

Brussels, 9th October 2023

Open letter

Call for a renewed EU action plan on organ donation and transplantation in the 2024-2029 mandate

*Dear upcoming presidencies of the Council of the EU,
Dear European Commission Directorate General for Health and Food Safety (DG SANTE),
Dear Members of the European Parliament and candidates in the 2024 European elections,*

On European day of organ donation and transplantation, the European Kidney Health Alliance (EKHA), together with the undersigned 25 organisations, is renewing its call for a second EU action plan during the 2024-2029 mandate.

Background

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 Europe¹. Echoing the European Commission's 2017 impact study, the total number of organ donors increased by 17% during the action plan's period, including an increase of 29,5% in living organ donors and of 12% in deceased organ donors². However, these rates have stalled since the end of the action plan³, with some countries even experiencing a decrease⁴, while the need of transplanted organs in Europe continues to rise⁵.

In this letter, we give you the three main reasons why revived action on organ donation and transplantation would contribute to the objectives of the European Health Union and should be on top of your priority list during the next mandate.

Transplantation saves lives and money

In Europe, non-communicable diseases (NCDs) have become a major health issue over the last decades, affecting one in four Europeans and causing 86% of European deaths⁶. A substantial number of NCD patients evolve to a status of terminal and irreversible organ failure⁷, for which transplantation (most commonly of the kidney, liver, heart and lung⁸) is often the only life-saving option. Considered as one of the greatest medical advances of the 20th century⁹, organ transplantation improves quality of life, eliminates debilitating symptoms of chronic organ failure, facilitates social reintegration, and is cost-effective for both patients and healthcare systems¹⁰. Even in end-stage kidney disease, where dialysis as a therapeutic alternative is available on a large scale, transplantation constitutes the best treatment option when feasible¹¹. Importantly, transplantation may have substantial environmental benefits given

¹ 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

² Ibidem

³ Vanholder, R., Domínguez-Gil, B., Busic, M. *et al.* Organ donation and transplantation: a multi-stakeholder call to action. *Nat Rev Nephrol* 17, 554–568 (2021). Accessible from: <https://doi.org/10.1038/s41581-021-00425-3>

⁴ The European Society for Organ Transplantation, Tackling inequalities in organ transplantation: a pathway forward, 2022. https://esot.org/wp-content/uploads/2022/10/EM012518_ESOT_ActionDay_ThinkTankReport_2201005_v0-8_FH.pdf

⁵ European Parliament, Organ donation and transplantation: facts, figures and European Union action, April 2020. Accessible from: [https://www.europarl.europa.eu/RegData/etudes/BRIE/2020/649363/EPRS_BRI\(2020\)649363_EN.pdf](https://www.europarl.europa.eu/RegData/etudes/BRIE/2020/649363/EPRS_BRI(2020)649363_EN.pdf)

⁶ 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-the-Thematic-Network-on-Organ-Donation-and-Transplantation.pdf

⁷ Ibidem.

⁸ Ibidem.

⁹ European Parliament, Organ donation and transplantation: facts, figures and European Union action, April 2020. [https://www.europarl.europa.eu/RegData/etudes/BRIE/2020/649363/EPRS_BRI\(2020\)649363_EN.pdf](https://www.europarl.europa.eu/RegData/etudes/BRIE/2020/649363/EPRS_BRI(2020)649363_EN.pdf)

¹⁰ 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-the-Thematic-Network-on-Organ-Donation-and-Transplantation.pdf

¹¹ European Kidney Health Alliance (EKHA), Open letter: Life after COVID-19: Time to realise a second EU action plan on organ donation and transplantation. January 2021. Accessible from: <https://ekha.eu/blog/ekha-open-letter-to-eu-policymakers-life-after-covid-19-time-to-realise-a-second-eu-action-plan-on-organ-donation-and-transplantation/>

the elevated carbon footprint left by frequent hospitalisations of organ failure patients and the sophisticated technological interventions (such as cardiac support or dialysis) they must undergo¹².

Shortcomings in organ donation and transplantation remain high across the EU

Despite a good European track record in the field of transplantation compared to other continents¹³, the demand for transplantation still far outweighs the supply¹⁴, resulting in **some 18 patients dying every day waiting for a transplant**¹⁵. Furthermore, significant variations in both living and deceased organ donation persist between member states due to the lack of homogenised practices¹⁶. As a consequence, differences in annual organ transplantation rates across the EU remain substantially high, with over 10 fold difference between countries with the highest and lowest annual rates¹⁷. With respect to access, marked inequities can be observed for specific subgroup in societies, including minorities and those with low levels of health literacy¹⁸. This situation was further exacerbated during the COVID-19 pandemic, where a reduction in organ donation and transplantation rates reached as high as 80% in some member states¹⁹.

