

# EKHA OPEN LETTER TO EU POLICYMAKERS ON BEHALF OF THE EUROPEAN ORGAN DONATION AND TRANSPLANTATION COMMUNITY

# "LIFE AFTER COVID-19: TIME TO REALISE A SECOND EU ACTION PLAN ON ORGAN DONATION AND TRANSPLANTATION"

Brussels, 13 January 2021

To:

President of the European Commission, Ms. Ursula Von der Leyen, European Commissioner for Health and Food Safety, Ms. Stella Kyriakides, European Parliament President, Mr. David Sassoli Portuguese Minister of Health, Ms. Marta Temido & health attachés of the 27 EU Member States, National Competent Authorities for Organ Donation and Transplantation of the 27 EU Member States

The European Kidney Health Alliance (EKHA), joined by the co-signatories below, herewith renews its call for a Second EU Action Plan on Organ Donation and Transplantation in light of the ongoing COVID-19 crisis and its heavy toll on organ donation and transplantation across the EU Member States.

Organ transplantation is a life-saving treatment for patients with end-stage organ failure, offering a better quality of life at lower societal cost. Even in end-stage kidney disease, where dialysis as a therapeutic alternative is available on a large scale, transplantation constitutes the best treatment option.

Organ donation and transplantation in the EU advanced remarkably between 2009 and 2015, thanks to the momentum achieved by the EU Action Plan on Organ Donation and Transplantation. With strong, proactive support from the Member States, the EU Action Plan helped increase organ availability, enhance efficiency and accessibility of transplant systems and improve quality and safety<sup>1</sup>. However, since the end of the EU Action Plan, progress has levelled off, despite the surging need for transplanted organs<sup>2</sup>. In 2019, EKHA was nominated by the European Commission to lead a Thematic Network on Improving Organ Donation and Transplantation in the EU, which culminated in a multi-stakeholder Joint Statement with policy calls and recommendations to address the following long-standing challenges:

- significant variation in both living and deceased organ donation rates across the EU.
- significant variation in annual organ transplantation rates per million population across the EU, with over tenfold difference between countries with the highest and lowest annual rates.
- marked inequities in access to transplantation for specific subgroups in society, including minorities and those with lower levels of health literacy.
- persistent shortage of available organs, as illustrated by the ever-growing waiting lists and . people deteriorating or dying while awaiting transplantation.
- considerably lower survival outcomes of transplanted patients compared to the general • population, due to complications such as cancer, vascular disease and infections.

The outbreak of the COVID-19 pandemic has exacerbated these existing challenges while bringing to fore the vital role of transplantation once again. During the pandemic, a substantial number of patients that could have been transplanted died while waitlisted, due to dramatic reductions in organ donation and transplantation reaching as high as 80% in some EU countries<sup>3</sup>. Transplants from deceased donors were limited to extremely urgent situations only; while living donation programmes were suspended amid the lockdown and fear of infection further curtailed living donation in many cases.

While plummeting transplantation rates always have profound implications for long-term outcomes, they are particularly alarming in a pandemic context, whereby minimising chronic disease patients' need for hospital visits is of vital concern to reduce their risk of exposure as a highly vulnerable group. It has been shown that during the outbreak, the risk of being infected by COVID-19 was more than 4 times

<sup>&</sup>lt;sup>1</sup> European Commission FACTOR Study on the uptake and impact of the EU Action Plan on Organ Donation and Transplantation (2009-2015) in the EU Member States

 <sup>&</sup>lt;sup>2</sup> See <u>Council of Europe Newsletter Transplant volumes</u> since 2015
 <sup>3</sup> According to the June 2020 <u>COVID-19 statement</u> of EU National Competent Authorities for Organ Donation and Transplantation



**lower for kidney transplant recipients than for haemodialysis patients**<sup>4</sup>. This is mainly because transplant patients can be managed at home, while haemodialysis still mostly takes place in hospital settings. Therefore, **promoting transplantation is integral to fostering future preparedness for other mass infectious disease emergencies** we may likely encounter in the years to come.

On the other hand, **despite lower infection rates, transplant patients infected with COVID-19 have been among the risk groups with the highest mortality**<sup>5,6</sup>, stressing the need for developing approaches towards lowering the risk of infectious morbidity and mortality for transplant recipients. An important means to address this would be giving priority to organ transplant recipients and patients with organ failure on waiting lists in the vaccination campaigns against COVID-19<sup>7</sup>. However, though urgently needed, data on the efficacy and adverse effects of different types of vaccines in transplant populations is currently not available due to their exclusion from clinical studies<sup>8</sup>.

It is clear that we need to act now to stem and turn the tide, by tackling both immediate COVID-19related issues and other persistent problems preceding the pandemic, through a long-term vision. While some excellent recommendations have been made to address the impact of COVID-19, **there remains a pressing need for EU-level guidance and support to Member States in the implementation of these recommendations for lasting improvements**. This goes hand-in-hand with harmonising different approaches among countries, facilitating coordination and monitoring progress.

