



# EKHA General Assembly June 28, 2022

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

# AGENDA

## **10.00 – 10.15: Welcome and Activity Reports**

- Adoption and approval of the agenda
- Presentation of Activities and Finance Accounts 2022
- For vote: change of BoD members :
  - Agnes Fogo to resign as BoD member for ISN
  - Masaomi Nangaku proposed to be the new BoD member for ISN
- Governance: president elect / vice chair / special advisor.

## **10.15 – 10.20: Questions, Discussion and Discharge of the BoD**

## **10.20 – 11.00: Achievements and running projects**

- Presentation of achievements of 2022 and first semester of 2023
- Presentation of running EKHA projects including PREVENTCKD

## **11.00 – 12.00: interactive discussion on the EKHA work for affiliates**

- Interactive discussion to identify the wishes of the affiliate members and how EKHA can increase their support by reviewing the answers to the questions that were sent to the members prior to the meeting by mail

## **12.00 – 13.00: Introduction of new members**

- New members: EUtox, Greek society of Nephrology, Hungarian Society of Nephrology, KfH Kuratorium für Dialyse, NVBN, Renaloo, Swedish Society of Nephrology , GNFB
- Tour du table for updates from other affiliated members

## **13.00 – 13.45: Lunch**



# FINANCE

15 February 2023 10:42

Company: 732847767 - European Kidney Health Alliance VZW

Page 2 of 4

Internal year statement - Extensive report (Association)

	Code	2022
		01-01-2022 - 31-12-2022
<b>EQUITY AND LIABILITIES</b>		
<b>CAPITAL AND RESERVES</b>	10/15	29.175,49
<b>Accumulated profits (losses)</b>	(+)/(-) 14	29.175,49
140000 - Profit carried forward (C)		29.175,49
<b>PROVISION AND DEFERRED TAXES</b>	16	
<b>AMOUNTS PAYABLE</b>	17/49	121.495,08
<b>Amounts payable within one year</b>	42/48	71.495,08
Trade debts	44	71.495,08
Suppliers	440/4	71.495,08
440000 - Suppliers (C)		68.946,14
444000 - Invoice to be received (C)		1.892,69
444500 - Credit notes to issue (C)		656,25
<b>Accruals and deferred income</b> (explanation 6.8)	492/3	50.000,00
493000 - Deferred income (C)		50.000,00
<b>GL accounts not in the standard Belgian schema</b>	BXX	
<b>TOTAL LIABILITIES</b>	10/49	150.670,57

The BoD is asked to approve of the accounts of 2022 as audited by EY

	Code	2022
		01-01-2022 - 31-12-2022
<b>INCOME STATEMENT</b>		
<b>Operating income</b>	70/76A	345.108,41
Contributions, gifts, legacies and grants (explanation 6.9)	73	338.080,12
730000 - Membership fees (C)		114.826,85
731000 - Sponsorship fees EKHA Forum (C)		198.066,67
731010 - Other fees (C)		186,60
731100 - Gift (C)		25.000,00
Other operating income	74	7.028,29
743100 - Miscellaneous revenues - VAT Regularizations (C)		7.028,29
<b>Operating charges</b>	60/66A	363.646,66
Services and other goods	61	361.185,72
612400 - Subscriptions Microsoft (D)		403,72
612450 - Restaurant/catering (D)		2.464,10
612500 - Hotel costs (D)		3.861,28
612600 - Travel expenses (D)		2.671,51
613000 - Accounting fees (D)		5.441,33
613001 - Drukwerken (D)		560,49
613200 - Fees Interel support projects (D)		25.084,09
613300 - Various fees (D)		27.486,39
613301 - Internship compensation Communication (D)		1.604,07
613400 - Fees Buiten de lijnen (D)		89.436,58
613500 - Fees Triumph (D)		36.611,88
613550 - Fees Triumph - projects support (D)		12.048,50
613600 - Website (D)		1.319,34
614100 - insurance (D)		245,81
615000 - Membership fees ECDA (D)		4.397,82
615300 - Publicatiekosten (D)		140,24
616000 - Forum EKHA (D)		32.903,24
616010 - Events, conferences (D)		6.934,74
616100 - Annual public affairs (D)		105.791,12
616200 - BOD Meeting (D)		1.779,47
Other operating charges (explanation 6.9)	640/8	2.460,94
644100 - Non-deductible VAT (D)		2.460,94
<b>Operating profit (loss)</b>	(+)/(-) 9901	-18.538,25
<b>Financial income</b>	75/76B	0,10
Recurring financial income	75	0,10
Other financial income (explanation 6.10)	752/9	0,10
759000 - Other financial income (C)		0,10
<b>Financial charges</b>	65/66B	411,13
Recurring financial costs (explanation 6.10)	65	411,13
Other financial charges	652/9	411,13
654000 - Realised exchange losses (D)		2,92
657000 - Other financial charges (D)		408,21
<b>Profit (Loss) of the financial year before taxes</b>	(+)/(-) 9903	-18.949,28
<b>Gain (loss) of the period available for appropriation</b>	(+)/(-) 9904	-18.949,28
<b>Withdrawal from untaxed reserves</b>	789	
<b>Transfer to untaxed reserves</b>	689	
<b>Profit (loss) of the financial year available to be appropriated</b>	(+)/(-) 9905	-18.949,28

# CHANGE OF BOD MEMBERS ISN

**The Board of Directors of EKHA is asked to approve of the following change in representation of ISN to the EKHA BoD**

- Agnes Fogo to resign as BoD member for ISN



- Masaomi Nangaku proposed to be the new BoD member for ISN





# PRESIDENT ELECTIONS

The BoD is asked to prolong the current president mandate of Raymond Vanholder with one additional year, creating enough time to find a successor and approving the following:

- Raymond Vanholder extends his Presidency for another 2 years in June 2023, so his next term would end in June 2025, instead of June 2024.
- A candidate will then be suggested as president elect in the General Assembly of June 2024, that will become EKHA President as of June 2025.
- Raymond Vanholder will be Past President as June of then and being active in this role until June 2026.

