



GENERAL ASSEMBLY

May 11, 2024
09.00 – 1100 CEST

Online

Agenda

9.00 – 09.10 CEST: Welcome and Activity Reports

- Adoption and approval of the agenda
- Presentation of Activities and Finance Accounts 2023

9.10 – 9.20 CEST: For vote

- Additions and changes to the BoD:
- Governance: adaptation of the statutes, to grant voting rights to the affiliated members
- President elections – Nomination of Valérie Luyckx to become EKHA President elect as of July 2024

9.20 – 9.25 CEST: Questions, Discussion and Discharge of the BoD

9.25 – 09.45 CEST: Achievements and running projects

- Presentation of achievements of 2023 and first semester of 2024
- Presentation of running EKHA projects
- Planning of 2024 and beyond

9.45 – 10.15 CEST: Discussing the outcome of the 2024 EP Elections & EKHA follow up

10.15 – 10.55 CEST: Introduction of new members

- New full members: ESOT, ERKNET and ESPN
- New affiliated members: CompCure, Romanian Society of Nephrology, French speaking Belgian nephrologists (GNFB)
- Tour de table for updates from other affiliated members

10.55 – 11.00 CEST: concluding words by Prof. Raymond Vanholder – EKHA President

Activities and Finance Accounts 2023

| | | 01-01-2023 - 31-12-2023 |
|---|--------|-------------------------|
| INCOME STATEMENT | | |
| Operating income | 70/76A | <u>550.116,88</u> |
| Contributions, gifts, legacies and grants (explanation 6.9) | 73 | 427.682,93 |
| 730000 - Membership fees (C) | | 133.643,50 |
| 731000 - Sponsorship fees EKHA Forum (C) | | 279.076,68 |
| 731010 - Other fees (C) | | |
| 731100 - Gift (C) | | 14.962,75 |
| Other operating income | 74 | 122.433,95 |
| 743000 - Miscellaneous operating income (C) | | 3.205,85 |
| 743100 - Miscellaneous revenues - VAT Regularizations (C) | | |
| 744000 - Project Europese Commissie (C) | | 119.228,10 |

| | | |
|--|--------------|------------------|
| Financial income | 75/76B | <u>0,38</u> |
| Recurring financial income | 75 | 0,38 |
| Other financial income (explanation 6.10) | 752/9 | 0,38 |
| 757010 - Payment differences on purchase (C) | | 0,38 |
| 759000 - Other financial income (C) | | |
| Financial charges | 65/66B | <u>261,87</u> |
| Recurring financial costs (explanation 6.10) | 65 | 261,87 |
| Debt charges | 650 | 50,80 |
| 650010 - Late payment fees (D) | | 50,80 |
| Other financial charges | 652/9 | 211,07 |
| 654000 - Realised exchange losses (D) | | 65,82 |
| 657000 - Other financial charges (D) | | 145,25 |
| Profit (Loss) of the financial year before taxes | (+)/(-) 9903 | <u>51.647,00</u> |
| Gain (loss) of the period available for appropriation | (+)/(-) 9904 | <u>51.647,00</u> |

| | | 60/66A | 498.208,39 |
|--|--------------|--------|-------------------|
| Operating charges | | | <u>498.208,39</u> |
| Services and other goods | 61 | | -41,92 |
| 612400 - Subscriptions Microsoft (D) | | | 3.906,53 |
| 612450 - Restaurant/catering (D) | | | 2.406,56 |
| 612500 - Hotel costs (D) | | | 5.590,35 |
| 612600 - Travel expenses (D) | | | 6.855,67 |
| 613000 - Accounting fees (D) | | | 78,62 |
| 613001 - Drukwerken (D) | | | 5.393,24 |
| 613022 - Auditor Fees (D) | | | 49.761,27 |
| 613200 - Fees Dentons support projects (D) | | | 14.901,97 |
| 613300 - Various fees (D) | | | |
| 613301 - Internship compensation Communication (D) | | | 55.163,48 |
| 613400 - Fees Buiten de lijnen (D) | | | 47.191,91 |
| 613450 - Erelonen Buiten de lijnen - projecten (D) | | | 40.237,80 |
| 613500 - Fees Triumph (D) | | | 30.308,11 |
| 613550 - Fees Triumph - projects support (D) | | | 1.358,49 |
| 613600 - Website (D) | | | 68.808,67 |
| 613700 - Project EKPF (D) | | | 245,81 |
| 614100 - insurance (D) | | | 4.308,11 |
| 615000 - Membership fees ECDA (D) | | | |
| 615300 - Publicatiekosten (D) | | | 32.041,58 |
| 616000 - Forum EKHA (D) | | | 16.381,64 |
| 616010 - Events, conferences (D) | | | 112.097,04 |
| 616100 - Annual public affairs (D) | | | 1.213,46 |
| 616200 - BOD Meeting (D) | | | |
| Other operating charges (explanation 6.9) | 640/8 | | |
| 644100 - Non-deductible VAT (D) | | | |
| Operating profit (loss) | (+)/(-) 9901 | | <u>51.908,49</u> |

- EKHA has closed 2023 with a positive result of €51,647.00
- The accumulated results for 2020-2023 are € 77.268,83
- The EKHA BoD is asked to approve the accounts for 2023



FOR VOTE

Additions and changes to the BoD

NEW FULL BOARD MEMBERS

European Society for Organ Transplantation (ESOT)

1st representative: Gabriel Onicscu, ESOT President

Advisor: Devi Mey, ESOT General Manager

The European Society for Paediatric Nephrology (ESPN)

1st representative: Dieter Haffner, ESPN President

Advisor: Elena Levtchenko, ESPN council member

European Reference Network for Rare Kidney Diseases (EKNet)

1st representative: Franz Schaefer, ERKNET President

Advisor: Djalila Mekhal, ERKNET Expert

CHANGES TO BOD ADVISORS

- Anne Hrasdsky to resign as BoD advisor for ISN
- Magdalena Machalska proposed to be the new BoD advisor for ISN

- Martijn Ubbink to resign as BoD advisor for the Dutch Kidney Foundation
- Wouter Eigelaar proposed to be the BoD advisor for the Dutch Kidney Foundation

Governance adaptation: context

▪ Enhanced network

- Increased awareness on EKHA amongst the European Commission and DG Santé and MEP's
- EKHA recognized as a go-to-partner in the EU political arena on CKD
- Substantial growth of the network in the past 5 years:
 - ✓ 2019: 4 full partners, 14 affiliated partners, no sponsor packages
 - ✓ 2024: 8 full partners, 35 affiliated partners, 13 commercial partners

▪ CKD awareness is rising

- CKD included in key European Commission and European Parliament reports,
- EU grant to enhance prevention on CKD,
- call to actions well received.

▪ Enhancement of the EKHA democracy / more leverage for associated partners

- Further professionalizing of the collaboration between EKHA and the EKHA network, via projects, more contact moments to share ideas, strategize and exchange information.

Governance adaptation – actions

Suggested action by the EKHA BoD

- Adaptation of the statutes, to be effectuated after the General Assembly of 2024, to grant voting rights to the affiliated members during the EKHA GA
- Consideration of changing the governance in are more bimodal structure (like KHI or ERA curatorium)
- *Both actions will be effectuated in the second semester of 2024*

Possible actions to be further discussed

Further exchange of ideas to enhance the input and possibilities for the affiliated members such as

- a) More direct collaboration on Public Affairs (elections, presidencies, issues)
- b) Interactive session on annual plans (for instance end of November/beginning of December)
- c) Project collaboration
- d) Rotating system where a more important role and vote is given to a few national associations each year, for instance 1 per region (east, north, west, south, centre)
- e)other ideas?

President Elections



- The EKHA BoD nominates Valérie Luyckx as the next EKHA President as of June 2025
- As of June 2025, Raymond Vanholder will be connected to EKHA in the role of Past-President until June 2026

- Dr Luyckx obtained her MBBCh from the University of the Witwatersrand, South Africa.
- She trained in Internal Medicine at the University of Miami and in Nephrology at the Brigham and Women's Hospital and Massachusetts General Hospitals. She holds an MSc in Public Health from the London School of Hygiene and Tropical Medicine and a PhD in Biomedical Ethics at the University of Zurich.
- She has held faculty positions at the University of the Witwatersrand, Harvard Medical School and the University of Alberta. She is currently based at the University of Zurich in the Department of Public and Global Health and the Zurich Children's Hospital and holds affiliate positions at Harvard Medical School and the University of Cape Town.
- Her research activities include the challenges of justice, ethics and moral distress relating to resource allocation for the management of kidney disease in resource limited regions and in emergencies.
- She is an active advocate for prevention of non-communicable diseases, especially kidney health, calling attention to the social determinants of health, with the goal of supporting equity and fair priority setting for quality kidney care in resource limited settings, and supporting local expertise.
- She is chair of the Advocacy Working Group of the International Society of Nephrology (ISN), chair of the Ethics Committee at the European Renal Association (ERA) and a board member of the EuDial working group of the ERA.
- She is actively involved in the ISN and ERA Taskforces for Renal Disasters.
- She is a board member of the International Society for Priorities in Health.
- She serves on the Swiss Central Ethics Committee (ZEK).
- She is a consultant in the Health Ethics & Governance Unit and the NCD teams at the World Health Organization.

Achievements 2023 & running projects

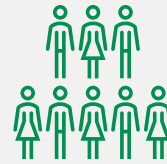
EKHA accomplishments of 2023 in summary



Collaboration with 3 consecutive Presidencies of the Council of the EU



Started first EU granted project, PREVENTCKD, first results to be presented in 2024



Expansion of the network with 1 full partner and 5 affiliate members in total 38 members and 10 supporters)



CKD included in key EU reports and policies of health committees



Numerous scientific publications, position papers and presentations



Enhancing our position as a go-to partner for any EU initiative on kidney disease



Campaigns and high-level events with strong ambassadors, such as Tina Turner



Close collaboration with Members of the European Parliament in various events



Policy call to address rare kidney diseases in health care plans



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



Advocacy activities with European institutions

European parliament sub-committee on public health

February 2023: Creation of EP Public Health Subcommittee (SANT), established under the umbrella of the Committee on the Environment, Public Health and Food Safety (ENVI).

- SANT set to produce an Own-Initiative report on NCDs.
- EKHA proposed amendments on the draft report and actively engaged with MEPs to present recommendations for the report.

Key results

Report includes EKHA recommendations and important calls for kidney patients

- ❖ 28 compromise amendments relay EKHA messages
- ❖ 3 mention kidney diseases



EU NCD Initiative

The European Commission launched in December 2021 [the Healthier together – EU non-communicable diseases \(NCD\) initiative](#)

- support EU countries in identifying and implementing effective policies and actions to reduce the burden of major NCDs
- covers the 2022-2027 period and includes 5 strands: health determinants; CVDs; diabetes; chronic respiratory diseases; mental health.

March 2023: ENVI Exchange of Views with European Commission

EKHA Questions:

Organ donation and transplantation is not mentioned in the NCD initiative toolkit, however it is a significant issue in Europe affecting many patient with chronic diseases. How is the European Commission planning to address the unmet needs in organ donation and transplantation through the NCD initiative?

Is the Commission considering to update the EU NCD initiative toolkit in the future to extend it to other NCDs such as kidney disease?

Have Member States already started implementing some of the best practices included in the NCD initiative toolkit? How does the Commission intend to keep the European Parliament abreast of the implementation progress?

European Commission's answers:

NCD initiative will be looking at areas not mentioned before, like kidney disease.

Not excluding ODT but it will be a mix of EU SoHO Regulation & NCD initiative.



Cesar Luena
S&D, Spain



Katerina Konecna
The Left, Czechia



Marian-Jean Marinescu
EPP, Romania

European Parliament COVI Committee

- Special committee on 'COVID-19 pandemic: lessons learned and recommendations for the future' (COVI).
- Tasked with looking into the EU's response to the pandemic & the lessons learnt
- Four key pillars: health, democracy and fundamental rights, societal and economic impact, and the EU and the World.

EKHA worked very closely with members of the committee to ensure appropriate attention to vulnerable people such as CKD patients in future health crises.

Key result

EKHA recommendations on the need to protect the immunocompromised population were included in the final report.

EKHA Recommendations

- Increase the use of home treatment and telemedicine
- Stimulate research and innovation
- Foster health promotion and disease prevention
- Improve protection of immunocompromised people ahead and during pandemics



MEP Peter Liese
(EPP, Germany)



MEP Aldo Patriciello
(EPP, Italy)



MEP Juozas Olekas
(S&D, Lithuania)

Belgian Presidency of the Council of the EU



In March 2023, EKHA in collaboration with **Belgian Society of Nephrology (SBN)**, **French speaking Belgian society of nephrology (GNFB)** and the **Dutch speaking Belgian society of nephrology (NBVN)** met with representatives of the Belgian Presidency of the Council of the EU to present EKHA priorities.

- As a direct result of this meeting, the Belgian Presidency team invited EKHA to participate in a stakeholder consultation on the Presidency's priorities in health.
- Prof. Raymond Vanholder attended on behalf of EKHA.
- Meeting objective: invite stakeholders to share their opinions and engage in an open discussion on the themes that Belgium intends to bring to the table during the Presidency.

Prof. Vanholder discussed with BE Presidency team and pointed out:

- our efforts on transplantation with the Spanish and Hungarian Presidencies
- our wish that kidney diseases be mentioned in official documents of the Presidency on health
- the need for innovation in nephrology, including for dialysis and its environmental impact

Spanish Presidency of the Council of the EU



Santander Transplant Summit 2023

On 9-10 November the Spanish Presidency hosted the Santander Transplant Summit 'Towards Global Convergence in Transplantation: Sufficiency, Transparency & Oversight'

- **Daniel Gallego (EKPF President)**, spoke on behalf of EKHA and EKPF, his presentation highlighted:
 - Humanistic burden of transplant
 - Patient concerns
 - Patient centricity
 - Maximising transplant potential
 - Sustainable workforce
 - Data-driven decisions and improvements
 - Prioritising immunocompromised patients
 - Call for a second EU Action Plan on organ donation and transplantation

Update:

- World Health Assembly Resolution on Transplantation was adopted at the 77th World Health Assembly (June 2024)
- Based on the outcomes of Santander Transplant Summit

EKHA open letter on organ donation & transplantation

- Published on 9 October, on the occasion of European Day for Organ Donation and Transplantation and endorsed by 25 organisations

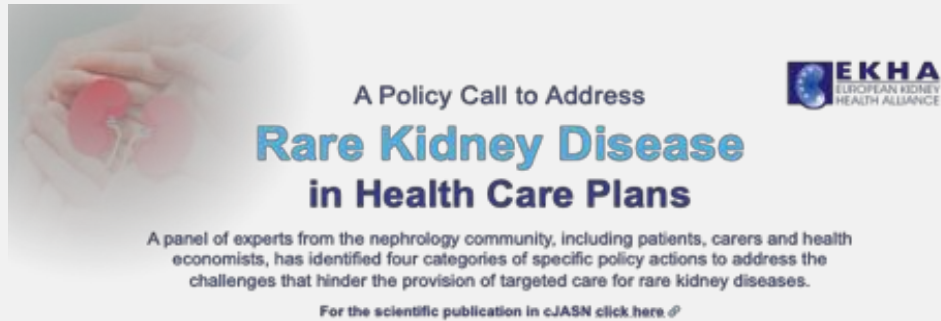
Call for a renewed EU action plan on organ donation and transplantation in the 2024-2029 mandate

Key results

- Well received in EU media & Network.
- EKHA was contacted to meet with the Permanent Representation of Hungary to the European Union to discuss collaboration on this topic during the presidency.
- Reply from Commissioner For Health and Food Safety, Commissioner Stella Kyriakides.



Policy call to address rare kidney disease in healthcare plans



Awareness and prioritisation

- Recommend early diagnosis in national plans
- Launch education campaigns targeted towards physicians and patients
- Raise awareness of chronic kidney disease and rare kidney diseases amongst policymakers and the general population
- Develop policy guidelines specific to rare kidney diseases

Management

- Develop clinical guidelines specific to rare kidney diseases
- Improve access to innovative therapies
- Design and implement rare kidney diseases registries
- Conduct PROM^o-oriented studies
- Launch multi-disciplinary teams with a focus on rare kidney diseases

^opatient-reported outcome measure



Diagnosis

- Introduce policies to promote genetic testing
- Implement urine screening programmes
- Advance research for diagnostic tools
- Advance genome and biomarker research

Therapeutic innovation

- Allocate research & development funds to rare kidney diseases
- Generate evidence to expand understanding of rare kidney diseases
- Identify and validate surrogate endpoints
- Conduct large-scale multicentric studies
- Increase acceptance of alternative statistical methods

On December 12, 2023, EKHA published a new infographic calling on policymakers to address rare kidney diseases in health care plans.

A panel of experts from the nephrology community has identified policy actions to address the challenges that hinder the provision of targeted care for rare kidney diseases. These recommendations constitute a holistic approach to all aspects of rare kidney disease care to improve health outcomes, reduce the economic impact, and bring benefits to society. Read the infographic [here](#).

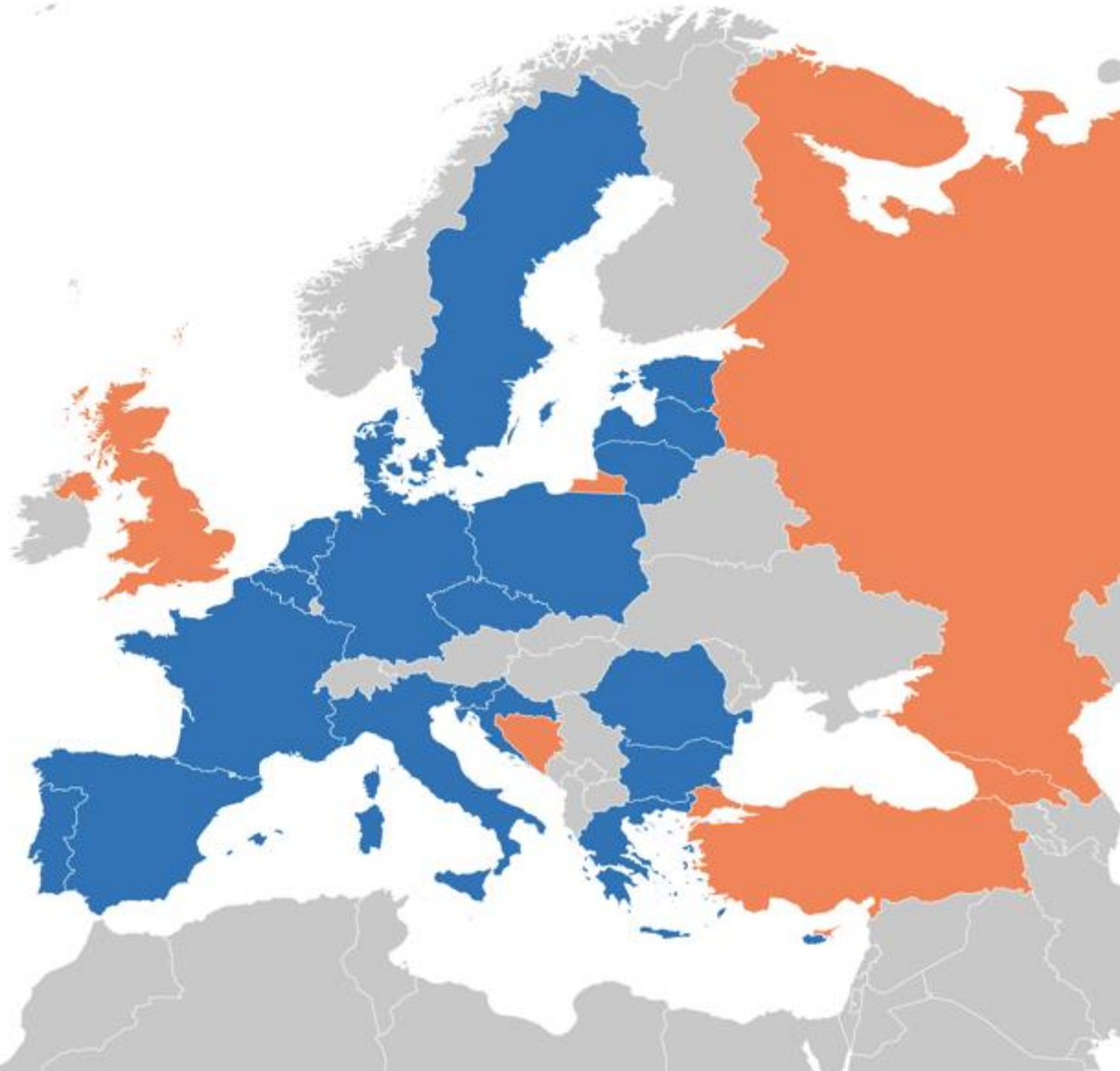
The infographic sums up the main conclusions of the panel, that was written down in a scientific article published in *CJASN* and can be found [here](#).