EKHA therefore fully supports the call for collaborative action articulated in the June 2020 <u>COVID-19</u> <u>statement</u> of the EU National Competent Authorities for Organ Donation and Transplantation, and further urges EU policymakers to move the dial on realising a Second EU Action Plan on Organ Donation and Transplantation, in line with the calls and recommendations of the 2019 EKHA Joint Statement. A comprehensive follow-up EU Action Plan would be best placed to tackle the mounting pressure on national organ donation and transplantation programmes in the face of the COVID-19 pandemic and beyond. The time is now to build on the EU organ donation and transplantation community's achievements the past years, to ensure the maximum benefit for our patients.

Yours sincerely,

Prof. Raymond Vanholder, EKHA President

15

This open letter is part of an EKHA project that has been made possible thanks to an unrestricted educational grant by Astellas Pharma Europe Ltd, who has not influenced the content.

<sup>&</sup>lt;sup>4</sup> Quintaliani, G., Reboldi, G., Di Napoli, A. *et al.* Exposure to novel coronavirus in patients on renal replacement therapy during the exponential phase of COVID-19 pandemic: survey of the Italian Society of Nephrology. *J Nephrol* 33, 725–736 (2020). <u>https://doi.org/10.1007/s40620-020-00794-1</u>

<sup>&</sup>lt;sup>5</sup> Williamson, E.J., Walker, A.J., Bhaskaran, K. *et al.* Factors associated with COVID-19-related death using OpenSAFELY. *Nature* 584, 430–436 (2020). <u>https://doi.org/10.1038/s41586-020-2521-4</u>

<sup>&</sup>lt;sup>6</sup> Coll, E., Fernández-Ruiz, M., Sánchez-Álvarez, J.E. *et al.* COVID-19 in transplant recipients: The Spanish experience. *Am J Transplant* 00, 1-13 (2020). <u>https://doi.org/10.1111/ajt.16369</u>

<sup>&</sup>lt;sup>7</sup> <u>https://www.kidneycareuk.org/news-and-campaigns/news/covid-19-vaccination-adult-patients-kidney-disease/</u>

<sup>&</sup>lt;sup>8</sup> ERA-EDTA Council, ERACODA Working Group, Chronic kidney disease is a key risk factor for severe COVID-19: a call to action by the ERA-EDTA, *Nephrology Dialysis Transplantation*, gfaa314, <u>https://doi.org/10.1093/ndt/gfaa314</u>







# Member of the European Parliament (MEP) Group for Kidney Health

- Brando Benifei (S&D, Italy)
- Biljana Borzan (S&D, Croatia)
- Martin Buschmann (Non-attached, Germany)
- Olivier Chastel (Renew Europe, Belgium)
- Cindy Franssen (EPP, Belgium)
- Rasa Juknevičienė (EPP, Lithuania)
- Peter Liese (EPP, Germany)
- Marian-Jean Marinescu (EPP, Romania)
- Sara Matthieu (Greens/EFA, Belgium)
- · Liudas Mažylis (EPP, Lithuania)

- · Juozas Olekas (S&D, Lithuania)
- · Aldo Patriciello (EPP, Italy)
- · Jutta Paulus (Greens/EFA, Germany)
- Sirpa Pietikäinen (EPP, Finland)
- Manuel Pizarro (S&D, Portugal)
- Karlo Ressler (EPP, Croatia)
- Christel Schaldemose (S&D, Denmark)
- · Annie Schreijer-Pierik (EPP, Netherlands)
- Ruža Tomašić (ECR, Croatia)
- Hilde Vautmans (Renew Europe, Belgium)

## National Competent Authorities

## **Bulgaria**

• Изпълнителна агенция Медицински надзор – Executive Agency Medical Supervision

# Czech Republic

Koordinační Středisko Transplantací (KST) – Coordination Centre for Transplantation

# France

Agence de la Biomédicine – French Agency of Biomedicine

## Ireland

· Deonú agus Trasphlandú Orgán Éireann – Organ Donation Transplant Ireland (ODTI)

# Italy

Centro Nazionale Trapianti – Italian National Transplant Centre

# Lithuania

- Nacionalinis Transplantacijos Biuras prie Sveikatos Apsaugos Ministerijos National Transplant Bureau under the Ministry of Health
- Valstybinė Akreditavimo Sveikatos Priežiūros Veiklai Tarnyba (VASPVT) State Health Care Accreditation Agency under the Ministry of Health

## Malta

Healthcare Standards Directorate

## Portugal

Instituto Português do Sangue e da Transplantação, IP (IPST, IP) – the Portuguese Blood and Transplant Institute
 Slovakia

• Národná Transplantačná Organizácia (NTO) – National Transplant Organisation

## Slovenia

Slovenija-Transplant – Institute of the Republic of Slovenia for the Transplantation of Organs and Tissues