Questions  
Discussions  
Discharge of the BoD



# Achievements of 2022 and first semester of 2023



# Strengthening the work of our network by means of advocacy



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

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



Physicians



Nurses



Patients



Foundations



Individuals



Commercial  
partners



Members of European Parliament (22)

- EKHA is a **non-profit organisation** whose aim is to propose solutions for the challenges of Chronic Kidney Disease in Europe **through EU-level advocacy**.
- EKHA works on the principle that the issue of kidney health and disease must be considered at European level and that **both the European Commission and European Parliament have vital roles to play in assisting national governments** with these challenges.
- EKHA advocates for more **effective prevention and a more efficient care pathway** intended to facilitate the **provision of high-quality care and affordable treatment to all Europeans equally**.

# EKHA members in 2023 (8 new)

## 5 FULL MEMBERS:



## 30 AFFILIATE MEMBERS:



## 10 SUPPORTERS:



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



# Members of the European Parliament (MEP) Group for kidney Health

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

New Vice-Chair of  
the MEP Group

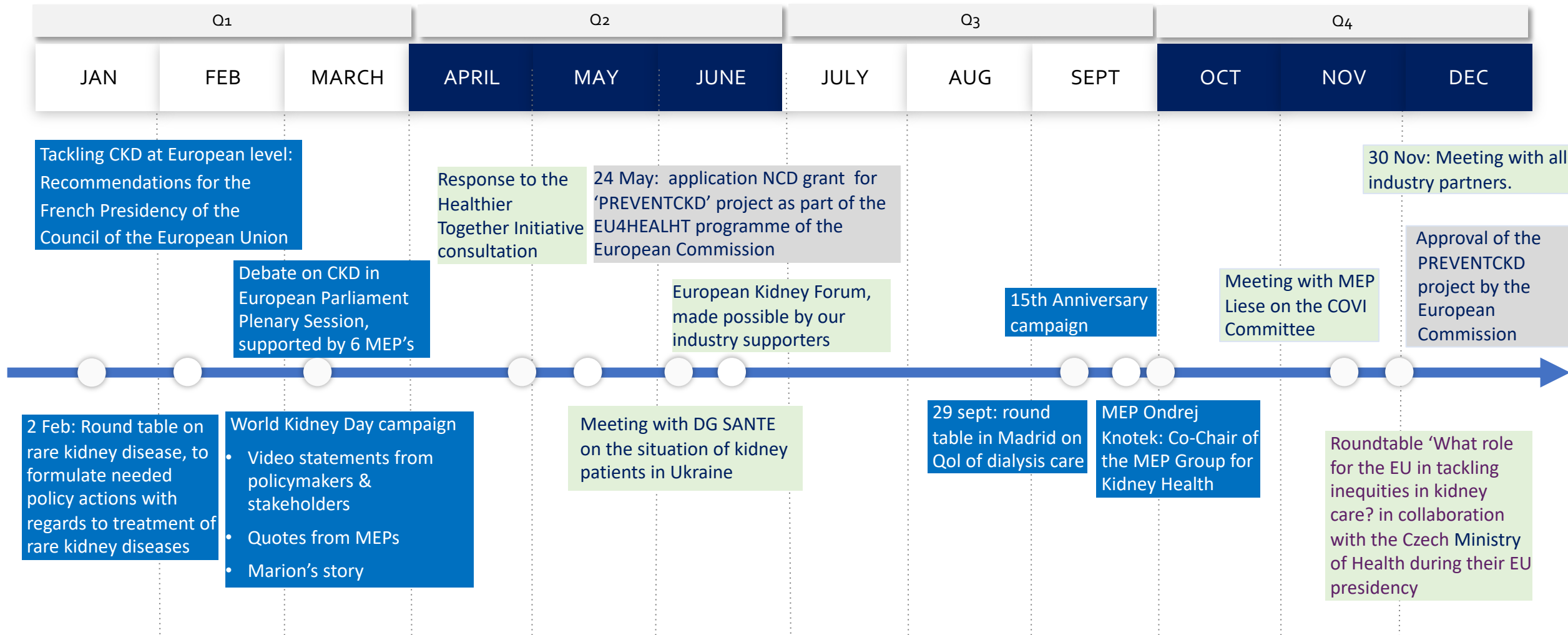


# EKHA President collaborations & actions

- **ERA Renal Disaster Relief Task Force:** group for support and advice for Ukrainian nephrologists
- **International Home Dialysis Roundtable :** work group including EKHA and the Patients Federation, an initiative to promote home dialysis (supported by Baxter / repository).
- **Economist impact:** project by the Economist Group to define barriers to early detection and intervention for CKD.
- **Think tank on patients' education (Baxter)**
- **My kidney journey:** member of advisory board; website development to describe for patients the possible trajectories especially in advanced stages of CKD (Baxter)
- **IMI projects in the pipeline: one on PROMs and one on green nephrology (both via FMC)**
- **Rare kidney Disease policy Statement (Novartis)**
- **Work Group on promotion patient quality of life (especially anemia related) (GSK)**
- **EACH:** advocacy project for more attention for cardiac health
- **EFPIA** (European Federation of Pharmaceutical Industries and Associates): workgroup to draw attention for cardiovascular disease
- **Global Sustainable Kidney Care Initiative:** workgroup to move towards green nephrology
- **Paper on inequities in kidney disease (Nature Reviews Nephrology)**
- **Union:** advocacy for more attention for immune compromised patients
- **EUTox:** uraemia work group with a EU COST project (educational project for young researchers)



# Summary: overview of public affairs & collaboration successes





**EU COMMISSION  
& PARLIAMENT**



# French presidency of the council of the EU

**French Presidency  
of the Council of  
the EU**  
January-June 2022



## Outreach in 2021

Together with French  
partner organisations  
*SFNDT, France Rein,*  
and *Renaloo*



## Succesfull meetings with French representatives

Antoine Malandain,  
Ministry for Europe  
and Foreign Affairs  
  
Dimitri Grygowki,  
Ministry for Solidarity  
and Health



## Commitments from French officials

Include CKD in France's  
response to Member  
State Consultation on EU  
NCD initiative *Healthier  
Together* (tbc)  
  
