

European Kidney Forum 2025: "Early Detection, Better Outcomes – Advancing Kidney Disease Screening in the EU"

28 January 2025, European Parliament, Brussels

Summary Report



On 28 January 2025, the European Kidney Health Alliance (EKHA) and the MEP Group for Kidney Health hosted the 2025 European Kidney Forum: **"Early Detection, Better Outcomes: Advancing Kidney Disease Screening in the EU."** This event, moderated by Tamsin Rose, aimed to spotlight the role of early detection in preventing the progression of kidney diseases, improving patient outcomes, and strengthening healthcare systems. The discussions focused on the integration of kidney disease prevention into the EU's broader health policies and strategies, particularly in relation to the links between other non-communicable diseases (cardiovascular diseases, diabetes) and chronic kidney disease (CKD). The Forum gathered insights from European Union policymakers, healthcare professionals, patient advocates, and others to consider the great value that EU action can bring in addressing kidney diseases. This hybrid meeting took place in the **European Parliament in Brussels, Belgium**, and was **co-hosted by Members of the European Parliament (MEPs) Tomislav Sokol, András Kulja, and Hilde Vautmans**.

Opening Statements

MEP Tomislav Sokol (EPP, Croatia), Member of the Committee on Public Health (SANT), opened the Forum by discussing the increase in EU support of healthcare compared to before 2019. However, MEP Sokol pointed out that this support is losing momentum. He emphasised the importance of continuing the

"What is important is that we maintain the level of public debate here in Parliament. The more stakeholders are involved and active—not only at the EU level but also at the national level—the greater the chance for healthcare to remain a priority for the EU."

- Tomislav Sokol, MEP

conversation on healthcare within the European Parliament and at the Member State level to ensure it remains a priority across all areas of policymaking.

In his concluding remarks, MEP Sokol highlighted the importance of the creation of the newly formed Public Health Committee, which was previously a Parliamentary subcommittee under the Committee on Environment, Public Health and Food Safety (ENVI). Health was often seen as a secondary policy issue in the past, he noted, but with the creation of the SANT Committee, there are now opportunities to discuss a broader range of topics, including kidney health.



Session 1: Improving Kidney Disease Screening in the EU

❖ Testimonial: Experience from Rare Kidney Disease Patients

Ms. Marianne Silkjær Nielsen (Founder, CompCure) delivered a powerful testimonial, sharing her young daughter's experience suffering from a rare kidney disease to highlight the lack of diagnostic options and of specialised treatment for people with rare kidney conditions. She recounted numerous unsuccessful medical visits and therapies that provided no diagnosis but caused significant side effects. While the nephrologists involved in her daughter's treatment were highly skilled, Ms. Silkjær Nielsen noted that they lacked the evidence base necessary for optimal clinical decision-making.

This experience led to the founding of CompCure, now the largest registry for the rare kidney diseases C3 Glomerulopathy (C3G) and Immune Complex Membranoproliferative Glomerulonephritis (IC-MPGN). The organisation's mission is to increase awareness of these diseases to improve specialised diagnosis and treatment. Ms. Silkjær Nielsen explained that while these kidney diseases are rare, the diagnostic journey is not unique. It results in emotional and physical turmoil not only for those directly affected but also for their family members.

She concluded her remarks by presenting four policy recommendations:

"The care we provide to patients makes a huge difference, and we must ensure structured access to diagnosis and treatment."

- *Marianne Silkjær Nielsen,
Founder of CompCure*



- 1) the expansion of early-detection screening programs
- 2) improved access to expert care
- 3) greater availability of medications and clinical trials
- 4) the inclusion of kidney health in public healthcare plans.

