

The European Kidney Health Alliance



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 was created in 2007 and today is led by the following full members



The European Renal Association – European Dialysis and Transplant Association (ERA-EDTA)



The European Kidney Patients' Federation (EKPF)



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



The Dutch Kidney Foundation (DKF)



Full list of our affiliate members
is available on our website:

ekha.eu

Did you know?

As of 2019, EKHA has become a legal entity with greater independence and transparency, allowing it to better represent the EU kidney community. The association status also delivers new benefits for EKHA members, including enhanced opportunities to apply for EU research funding and participate in EU projects.

Join us – Become a member of EKHA!



EKHA welcomes new full and affiliate members. See the last page of this brochure and visit our website for more details on membership options and how to apply:

ekha.eu

Testimonials from our members

THE RUSSIAN DIALYSIS SOCIETY

"The Russian Dialysis Society became an affiliate member of EKHA in 2014 and since 2015, our representatives have been attending the European Kidney Forum every year. Our aims are the same as EKHA's aims: we promote appropriate and affordable treatment for all our citizens, and wish to promote the highest quality of care. Therefore, our membership to EKHA is helpful in addressing many of our challenges in Russia: For instance, EKHA Recommendations for Sustainable Kidney Care are now gradually implemented in our country, and the discussions of the European Kidney Forum have informed our exchanges with healthcare authorities."

Prof. Dr. Elena Zakharova, President

EUROPEAN KIDNEY PATIENTS' FEDERATION (EKPF)

"For over a decade, the EKPF has been a contributing member of EKHA. In our experience, the interests of patients can be best heard through a unified voice. EKHA is that voice, as it represents patients throughout Europe with the aim to improve their quality of life. As patient representatives we believe that our needs must be addressed and tackled by improving knowledge and promoting a dialogue between all stakeholders. Better outcomes are achieved thanks to reliable organizations like EKHA – together, we form a whole that is more than the sum of its parts."

**Coert J.J. van Ee, President
Daniel Gallego, Secretary**

Kidney disease facts and figures

- 1) 1 in 10 Europeans has some degree of impaired kidney function severe enough to impact their health status.
- 2) Kidney disease can be a “silent disease” with few or no symptoms until its later stages.
- 3) Prevalence of Chronic Kidney Disease (CKD) is projected to rise, and by 2040, is set to become the 5th leading cause for years of life lost from disease.¹
- 4) Although only 0.1-0.2% of the general population are patients treated by kidney replacement therapy, this group consumes at least 2% and up to 5-6% of healthcare budgets.²

- 5) Given the surging number of patients, kidney replacement therapy is expected to impose an increasingly heavy burden on the European economy.
- 6) Kidney disease is preventable through addressing lifestyle factors such as optimising nutrition, increasing physical activity, smoking cessation, consuming alcohol responsibly and mitigating environmental factors such as pollution.



1 in 10
Europeans have some degree of kidney disease, but many people don't know it (silent disease)



1 in 5
people with high blood pressure has kidney disease



Transplantation is the preferred treatment and also the cheapest, dialysis costing up to **80 000 €** per year per patient



1 in 3
people with diabetes has kidney disease



EKHA works at EU level to improve kidney care at National level



1. Foreman K.J., Marque, N., Dolgert, A. (2018). Forecasting life expectancy, years of life lost, and all-cause and cause-specific mortality for 250 causes of death: reference and alternative scenarios for 2016–40 for 195 countries and territories. *Lancet* 2018; 392: 2052–90

2. Vanholder, R, Annemans L, Brown E, et al. Reducing the costs of chronic kidney disease while delivering quality health care: a call to action. *Nature Reviews Nephrology* 2017; 13(7):393-409.

EKHA Policy Actions

- 1) **Raise awareness** of the importance of kidney health and of the need for action to improve the early detection of chronic kidney disease.
- 2) **Promote a uniformly high standard of care** for those with kidney disease throughout Europe, by developing consistent strategies for educating and training.
- 3) **Facilitate exchange of information** between the European Kidney Community, the EU institutions and organisations in charge of health policy throughout Europe.
- 4) **Cooperate with EU organisations** in addressing areas linked to kidney disease.
- 5) **Support the development of novel strategies and therapeutic approaches** for the prevention, detection and management of kidney disease through research and its translation into clinical practice.
- 6) **Focus on four main pillars of action:**
 1. prevention and early detection
 2. patient choice
 3. organ donation and transplantation
 4. treatment and reimbursement strategies.

