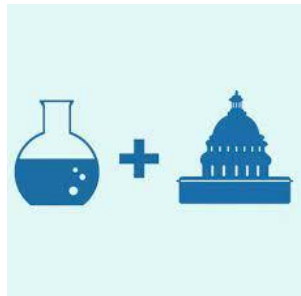




The important interaction between science and advocacy at influencing European politics

BANTAO Meeting Thessaloniki
October 20, 2023
Raymond Vanholder, EKHA President



Agenda

- Introduction to the European Institutions
- Introduction on EKHA and its advocacy endeavours.
- How the activities of EKHA and ERA complement each other.
- Call to action: support the EKHA manifesto that will be launched ahead of the European elections in spring 2024



EU History



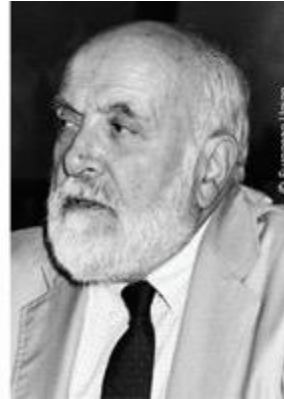
J. Monnet



R. Schumann



K. Adenauer



A Spinelli



PH. Spaak



JW. Beyen



J. Beck



F Mitterrand – H Kohl

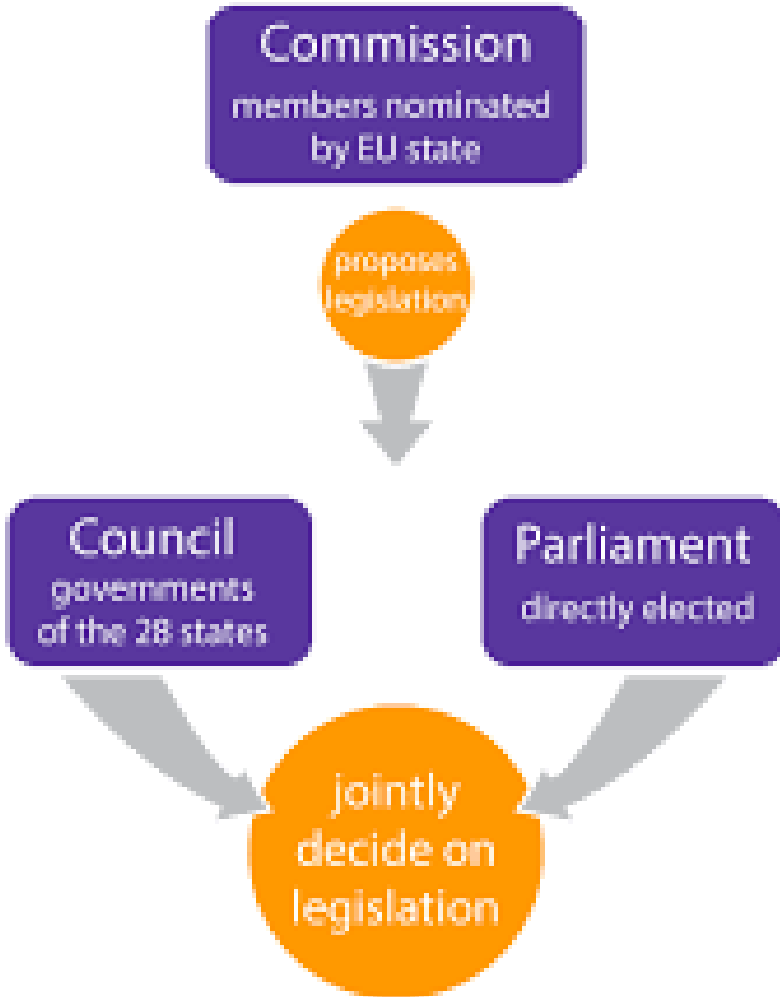
European Coal and Steel Community – 1951
European Economic Community – 1957
European Union – 1973

EU History



YEAR	COUNTRIES
1951	Belgium, France, Germany, Italy, Luxembourg, the Netherlands
1973	Denmark, Ireland, UK
1981	Greece
1986	Portugal, Spain
1995	Austria, Sweden
2004	Czechia, Cyprus, Estonia, Latvia, Lithuania, Hungary, Malta, Poland, Slovenia, Slovakia
2007	Bulgaria, Romania
2013	Croatia
2020	Brexit

EU basic structure



Controlling organs

- European Central Bank
- European Court of Justice
- European Court of Auditors



EUROPEAN COMMISSION



COUNCIL

European Commission



- **1 President**
- **8 Vice-Presidents**
- **18 Commissioners**
- **Appointed by their countries**

