European Kidney Health Alliance

Kidney Manifesto

 An EU strategy to improve kidney care during the 2024-2029 mandate



- An EU strategy to improve kidney care during the 2024-2029 mandate

Endorsers



1. Association for the Use of Artificial Kidneys Paris (AURA Paris)



2. Association of Nephrologists of Bosnia and Herzegovina.jpg



3. Cardiorenal Forum



4. Dutch Kidney Foundation (DKF)



5. Dutch Kidney Patients Society (NVN)



6. Dutch-speaking Belgian Society of Nephrology (NBVN)



7. European Kidney Patients' Federation (EKPF)



8. European Liver Patients' Alliance (ELPA)



 European Dialysis and Transplant Nurses Association/ European Renal Care Association (EDTNA/ERCA)



10. European Rare Kidney Disease Reference Network (ERKNet)



11. European Renal Association (ERA)



12. European Society for Organ Transplantation (ESOT)

- An EU strategy to improve kidney care during the 2024-2029 mandate

Endorsers



13. European Society for Paediatric Nephrology (ESPN)



14. Federation of European Patients Groups affected by Rare/Genetic Kidney Diseases (FEDERG)





15. German Society of Nephrology (DGfN)



16. Institute of Biomedical Research of Salamanca (IBSAL)



17. International Diabetes Federation Europe (IDF Europe)



18. Kidney Health Outcomes-Oriented Cooperative Research Networks (RICORS 2040)



19. Lithuanian Kidney Foundation



20. National Association of Hemodialysis Dialysis and Transplantation Onlus (ANED-Onlus)



21. Polycystic Kidney Disease France (PKD France)



22. Portuguese Kidney Patients Association (APIR)



23. Renaloo



24. Russian Dialysis Society

- An EU strategy to improve kidney care during the 2024-2029 mandate



25. Spanish Federation of Kidney Patients (ALCER)



26. Spanish National Transplant Organisation (ONT)



27. Swedish Society of Nephrology



28. The International Society of Nephrology (The ISN)



29. University of Salamanca



30. Working Group on Renal and Vascular Prevention of the Spanish Society of Nephrology

Industry endorsers



1. Astellas Pharma



2. Hansa Biopharma



3. Novo Nordisk

- An EU strategy to improve kidney care during the 2024-2029 mandate

Individual endorsers

- 1. Dr. Fernanda Ortiz (Adjunct Professor, University of Helsinki; Chief of the Outpatient Clinic of Nephrology, Helsinki University Hospital; Board Member, European Society of Organ Transplantation)
- 2. Prof. Nicolas Roberto Robles (Full Professor of Nephrology, Universidad de Extremadura; Head, Nephrology Department and Hypertension Unit, Hospital Universitario de Badajoz, Spain)
- 3. Prof. Pierre Ronco (Professor of Nephrology, Sorbonne University; Director, Renal Division and Research Unit, INSERM Unit 1155, Paris, France)
- 4. Prof. Vladimír Tesař (Head, Department of Nephrology, General University Hospital, Charles University, Prague, Czech Republic)
- 5. Dr. J. Emilio Sánchez Álvarez (Head of Nephrology Department, Hospital Universitario Central de Asturias, Oviedo, Spain; Current President, Spanish Society of Nephrology).

European Kidney Health Alliance

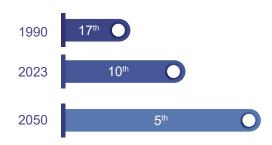
Kidney Manifesto

- An EU strategy to improve kidney care during the 2024-2029 mandate

We call on the European Commission, European Parliament and Council of the European Union to: 1) recognise kidney disease as a public health emergency 2) prioritise kidney health in relevant initiatives 3) work towards the adoption of an ambitious EU policy plan on kidney health

Chronic kidney disease (CKD) is one of the highest-burden non-communicable diseases (NCDs).

CKD is currently the 9th leading cause of death globally, up from 17th in 1990^{1,2}.



IF WE DON'T ACT NOW CHRONIC KIDNEY DISEASE WILL BECOME THE 5TH LEADING CAUSE OF DEATH BY 2050⁵.