Organisation & collaboration

Expansion of the EKHA network in 2023

23 countries



EKHA consists of 48 organisations covering 23 European countries :

- 6 full partners
- 32 affiliated partners
- 10 industry partners

In 2023 our network grew with:

1 new full partner:

- The European Society for Organ Transplantation



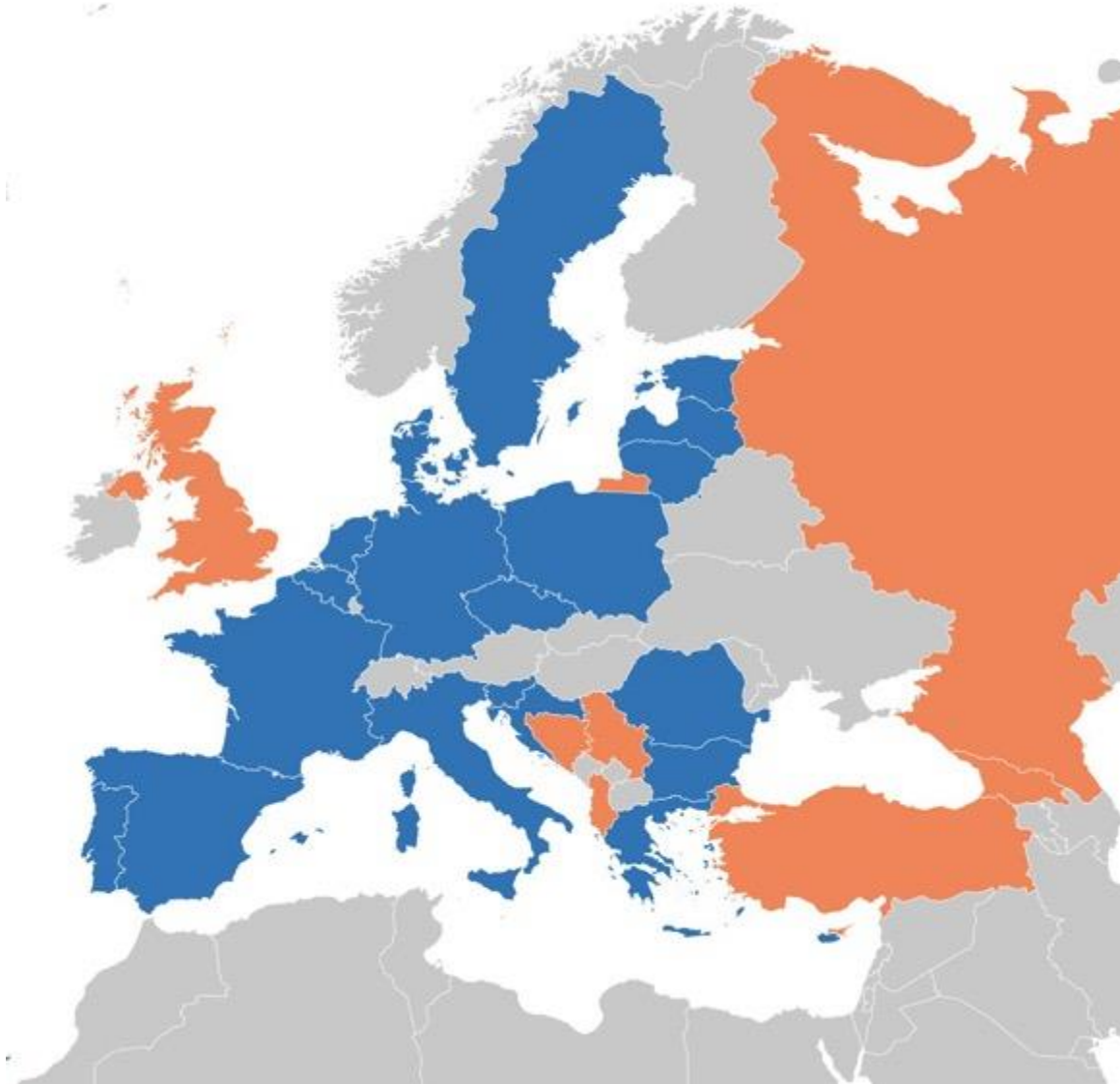
5 new affiliated partners

- KfH Kuratorium für Dialyse
- French speaking Belgian Nephrologists
- Eutox
- Romanian Society of Nephology
- CompCure



Expansion of the EKHA network in 2024 – status June

25 countries



EKHA consists of **56** organisations covering **25** European countries :

- 8 full partners
- 35 affiliated partners
- 13 industry partners

In 2024 our network (so far) grew with:

2 new full partners:

European Rare Kidney Disease Reference Network
European Society for Paediatric Nephrology



3 new affiliated partners

The Association for the Use of the Artificial Kidney in the Paris Region
Albanian Association of Nephrology
Serban Society of Nephrology



3 new industry partners

Bayer
Novo Nordisk
SOBI



EKHA Members overview status June 2025

8 FULL MEMBERS



35 AFFILIATE MEMBERS:



13 SUPPORTERS:



EKHA is a member of **ecda**, **EU4health** and **each**
 european chronic disease alliance
 European Alliance for Cardiovascular Health



MEP Group for kidney Health



EKHA's advocacy work is actively supported by the 22 members of the European parliament that together form the MEP Group for Kidney Health, for which EKHA holds the secretary. Together we create awareness for Chronic Kidney Disease at different policy levels in the EU via campaigns, events and tabling questions during various important reports of the EU commission.

EKHA Project collaboration – PREVENTCKD

Call for proposals on prevention of NCDs - other NCDs

The call targets activities on the transfer of best practices and approaches, which contribute to tackling the burden of NCDs other than those in the five action strands of the 'Healthier Together' initiative.

CONSORTIUM PARTNERS

EKHA (Coordinator)
EKPF
EUTOX
IMEC
ISN
ISS Fundación UAM
RENALOO



OUTPUT OF THE PROJECT (March 2025)

- Data collection on CKD: retrieving new data and updating existing data (in collaboration with AstraZeneca's INSIDE CDK project)
- European code for Kidney Health
- Development and implementation of transferable albuminuria & serum creatinine screening campaigns
- Collect best practices on CKD prevention

The objectives of the project:

- Increase awareness on the characteristics, implications and impact of CKD at EU population level and EU policy level
- Preventing CKD from developing;
- Screening population at risk;
- Stimulate health-management for people with kidney disease prior to the stage necessitating kidney replacement therapy.



Co-funded by
the European Union

EKHA Project collaboration – KitnewCare and HomeFirst

Developing a framework/model to environmentally sustainable and climate-neutral health and care systems using the Kidney care pathway



EKHA became dissemination partner of a 5-year project called KitNewCare. This consortium, existing of 19 organisation of various scientific organisations of the kidney world, patient organisation and industry (amongst others EKPF and EDTNA/ERCA), has the aim to develop a framework/model to environmentally sustainable and climate-neutral health and care systems using the Kidney care pathway.

Pilot countries:

-  Belgium
-  France
-  Italy
-  Netherlands
-  Denmark
-  Spain
-  United Kingdom

HomeFirst: Expanding Patient Access by to Home Hemodialysis (HHD increase ease of chronic dialysis patient access to home hemodialysis care in Europe

Intended outcome: **state-of-the-art HHD inclusion criteria** to better meet patient needs and that can be adapted in home dialysis care protocols, to ensure that needed care is provided by health systems in European “pilot countries”. The project is coordinated by EKHA and supported by MOZARC medical

The following output:

- Whitepaper (September 2024)
- Scientific paper (June 2025)
- Policy paper / event (September 2025)

Is created together with a working group 25 person) of CKD patients, renal nurses and nephrologist of the 6 pilot countries.

Collaboration with European Chronic Disease Alliance (EDCA)



CKD and NCD Prevention Code

- EKHA & ECDA are collaborating to create a NCD prevention code
- The code will have a specific section for each NCD. EKHA will ensure that the content is aligned with the CKD code.



Paper on Environmental Health

- Fully aligning the revised EU Ambient Air Quality Directives with the WHO Air Quality Guidelines.
- Introducing EU provisions to strengthen the effectiveness of countries' air quality plans.
- Supporting integrated policy approaches & greater research on broader environmental risk factors that play a role in the onset of diseases and warrant political attention
- New messages on the impact of the healthcare sector on the environment, using the example of dialysis

Collaboration with the European Alliance for Cardiovascular Health (EACH)

Fact Sheet

CHRONIC KIDNEY DISEASE

Numbers don't lie.



CHECK YOUR NUMBERS

Data-driven policy for cardiovascular health.



1 CHRONIC KIDNEY DISEASE (CKD)



Chronic Kidney Disease (CKD) affects approximately

100 MILLION PEOPLE IN EUROPE

AND IS PREDICTED TO BECOME

#5

leading cause of life years lost by 2040

Source: Foreman, Lancet, 2018

2 PREVALENCE



The pooled prevalence of possible CKD in Europe is **12%**



with many CKD patients unaware of their condition due to lack of **EARLY DIAGNOSIS.**

Source: Verhulder, Clin Kidney J, 2021

3 DIAGNOSIS AND TREATMENT



1 + 3 patients with cardiovascular disease DEVELOPS CKD

RISK OF CARDIOVASCULAR DEATH IS

2x from the early-on stages, and up to **1000x** at the advanced stages.

Source: Aronson, Rev Esp Cardiol, 2013; Matsushita, Nat Rev Nephrol, 2020; Foley, Am J Kidney Dis, 1998

4 ECONOMIC IMPACT



Chronic Kidney Disease (CKD) creates A SUBSTANTIAL ECONOMIC BURDEN, leading to healthcare costs that reach:

€140 billion annually in Europe.

Source: Verhulder, Clin Kidney J, 2021

CHECK YOUR NUMBERS



EKHA is member of the alliance for Cardiac Health (EACH). One of the projects was to develop visuals on the cardiovascular disease burden.

Alongside four factsheets on CVD and one on stroke, EKHA helped develop a factsheet on CKD, considering the bi-directional link between CVD and CKD.

Campaigns & Events



World Kidney Day

On March 9, during World Kidney day, EKHA held an online campaign on the **World Kidney Day 2023** theme 'Preparing for the unexpected, supporting the vulnerable' highlighting the significant impact of disastrous events on the kidney community. Disasters result in serious disruptions of the functioning of a society causing widespread human, material, economic or environmental losses.

Prof. Em. Raymond Vanholder, Prof. Dr. Dmytro Ivanov, Prof. Dr. Serhan Tuğlular, and Mr. Daniel Gallego discuss how and why those affected by kidney disease are particularly affected by disaster situations, as well as their needs in times of crisis. Click [here](#) for the full conversation.



There is also a big impact on patient's mental health, having lost so many fellow patients to COVID-19 and living in constant fear of infection. We saw many patients with zero immune response after full doses of vaccination, so you can imagine the fear and uncertainty they must deal with.

Mr. Daniel Gallego
PRESIDENT, EUROPEAN KIDNEY PATIENTS FEDERATION

Nephrologists and patients need clear guidelines on nephrology care when faced with disaster situations. These could also be shared with governments and healthcare professionals to inform them how to better care for patients.

Prof. Dr. Dmytro Ivanov
PRESIDENT, INTERNATIONAL ASSOCIATION OF NEPHROLOGISTS

It is our responsibility as medical community, together with patients, to convince policymakers that disaster preparedness should include kidney disease. We need more patient advocacy, involvement, and empowerment.

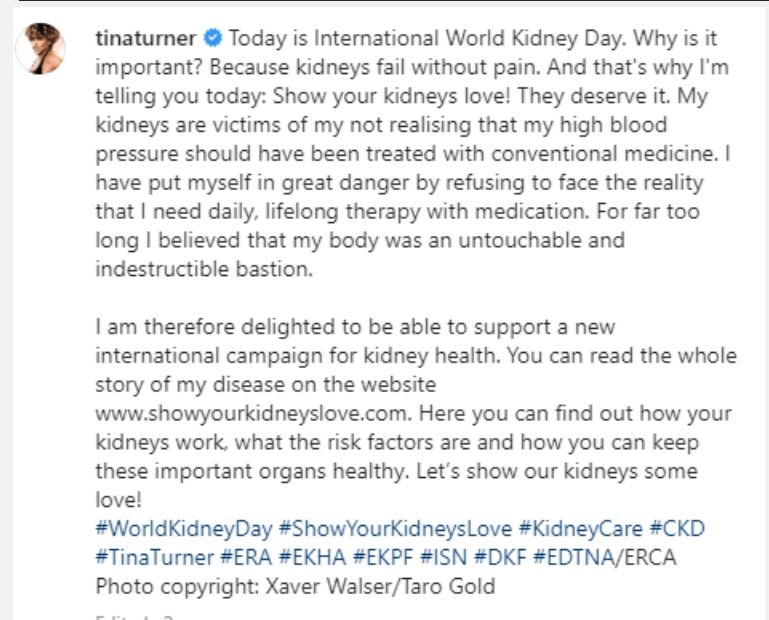
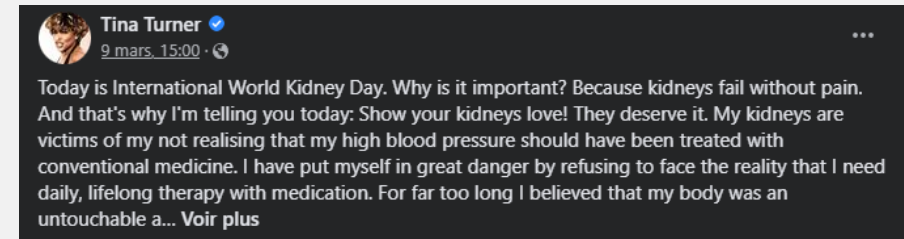
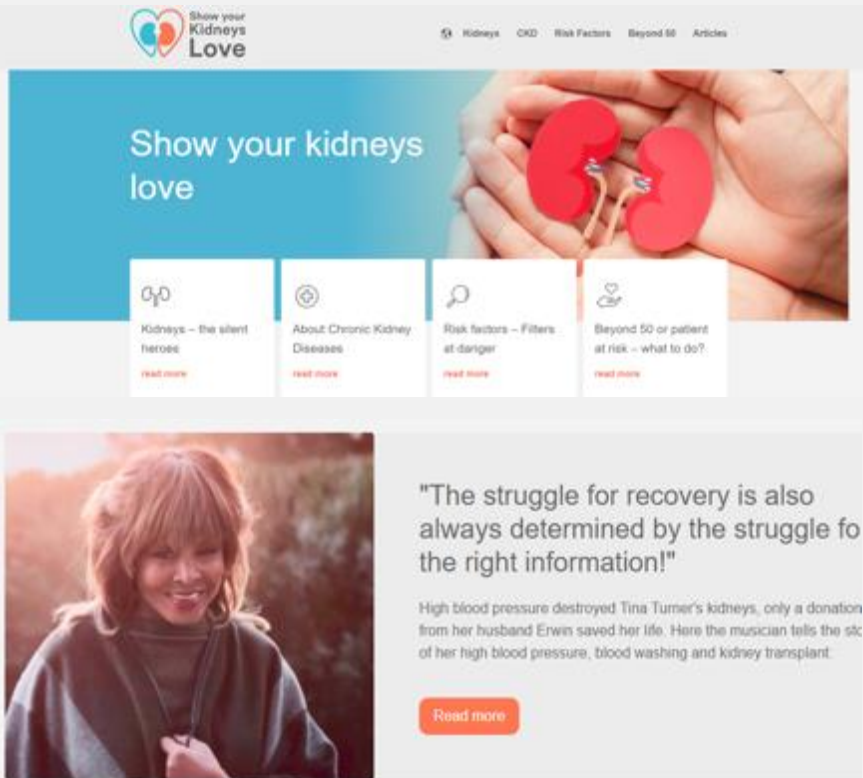
Prof. Em. Raymond Vanholder
PRESIDENT, EUROPEAN KIDNEY HEALTH ALLIANCE

Preparedness is crucial. Disasters may occur anywhere but preparation is vital to mitigate effects, which implies planning during the disaster-free period. Collaboration between national and international nephrology societies is essential. This should also include nurses and other healthcare professionals in contact with kidney patients as well as patients themselves.

Prof. Dr. Z. Serhan Tuğlular
CHAIR, RENAL DISASTER RELIEF TASK FORCE OF THE EUROPEAN RENAL ASSOCIATION

Awareness raising campaign with Tina Turner

The Show your Kidneys Love campaign draws from the inspirational story of Tina Turner, who leaves both a musical and medical legacy as she recounts her struggle with CKD. In sharing her story, Tina Turner hoped to raise awareness about CKD and the importance of screening and early detection: a simple urine test could prevent dialysis and transplantation.



- Launched on World Kidney Day 2023
- Facebook & Instagram: **45,000 likes + 1200 comments** from fans sharing their direct or indirect story with kidney disease
- Media coverage: headlines in German, Austrian and Belgian newspapers, including a mention in a German TV channel
- Follow up with an **infographic** that outlines our kidneys' role, the impacts of chronic kidney disease (CKD), key risk factors, and offers insights on ways to prevent CKD.



Celebrating 80 years of dialysis: time again for science fiction



Event on April 26, to raise awareness of the need for innovative kidney replacement therapies in the European Parliament hosted by MEP Knápek (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 Kolff](#)

Key take aways

- Lack of awareness about CKD & the need for innovation at EU level
- Need patient-centred research & innovation
- EU needs binding, ambitious targets for innovation in health
- ERC provides grants for ground-breaking, frontiers research.
- EKHA members invited to apply for ERC Grants.

