


CKJ REVIEW

Combating the rising tide of kidney advocacy in Europe: the seminal role of the European Kidney Health Alliance (EKHA)

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ABSTRACT

Chronic kidney disease (CKD) is one of the most prevalent and fatal chronic diseases. However, the political attention CKD receives is not proportional to its significant human, economic and ecological burden. One major reason is the lack of awareness among the general population and policymakers. As a result, investment in the therapeutic approaches to CKD have largely remained inadequate, while existing therapies did not change for decades. To respond to the lack of awareness of CKD, several European and international kidney care societies, supported by national and regional organizations, founded the European Kidney Health Alliance (EKHA) in 2007. This Alliance is a Brussels-based advocacy organization representing people with kidney diseases and the kidney care community at the European Union level, and from there, also at the country level. EKHA's aim is to ensure that every candidate for kidney care, irrespective of stage of kidney disease, receives optimal and timely treatment, which is affordable at a societal and individual level. This

Received: 27.11.2024; Editorial decision: 23.12.2024

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publication reviews the European political landscape, EKHA's history, points of focus and tools for harnessing available data into advocacy on CKD. Areas discussed include prevention and screening of CKD, its health-economic and environmental impact, and the need to facilitate kidney transplantation and home dialysis. We also examine EKHA's specific approaches to enhance kidney care, its affordability and its sustainability. The EKHA model aims at forestalling the burden of CKD and its underestimated economic and ecologic impact.

Keywords: advocacy, EKHA, European Kidney Health Alliance, European Union, policy

INTRODUCTION

Worldwide, chronic kidney disease (CKD), currently estimated to affect 850 million people [1], is more prevalent than cancer, diabetes, cardiovascular disease, stroke or chronic respiratory disease [2, 3], and is one of the fastest growing causes of death, projected to be the fifth leading death cause by 2050 [4]. In Europe, CKD is still surpassed in prevalence by cancer [3], but the gap is narrowing (Fig. 1). The numbers of people with CKD are likely underestimated, given the challenges of identifying early kidney disease. The societal, economic, ecological and human burdens are immense [5, 6], but kidney disease also has a significant impact on the social and family lives of those affected [6]. Despite being a major public health issue, CKD is often overlooked by policymakers, leading to a distorted health-economic approach—high expenditure on kidney disease management, particularly for kidney replacement therapy (KRT), yet disproportionately low investments in screening (case finding), prevention and innovative research.

Europe is no exception to this general trend. In response, several organizations advocating for kidney health joined forces to establish the European Kidney Health Alliance (EKHA) [7] with the intent to influence European health policy towards better kidney health and kidney care [8]. This manuscript reviews EKHA's efforts over the past years, and outlines potential actions at the national and regional levels that could complement EKHA's European Union (EU)-focused initiatives.

POLITICAL LANDSCAPE OF THE EU

EKHA primarily seeks to influence all levels of the EU that have the capacity to impact healthcare policies of the Member States of the EU and of the associated countries.

EU political activities are conducted by three bodies: the European Commission, the Parliament and the EU Council. The Commission currently consists of a President and 26 Commissioners, each of which is covering a specific portfolio, and is supported by an administrative staff spread across General Directorates. The Council is composed of government leaders or of portfolio ministers from each Member State. Interaction with the national level usually occurs through the rotating EU Council Presidencies which are held consecutively for one semester by each Member State.

Details on EU policy can be found in the [Supplementary data](#).

HISTORY AND STRUCTURE OF EKHA

EKHA was established in 2007 (for founding members, see Table 1) and has currently eight full members. Those are major European and international societies focused on kidney issues (Table 1), which compose the Board of Directors, and represent a wide spectrum of kidney health interests (Table 1). Addition-

ally, EKHA has 36 affiliated members representing 26 countries (Table 1, Fig. 2), including 6 national patient organizations.

Details on EKHA's history and structure can be found in the [Supplementary data](#).

EKHA ACTIVITIES

Originally, EKHA's activities primarily focused on an annual Forum organized in the European Parliament involving patients, professionals, policymakers, administrators and other stakeholders. Particularly after statutory changes in 2019 and once the COVID-19 crisis came to an end, EKHA expanded its activities, organizing more than one event each year covering various kidney-related topics. This expansion was driven by the understanding that not all policymakers are interested in the same issues, and raising awareness requires repeated engagement. Given the complexity and diversity of kidney diseases and therapies, it is more effective to address some of those issues separately, while ensuring that overall no groups are excluded. However, the Forum remained the core event, supplemented by targeted actions on World Kidney Day (WKD), aligned with the WKD topic.