CKD is expensive to treat.

Annual healthcare costs reach



CO:

CKD is associated with a substantial environmental burden.

Dialysis consumes enormous amounts of water⁹, generates lots of plastic waste^{10,11}, and is responsible for up to 50% of healthcare greenhouse gases emissions¹².

Worldwide more than **850 million** individuals have kidney diseases³.



Patients suffer from poor quality of life due to the many side-effects of treatments.



This results in significant productivity losses, with unemployment rates in patients with CKD reaching up to

75%_{6,7}.

CKD suffers from a blatant lack of recognition in European health policies and initiatives.

This results in a lack of awareness and absent prevention measures, late diagnosis, gaps in funding for research and innovation and poor patient outcomes.

- An EU strategy to improve kidney care during the 2024-2029 mandate

The European Kidney Health Alliance identified three key priorities to improve kidney health and tackle the longstanding challenges everywhere in Europe.

Improve the primary and secondary prevention of kidney disease

CKD's main risk factors are hypertension, cardiovascular diseases (CVDs), diabetes, obesity, environmental pollution, dehydration, cancer therapies, infections (e.g., covid-19) and acute kidney injury. Many of these risk factors are gaining in importance in our societies, leading to a continuous increase in CKD prevalence and burden across EU Member States¹³. Now already, the share of global healthcare expenditure of kidney daily care is proportionally 10-20 times higher than the proportion of patients treated14, and this figure will only worsen if the current model is maintained. The EU should play a key role in improving and harmonizing CKD prevention measures across Member States to reverse this worrying trend. If CKD is diagnosed and treated early, kidney failure, cardiovascular complications and death can be postponed by 15-25 years 15,16. It is worthwhile to note that around 11.9 % of adults and most children with kidney failure have a rare kidney disease. Yet, screening and early diagnosis for rare kidney diseases remain challenging, as a consequence of poor awareness and inadequate diagnostic tools. Urgent action is needed in this area, as early intervention allows control over lifestyle measures and the uptake of therapeutics, delaying the need for dialysis^{17,18}. In addition, CKD early detection aligns with that of hypertension, diabetes and CVDs, and integrating CKD into these disease programmes is a low hanging fruit for improving NCD prevention. Considering the significant environmental impact of dialysis, reducing CKD prevalence will also help improve the sustainability of healthcare systems.

Furthermore, preventive medicine in nephrology must prioritise the elderly, whose numbers are rapidly growing due to global population aging. Hypertension, a common condition among older adults, is a major risk factor for declining kidney function. Efforts to preserve kidney health in this population should focus on preventing acute kidney injury, which is increasingly recognised as a significant driver of chronic kidney disease among the elderly. The rising prevalence of acute kidney injury in this age group highlights an urgent need for targeted preventive strategies.

► Facilitate the implementation of an EU initiative for CKD prevention

An EU initiative for CKD prevention, focusing on both modifiable risk factors and early detection, could tremendously help avoid or slow down the onset of disease and delay the need for kidney replacement therapy (KRT). The EU CKD initiative must contain measures to improve general population's awareness, access and participation in screening programmes as well as joint health checks for co-occurring diseases such as CVDs and diabetes. The EU4Health project 'PreventCKD', which aims to define the best preventive interventions to tackle CKD, could serve as a basis for this initiative. The EU CKD initiative could be part of a comprehensive EU action plan on CKD or a wider NCD framework, which would provide a unified guide to best practices for the prevention, diagnosis and management of NCDs.



Recommendation for action

- Systematically integrate CKD into the EU's NCD prevention programmes for 2024-2029, including those focused on hypertension, cardiovascular health, and diabetes.
- Develop and implement an EU NCD Framework, which includes an EU initiative for CKD prevention by 2029.