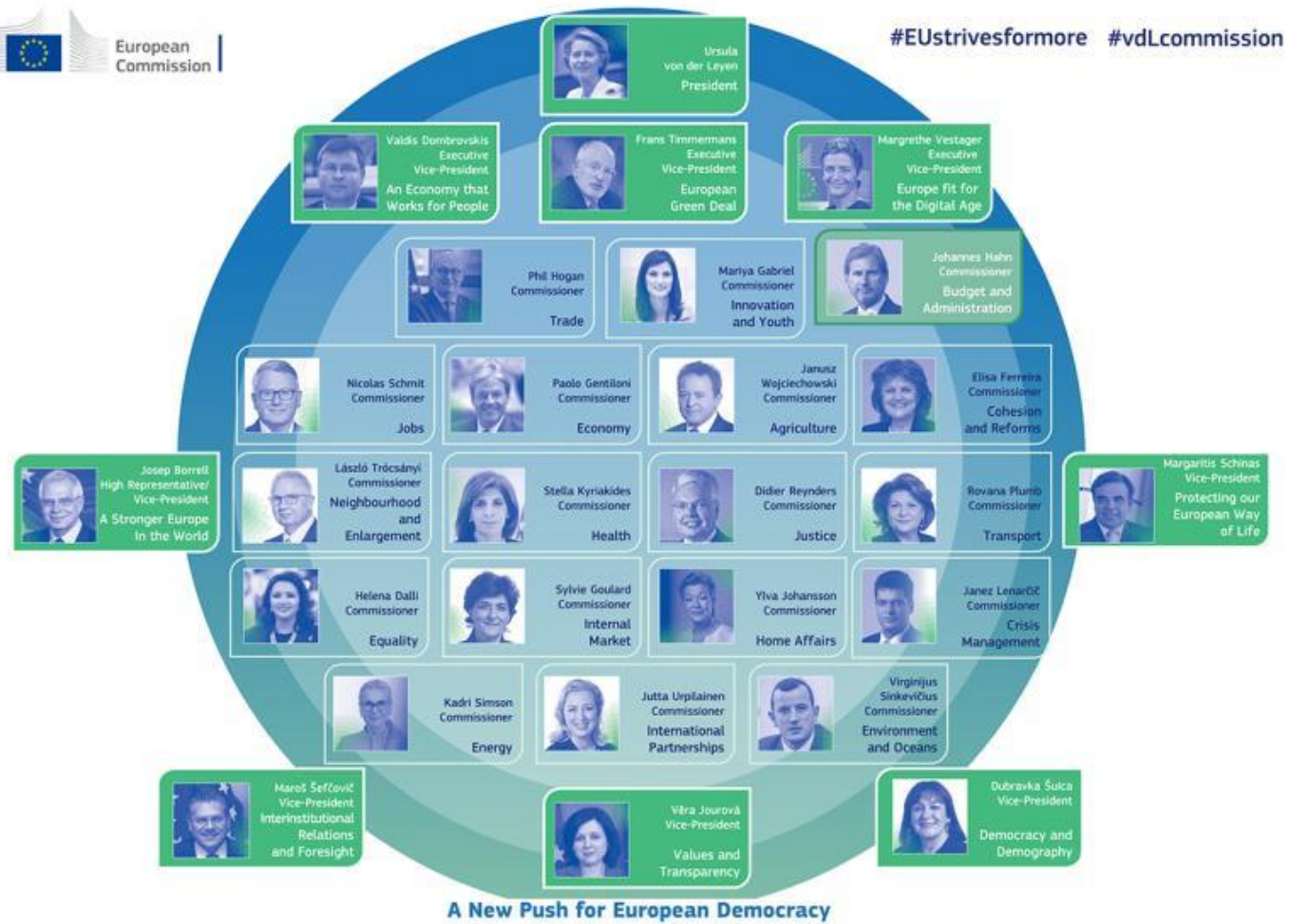
2019-2024

Presidency of the council of the European union



- **Rotational basis per semester**
 - 2022 France, Czechia
 - 2023 Sweden, Spain
 - 2024 Belgium, Hungary

General directorates



33 General Directorates

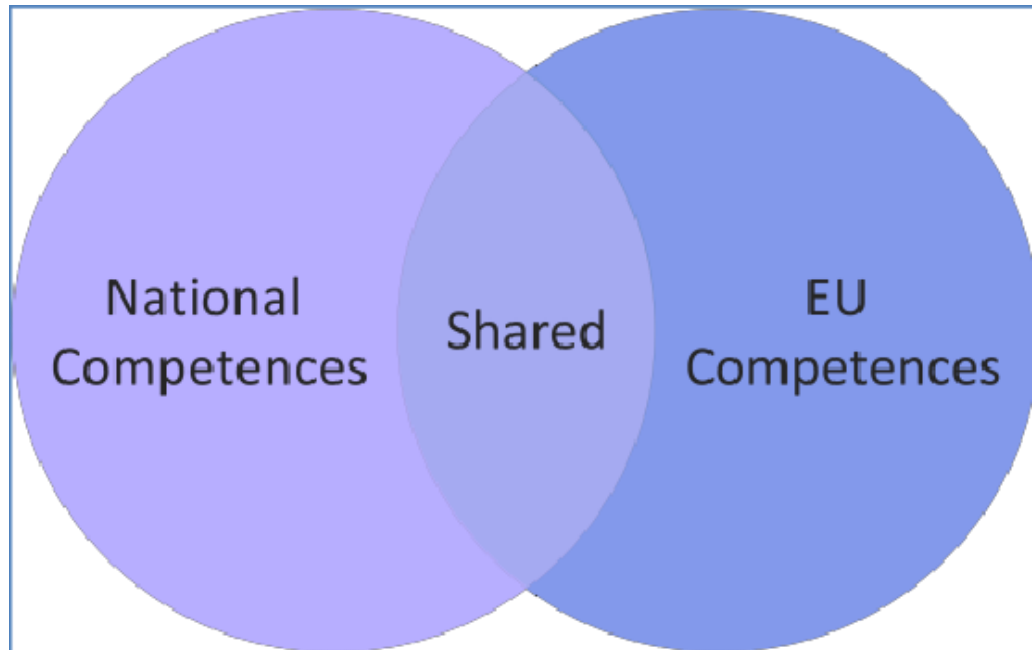
- Health and food safety (SANTE)
- Research and innovation (RID)
- Health and consumer protection (SANCO)
- Informatics (DIGIT)
- Environment (ENV)
- Humanitarian aid and civil protection (ECHO)
- Education and culture (EAC)