Key results

- ❖ New EKHA supporter: Prof Liselotte Højgaard (European Research Council - ERC)
- ❖ Documentary well-received



Celebrating 80 years of dialysis: sharing stories

Patient story and poster exhibition displayed during the event of April 26 and networking reception

A tribute to Delphine

Delphine was a kidney failure patient who died on the 18th of June 2022, at the age of 45 years old, ten days after voluntarily stopping her dialysis treatment. She had suffered kidney disease in her childhood and had been bound to a dialysis machine ever since. She only came out of it three times for short-lived transplants. The most recent one lasted less than a year. Delphine's life-long suffering had inspired her to create a blog where she would share her story with others, and to be involved in patient associations.

A few months before she passed away, Delphine had expressed her wish to end dialysis, thus her life. She consulted the palliative care team and the hospital's psychiatrists who did not diagnose depression. On the 9th of June, Delphine announced to her community that she will no longer undergo dialysis. She was hospitalized on the 12th of June and the nephrology and palliative care teams accompanied her up till the end. On the 17th of June, Delphine was still communicating with her family and her many followers on Twitter. She died during the night.

The alternation of dialysis and transplantation kept Delphine alive for more than three decades. Her life could have been longer, even if the hope of a fourth transplant was slim. Yet, she made the choice to end her life, which she felt was no longer worth living.

Dialysis saves lives but it can also considerably affect patients quality of life. The vast majority of patients must undergo dialysis three times a week for a duration of four hours each. This is the minimum necessary for survival, but it comes at a high price: dependence on the machine, exhaustion, persistent symptoms, dietary constraints, thirst, burden of travelling to and from the dialysis centre, struggle in maintaining a professional activity and going on holidays, loss of freedom, and many more.

These difficulties are undoubtedly more bearable when a transplant is expected. But when this prospect is distant, unlikely or simply impossible, dialysis can become, in the words of patients: a prison, a nightmare, a hardship, hell.



The story of Delphine should serve as a wake-up call for European and national policy makers. Current research and promising prototypes in kidney replacement therapies offer new hopes to patients. More funding and incentives are now needed to fully unlock their potential. No single kidney patient should ever feel again that life is not worth living.



The world urgently needs drastically better KIDNEY REPLACEMENT THERAPIES

Present therapies are inadequate



Kidney Failure
"Kidney failure means that without kidney replacement therapies, the patients die"



Transplantation

Best & cheapest kidney replacement therapy option but:
- Structural shortage of transplant kidneys (many patients die while on the waiting list)
- Immunosuppressive drugs prevent transplant rejection but also increase risk of cancer & infections
- Still up to 25% shorter life expectancy



Dialysis

Most widely used kidney replacement therapy 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 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 per patient annually in Europe



High mortality
The average life expectancy of patients on dialysis is worse than most people diagnosed with cancer; 2/3 of patients die without access to kidney replacement therapies

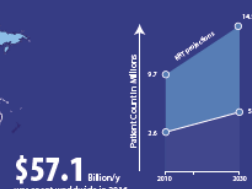


A substantial carbon footprint
Dialysis generates lots of plastic waste and is responsible for up to half of healthcare emissions. The quantity of CO2 emitted by one hemodialysis is equivalent to that of a 238 km car drive

Worldwide costs keep rising unsustainably



Yearly Dialysis Cost & Country Wealth
 1.7 billion\$ per year in low-lower income countries
 19.7 billion\$ per year in upper-middle income countries
 45.7 billion\$ per year in high income countries



\$57.1 billion\$ was spent worldwide in 2016 (including transplantation and acute kidney injury)

Legend:
 ■ Patients needing kidney replacement therapies
 ■ Patients receiving kidney replacement therapies*

Bundle the best brains to build better treatments



THE HISTORY OF DIALYSIS

MID-19TH CENTURY



Thomas Graham (1805-1869) discovered the phenomenon of osmosis and published the laws of it.

1913



Dr. Willem Kolff participated in the first artificial kidney experiment at the University of Groningen.

1924



Dr. George Minot performed the first artificial kidney experiment in Boston.

1942



Dr. Willem Kolff performed the first artificial kidney experiment in Groningen.

1945



Dr. Willem Kolff performed the first artificial kidney experiment in Groningen.

1950's



Dr. Willem Kolff performed the first artificial kidney experiment in Groningen.

1954



The first artificial kidney experiment in Boston.

1962



The first artificial kidney experiment in Boston.

1965



The first artificial kidney experiment in Boston.

1967



The first artificial kidney experiment in Boston.

MID 1970's



The first artificial kidney experiment in Boston.

1989



The first artificial kidney experiment in Boston.

The basic concept of hemodialysis has hardly changed since the original prototype developed by Dr. Willem Kolff in 1942. Current dialysis treatments remain inefficient and difficult to use for patients, costly for healthcare systems and polluting for the environment.

There is a pressing need to stimulate innovation in this field.

Annual Policy event in the European Parliament

2023 European Kidney Forum

- ❖ Highlight the benefits of switching to green nephrology for patients, healthcare systems and the economy
- ❖ Promote cost-efficient solutions in the short and long run to alleviate the environmental burden of kidney care and spur innovation
- ❖ Discuss ways to reduce the negative impact of climate change and the energy crisis on kidney patients and healthcare systems
- ❖ Raise awareness of the bidirectional links between kidney health and the environment
- ❖ Create a forum for all parties involved (industry, patients, healthcare professionals, dialysis centers, decision-makers) to collaborate on green nephrology
- ❖ Identify and push forward relevant EU initiatives that can support the green nephrology transition

The FORUM was made possible with the support of the following EKHA supporters:



European Kidney FORUM 2023

Key take-aways

- ↔ Bi-directional link between kidney care and the environment
- 🕒 The need for concrete and forward-looking solutions to the environmental burden of dialysis: Green Nephrology practices
- 👨‍⚕️ Important role of healthcare providers in promoting Green Nephrology
- 👨‍⚕️ Important role of prevention, transplantation and innovation in limiting the environmental impact of dialysis
- 🇪🇺 Role of the EU in increasing awareness, providing funding, and putting these issues high on the EU policy agenda.

Key results

- ❖ Highly interactive event with participation from wide range of stakeholders
- ❖ 55 participants incl.: doctors, nurses, patient representatives, industry, policymakers from the Commission and Parliament
- ❖ Attendance of several MEPs and their assistants
- ❖ Outstanding engagement on social media / very positive feedback from all attendees
- ❖ New and stronger relationships with MEP Juozas Olekas, European Commission Policy Officer Ms Petra Leroy Cadova and non-profit organisation Healthcare Without Harms



Communication & publications



EKHA Publications 2023

EKHA POSITION PAPERS

- **Open letter:** Call for a renewed EU action plan on organ donation and transplantation in the 2024-2029 mandate. Available [here](#)
- **Improving care and awareness of CKD** – Raymond Vanholder, Eveline Scheres. Available [here](#)
- **A Stitch in Time: Early Intervention to Tackle Europe’s NCD Crisis** – PHSSR EU EXPERT ADVISORY GROUP REPORT including Raymond Vanholder. Report is available [here](#)
- **Transplantation in Germany in a European context** – Raymond Vanholder, editorial in DIATRA magazine 4-2023. Available [here](#).



EKHA HAS AUTHORED OR CONTRIBUTED TO THE FOLLOWING SCIENTIFIC PUBLICATIONS

- Vanholder et al, **Inequities in kidney health and kidney care.** Nat. Rev. Nephrol 2023. Available [here](#)
- Sever et al. **Disasters in kidney care: pitfalls and solutions.** Nat. Rev. Nephrol 2023. Available [here](#)
- Pawlowicz-Szarska et al, **Distribution, preparedness and management of Ukrainiann adult refugees on dialysis – an international survey by the Renal Disaster Relief Task Force of the European Renal Association.** Nephrol. Dial. Transplant 2023. Available [here](#).
- Vanholder et al, **Policy forum in the European Parliament: Calling for a paradigm shift towards green kidney care.** J. Nephrol 2023. Available [here](#).
- Vanholder et al, **A policy call to address rare kidney disease in health care plans.** Clin. J. Am. Soc. Nephrol., 2023. Available [here](#).
- 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
- Ramada et al, **Portable, wearable and implantable artificial kidney systems: needs, opportunities and challenges.** Nat. Rev. Nephrol 2023. Available [here](#).
- Tuglular et al, **Lessons learnt during the war in Ukraine: a report from the Renal Disaster Relief Task Force of ERA.** Nephrol. Dial. Transplant. 2023. Available [here](#).
- Boenink et al. **Factors influencing kidney transplantation rates.** Nephrol. Dial. Transplant, 2023. Available [here](#).
- Stigant et al, **Our Shared Responsibility – The Urgent Necessity of Global Environmentally Sustainable Kidney Care.** Kidney Int, 2023. Available [here](#).

EKHA presentations and lectures (1st semester 2023)

1. R. VANHOLDER. Nephrology in crisis situations – from earthquakes to COVID-19. International Pediatric Nephrology Association (IPNA) - American Society of Pediatric Nephrology (ASPN). Third annual global health online symposium (virtual). February 8, 2023
2. R. VANHOLDER. Structure of European Kidney Health Alliance. PerMedik – improved outcomes based on big data. Second work group meeting. Pissouri Beach, Cyprus. March 2-4, 2023.
3. R. VANHOLDER. European Kidney Health Alliance. EUTox meeting. Pissouri Beach, Cyprus, March 4, 2023.
4. O. KNOTEK, R. VANHOLDER, D. GALLEGO, K. NAEEM, D. HUMPHREYS. Panel discussion. Chronic kidney disease: driving change to address the urgent and silent epidemic in Europe. Webinar organized by Economist Impact (virtual). March 7, 2023.
5. R. VANHOLDER. An eye into the International Home Dialysis Resource Center. 2023 Global Home Dialysis Summit (virtual). March 15, 2023.
6. R. VANHOLDER. Introductory remarks. Celebrating 80 years of dialysis. European Parliament. Brussels, April 26, 2023.
7. R. VANHOLDER. European Kidney Health alliance -Accomplishments and importance of being a member of both European renal association and European Kidney Health Alliance. Meeting with the National Societies of Nephrology of European countries. Milan, June 14th, 2023.
8. R. VANHOLDER. Is there still a place in the future for home hemodialysis? 60th congress of the European Renal Association, Milano, 15-18 June, 2023.
9. R. VANHOLDER, E. SCHERES. The important interaction science and advocacy at influencing European policy. European Kidney Health Event, 60th congress of the European Renal Association, Milano, 15-18 June, 2023.
10. R. VANHOLDER. The future of kidney care. Meet Mozarc Medical: building the future of kidney care together. Milano, 16 June, 2023.
11. R. VANHOLDER. Raising awareness of CKD as global health priority.:European Kidney Health Alliance (EKHA). Global Alliance for Kidney Health Steering Committee Meeting. Global Alliance for Patient Access (GAfPA). Milano, 17 June, 2023.
12. R. VANHOLDER. Health care in disasters: from earthquakes to armed conflicts. Probus group Groene Rand. Ter Heide, Lembeke, 22 June 2023.
13. R. VANHOLDER. Kidney health and the environment: a neglected bidirectional link. European Kidney Forum: The future of kidney care – Investing in green nephrology to meet the European Green Deal targets. European Parliament, Brussels, June 28th, 2023.
14. R. VANHOLDER. Concluding remarks. European Kidney Forum: The future of kidney care – Investing in green nephrology to meet the European Green Deal targets. European Parliament, Brussels, June 28th, 2023.
15. R. VANHOLDER. Nephrology in crisis situations – from earthquakes to armed conflicts. Global eventg kidney patients care: lessons for the future. Fifth annual global summit on kidney disease innovations. American Association of Kidney Patients / George Washington University School of Medicine and Health Sciences (virtual). Washington DC, USA, June 28-29, 2025.

EKHA presentations and lectures (2nd semester 2023)

16. R. VANHOLDER. Is there enough resilience in the system? Caring in times of crisis. 21st Congress of the European Society of Organ Transplantation (ESOT). Athens, 17-20 September 2023.
17. R. VANHOLDER. A policy call to address rare kidney disease in healthcare plans. Spotlight on rare diseases – stakeholders respond to organized patient voices. 48th national patient meeting USA. American Association of Kidney patients (virtual). September 20-22, 2023.
18. R. VANHOLDER. Reimbursement of dialysis. Nordic PD Council Meeting. Gdansk 2-3 October, 2023 (virtual).
19. R. VANHOLDER. Sustainable dialysis in practice. Hemodialysis update: from theory to practice. Edegem, 6-7 October 2023.
20. E. SCHERES. Setting the scene at Roundtable “Doing better for Europe’s NCD population: earlier intervention to transform outcomes for people and planet”. Brussels, European Parliament, October 10, 2023
21. R. VANHOLDER. Plenary lecture: Chronic kidney disease: an update. 10th Congress of the Croatian Society of Nephrology. October 12-15, 2023.
22. E. SCHERES, J. FINDERUP. EDTNA/ERCA session “The pivotal role of kidney nurses in managing kidney disease” during their 51st International Congress. Vilnius October 16, 2023.
23. R. VANHOLDER. European Kidney Health Alliance (EKHA). 18th BANTAO Congress / Meeting Hellenic Society of Nephrology. Thessaloniki, October 19-22, 2023.
24. R. VANHOLDER. Towards green kidney care. Vlaamse Universiteit Brussel (VUB). Jette, 6 November, 2023.
25. R. VANHOLDER. Green nephrology. Italian Society of Nephrology, Bologna, 18 November, 2023.
26. R. VANHOLDER. Making dialysis more sustainable. Lent/Nijmegen, 29 November, 2023.
27. R. VANHOLDER. How to do advocacy. EuroPD meeting, Brugge, 30 November, 2023.

EKHA Social Media Presence

Twitter

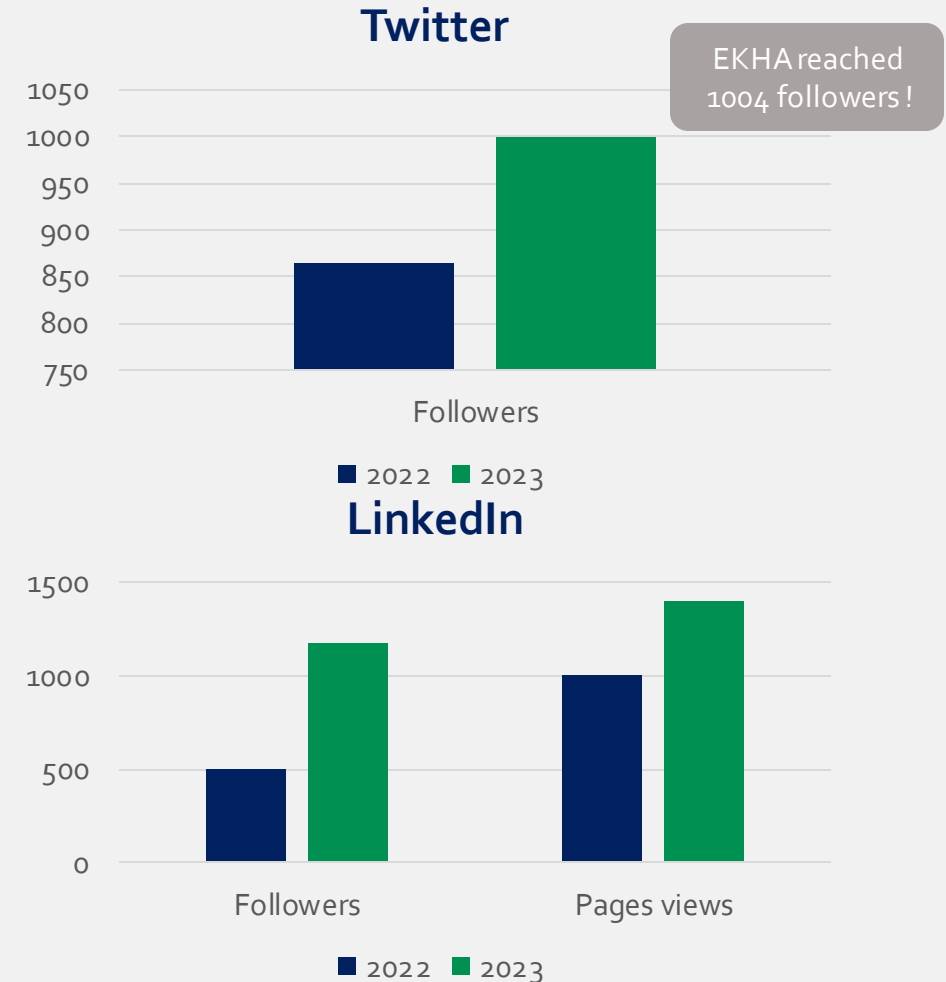
- In 2023, EKHA twitter posts made 177.6K impressions
- On average EKHA earned
 - 1 link click per day
 - 3 likes per day
 - 1 retweet per day


In 2022, these numbers were zero !

LinkedIn

- In 2023, EKHA LinkedIn posts made 60K impressions
- EKHA achieved in 2023
 - 1400 pages views
 - 1183 followers

20K more than in 2022 !





Public Affairs activities in 2024 (Q1-Q2)

EKHA Kidney Manifesto & Show Your Kidneys Love infographic



EKHA launched its Kidney Manifesto and "Show Your Kidney Love" infographic

- Successful dissemination through EKHA's social media channels, website, and the EKHA Network
- Shared with EU policymakers, including Members of the European Commission, European Parliament, and Council of the EU
- Distribution to EU journalists for wider visibility.



Engagement and media coverage

- Manifesto and Infographic were well-received and gained significant online traction
- Featured in Politico Pro Healthcare Newsletter (prominent EU health news outlet)



Acknowledgment and Meetings

- Confirmation of receipt and thanks received from multiple members of the European Commission, including Commissioner Kyriakides.
- Met with Stefan Schreck (Adviser for Stakeholders Relations, Public Health, Cancer, and Health Security, DG SANTE) in mid-February.