# Spain

Organización Nacional de Trasplantes (ONT) – National Transplant Organization

# Stakeholder Organisations

- · Associação Portuguesa de Insuficientes Renais (APIR) Portuguese Association of Renal Failure Patients
- Balkan Cities Association of Nephrology, Dialysis, Transplantation and Artificial Organs (BANTAO)
- Belgian Society of Nephrology (BVN-SBN)
- Belgian Transplantation Society (BTS)
- Cooperative European Paediatric Renal Transplant Initiative (CERTAIN)
- Czech Transplant Team (CTT)
- Dialysis, Nephrology and Kidney Transplantation Union of Georgia (DNT Union of Georgia)
- Digestive Cancers Europe (DiCE)
- Donation and Transplantation Institute (DTI)
- Eesti Nefroloogide Selts Estonian Society of Nephrology
- Eurocarers
- European AIDS Treatment Group (EATG)
- European Dialysis and Transplant Nurses Association and the European Renal Care Association (EDTNA/ERCA)
- · European Kidney Patients' Federation (EKPF)
- European Liver Patients' Association (ELPA)



- European Network for Smoking and Tobacco Prevention (ENSP)
- European Pain Federation (EFIC)
- European Patients' Forum (EPF)
- European Renal Association and the European Dialysis and Transplant Association (ERA-EDTA)
- European Renal Association and the European Dialysis and Transplant Association Registry (ERA-EDTA Registry)
- European Society for Blood and Marrow Transplantation (EBMT)
- European Society for Organ Transplantation (ESOT)
- European Society for Paediatric Nephrology (ESPN)
- European Society of Intensive Care Medicine (ESICM)
- European Society of Surgical Oncology (ESSO)
- Eurotransplant
- Federación Nacional de Asociaciones para la Lucha Contra las Enfermedades del Riñón (ALCER) Spanish Federation
  of Kidney Patients
- France Transplant
- $\boldsymbol{\cdot}$  Gyvastis Lithuanian Association of Nephrology Patients
- Health First Europe
- Icelandic Renal Association (FÍSN)
- Kidney Care UK
- Lietuvos Inkstų Fondas Lithuanian Kidney Foundation
- Lietuvos Nefrologijos, Dializes ir Transplantacijos Asociacija (LNDTA) Lithuanian Nephrology, Dialysis and Transplantation Association
- Macedonian Society of Nephrology, Dialysis, Transplantation and Artificial Organs (MSNDTAO)
- Magyar Nephrologiai Társaság (MANET) Hungarian Society of Nephrology
- Nederlandse Federatie voor Nefrologie Dutch Federation for Nephrology
- · Nierpatiënten Vereniging Nederland (NVN) Kidney Patients Association Netherlands
- Nierstichting Nederland Dutch Kidney Foundation (DKF)
- Norsk Nyremedisinsk Forening Norwegian Society of Nephrology
- O'zbekiston Nefrologiya Xizmati Uzbekistan Nephrology Service
- PKD International
- Radboud University Medical Centre (Radboudumc)
- Red de Investigación Renal (REDinREN) The Renal Research Network
- The Renal Association
- Shoqata Shqiptare e Nefrologjise Albanian Society of Nephrology
- · Slovenská Transplantologická Spoločnosť (STS) Slovak Transplant Society
- Slovensko Nefrološko Društvo Slovenian Society of Nephrology
- Sociedade Portuguesa de Transplantação (SPT) Portuguese Transplantation Society
- · Società Italiana di Nefrologia Pediatrica (SINePe) Italian Society of Paediatric Nephrology
- Société Francophone de Néphrologie, Dialyse et Transplantation (SFNDT) Francophone Society of Nephrology, Dialysis and Transplantation
- Udruženje ljekara za Nefrologiju, Dijalizu i Transplantaciju bubrega u Bosni i Hercegovini (UNDT BiH) Society of Nephrology, Dialysis and Kidney Transplantation in Bosnia and Herzegovina
- United European Gastroenterology (UEG)
- University of Nicosia Medical School
- Universitair Ziekenhuis Gent (UZGENT) Ghent University Hospital
- Vlaamse Organisatie van het Paramedisch Personeel der Dialyse en Transplantatiecentra (ORPADT Flanders) –
  Organisation of Flemish Renal Nurses
- Ελληνική Νεφρολογική Εταιρεία (ENE) Hellenic Society of Nephrology (HSN)
- Ελληνική Νεφρολογική Εταιρεία Νοσηλευτών (ENEN) Hellenic Nephrology Nursing Association (HENNA)
- Российское Диализное Общество (РДО) Russian Dialysis Society



# **About EKHA**

EKHA is an alliance of European and national societies dedicated to reducing the burden of kidney disease in Europe and improving the outcomes for kidney patients. It brings together patients, nurses, foundations and physicians to provide consensual and authoritative advice to policymakers on all aspects of kidney disease: prevention, treatment, access to care, education and research.

As EKHA, we are committed to sensitising the European Parliament and the Commission to the importance of kidney health, and ensuring that they assist national governments in listening to the needs of the European renal community.

- 🎔 @EKHA\_EU
- & www.ekha.eu
- Subscribe to EKHA's YouTube channel