EKHA's activities focus on representing the entire kidney health community, particularly individuals with kidney disease and their families, who remain the main focus of all efforts. Their contributions alongside those of kidney care professionals are crucial in capturing the attention and continuous interest of policymakers. EKHA's community is further completed by the renal nurses, who play a vital role in kidney care, together with other professionals including engineers, biochemists and technicians, who all are important for delivering quality care.

Although EKHA focuses primarily on the EU, attention is also given to non-EU countries when relevant. Several of EKHA's affiliated members represent non-EU countries (Fig. 2), some of which are candidate countries or have agreements with the EU. Despite Brexit, EKHA keeps an open communication with UK kidney-related organizations which continue to participate in EKHA activities and publications [9]. EKHA's contacts also include the USA, through regular communication with the American Association of Kidney Patients (AAKP).

EKHA also collaborates with other organizations, provided they do share EKHA's goals and their initiatives favor kidney health. In this context, EKHA is a member of the European Alliance for Cardiovascular Health (EACH), a multistakeholder organization raising awareness of cardiovascular disease [10], of which CKD is both a major cause and consequence [11, 12]. Discussions are also underway to explore similar collaborations with diabetes associations. Finally, EKHA held the Chairmanship and Secretariat of the European Chronic Disease Alliance (ECDA) from 2017 to 2024. ECDA is an umbrella group of 12 organizations, representing virtually all important non-communicable diseases (NCDs) [13], including diabetes, cancer, cardiovascular,

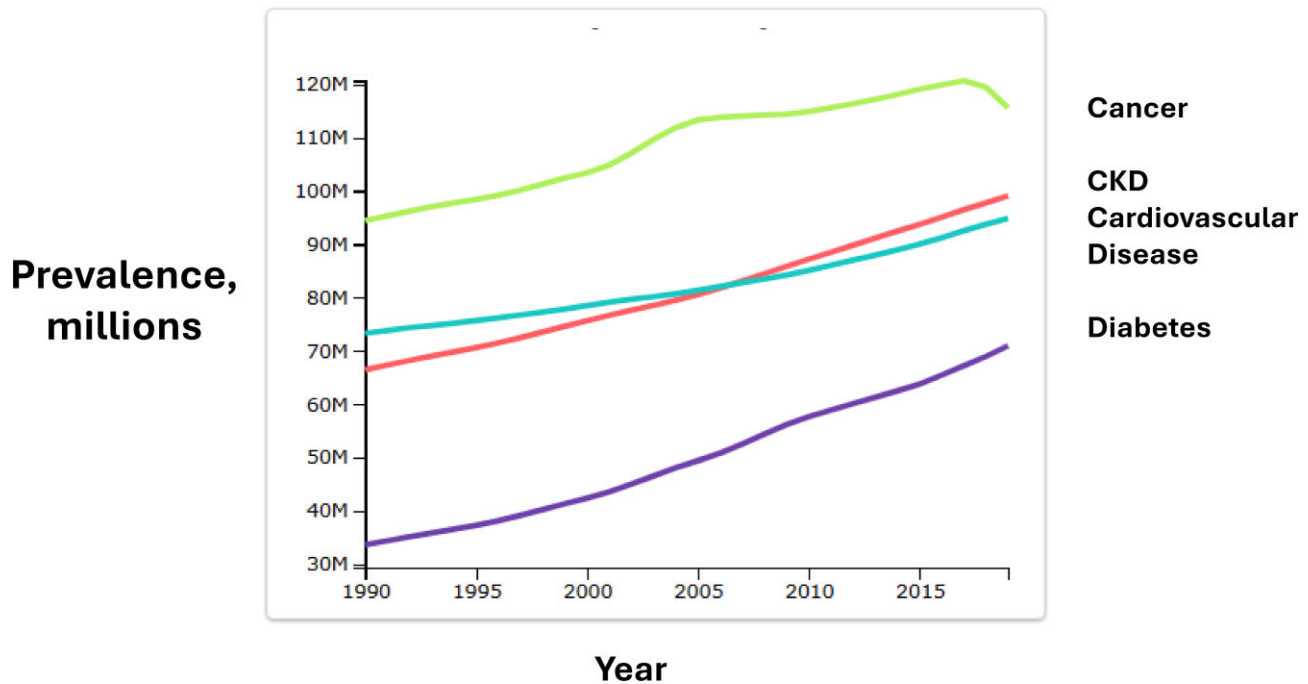


Figure 1: Evolution of prevalence in Europe of four major NCDs, starting in 1990. The last registration year is 2019. Data were calculated based on the statistics of the Global Burden of Disease (GBD). Green: cancer; red: CKD; blue: cardiovascular disease; purple: diabetes.