Open for endorsement

Hungarian Presidency of the Council of the EU: Workshop on Organ Donation and Transplantation



EKHA Open Letter on Organ Donation & Transplantation

- EKHA met with HU Perm. Rep. and Ministry of the Interior to discuss plans for the Presidency
- HU asked EKHA to contribute to the drafting of Council Conclusions on Organ Transplantation



Workshop on Organ Donation and Transplantation

- EKHA proposed to convene a workshop gathering EU stakeholders in this area, to inform the Council Conclusions
- EKHA and the HU Perm. Rep. organised a successful workshop on Organ Donation and Transplantation with >25 stakeholders



Workshop Report

- EKHA drafted a concept paper reflecting the insights gathered in the workshop
- This report was submitted to the HU Presidency to inform the shaping of its Council Conclusions

HU Presidency of the EU: next steps

Council Conclusions on organ transplantation

- Current **draft based on EKHA's concept paper** developed after January's workshop
- Include **call for a second EU action plan on organ donation and transplantation**
- The Presidency expects **straightforward adoption** of the Council Conclusions

Events

High-Level Conference on Organ Transplantation (10-11 July)

- **Prof. Vanholder** to speak on the panel on inequities in organ donation and transplantation
- Adoption of **Council Conclusions on Organ Transplantation**

High-Level Conference on Cardiovascular Disease (3-4 July)

- **Eveline Scheres** to attend on behalf of EKHA
- Adoption of **Council Conclusions on Cardiovascular Disease**



Renew Europe workshop

Background

- "Healthcare in the EU: A Patient-Centric Approach"
- Organised by the Renew Europe (centrist) group in the European Parliament
- Brought together leading European patient/health organizations
- In-depth dialogue on the healthcare achievements during the current mandate
- Explore priorities for the next mandate



Outcomes

- EKHA participation
- Shared position on current mandate: lack of attention given to CKD in EU policies
- Shared priorities for the next mandate
 - Improving prevention
 - 2nd EU Action Plan on organ donation and transplantation
 - Foster innovation in kidney therapies



World Kidney Day 2024

Kidney Health for All – Advancing Equitable Access to Care and Optimal Medication Practice

Online communications campaign

- To draw attention to World Kidney Day

Activities

- Series of social media posts (incl. visuals)
- Website article published on WKD 2024
- Inclusion in March Newsflash
- Article shared with EU media channels

Outcomes

- High engagement on social media
 - Twitter: >100 likes and retweets
 - LinkedIn: >200 likes and reposts



Engagement with the BE Presidency of the EU



EKHA met with representatives of the Belgian Presidency of the Council of the EU to present EKHA priorities

March 2023



BE Presidency team invited EKHA to participate in a stakeholder consultation on the Presidency's priorities in health

November 2023



EKHA invited to attend the High-Level Conference on the Future of the EU Health Union

26-27 March 2024



EKHA invited to attend and speak at the High-Level Conference on Needs-driven healthcare and innovation policy

17-18 April 2024

BE Presidency High-Level Conference 'Health-related needs as drivers for healthcare policy and innovation'

Outcomes

Patient testimony on unmet needs related to kidney disease (EKHA representative)

- Burden of dialysis on patient quality of life and health systems
- Lack of innovation in KRTs and promising new KRTs
- Transplantation & EU's role in addressing organ shortages
- Call on the EU to invest in solutions that address the needs of kidney patients

Networking

- Reconnect & strengthen EKHA relationships
 - European Directorate for the Quality of Medicines & Healthcare (EDQM)
 - Friends of Europe (FoE)
 - Belgian Healthcare Knowledge Centre (KCE)



ECDA Policy Debate



Policy Debate

- ECDA organised a pre-recorded policy debate w/ experts, MEPs and the Commission on NCD Prevention
- Launch planned for World Health Day (7 April)



Communications content

- EKHA drafted the communications content to promote the event

Video message

- Daniel Gallego shared a video message on behalf of EKHA, which will be used to promote the event



European Kidney Forum 2024 2025



- Week of 27 January 2025
- Brussels European Parliament



- Logistical challenges in booking venues before September due to EU elections
- Allow adequate time to create a compelling, successful exhibition
- Fewer legislative responsibilities in January: opportune moment to connect with MEPs

Exhibition "*Improving CKD screening and early detection in Europe*"

- Raise awareness & call for better secondary prevention in Europe
- Share EKHA Kidney Manifesto recommendations

Interactive event

- Informational brochures & exhibition-style informative posters
- At-home screening kits
- Interactive VR headsets
- Livestream Dialysis

Roundtable:

- Kick-off the exhibition with a 1,5h Roundtable in the EP



EKHA social media presence

Twitter & LinkedIn



- Maintained a high level of activity and engagement on social media through regular updates on X (Twitter) and LinkedIn
 - EKHA activities
 - Publications
 - Latest EU health policy developments



- >1000 followers on X and >1500 followers on LinkedIn



Activity planning 2024 and 2025

2024

- June 11: EKHA General Assembly
- June – December: EP elections campaign
 - MEP outreach 17-19 September in Strasbourg
- September 30: follow up industry meeting of May 16
- October: draft action plan for 2025
- October 24: EKHA online network meeting for all members: follow up on the workshop on organ donation and transplantation
- December: definite action plan for 2025

2025 (first provisional planning)

- Week of January 27: EKHA FORUM, Exhibition and network meeting
- March: EKHA online network meeting (topic t.b.d)
- March 13: World Kidney Day
- June: General Assembly and Industry network meeting
- September: possible launch of 'home first'
- November: EKHA online network meeting (topic t.b.d)



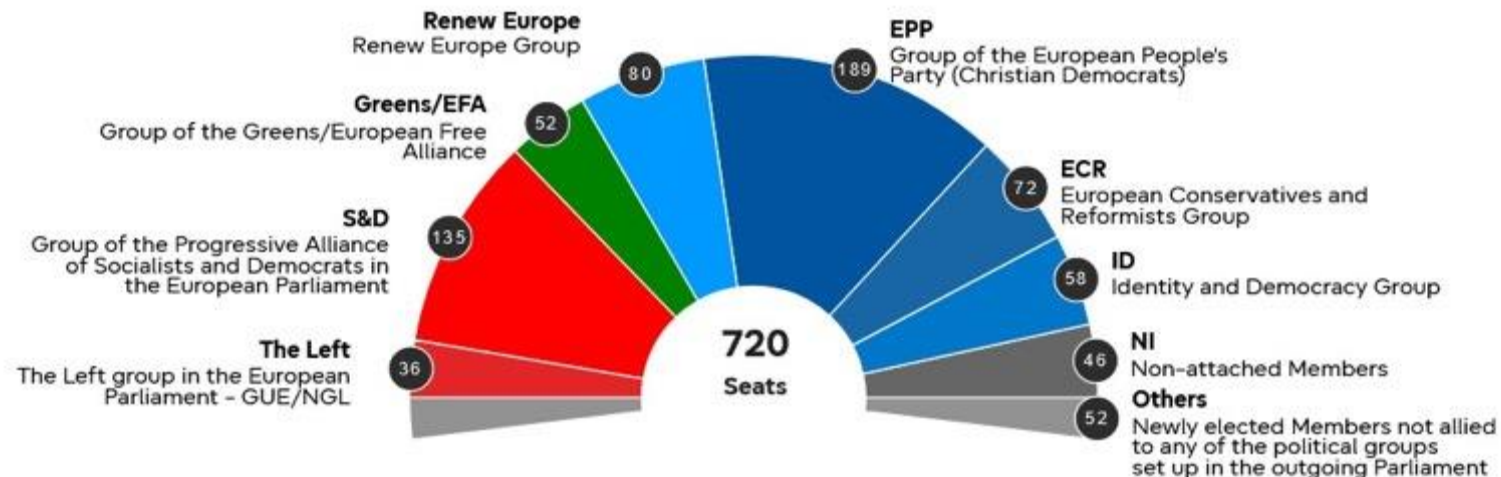
Discussing the outcome of the 2024 EP Elections & EKHA follow up

EU Elections outcomes

- Shift to the right, with populists and far right taking up to 25% of the European Parliament seats
- Centre-right EPP wins the elections and remains the largest political group:
 - A controlling position within the EP
 - Holding almost half the seats in the European Council and similar domination of the future Commission
 - Their agenda focused on competitiveness, security and less burdens on business and farmers will win out.
- EPP, the Socialists (S&D) and Liberals (Renew) should be able to form a pro-European majority

European Parliament 2024 - 2029

Provisional results



Overarching trends

- Shift to the right, means a pro-business agenda (Competitiveness, bringing manufacturing back to Europe, promoting innovation, promoting business-friendly environment)
- EPP seen as the winner of these elections, good news for health

European Green Deal

An unfinished business

European Defence

A response to the Ukraine war

Industrial Sovereignty

Industrial Sovereignty

Global Trade

As a tool to secure supply chains

Artificial Intelligence

Playing catch up with technology

De-risking Approach

Not de-coupling from China

Health priorities of main political groups



- **Equity** tackled (health, gender, age, territorial equity)
- Cross-border **health threats**
- **Resilience** of health systems, diversification of **supply chains**, boosting the health **workforce**
- **Rare disease:** Improving access to clinical trials, Boosting research funding
- **Flagship initiatives:** *European actions plans on rare diseases, CVDs and Alzheimer's and dementia, European Guarantee for older citizens*



- EU cooperation on health threats and shortages
- **Timely access to innovation incl. for rare diseases, fair & transparent medicines' pricing**
- Initiatives for **common EU public research on vaccines & lifesaving medicines**
- Guarantee access to **sexual-reproductive rights**

Flagship initiatives: *Strategy on Age Equality; Anti-Discrimination Directive; European Plan for Affordable Housing; EU Strategy for Combatting Homelessness, European Mental Health Strategy*



- **Almost no mentioning of health in the Manifesto** aside from right to abortion.
- **Health equity** partially addressed, in terms of LGBTI+ rights and gender equity
- Suggests to **enshrine LGBTI+ rights in EU legislation;** fast-track the **Horizontal Equal Treatment Directive**

Overarching health trends

European pharmaceutical package

Patient access, pharma incentives

Digitalisation and European Health Data Space

Common approach on primary, secondary use

Crisis preparedness, planning & resilience

Pandemic Treaty and HERA

Strategic autonomy

Medicines supply security

Global health

EU's agenda on international scene

One Health

Antimicrobial Resistance

Possible health champions – returning MEPs



Hilde Vautmans
Renew, AFET



Sirpa Pietikäinen
EPP, ECON, FEMM, Rapporteur common
European action on care



Dolors Montserrat
Former Minister of Health of Spain; rapporteur
A pharmaceutical strategy for Europe



Ondrej Knotek
Renew, REGI, ENVI, SANT,



Andreas Glück
Medical doctor (surgeon); shadow rapporteur
for SoHO



Peter Liese
Medical Doctor; EPP coordinator in ENVI



Tiemo Wölken
S&D coordinator in ENVI; rapporteur
Pharmaceutical Regulation and the HTA Regulation

Possible new Health champions – new MEPs



Marta Temido

Former Minister of Health
Master's in Health Economics and
PhD in International Health



Leire Pajín

Former Minister of Health, Social
Policies and Equality of Spain



Vlad Voiculescu

Former Minister of Health of Romania
Founder of Cyostatics Network and MagiCAMP
Association



Wouter Beke

Former Flemish Minister for Welfare, Public
Health, Family and Poverty Reduction



Yvan Verougstraete

Founder of Pharmacies chain Medi-Market in
Belgium and Luxembourg



Alma Ezcurra

President of the Health Committee of the Madrid
Regional Assembly

Possible new Health champions – new MEPs



Mélissa Camara

Activist on certain key health issues like asthma and equity issues for the most vulnerable groups



Grégoire Allione

Firefighter; Director of the National School of Fire Officers



Jascha Dopp

Civil servant, referee for EU affairs incl. health)



Sylvie Gustave

PhD in Neuroscience and Neurobiology



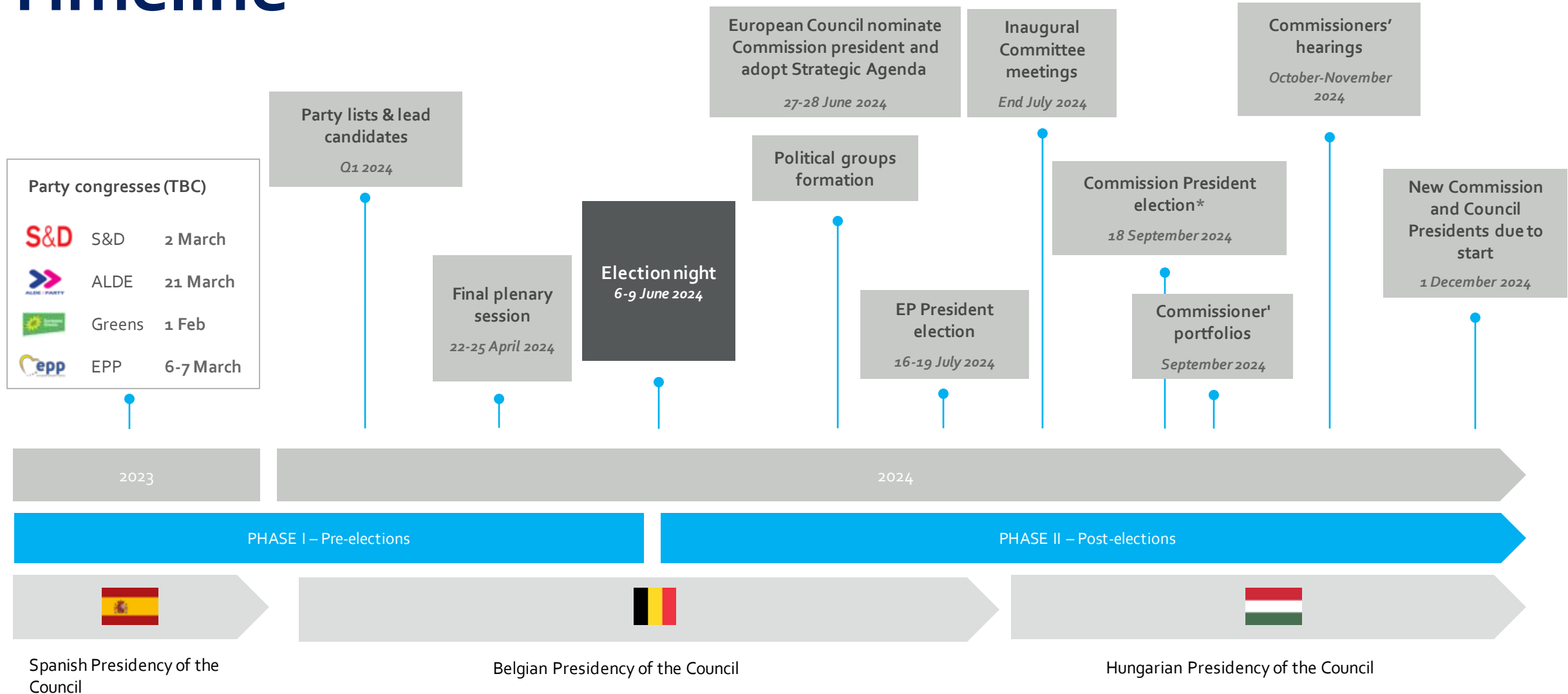
Laurent Castillo

Medical doctor and Professor of Medicine and Surgery

MEP Group for Kidney Health

| | | | | | | | |
|--|---|---|---|--|--|--|---|
|  <p>Hilde Vautmans (Renew Europe, BE) CO-CHAIR</p> |  <p>Ondřej Knotek (Renew Europe, CZ) CO-CHAIR</p> |  <p>Peter Liese (EPP, DE)</p> |  <p>Aldo Patriciello (EPP, IT)</p> |  <p>Sirpa Pietikäinen (EPP, FI)</p> |  <p>Christel Schaldemose (S&D, DK)</p> |  <p>Annie Schreijer- Pierik (EPP, NL)</p> |  <p>Frances Fitzgerald (EPP, IE)</p> |
|  <p>Martin Buchmann (NA, DE)</p> |  <p>Olivier Chastel (Renew Europe, BE)</p> |  <p>Brando Benifei (S&D, IT)</p> |  <p>Cindy Franssen (EPP, BE)</p> |  <p>Rasa Juknevičienė (EPP, LT)</p> |  <p>Marian-Jean Marinescu (EPP, RO)</p> |  <p>Liudas Mažylis (EPP, LT)</p> | |
|  <p>Juozas Olekas (S&D, LT)</p> |  <p>Biljana Borzan (S&D, HR)</p> |  <p>Cesar Luena (S&D, ES)</p> |  <p>Jutta Paulus (Greens/EFA, DE)</p> |  <p>Karlo Ressler (EPP, HR)</p> |  <p>Sara Matthieu (Greens/EFA, BE)</p> |  <p>Ruža Tomašić (ECR, HR)</p> | |

Timeline



**TBC: The election of the Commission President could already occur during the July plenary session, instead of the September plenary session, if political groups opt for this.*

EKHA EU Elections outreach



Manifesto endorsement

- EKHA Manifesto is open for endorsement
- Show a united kidney health community and strong support



Communication campaign

- Launch communication campaign to disseminate EKHA's Kidney Manifesto in the wake of the EU Elections



Outreach to MEPs

- Reach out to newly elected MEPs to congratulate & request a meetings
- Share Manifesto and meeting
- Invite to join the MEP Group for Kidney Health



Commissioners' Hearings

- Work with MEPs to raise EKHA question at the Commissioner's Hearings (oral & written)



Strasbourg Plenary: Outreach to MEPs

Concept

- Strasbourg EP Plenaries present **perfect opportunities to network with MEPs**
- **The EKHA PA team to travel to Strasbourg after the EU Elections**
 - Meet MEPs
 - Introduce MEPs to EKHA & its priorities for the new mandate
 - Invite MEPs to join the MEP Group for Kidney Health
- The team: **Ray Vanholder, Eveline Scheres, Alicia Bé**
- Dates: **16-19 September**

Objectives

- Schedule **formal meetings with MEPs**
- Attend plenary sessions and committee meetings to **identify key MEPs**
- Attend networking events to **interact informally with MEPs & build relationships**



EU Elections 2024: communications toolkit

A communications toolkit to reach out to MEPs & disseminate the Kidney Manifesto & foster productive relationships

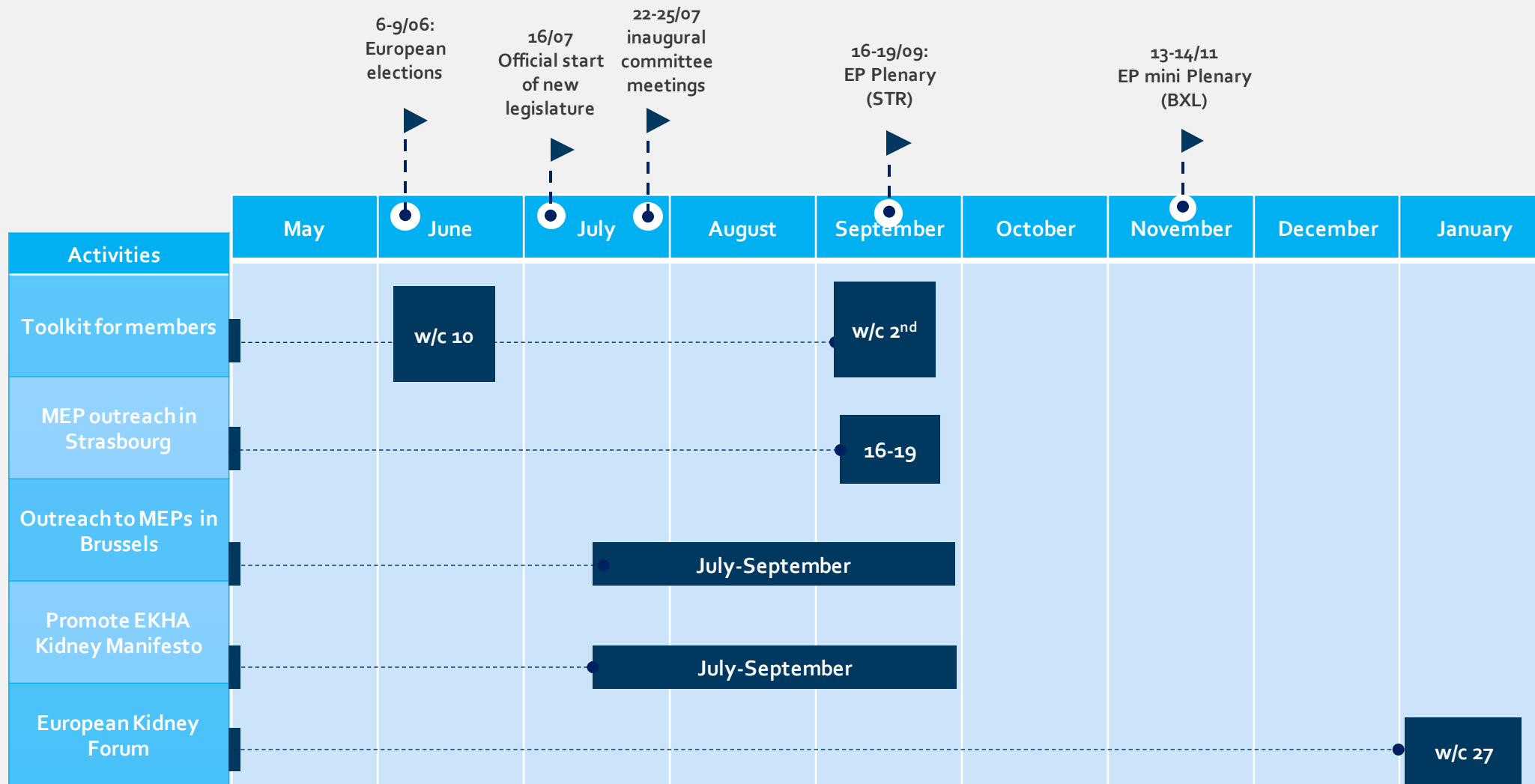
Contents

- **Elections outcomes**
 - Analysis of results
 - Facts & figures
- **Messaging guide**
 - Summary of the key priorities and messages of the Kidney Manifesto, with the key targets.
- **Template letter**
 - A template letter that members can adapt.
- **Template social media & website contents**
 - 3-4x template social media posts for social media.
 - Template website article.
- **List of elected MEPs**

Timeline

- Toolkit will be shared following the General Assembly
- September: re-circulate full toolkit







Introduction of new members



LEADING THE WAY IN TRANSPLANTATION

June 2024

WHO WE ARE

The European Society for Organ Transplantation (ESOT) was founded in 1982 and is dedicated to the pursuit of excellence in organ transplantation. Facilitating a wealth of international clinical trials and research collaborations over the years, ESOT remains committed to its primary aim of improving patient outcomes in transplantation. With over 1500 members from around the world, ESOT is an influential international organisation and the facilitator of the biennial congress which hosts approximately 3,500 experts who come to meet to explore and discuss the latest scientific research.

