



# General assembly

June 15, 2022 / 11.00-14.00 CEST

European Respiratory Society  
49-51 Rue de Trèves, Brussels

[info@ekha.eu](mailto:info@ekha.eu)

# Activities of 2021

# EKHA network expansion since 2021

EKHA is an EU Nephrology advocacy platform in which a broad scope of organisations and individuals work together for the benefit of kidney patients.

Together we form strong collaboration that focusses on lowering the socio-economic burden of CKD by creating awareness for CKD as a neglected disease.



The EKHA platform connects:



Physicians



Nurses



Patients



Foundations



Individuals



Industry

EKHA is a member of



and EU4health



1 new full member  
ISN

8 new affiliated members from:

Belgium

Croatia

Czech Republic

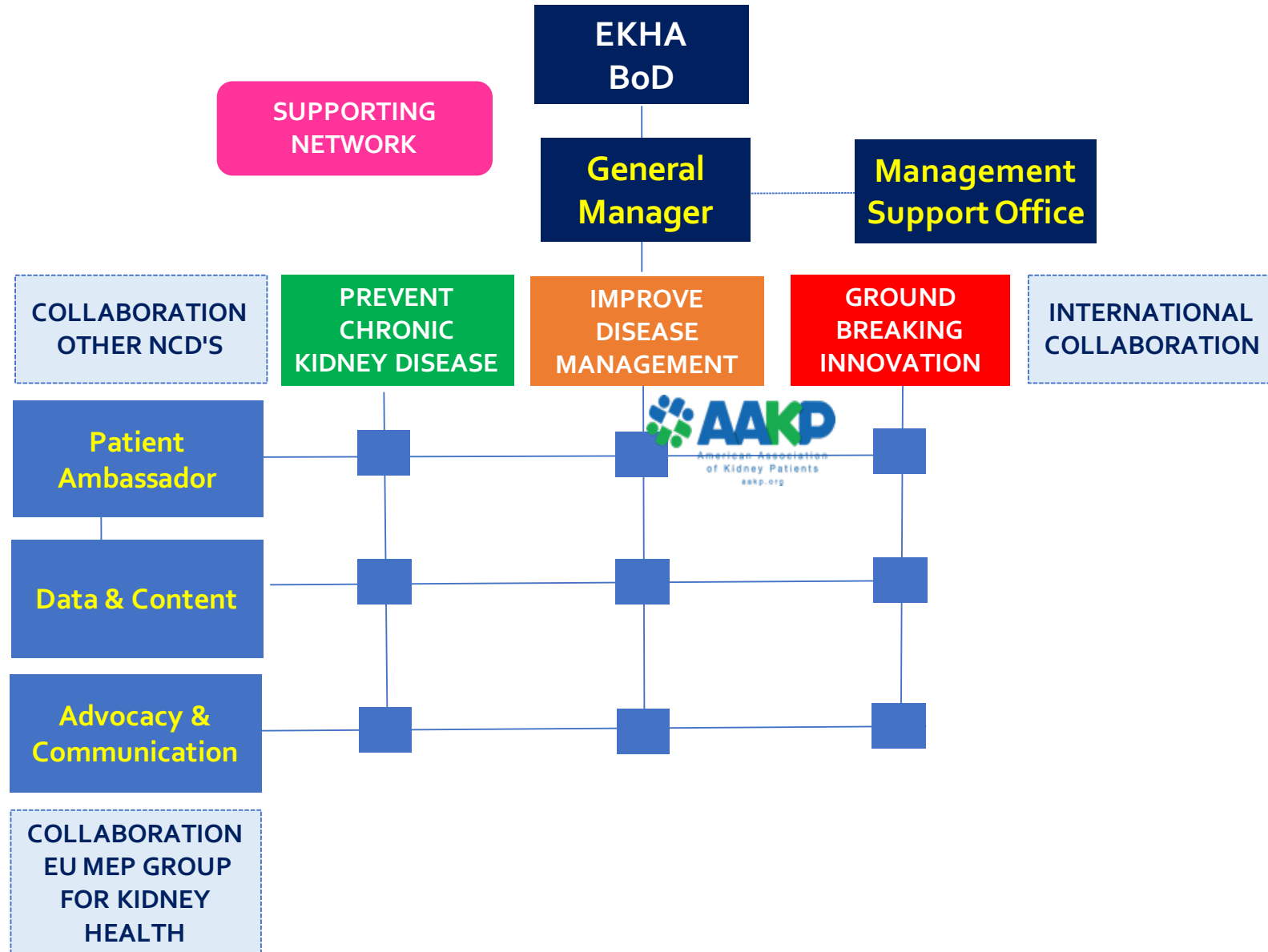
UK (x2)

Latvia

Lithuania

Poland

# EKHA organisation





# Network – collaboration

MEP Group for  
Kidney Health:  
3 new  
members and a  
new Vice-Chair



Frances Fitzgerald  
(EPP, Ireland)



Ondrej Knotek  
(Renew, Croatia)



Cesar Luena  
(S&D, Spain)



**Vice-Chair role:**  
Manuel Pizarro  
(S&D, Portugal)

Further strengthening of the  
organisation with:

- Ambassadors
- Working groups
- Supporters
- Collaboration criteria
- and a Linked-in account



## Artificial Organs



Scientific Journal  
Twitter collaboration:  
retweets on @ArtifOrgans



Increasing collaboration  
opportunities with commercial  
parties via support packages,  
based on collaboration criteria  
that safeguard EKHA's  
independency



EKHA started a collaboration  
with the American  
Association of Kidney  
Patients (AAKP), the oldest  
and largest independent  
kidney patient organization  
in the U.S. that initiated the  
Decade of the Kidney™

# Public affairs – meetings with politicians (1)

## Meeting of EKHA and EKPF with EU Commissioner Stella Kyriakides on Friday 26 February, 2021

- Discuss the main challenges of kidney disease and burden in Europe
- The impact of COVID-19 on kidney disease

### Outcomes

- Strong commitment from Commissioner Kyriakides to support:
  - Decade of the Kidney™
  - World Kidney Day
  - EKHA Call to Action
- Direct contact with EU Commissioner and her team
- Visibility on Twitter:
  - Tweets from Kyriakides Twitter account and DG SANTE's Twitter account
  - 31 retweets, 106 likes



# Public affairs – meetings with politicians (2)

Meeting with António Lacerda Sales, the Portuguese Deputy Minister for Health on 28 April, 2021

Organised together with the National Competent Authority 'Institute of Blood and Transplantation in Portugal (IPST)', the Portuguese Society for Transplantation (SPT) and the Portuguese Society for Renal Failure (APIR).

