EKHA Membership

Full Members - founding members of the Alliance:

- **EKPF**: European Kidney Patients’ Federation
- **EDTNA/ERCA**: European Dialysis & Transplant Nurses Association/European Renal Care Association
- **DKF**: Dutch Kidney Foundation
- **ERA-EDTA**: European Renal Association – European Dialysis and Transplant Association
EKHA’s Growing Membership

Affiliate Members - *European national and other non-profit kidney organisations:*

1. **Bosnia:** Society of Nephrology, Dialysis and Transplantation of Bosnia & Herzegovina
2. **Estonia:** Estonia Society of Nephrology
3. **France:** French Speaking Society of Dialysis and Transplantation
4. **Germany:** German Society of Nephrology
5. **Georgia:** Dialysis, Nephrology and Kidney Transplantation Union of Georgia
6. **Italy:** Italian Society of Nephrology
7. **Netherlands:** Dutch Kidney Patients Association
8. **Portugal:** Portuguese Society of Nephrology
9. **Russia:** Russian Dialysis Society
10. **Slovenia:** Slovenian Society of Nephrology
11. **Spain:** Spanish Dialysis Foundation
12. **Spain:** Spanish Society of Nephrology
13. **Turkey:** Turkish Society of Nephrology
EKHA’s New Legal Status

- EKHA has been incorporated as a **Non-Profit Association (VZW) under Belgian law** as of 26 August 2019.

- The new legal status boosts EKHA’s impact and credibility by making it a more independent and transparent entity, with power and mandate to represent the kidney community in policy and strategy fora. Through its new statutes, a clear and efficient framework for good governance for EKHA has been put in place.

- The transition also allows EKHA and its members to benefit from multiple opportunities, such as applying for grants and joining initiatives at the EU level.
EKHA Board of Directors

The activities of EKHA are conducted under the responsibility of its Board of Directors, composed of a designated President and one or two representatives from each full member organisation.

EKHA President: Professor Raymond Vanholder (Belgium)

- EKPF: Mr Coert van Ee (Netherlands)
- EDTNA/ERCA: Ms Edita Noruišienė (Lithuania), Mr Alois Gorke (Germany)
- ERA-EDTA: Professor Carmine Zoccali (Italy),
- DKF: Mr Tom Oostrom (Netherlands), Mr Martijn Ubbink (Netherlands)
Chronic kidney disease (CKD) is a major and growing health burden in Europe. One in 3 Europeans is at an increased risk of developing CKD. A staggering 1 in 10 already has impaired kidney function severe enough to affect their health status. The current rise in diabetes, obesity and ageing will further worsen this situation unless there is greater focus and concerted action by European health policy makers.

Being a ‘silent disease’ with few or no symptoms until it is too late, CKD receives little attention, particularly when compared with other chronic diseases. These Recommendations for Sustainable Kidney Care defined by the European Kidney Health Alliance (EKHA) are a common effort by stakeholders to propose solutions for the challenges of CKD in Europe through 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.

**Burdon of CKD in Europe**

One in 3 Europeans have at least one clinical sign of existing CKD, such as the presence of protein in the urine — an indication of reduced kidney function. Perhaps even more startling is that an estimated 90% of these individuals are unaware they have early-stage CKD, as they experience few or no symptoms.

Nevertheless, from its early stages onwards, CKD is associated with an increased risk of complications and death, to a large extent attributable to an ensuing cardiovascular event. Diabetes is the leading cause of kidney disease, followed by high blood pressure (hypertension). The disease progresses faster by patients with CKD is linked with the effects of these concurrent diseases. Although progress has been made in recent years, end-stage kidney disease kills more people each year than breast cancer, prostate cancer or even road traffic accidents.[1](#)

Globally there was an 82% increase in the number of deaths from CKD between 1990 and 2017.[2](#)

Patients who eventually reach end-stage kidney disease need renal replacement therapy (RRT) via dialysis or kidney transplantation. Data from the European Renal Association-European Dialysis and Transplant Association (ERA-EDTA) Registry shows that the prevalence of people on RRT across Europe increased by 33.9% from 2011 to 2012 to reach 736.7 per million population.[3](#)

In Europe 1 in 10 adults has some degree of kidney disease, but many people don’t know they have it or that they are even at risk.