Include CKD in France's  
position on the *European  
Health Union* (tbc)  
  
French Presidency label  
for *World Kindey Day*  
(tbc)



# Recommendations to the French Presidency of the EU

**EKHA launched a set of recommendations to tackle CKD at EU level**, together with its French partners *SFNDT*, *France Rein*, and *Renaloo*.

**Calls on the French Presidency to make CKD an EU health priority:**

1. Prevent CKD or at least delay its progression
2. Improve access to existing treatment options and stimulate research to develop more innovative treatments
3. Recognise the high vulnerability of patients and their needs in times of pandemic
4. Promote green dialysis

**Launched on 19 January 2022 in FR and EN.**



# Recommendations to the French Presidency of the EU

## Media Coverage

**Dods**  
(EU media,  
thousands of  
subscribers)



1x announcement

**Dods EU**

Your Dods Monitoring Alerts for 19/01/2022



**Multiple stakeholders - Tackling Chronic Kidney Disease at European level: recommendations to the French Presidency of the Council of the EU**

19/01/2022

EU Stakeholder - Press Releases

**Twitter**



10x original tweets

34.2k impressions  
(number of times users saw the tweets)

906 engagements  
(number of times users interacted with the tweets)

**LinkedIn**



10x original posts

2484 impressions

84 reactions

Pinned Tweet



**EKHA** @EKHA\_EU · 19 Jan

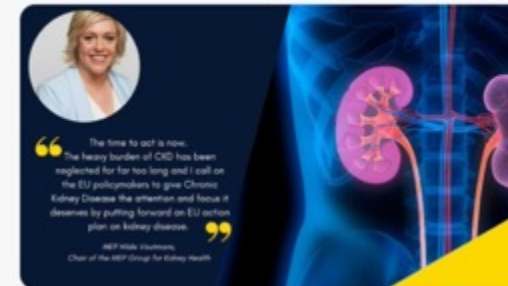
Today, we are launching recommendations for @Europe2022FR 🇫🇷 to tackle #ChronicKidneyDisease at EU level, together with our French partners @com\_SFNDT, @FranceRein, @Renalooo  
Read our Recommendations (FR & EN versions): [bit.ly/33wPniT](https://bit.ly/33wPniT)  
Check our thread below 📌 #PFUE2022



You Retweeted

**Hilde Vautmans** @hildevautmans · 19 Jan

As member of the MEP Group for #KidneyHealth, I am happy to support @EKHA\_EU recommendations to tackle #CKD at the #EU level. Read the detailed set of recommendations here [bit.ly/3fQW1mZ](https://bit.ly/3fQW1mZ)



**EKHA** @EKHA\_EU · 19 Jan

Building on the @Europe2022FR meeting on the resilience of health systems that took place yesterday, we launched today a set of recommendations to alleviate the impact of #CKD on patients & health systems.  
Read it here [bit.ly/3fQW1mZ](https://bit.ly/3fQW1mZ)  
#PFUE2022



**EKHA** @EKHA\_EU · 20 Jan

Did you know? Many cases of #CKD could be avoided through better #prevention. This can be achieved by reducing exposure to key lifestyle #riskfactors & increasing #screening of at-risk populations.  
Read our recommendations to @Europe2022FR [bit.ly/3fQW1mZ](https://bit.ly/3fQW1mZ)  
#PFUE2022

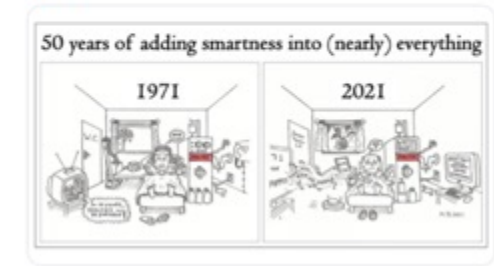


EKHP and 9 others



**EKHA** @EKHA\_EU · 20 Jan

Did you know? #CKD treatments have not changed significantly in the last 50 years and remain highly burdensome for patients.  
We call on the EU to stimulate research into promising & innovative CKD therapies.  
Read our Recommendations to @Europe2022FR [bit.ly/3fQW1mZ](https://bit.ly/3fQW1mZ)  
#PFUE



# Follow-up WITH the French Ministry of Health

## 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 on 10 February 2022
- Aims to reinforce the European Health Union & to be signed by all EU Member States
- 3 mentions of Chronic Kidney Disease
  - First time that the impact of CKD is recognised in an official EU document
  - Likely to lead to Council recommendations
- [...] 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 [...].