liver and neurological diseases, which are all closely linked with kidney disease [6, 14].

TACKLING PERSISTENT MISUNDERSTANDINGS ABOUT KIDNEY HEALTH

Tenacious misconceptions about kidney disease remain a challenge. Many policymakers believe that the population affected by kidney disease is limited to those with advanced kidney disease, and that consequently dialysis and transplantation fully address the issue of kidney care and fully and permanently resolve kidney disease issues. In addition, they view those therapies as expensive for only a few people, while ignoring the large majority of people with CKD dying prematurely before they ever should receive KRT. Others assume that kidney disease will disappear if diabetes and cardiovascular disease are eliminated. Not only is this unlikely as kidney diseases have diverse causes, but in addition, diabetes and cardiovascular disease will not be easy to eliminate without consideration of kidney health, CKD being a distinct entity, requiring distinct therapeutic approaches for each cause. Finally, the prevalence of CKD and its impact on outcomes of other disorders such as diabetes, cardiovascular disease or cancer are often underestimated, largely because CKD remains asymptomatic until advanced stages, hence its depiction as silent killer. Through consistent advocacy, EKHA seeks to clarify these misconceptions.

FOCUS POINTS

EKHA's mission is to address the challenges of CKD in Europe by advocating for effective prevention and optimal therapy, ensuring that appropriate and affordable quality care is accessible to all who need it [7]. This is achieved by concentrating on key

themes, many of which intersect with each other. Most targets were established in 2015 through the EKHA Recommendations for Sustainable Care [15], which provided a framework for many of EKHA's subsequent actions.

Table 2 summarizes EKHA's focus points, the most important problems and potential targets for solutions.

Prevention

The optimal way to avoid problems related to a disease is to assure it does not occur. CKD prevention can be primary, aiming at the disease itself and at its main risk factors like diabetes and hypertension, often through lifestyle measures; secondary, focusing at slowing disease progression once it has occurred; or tertiary, preventing complications of existing disease [16]. EKHA addresses the entire spectrum of prevention, and secured an EU support package (PREVENTCKD) to develop policy recommendations for improving future kidney health through prevention [17] (see below).

Screening

Adequate prevention is impossible without efficient screening (case finding). Screening is also the only way to obtain accurate prevalence figures, which are currently based on extrapolations that are likely underestimates, as early CKD remains largely underdiagnosed (and undertreated) in Europe [18]. Screening has long relied on serum creatinine measurements which detect CKD only at a relatively advanced stage, when the damage is irreversible. EKHA currently advocates for the implementation and reimbursement of systematic albuminuria screening which can detect CKD at an earlier stage, but also unidentified risk factors like hypertension, cardiovascular disease and diabetes

Table 1: EKHA's full and affiliated members.**Full members**

Dutch Kidney Foundation (Nierstichting Nederland)
 European Dialysis and Transplant Nurses Association/European Renal Care Association^a
 European Kidney Patients' Federation^b
 European Renal Association^a
 European Society for Paediatric Nephrology
 European Society for Organ Transplantation
 European Reference Network for Rare Kidney Diseases
 International Society of Nephrology^a