**What does kidney disease cost?**

The cost of treating CKD is formidable. Hospital-based haemodialysis — the most common form of dialysis — alone costs up to €80,000 per year per patient. Moreover, this does not take into account the lost productivity caused when CKD interferes with a person’s work, or prevents patients from working altogether.

Dialysis is resource-intensive, costing up to €80,000 per year, per patient, depending on the country and method.[4](#)

In general, RRT consumes 2% of overall healthcare expenditure in Europe, for only 0.2% of the population. The total direct cost of RRT across Europe is unknown, but one estimate puts it at up to €13 billion per year. There are additional healthcare costs of co-interventions needed to sustain RRT and to treat its complications, indirect costs associated with the time patients are absent from work while undergoing treatment, and ancillary costs such as transportation to and from the clinic.

These figures also exclude the medical costs incurred before patients reach end-stage CKD — a population estimated to be around 10 times larger than the population on RRT.

In England, for example, the cost of CKD to the healthcare system was estimated at £3.60 to £3.84 billion (2009–2010 prices), representing around 1.3% of all spending.[5](#) Importantly, more than half of this sum was spent on RRT provided for only 2% of the CKD population, illustrating the high cost of RRT.

High costs were also associated with the cardiovascular complications associated with CKD. It was estimated that in one year in England, approximately 7000 excess strokes and 12,000 excess heart attacks occurred in the CKD population, as compared with matched individuals without CKD.

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EKHA supports policies aimed at reducing the variation across the EU in access to organ donation and transplantation.

Key asks:

1. Promotion of **equitable access to transplantation** for all valid candidates, informed by EU-wide strategies

2. Improving **living donor transplantation**, through donor exchange programmes and supportive compensation and legislation

3. Increased awareness of the need to **optimize deceased organ retrieval processes**, through opt out schemes and expanded donation criteria

4. Provision of **appropriate support to Member States**, reflecting the multi-speed and multi-level patchwork that exists across the EU

**Continued focus in 2020 EU Kidney Forum**
2019 European Kidney Forum
25 June, Brussels
2019 European Kidney Forum
Organ Donation and Transplantation in Europe –
Are we meeting the needs of patients?
Brussels, 25 June 2019

• Annual policy event hosted by the MEP Group for Kidney Health.

• Goal: Sharing knowledge and exchanging best practices to improve organ donation and transplantation across Europe and meet patients’ needs.

• Gathered 56 delegates.

• Panel discussion featured speakers from European Commission DG SANTE, Spanish National Transplant Organisation, Ministry of Health of Croatia, European Society for Organ Transplantation (ESOT), Technical University of Munich

• In a live poll, participants called for a second EU Action Plan on Organ Donation and Transplantation.

• Sponsored by Astellas, Amgen, B.Braun, CSL Behring and Vifor Pharma.
Key conclusions:

• While practices and outcomes are diverse, similar challenges prevail in organ donation and transplantation across Europe.

• Solutions lie in sharing good practices, tackling inequities in access, engaging the public as well as political leadership, and improving benchmarking.

• Rather than focusing exclusively on increasing the transplantation rate, greater attention should be placed on fostering quality and enduring outcomes for patients.
Annual Welcome Meeting of Affiliate Members
Presentations about progress, successes & challenges

Mark Murphy
CEO
Irish Kidney Association
*Overview of organ donation and transplantation in Ireland*

Tom Oostrom
Director
Dutch Kidney Foundation
*Overview of organ donation and transplantation in the Netherlands*

Helena Zakharova
President
Russian Dialysis Society
*Overview of organ donation and transplantation in Russia*

Fiona Loud
Policy Director
Kidney Care UK
*Overview of organ donation and transplantation in the UK*
EKHA Policy Actions in 2019
EU Thematic Network on Organ Donation and Transplantation

In 2019, EKHA led a European Commission Thematic Network on Improving Organ Donation and Transplantation in the EU, on DG SANTE’s Health Policy Platform.

The main outcome of this multi-stakeholder thematic network has been a Joint Statement, entitled ‘A Shared Vision for Improving Organ Donation and Transplantation in the EU’.