# Outreach to EU Commissioners Gabriel & Kyriakides



**Mariya Gabriel**, EU Commissioner for Innovation, Research, Culture, Education and Youth

Letter sent on 25 January 2022, on behalf of Prof. Vanholder

- Request for a meeting to discuss the research priorities of the kidney health community and explore the possibilities for a collaboration to develop innovative CKD treatments.
- Invitation to give keynote speech at European Kidney Forum 2022.



**Stella Kyriakides**, EU Commissioner for Health and Food Safety

Letter sent on 27 January 2022, on behalf of Prof. Vanholder

- Express concern over the fact that CKD is not listed amongst the priority diseases of the new EU NCD initiative 'Healthier Together'.
- Provide reasons as to why CKD should be included in the 'Healthier Together' initiative.

# European Parliament engagement: COVI Committee

- **COVI Committee:** Special Committee of the European Parliament on the COVID-19 pandemic: 'lessons learned and recommendations for the future'
- Meetings with MEPs who are both members of the COVI Committee and the MEP Group for Kidney health to **discuss how the lessons learned from the COVID-19 crisis could contribute to improving the life of CKD patients.**
- The main goal is for the **COVI Committee's report** on the lessons learned from the pandemic and recommendations **to address the significant challenges and unmet needs in kidney disease management and research.**



MEP Peter Liese  
(EPP, Germany)  
Meeting on 23/11



MEP Aldo Patriciello  
(EPP, Italy)  
Meeting date TBC



MEP Jutta Paulus  
(Greens/EFA, Germany)  
Meeting date TBC

## Outcomes

- Discussions with MEP Liese's team member, who was very **receptive to EKHA's messages** on the situation of CKD patients in Europe, how the pandemic has shed light on the shortcomings in the delivery of care of CKD and how the lessons learned from could contribute to improving the life of CKD patients.
- The possibility of further meetings to discuss **green nephrology** and **MEP Liese's participation in the EKF2023** were considered.
- Meeting allowed to get **further insights on the timeline** in the Parliament, on the priorities of the MEP and have a first contact with the assistant.



The European Commission has launched in December 2021 the Healthier together – EU non-communicable diseases (NCD) initiative to support EU countries in identifying and implementing effective policies and actions to reduce the burden of major NCDs and improve citizens' health and well-being.

The initiative covers the 2022-2027 period and includes 5 strands:

> health determinants > cardiovascular diseases > diabetes > chronic respiratory diseases > mental health and neurological disorders <

**Since CKD is not include in the initiative EKHA engaged into the following actions:**

- Pushed for the inclusion of CKD into this new initiative
- 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
- 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.

Healthier together- EU  
Non-Communicable  
Diseases Initiative





EKHA submitted a project called PREVENTCKD as response to the [Call for proposals on prevention of NCDs - other NCDs](#), by the European Commission, which made mention of kidney disease. The objective of the call is to target NCDs other than those in the five action strands of the 'Healthier Together – EU NCD Initiative' and cancer; for example, kidney diseases, by increasing awareness, sharing knowledge, and building capacity to improve public health, especially at local level.

## EKHA constituted a consortium together with:

- The European Kidney Patient Federation (EKPF)
- Eutox (a working group of the European Society of Artificial Organs (ESAO))
- IMEC
- International Society of Nephrology
- RENALOO



The project was approved by the EC  
at the end of 2022 and will run from  
March 2023 to March 2025

## Objectives PREVENTCKD 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, to enhance quality of life, mental health and delay the process of deterioration of the kidney function and to minimize societal cost.



## Work Packages

1. Data collection on CKD: retrieving new data and updating existing data
2. Development and implementation of the Prevention code
3. Development and implementation of a transferable albuminuria screening campaign
4. Identification and comparison of existing (best)practices in all the above prevention areas, as well as identification of evidence gaps

# EKHA & EKPF activities on Ukraine

- **EKHA – EKPF open letter to the European Commission & journal article**
  - **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
- **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

# Meeting with the European Commission on Ukraine

- On 8 June 2022, **EKHA, EKPF, and ERA** met with DG SANTE representatives to discuss about the situation of kidney patients in Ukraine
- EKHA, EKPF and ERA presented the challenges encountered by kidney patients on the ground, highlighted the work of the three organisations so far, in particular the Renal Disaster Relief Taskforce and proposed forward-looking solutions on the short and long term.