- An EU strategy to improve kidney care during the 2024-2029 mandate

Improve organ donation and transplantation in the EU

A substantial number of NCD patients evolve to organ failure, for which transplantation is often the only life-saving option¹⁹. Even for CKD patients, where dialysis exists as an alternative, kidney transplantation is considered as the best and most cost-effective therapy²⁰. Between 2009 and 2015, the EU action plan on organ donation and transplantation achieved considerable success by augmenting organ availability, enhancing efficiency and accessibility of transplant systems and improving quality and safety across Europe²¹. However, improvements have stalled since then, while the need of transplanted organs has continued to rise²².

Over the period of the EU action plan on organ donation and transplantation:



► Update the EU Action Plan on Organ Donation and Transplantation

A comprehensive update of the EU action plan on organ donation and transplantation would help harmonise different approaches among countries, facilitate coordination and monitor progress²³. The action plan would also be a good lever to stimulate research and innovation in line with the 2024 Council Conclusions on enhancing organ donation and transplantation to increase the effectiveness of transplantation, thereby improving long-term transplant survival, and reducing waiting times in the EU²⁴. The need for up-to-date and bold action on organ donation and transplantation benefits from a large support and has a strong scientific basis:

- A European Commission's impact study assessed the success of the first EU action plan and reaffirmed the need and added value of a new, adapted plan²⁵.
- Member States noted that the first action plan helped them improve national approaches and set a shared agenda²⁶.
- More than 91 stakeholders, including civil society, national competent authorities and MEPs called on the EU institutions at several instances to realise a second EU action plan^{27,28}.



Recommendation for action

• Develop a comprehensive update of the EU action plan on organ donation and transplantation in the 2024-2029 mandate, including clear objectives, targets, monitoring plans and solid funding, in line with the 2024 Council Conclusions on enhancing organ donation and transplantation.

- An EU strategy to improve kidney care during the 2024-2029 mandate

Foster innovation in kidney therapies

In 2023, a European Commission study defined kidney disease as a "high-burden under-researched medical condition", meaning that it receives insufficient research funding relative to its burden²⁹. Indeed, the basic concept of dialysis has barely changed since the 1940s, and all other KRTs and pharmacological approaches to delay progression of kidney failure have progressed at an incredibly slow pace³⁰. Likewise, innovation in therapies for rare kidney diseases has been lagging. The efficacy of accepted therapies may differ per individual, while some rare kidney diseases are without therapeutic options31. This inertia does not only affect patients, who suffer from poor quality of life, but also healthcare systems, which must bear the elevated costs of current KRTs. The substantial carbon footprint of dialysis is just another reason why new treatments are urgently needed. Despite this blatant gap, kidney diseases are missing from the key research areas list of the European Commission³².

Stimulate partnerships for innovative kidney therapies

The cost and burden of CKD should be equally matched with research and innovation investments. The EU should support diverse funding mechanisms to stimulate the development of innovative drugs, devices, and preventive strategies for kidney care. This would not only restore the EU's position as a global leader in medical innovation but also reduce dependence on other countries for new therapies.33 As an example, the Innovative Health Initiative (IHI) could play an essential role by including innovation in kidney therapies, prevention, and early detection among IHI call topics. Similarly, Horizon Europe's 'Health' cluster should include calls for proposals aimed at new, innovative kidney therapies, considering the great promise of xenotransplantation³⁴ and new wearable and implantable artificial kidney systems³⁵. Looking ahead, the Next Framework Programme (FP10) should also prioritise kidney disease research, encouraging investment in both therapeutic and preventive innovations.



Recommendation for action

- Dedicate at least two calls for proposals to innovative kidney therapies, including one on organ donation and transplantation research, in the Horizon Europe annual work programmes 2024-2029.
- Dedicate two IHI calls for proposals to innovative kidney therapies in 2024-2029.