11 Services

EUROPEAN PARLIAMENT

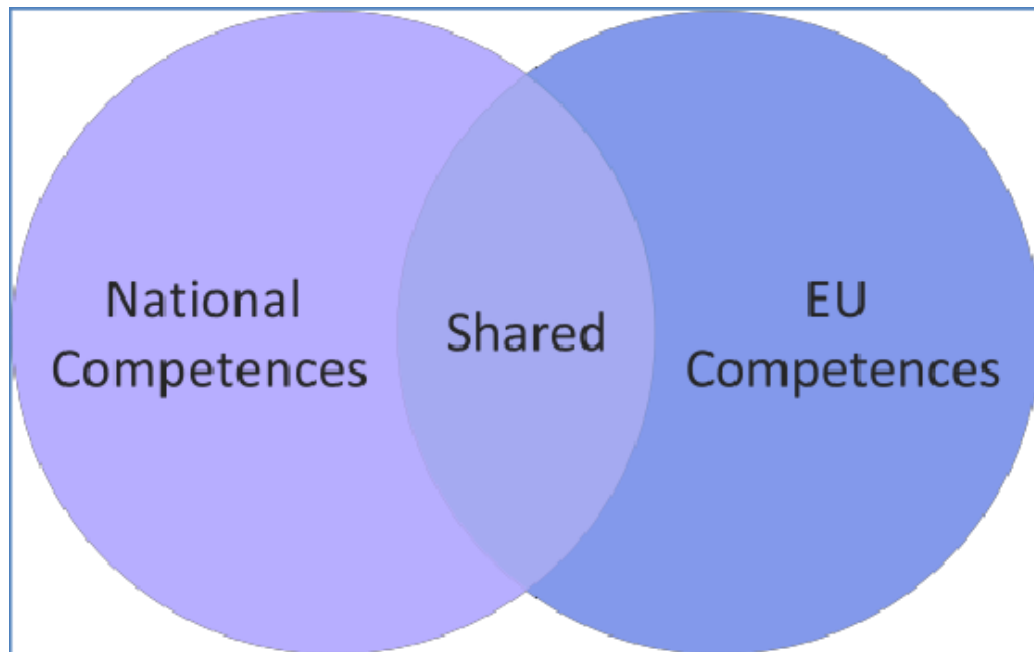
- 705 Members of European Parliament
- 7 Fractions
 - The Left 5.5%
 - Socials & Democrats 20.7%
 - Greens 10.4%
 - Renew 13.9%
 - European Popular Party 25.4%
 - European Conservatives and Reformists 8.9%
 - Identity and Democracy
- Committees
 - ENVI: environment, health & food safety

Eu competences vs member states



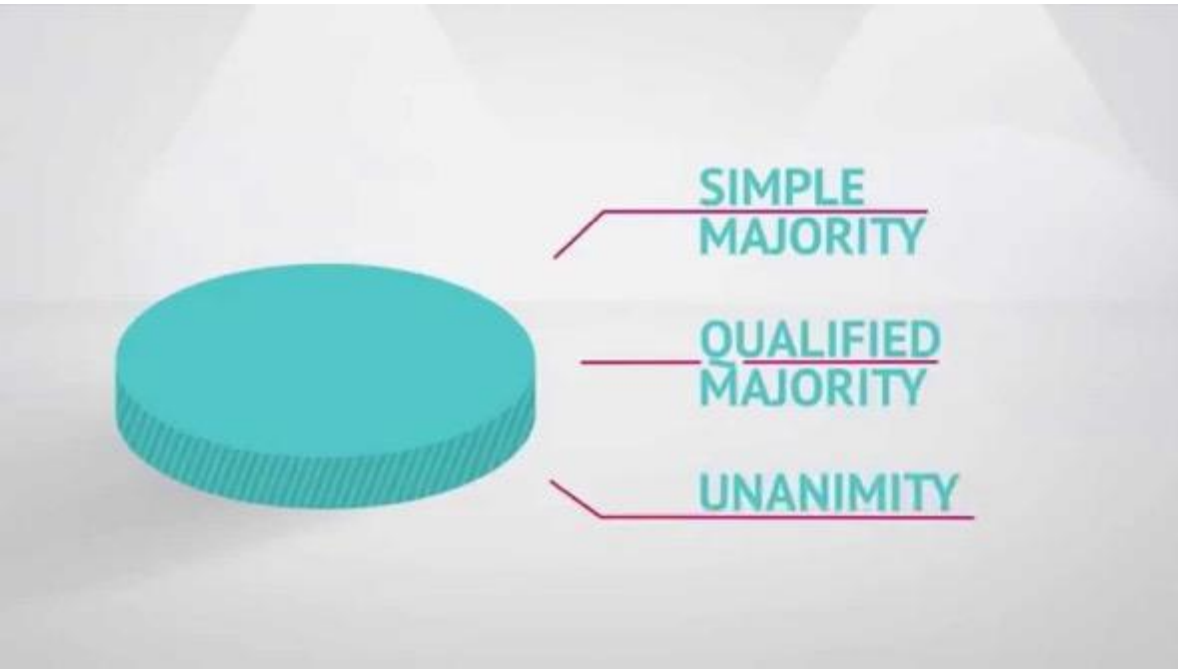
EXCLUSIVE	SHARED	SUPPORTING
Customs	Internal market	Health
Competition	Agriculture	Industry
Monetary (Euro)	<i>Environment</i>	Culture
Fishery	Transport	Tourism
Commerce	Energy	Education
International agreements	Justice	Disaster prevention
	<i>Safety</i>	Administration
	Foreign affairs	
	<i>Humanitarian aid</i>	

