

EKPF ANNUAL SUMMIT REPORT

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2022

ATHENS, GREECE

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EKPF represents over 75 million of people with kidney health conditions in Europe

Its membership brings together 27 national kidney patients federations from 26 different countries across Europe.
Its mission is to improve:

- Voice
- Choice
- Involvement
- Safety
- Autonomy
- Quality of life
- Innovation and research

EKPF
EUROPEAN KIDNEY PATIENTS' FEDERATION
CEAPIR



ATTENDANCE







The Annual Summit was held both in person and virtually. After the pandemic, we held our first Annual Summit in 2021 in Madrid. Due to the sanitary conditions it was difficult for many of the organizations to get together.

However, 2022 has been a year of coming together again and growing. Thus, in the Annual Summit 2022 held in Greece we had the following participants:

- 30 representatives of organisations who attended in person.
- 15 organisations attended in person
- a total of 60 people, including patient representatives and collaborators.

Chelsea Moran and Dr. Kawachi - Astellas

The diagnosis of anaemia as a symptom of CKD can have a negative emotional impact, with worry and anxiety being the most common feelings experienced at the time of diagnosis4. 4 Beyond the diagnosis, people living with anaemia of CKD often experience more difficulties, with greater anxiety and depression compared to patients without anaemia4, and a lower health-related quality of life4. Dr Kawachi, Professor of Social Epidemiology at the Harvard T.H. Chan School of Public Health, spoke about the impact of mental health on the health outcomes of people living with chronic diseases, including anaemia of CKD, and why - and how - tailored mental health support should be integrated into patient care. Following the meeting, Dr Kawachi said: “People with symptomatic anaemia of chronic kidney disease experience greater problems with anxiety and depression than patients without anaemia, so it is essential to incorporate mental health support into their care to help them achieve a better health-related quality of life.









Ava Lloyd AstraZeneca

Ava spoke about the impact of COVID-19 on people living with kidney disease and key lessons learned from the pandemic. She highlighted the need for additional measures to ensure a better quality of life for people who are immunocompromised, especially kidney patients who are especially vulnerable to severe COVID-19 related outcomes. Another key lesson was the need to prevent and detect kidney disease much earlier, before it becomes unsustainable for patients and health systems that were placed under increased pressure as a result of the pandemic.



Sandra Gaisch-Hiller - Baxter

The presentation underlined the importance of patient empowerment through education, i.e. enabling patients to have the information they need to take more control over decisions that affect their health and to take an active role in managing their health. Baxter presented a European patient education project created in collaboration with a group of healthcare professionals, patients and their families to support the needs of CKD patients. My Kidney Journey provides patients, their families and the wider community with the information and resources they need to plan a healthy and fulfilling life while receiving renal replacement therapy. The platform answers the most frequently asked questions among people diagnosed with kidney disease and provides information on all treatment options, dialysis, kidney transplantation and conservative renal treatment, psychosocial support, diet and exercise to encourage self-management behaviour. My Kidney Journey supports pre-dialysis and dialysis education, encourages shared decision-making and helps patients and their caregivers select the treatment option most in line with their personal goals. The platform, supported by several regional and local nephrology and patient associations, is available in 40 countries in more than 20 different languages.





Daniela Esser - Bayer



Based on the idea that both patients and physicians are very active online, engaging communities on social media is an opportunity to reach multiple patients and physicians. Bayer is currently able to do this through a number of activities:

Kidney Disease Forum: Specific channels designed to enable the exchange of knowledge about CKD between physicians on Twitter and patients on Facebook.

Let's Talk CKD: Customised multi-phase clinical campaigns to share best practices in CKD management, educate multidisciplinary stakeholders about the silent nature of CKD in T2D and the need for early diagnosis.

Giving patients a voice and highlighting the reality of living with CKD by partnering with the EKPF to conduct a European survey of people with T2D and CKD to better understand how their disease affects them.

Bayer also shared information gathering as a priority goal, as they want to provide support to the CKD community, based on real information from people living with CKD, as well as from the CKD community. They conducted a survey to ask the expert audience at the summit about their local priorities for supporting people with CKD. The top three priorities from the audience were: general disease awareness, mental health