## Outcomes:

Mr. Lacerda Sales supported the idea of a second EU action plan on Organ Donation and Transplantation and actions to put the topic high on the EU agenda



# Public affairs – meetings with politicians (3)

## Meeting of EKHA, EKPF & ISN with John Ryan – Acting Director of the Commission Public Health directorate at 23 November

- Discuss the current challenges in Chronic Kidney Disease in Europe and share our priorities to improve kidney health for the 2020-2030 decade.
- Ask for acknowledgement of CKD, lacking in EU programs
- Explore collaboration possibilities

### Outcomes

- Support to promote kidney health in Europe which was also directly requested by the Cabinet of EU commissioner Stella Kyriakides
- Check for possibilities to include CKD into the EU Roadmaps on Non-Communicable Disease (NCDs), a new approach to tackling NCDs.
- Invitation to join the NCD stakeholder groups and give feedback to the proposed approach to ensure that CKD is fully part of the initiative.
- Support in outreach to EU Research and Innovation Commissioner Gabriel
- Blog/Q&A piece on World Kidney Day, to bridge the knowledge gap on CKD to improve kidney care amongst policy makers.
- WHO does not mention CKD as an NCD. Mr. Ryan promised that he would support us by mentioning this to the WHO.



# Public affairs – meetings with politicians (4)

Meeting Dimitri Grygowski, advisor to the French Minister of Health Olivier Véran, 17 December 2021

**Joint meeting between EKHA, Société Francophone de Néphrologie, Dialyse, et Transplantation (SFNDT), France Rein, and Renaloo.**

- Explore possibilities to ask attention for CKD, during the French Presidency of the European Council (January – June 2022)

## Outcomes

- Mr. Grygowski expressed strong interest & support, suggesting that the four organisations organise an event, endorsed by the French Presidency in relation to World Kidney Day (WKD) 2022, to increase the visibility of kidney diseases at the EU level.
- Idea to hold press release together with the Kidney MEP's is now further explored to be held in the week of the 10<sup>th</sup> of March 2022.





## Public affairs – Actions (1)

# EKHA open letter on Organ Donation and Transplantation

**EKHA published an open letter – launched on January 13<sup>th</sup> 2021 – calling for a new EU Action Plan on Organ Donation and Transplantation in the context of COVID-19**

## Outcomes & reach

- Addressed to EU policymakers
- Endorsed by **91** stakeholders
- 1x article on website
- 3x original Tweets
- Announcement in Dods (*main EU monitoring service, thousands of subscribers*)
- Twitter: Total of 12K impressions | Engagement rate : 1.6% | Retweets : 22x | Likes: 44x | Link clicks: 22x



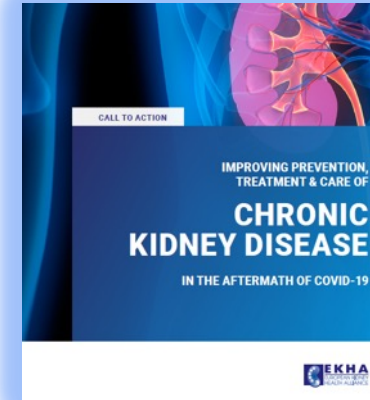
# Public affairs – Actions (2)

## CALL TO ACTION TO IMPROVE CKD PREVENTION, TREATMENT AND CARE IN THE AFTERMATH OF COVID-19

Launched on February 26<sup>th</sup> 2021, as part of the meeting with EU Health Commissioner Stella Kyriakides.

### Outcomes & reach

- Addressed to EU policymakers
- Endorsed by 90 stakeholders
- 1x article on website
- 6x original Tweets
- Announcement in Dods (*main EU monitoring service, thousands of subscribers*)
- Twitter: Total of 20.4K impressions | Engagement rate : 1.9% | Retweets : 42x | Likes: 82x | Link clicks: 71x



### Dods EU

Your Dods Monitoring Alerts for 26/02/2021



### EKHA - EKHA launches a call to action to improve CKD prevention, treatment and care in the aftermath of COVID-19



26/02/2021

EU Stakeholder - Press Releases

On 26 February, the European Kidney Health Alliance (EKHA) launched a call to action calling on EU leaders to improve Chronic Kidney Disease (CKD) prevention, treatment and care in the aftermath of COVID-19.

EKHA @EKHA\_EU · 26 Feb

📢 Our [#CallToAction](#) is published! We, together with 89 stakeholders are asking [EU](#) policy makers to improve the prevention, treatment and care of [#ChronicKidneyDisease](#) as a matter of priority 🚨 Read the full statement here [bit.ly/3pUf9TC](https://bit.ly/3pUf9TC)



### Four key recommendations:

1. Augment efforts on CKD prevention;
2. Collect and share data on CKD at EU level;
3. Promote home therapies, transplantation and the uptake of digital tools;
4. Make research and innovation in Kidney Replacement Therapy an EU priority.

# Public affairs - input



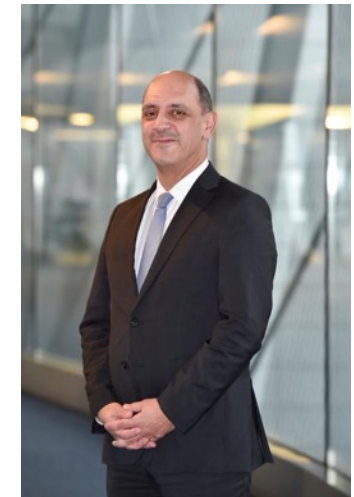
EKHA provided input to the [expert panel for effective ways of investing in health on resilient health and social care](#).

EKHA strongly urged the inclusion of CKD in the opinion of the expert panel, commissioned by the European Commission.

As a result, CKD was included in the final opinion as a higher risk factor for COVID-19 infection and serious negative outcomes.

## Written questions on Organ Donation & Transplantation

Following EKHA's outreach to MEPs, Mr. Manuel Pizarro and Mrs. Jutta Paulus submitted a written question to the European Commission on the need for a second EU action plan on Organ Donation and Transplantation.





# Public affairs – Decade of the kidney™ (1)

The Decade of the Kidney™ is a Pan-European Campaign which aims to put the spotlight on kidney disease at EU level for the next 10 years. The campaign was first initiated in the United-States by the American Association of Kidney Patients (AAKP) in 2019.