❖ **The ABCDE model as a best practice for the EU**

Professor Alberto Ortiz (Chair of the Registry and Renal Science; Chair-elect, European Renal Association) discussed the “ABCDE” method of kidney disease prevention, which translates to **A**lbuminuria, **H**igh **B**lood Pressure, **H**igh **C**holesterol, **D**iabetes, and **E**stimated Kidney Function. These five key points are necessary aspects in detecting and testing (for) CKD. Professor Ortiz noted that starting the relevant therapies based on albuminuria levels when kidney filtration function is still normal can delay the need for dialysis for approximately two years, as opposed to waiting until kidney function has significantly declined. Implementing early diagnosis and prevention of CKD via the ABCDE approach should be recommended by the EU to Member States, as the model aligns with the EU’s commitment to address noncommunicable diseases in an integrated manner. Professor Ortiz noted that sometimes the best practices can be those with the lowest cost, especially overall costs, specifically mentioning testing for albuminuria, which is cost-effective within the preliminary screening process. Professor Ortiz concluded by showcasing inspiring examples from Spain, where the city of Madrid is developing a urine and blood screening program modelled on the colon cancer screening program, and the Netherlands, where the possibility for home-based screening for albuminuria is being studied.



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- *Alberto Ortiz, Chair of the Registry and Renal Science; Chair-elect, European Renal Association*

❖ Example of multistakeholder and cross-border collaboration with the PREVENTCKD Project



Ms. Eveline Scheres (General Manager, EKHA) highlighted the EU4HEALTH-funded PREVENTCKD project as a key initiative aimed at raising awareness about kidney disease and its prevention. The project is an acknowledgement of the urgent need to create awareness on the high negative impact of chronic kidney disease on people and the planet, and on the costs associated with CKD. The project aims to create a framework for the early detection and prevention of CKD by gathering data, raising awareness, and implementing screening campaigns. Ms. Scheres noted that CKD had previously been overlooked in discussions about non-communicable diseases. However, in recent years, the European Commission has given CKD a greater priority. One of the outputs of the PREVENTCKD project is the upcoming launch of the European Kidney

Health Code, which will be a comprehensive document designed to inform EU policymakers, healthcare professionals, patients, and the general public about the risks of CKD and ways to prevent or slow its progression.

To ensure the success of these initiatives, Ms. Scheres stressed that policymakers must prioritise CKD as a public health issue. This includes allocating resources for national and local screening programs, ensuring the availability of accurate data to inform decision-making, and fostering multistakeholder collaboration. She emphasised the importance of EU coordination and highlighted successful partnerships and cross-border initiatives within the PREVENTCKD project. In her concluding remarks, Ms. Scheres noted that while the PREVENTCKD project is nearing completion, with great first steps in CKD prevention already taken and mapped, it is crucial to continue building momentum and turn these ideas into actionable policy outcomes.

❖ Testing for CVD, diabetes, and kidney disease – Benefits of joint screening approaches

Dr. Susan Connolly (Consultant Cardiologist, University Hospital Galway, Ireland) began her intervention by discussing Ireland's National Chronic Disease Management Program, highlighting three primary care programs that focus heavily on early prevention and treatment. One of these programs incentivises general practitioners (GPs) to screen patients who may come in for unrelated reasons but are identified as being at potential risk for cardiovascular disease or diabetes. Dr. Connolly also outlined a primary prevention program for patients confirmed to be at high risk for these noncommunicable diseases, as well as a treatment program for patients with established conditions, which takes a more hands-on, intensive approach.

Recently, CKD has been incorporated as the fourth disease area into Ireland's Chronic Disease Management Programs, made possible due to the shared risk factors and symptoms between CKD, diabetes, and cardiovascular disease. Dr. Connolly also discussed the work of community hubs in Chronic Disease Management Programs, where there is greater opportunity for multidisciplinary collaboration in an easily accessible environment outside the hospital. She emphasised that these hubs offer patients a much more integrated care team and system, providing a broader scope of disease management and a more streamlined approach compared to what is typically offered in hospital settings.



“Noncommunicable diseases often occur together, and it is important to have an approach that addresses them holistically. Diseases do not exist in silos. An integrated approach is needed, one that puts the person at the center, rather than focusing solely on one disease.”