Liviu Constantinescu - Fresenius

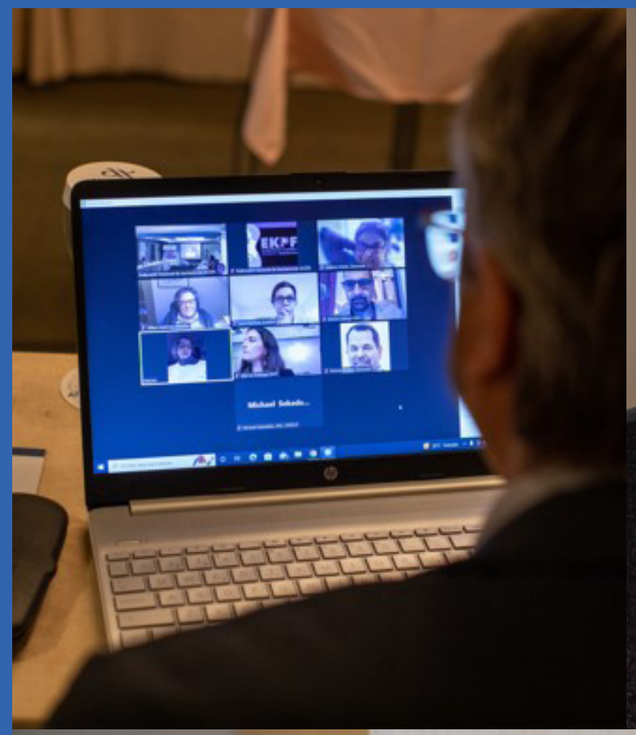
International comparisons show that much more can be done to raise CKD awareness, broaden treatment options and increase the quality of care for renal patients. To achieve results in these areas it is necessary that renal care providers, patient associations and medical professionals join efforts and actively develop programs together. On the provider side, Fresenius Medical Care partners with patients across the whole patient journey, setting clear objectives for each step: to develop awareness and increase disease management knowledge, to improve psychological comfort and facilitate social integration into the dialysis units and to increase engagement in the therapy. Each of these objectives are followed by dedicated program, realized by qualified staff members: bedside education, onboarding and assistance programs, regular patient experience assessment, to mention just a few. Fresenius has also committed to externally report patient experience and grievance management results as part of its Corporate Sustainability Program.

Matthias Rohrbeck - Novartis

“Embark on a journey through our kidney from macroscopic to microscopic anatomy and explore the structures of the kidney in unprecedented detail. With Insight Kidney you can learn something about the structure of the kidneys and their functions without having to go through an anatomy tome. For the first time, Insight Kidney has visualized pathological changes in addition to anatomically correct representations. Having an illness is already very hard to bear. Not understanding an illness and not knowing what is happening to your body makes it even harder and even more unbearable. As a sufferer, as a family member or as a knowledge seeker, one searches the internet for information and it is hard to find these. You can go on a discovering voyage on your own and learn more about certain rare renal diseases with Insight Kidney.”

Helen Stoop
Takeda

Every transplant offers a patient the opportunity of more years lived in better health. For every transplant to carry the best possible chance of success, transplant teams work extremely hard to prevent or proactively manage CMV and other viral infections when they occur but, for a small number of patients, these infections can still cause significant problems after their transplant. Policymakers have crucial roles to play in supporting high quality patient-centred transplant services, including through setting national priorities, encouraging investment into health and care services, and sharing of best practice both within and between different countries. Policymakers can also encourage scrutiny of national services, to identify variations in approach and performance. In Every Transplant Matters Takeda sought to understand how a supportive policy environment could facilitate national transplant services and patient organisations to enhance transplant care for every patient, with a particular focus on tackling post-transplant infections. The report identifies commonalities and points of divergence, best practices, and suggests potential policy solutions.







Michaela Blomstrand
Diaverum

Diaverum was represented by Michaela Blomstrand, Director Global Patient Experience & Community Affairs, who spoke on Diaverum's approach to patient experience throughout their 440 clinics across 23 markets.

The presentation included:

A walk through of their patient experience framework, illustrated as a pyramid with basic need at the bottom building towards more purpose-driven activities, because everyone deserves a fulfilling life. How patient experience is embedded in everything they do – from care delivery, to digital innovations and true care culture. Their 360-degree approach to patient feedback, from regular temperature check-ins to more comprehensive annual surveys on perception of care and quality of life.

George Baliouskas
Bookdialysis

Haemodialysis patients need to be able to travel safely, confidently and easily. Sometimes it is not easy to find dialysis treatments abroad, communicate with the clinic and get all the information across. That's why our solution is to make the platform easy to book, both for you and for others. It must also be fast and reliable so that patient safety can be guaranteed.

The next steps are to strengthen global partnerships and community, amplify customer service excellence, continuously enhance platform services and document and share learnings on the field. The partnership of clinics is essential: digital tools to manage their availability and appointments.



PREMIUM

astellas

AstraZeneca

Baxter

Bayer

CSL Vifor

FRESENIUS MEDICAL CARE

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DIAVERUM

Takeda

CORPORATE

Bristol Myers Squibb