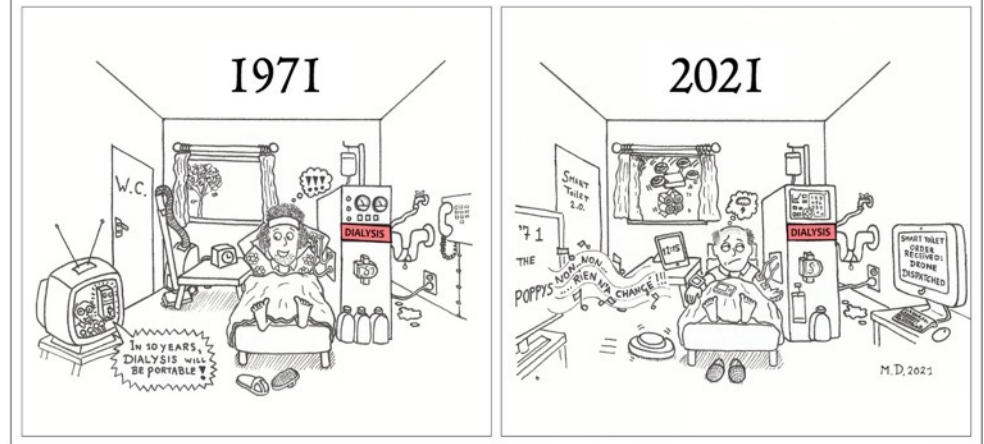
European launch on Twitter & website on World Kidney Day (March 11<sup>th</sup>, 2021)

- 4 original tweets
- 2 website articles in the news section of [www.ekha.eu](http://www.ekha.eu)
- New webpage “The Decade of the Kidney™
- Announcement in Dods (*main EU monitoring service, thousands of subscribers*)

Creative assets to support amplification

- One campaign visual
- One cartoon to be shared on social media

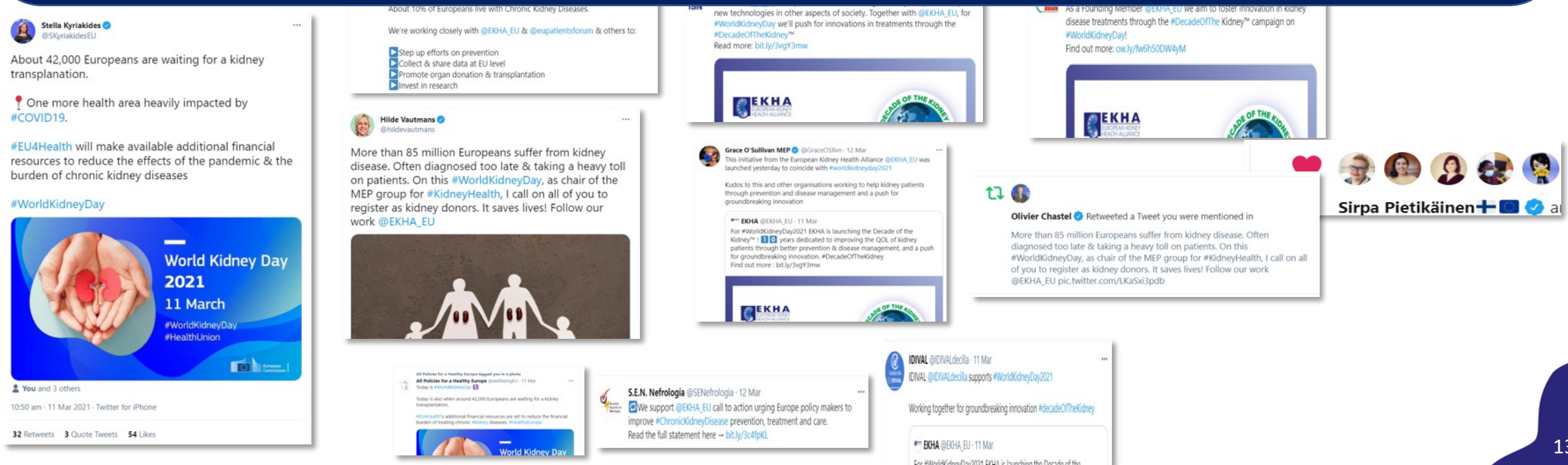
50 years of adding smartness into (nearly) everything



# Public affairs – Decade of the kidney™ (2)

## Outcomes and reach of the launch / stakeholder engagement

- Campaign shared by EKHA Board of Director members on Twitter
- Campaign relayed / liked by key stakeholders (including Health Commissioner Stella Kyriakides)
- Twitter: Total of **20K impressions** | Engagement rate : **1.4%** | Retweets : **61x** | Likes: **93x** | Link clicks: **38x**



# Event – Annual European kidney Forum (1)

## GOALS

- Share knowledge and exchange best practices to improve access to kidney disease treatments in Europe
- Discuss how to mitigate the impact of COVID-19 on kidney care.



184 Attendees (digital)

Click [HERE](#) for a short compilation and the main messages of the Forum

## Unmet needs & challenges in access to treatments in Europe: The case of Chronic Kidney Disease



**Stella Kyriakides,**  
Commissioner, DG SANTE



**Daniel Gallego,**  
President, EKF



**Hilde Vautmans,**  
Chair, MEP Group for  
Kidney Health



**Henning Søndergaard,**  
Danish Kidney Association



**Manuel Pizarro,**  
Co-Chair, MEP Group for  
Kidney Health



**Raymond Vanholder,**  
President, EKHA



**Jan De Maesseneer,**  
Professor in Family Medicine and Primary  
Care, Ghent University



**Stefan Schreck,**  
Advisor for Stakeholder  
Relations, DG SANTE



**Lieven Annemans,**  
Senior Professor of Health  
Economics, Ghent  
University



**Jeanette Finderup,**  
Clinical Nurse Specialist, EDTNA/ERCA



### GOLD SPONSORS



**Baxter**

with the support of Amgen

### SILVER SPONSORS



Click [HERE](#) for a written report of the event



# Event – Annual European kidney Forum (2)

## EU MEDIA (1)

**Euractiv** (major EU news outlet, thousands of subscribers)

- ✓ Special Report published during the weeks of June 14th to 7th July
- ✓ 4 editorial pieces
- ✓ 1 op-ed published beginning of September
- ✓ Advertising of the European Kidney Forum & the Decade of the Kidney on Euractiv's homepage

## Analytics

- ✓ 2348 page views
- ✓ 388 shares on social media
- ✓ 85 clicks in the Special Report section of the newsletter
- ✓ 267 clicks on EKHA logo

### Patient autonomy, education must be priorities for tackling kidney disease

By Gerardo Ferrana and Giedre Peasekyte | EURACTIV.com



With incidences of kidney disease predicted to rise in the next decade, health authorities are calling for more efforts to ensure patient autonomy and investment in training for both practitioners and patients.

Around 400 million people worldwide have some form of kidney disease. In the European Union, while kidney disease accounted for nearly double in 2019, it was majority of deaths from kidney disease as well as deaths from kidney cancer combined people aged 45 or above.

"We should promote more autonomy, education and materials that enable real shared decision making," he told EURACTIV.com.

He added that despite practitioners being aware of the treatment options for kidney disease, fast changes in the market require an ongoing process of

However, if detected early and managed appropriately, dialysis can be

### Promising portable kidney faces innovation, portability bottlenecks

By Gerardo Ferrana | EURACTIV.com



Portable artificial kidney is viewed as the next big thing in the field of home treatment that could stop dialysis being a full-time job for patients, but barriers to its rollout persist.

In a recent study more than 1,000 health specialists agreed that despite the future of kidney replacement therapies considered

But according to Jasper Bouman from the Dutch Kidney Foundation, there is a steadily growing threat of these devices becoming obsolete as the industry moves towards a more holistic model.

"These devices are not yet actively promoted by doctors or the carriers

the top of that, several national reimbursement systems do not yet seem ready to accommodate the local culture of home treatment, though policymakers often stress the necessity to make home healthcare more feasible.