Eu competences vs member states



EXCLUSIVE	SHARED	SUPPORTING
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	Safety	Administration
	Foreign affairs	
	Humanitarian aid	
	Public health	

Voting procedure



- Simple majority
 - 14 Council members pro
 - Procedural matters
- Qualified majority
 - 55% (15) [72%] of members states pro, representing 65% of EU population
 - Proposal by Commission (80% of legislation)
- Blocking minority
 - 4 member states contra representing 35% of EU population
 - Proposal returns to Commission
- Unanimity
 - For “sensitive” matters
 - Foreign affairs, security, EU finances, EU membership, some legal matters

Strengthening the work of our network by means of advocacy



is *the* European Nephrology advocacy platform in which a broad scope of organisations and individuals work together for healthy kidneys and the benefit of people with kidney diseases.

The EKHA platform connects the following groups of the Nephrology world:



Physicians



Nurses



Patients



Foundations



Individuals



Commercial partners



Members of European Parliament (22)

- EKHA is a **non-profit organisation** whose aim is to propose solutions for the challenges of Chronic Kidney Disease in Europe **through EU-level advocacy**.
- 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.
- EKHA advocates for more **effective prevention and a more efficient care pathway** intended to facilitate the provision of **high-quality care and affordable treatment to all Europeans equally**.

EKHA members in 2023

5 FULL MEMBERS:



31 AFFILIATE MEMBERS:



10 SUPPORTERS:

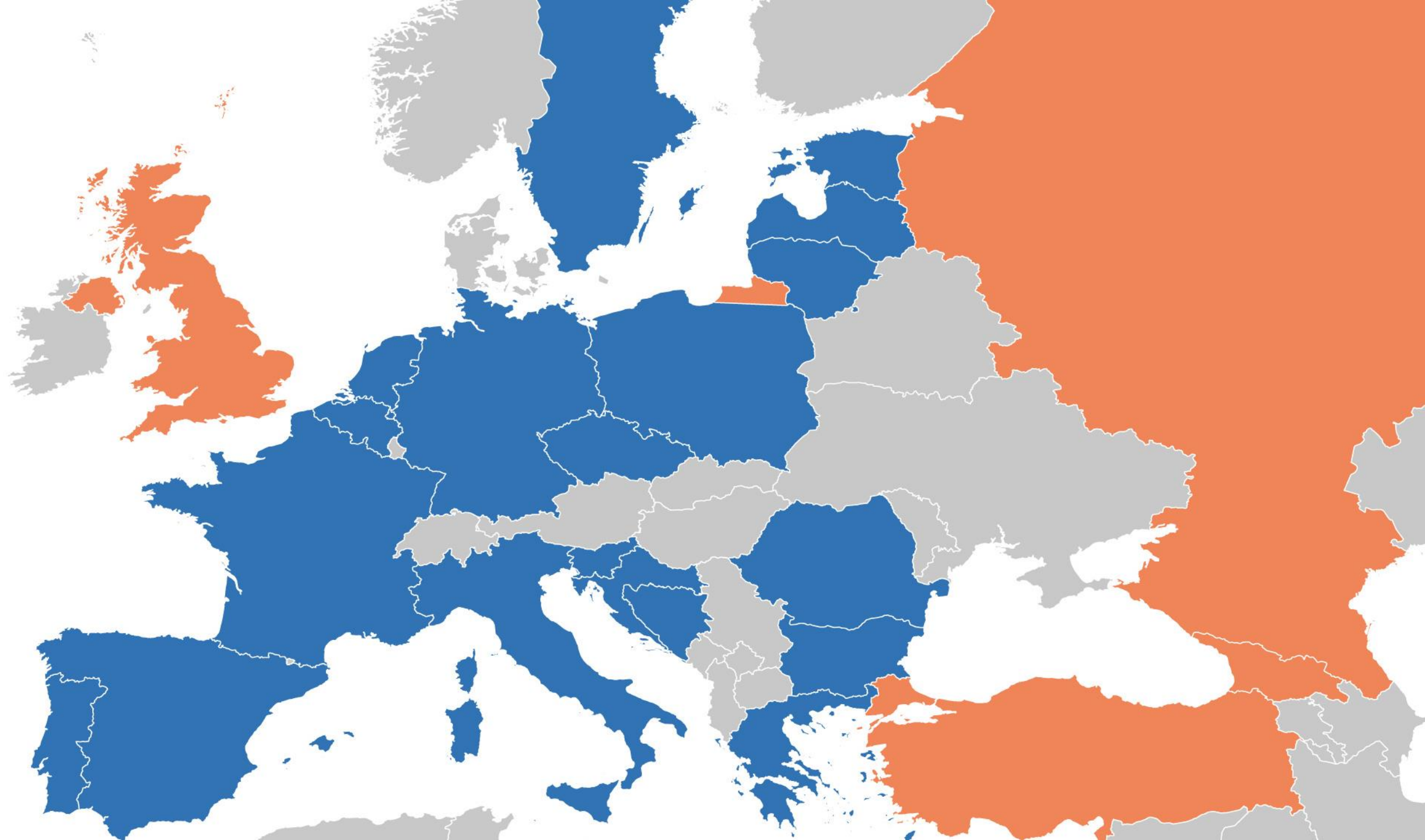


EKHA is a member of **ecda** and **EU4health**



EKHA is supported in their advocacy by the 22 members of the MEP Group for kidney health