- Elisabeth Dupont, Regional Manager, IDF Europe

Ms. Elisabeth Dupont (Regional Manager, IDF-Europe) began by noting the growing link between diabetes and CKD, emphasising the importance of screening and diagnosis for both conditions to provide the best quality of life for patients. Ms. Dupont stressed that diseases do not exist in silos and highlighted the need for a

more integrated approach that focuses on patients' specific experiences, rather than solely on their disease. She also discussed how noncommunicable diseases often occur together, advocating for an approach that addresses and screens for all major health risks simultaneously.

Session 2: Policy Meets Prevention: What's Next on the Agenda for Kidney Health?

❖ Kidney health in past and upcoming EU presidencies

Ms. Kitti Almer (Public Health Attaché, Hungarian Permanent Representation to the EU) noted that during Hungary's six-month Presidency of the Council of the European Union, noncommunicable diseases were a key focus. Ms. Almer thanked EKHA, which played an important role in shaping the Council Conclusions on organ donation and transplantation. She explained that the negotiation process for these conclusions was efficient and secured a commitment from the European Commission to update the 2009-2015 EU Action Plan on Organ Donation and Transplantation.



At the same time, Council Conclusions on cardiovascular diseases highlighted the connections between CVDs, kidney disease, and diabetes. The newly appointed EU Commissioner for Health and Animal Welfare, Olivér Várhelyi, announced a European-level cardiovascular action plan, a first of its kind. While the plan specifically focuses on cardiovascular diseases, Ms. Almer stressed that it will also address kidney disease and diabetes, given the interconnected nature of these noncommunicable diseases. Echoing Ms. Dupont's earlier comments, she emphasised that these diseases do not occur in isolation and that patient-centered care should take precedence over a disease-focused approach.

❖ Kidney disease on the global public health agenda

Dr. Valérie Luyckx (University Children's Hospital and Department of Public and Global Health, Epidemiology Biostatistics and Prevention Institute, University of Zurich, Switzerland) presented 2021 data from the World Health Organisation, which showed that kidney disease was the ninth leading global cause of death, with the number of people dying from kidney disease increasing by 95% between 2000 and 2021. Dr. Luyckx also cited the Global Burden of Disease study, which estimated that around 674 million people worldwide are living with chronic kidney disease, yet this burden has remained largely without appropriate measures.



Dr. Luyckx highlighted the strong correlation between CKD, hypertension, and diabetes, noting that only 40% and 60% of patients affected by diabetes and hypertension are diagnosed as such. Those who remain untreated are at a higher risk for kidney disease. She also explained that, while kidney care is available in most parts of Europe, kidney disease remains the leading cause of catastrophic health expenditure in regions outside Europe.

In conclusion, Dr. Luyckx cited the United Nations’ Sustainable Development Goals, noting that all 17 goals impact kidney health. She emphasised the need to focus on global and planetary health to support not only kidney diseases but also other health challenges.

❖ **Looking ahead: Opportunities for kidney health in the new EU mandate**

MEP András Kulja (EPP, Hungary), a member of the European Parliament’s SANT Committee, began by sharing his background as a surgeon before transitioning into politics. With the creation of the SANT Committee, MEP Kulja hopes that the European Parliament will be better positioned to address healthcare shortages and the devastating effects of chronic illness, fostering a more comprehensive approach to these issues. Raising awareness among fellow MEPs is also crucial to bringing greater attention to the problem, he highlighted.



In relation to kidney disease, MEP Kulja emphasised the importance of numbers, especially those related to the staggering costs per patient, in presenting the issue more clearly. Furthermore, MEP Kulja discussed the power of education, particularly its role in counteracting misinformation.

He concluded by stressing that to increase the impact of prevention efforts, a level of trust must be established within society—something that educational initiatives and transparent healthcare programs can foster.