EKHA projects and initiatives

MEP Group for Kidney Health



European Parliament

The MEP Group for Kidney Health brings together a group of Members of the European Parliament (MEPs) committed to improving the policy response to the growing burden of kidney disease in Europe. Active since 2008, the MEP Group

for Kidney Health engages with experts from the kidney community including patients, physicians, researchers, health economists, nurses and European policymakers, to discuss key topics and activities related to kidney health. In this way, MEPs receive valuable information relevant to their current work and are better able to hold the European Commission to account as it drafts new proposals that impinge on kidney disease or organ donation and transplantation.

Currently chaired by MEP Hilde Vautmans, the MEP Group for Kidney Health meets once to twice yearly for concise and focused meetings.

EKHA-led EU Thematic Network on Improving Organ Donation and Transplantation in the EU



The European Commission 2019 Thematic Network on Improving Organ Donation and Transplantation in the EU, coordinated by EKHA, brings together a multidisciplinary network with the collective goal of optimising organ donation and transplantation levels in the EU and ensuring this topic remains an EU political priority.

The main output of the Thematic Network is a Joint Statement on Organ Donation and Transplantation, endorsed by co-signing organisations and MEPs. This stakeholder-led tool offers a unique opportunity to shape future policy for organ donation and transplantation in Europe, as it comprises actionable policy calls and recommendations to drive efforts at EU, Member State and stakeholder level.

The European Kidney Forum



The annual European Kidney Forum hosted by EKHA and the MEP Group for Kidney Health gathers policymakers, patient associations, medical professionals, and representatives from the private sector. In line with the EKHA Recommendations for Sustainable Kidney Care, the Forum focuses each year on a specific theme related to the quality of life, outcomes, or access to care for kidney patients.

The European Kidney Forum gives EKHA Members the opportunity to meet with policymakers, exchange knowledge and experiences, and discuss kidney health and patient care in their country.

The Gift of Life Campaign



EKHA launched the Gift of Life campaign to propagate kidney transplantation within Europe. This initiative raises awareness for a coordinated EU effort in regard to kidney donation and transplantation as well as appropriate legal, structural and ethical frameworks in

EU member states to boost donation rates. Many relevant tools and materials can be found on the EKHA website, which may offer support in developing a campaign strategy, messages and outreach.

European Chronic Disease Alliance (ECDA)



United to reverse the rise in chronic disease



EKHA is an active member of the European Chronic Disease Alliance, a group that drives policy debate around chronic diseases. Within ECDA, we work together with partner organisations representing different issue areas to reverse the alarming rise in chronic diseases in Europe by providing leadership and policy recommendations on health determinants.

EKHA Membership

EKHA welcomes the involvement of European and national not-for-profit kidney-related organisations representing patients, nurses and/or physicians.

Full Members

Full Members are the driving force behind all EKHA initiatives and policy. Their position gives unique influence and involvement that is critical to our operations.

Affiliate Members

Affiliate Members have the opportunity to provide input into EKHA's policy work and are kept informed of all kidney-related initiatives and activities undertaken at EU level.

Benefits	Membership type
Invitation to attend Annual General Assembly, where members can shape EKHA's agenda by proposing initiatives	Full and affiliate members
Invitation to participate in annual European Kidney Forum and Welcome Meeting for Affiliate Members	Full and affiliate members
Email notifications of EU initiatives of relevance to kidney community (Public Health, Research, etc.)	Full and affiliate members
Guidance and resources to complement national advocacy/profiling activities	Full and affiliate members
Attendance at the bi-annual Board of Directors Meeting	Full members
The power to nominate candidates for membership of the Board of Directors	Full members
Agenda setting and vote at the General Assembly	Full members
Active participation in the core activities of the Association, including contribution to agenda-setting and policy formulation	Full members
Active involvement in the agenda-setting of meetings organized by EKHA at EU level.	Full members

Follow us!

EKHA has a Twitter account with a growing following, helping us reach a broader audience about the importance of CKD prevention and treatment, as well as provide news and updates on our activities.

@EKHA_EU 

ekha.eu 

The EKHA Secretariat is managed by Interel European Affairs, based in Brussels.

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EKHA is registered as an NGO in the EU Transparency Register under the number 582565214754-24 and as a VZW in Belgian law under the number 0732.847.767