Affiliated members

Albanian Society of Nephrology
 Association for the Use of the Artificial Kidney in the Paris Region
 Belgian Nephrology Society
 Belgian nephrologists Society—French speaking (GNFB)
 Bosnia and Herzegovina (UNDT) Society of Nephrology, Dialysis and Transplantation
 CompCure^b
 Croatian Society of Nephrology
 Czech Society of Nephrology
 Dutch Kidney Patients Association^b (NVN)
 Estonian Society of Nephrology (ENS)
 European Uremic Toxin Work Group of the ESAO
 French Society of Dialysis & Transplantation (SFNDT)
 Finnish Society of Nephrology
 Georgia Society of Dialysis, Nephrology and Kidney Transplantation Union
 German Society of Nephrology
 Greece Society of Nephrology
 Hungarian Nephrology Society
 Italian Society of Nephrology
 Kidney Care UK^b
 Kuratorium für Dialyse und Nierentransplantation
 Latvian Association of Nephrology
 Lithuanian Nephrology Dialysis and Transplantation Association
 National Kidney Federation^b
 Nederlandstalige Belgische Vereniging voor Nefrologie
 Polish Nephrology Society
 Portuguese Society of Nephrology
 Renaloo^b
 Romanian Society of Nephrology
 Russian Dialysis Society
 Serbian Society of Nephrology
 Slovenian Society of Nephrology
 Spanish Dialysis Foundation^b
 Spanish Society of Nephrology
 Sweden Society of Nephrology
 Turkish Society of Nephrology
 Ukrainian Nephrology Association

^aFounding members. At the moment of the foundation of EKHA, ERA was named European Renal Association–European Dialysis and Transplant Association (ERA-EDTA) and EKPF was named CEAPIR (standing for Confederación Europea de Asociaciones de Pacientes con Insuficiencia Renal). The fourth founding partner was the International Federation of Kidney Foundation (IFKF), which is no longer a full member.

^bPatient organization.

GNFB: Groupement des Néphrologues Francophones Belges; ESAO: European Society of Artificial Organs.

[19, 20]. This test is of particular interest because of its cost-effectiveness [20].

Quality of life

The traditional focus on survival and managing mainly the life-threatening complications of CKD has neglected its impact on

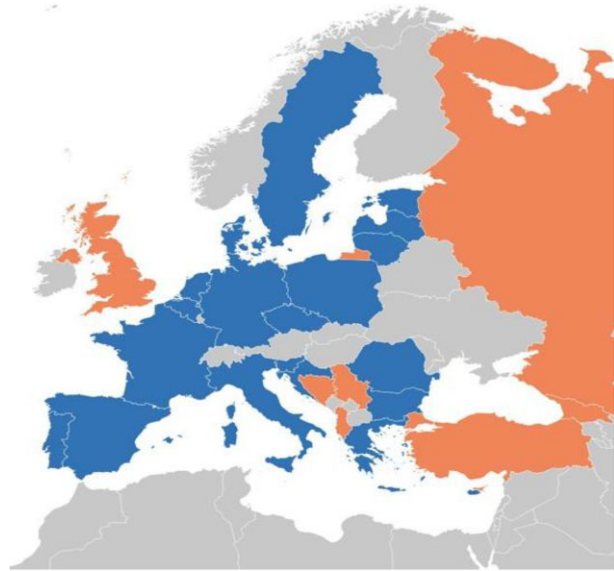


Figure 2: Affiliated membership of EKHA at the date of article submission (27.11.2024), representing 26 nations. Blue: EU member states; orange: non-EU member states; gray: no affiliated members.

non-life-threatening but distressing consequences such as fatigue and itching [21], as well as on sexual, mental, social, family and professional life [6]. These issues are particularly problematic when children are affected [22], who along with the same problems affecting adults, experience growth and development retardation, and learning problems. EKHA consistently highlights these quality of life aspects by giving people with CKD, their families and their caregivers the platform to share their stories.

Inequity

Specific attention is given to vulnerable groups, especially minorities, migrants and individuals with limited health literacy, where cultural, philosophical and language factors exacerbate inequities [23]. In addition to increased risk, limited access to quality care and unfavorable living conditions also play a negative role. Inequities notably affect certain social groups, but disparities also exist between and within countries and between urban and rural areas.

Health economy

The societal cost of CKD is higher than that of other major chronic diseases [6]. While the cost of dialysis per person is extremely high, the overall cost of all non-dialysis CKD is even greater, due to its much higher prevalence and multiple associated complications, particularly cardiovascular events [14]. Additionally, productivity losses of patients and their caregivers with unemployment rates recorded up to 75% further increase societal cost [24].

Environment

Healthcare is one of the most environmentally harmful economic sectors [25], with kidney care occupying an especially unfavorable position, due to dialysis, which requires

Table 2: EKHA's focus points, associated problems and principal targets for advocacy.