ESOT attracts the foremost transplantation experts as members and has an impressive track record in promoting research, supporting more extensive education, and promoting changes in European policy.



OUR MISSION, OUR VISION



Our Mission

To improve outcomes for patients with terminal organ disease by means of transplantation, organ regeneration and substitution.

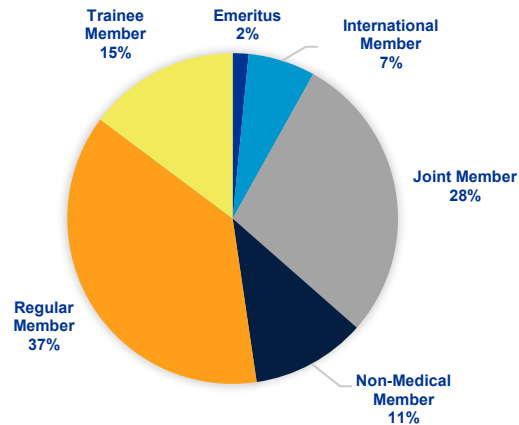
Our Vision

- To promote sustainable scientific advancement through multidisciplinary communities of healthcare professionals
- To deliver first-class education, training and career advancement opportunities to all healthcare professionals, with specific training programmes for low-income countries
- To work with partner organisations, professional bodies and competent authorities to improve public and institutional awareness of organ donation and the latest research in the field
- To develop and promote policies for equitable access to transplantation and related therapeutic strategies

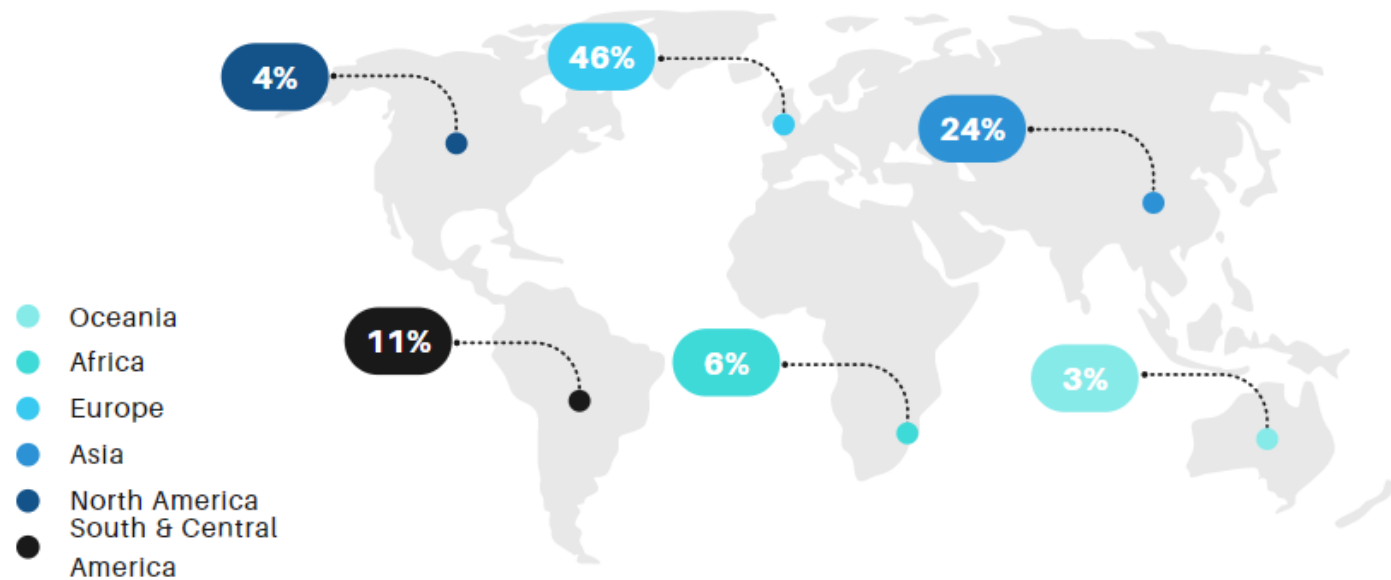
ESOT HAS OVER 1,500 ACTIVE MEMBERS WORLDWIDE

TOP 10 COUNTRIES

UNITED KINGDOM
THE NETHERLANDS
ITALY
SPAIN
GERMANY
BELGIUM
UNITED STATES
GREECE
AUSTRIA
SWITZERLAND



ESOT Membership per continent



Omnichannel community:

6,800 [Twitter](#) followers | 3,100 [LinkedIn](#) followers | 800 [Instagram](#) followers | 2,500 [facebook](#) followers | 3,200 [ESOT App](#) Subscribers

ESOT SECTIONS & COMMITTEES

The Society is made up of a council, general assembly, expert groups and committees. There are currently eight expert groups:

- ECTORS, for Cell Therapy and Organ Regeneration
- ECTTA, which focuses on the heart and lungs
- EDTCO, which aims to support health care professionals to provide clinically effective programmes on organ and tissue donation, procurement and transplantation
- EKITA, which focuses on the kidney
- ELITA, which focuses on the liver and intestines
- ELPAT, that brings continuity and progress in European research and dialogue on “Ethical, Legal and Psychosocial Aspects of organ Transplantation”.
- EPITA, which focuses on the pancreas and islets
- VCA, for Vascularized Composite Allotransplantation

In addition to these groups there are the committees. Currently there are four committees: the Education Committee, the Basic Science Committee, the Allied Healthcare professionals and the Young Professionals in transplantation (YPT).



ESOT LONG TERM ACTION PLAN

- Develop **evidence-based guidelines and position papers**, providing clinical practice guidance in areas of transplantation which are becoming more prominent or where uncertainties exist
- Build a network of '**centres of excellence**' to promote best clinical practice and research, advance scientific and training exchanges, and benchmark the growth and development of transplantation in developing countries.
- Develop a **European registry** for all solid organ transplantations, to identify, facilitate and foster specific research projects
- Build on the success of the ESOT journal - **Transplant International** – through the publication and promotion of high-level scientific research reports in the field of organ donation, transplantation, organ regeneration and substitution, together with official ESOT statements and papers
- Organize a **biennial congress** for the global Transplant Community with a variety of topics designed to stimulate and drive education and deliver the most ground-breaking advancements in the field
- Organize targeted **educational events and activities** based upon specific specialties and level of training/career development, including expanding the educational offering for fellowships and research grants
- Develop projects in **collaboration with other international societies**, to promote advancement, education, awareness and policy change

ESOT COLLABORATIONS & MEMBERSHIPS

EPHA MEMBERSHIP

ESOT will be collaborating with the [European Public Health Alliance \(EPHA\)](#).

EPHA is a member-led organisation made up of public health NGOs, patient groups, health professionals and disease groups, who work to improve health and strengthen the voice of public health in Europe.

EMA

ESOT is involved in the [European Medicines Agency's \(EMA\)](#) activities and will be listed as part of the healthcare professional organisations published on the Agency's website. The EMA is a decentralised agency of the European Union (EU) responsible for the scientific evaluation, supervision and safety monitoring of medicines in the EU.

ECDC

ECDC's Network for the Microbial Safety of Substances of Human Origin (SoHO-Net) was established to facilitate cooperation between ECDC and European Union/European Economic Area (EU/EEA) Member States. This collaboration brings together nominated EU/EEA professionals working in all types of SoHO entities and establishments. ESOT is participating as an observer

CD-P-TO

Set up by the Committee of Ministers under Article 17 of the Statute of the Council of Europe and in accordance with Resolution CM/Res(2021)3 on intergovernmental committees and subordinate bodies, their terms of reference and working methods. ESOT is participating as an observer

Recent consultations

- Immunocompromised patients (EMA)
- COVID-19 (EMA)
- Chagas disease (ECDC)
- HBV registry data – Elimination Plan of Viral Hepatitis by 2030 (ECDC)

EU POLICY – ESOT MANIFESTO

To celebrate ESOT's 40th anniversary, we launched ESOT Action Day on 28th April 2022.

Featuring leading voices from around Europe, this year's campaign will focus on addressing inequalities in organ transplantation across Europe by inspiring change and supporting existing EU initiatives through innovative solutions and shared thinking for the improvement of service delivery and sustainability in organ transplantation.

Please follow #ESOTaction for all the latest information

“For the last four decades, with greater challenges in recent times due to the Covid-19 pandemic, our community has been at the forefront of global health issues”

Luciano Potena, President of the European Society for Organ Transplantation (ESOT)

**Tackling Inequalities in
Organ Transplantation:
A Pathway Forward**



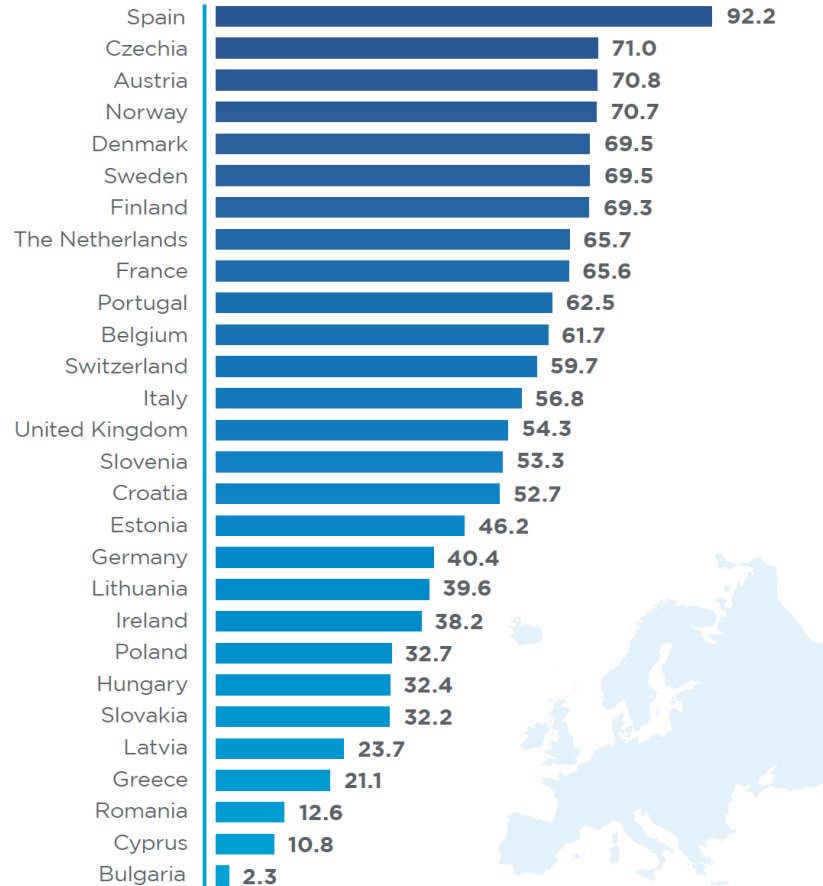
Find out more [here](#)

Inequality in Organ Transplantation Across Europe



Countries

The organ transplantation rate per million population in 2020 demonstrated significant variation across EU countries:¹



Population

Despite legal frameworks existing to prevent discrimination, equal access to transplantation remains a significant challenge for certain populations:

- 
Ethnic minorities: Comorbidities, such as diabetes, obesity and hepatitis B/C, are more prevalent in certain ethnic minority groups, often unfairly. This can negatively impact donation and transplantation rates, resulting in disproportionately high numbers of ethnic minority patients remaining on waiting lists.²⁻⁴
- 
Migrants: Migrants face barriers in access to transplant services, including lower awareness, a lack of full healthcare coverage, linguistic obstacles and cultural differences.⁵
- 
Gender bias: Women donate more organs than they receive, with men making up the majority of organ transplant recipients. While this reflects the increased incidence of conditions that require transplantation amongst men, psychological and socio-economic factors also contribute.⁶
- 
Socioeconomics: Patients with higher income and education have greater access to the transplant waitlist and kidney transplantation compared with patients with lower income and minimal education.^{1,7}
- 
Restricted groups: Both children (due to difficulties finding appropriately sized organs) and highly sensitised individuals (due to a restricted donor pool) face difficulties in receiving a transplant.⁸
- 
Regional: Data from Italy, France and Spain have shown that there are significant regional variations in the number of transplants performed.⁹ In many countries, transplant centres are not evenly distributed across their territory, with wealthier areas typically having the most centres.

References:

1. Statista. Rate of patients receiving a transplant per million population in Europe from 2019 to 2020, by country. Available at: <https://www.statista.com/statistics/537926/total-number-of-patients-transplanted-in-europe/> [Accessed 30 March 2022]. 2. Zhang, Ye., Gerdtham, Ulf-G., Rydell, Helena., Jarl, Johan. Socioeconomic Inequalities in the Kidney Transplantation Process: A Registry-Based Study in Sweden. *Transplantation Direct*. 2018;4(2):e346. doi: 10.1097/TXD.0000000000000764. 3. Ikram, U.Z., Kunst, A.E., Lamkaddem, M., Stronks, K. The disease burden across different ethnic groups in Amsterdam, the Netherlands, 2011-2030. *European Journal of Public Health*. 2014;24(4):600-605. doi: <https://doi.org/10.1093/eurpub/ckt136>. 4. Vanholder, R., Dominguez-Gil, B., Busic, M. et al. Organ donation and transplantation: a multi-stakeholder call to action. *Nat Rev Nephrol*. 2021;17:554-568. doi: <https://doi.org/10.1038/s41581-021-00425-3>. 5. Poulakou, G., Len, O. & Akova, M. Immigrants as donors and transplant recipients: specific considerations. *Intensive Care Med*. 2019;45:401-403. doi: <https://doi.org/10.1007/s00134-019-05534-z>. 6. Melk, A. et al. Equally Interchangeable? How Sex and Gender Affect Transplantation. *Transplantation*. 2019;103(6):1094-1110. doi: 10.1097/TP.0000000000002655. 7. Vart, P., Gansevoort, RT., Joosten, MM., Bültmann, U., Reijneveld, SA. Socioeconomic disparities in chronic kidney disease: a systematic review and meta-analysis. *Am J Prev Med*. 2015;48(5):580-92. doi: 10.1016/j.amepre.2014.11.004. 8. Lewis, A., Koukoura, A., Tsianos, G.I., Gargavanis, A.A., Nielsen, A.A., Vassiliadis, E. Organ donation in the US and Europe: The supply vs demand imbalance. *Transplant Rev (Orlando)*. 2021;35(2):100585. doi: 10.1016/j.tre.2020.100585.



EU POLICY

ESOT is at the heart of driving change in organ transplantation across Europe and is in a unique position to work and engage with partners, policy makers and stakeholders to influence medical practice at the national and international level.

ESOT will work with its partners to develop white papers, calls to action, EU Parliament events, awareness initiatives and much more.

The ESOT Policy and Public Affairs strategy focuses on two main goals:

- The wider implementation of effective policies to enable individuals/patients to follow ESOT recommendations and guidelines
- To place organ transplantation as a priority agenda at the national, European and international levels

Find out more [here](#)

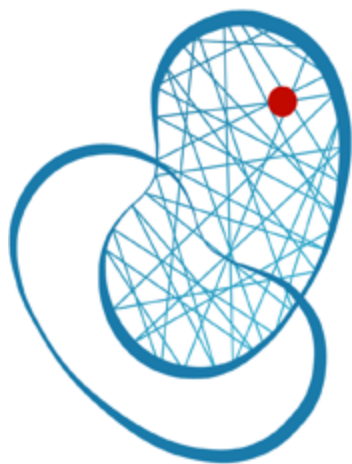


A level playing field for transplant patients
Spurring action across Europe

Tuesday, 27 September 2022 | 17:00-18:30

This session is initiated and organised by Takeda and the European Society for Organ Transplantation (ESOT).