## INFORMATION PROVIDED BY THE COMMISSION

- DG Santé is **adjusting its workplan** to the situation in Ukraine
- EC cannot act inside Ukraine, so it has **set up a system of medical evacuation** to transport patients from the country to the EU (transplant patients qualify for this)
- All requests for medicines and other needs must be addressed by the Ukrainian Ministry of Health to the Emergency Response Coordination Centre from DG ECHO, which then coordinates with Member States

## Outcomes

- The Commission is willing to receive information from the RDRT
- They can facilitate a meeting with DG Research
- Very willing to keep the dialogue open with EKHA, EKPF and ERA on Ukraine and kidney health in general

### EC active participants in the meeting:

- **Philippe Roux**, Head of Unit 'Health information and integration in all policies',
- **Marianne Takki**, Team Leader, Health Promotion, Disease Prevention, Financial Instruments,
- **Dirk Meusel**, policy officer, public health, and health security.

**AWERENESS  
RAISING  
CAMPAINGS  
& EVENTS**



# 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



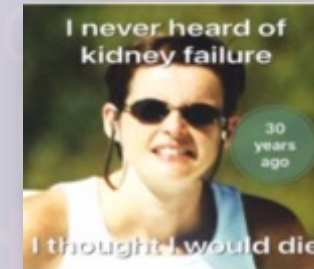
## MEP Quotes

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



## CKD Patient Story

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



## EKHA website

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



# World Kidney Day 2022 – Europe plenary debate on CKD

## European Parliament Plenary:

- Debate '*A systematic EU approach to Chronic Kidney Disease*' took place on WKD 2022 between:
- MEPs Sirpa Pietikainen (EPP, FI), Jutta Paulus (Greens, DE), Nicolas Gonzalez Casares (S&D, ES), 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 – Infographic on KTR

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

### Kidney Failure: Present therapies are inadequate!



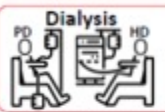
Kidney Failure  
is also known as:  
End Stage Kidney Disease  
**No KRT? You Die!**



**Transplantation**

Best & cheapest available KRT option, but:

- Structural Shortage of Transplant Kidneys
- Immune suppression drugs prevent transplant rejection but also increase Risk of Cancer & Infections
- 25% of patients are medically unfit for transplantation
- Up to 25% shorter remaining Life Expectancy



**Dialysis**

Most widely used available KRT option, but:

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

### Dialysis is associated with...

#### Low Quality of Life

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

#### High Cost to Society

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

#### High Mortality

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

5-year survival on dialysis is **lower** than for most cancer treatments  
**3/4** of patients die without KRT access

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!



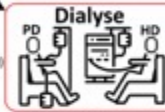
Nierenversagen  
ist auch bekannt als  
Nierenerkrankung im Endstadium (ESRD)  
**Keine Therapie?  
Du stirbst!**



**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...

#### Niedriger Lebensqualität

Die gesundheitsbezogene Lebensqualität von Dialysepflichtigen beträgt  
**↓ 27% – 49%**  
schlechter als in der Allgemeinbevölkerung

#### Hohen gesellschaftlichen Kosten

Die Dialysetherapie ist kostenintensiv - bis zu  
**€80.000**  
pro Patient und Jahr, je nach Land und Dialysemethode

#### Hoher Sterblichkeit

Jährliches Sterberisiko von Dialysepflichtigen ist  
**10 – 100x**  
höher als in der Allgemeinbevölkerung

Das 5-Jahresüberleben an der Dialyse ist **niedriger** als bei den meisten Krebsbehandlungen  
**3/4** der Erkrankten sterben ohne Therapieoption

Covid 19 macht es noch **schlimmer!**

### 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

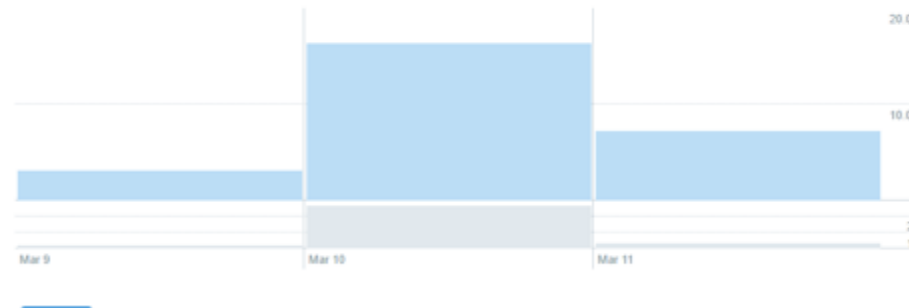
146

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.



# Annual European Kidney Forum in the EU parliament

## Key take aways:

- Pressing need of developing technological innovation, with patient, society and environment in mind
- The EU can offer guidance and champion green innovation nephrology
- Solid funding programme and international collaboration are needed
- Listening to patients is the most powerful activator for advocacy
- Need to engage with EU policymakers & EU key files to put green innovation in nephrology on the EU agenda

## Main successes:

- Attendance of **6** MEPs – Strong and open support from the European Parliament
- Outstanding engagement on social media
- Very positive feedback from EU policy makers, industry partners & attendees
- 75 online and onsite participants



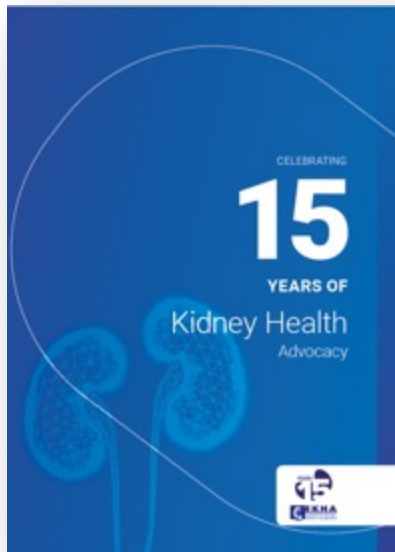
# EKHA 15<sup>th</sup> Anniversary Campaign