In 2019, over 50% of households in one member state reported difficulty in covering the costs of professional

### Kidney disease research pins hopes on new disruptive technologies

By Gerardo Ferrana | EURACTIV.com



New technologies for treating chronic kidney disease (CKD) are opening up possibilities for improving patients' quality of life, with the European Union playing a key role in health funding and research initiatives in the wake of the COVID-19 pandemic.

"We are going to be taking ambitious steps in the area of health and also importantly when it comes to research on Human (the EU's programme for research)" Health Commissioner Stella Kyriakides told the annual European Kidney Forum.

Not more substantial breakthroughs have been experienced in the field of CKD treatment since the

the EU's renewed ambition on health which has become a top priority as Europe emerges from the COVID-19 pandemic.

"With the new Horizon Europe work programme of 2021-25 there are new opportunities for research on chronic kidney disease that include dialysis and better care," Kyriakides added.

A key priority identified by health professionals for kidney disease treatment is the development of simpler, cheaper and more easily accessible dialysis systems.

### Commission: burden of levelling kidney treatment access falls mainly on member states

By Giedre Peasekyte | EURACTIV.com



Inequalities in kidney treatment access across the EU have a heavy burden on patients' health, says the EU Commission.

While inequalities across the EU when it comes to kidney disease treatments are well known by the European Commission, the ball is ultimately in member states' courts when it comes to expanding access, according to

This issue was highlighted during a [recent event](#) by Belgian EU lawmaker Hilde Vautmans, who also chairs the MEP group for kidney health.

"Choosing the most appropriate therapy is not possible for all patients

population can differ wildly across the bloc, ranging from almost 60 in Spain to less than 10 in Bulgaria.

The huge disparity between European countries shows there is much room for improvement, EKHA

### Kidney health and climate change: Shedding light on a long-neglected relationship

By Marine Faure and Raymond Vanholder | European Kidney Health Alliance (EKHA)



Chronic Kidney Disease (CKD) is often described as the invisible killer, mostly because patients have few or no symptoms until it is too late. On the practical level, this means that the disease, although devastating for both the individual

Marine Faure is a Senior Consultant at European Kidney Health Alliance.

The discussions around climate change are no exception. Kidney disease and climate change are rarely addressed together despite being

causing an abrupt reduction in kidney function. The frequency and intensity of heatwaves, the spread of infectious & parasitic diseases following floods and the expansion of tropical diseases to other parts of the world are all climate change effects that can give

# Event – Annual European kidney Forum (3)

## EU MEDIA (2)

### Health Policy Platform (4162 registered users)

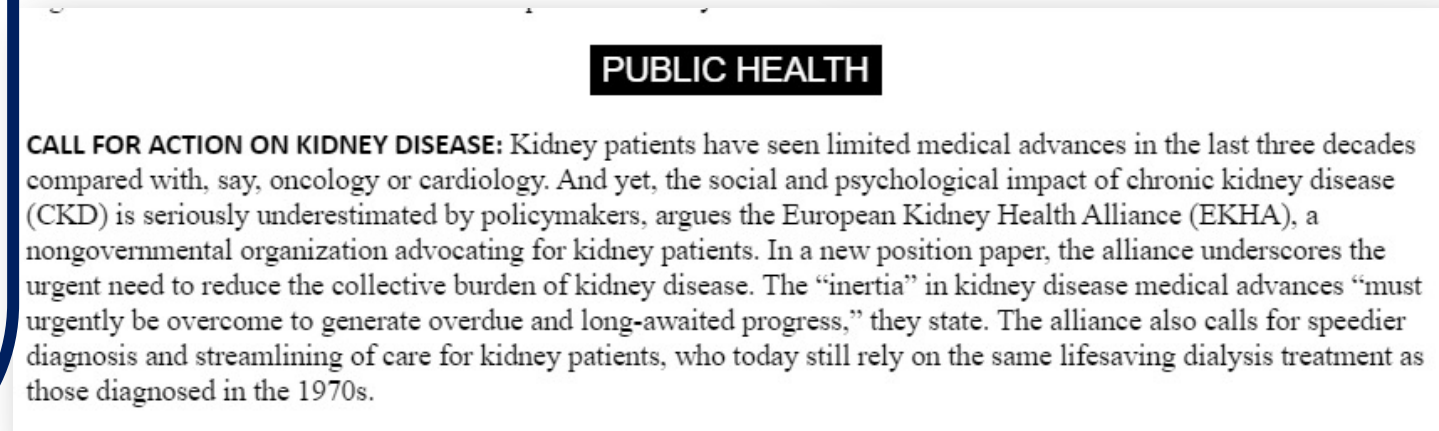
- ✓ Inclusion in event calendar
- ✓ 2x articles in news section + uptake in biweekly newsletter
- ✓ Post-event press release

### Politico Europe (major EU news outlet, thousands of subscribers)

- ✓ Full article in health-focused morning newsletter

### Dods (main EU monitoring service, thousands of subscribers)

- ✓ Announcement in 'Dods Alert'
- ✓ Uptake in event newsletter 'Stakeholder Bullet'
- ✓ Post-event briefing



# Event – Annual European kidney Forum (4)

## SOCIAL MEDIA

### Twitter

35x tweets from EKHA Twitter account

- ✓ 97.7K impressions
- ✓ 1.1% engagement rate
- ✓ 181 link clicks
- ✓ 174 retweets
- ✓ 273 likes