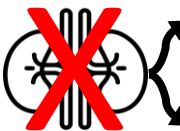


Where science meets advocacy – EKHA projects 2023

- PREVENTCKD:** to enhance CKD screening, data on prevalence and incidence, best practices and the creation of a CKD prevention code. The project is funded by the EC and supported by AstraZeneca, in collaboration with members of EKHA working group 1 and the following consortium partners:
 - EKPF — EUTOX – IMEC – ISN – RENALOO
- Collaboration with other major NCD societies**
 - International Diabetes Federation Europe (IDF)
 - European Association for Cardiac Health (EACH)
- Facilitate Home Haemodialysis care for chronic dialysis patients in Europe** (funded by Mozarc) in collaboration of a working group constructed of experts in the nephrology field (nephrologist, nurses and patient).
- Establishment of an international consortium for ground breaking innovation** in collaboration with:
 - Patient organisations EKPF and AAKP;
 - The co-chairs of the MEP Group For Kidney Health and (Hilde Vautmans and Ondrej Knotek)
 - the Co-Chairs of the USA bi-partisan Congressional Kidney Caucus Congressman Larry Bucshon and Congresswoman Suzan DelBene,
 - Members of EKHA working group 3

The world urgently needs *drastically* better Kidney Replacement Therapies !

Kidney Failure: Present therapies are inadequate!



Kidney Failure
(End Stage Kidney Disease) means:
Without Kidney Replacement Therapy
You Die!

Transplantation

Best & cheapest available KRT option, **but:**

- Structural Shortage of Transplant Kidneys, many Patients Die, while still on the Waiting List
- Immune suppression drugs prevent transplant rejection but also increase Risk of Cancer & Infections
- Still up to 25% shorter remaining Life Expectancy


Dialysis

Most widely used available KRT option, **but:**

- Substitutes max 10-15% of kidney filtration function
- Does not substitute all other kidney functions
- Significantly lower Quality of Life than Transplantation
- More Expensive & Resource-heavy than Transplantation
- Up to 70% shorter remaining Life Expectancy


Dialysis is associated with...

Low Quality of Life




Health-related Quality of Life for dialysis patients is
↓ 27% – 49%
worse than for the general population

High Cost to Society



Dialysis is resource-heavy, costing up to
€80,000 or \$89,000
per patient per year, depending on the country and dialysis method

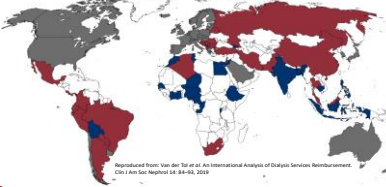
High Mortality



Annual death risk of dialysis patients is
10 – 100x
higher than in general population

Covid-19 makes it even worse!
5-year survival on dialysis is **lower** than for most cancer treatments
2/3 of patients die without KRT access

World-Wide Costs Keep Rising Unsustainably!

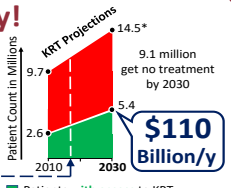


Yearly Dialysis Cost & Country Wealth

- \$ 1.7 Bn/y, low/low income
- \$ 9.7 Bn/y, upper-middle income
- \$45.7 Bn/y, high income countries

\$57.1 Billion/y spent in 2016
(note: excl. transplants & AKI)


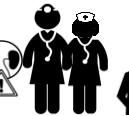




KRT Projections




9.7 million in 2010, 14.5* million in 2030
9.1 million get no treatment by 2030
\$110 Billion/y

Legend:
■ Patients with access to KRT
■ Those dying without access to KRT

Bundle the Best Brains to Build Better Treatments!


 DECADE OF THE KIDNEY
 INTERNATIONAL SOCIETY OF Nephrology (ISN)
 EUROPEAN ASSOCIATION OF Nephrology (EAN)

Where science meets advocacy – a snapshot of activities



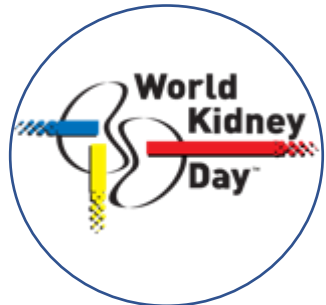
EKHA Recommendations on CKD prevention, treatment and care to inform EU policies and initiatives



Annual European Kidney Forum in the European Parliament hosted by the MEP Group for Kidney Health



Regular meetings with policy makers from the European Parliament, European Commission and Member-States



Annual EU policy-focused campaign on World Kidney Day



Peer-reviewed articles on CKD with a policy angle (34)



Active posting on EKHA social media (X and LinkedIn)