Focus points	Associated problems	Principal targets for advocacy
Prevention	<ul style="list-style-type: none"> - No systematic prevention program for CKD in the EU - Insufficient education of general public, students and professionals on kidney health, causes of CKD and how to prevent CKD - Suboptimal therapy for the main causes, diabetes and hypertension - Insufficient awareness of rare kidney diseases and their causes - Suboptimal prevention and treatment of the complications of CKD 	<ul style="list-style-type: none"> - Harmonized EU program for prevention of CKD, its progression and its complications - Education/information on kidney health of the general public, people with risk factors of CKD, medical students and kidney care professionals - Guidelines for general practitioners and non-nephrology specialists - Investment in research on health-economic effects of CKD prevention
Screening	<ul style="list-style-type: none"> - No harmonized CKD screening program in the EU - Screening too much focused on serum creatinine, with late detection of kidney disease - Screening inadequate in individuals at risk and virtually non-existent in the general population - Inadequate use and lack of reimbursement of early screening by determination of albuminuria, particularly for non-diabetics - Inadequate screening of rare kidney diseases (including use of genetic markers for CKD) 	<ul style="list-style-type: none"> - Advocate for harmonized CKD screening program in the EU - Advocate for reimbursed genetic screening of rare kidney diseases - Promotion of albuminuria for screening of early CKD and its risk factors - Education of general population, medical students, general practitioners and specialists, including pediatricians - Investment in research on health-economic and outcome impact of early screening followed by adequate prevention - Invest in research on accurate and affordable biomarkers of CKD
Quality of life	<ul style="list-style-type: none"> - Insufficient attention for quality of life, social and familial aspects of CKD - Insufficient attention for disturbed growth, development and education of children 	<ul style="list-style-type: none"> - Investment in research of quality of life aspects of CKD - Investment in research on the impact of CKD on growth, development and school education of children
Inequity	<ul style="list-style-type: none"> - Risk of CKD is increased in underprivileged people (minorities, the poor, the less educated, refugees) - The same groups have less timely access to quality healthcare - Their living circumstances increase the health risks and decrease the possibilities for a healthy lifestyle 	<ul style="list-style-type: none"> - Invest in research on inequities as risk factors of CKD - Advocate for attention and correction by policymakers and health professionals of inequities affecting kidney health - Advocate for attention for optimal kidney care in disadvantaged groups and in remote and rural areas
Health economy	<ul style="list-style-type: none"> - Societal cost of dialysis is high - Overall cost of CKD not on dialysis is higher than that related to dialysis, due to the significantly higher number of non-dialyzed individuals with CKD - Unemployment in CKD is high 	<ul style="list-style-type: none"> - Investment in research on health-economic burden of CKD - Advocate for approaches reducing the cost of CKD (e.g. prevention, transplantation, home dialysis) - Advocate for research on affordable CKD therapies, including dialysis - Advocate for solutions to diminish unemployment in CKD
Environment	<ul style="list-style-type: none"> - Significant negative impact of global warming and air pollution on kidney health - Substantial greenhouse gas emission and water and plastic waste generation by dialysis - Insufficient awareness of the environmental impact of kidney care by policymakers and medical professionals 	<ul style="list-style-type: none"> - Advocate for measures reducing the impact of environment on kidney health - Create awareness on the environmental footprint of kidney care/dialysis - Advocate for approaches forestalling (hemo)dialysis and for environment-friendly dialysis - Investment in research on forestalling dialysis and on environment-friendly dialysis - Advocate for transparency on the environmental impact of the manufacturing and disposal of dialysis material - Recommendations for environmental best-practices in kidney care
Transplantation	<ul style="list-style-type: none"> - Less than 50% of Europeans on KRT are living with a functioning graft - There are more than 10-fold differences among EU countries in donation and transplantation numbers - Organization of transplantation programs is divergent among European countries, and often not enough structured - Survival of many grafts is too limited 	<ul style="list-style-type: none"> - Second EU action plan on organ donation and transplantation, including combating organ trafficking - Strive for harmonized donation and transplantation programs all over Europe - Generate political willingness to optimize transplantation programs and promote exchange of best practices - Investment in research to improve graft longevity - Information of general public and medical professionals with special attention for disfavored populations

