

European Kidney Forum 2022

The Decade of the Kidney™
10 years to bring innovative and green treatments to
kidney patients in Europe

Hybrid event moderated by Tamsin Rose



15 June 2022
Event Report



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On the 15th of June, the European Kidney Health Alliance (EKHA) and the MEP Group for Kidney Health hosted the 2022 European Kidney Forum: 'The Decade of the Kidney™: 10 years to bring green innovation to kidney patients'. This event, moderated by Tamsin Rose, was organised as part of the Decade of the Kidney™, an EKHA-led campaign which aims to put the spotlight on Chronic Kidney Disease (CKD) at the EU level within the next ten years. The discussions focused on identifying the challenges with current kidney disease treatments (primary and secondary prevention) from a patient, society and environmental perspective, and exploring ways to ramp up innovation. The Forum gathered insights from European patients, policy makers, healthcare professionals and scientists but also looked at inspiring examples and success stories from the United-States of America (US) with US policy makers and patients. The hybrid meeting took place in the European Parliament in Brussels.

OPENING STATEMENTS



"I call on my fellow MEPs and on the European Commission to facilitate research on green innovation in nephrology. In particular, the EU can learn from the US model, where kidney health was put high on the policy agenda. The MEP Group for Kidney Health calls on all European nephrology stakeholders to align with these initiatives and avoid missing the boat of ecologic transition vis-a-vis other European innovation areas or other world regions."
MEP Hilde Vautmans,
Chair of the MEP Group for Kidney Health

MEP Hilde Vautmans, Chair of the MEP Group for Kidney Health opened the Forum by stating that she remains shocked to see that **Kidney Replacement Therapies (KRT) have barely evolved since their development more than 50 years ago**. She recalled that COVID-19 further demonstrated the need to find alternatives to current kidney therapies. She highlighted that innovation is not only pressing from a patients' perspective, but also from an environmental perspective, as there is a strong link between ecology and kidney health. The EU recently launched several initiatives to make the EU an ecologic forerunner, and building on these will prove essential in fostering green innovation in nephrology. MEP Vautmans concluded her opening statement by calling on EU policy makers to facilitate research, and ensure that nephrology benefits from the same level of green innovation as other EU innovation areas.

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“The EU must profit from lessons learnt from the COVID-19 pandemic and the war in Ukraine, which clearly point to the need to make kidney treatments more patient-centric and sustainable.”
MEP Ondřej Knotek,
Member of the MEP Group for Kidney Health

MEP Ondřej Knotek, Member of the MEP Group for Kidney Health, said a few words about the situation in Ukraine. Kidney disease treatments require stable conditions, access to water and electricity, and this is not the case in a war zone. **He stressed that the situation of kidney patients in Ukraine is another reason to put kidney health at the forefront of health policy.** He noted that the Ukrainian conflict occurred on top of the COVID-19 pandemic, and further demonstrated the vulnerability of kidney patients. The EU must profit from lessons learnt from the pandemic and the war in Ukraine, that clearly point to the need to make kidney treatments more patient-centric and sustainable.



Prof. Raymond Vanholder, President of EKHA, stated that the environment has a huge impact on our lifestyle, and vice versa – this is true for kidney disease too. Indeed, significant water waste is associated with dialysis. **Each dialysis session consumes 400-500 litres of drinking water, and produces large amounts of plastic and energy waste, as well as CO2 emissions.** He presented the EKHA recent publication “The European Green Deal and nephrology: a call for action by the European Kidney Health Alliance”, which describes the ecological impact of nephrology but also provides potential solutions. Prof. Vanholder noted that green nephrology is among the key topics of the Decade of the Kidney™ campaign.

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Session 1: Current challenges in kidney disease treatments

» Patient Testimony



"The EU could become a pioneer in recognizing CKD for what it is: A disease that affects 100 million European citizens and that accounts for €140 billion of the European health budget."

*Emily Petrides,
Vice-President of the European Kidney Patients' Federation (EKPF)*

Emily Petrides, Vice-President of the European Kidney Patients' Federation (EKPF), shared the patient's perspective by telling her story. Adult Polycystic Kidney Disease (APKD) runs in her family. When she was 10 years old, she lost her 43-years-old father to APKD. Ms. Petrides carries the same gene and was diagnosed with APKD and liver disease at the age of 16. She talked about her diagnosis, the frequent medical visits, and expressed her constant fear of dying. Ms. Petrides developed rapid kidney failure at the age of 30, after her pregnancy, and in 2007, she received a kidney transplant from her mother. **She stressed that not all kidney patients are so fortunate; only 20% are eligible for transplantation.** She reminded that transplantation does not give a clean bill of health, and that she has been in and out of hospital over the years for issues related to her kidney transplant. As a patient advocate, Ms. Petrides expressed patients' anguish concerning the alarming growth of CKD in Europe. Numbers demonstrate that the current protocols and treatments are not adequate: hospitals are reaching their capacity limits, and the availability of kidneys for transplantation is minimal. Ms. Petrides concluded that dialysis is not a curative treatment, but a prolongation of life until CKD patients receive a transplant or die. Therefore, dialysis is in desperate need of innovation and reengineering.