Mentions: 33x incl. tweets from the European Commission and MEPs

New followers: 15x

Profile visits: 3,525x

### LinkedIn

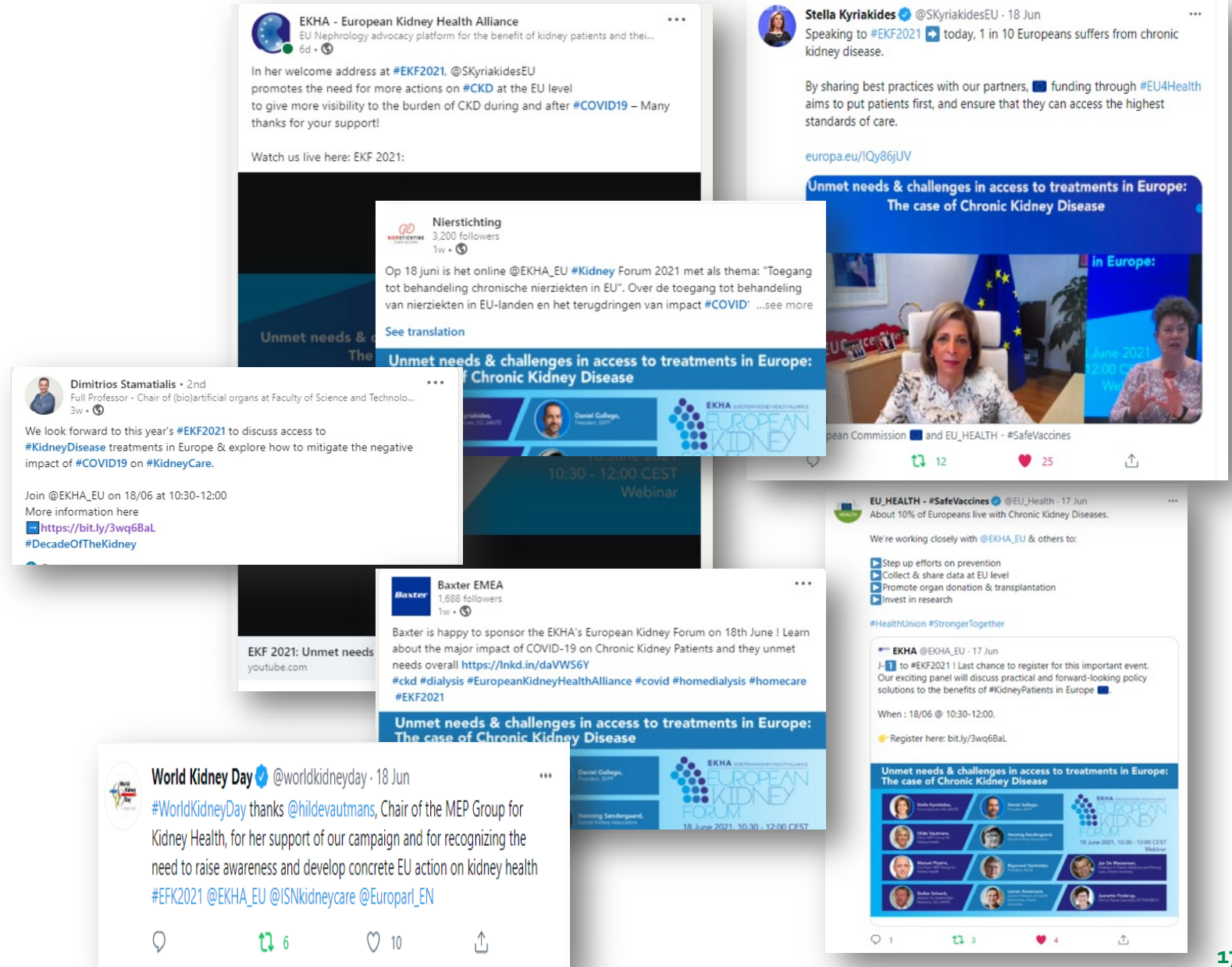
2x post from EKHA LinkedIn account

102 views

Mentions: 7x

7,500+ connections

64x likes





# Presentations by EKHA president Raymond Vanholder

## Q1+Q2 2021

- It's the economy stupid! Association between reimbursement policy and PD uptake. Joint ISPD and EuroPD meeting (virtual). 28 February-2 March, 2021
- What does living well with kidney disease mean to me? Webinar of the European Kidney Patient Federation at the occasion of World Kidney Day. 10 March, 2021
- Workshop EU4Health Program 2021 – potential solutions for a healthier European Union. Breakout session on prevention. 24 March, 2021.
- The need for patient-driven innovations in kidney care. Global summit on innovations in patient centred kidney care. A partnership event by The American Association of Kidney Patients and George Washington University School of Medicine and Health Sciences (virtual). May 13-14, 2021
- Green nephrology: the European perspective. ERA-EDTA Webinar. May 20, 2021.
- The decade of the kidney: a call for joint action. National Societies' meeting of ERA-EDTA. June 4, 2021
- The burden of kidney disease: the unbearable lightness of disregard. Session: Avoiding a crash landing of nephrology by creating awareness. 58th congress of the ERA-EDTA (virtual), Berlin, June 5-8, 2021

## Interviews



**2021 Nephrology Congress.**  
Click [HERE](#) for the interview  
(starts at 6,42 min)

[Politico Article \(24 dec\)](#)  
**Chronic kidney disease:  
A neglected crisis**

Click [HERE](#) for the interview with  
Raymond Vanholder

## Q3+Q4 2021

- The underestimated burden of kidney disease: the need of innovation. 47th annual congress of the European Society for Artificial Organs (virtual). London, 8-12 September 2021
- Investment in prevention of end-stage kidney disease vs. dialysis for all – a dilemma. Resident program. Life/2021. Frankfurt, 15-19 September, 2021.
- Costs of kidney care and kidney replacement therapy. What about the future? Life/2021. Frankfurt, 15-19 September, 2021
- The need for education in CKD. European Kidney Patient Federation Webinar on kidney disease and health education. 28 September, 2021
- Inequalities in uptake of kidney care: an ethical challenge. ISN/ASN/ERA webinar on ethical issues in nephrology. 29 September, 2021
- Green nephrology: the European perspective. 21st Katowice Seminar on Nephrology. Katowice, 25-27 November, 2021
- Nephrology in crisis situations: from earthquakes to COVID-19. European Dialysis and Transplantation Nurses Association – European Renal Care Association (EDTNA-ERCA) Webinar. 9 December 2021

# EKHA publications of 2021

1. STEL V.S. et al. Supplemented ERA-EDTA registry data evaluated the frequency of dialysis, kidney transplantation and comprehensive conservative management for patients with kidney failure in Europe. *Kidney Int.*, 100, 182-185, 2021
2. SEVER M.S. et al. Mass disasters and burnout in nephrology personnel – from earthquakes and hurricanes to COVID-19 pandemic. *Clin J Am Soc Nephrol*, 16, 829-837, 2021
3. VANHOLDER R., LAMEIRE N. COVID-19 and policy changes for kidney disease: the need for a 'decade of the kidney'. *Nephrol Dial Transplant*, 36, 8-11, 2021
4. VLAHOU A. et al. Data sharing under the general data protection regulation – time to harmonize the law and research ethics? *Hypertension*, 77(4):1029-1035, 2021
5. DE JONG R.W. et al. Results of the European EDITH nephrologist survey on factors influencing treatment modality choice for end-stage kidney disease. *Nephrol. Dial. Transplant.*, 2021. Doi: 10.1093/ndt/gfaa342
6. DE JONG R. et al. Patient-reported factors influencing the choice of their kidney replacement treatment modality. *Nephrol. Dial. Transplant.*, 2021 Doi: 10.1093/ndt/gfab059
7. KELLY D.M. et al, on behalf of the ISN Western Europe Regional Board. International Society of Nephrology Global Kidney Health Atlas: structures, organization, and services for the management of kidney failure in Western Europe. *Kidney Int. Suppl.*, 11, e106-e118, 2021
8. VANHOLDER R. et al. Fighting the unbearable lightness of neglecting kidney health: the decade of the kidney. *Clin. Kidney J.*, 14(7),1719-1730, 2021
9. VANHOLDER R. et al. Organ donation and transplantation: a multistakeholder call to action. *Nat. Rev. Nephrol.*, 17, 554-568, 2021
10. MENDU L.M. et al. Expanding utilization of home dialysis: an action agenda from the first international home dialysis round table. *Kidney Med.*, 3, 635-648, 2021 Doi:
11. LAMEIRE N., VANHOLDER R. Health literacy problems of kidney patients. *Nephrol. Dial. Transplant.*, 2021