❖ **Policy recommendations to improve early detection – EKHA’s wish list to decision makers**

Mr. Daniel Gallego (President, European Kidney Patients’ Federation [EKPF]) shared his personal experience as a dialysis patient, noting that he will mark 30 years on dialysis in 2025. While expressing gratitude for the transplant he received (despite unsuccessful) and the treatment he has had so far, Mr. Gallego emphasised that kidney replacement therapies remain inadequate due to organ shortages, the risk of transplant rejection and the numerous issues associated with dialysis. He stressed the importance of elevating CKD on the public health agenda to address prevention and early detection, which could help avoid the need for kidney replacement therapy and provide patients with a better quality of life.



Mr. Gallego highlighted the value of raising awareness and educating people about CKD and kidney function, especially in schools and on a global scale. He also referred to Professor Ortiz’s ABCDE model for early detection and Dr. Connolly’s primary-care approach to delay the progression of chronic kidney disease. In conclusion, Mr. Gallego pointed to the potential of AI in identifying risks that might not be immediately recognised by physicians and underlined the importance of CKD data to engage MEPs and translate the issue into a political focus.

❖ **Personal Testimonial**

Ms. Tülin Sahin, a Danish-Turkish model and presenter, is also a strong advocate for kidney health, with a personal connection to the disease through her mother, who is a kidney patient and recently received a transplant. She shared her experience of her mother being on dialysis, highlighting that kidney disease does not only affect the individual but the entire family. She expressed her commitment to continuing her advocacy efforts by highlighting the fact that she was filming the discussions at the forum and reception for her TV show, which reaches more than 7 million Turkish-speaking viewers in Turkey and around the world.



Concluding Remarks

Professor Raymond Vanholder (EKHA President) described CKD as a "silent killer," noting that the disease often progresses undetected, causing irreversible damage before it is diagnosed. To improve prevention, lifestyle changes are necessary, particularly addressing obesity, alcohol consumption, and smoking, which contribute to CKD. Professor Vanholder also pointed to issues not directly addressed at this year's European Kidney Forum, such as the impact of pollution and climate change, and the need to prevent as much as possible the functional deterioration of transplanted kidneys, which also includes the development of innovative approaches allowing for better preserving the longevity of transplanted kidneys than is currently the case.



He emphasised the value of the ABCDE model, particularly the testing for albuminuria, which is an effective and cost-efficient tool for early detection that should be systematically implemented. Education for both healthcare professionals and the general population is crucial for advancing policy on early detection and prevention. In conclusion, Professor Vanholder stressed the importance of increased funding to enhance awareness, screening, innovation, and research in the fight against CKD.

MEP András Kulja thanked EKHA and the audience for the opportunity to co-host the event (together with MEP Sokol), and for EKHA's contribution and dedication to advancing kidney health across Europe. Grateful for the exchange of experiences, ideas and knowledges between patient associations, healthcare professionals, industry and policy makers, MEP Kulja hopes to create a solid foundation to advance these issues further and move towards a better and healthier Europe.

❖ **Networking Reception**

Following the European Kidney Forum's Policy Roundtable, MEP Hilde Vautmans (Renew, Belgium) hosted a networking reception in the European Parliament's Spaak Building in Brussels. At this reception, MEP Vautmans, in her role as Acting Chair of the MEP Group for Kidney Health, along with co-hosting MEPs Tomislav Sokol and Andras Kulja, as well as MEP Adam Jarubas (EPP, Poland), Chair of the Parliament's SANT Committee, delivered remarks. The occasion also marked the official relaunch of the MEP Group for Kidney Health for the 2024–2029 EU political term.

During the reception, Ms. Marion Braks, a member of the EU4Health-funded PREVENTCKD Project, in which EKHA is involved, presented the European Kidney Health Code.

The exhibition also featured virtual reality headsets offering an immersive experience and showcasing how medical education about rare renal diseases is being taken to the next level. Informative posters highlighted key statistics, screening efforts, including a landmark campaign on the importance of early detection featuring Tina Turner, and the history of dialysis as kidney disease's most utilised treatment.



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