» The links between current treatments for kidney patients and environmental pollution



"There is a profound urgency in healthcare and beyond to reduce our carbon footprint. In nephrology there are things we can do tomorrow that will make a difference. If we miss the boat we will run out of time very rapidly."

*Dr. Mark Harber,
Consultant Nephrologist, Royal Free Hospital London*

Dr. Mark Harber, Consultant Nephrologist at the Royal Free Hospital London, explained that the prevalence of KRT is expected to grow worldwide. As such, any innovation that reduces the carbon footprint of KRT and improves the quality of life of patients is going to have major implications beyond Europe. Dr. Harber illustrated the size of the issue by looking at the contribution of nephrology to the climate emergency. **Numbers demonstrate that kidney patients have a carbon footprint 18 times greater than the average patient.** He then discussed mitigation measures for water use, waste production, energy use, and travel emissions caused by dialysis. Transplantation is much cheaper, greener and associated with better quality of life than dialysis. However, there continues to be huge variations in access to transplantation across the EU. He concluded by stating that there is a lot that we can and must do now, such as preventing or refraining progression of kidney insufficiency, improving access to transplantation, implementing maximal conservative management (supporting patients with end stage renal disease without resorting to KRT), and reducing the environmental footprint of dialysis. Dr. Harber highlighted that **the EU can offer guidance and protocols, data and monitoring, and most importantly championing these changes in nephrology.**

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“An average dialysis facility consumes the equivalent of an Olympic swimming pool of fresh water every year.”
Dr. Ilaria de Barbieri,
President and Scientific Board Chair, European Dialysis and Transplant Nurses Association/ European Renal Care Association (EDTNA/ERCA)

Dr. Ilaria de Barbieri, President and Scientific Board Chair of the European Dialysis and Transplant Nurses Association/European Renal Care Association (EDTNA/ERCA), shared practical strategies to reduce the environmental burden of dialysis. Dr. de Barbieri highlighted the important waste production of KRT, in terms of water, energy, plastic, and chemicals. To put things into perspective, Dr. de Barbieri explained that **an average dialysis facility consumes the equivalent of an Olympic swimming pool of fresh water every year**. She explained that EDTNA/ERCA created in 2011 environmental guidelines for dialysis, and issued a practical guide to reduce the environmental burden of dialysis through simple strategies to improve the eco-friendliness of dialysis units. In 2019, EDTNA/ERCA introduced an environmental check list to assess the performance of dialysis units worldwide, which can be used to evaluate the environmental impact of a dialysis unit, and identify areas for improvement. The check list also provides potential solutions to improve the unit’s environmental score. EDTNA/ERCA also works to support nurses’ education and create environmental awareness among kidney healthcare professionals.

» **Back to the future: How could the life of a person with kidney disease look like in 2030 ?**



“We must bundle the best brains to build better treatments: patients, doctors and nurses, policy makers, inventors and investors, engineers, and entrepreneurs fuelling the Decade of the Kidney™.”
Dr. Fokko Wieringa,
Principal Scientist, Connected Health Solutions, Interuniversity Microelectronics Centre (IMEC)

Dr. Fokko Wieringa, Principal Scientist of the Connected Health Solutions Department at the Interuniversity Microelectronics Centre (IMEC), presented what life with kidney failure could look like in 2030. He started by a brief overview of dialysis since its invention by Dr. W. J. Kolff. Dialysis was popularized in the 1970s in the US, and benefited from large investments. The atmosphere in the 1970s was optimistic, as nephrology was at the forefront of medical research & technology. **In 1972, 90% of dialysis patients benefited from home dialysis, which allowed a significant degree of freedom**, explained Dr. Wieringa. Portable dialysis was developed in the 1970s. However, it was deemed commercially uninteresting, and dialysis innovation rapidly ceased. Dr. Wieringa reminded that dialysis is not an end solution, and innovation is urgently needed to find alternatives. He then presented the ‘Technology Roadmap for Innovative Approaches to Renal Replacement Therapy’, written together with US colleagues. The roadmap defines steps that would allow kidney patients to travel with a portable dialysis machine by 2024, and achieve implantable artificial kidneys by 2030. He emphasised that these goals can be reached from the technology perspective. Nonetheless, a solid funding programme and international research collaboration are required.

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Session 2: Roundtable: Countdown to 2030: how can the European Union help scale up green innovation for kidney disease in the next ten years?

The second half of the event consisted of a roundtable between:

- **MEP Jutta Paulus**, Member of the MEP Group for Kidney Health
- **MEP Ondřej Knotek**, Member of the MEP Group for Kidney Health
- **Dr. Murray Sheldon**, Associate Director for Technology and Innovations of the Center for Devices and Radiological Health, Food & Drug Administration (FDA)
- **Paul T. Conway**, Chair of Policy and Global Affairs and Past President of the American Association of Kidney Patients (AAKP)



“Significant progress can be made if you provide a platform/meeting place for collaboration and partnership between government, industry, academia, patients, regulatory and reimbursement agencies.”