ERKNet

The European
Rare Kidney Disease
Reference Network



72 centres/
100 units



70.000 patients
with rare kidney diseases



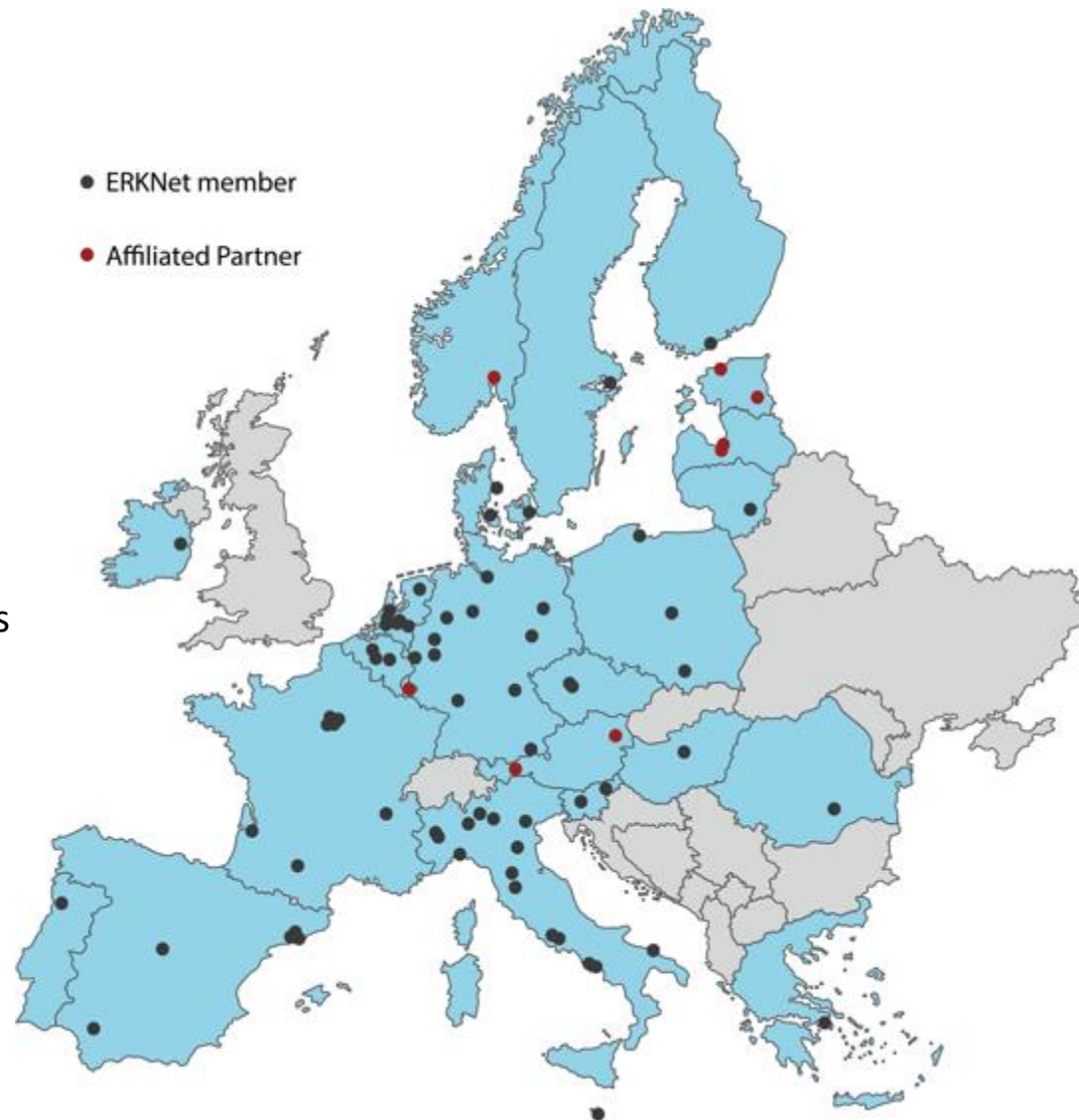
24 EU countries



33 European Patient
Advocates (ePAG)

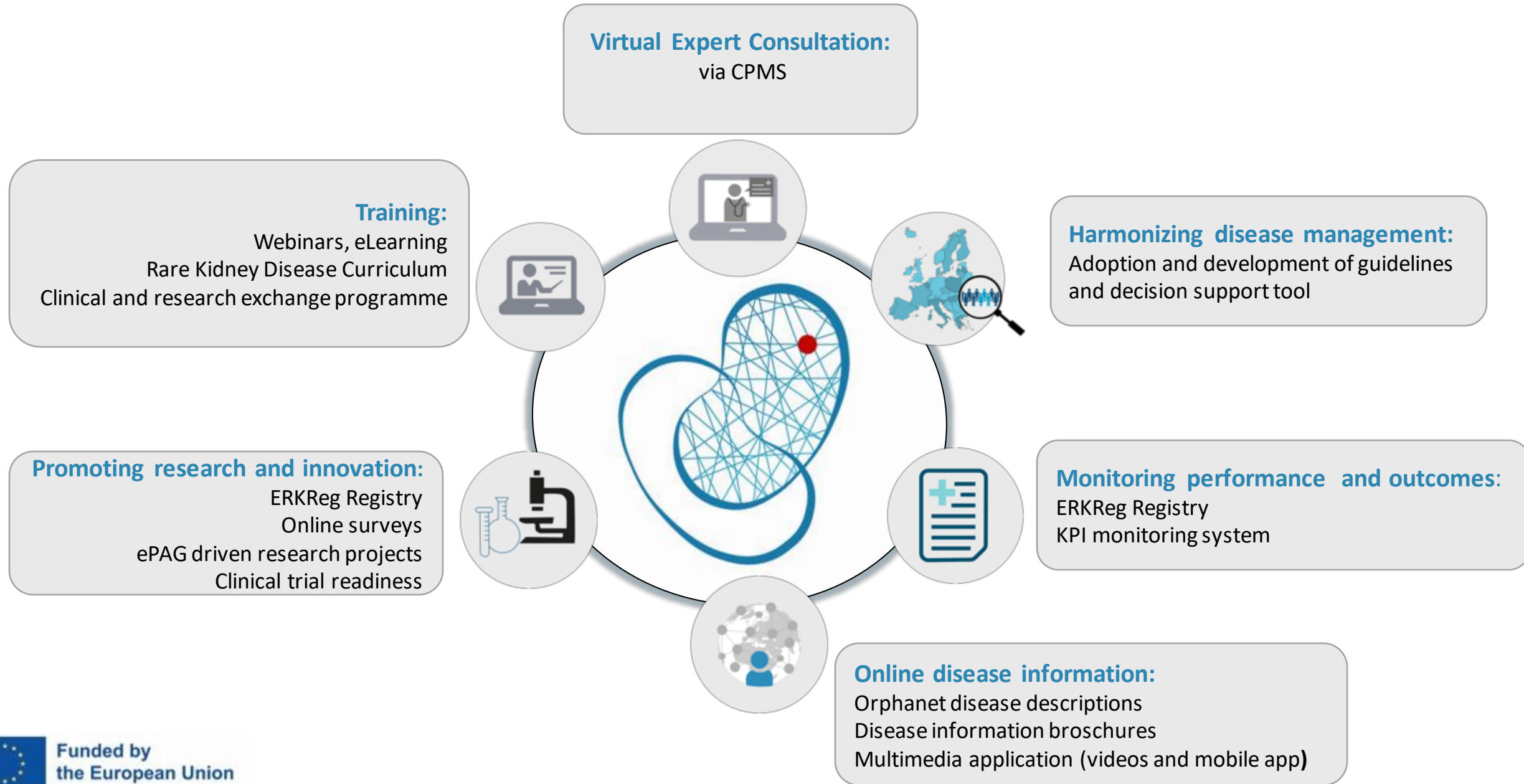
● ERKNet member

● Affiliated Partner



Funded by
the European Union

Objectives of ERKNet

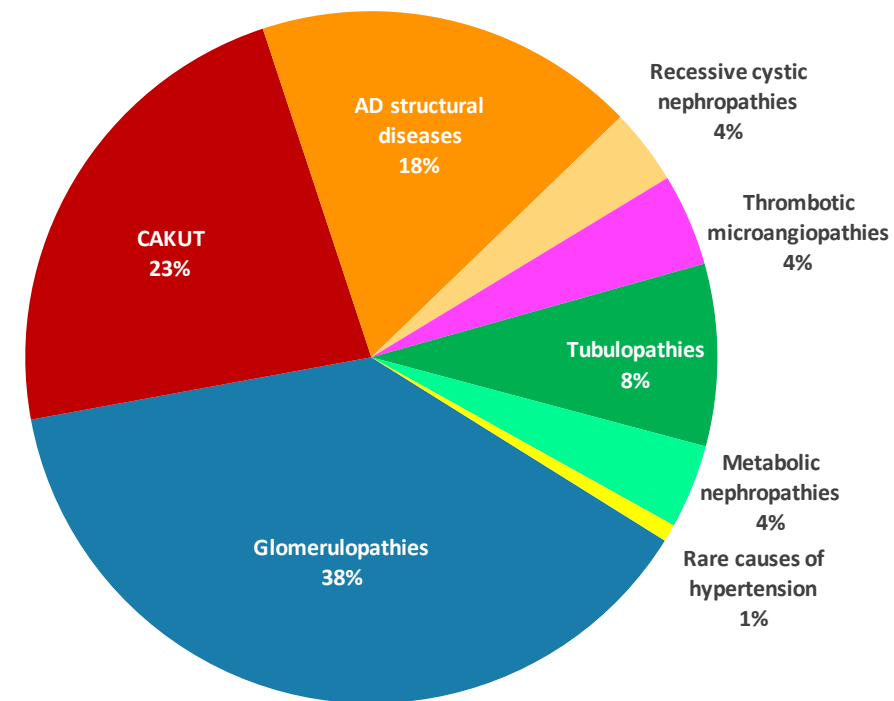
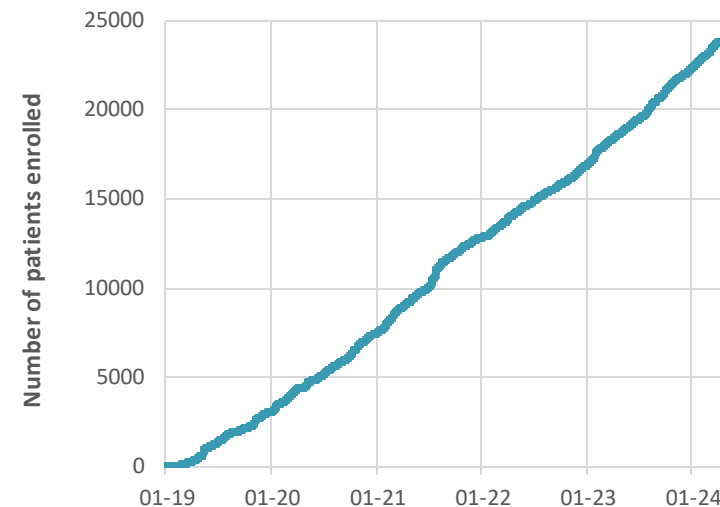




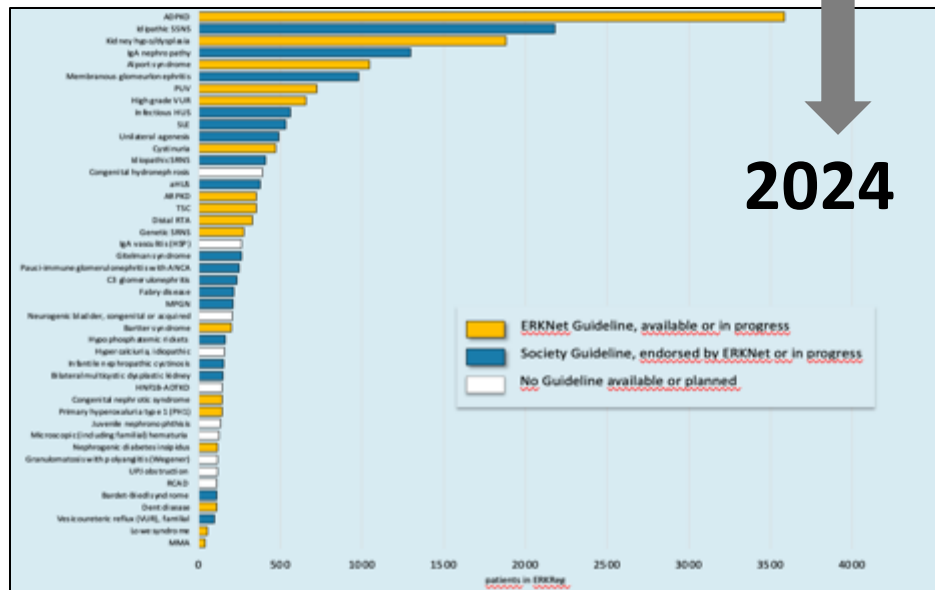
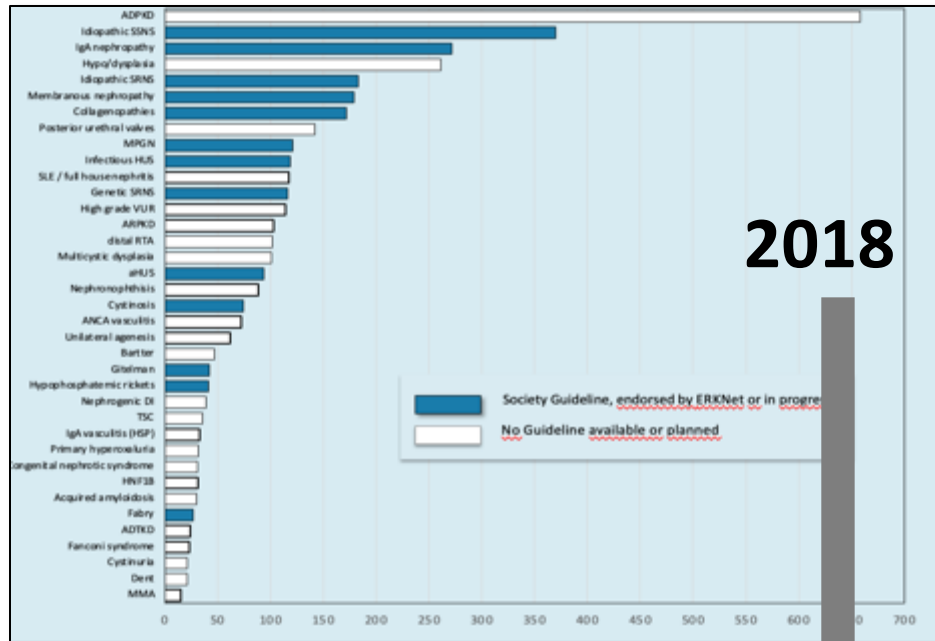
ERKReg

The European Rare Kidney Disease Registry

- Centralized online registry
- 25,000 patients enrolled since 1/2019 in 100 specialized units in 24 countries
- 2/3 pediatric and 1/3 adult patients
- 100 new patients added per week
- Annual follow-up: approx. 75%
- Open also to interested non-ERKNet sites globally



Transformation Of Rare Kidney Disease Guideline Landscape



ERKNet Guideline Projects

- Joint effort by clinicians and patients
- **14** published CPGs / Consensus statements
- **14** ongoing projects
- 41 documents from other societies endorsed
- Access facilitation:
Guideline Mobile App → coming soon

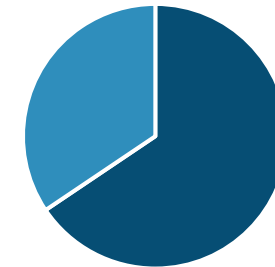
ERKReg and Key Performance Indicator (KPI) Monitoring

- Patient information collected in ERKReg
 - >60 disease group-specific KPIs based on CPGs
 - Continuous Monitoring and Benchmarking of centre performance
- Harmonization of patient care at best-practice level

Impact on patient care – European Rare Kidney Disease Specialist Education

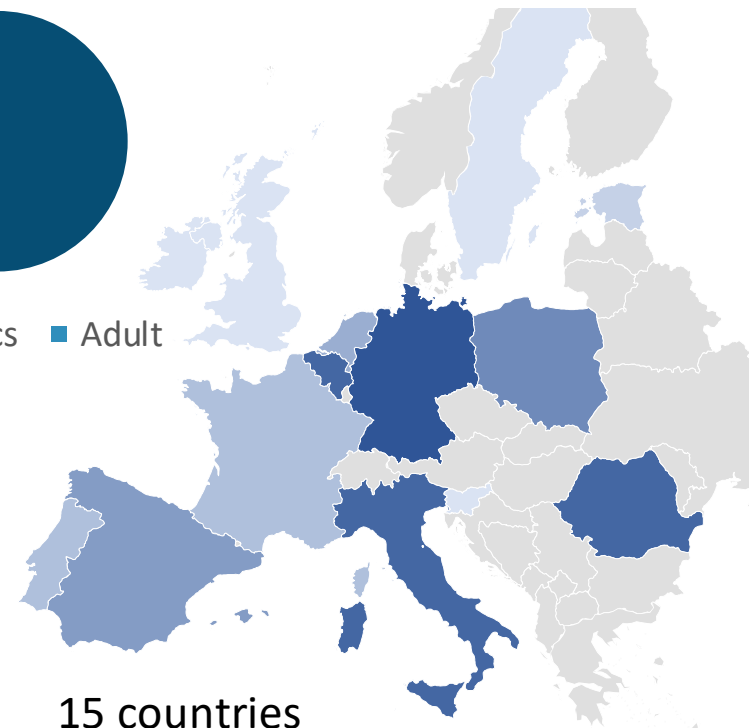
| | | |
|---|--|---|
| Clinical experience 2 years in the field of rare kidney diseases  | Webinars 3 years every 2 weeks  including Webinar-related exams 54 topics pediatric & adult diseases Requirements: Attendance to 80% of ERKnet Webinars ≥ 75% correct answers in the exams | eLearning cases  topic related cases basic & complex tests Requirements: Processing of 80% of all cases ≥ 75% correct answers |
|---|--|---|

First class graduated in 12/2023:
**63 „European Rare Kidney
Disease Specialists“**

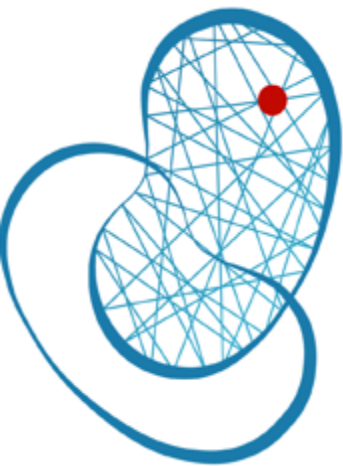


■ Pediatrics ■ Adult

4 Classes: 347 students from 65 ERKNet HCPs in 22 countries
| 106 webinars | 31 eLearning cases | 8 workshops / CME courses



Follow us on
social media
or visit our
website
www.erknet.org



ERKNet

The European
Rare Kidney Disease
Reference Network



Funded by
the European Union

Instagram



Facebook



LinkedIn



Twitter/X



ESPN
**European Society
for Paediatric Nephrology**



ESPN

Our Mission

ESPN was founded in 1967 to promote and disseminate knowledge in paediatric nephrology through research, teaching, scientific meetings, networking, and collaborative activities.

By bringing together clinical professionals and researchers ESPN encourages a strong European paediatric nephrology community.

Our ultimate mission is to advance the care of children with kidney diseases.