## Social media campaign, September - October 2022

- New logo for EKHA 15 years
- Series of quote cards with insights from supporter MEPs and EKHA BoD members
- Updated EKHA factsheet to highlight achievements in the past 15 years

## Networking reception, 15 June 2022

- High-level attendance
- Attendance from 40 people
- Awarded MEP Vautmans & MEP Knotek for their support



# ROUND TABLES





# Roundtable in the European Parliament – Brussels

Roundtable:

## What role for the EU in tackling inequities in kidney care ?

30 November 2022, 15:00-17:00 CET

Brussels, European Parliament, room SPINELLI 8F388

Followed by a networking coffee, 17:00-18:00 CET

Hosted by MEP Ondřej Knotek

Event of the Czech Society of Nephrology and the European Kidney Health Alliance  
Under the Auspices the Minister for European Affairs of the Czech Republic Dr. Mikulas Bek  
and the Czech Presidency of the Council of the European Union



- **30 November 2022, 15:00-17:00**; followed by a networking coffee
- **Collaboration with Czech Society of Nephrology**
- Under the Auspices of the Czech Presidency of the Council of the EU
- **Hosted by MEP Ondřej Knotek**, Co-Chair of the MEP Group for Kidney Health
- Workshop format with EU policy makers, EKHA Board members and relevant stakeholders
- The roundtable looked at **inequities in access to different kidney replacement therapies across European countries and among specific subgroups in society**
- Participants will discussed the role of the EU in improving the access to kidney care for all European patients, and **develop concrete policy recommendations.**

# Round table on rare kidney disease – online

In 2022 an expert panel (consisting of nephrologist, economists and patients) formulated the following policy actions with regards to treatment of rare kidney diseases. Whitepaper and scientific article will be published in 2023.

## Awareness and prioritisation

- Recommend early diagnosis in national plans
- Launch education campaigns targeted towards physicians and patients
- Raise awareness on CKD and RKD amongst policymakers and the general population
- Develop guidelines specific to RKD

## Diagnosis

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

## Factors affecting rare kidney diseases

## Management

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

## Therapeutic innovation

- Allocate R&D funds to RKD
- Generate evidence to expand understanding of RKD
- Identify and validate surrogate endpoints
- Conduct large scale multicentric studies
- Increase acceptance of alternative statistical methods

# Round table: ways to enhance QoL in dialysis care – hybrid

## Key findings panel:

- There is an urgent need to listen to and empathize with patients.
- Both patients and healthcare professionals should receive proper education on CKD and dialysis.
- Patients should play a more active role in advocating for the improvement of their QoL and should speak with one voice.
- Calling on the European Union and Member States to work together to develop a patient-centered approach to dialysis care.

## Key findings audience:

- **Patient advocacy** is instrumental in improving kidney care. As such, patients must be included in advocacy efforts to raise awareness of their needs.
- **Complete psychosocial care**, which gives access to social workers and psychologists, also contributes to achieving a higher QoL. Family members and caretakers also need to be involved in the conversation.
- **A patient-centric approach** puts patients in control over aspects that influence their QoL. A patient-centric approach takes patients' needs, desires and education into account.
- There is a need to **improve patients' health literacy**. Patients' education must be tailored to their perspective, and start at the onset of their disease (pre-dialysis).



## Roundtable on ways to enhance quality of life in dialysis care

Hybrid event

29th September 2022

14:30-18:00 CEST

Room Mate Oscar Hotel, Plaza Pedro  
Zerolo 12, Madrid, Spain & online



# Achievements Q1-Q2 2023



## World Kidney Day

- Show your kidney love campaign with Tina Turner
- Q&A article on EKHA website
- Social media campaign



## PREVENTCKD

- Kick off first EKHA Project financed with an EU grant together with consortium partners and HaDEA / EC

## EP event on dialysis

- Attendance from MEPs' offices, EKHA members and partners
- Support secured from representative of the European Research Council

## EKHA amendments in EP report

- EKHA amendments on the needs of the immunocompromised population in times of pandemics included in the COVI Committee report

## Meetings MEPs of the SANT Committee

- Meetings with 4 MEPs to inform the SANT report on non-communicable diseases



## Meeting with EU Belgian Presidency

- Meeting with representatives of Belgian Ministry of Health ahead of upcoming EU presidency
- Successful collaboration with Belgian societies
- Briefing on CKD

## CKD mentioned in EP event on NCDs

- Kidney disease mentioned in EP hearing on the healthier together initiative by MEP Katerina Konecna
- Topics: organ donation and transplantation and the inclusion of kidney disease in the initiative

## Discussion with industry partners

- EKHA and EKPF meeting with Baxter to discuss self-management tool
- EKHA industry meeting
- Multi-stakeholder coalition project

## European Kidney Forum 2023

- Green Nephrology
- High-level speakers secured

## EKHA social media platforms

- Twitter: 64 new followers & 107.7K impressions
- LinkedIn: 475 new followers / 35.6K impressions
- Website: 10 new articles