The call for a second EU action plan is evidence-based and benefits from a large support

The European Commission's impact study on the first EU action plan called for the need and added value of a new, improved plan to cover areas such as communication, education of professionals, exchange of experiences on minorities and new population groups, end-of-life care, and research²⁰. Member states echoed the Commission's study and noted that this action plan helped improve national policy and activity of organ donation by enabling a shared agenda and the exchange of know-how²¹. Several Members of the European Parliament (MEPs) also strongly expressed their support for a renewed action plan, by the means of parliamentary questions²² or public declarations.²³ In 2020, more than 91 stakeholders, including civil society, national competent authorities and MEPs requested the Commission to realise an enhanced action plan without delay²⁴.

Conclusion

It is clear that a new EU action plan on organ donation and transplantation would help harmonise different approaches among countries, facilitate coordination and monitor progress. The action plan would also be a good lever to stimulate research and innovation in order to increase the effectiveness of transplantation and thereby reducing waiting times in the EU. The 2024 European elections, taking

¹² Raymond Vanholder, John Agar, Marion Braks, Daniel Gallego, Karin G F Gerritsen, Mark Harber, Edita Noruisiene, Jitka Pancirova, Giordina B Piccoli, Dimitrios Stamatialis, Fokko Wieringa, The European Green Deal and nephrology: a call for action by the European Kidney Health Alliance, *Nephrology Dialysis Transplantation*, Volume 38, Issue 5, May 2023, Pages 1080–1088. Accessible from: <https://doi.org/10.1093/ndt/gfac160>

¹³ 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-the-Thematic-Network-on-Organ-Donation-and-Transplantation.pdf

¹⁴ European Parliament, Organ donation and transplantation: facts, figures and European Union action, April 2020. Accessible from: [https://www.europarl.europa.eu/RegData/etudes/BRIE/2020/649363/EPRS_BRI\(2020\)649363_EN.pdf](https://www.europarl.europa.eu/RegData/etudes/BRIE/2020/649363/EPRS_BRI(2020)649363_EN.pdf)

¹⁵ 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-the-Thematic-Network-on-Organ-Donation-and-Transplantation.pdf

¹⁶ Ibidem.

¹⁷ Ibidem.

¹⁸ Ibidem.

¹⁹ European Commission, Statement on organ donation and transplantation and the COVID-19 pandemic: EU National Competent Authorities on organ donation and transplantation. June 2020. Accessible from: According to the June 2020 COVID-19 statement of EU National Competent Authorities for Organ Donation and Transplantation. Accessible from: https://health.ec.europa.eu/system/files/2020-07/organs_ncastatement_covid19_en_0.pdf

²⁰ 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

²¹ Ibidem.

²² European Parliament. Parliamentary Question from MEP Manuel Pizarro: "Organ Donation and Transplantation in the EU" (2021). Accessible from : https://www.europarl.europa.eu/doceo/document/E-9-2021-002498_EN.html

²³ Euractiv. "MEP: Revised EU Framework, new action plan for organ donation needed." » (2020). Retrieved from <https://www.euractiv.com/section/health-consumers/news/mep-revised-eu-framework-new-action-plan-for-organ-donation-needed/>

²⁴ European Kidney Health Alliance (EKHA), Open letter: Life after COVID-19: Time to realise a second EU action plan on organ donation and transplantation. January 2021. Accessible from: <https://ekha.eu/blog/ekha-open-letter-to-eu-policymakers-life-after-covid-19-time-to-realise-a-second-eu-action-plan-on-organ-donation-and-transplantation/>

place in a context of global organ shortage crisis, constitute the perfect opportunity to move the dial on this pending measure and bring life-saving changes to patients. The upcoming high-level conference of the Spanish Presidency of the Council of the European Union on global convergence in transplantation²⁵ is a step in the right direction that should inspire the next Commission and Parliament's mandates and priorities of the upcoming EU presidencies.

If not now, when?

Yours sincerely,

Raymond Vanholder, EKHA President, together with the following organisations:

Cooperative European Paediatric Renal Transplant Initiative CERTAIN

Czech Transplant Coordination Centre

Dutch Kidney Foundation

Estonian Nephrological Society

Estonian Society for Biomedical Engineering and Medical Physics

European Dialysis and Transplant Nurses Association/European Renal Care Association

European Kidney Patients' Federation

European Renal Association

European Society for Organ Transplantation

Federation of European Patient Groups affected by Rare/Genetic Kidney Diseases

Francophone Society of Nephrology, Dialysis and Transplantation

German Society of Nephrology

Hellenic Society Of Nephrology

Hungarian Society of Nephrology

International Society of Nephrology

KfH Board of Trustees for Dialysis and Kidney Transplantation e. V.

Kidney Patients Association Netherlands

Latvian Association of Nephrology

Portuguese Society of Nephrology

Renaloo

Russian Dialysis Society

Slovenian Society of Nephrology

Spanish Kidney Research Network

Spanish National Transplant Organization

Swedish Society of Nephrology

²⁵Spanish Presidency Council of the European Union, Towards global convergence in transplantation : sufficiency, transparency and oversight, 9-10 November 2023. Accessible from: <https://spanish-presidency.consilium.europa.eu/en/events/towards-global-convergence-transplantation-sufficiency-transparency-oversight/>



