



YEAR PROGRAM 2022

VERSION 1.1 FEBRUARY 2022

info@ekha.eu

ABOUT EKHA

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 at EU political level.

EKHA's works focusses on: Proactive Advocacy in the EU political area and in member states by: campaigns, meetings with high level politicians, whitepapers, scientific articles, questions for the EU commission, feedback on EU programmes, collaboration in EU projects, targeted actions at WKD and the organisation of the annual EU kidney Forum.



The EKHA platform connects:



Physicians



Nurses



Patients



Foundations



Individuals



Industry

EKHA is a member of

FULL MEMBERS:



AFFILIATE MEMBERS:



DIALYSIS, NEPHROLOGY AND KIDNEY TRANSPLANTATION UNION OF GEORGIA



and EU4health

EKHA PROGRAM 2022 – (1)

Advocacy

Q1

- Tackling Chronic Kidney Disease at European level : Recommendations to the EU French Presidency
- Questionnaire to research screening at and EU GP level
- Outreach to EU Commissioners for Health and Innovation & Research
- Report on the added value of a disease management tool to support people with CKD in their self-management
- Advocacy to include CKD in the EU commission NCD strategy > Oral question by MEP Group for kidney health in the EU commission to include CKD into their NCD strategy in collaboration with Kidney Health Group MEP's

Q2

- Presenting results of Questionnaire on screening
- Advocacy to include CKD in the EU commission NCD strategy (ongoing)
- Potential outreach to Czech and Swedish Presidencies

Q3

- Advocacy to push for better therapies for kidney patients that are accessibly for all European patients.
- Potential proposal for an ENVI workshop on CKD
- Advocacy to include CKD in the EU commission NCD strategy (ongoing)

Q4

- Advocacy for the establishment of a international consortium for ground breaking innovation
- Advocacy (where possible with other NCD's) for more comprehensive screening
- Advocacy to include CKD in the EU commission NCD strategy (ongoing)

Publications & Presentations

- Presentation by EKHA President Raymond Vanholder on "Screening of CKD" on Health Resilience Meeting at the World Expo in Dubai (January 30th)
- Article on the future of dialysis (journal: Kidney Dialysis)
- White paper on policy recommendations needed for rare kidney diseases
- Article on Green Nephrology (NDT)
- Presentation by EKHA President Raymond Vanholder: "Plea for an integration of CKD among the health priorities of the European Union" at:
 - SFNDT webinar (8/3)
 - Croatian society of nephrology symposium about World kidney day (11/3)

- Article on transplantation in disasters (journal to be decided – covers transplantation and the EU4Health theme of disaster preparedness).
- Publication on EKHA and the decade of the kidney™ (NDT)
- Publication on policy recommendations & actions for rare kidney diseases (journal TBD)
- ERA Symposium > presentations by EKHA President Raymond Vanholder:
 - Safer at home: organizing and monitoring home dialysis program
 - EKHA and the decade of the kidney™.

- TBD

- Scientific article on the benefits of a self-management tool for people with CKD

EKHA PROGRAM 2022 (2)

EKHA Events / Actions

EKHA Meetings

Member /Supporters conferences

Q1

- EKHA Policy Roundtable on Rare Kidney Diseases (powered by Novartis)
- Action at WKD with amongst other the launch of a Q&A with John Ryan Deputy Director General for Health (DG Santé) in collaboration with ISN.

- MEP Group for Kidney Health Chairs introduction meeting with the Chairs of USA kidney caucus
- MEP Group for Kidney Health lunch meeting
- EKHA Board Meetings
- Working group meetings

- ISN World Congress of Nephrology 2022 (Feb 24-27)
- World Kidney Day (March 10)

Q2

- Annual EU kidney Forum that this year will be about innovation and green Nephrology
- EKHA General Assembly
- Thematic webinar / round table (topic to be decided)

- MEP Group for Kidney Health Chairs & the Chairs of USA kidney caucus, follow up meeting
- EKHA Board Meeting
- Working group meetings

- ERA congress Paris (May 19-22)
- 75th World Health Assembly (May 22-28)