# European Kidney Forum 2023

2023 European Kidney Forum

MEP Group for Kidney Health event

## THE FUTURE OF KIDNEY CARE

Investing in green nephrology to meet the European Green Deal Targets

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

European Parliament Brussels, SPAAK 7C50

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



### Programme

Chaired by: Tamsin Rose

#### 15:00-15:15 Opening remarks

- MEP Hilde Vautmans, Co-Chair, MEP Group for Kidney Health
- MEP Juozas Olekas, Member, MEP Group for Kidney Health
- MEP Ondřej Knótek, Co-Chair, MEP Group for Kidney Health (video)

#### 15:15-15:30 Setting the scene

*Kidney health and the environment: a neglected bidirectional link*

- Prof Raymond Vanholder, President, European Kidney Health Alliance
- The energy crisis and dialysis care: how are patients and health systems coping?
- Ms Fiona Loud, Policy Director, Kidney Care UK

#### 15:30-16:45 Panel discussion: Joining forces to improve kidney health and foster greener nephrology practices

##### Panel 1

- Mr Daniel Gallego, President, European Kidney Patients' Federation
- Prof Giordina Piccoli, Nephrologist, Nephrology Service, Le Mans Hospital Centre, France
- Dr Ilaria de Barbieri, President and Scientific Board Chair, European Dialysis and Transplant Nurses Association/European Renal Care Association
- MEP Juozas Olekas, Member, MEP Group for Kidney Health

Q&A

##### Panel 2

- Ms Arianna Gamba, Director of Programmes, Healthcare Without Harm Europe
- Ms Charlotte Roffiaen, European Policy and Advocacy Advisor, Renaloo
- Dr Fokko Wieringa, Principal Scientist, Connected Health Solutions Department, IMEC, The Netherlands
- Ms Petra Leroy Čadová, Policy Officer, Innovative Health Initiative, DG for Research and Innovation, European Commission

Q&A

#### 16:45-16:55 Concluding remarks

- Commissioner Stella Kyriakides, Commissioner, DG for Health and Food Safety, European Commission
- Prof Raymond Vanholder, President, European Kidney Health Alliance

#### 16:55-17:00 EKHA Declaration of Intent & Guiding Principles

#### 17:00-18:30 Networking reception



# Scientific papers on issues concerning CKD in 2023

**In 2023 EKHA President Raymond Vanholder was main author or co-author of 7 scientific articles on CKD. The latest is:**

- Vanholder et al, **A policy call to address rare kidney disease in health care plans**. Clin. J. Am. Soc. Nephrol. Available from: Doi: 10.2215/CJN.0000000000000220

**Also our working group members publish scientific articles:**

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

**And more articles will follow soon!**

- In Nat Rev Nephrol: on **inequities and vulnerable populations** (WKD 2023 theme)

**Science meets advocacy**

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

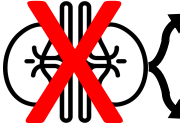


# Where science meets advocacy – EKHA projects 2023

1. **PREVENTCKD:** to enhance CKD screening, data on prevalence and incidence, best practices and the creation of a CKD prevention code. The project is funded by the EC and supported by AstraZeneca, in collaboration with members of EKHA working group 1 and the following consortium partners:
  - EKPF — EUTOX – IMEC – ISN – RENALOO
2. **Exploration of a self management tool** for people living with CKD (funded by Baxter) in collaboration with members of EKHA working group 2.
3. **Facilitate Home Haemodialysis care for chronic dialysis patients** in Europe (funded by Mozarc) in collaboration of a working group constructed of experts in the nephrology field (nephrologist, nurses and patient).
4. **Establishment of an international consortium for ground breaking innovation** in collaboration with:
  - Patient organisations EKPF and AAKP;
  - The co-chairs of the MEP Group For Kidney Health and (Hilde Vautmans and Ondrej Knotek)
  - the Co-Chairs of the USA bi-partisan Congressional Kidney Caucus Congressman Larry Bucshon and Congresswoman Suzan DelBene,
  - Members of EKHA working group 3

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

### Kidney Failure: Present therapies are inadequate!



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

**Transplantation**

Best & cheapest available KRT option, but:

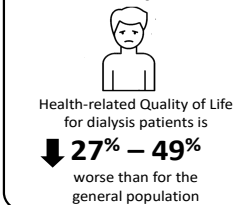
- Structural Shortage of Transplant Kidneys, many Patients Die, while still on the Waiting List
- Immune suppression drugs prevent transplant rejection but also increase Risk of Cancer & Infections
- Still up to 25% shorter remaining Life Expectancy

**Dialysis**

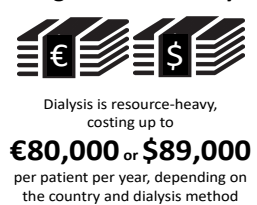
Most widely used available KRT option, but:

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

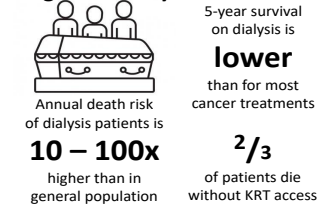
### Dialysis is associated with... Low Quality of Life