Scientific papers on issues concerning CKD in 2023

In 2023 EKHA published 11 scientific articles on CKD. The latest are

- Vanholder et al, **A policy call to address rare kidney disease in health care plans.** Clin. J. Am. Soc. Nephrol. Available from: Doi: 10.2215/CJN.0000000000000220
- Vanholder et al, **Inequities in kidney health and kidney care.** Nat. Rev. Nephrol. Available from: 10.1038/s41581-023-00745-6

Also EKHA working group members publish scientific articles:

- Wieringa et al, **Coordinating efforts to optimize next-generation kidney replacement therapies: the European Kidney Health Alliance work group 'Breakthrough innovation.** Clin. Kidney J., 16, 885-890, 2023

Science meets advocacy

- Announcement of the European Kidney Forum Vanholder et al in J Nephrol. 36, 1225-1227, 2023
- Article in Health Quarterly Issue 25: **Improving care and awareness of CKD, written by Raymond Vanholder and Eveline Scheres**



Campaigns and events with strong ambassadors (2023)

World Kidney Day

Awareness-raising campaign 'Show Your Kidneys Love' with Tina Turner

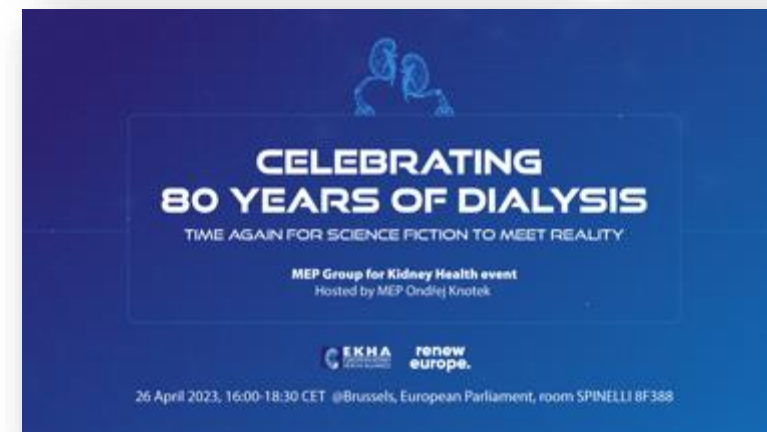
Online campaign: written conversation on the vulnerability of kidney patients during disastrous events

Celebrating 80 years of dialysis: Time again for science fiction



Successful event in the European Parliament, hosted by MEP Knotek (Czechia), commemorating the invention of dialysis & reminding the urgency of innovation.

The event was organized in close collaboration with Fokko Wieringa, Phd (chair EKHA of working group 3 on ground-breaking innovation) who created [a short movie on the inspiring live of Dr. William Kolf](#)





Welcome to our
Forum!

Annual policy event in the European Parliament

2023 European Kidney Forum

MEP Group for Kidney Health event

THE FUTURE OF KIDNEY CARE

Investing in green nephrology to meet
the European Green Deal Targets

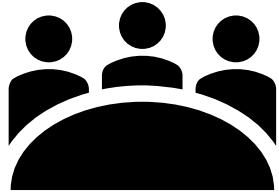
28 June 2023, 15:00 -17:00 CEST

European Parliament Brussels, SPAAK 7C50

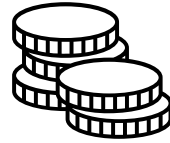
Hosted by MEP Hilde Vautmans, MEP Juozas Olekas, MEP Ondřej Knotek



EKHA advocacy achievements



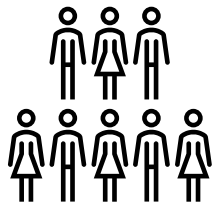
CKD mentioned in high-level parliamentary debates



EU funding secured for CKD prevention and early diagnosis



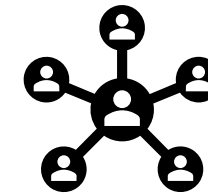
CKD included in key EU reports, initiatives and policies



The CKD community represented annually in the European Parliament



EKHA seen as a go-to partner for any EU initiatives on kidney disease



Strong network of EU policy makers established to support efforts on CKD

EKHA communication achievements

Growing network on social channels

EKHA @EKHA_EU · 22h
Experts & policymakers will address the environmental impact of kidney care & how green nephrology can help achieve the #EUGreenDeal Targets at the #EKF2023
Register: bit.ly/3VV756H

2023 European Kidney Forum
MEP Group for Kidney Health event
THE FUTURE OF KIDNEY CARE
Investing in green nephrology to meet the European Green Deal Targets
28 June 2023, 18:00 - 17:00 CEST
European Parliament Brussels, SP/SAK, FCSG
Hosted by MEP Jussara Chikwa, MEP Jussara Chikwa, MEP Ondrej Kizisek