- 1. Vanholder, Raymond, et al. "Fighting the unbearable lightness of neglecting kidney health: the decade of the kidney." Clinical kidney journal 14.7 (2021): 1719-1730
- 2. Karolinska Institutet, Chronic Kidney Disease a growing threat against global public health. Published in 2020, updated in 2021.
- 3. Kitty J Jager, Csaba Kovesdy, Robyn Langham, Mark Rosenberg, Vivekanand Jha, Carmine Zoccali, A single number for advocacy and communication—worldwide more than 850 million individuals have kidney diseases, Nephrology Dialysis Transplantation, Volume 34, Issue 11, November 2019, Pages 1803–1805, https://doi.org/10.1093/ndt/gfz174
- 4. Vanholder, Raymond, et al. "Fighting the unbearable lightness of neglecting kidney health: the decade of the kidney." Clinical kidney journal 14.7 (2021): 1719-1730.
- 5. Vollset, Stein Emil, et al. "Burden of disease scenarios for 204 countries and territories, 2022–2050: a forecasting analysis for the Global Burden of Disease Study 2021." The Lancet 403.10440 (2024): 2204-2256.
- 6. Danuser, Brigitta, et al. "Employment 12 months after kidney transplantation: an in-depth bio-psycho-social analysis of the Swiss Transplant Cohort." PLoS One 12.4 (2017): e0175161.
- 7. Đukić, M., & Zibar, L. (2019). Employment in patients with renal replacement therapy. Southeastern European Medical Journal: SEEMEDJ, 3(1), 11-20.
- 8. Ortiz, Alberto. "RICORS2040: the need for collaborative research in chronic kidney disease." Clinical kidney journal 15.3 (2022): 372-387.
- 9. Rope, Robert. "Green Dialysis: What to Do with Discarded Water Used during Dialysis?" Renal Fellow Network (2018). Accessible from www.renalfellow.org/2016/12/08/green-dialysis-what-to-do-wi/.
- 10. Agar, John WM. "Green dialysis: the environmental challenges ahead." Seminars in dialysis. Vol. 28. No. 2. 2015.
- 11. Blankestijn, Peter J., et al. "Lancet Countdown paper: what does it mean for nephrology?." Nephrology Dialysis Transplantation 34.1 (2019): 4-6.
- 12. Malik, A., Lenzen, M., McAlister, S., & McGain, F. (2018). The carbon footprint of Australian health care. The Lancet Planetary Health, 2(1), e27-e35.
- 13. Ibid.
- 14. Vanholder, Raymond, et al. "The European kidney health alliance (EKHA) and the decade of the KidneyTM." Nephrology Dialysis Transplantation 38.5 (2023): 1113-1122.
- 15. Heerspink, Hiddo JL, et al. "Estimated lifetime benefit of novel pharmacological therapies in patients with type 2 diabetes and chronic kidney disease: A joint analysis of randomized controlled clinical trials." Diabetes, Obesity and Metabolism 25.11 (2023): 3327-3336.
- 16. McEwan, Phil et al. "Extrapolated longer-term effects of the DAPA-CKD trial: a modelling analysis." Nephrology, dialysis, transplantation: official publication of the European Dialysis and Transplant Association European Renal Association vol. 38,5 (2023): 1260-1270. doi:10.1093/ndt/gfac280
- 17. Vanholder, Raymond, et al. "A policy call to address rare kidney disease in health care plans." Clinical Journal of the American Society of Nephrology 18.11 (2023): 1510-1518
- 18. Kidney Research UK. "Treatments could reduce the burden of kidney disease on patients" (2024). Available at: https://www.kidneyresearchuk.org/2024/03/14/study-suggests-rare-kidney-diseases-treatments-could-dramatically-reduce-the-burden-of-kidney-disease-on-patients-and-the-nhs/
- 19. European Kidney Health Alliance (EKHA). "Joint Statement (Thematic Network): A shared vision for improving organ donation and transplantation in the EU." (2019). Accessible from https://ekha.eu/wp-content/uploads/FINAL_Joint-Statement-of-theThematic-Network-on-Organ-Donation-and-Transplantation.pdf