# Activities of 2022

## First semester

# Introduction meeting MEP's – USA Kidney Caucus

January 12, 2022

- Need for innovation in kidney care since the total burden of kidney disease continues to expand rapidly.
- Collaboration to accelerate the progress led by patient organisations (AAKP – EKPF).
- Important pieces of the “kidney innovation puzzle” are present on both sides of the Atlantic (and indeed around the world) and combining them could speed-up innovation tremendously.
- Jointly, we can more effectively push past the status quo of kidney care and speed up the deliverance of cutting-edge prevention and treatments to the kidney patients

## Next step:

- Launching a '**declaration of intent**' to support the collaboration of an international framework for new innovative and affordable Kidney Replacement Therapies (KRT's) in response to Horizon Europe's Strategic Orientations for Research and Innovation and the Advancing American Kidney Health (AAKH) Executive Order

MEP **Hilde Vautmans**  
Chair MEP Group for  
kidney Health



Congresswoman  
**Susan Delbene**  
Co chair American  
Kidney Caucus



Congressman  
**Larry Bucshon**  
Co chair American  
Kidney Caucus



# Round table on rare kidney disease

2 & 3 February 2022

Participants	Job title
<b>Doctor Manuel Pizzaro</b>	<ul style="list-style-type: none"><li>• Member of European Parliament, Vice-chair of the MEP group for kidney health.</li></ul>
<b>Professor Rosanna Coppo</b>	<ul style="list-style-type: none"><li>• Director, Nephrology, Dialysis and Transplantation Unit. Regina Margherita Children's University Hospital, Turin, Italy</li></ul>
<b>Professor Fadi Fakhouri</b>	<ul style="list-style-type: none"><li>• Head of the Nephrology Department at CHUV and Full Professor at University of Lausanne, Switzerland</li></ul>
<b>Alister Humphreys</b>	<ul style="list-style-type: none"><li>• IgAN patient based in the UK</li></ul>
<b>Professor Panos Kanavos</b>	<ul style="list-style-type: none"><li>• Associate Professor of International Health Policy in the Department of Health Policy at London School of Economics and Political Science, UK</li></ul>
<b>Doctor Ionut Nistor</b>	<ul style="list-style-type: none"><li>• A Nephrologist working at the Nephrology Department, "Gr. T. Popa" University of Medicine and Pharmacy, Iasi, Romania</li></ul>
<b>Professor Alberto Ortiz Arduan</b>	<ul style="list-style-type: none"><li>• Chief of Nephrology, Fundación Jimenez Diaz &amp; Professor of Medicine, Autonomous University of Madrid, Spain</li><li>• Clinical Nephrology Governance Chair, ERA</li></ul>
<b>Professor Franz Schaefer</b>	<ul style="list-style-type: none"><li>• Professor of Pediatrics and Chief of the Pediatric Nephrology Division at Heidelberg University Hospital, Germany</li><li>• He founded the European Rare Kidney Disease Reference Network (ERKNet) and is the ERKNet Coordinator</li></ul>

## Objective:

Identify policy solutions to improve the diagnosis, treatment, and management of rare kidney diseases

**Output:** A policy insights paper addressing the human and societal burden of chronic kidney disease and rare kidney diseases in national plans: a call for policy intervention

**Barriers** hindering the uptake of targeted approaches for rare kidney diseases:



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# Update on the French Presidency of the EU

## Workpaper on defining a public Health Policy for the EU

EKHA worked closely with the French Ministry of Health on the 'Draft Grenoble Declaration': brought forward by French Presidency during meeting of EU Health Ministers at February 10, 2022

Aims to reinforce the European Health Union & to be signed by all EU Member States

→ First time that the impact of CKD is recognised in an official EU document

→ Likely to lead to Council recommendations

→ 3 mentions of Chronic Kidney Disease

- [...] chronic kidney disease [...] are all major challenges that demand joint and consistent actions and therefore more useful for Member States.
- [...] The cost of chronic kidney disease is another – inadequately documented – example of the impact of an ageing population on the EU's economic growth prospects.
- The research and treatment of rare diseases, chronic kidney disease, etc., has the characteristics of European public interest [...].



# Update on the Healthier Together Initiative

## EKHA pushes for the inclusion of CKD into this new initiative of the EU Commission

- Letter signed by Raymond Vanholder to EU Commissioner for Health Stella Kyriakides
- Oral question to the EU Commission tabled by 7 MEPs and debated in European Parliament Plenary on World Kidney Day (March 10)
- Emily Petrides, EKPF Representative, conveyed EKHA's messages to Stella Kyriakides, resulting in a suggestion to organise an official meeting between EKHA and EU Commissioner Stella Kyriakides.
- Input to the stakeholder consultation (end of April).

### Next step:

- Keep pushing for a wide EU action plan on CKD (e.g. EU framework on NCDs with strands for each NCD) that will include a policy roadmap





# World Kidney Day 2022 - European Plenary Debate on CKD

## European Parliament Plenary:

- Debate '*A systematic EU approach to Chronic Kidney Disease*' took place on WKD **March 10, 2022** between:
- MEPs Sirpa Pietikainen (EPP, FI), Nicolas Gonzalez Casares (S&D, ES), Jutta Paulus (Greens, DE), Joao Pimenta Lopes (The Left, PT), Juozas Olekas (S&D, LT), Brando Benifei (S&D, IT)
- Stella Kyriakides, EU Commissioner for Health and Food Safety



## Outcomes:

- Powerful and impactful statements from MEPs
- Commission response: does not intend to extend the NCD initiative to CKD, BUT committed to work on reducing the burden of CKD through other actions
- CKD high on the EU agenda means strong momentum around the disease, with a wide support from across all parliamentary groups.

# World Kidney Day 2022 - Awareness Raising Activities

## Video statements from EU policymakers and stakeholders

- MEP Hilde Vautmans
- MEP Manuel Pizarro
- MEP Cesar Luena
- MEP Jutta Paulus
- Olivier Véran, French Minister for Solidarity and Health
- John F. Ryan, Director for Public Health, DG SANTE
- Prof. Raymond Vanholder, EKHA President



## MEP Quotes

- MEP Hilde Vautmans
- MEP Manuel Pizarro
- MEP Cesar Luena
- MEP Jutta Paulus
- MEP Ondrej Knotek

"As the Chair of the MEP Group for Kidney Health, and on World Kidney Day, I call on Commissioners Stella Kyriakides and Mariya Gabriel to tackle CKD together with us and to create and implement an EU systematic approach. It is crucial to extend the new EU Initiative on Non-communicable Diseases 'Healthier Together' to CKD."