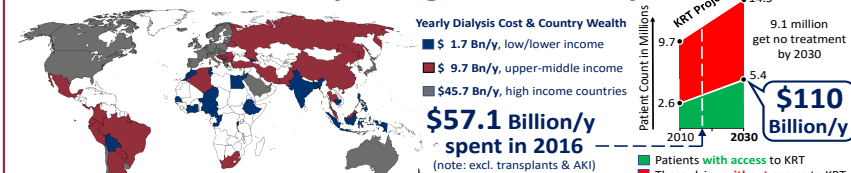
### High Cost to Society



### High Mortality



### World-Wide Costs Keep Rising Unsustainably!



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



**Patients Doctors & Nurses Policy makers Inventors & Investors Engineers Entrepreneurs**

**DECADE OF THE KIDNEY**  
INTERNATIONAL ASSOCIATION OF KIDNEY PATIENTS

**EKPF**  
EUROPEAN KIDNEY PATIENTS FEDERATION

**EKHA**  
EUROPEAN KIDNEY HEALTH ALLIANCE

# EKHA overall advocacy achievements



CKD mentioned in high-level parliamentary debates



EU funding secured for CKD prevention and early diagnosis (PREVENTCDK)



CKD included in key EU reports, initiatives and policies



The CKD community represented annually in the European Parliament

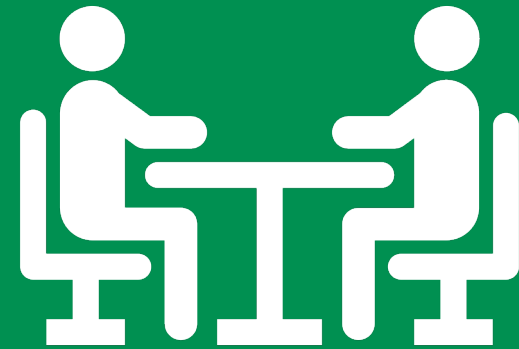


EKHA seen as a go-to partner for any EU initiatives on kidney disease



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

**Interactive discussion to  
identify the wishes of the  
affiliate members  
and how EKHA can increase  
their support**



# Connecting the network (1)

## Q: How can we further improve our collaboration?

- Involve more patients, take their limitations into account (low energy for travelling/long meetings, covid risks)
- Learn more about other members' activities, strategies, national situations, etc.
- More shared projects and more interactive (virtual) meetings / catch up talks
- Professional support to the nephrology society
- To do this kind of questionnaires regularly. Specifically questions number 2 and 3 on national political issues and how EKHA can support.
- Short regular exchange about the state of the CKD situation in the individual countries.

# Connecting the network (2)

## Q: What should be – to your opinion – the highest priority for EKHA to work on?

- The contact and working with the EU policymakers is unique for EKHA. So this should be the main focus of EKHA. Information has to flow in both directions.
- EKHA should stress the importance of kidney disease in public health and convince lawmakers to increase funding of measures that confer renal protection
- Bringing CKD into the "European consciousness". Support innovations in renal replacement therapy with all our Equal access to all modalities of RRT in all countries (i.e. advocate for approximately equal reimbursement in countries).
- Continue to get kidney failure on the agenda of EU to stop increasing CKD (failure/death cause) address issues (like covid, shortage of medication, quality of care, prevention)
- Clear information on healthy life style by EU/WHO
- Increasing opportunities to get EU funds for joint projects
- To inform governments and people for chronic Kidney disease and how to prevent it
- Organ transplantation and CKD prevention.
- The most urgent task should be the decrease of the incidence of CKD by education of the whole society from the medical staff to the politicians.

# Connecting the network (3)

## Q: How can we better share knowledge and activities of the network?

- The meeting in Milan was excellent (the idea and the execution). This should be repeated.
- Newsletters, mails, social media, meetings, everything is already there.
- A regular external newsletter would be a great idea, to be distributed to the Brussels health bubble and all other concerned / interested stakeholders. It could also be an opportunity to talk more about EKHA's members activities.
- The Prevent CKD project - analogue to EU Cancer Code - can make a website in 24 languages of EU (or more) with scientific validation/actualisation, for stage 1/2/3. Most kidney associations are oriented to Stage 4/5. Stage 1/2/3 is a much broader group of (future) patients.
- Webinars to share knowledge on national and EU projects (e.g. sharing of best practises)
- Regular meetings for discussions
- Install a virtual platform



# Connecting the network (4)

## Q: Other suggestions, ideas, questions?

- Show, how the representation of nephrologists, patients, nurses, foundations, industry and providers works. In Germany, we have laws, which prohibits the cooperation of all these groups at all time. Perhaps, there is a chance for an European law, which overrules these national laws.
- Promote "green nephrology" less water, less electricity, lower CO<sub>2</sub> footprint.
- More information on EU health policy news would be very welcome.
- Prepare a tv spot that can be distributed to all the members and with collaboration of all them and the possibility to present it for one month in all the countries the same period (with additional fundraising)
- Webinars may help

## **Introduction of new members:**

NVBN, Greek society of Nephrology, KfH

Kuratorium für Dialyse, Renaloo

Hungarian Society of Nephrology, Swedish

Society of Nephrology , Eutox, GNFB



**Tour du table for  
updates from other  
affiliated members**



**A BIG THANK YOU** to all our members, working group members, MEP's, supporters and other people involved in our network for their collaboration in 2022 with EKHA, to raise awareness for the impact of Chronic Kidney Disease and to push for:

- Prevention of CKD
- Better disease management of CKD
- Ground breaking Kidney Replacement Therapies

**TOGETHER WE CAN MAKE THE DIFFERENCE!**

thank you!

[www.ekha.eu](http://www.ekha.eu)

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