ESPN

Who We Are

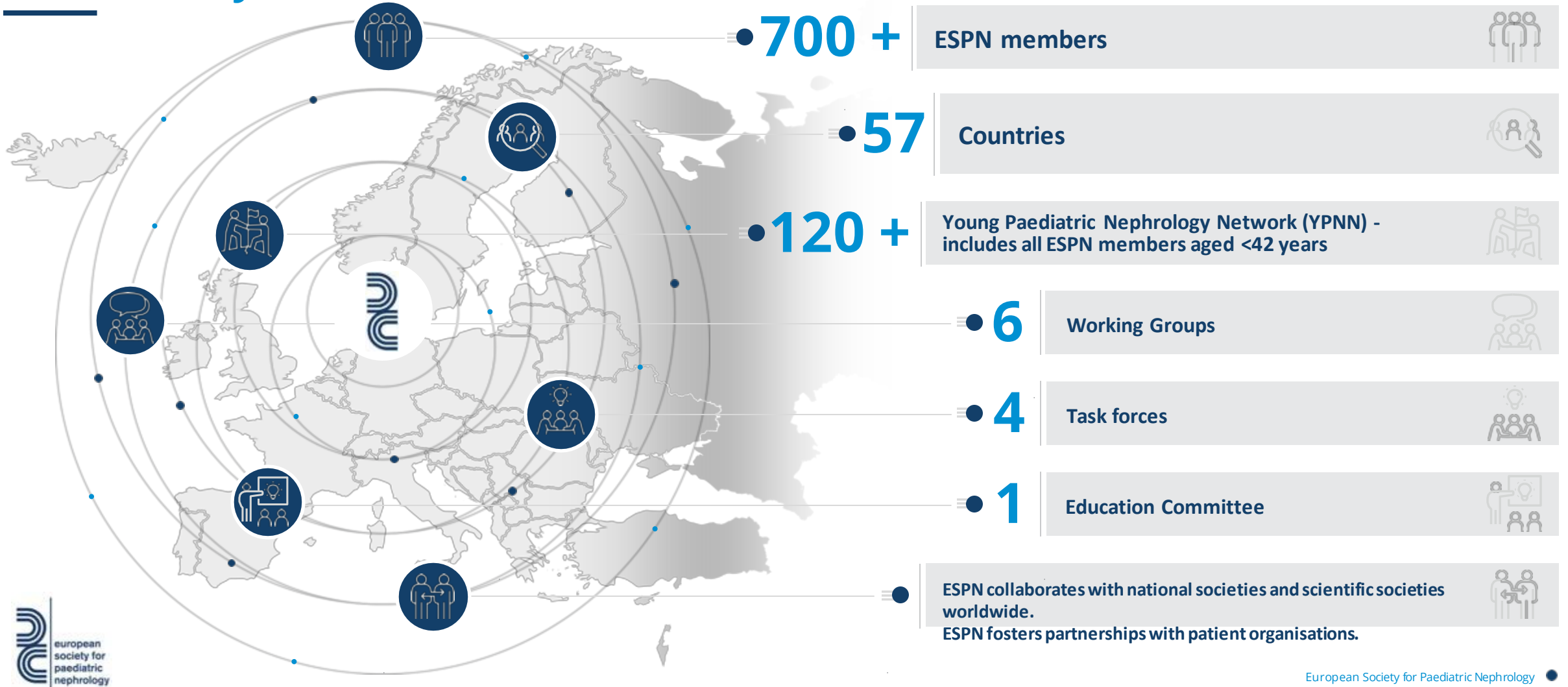
ESPN is a volunteer-led, nonprofit, charitable medical society. It is an independent, non-governmental organisation.

ESPN is the main scientific society for healthcare providers and researchers dedicated to Paediatric Nephrology across Europe.

ESPN is a diverse and inclusive Society in all aspects of its activities.

All individuals operating within ESPN must disclose annually their potential conflicts of interest.

ESPN Community



ESPN Activities

Workinggroups

- CAKUT / UTI / bladder dysfunction
- Chronic kidney disease – mineral bone disorder (CKD-MBD)
- Dialysis
- Glomerular diseases
- Inherited kidney disorders
- Transplantation

Task forces

- Disaster
- Fundraising
- History
- Paediatric Renal Nutrition
- Transition

Education Committee

Young Paediatric Nephrology Network (YPNN)



Scientific Meetings

- ESPN Annual Meeting / Paediatric KidneyWeek
- ESPN Research Conference / ESPN Academy
- Participation in meetings organised by other societies

Grants

- General Research Grant
- Working Group Grant
- Young Investigator Award
- Training grants

Honors and Awards

- Fellow of the European Society for Paediatric Nephrology (FESPN)
- Honorary Membership
- Golden Kidney Award



Research and Publications

- Endorsement of research projects, guidelines, and other publications
- Promote ESPN/ERA Registry and other research collaborations

Education and Training

- ESPN certificate in Paediatric Nephrology (ESPN Board Examination)
- IPNA-ESPN Junior Master Classes
- Joint educational webinars with ERKNet and IPNA
- Mentorship program

ESPN collaborates with...

Other societies & networks within Europe

- European Paediatric Association (EPA)
- European Rare Kidney Diseases Network (ERKNet)
- European Renal Association (ERA)
- European Society for Paediatric Urology (ESPU)
- National Paediatric Nephrology Societies

International/regional societies & networks

- International Pediatric Nephrology Association (IPNA)
- International Pediatric Transplant association (IPTA)
- International society of Nephrology (ISN)
- Pediatric Nephrology research Consortium (PNRC)
- African Paediatric Nephrology Association (AFPNA)
- American Society of Pediatric Nephrology (ASPNA)
- Asian Pediatric Nephrology Association (AsPNA)
- Japanese Society for Pediatric Nephrology (JSPN)
- Korean Society of Pediatric Nephrology (KSPN)

Patient Organizations and Patient Advocates

The ESPN

Organisational Structure and Governance

ESPN Council

EXECUTIVE COUNCILLORS



President
Dieter Haffner
Hannover, Germany



Assistant President
Francesco Emma
Rome, Italy



Treasurer
Jun Oh
Hamburg, Germany

COUNCIL MEMBERS



Arend Bökenkamp
Amsterdam, NDL



Ayşe Balat
Gaziantep, Turkey



Fabio Paglialonga
Milan, Italy



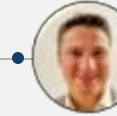
Jerome Harambat
Bordeaux, France



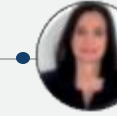
Karolis Azukaitis
Vilnius, Lithuania



Malgorzata Wasiak
Warsaw, Poland



Matko Marlais
London, UK



Stella Stabouli
Thessaloniki, Greece

Ex officio ESPN
Council Members /
Chair positions

ESPN Annual Congress

President: **Gema Ariceta**
Barcelona, Spain

ESPN/ERA Registry

Chair: **Enrico Vidal**
Padova, Italy

Young Paediatric Nephrology Network (YPNN)

Chair: **Rute Baeta Baptista**
Lisbon, Portugal

Vice-chair: **Fabio Paglialonga**
Milan, Italy

ESPN Working Groups chairs

CAKUT/UTI/bladder dysfunction

Chronic kidney disease/mineral and bone disorders (CKD-MBD)

Dialysis

Glomerular diseases

Inherited kidney disorders

Transplantation

ESPN task forces

Disaster Task Force

Fundraising Task Force

History Task Force

Paediatric Renal Nutrition Taskforce

Transiion Taskforce

ESPN standing committies

Education Committee

Intro to CompCure

**EKHA General Assembly
11 June 2024**

Prepared by Marianne Silkjaer
Nielsen



This is my daughter.
Her name is Esther, and she is
10 years old



Esther is sporty, she is happy most of the time, and
she is alive...
...and I take nothing of that for granted.

Esther's life could have been very different.

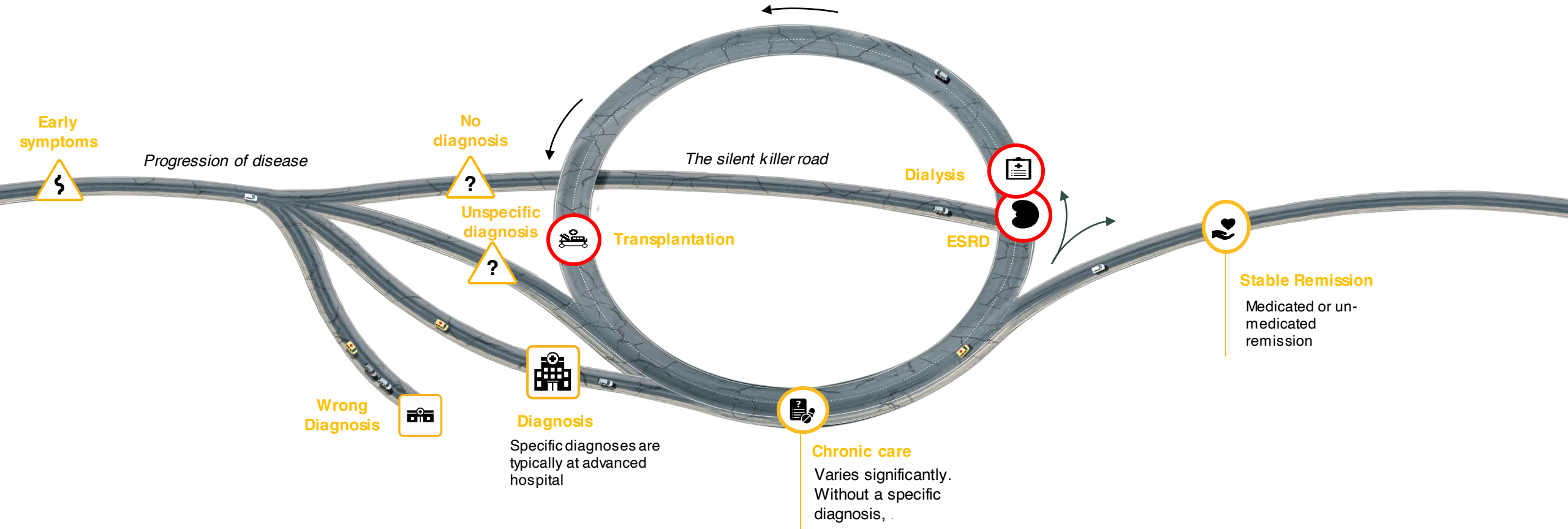
In 2019 she was diagnosed with a rare kidney disease...
We were told that she would never get a "good life".



Esther is lucky. She receives excellent medical care by highly skilled nephrologists, and she responds to her off-label therapy... Nevertheless, her journey is still difficult. The lack of evidence and awareness continues to cause issues.

The “broken patient journey“

The diagnostic processes, treatments and standards of care vary significantly



Resourceful patients and families have much better chances of navigating the patient journey...

It is our mission to support nephrologists in guiding all their patients and families in the right direction

"We are more than our kidneys, we are also humans!"

Common complications that may be correlated to the diseases

Complications reported by patients and caregivers

Psychologic: Stress, anxiety, depression, insomnia, disturbances...

Neurological: Headache, stroke, dizziness, pain, paralysis...

Ophthalmologic: Drusen, glaucoma, momentary visual impairment...

Cardiovascular: Hypertension, cholesterol, atherosclerosis, arrhythmia...

Hematologic: Anemia, albuminemia, erythropoietin deficiency, sepsis...

Nephrological: Proteinuria, hematuria, inflammation, ESRD...

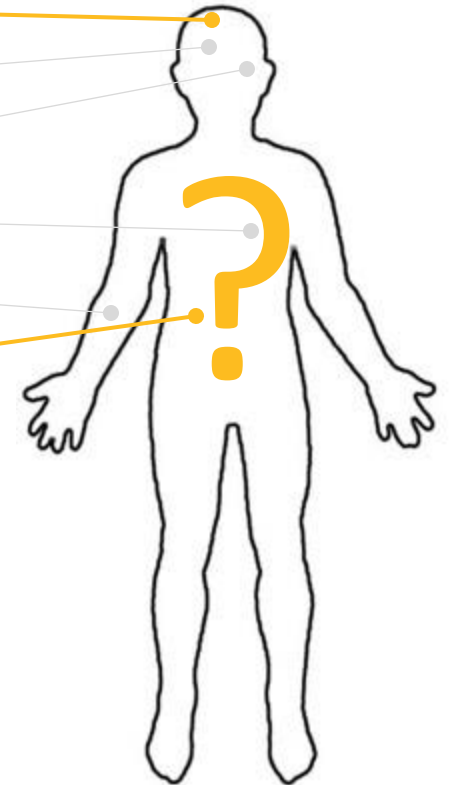
Immunological: Multiple infections, adenoidectomy, tonsillectomy...

Dermatologic: Rash, eczema, pruritus, warts, molusco contagioso...

Systemic: Fatigue, edema, muscle cramps, general feeling of weakness...

Other: Impaired hearing, diminished appetite, nausea, pain, diabetes...

Daily life: Loss of productivity, employability, school attendance, concentration issues, social limitations, financial impact, impact on family life and relationships, etc.



The objectives of CompCure

As defined in our Articles of Association

OBJECTIVES

The objectives of the Association are to:

1. Strengthen the understanding of complement driven kidney diseases, including the pathophysiology, natural history and overall burden of disease to patients, caregivers and society.
2. Improve the long-term outcome for patients through early diagnoses, improved treatment guidelines, development and access to disease modifying medicine and ultimately curative therapies.
3. Increase the awareness of complement driven kidney diseases broadly across healthcare institutions, health care authorities, regulators and other relevant stakeholders.
4. Develop a platform and infrastructure that will produce best practices on how to generate evidence, knowledge, and productively address the high unmet medical needs and rare diseases burden beyond kidney diseases.



It is the cross-functional collaboration and productive partnerships that secure progress

Productive and well-established partnership with the ERKnet.





Promising new partnerships, e.g. with EKHA 😊

Commitment from nephrologists from- and outside Europe: On track to build the biggest registry for C3G and IC-MPGN globally.

High expectations to EKHA collaboration

How can we support you addressing **Rare Kidney Diseases** in Health Care Plans?

A Policy Call to Address Rare Kidney Disease in Health Care Plans

Raymond Vanholder ^{1,2}, Rosanna Coppo,³ Willem J.W. Bos ^{4,5}, Elaine Damato,⁶ Fadi Fakhouri ^{7,8}, Alister Humphreys,⁹ Ionut Nistor,^{10,11,12} Alberto Ortiz ^{13,14}, Michele Pistollato ¹⁵, Eveline Scheres,¹ and Franz Schaefer ¹⁶

Abstract

Despite a large number of people globally being affected by rare kidney diseases, research support and health care policy programs usually focus on the management of the broad spectrum of CKD without particular attention to rare causes that would require a targeted approach for proper cure. Hence, specific curative approaches for rare kidney diseases are scarce, and these diseases are not treated optimally, with implications on the patients' health and quality of life, on the cost for the health care system, and society. There is therefore a need for rare kidney diseases and their mechanisms to receive the appropriate scientific, political, and policy attention to develop specific corrective approaches. A wide range of policies are required to address the various challenges that target care for rare kidney diseases, including the need to increase awareness, improve and accelerate diagnosis, support and implement therapeutic advances, and inform the management of the diseases. In this article, we provide specific policy recommendations to address the challenges hindering the provision of targeted care for rare kidney diseases, focusing on awareness and prioritization, diagnosis, management, and therapeutic innovation. In combination, the recommendations provide a holistic approach aiming for all aspects of rare kidney disease care to improve health outcomes, reduce the economic effect, and deliver benefits to society. Greater commitment from all the key stakeholders is now needed, and a central role should be assigned to patients with rare kidney disease to partner in the design and implementation of potential solutions.

CJASN 18: 1510–1518, 2023. doi: <https://doi.org/10.2215/CJN.0000000000000220>

A strong publication that calls for action

- Particular scientific and political attention to rare kidney diseases needed.
- Awareness
- Improve and accelerate diagnosis
- Implement therapeutic advances
- Inform mgmt. of the diseases

How can we make sure that the conclusions of this article reach the key audiences?

The rare renal reality

- Most rare kidney diseases are orphan.
- Many of the affected patients are children.
- The Manifesto does not include the word “rare”

Collaboration to drive better outcome across common and rare kidney diseases?

- Make an impact on the journey end-to-end: Prevention, diagnosis, treatment, improved organ-donation and transplantation
- Incorporate renal health in major EU health programs, like “Healthier together – EU non-communicable diseases initiative”
- Advocate for national health plans, where there are sections dedicated to rare kidney diseases.

Looking forward to working with you 😊

ROMANIA and Romanian Society of Nephrology

- **Population** – 19.05 million – 17.5% over 65years
- GDP - 2023 - 300.7 billion USD – GDP per capita around 15 786 USD
- **CKD Risk factors**
 - DM 11.5% prevalence -The PREDATORR study
 - HT 45% prevalence - The 2 SEPHARD studies
- **CKD prevalence** 9-10% (stage 3 and up) – data from 2008 and 2012

The Romanian Renal Registry

- Since 1974 – in 1981 - 124 patients treated in 2 HD centers
- **The Actual RRR** – compulsory electronic data collection from all RRT centers – reporting to ERA Registry
 - 142 RRT centers
 - Incident ESKD patients (2022) – 191.8 pmp
 - Prevalent ESKD patients treated by RRT (2022) – 24054– mean age 63 years, median 65.6 years



Renal Tx (National Renal Transplant Association)

Romanian Society of Nephrology (RSN)



Founded in 1991

Active members – around 370 nephrologists (out of around 450)

! President (for 2 years), Prof Ina Kacso – Cluj – contact – inakacso@yahoo.com

1 President elect., Prof Gener Ismail – Bucharest – contact – gener732000@yahoo.com

4 Vice presidents, Board of The RSN (elected for 4 years)

Events organized by The RSN

- National Congress – every 2 years
- National Conference – every alternate years
- Summer school for young nephrologists

Events supported and or endorsed by The RSN

- Renal Failure Academy - international (with ERA or ISN)
- With other medical associations, universities
 - NefroCarDia (nephrology, cardiology, diabetes)
 - NefroDiab (nephrology, diabetes)
 - Nephro-geriatria
 - Nephro-oncology
 - The IgAN Academy
 - Local conferences for increasing the awareness of CKD and AKI

Ongoing or future projects of The RSN

- Endorsing the National project of the Ministry of Health: “Early detection and management of CKD”
- Increasing the number of kidney biopsy centers and the number of KB pathologists
- Increasing the number of nephrologists
- Development of “KB registry” and the “National registry of pre-dialysis CKD
- Supporting education and research of young nephrologists
- Development of regional interaction projects with other EU and Balkan Nephrology societies and The EKHA

On behalf of The RSN

Prof Adalbert Schiller MD PhD

“Victor Babes” University of Medicine and Pharmacy

Vice president of The Romanian Society of Nephrology

Contact schiller.adalbert@gmail.com



Tour de table: updates from affiliated members

**The evidence is clear:
the time for action is
now. We can halve
emissions by 2030.**

- Modify conventional dialysis processes

Conventional Step innovation

Easy, anywhere CFP monitoring

- Establish categories for total sustainability balances

Patient Outcome

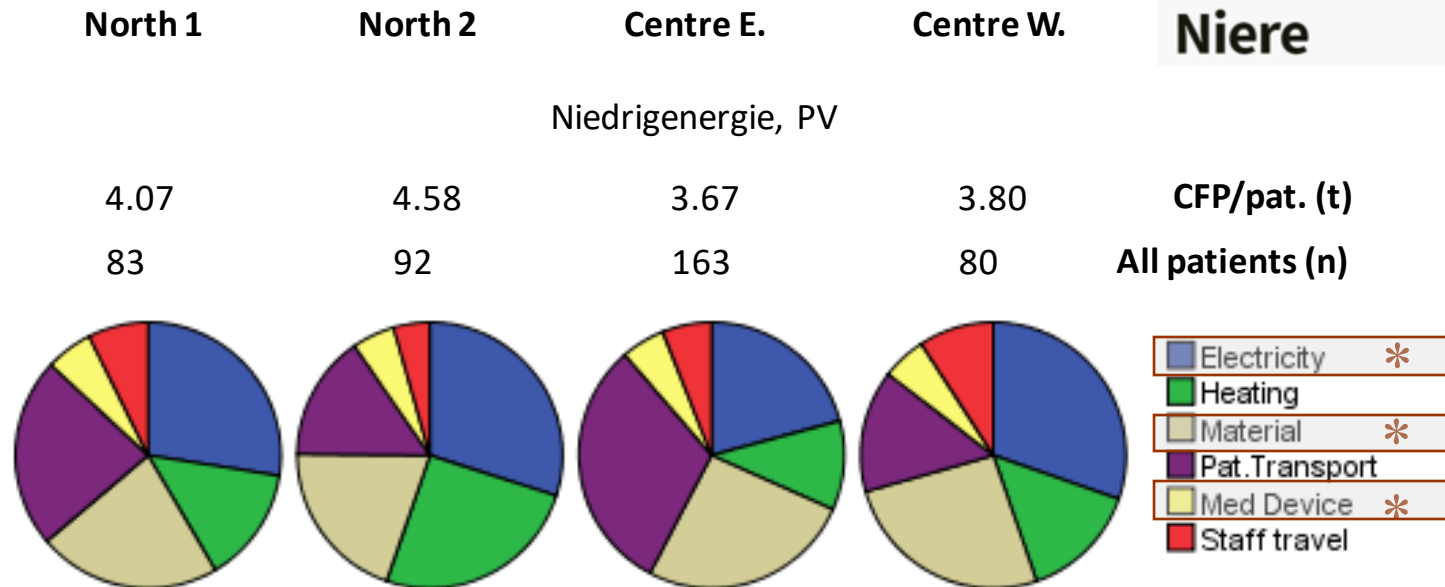
Disruptive treatments

- Associate PRO with solute modelling

- Be aware of logistic CFP

2021 categories of CO2 emissions in pilot centres

Kommission Klima, Umwelt und Niere



<https://carbonfootprintdialysis.com/>

Kennen Sie den CO₂ Footprint Ihrer Dialyseeinrichtung?