—MEP Hilde Vautmans

"CKD is all too often tackled through the spectrum of other chronic diseases. Addressing CKD prevention through a common response to other major NCDs will not be sufficient. As Co-chair of the MEP Group for Kidney Health, I call on the EU Commission to extend the 'Healthier Together' NCD initiative to CKD, finally putting it high on the EU policy agenda."



—MEP Manuel Pizarro

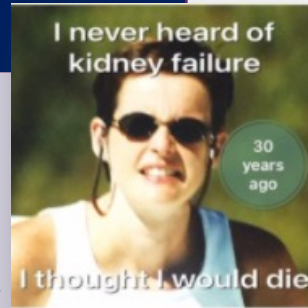
"We need a holistic and systematic approach to CKD. We need more investment in early diagnosis because a lot of people don't even know that their kidneys are not working properly. We have to ensure that CKD is finally tackled at the European level."



—MEP Jutta Paulus

## CKD Patient Story

- Marion's story:
- *'I had never heard of kidney failure, I thought I would die'*



## EKHA website

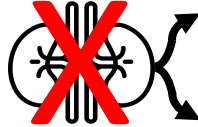
- Page dedicated to WKD :
  - Short article
  - Video statements
  - Marion's story
  - EKHA, AAKP, EKPF Infographic on KRT
  - SFNDT infographic & TV programme on WKD



# World Kidney Day 2022 -Awareness Raising Activities

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


### Kidney Failure: Present therapies are inadequate!



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

**Transplantation**

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

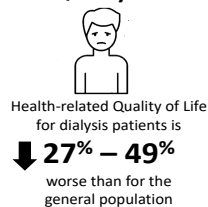


**Dialysis**

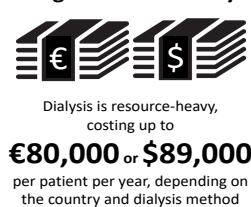
Most widely used available KRT option, **but**:

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

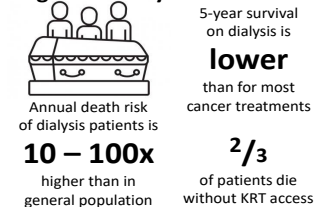
### Dialysis is associated with... Low Quality of Life




### High Cost to Society

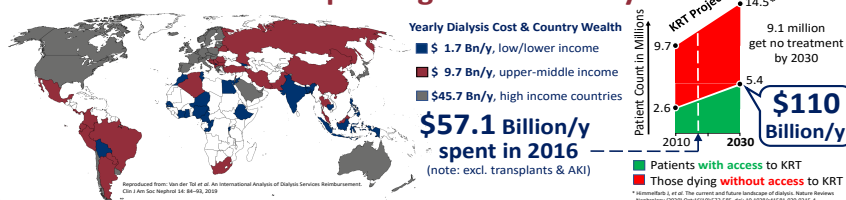


### High Mortality



 Covid-19 makes it even **worse!**

### World-Wide Costs Keep Rising Unsustainably!




### Bundle the Best Brains to Build Better Treatments!



## Die Welt braucht dringend *deutlich* bessere Nierenersatztherapien !


### Nierenversagen: Derzeitige Therapien sind ungenügend!



**Nierenversagen**  
ist auch bekannt als  
Nierenerkrankung im Endstadium (ESRD)  
**Keine Therapie?  
Du stirbst!**

**Transplantation**

- Beste & kostengünstigste verfügbare Therapieoption, **aber**:
- Strukturelle Knappheit an Transplantationsnieren
- Immunsuppressiva verhindern Transplantatabstoßung erhöhen aber auch das Risiko von Krebs und Infektionen
- 25 % der Patienten sind medizinisch nicht transplantabel
- Bis zu 25 % kürzere verbleibende Lebenserwartung



**Dialyse**

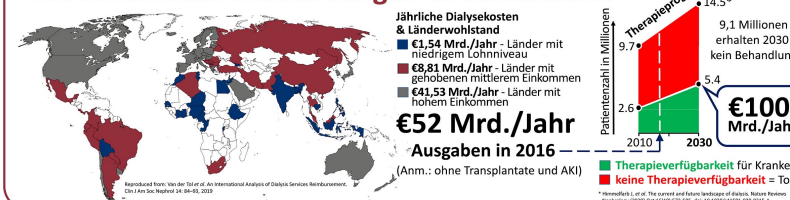
Am weitesten verbreitete verfügbare Therapieoption, **aber**:

- Ersetzt maximal 10-15 % der Nierenfiltrationsfunktion
- Ersetzt nicht alle anderen Nierenfunktionen
- Deutlich geringere Lebensqualität als eine Transplantation
- Teurer und ressourcenintensiver als eine Transplantation
- Bis zu 70 % kürzere verbleibende Lebenserwartung

### Die Dialyse geht einher mit...



### Die weltweiten Kosten steigen unaufhaltsam!



### Gemeinsam bessere Behandlungen entwickeln!





# World Kidney Day 2022: outcomes

POLITICO

- EU media coverage of EP Plenary Debate
  - Dods
  - Politico Pro Morning Health Care newsletter
- Significant social media engagement with EKHA's awareness raising material (videos, quotes, patient story, etc.)



MORNING  
HEALTH CARE

NON-COMMUNICABLE DISEASES

Retweets without comments

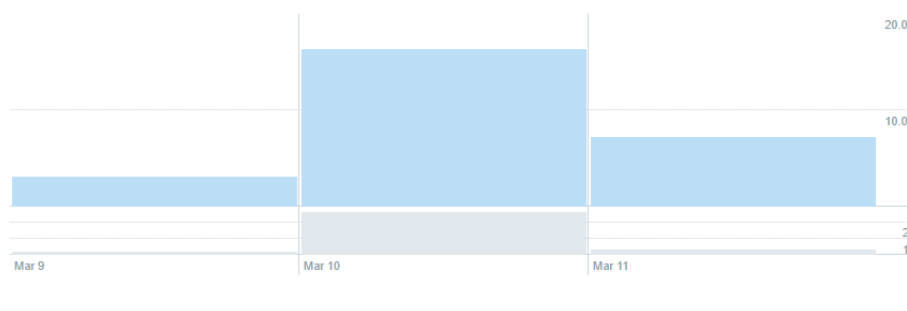
146

26 Retweets without comments

Mar 11

On average, you earned **49 Retweets without comments** per day

Your Tweets earned **26.6K impressions** over this 3 day period



Likes

260

Mar 11  
46 likes

On average, you earned **87 likes** per day

Link clicks

51

Mar 11  
8 link clicks

On average, you earned **17 link clicks** per day

**NO KIDNEYING AROUND ON CKD:** Health Commissioner Stella Kyriakides addressed the European Parliament on Thursday to talk about chronic kidney disease (CKD), a condition which affects as many as one in 10 Europeans. It's a topic that has only gained prominence due to how vulnerable patients with CKD are to the coronavirus.

**Taking action:** The Commission isn't sitting on its hands, said Kyriakides. Kidney disease is squarely in DG SANTE's cross-hairs through its new noncommunicable disease program "Healthier Together." The program targets cardiovascular disease and diabetes — both of which contribute to the prevalence of CKD.