Q3

- Thematic webinar on screening

- EKHA Board Meeting
- Working group meetings
- High level political meeting

- 50th EDTN/ERCA International Conference (Rotterdam, September 10-13)

Q4

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

- EKHA Board Meeting
- Working group meetings
- MEP Group for Kidney Health lunch meeting
- EKHA industry supporters network meeting

EKHA WORKING GROUPS PROGRAM 2022

EKHA has 3 working groups (WG). The groups exist of people of EKHA member organisations (profit and non profit) and people from the nephrology world who contribute with their expertise. In collaboration with EKHA headquarters they carry out tasks and actions to achieve, amongst other, the 3 strategic goals of EKHA. The 2022 task are as follows:



WG1: Prevention & screening

Research via a survey to:

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



WG 2: Disease Management

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



WG 3: Ground Breaking Innovation

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



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

PLANNING WORKING GROUP 1 -2022

EKHA working group 1 works on the strategic goal to prevent people from getting kidney disease.



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.

Q1

- Def version of questionnaire ready and digitalisation
- Determination of dissemination channels
- Disseminating of questionnaire (15 February – 18 March)
- Processing information of the questionnaire

Q2

- Analysing the information
- Drawing up report with main result
- Teaming up with other NCD NGO's

Q3

- Whitepaper on screening
- Thematical Webinar

Q4

- Advocacy action in the EU commission and at National Authorities

PLANNING WORKING GROUP 2 - 2022

EKHA working group 2 works on the strategic goal to improve disease management by educating politicians, care givers (GP's, Specialists) and scientists on the impact of unhealthy kidneys.



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.

Q1

- Research amongst people with ESKD, nephrologist and renal nurses on the possible added value of a disease management tool
- Article containing the main findings of the report
- Division of tasks: article – follow up steps for further research – inclusion of relatives - conceptual design

Q2

- Conceptual design of the format content of a possible digital self management tool
- Testing of the conceptual design
- Finding sponsors / budget for the tool

Q3

- Design of the tool
- Article on the benefits of self-management via a tool

Q4

- Introduction of the tool
- Thematic Webinar

PLANNING WORKING GROUP 3 - 2022

EKHA working group 3 works on the strategic goal to include CKD as a research priority of the European commission to obtain better treatments via innovation.



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



Q1

- Meeting between MEP Group for kidney health chairs, and chairs of the USA kidney Caucus (January 12, 2022)
- Creating draft of the declaration of intent + guiding principles (Working Group Members)
- Pushing the innovation message forward via an infographic at World Kidney Day (10 March)
- EKHA partner feedback on the Declaration of intent (between 7-18 March)
- Presenting the declaration of intent to MEP Group for Kidney during a lunch meeting (29 March)

Q2

- Seeking further stakeholder support for the declaration of intent (EKHA network)
- Creation of a whitepaper stressing the need of a consortium
- Agenda topic of the EU Annual Kidney Forum
- Follow up meeting between MEP Group for kidney health chairs, and chairs of the USA kidney Caucus

Q3

- Further preparations to sign the declaration of intent

Q4

- Launch of the declaration of intent
- Thematic Webinar

EKHA COLLABORATION BENEFITS



NETWORK

- Visible, appreciated and leading advocacy platform representing the Kidney World on an EU level
- Participation possibilities via EKHA working groups
- Information on EKHA activities via the EKHA newsflash with the possibility to inform on own collaboration projects with EKHA



PUBLIC AFFAIRS

- Building momentum for improved kidney health at EU level.
- Public Affairs synergies via activities on shared CKD goals that are beneficial on both EU and national level for EKHA members and supports
- Access to high level EU politicians and Kidney Members of EU Parliament (MEP's)



KNOWLEDGE SHARING

- Insights via regular academic EKHA publications
- Exchange of information and good practices
- Research, tools and actions by the EKHA working groups on prevention, screening, disease management and Kidney Replacement Therapy innovations



MEETINGS / EVENTS

- EU Kidney Forum
- EKHA General assembly for members and supporters
- Industry network meeting
- Kidney MEP meetings
- Thematic webinars and round tables
- Advocacy actions

"If you want to go fast, go alone. If you want to go far, go together"



Contact us at
info@ekha.eu