Dr. Murray Sheldon,

Associate Director for Technology and Innovations, Center for Devices and Radiological Health, Food & Drug Administration (FDA)

Dr. Murray Sheldon presented the US Kidney Health Initiative (KHI), a government-led initiative that was created in 2012 as a public-private partnership between the American Society of Nephrology (ASN) and the US Food and Drug Administration (FDA). It aims to catalyse innovation and the development of safe and effective patient-centred therapies for kidney disease. The KHI started as a collaboration between international stakeholders to find solutions to tackle the challenges encountered by kidney patients worldwide. Dr. Sheldon explained that the KHI came up with the ‘Technology Roadmap for Innovative Approaches to Renal Replacement Therapy’. The roadmap identifies milestones for achieving bio-artificial or bioengineered alternatives to dialysis by 2030. Dr. Sheldon stressed that a strong funding mechanism is needed to achieve the milestones set by the roadmap. In the US, this led to the creation of the Kidney Innovation Accelerator ‘Kidney X’, a public-private accelerator that engages researchers, innovators and investors to bring breakthrough kidney therapies to patients.



“The ideal of patients is to have access to technologies that put patients’ quality of life first.”

Paul T. Conway,

Chair of Policy and Global Affairs, and Past President of the American Association of Kidney Patients (AAKP)

Paul T. Conway shared that for kidney patients, **it is essential that the designs of technological innovation are patient-informed, rather than solely clinically-informed.** Mr. Conway highlighted that the KHI strongly believes that the number one priority of innovation is to improve the quality of life of patients. He explained that implantable artificial kidneys and xenotransplantation are preferred options. Moving forward, these innovations could achieve what patients define as quality of care, which is the alignment of treatments to patients’ human aspirations.

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MEP Jutta Paulus expressed that it is crucial to have a One Health approach to kidney health. The One Health approach stresses that human, animal and environmental health impact each other, and one cannot be considered without the others. Coming from a pharmacy background, she recalled the importance to focus on prevention of CKD risk factors. She also noted that more research is needed on the environmental and financial implications of KRT. Nonetheless, considering current numbers, it would be highly appropriate to find an approach to improve kidney disease treatments whilst ensuring that patients' wellbeing is the top priority. MEP Paulus reminded that the current EU multiannual financial framework dedicated €5.3 billion to health. However, **public-private partnerships should be encouraged to complement the EU health budget**, as €5.3 billion are not sufficient to cover every health issue. She also invited relevant stakeholders to submit proposals on improving treatments for kidney patients within the non-communicable diseases stream of the 2022 EU4Health work programme.

MEP Ondřej Knotek added that more awareness on CKD is needed at the policy level. The Parliamentary debate on CKD that took place in March 2022 during the European Parliament Plenary Session was a successful first step. MEP Knotek stressed that EKHA and the MEP Group for Kidney Health, together with all kidney health stakeholders, should build on this momentum. **Notably, he suggested to launch a motion for resolution in the European Parliament, and demand that the European Commission come up with concrete actions to improve the burden of CKD.** MEP Knotek noted that, as a member of the MEP Group for Kidney Health, he will give high political priority to securing the funding urgently needed to achieve innovation in KRT.

Paul T. Conway gave insights into the advocacy process that led to kidney disease being high on the US political agenda. Mr. Conway underlined that **listening to patients is the most powerful activator for advocacy.** He explained that the AAKP is used to working with US elected leaders, and have assembled a Board of Directors with a tremendous background in politics. The AAKP decided to hold elected leaders accountable, to impact research, and help allies in the private sector get the patient data needed for creating human-centric designs. The AAKP relied on technologies such as social media and high-impact media to work with elected leaders to formulate the agenda, the budget priorities, and give a voice to patients.

Dr. Murray Sheldon emphasized that kidney disease is a worldwide problem. CKD is expected to become the 5th cause of death globally by 2040 and 14.5 million people will be affected. Yet only a third will be treated due to economic, social and political factors. This will contribute tremendously to the financial and ecological burdens worldwide. Dr. Sheldon stated that CKD prevalence is increasing rapidly in countries with emerging economies that do not have the ability to handle the oncoming onslaught. Worldwide issues require worldwide efforts, stated Dr. Sheldon. **His vision is to bring a wide range of diverse expertise from all over the world to work together to develop a variety of implantable artificial kidneys, and manufacture sufficient quantities for all kidney disease patients on earth.** Dr. Sheldon stressed that to have an impact on ecology, alternatives to dialysis must be developed.

Paul T. Conway congratulated the international consortium that is being put in place between the US Kidney Caucus, EKHA, and the MEP Group for Kidney Health. There is a strong basis at the government level to collaborate on kidney health, but patients have a key role to play and the power to bring the burden of kidney disease to the table faster.

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Concluding remarks



Prof. Vanholder thanked all speakers and participants for their important contributions. He stressed the need for more patient stories as these show the reality of patients and urgency for innovative kidney disease treatments. Prof. Vanholder emphasised the pressing need of developing technological innovation, both from the patient, society and environment perspectives. He thanked MEP Vautmans and MEP Knotek for their strong support and willingness to move things forward at the EU level.

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