**In the works:** Meanwhile, the health commissioner said, the 2020 Horizon Europe research programs includes 40 projects directly addressing CKD backed by €64 million with another 24 projects related to kidney transplants with a total of €47 million of funding — while the 2021 work program includes a call for the development of portable dialysis.

**A standalone program?** Finnish MEP Sirpa Pietikäinen (European People's Party group) said that the Commission should consider putting CKD at the same level as its other standalone programs like in cardiovascular disease. "Kidney disease is a silent killer. We do not raise it as a big issue at our member state level," she said.

# EKHA & Partners activities on Ukraine

- **EKHA-EKPF open letter to the European Commission & journal article (March 8)**

- Aim:

- Alert EU policy makers and the public on the dire situation of CKD patients in Ukraine and neighboring countries
    - Propose short and long-term solutions to protect CKD patients in time of war

- Outcomes:

- High engagement on social media
    - Appreciation received from Stella Kyriakides' cabinet and DG SANTE
    - Meeting with DG Santé, together with EKPF & ERA at June 8

- **EKHA participation to the European Commission stakeholder group on supporting Ukraine**

- EKHA participated in two meetings and raise CKD patients' needs on the ground and surrounding countries

# EU4Health – call for proposal on CKD



## Project overview

- The European Commission published a call for proposals on prevention on NCDs which mentions CKD
- Target NCDs other than those in the 5 action strands of the Healthier Together initiative (cardiovascular diseases, diabetes, chronic respiratory diseases, mental health and neurological disorders)
- The aim is to increase awareness, share knowledge, build capacity to improve public health by primary and secondary prevention
- EKHA applied as coordinator (deadline was May 24) together with a consortium of the following partners
  - EKPF
  - EUtox
  - IMEC
  - ISN
  - Renaloo

### Issue



CKD is a neglected disease suffering from low awareness on its severity and prevalence, whereas it has a very high EU-wide burden.

### Topic



Primary prevention is key for CKD, as it is in many cases preventable

### Intention of project proposal



Putting forward activities implementable in various EU Member States, geared towards the following objectives:

- 1) Increase awareness of CKD at EU population level and EU policy level
- 2) Increased prevention of CKD by composing a CKD prevention Code
- 3) Implementation of wide-scale screening of the populations that are of risk of developing CKD in Member States

# Running projects Working Groups



## **WG1: Prevention & screening**

Research via a survey to:

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



## **WG 2: Disease Management**

Research for need and use of a Disease Management Toolbox, to provide kidney patients with a practical tool to better manage kidney disease in all stages.

This tool should also be helpful to nurses, nephrologists, general practitioners and other specialists in supporting patients tackling their disease.



## **WG 3: Ground Breaking Innovation**

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

# Program second semester 2022

## Advocacy

## Collaboration & Meetings

## Events

Q3

- Ongoing monitoring of EU Commission activities with an impact on CKD
- Article on the Decade of the Kidney
- Scientific article on the benefits of a self-management tool for people with CKD
- Advocacy to push for better therapies for kidney patients that are accessibly for all European patients.

- Follow-up meeting Chairs MEP's for Kidney Health and the USA Kidney Caucus'
- EKHA Board Meeting
- Working groups meetings
- MEP Group for Kidney Health 'movie night
- Start NCD call project (?)

- Roundtable on QoL in Dialysis Care
- **50th EDTNA/ERCA International Conference**  
(10-14 September in Rotterdam)



Q4

- Ongoing monitoring of EU Commission activities with an impact on CKD
- Advocacy for the establishment of a international consortium for ground breaking innovation
- Advocacy (where possible with other NCD's) for more comprehensive screening

- EKHA industry supporters network meeting in Brussels
- EKHA Board Meeting
- Working group meetings

- Launch of a Declaration of intent at a Nephology conference (tbd) stating the support of patients, politicians, foundations and industry to establish an international consortium for kidney innovation

# Presentations by EKHA president Raymond Vanholder

## Q1+Q2 2022

- Raising the effectiveness of care acting early on chronic diseases ) the case of chronic kidney disease. Health care system resilience summit. 2020 World exposition (October 2021-March 2022). Dubai (virtual), 30-31 January 2022.
- Plaidoyer pour que la MRC soit intégrée dans les priorités de Santé par l'Union Européenne. 26ème Webinaire de la Société Française de Néphrologie, Dialyse et Transplantation (SFNDT) à l'occasion de la semaine du rein. Mars 8, 2022
- Reducing the burden of non-communicable diseases by promoting healthy lifestyle, self-care and early diagnosis. On-line interview. European Health Parliament, 11 March, 2022
- Advocacy to convince the EU to make CKD a health priority. On-line meeting by the Croatian Society of Nephrology. 11 March, 2022
- Nephrology: Past, Present, and What Does the Future Hold? Retirement celebration of M Couttenye, Antwerp, April 29, 2022.
- Sarton lecture: History of dialysis. Ghent, May 12, 2022.
- Getting EU health systems to be home centric. PD – Safer at home: growing and maintaining home dialysis programs. 59<sup>th</sup> Congress of the European Renal Association (ERA), Paris, 19-22 May 2022.
- CKD in Europe: 100 million people with kidney disease. 59<sup>th</sup> Congress of the European Renal Association (ERA), Paris, 19-22 May 2022.
- EKHA and the decade of the kidney. 59<sup>th</sup> Congress of the European Renal Association (ERA), Paris, 19-22 May 2022



# EKHA publications first semester 2022

1. VANHOLDER R., GALLEGO D., SEVER M.S. Wars and kidney patients: a statement by the European Kidney Health Alliance related to the Russian-Ukrainian conflict. J Nephrol, 35(2), 377-380, 2022
2. R. VANHOLDER. Future directions of dialysis. Kidney Dial, 2, 153-162, 2022
3. VANHOLDER R., AGAR J., BRAKS M., GALLEGO D., GERRITSEN K.G.F., HARBER M., NORUISIENE J., PANCIROVA J., PICCOLI G., STAMATIALIS D., WIERINGA F. The European Green Deal and nephrology: a call for action by the European Kidney Health Alliance. Nephrol Dial Transplant, 10.1093/ndt/gfac160
4. ....more to come shortly!

PUBLICATIONS



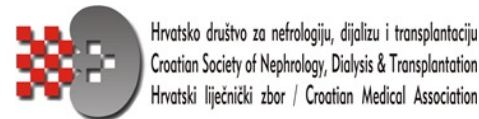


# EKHA in 2022

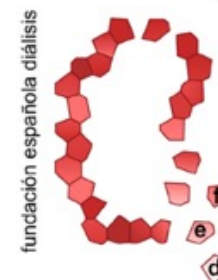
## FULL MEMBERS:



## AFFILIATE MEMBERS:



DIALYSIS, NEPHROLOGY AND KIDNEY  
TRANSPLANTATION UNION OF GEORGIA



EKHA is a member of  and 