Programme
Chaired by Tamsin Rose

- 15:00-15:15 Opening remarks**
 - MEP Jussara Chikwa, Co-Chair, MEP Group for Kidney Health
 - MEP Jussara Chikwa, Member, MEP Group for Kidney Health
 - MEP Ondrej Kizisek, Co-Chair, MEP Group for Kidney Health (Moderator)
- 15:15-15:20 Setting the scene**
Kidney health and the environment: a neglected bidirectional link
 - Prof Raymond Vanholder, President, European Kidney Health Alliance
The energy crisis and dialysis care: how are patients and health systems coping?
 - Ms Fiona Loud, Policy Director, Kidney Care UK
- 15:20-16:40 Panel discussion: Joining forces to improve kidney health and foster greener nephrology practices**
 - Prof Georges Pisoni, Nephrologist, Nephrology Service, Le Mans Hospital Centre, France
 - Dr Boris de Zeeuw, President and Scientific Board Chair, European Kidney and Transplant Nurses Association/European Renal Care Association
 - Dr David Gallez, President, European Kidney Patient's Federation
 - Ms Petra Lemay-Caslé, Policy Officer, Innovative Health Initiative, DG for Research and Innovation, European Commission
 - MEP Jussara Chikwa, Member, MEP Group for Kidney Health
 - Ms Andrea Daniels, Director of Programmes, Healthcare Without Harm Europe
 - Dr Fabian Witzke, Principal Specialist, Central Health Services Department, IMC, The Netherlands
 - Ms Charlotte Buffaux, European Policy and Advocacy Advisor, Renalink
- 16:40-16:50 Concluding remarks**
 - Commissioner Stella Kyriakides, Commissioner, DG Health and Food Safety, European Commission
 - Prof Raymond Vanholder, President, European Kidney Health Alliance
- 16:50-17:00 EKHA Declaration of Intent & Guiding Principles**
- 17:00-18:20 Networking reception**

Fiona Loud and 9 others
1 4 11 1,945

957 followers on twitter

www.ekha.eu

EKHA_EU

ekha-european-kidney-health-alliance

info@ekha.eu



Help us in spreading the message and follow us on "X" and Linked-in!

EKHA - European Kidney Health Alliance
1.026 volgers
4 d · 🌐

On 16 June, EKHA's leadership will speak at the [European Renal Association \(ERA\) Congress](#) in #Milan on the best approach to kidney-disease awareness-raising among European policymakers in the healthcare doma ...meer weergeven

Vertaling weergeven

60th ERA CONGRESS MILAN & VIRTUAL JUNE 15-18, 2023

Tom Oostrom en 15 anderen
1 commentaar · 2 reposts

Interessant Commentaar Reposten

1026 followers on linked-in



ERA versus EKHA

Collaboration to strengthen mutual goals

ERA

EKHA

Expertise

- Expert **education**
- Top quality **scientific** knowledge
- **Professional** networking

- **Advocacy**
- **EU policy**
- EU health legislation and initiatives
- **Creating awareness** about kidney diseases

Complementarity

- **Scientific** knowledge provided by ERA feeds the **advocacy work** of EKHA

- Information provided by EKHA and **advocacy efforts** by EKHA benefit ERA and help ERA reaching its goals

Tools

- **Congresses**, courses, webinars
- **Working groups**
- Fellowships
- Nephrology **journals**
- **Registry**

- **Fora** and meetings in the **European Parliament**
- **Meetings with EU policymakers**, administrators, members of the European Parliament
- Working groups
- **Round tables / webinars**

Membership

- **Individual members** with interests in nephrology
- Mostly **nephrologists**

- National and international nephrology **societies and organisations** in Europe
- Representing **nephrologists, patients, nurses, foundations, industry, providers**
- **Collaboration with Members of EU Parliament**

Shared goals of ERA and EKHA

ERA' GOALS

Promoting kidney health for all

- Prevent people from developing kidney disease
- Develop a global vision about kidney health beyond borders