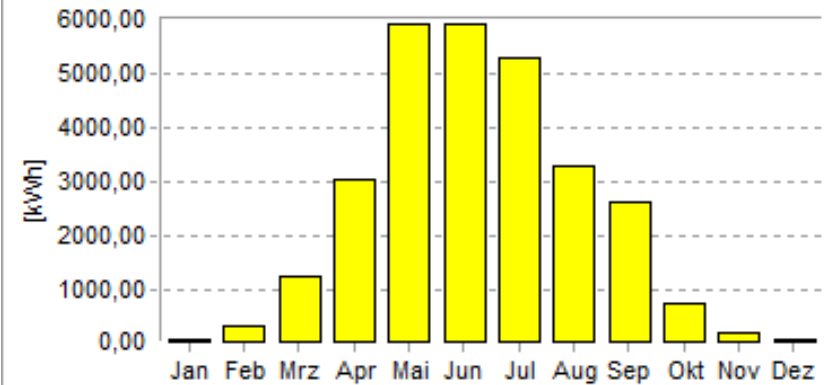
Reduction, example 1

CO2 – Reduction single centre 2023 (121 kWp)

elektr. Energie (5)

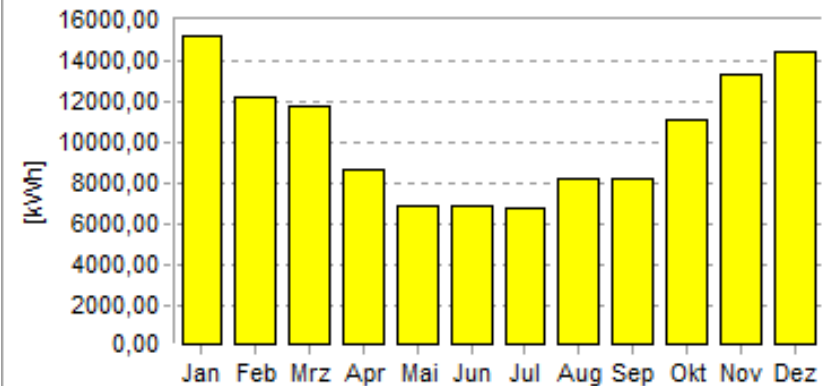


Strom Lieferung 78420000 für 2023



Summe: 28665.85 kWh, Max: 5944.30 kWh, Mittel: 2388.82 kWh

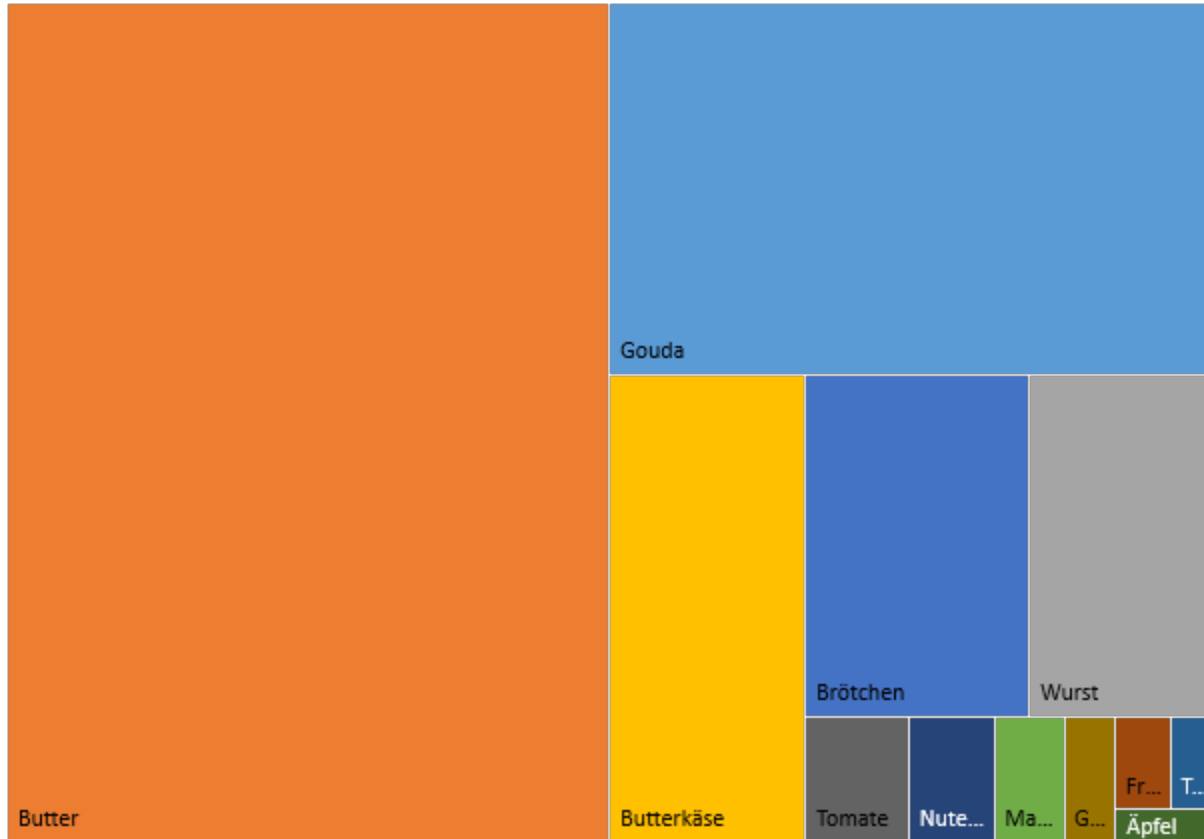
Strom Bezug 78420000 für 2023



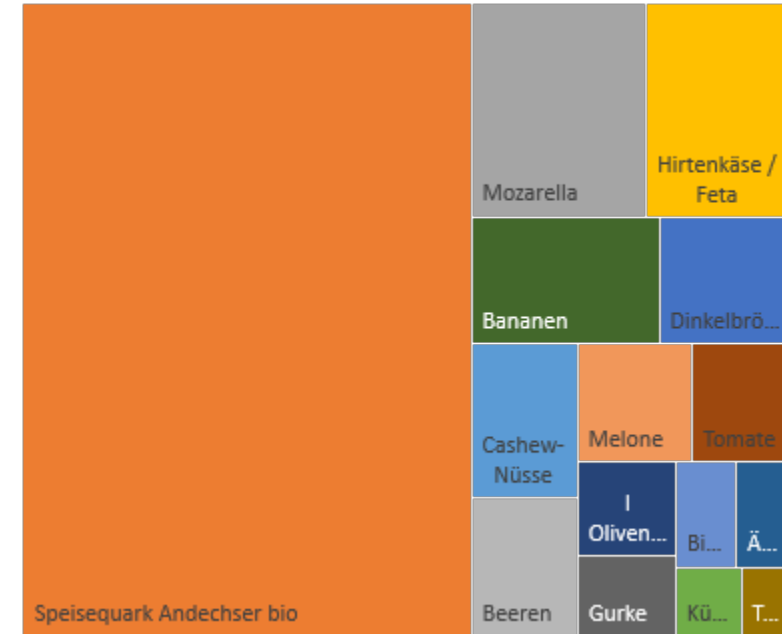
Summe: 123997.81 kWh, Max: 15299.88 kWh, Mittel: 10333.15 kWh

Reduction, example 2: planetary-health adapted dialysis snack (KfH Bremen)

Conventional Diet (148 kg-Equ./Pat.)



Planetary health (84 kg-Equ./Pat.)



Regards to Susi Knöller

* Normalised at 118 Pat. / Year



Hrvatsko društvo za nefrologiju
dijalizu i transplantaciju
Hrvatskog liječničkog zbora

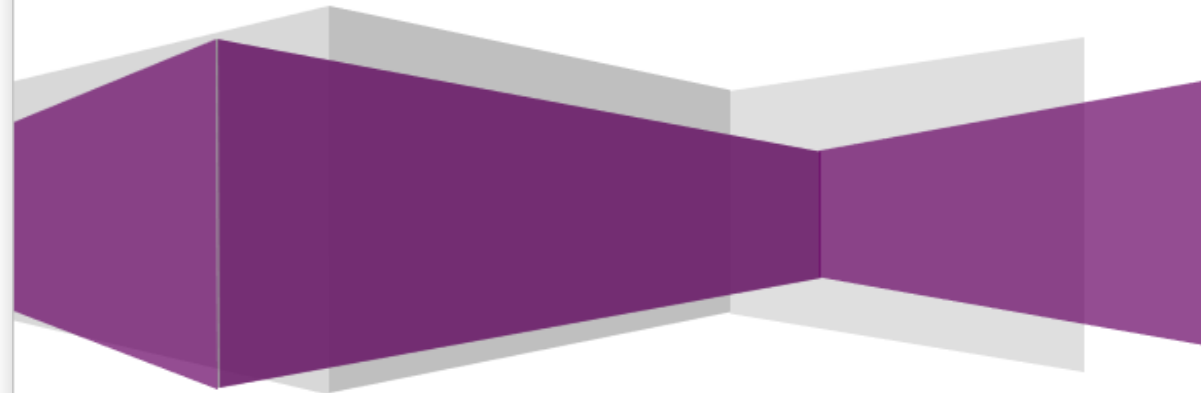


Ministarstvo
zdravstva

**ACTION PLAN FOR EARLY DETECTION AND
PREVENTION OF CHRONIC KIDNEY DISEASE
IN REPUBLIC OF CROATIA**

Panel kronične bubrežne bolesti

*Opis sučelja panela za praćenje bolesnika s
kroničnom bubrežnom bolesti (KBB)*



Naručitelj Hrvatsko društvo za nefrologiju, dijalizu i transplantaciju Hrvatskog
liječničkog zbora

Datum izrade: 18. 01. 2024.

Autor dokumenta: Dinko Đukić, MCS Grupa d.o.o.

Pavle Šoštarić-Varga, MCS Grupa d.o.o.

Chronic Kidney Disease Panel

Description of the panel interface
for monitoring CKD patients

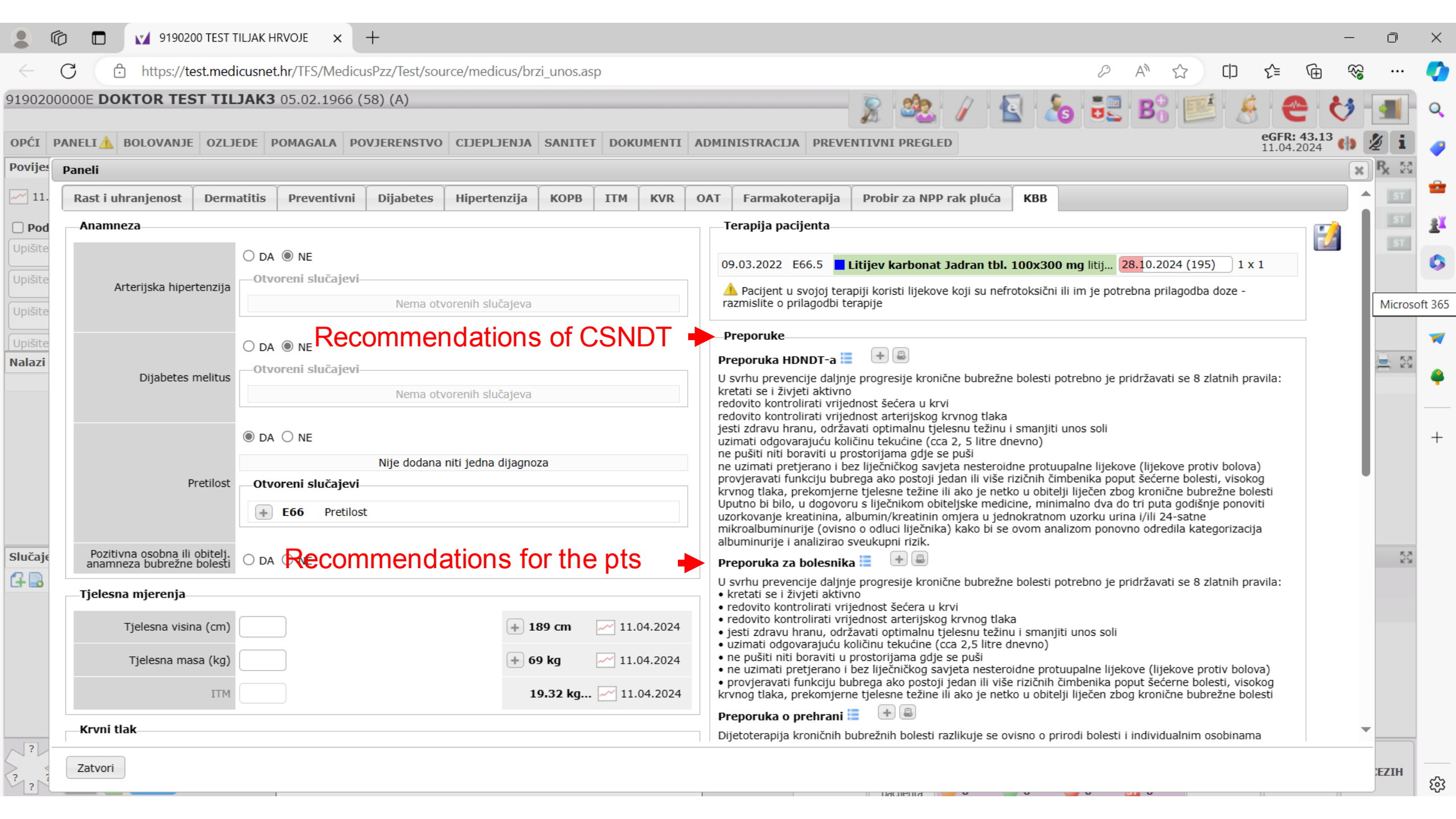
1. Svrha dokumenta

Svrha ovoga dokumenta je opis sučelja i procesa za praćenje pacijenata s kroničnim bubrežnim bolestima.

Ovim panelom omogućava se sveobuhvatan pregled stanja pacijenata oboljelih od KBB i omogućiti efikasno praćenje njihovog zdravstvenog stanja. Panel praćenja ima za cilj unaprijediti kvalitetu skrbi, pravovremeno prepoznati eventualne promjene u zdravstvenom stanju pacijenata te omogućiti prilagodbu terapije kako bi se spriječile daljnje komplikacije



Implementation in >1300 GP' offices



Povijes Paneli
Rast i uhranjenost Dermatitis Preventivni Dijabetes Hipertenzija KOPB ITM KVR OAT Farmakoterapija Probir za NPP rak pluća KBB

Anamneza

Arterijska hipertenzija DA NE
Otvoreni slučajevi
Nema otvorenih slučajeva

Dijabetes melitus DA NE
Otvoreni slučajevi
Nema otvorenih slučajeva

Pretilost DA NE
Nije dodana niti jedna dijagnoza
Otvoreni slučajevi
+ E66 Pretilost

Pozitivna osobna ili obitelj. anamneza bubrežne bolesti DA NE

Tjelesna mjerenja

| | | | |
|----------------------|--|-------------|------------|
| Tjelesna visina (cm) | | + 189 cm | 11.04.2024 |
| Tjelesna masa (kg) | | + 69 kg | 11.04.2024 |
| ITM | | 19.32 kg... | 11.04.2024 |

Krvni tlak

Terapija pacijenta

09.03.2022 E66.5 **Litijev karbonat Jadran tbl. 100x300 mg litij...** 28.10.2024 (195) 1 x 1

⚠ Pacijent u svojoj terapiji koristi lijekove koji su nefrotoksični ili im je potrebna prilagodba doze - razmislite o prilagodbi terapije

Preporuke

Preporuka HDNDT-a

U svrhu prevencije daljnje progresije kronične bubrežne bolesti potrebno je pridržavati se 8 zlatnih pravila: kretati se i živjeti aktivno redovito kontrolirati vrijednost šećera u krvi redovito kontrolirati vrijednost arterijskog krvnog tlaka jesti zdravu hranu, održavati optimalnu tjelesnu težinu i smanjiti unos soli uzimati odgovarajuću količinu tekućine (cca 2, 5 litre dnevno) ne pušiti niti boraviti u prostorijama gdje se puši ne uzimati pretjerano i bez liječničkog savjeta nesteroidne protuupalne lijekove (lijekove protiv bolova) provjeravati funkciju bubrega ako postoji jedan ili više rizičnih čimbenika poput šećerne bolesti, visokog krvnog tlaka, prekomjerne tjelesne težine ili ako je netko u obitelji liječen zbog kronične bubrežne bolesti Uputno bi bilo, u dogovoru s liječnikom obiteljske medicine, minimalno dva do tri puta godišnje ponoviti uzorkovanje kreatinina, albumin/kreatinin omjera u jednokratnom uzorku urina i/ili 24-satne mikroalbuminurije (ovisno o odluci liječnika) kako bi se ovom analizom ponovno odredila kategorizacija albuminurije i analizirao sveukupni rizik.

Preporuka za bolesnika

U svrhu prevencije daljnje progresije kronične bubrežne bolesti potrebno je pridržavati se 8 zlatnih pravila:

- kretati se i živjeti aktivno
- redovito kontrolirati vrijednost šećera u krvi
- redovito kontrolirati vrijednost arterijskog krvnog tlaka
- jesti zdravu hranu, održavati optimalnu tjelesnu težinu i smanjiti unos soli
- uzimati odgovarajuću količinu tekućine (cca 2,5 litre dnevno)
- ne pušiti niti boraviti u prostorijama gdje se puši
- ne uzimati pretjerano i bez liječničkog savjeta nesteroidne protuupalne lijekove (lijekove protiv bolova)
- provjeravati funkciju bubrega ako postoji jedan ili više rizičnih čimbenika poput šećerne bolesti, visokog krvnog tlaka, prekomjerne tjelesne težine ili ako je netko u obitelji liječen zbog kronične bubrežne bolesti

Preporuka o prehrani

Dijetoterapija kroničnih bubrežnih bolesti razlikuje se ovisno o prirodi bolesti i individualnim osobinama

Recommendations of CSNDT →

Recommendations for the pts →

Izveštaj o učinjenim analizama → radna grupa HDNDT i KoHOM

Report on the analyzes carried out → working group of CSNDT and KoHOM



thank you!

www.ekha.eu

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