection of living donors has excited the kidney community

Preventing CMV activation in transplantpatients and the new legislation on social protection of living donors were the topics chosen to close the second day. A work undoubtedly appreciated by the community of patients who celebrate the arrival of new laws that protect donors.

The ALCER National Congress in Salamanca concluded with the reinforcement of collaboration between professionals, patients and families, highlighting the importance of education, prevention and mutual support as pillars for improving the quality of life of people with kidney disease.

Juan Carlos Julián
ALCER Federation, Spain

The law on social and labour protection for living donors will come into force on 24 March in Spain.

After more than 10 years of effort and advocacy, a groundbreaking regulation has come to light, providing adequate protection to people who donate organs while alive (such as a kidney or part of their liver). It has been over a decade since the National Federation of ALCER Associations first advocating for proper protection for these donors. It was following the decline in living donations in Spain and after learning about a project by the Dutch Kidney Foundation in 2014, when ALCER became aware of the situation and began to demand legislation to regulate this protection. The Spanish Transplant Organisation (ONT) consistently supported this initiative. Not in vain, its former director, Rafael Matesanz, who was also a patron and vice-president of the ALCER Renal Foundation Spain, attempted to advance a similar proposal in 2012. However, as he confessed, "the socio-economic situation of those years made it impossible for the proposal to progress.""

The regulation published last 20th of December of 2024 in the Official State Gazette (BOE) is a complex legislation that involves the modification of nine regulations and the intervention of three ministries: Health, Labor and Social Security.
In 2014, the National Federation of ALCER Associations launched the “ConVida” campaign to promote living donation, co-organized with Astellas Pharma and supported by the ONT, the Spanish Society of Nephrology, the Spanish Transplant Society and the Spanish Society of Nephrological Nursing. It was not until 2017, within the framework of World Kidney Day and before the Health Commission of the Congress of Deputies, when the Federation publicly called for specific legislation on this matter. This demand gained further urgency after a news report from the HEPA association highlighting the problems faced by parents of children with liver diseases after donating part of their liver.

Subsequently, ALCER joined forces with the National Federation of Liver Patients and Transplant Recipients (FNETH) to advocate for suitable legislation, always with the support of the ONT, which played a decisive role in the process. Although initially the political party Ciudadanos championed the proposal, it was finally the socialist group that presented the first bill. This initiative was led by the former Minister of Health, María Luisa Carcedo, who played a fundamental role in its development. Carcedo became aware of the significance of this legislation in 2019, during the celebration of World Kidney Day, where she was invited by ALCER.
The bill was approved by a majority in the Congress of Deputies in 2023, but the parliamentary process was interrupted by the general elections, resuming in 2024. The Law was finally published in the BOE on December 21, 2024.
The legislation includes essential rights for living donors, most of whom are family members and people close to the recipients, adding even greater significance for organizations like ALCER and FNETH, which strike to improve the quality of life of patients and their loved ones. However, the Federation became particularly aware of the importance and fairness of this law when it learned of cases of altruistic and non-directed donors, known as "good Samaritans", who donate without personally knowing the beneficiaries. In 2022, ALCER publicly acknowledged these donors by presenting them with one of its social awards.
The Law for the Improvement of the Protection of Living Organ or Tissue Donors was officially published on December 21, 2024, but it will not take effect until March 24, 2025. This regulation will benefit both solid organ and bone marrow donors.
The law recognizes a series of paid leaves to address situations related to the living organ or tissues donation that were previously unregulated. Key measures include:
·Sick leave due to organ donation will be considered a special situation of temporary disability due to common contingencies. Donors will not need a prior contribution period to access economic benefits, which will be granted from the first day of sick leave and calculated at 100% of the regulatory base..
·The Workers' Statute and the Basic Statute of Public Employees have been amended to grant paid leave for attending information sessions, carrying out the necessary reports and clinical examinations, and covering other essential absences related to the donation process.
The main objective of this legislation is to provide comprehensive coverage to organ donors, ensuring they have adequate sick leave to undergo the required surgical procedures.

Juan Carlos Julián
ALCER Federation, Spain