Throughout the year, EKHA organized two webinars to engage with the Thematic Network Partners by exchanging ideas to further develop the Joint Statement and providing updates on the progress.
The Joint Statement offers a unique opportunity to shape future policy on organ donation and transplantation in Europe, as it comprises actionable policy calls and recommendations to drive efforts at EU, Member State, and stakeholder level.

CALLS:
- Mobilise political will to make organ donation and transplantation a priority
- Improve legal and institutional frameworks
- Streamline organisation and invest in leadership at all levels
- Allocate appropriate funds for organ donation and transplantation programmes
- Promote education and training among all stakeholders
- Eradicate inequities in organ donation and transplantation
- Boost benchmarking
- Leverage research
Endorsers of the Joint Statement

Developed in conjunction with National Competent Authorities, transplant organisations, medical professionals and patient associations, the Joint Statement was endorsed by 54 co-signing organisations and 19 Members of the European Parliament (MEPs).
The Joint Statement was presented to the European Commission on 17 October 2019 at the EU Health Policy Platform Annual Meeting in Brussels (watch full presentation here).
Engagement with the Croatian Presidency of the Council of the EU

• In August 2019, EKHA made an application to the upcoming Croatian presidency of the Council of the EU for next year’s European Kidney Forum to be hosted under the umbrella of the Presidency.

• The application was successful and the Croatian Presidency agreed to sponsor EKHA’s 2020 Kidney Forum on Organ Donation and Transplantation in the EU.

• Accordingly, the 2020 European Kidney Forum will build on the success of the 2019 Joint Statement as well as on the renewed political momentum around organ donation and transplantation, which was declared among the priorities of the Croatian Presidency.
EKHA Presentations

- Presentation by EKHA past-president Norbert Lameire at the EU National Competent Authorities for Organ Donation and Transplantation meeting (February)
- EKHA presentation in EUDONORGAN event (February)
- Presentation by Prof Vanholder in the ADPKD Summit (March)
- Presentation by Prof Vanholder at the annual ERA-EDTA Congress, Budapest and visibility at the ERA-EDTA Booth (June 2019)
- Presentation by Prof Vanholder at the EDTNA/ERCA, Prague (September 2019)
Published in 2019

• ‘How to increase kidney transplant activity throughout Europe—an advocacy review by the European Kidney Health Alliance’ (NDT, August 2019)

• ‘Nephrology and Public Policy Committee propositions to stimulate research collaboration in adults and children in Europe’ (NDT, September 2019)

Forthcoming:

• ‘A call for harmonization of European kidney care: dialysis reimbursement and distribution of kidney replacement therapies’

• Publication on the Joint Statement of the Thematic Network on Organ Donation and Transplantation
Driving the debate around Chronic Diseases

**Key leadership role:** EKHA holds the Chairmanship and Secretariat of the ECDA
ECDA Highlights from 2019

• **Open letters** to Dr. Ursula Von der Leyen, President-Elect of the European Commission; incoming Health Commissioner Stella Kyriakides, and health attachés of upcoming EU Council Presidencies (Finland, Croatia, Germany) explaining the importance of action in chronic diseases

• **Meetings** with Ms Anne Bucher, Director General of DG SANTE to discuss chronic disease prevention at EU level – call for a strategic framework; with Ingrid Keller from DG SANTE to discuss EU Steering group on promotion of prevention

• Project proposal to DG SANTE for **Horizon Europe on the economics of prevention**

• Speaking contribution in the European Parliament on **CHRODIS Plus WP 8 EU policy dialogue on employment and chronic diseases**
EKHA’s Online Presence

- **Regular website updates** on EU policy news and EKHA activities
- **Newsflashes to members** disseminating EU and national news and highlighting relevant events
- **EKHA_EU Twitter handle** with growing number of followers and impressions
2019 Accounts

Secretariat (Interel)  
EUR 38,500.00

Travel and accommodation  
(C. Zoccali and M. Fontana)  
EUR 4,407.21

Salaries (M. Fontana)  
EUR 5,000.00

FINAL TOTAL  
EUR 47,907.21
2020 Budget

Secretariat (Interel)  
EUR 43,425.00

Travel and accommodation  
(C. Wanner and M. Fontana)  
EUR 1,500.00

Salaries (M. Fontana)  
EUR 5,000.00

FINAL TOTAL  
EUR 49,925.00

FINAL BUDGET  
EUR 50,000.00
thank you!