- 21. Bouwman, Renée, et al. "Study on the uptake and impact of the EU Action Plan on Organ Donation and Transplantation (2009-2015) in the EU Member States." European Commission (2017).
- 22. European Kidney Health Alliance (EKHA). "Open letter: Call for a renewed EU action plan on organ donation and transplantation in the 2024-2029 mandate." (2023). Accessible from https://ekha.eu/wp-content/uploads/2023/10/EKHA_Open-letter-on-ODT_October-2023_PDF.pdf
- 23. European Kidney Health Alliance (EKHA), "Joint Statement (Thematic Network): A shared vision for improving organ donation and transplantation in the EU." (2019). Accessible from https://ekha.eu/wp-content/uploads/FINAL_Joint-Statement-of-theThematic-Network-on-Organ-Donation-and-Transplantation.pdf
- 24. European Kidney Health Alliance (EKHA), "Joint Statement (Thematic Network): A shared vision for improving organ donation and transplantation in the EU." (2019). Accessible from https://ekha.eu/wp-content/uploads/FINAL_Joint-Statement-of-theThematic-Network-on-Organ-Donation-and-Transplantation.pdf
- 25. European Commission, Study on the uptake and impact of the EU Action Plan on Organ Donation and Transplantation (2009-2015) in the EU Member States (FACTOR study), November 2017. Accessible from: https://health.ec.europa.eu/system/files/2019-03/2017_euactionplan_2009-2015_impact_exe_en_0.pdf
- 26 Ihid
- 27. EKHA. Open letter: Call for a renewed EU action plan on organ donation and transplantation in 2024-2029 mandate, 09th October 2023: https://ekha.eu/wp-content/uploads/2023/10/EKHA_Open-letter-on-ODT_October-2023.pdf
- 28. EKHA. Open letter: Open letter to EU policymakers: Life after COVID-19: time to realise a second EU action plan on organdonation and transplantation, 13th January 2021: https://ekha.eu/blog/ekha-open-letter-to-eu-policymakers-life-aftercovid- 19-time-to-realise-a-second-eu-action-plan-on-organdonation-and-transplantation/
- 29. European Commission, Directorate-General for Research and Innovation, Tuyl, L., Zinger, N., Heide, I. et al., "Scoping study on evidence to tackle high-burden under-researched medical conditions Discussion paper." Publications Office of the European Union (2023). Accessible from https://data.europa.eu/doi/10.2777/311040
- 30. Vanholder, Raymond, et al. "Fighting the unbearable lightness of neglecting kidney health: the decade of the kidney." Clinical kidney journal 14.7 (2021): 1719-1730.
- 31. Vanholder, Raymond, et al. "A policy call to address rare kidney disease in health care plans." Clinical Journal of the American Society of Nephrology 18.11 (2023): 1510-1518.
- 32. European Commission. "Health Research and Innovation." Research and Innovation. Accessible from https://research-and-innovation.ec.europa.eu/research-area/health_en
- 33. Vanholder, Raymond, et al. "Fighting the unbearable lightness of neglecting kidney health: the decade of the kidney." Clinical kidney journal 14.7 (2021): 1719-1730.
- 34. Financial Times. Transplanted Pig Kidneys provide 'life-sustaining' functions in humans for first time, published on 16th August 2023, https://www.ft.com/content/79a3d940-48c1-4d11-a115-b63fe95d2543
- 35. Ramada, D.L., de Vries, J., Vollenbroek, J. et al. Portable, wearable and implantable artificial kidney systems: needs, opportunities and challenges. Nat Rev Nephrol 19, 481–490 (2023). https://doi.org/10.1038/s41581-023-00726-9

About EKHA

EKHA is a non-profit association created in 2007 to propose solutions for the challenges of chronic kidney disease in Europe. It advocates for effective prevention and a more efficient care pathway intended to facilitate the provision of appropriate and affordable treatment to all Europeans equally, while promoting the highest quality of care. EKHA works on the principle that the issue of kidney health and disease must be considered at European level and that both the European Commission and European Parliament have vital roles to play in assisting national governments with these challenges. Besides the European Renal Association, the European Kidney Patients' Federation, the European Dialysis and Transplant Nurses Association/European Renal Care Association, the Dutch Kidney Foundation, the International Society of Nephrology, the European Society for Organ Transplantation, European Society for Paediatric Nephrology and the European Reference Network for Rare Kidney Diseases (Members of EKHA Board of Directors), over 37 organisations from across Europe are currently affiliated members of EKHA.