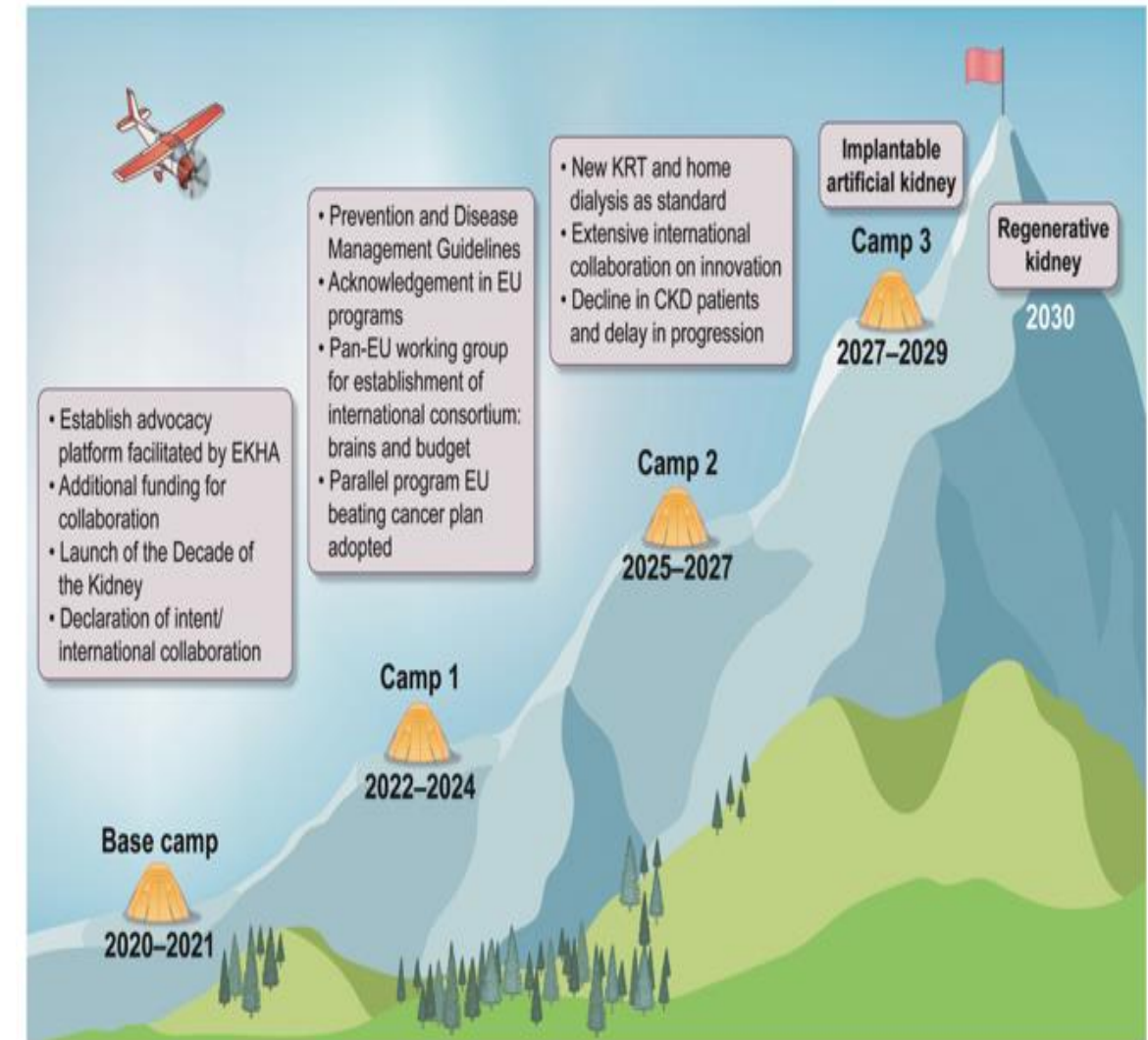
Improving kidney care for patients

- Promote equity of access to kidney diagnosis and treatment across Europe
- Generate respect for the patient voice

Strengthening the kidney community

- Foster a stronger sense of identity and community among members
- Reconsider the role of the modern nephrology professional specialist to inspire the next generation
- Address the pressing issues of nephrology workforce shortage and promote personnel recruitment and continuity

EKHA'S MISSION STRATEGY



European elections

Advocacy Priorities ahead of 2024 European Parliament Elections

EKHA key recommendations, short- and long-term objectives, concrete asks

Foster innovation in kidney disease treatments

Call on the EU to stimulate research, development, and green innovation of therapeutic alternatives for CKD, preferably in a international consortium

Organ donation and transplantation

Call on the EU to address the long-standing challenges in organ donation and transplantation

Potential ask: A 2nd EU action plan



Kidney Manifesto

For more information, membership and support:



Eveline Scheres
General Manager

For all your questions on:

- Organisation
- Membership possibilities
- Public affairs
- Support
- Sponsorship

eveline.scheres@ekha.eu

+31 6 32278149

**If you would like to stay tuned to EKHA activities or support our election manifesto, please contact Eveline Scheres or myself
(raymond.vanholder@ugent.be)**

thank you!

www.ekha.eu

 EKHA_EU

 ekha-european-kidney-health-alliance

 info@ekha.eu



Back-ups

EKHA ambitions, goals and instruments

EKHA MISSION

Less people to develop CKD, slow down progression of CKD and better quality of life for CKD patients.

EKHA VISION

Engage EU politicians to change EU policy to lower the socio-economic burden of CKD by creating awareness & urgency on CKD being a neglected disease in all stages.

STRATEGIC GOALS

Prevent people from getting kidney disease.

Improve **disease management** by educating politicians, care givers (GP's, Specialists) and scientists on the impact of unhealthy kidneys.

Push for **innovative green therapies** for kidney patient accessibly to all European patients and for fair prices

Include **CKD as a research priority** of the European Commission.

INSTRUMENTS

Advocacy expertise

Scientific Content

EKHA working groups

Patient engagement

Communication

Collaboration

EKHA Working groups

In 2021 EKHA starting with 3 working groups. The groups exist of people of EKHA member organisations and people from the nephrology world who contribute with their **expertise on nephrology**. They carry out tasks and actions to achieve, amongst other, the 3 strategic goals of EKHA. In 2021 they started with the following tasks:



WG1: Prevention & screening

Research via a survey to:

- analyse existing screening programs in primary care in Europe;
- to understand the general attitude to – and use of – CKD detection/screening in GP practises;
- to evaluate the feasibility of screening for kidney disease.



WG 2: Disease Management

Research for need and use of a Disease Management Toolbox, to provide kidney patients with a practical tool to better manage kidney disease in all stages. This tool should also be helpful to nurses, nephrologists, general practitioners and other specialists in supporting patients tackling their disease.



WG 3: Ground Breaking Innovation

Collaboration to push for an international framework for new innovative and affordable Kidney Replacement Therapies (KRT's) in response to Horizon Europe's Strategic Orientations for Research and Innovation and the Advancing American Kidney Health (AAKH) Executive Order



Aside from the working groups, EKHA installed an **AMBASSADOR GROUP** that exists of people living with kidney disease. Their tasks are to reflect on the output of the working groups, represent the patient voice in political meetings and provide patients insights on EKHA's strategic goals. These Ambassadors are therefor incorporated in the one of working groups.

Decade of the Kidney™ mission strategy