Table 2: Continued

Focus points	Associated problems	Principal targets for advocacy
Home dialysis (peritoneal dialysis and home hemodialysis)	<ul style="list-style-type: none"> - Uptake of home dialysis in Europe is low, despite definite benefits - There are substantial differences in uptake among countries - Implementation of home dialysis remains low and diverges among care-providing professionals and institutions 	<ul style="list-style-type: none"> - Plead for a harmonized EU approach to promote home dialysis - Awareness creation and information campaigns on home dialysis in people with advanced CKD, with specific programs for minorities and health illiterate - Advocate for user-friendly home dialysis equipment - Promotion of telemedicine for troubleshooting at home - Promote shared decision-making and patient empowerment
Crisis management	<ul style="list-style-type: none"> - People with kidney disease, particularly those on dialysis, are heavily affected in times of crisis - Policymakers usually do not consider kidney care as a primary concern for crisis management 	<ul style="list-style-type: none"> - Awareness creation among policymakers on the burden of people with kidney disease during crises - Advocacy for a kidney care model that is more sustainable in times of crisis by minimizing the need for dialysis and development of less resource-demanding dialysis strategies
Education	<ul style="list-style-type: none"> - Awareness on the functional importance of the kidneys and the risk factors of kidney disease is poor among the general public, and in people at risk of CKD or with CKD - Awareness is low among non-nephrology medical professionals 	<ul style="list-style-type: none"> - Promote awareness campaigns using all modern tools (press, videos, social media, infographics) to inform the general public about the role of the kidneys, as well as awareness creation among medical students and non-nephrology physicians - Advocacy to consider special tools for minorities and the less educated (e.g. cartoons), with help and advice from communication specialists
Workforce shortage	<ul style="list-style-type: none"> - Due to ageing of the current personnel, unfavorable working conditions, increasing demand and insufficient remuneration, nephrology suffers from a workforce shortage, creating a risk for suboptimal care, more complications and increased costs 	<ul style="list-style-type: none"> - Awareness creation among policymakers of the current workforce shortage in care and of the extra pressure for kidney care because of its high technicality - Promotion of alternatives that diminish the need of dialysis or allow dialysis with lower needs for supportive staff (peritoneal dialysis, home hemodialysis)
Personalized medicine	<ul style="list-style-type: none"> - There are few specific approaches to treat the broad array of kidney diseases - The input of people with CKD and their families in the therapeutic decision process is often limited 	<ul style="list-style-type: none"> - Advocate for more research and innovation in developing therapies for specific kidney diseases - Empowerment of patients in therapeutic decision making - Stimulation of the shared decision making model, including an important role for nurses
Research and innovation	<ul style="list-style-type: none"> - Therapeutic progress in CKD has not been the same in CKD as for other NCDs - The basic concept of dialysis did not change since many decades 	<ul style="list-style-type: none"> - Action towards more research and innovation in all phases of CKD - Promote the development of specific therapies refraining the progression of particular CKDs - Call for innovative kidney replacement therapies

Principal targets are examples of topics out of which EKHA can make a selection to focus upon in its policy actions.
CKD: chronic kidney disease; EU: European Union; KRT: kidney replacement therapy.

large amounts of energy causing significant greenhouse gas emissions, and generates vast quantities of water and plastic waste [5, 26, 27]. Moreover, climate changes and environmental pollution [28, 29] negatively impact kidney health, particularly through increased risks of dehydration, CKD and kidney stones [30], attributable to global warming.

Transplantation

Compared with dialysis, transplantation offers better survival, improved quality of life and lower cost and environmental impact [31–34]. However, less than half of those on KRT live with a functioning kidney graft, with striking disparities in transplantation rates among EU countries [35, 36]. This highlights the need for a second EU action plan on organ donation and transplantation [37], with focus on key aspects including organization, information, education and research on transplantation, besides proactive measures to combat organ trafficking [38, 39].

Home dialysis

Although the EU supports home therapies, home dialysis (peritoneal dialysis and home hemodialysis) is largely overlooked in these actions, despite clear benefits in quality of life, health-economics and environmental impact [6, 40, 41], and being the preferred choice of patients [42]. Home dialysis uptake in Europe remains around 12% of all dialysis [43], highlighting the urgent need for a paradigm shift towards prioritizing home dialysis as a primary dialysis option [35].

Crisis preparedness

The frequency of crises is rising, significantly affecting kidney care, as was experienced during the COVID-19 pandemic [44]. Similarly, earthquakes, armed conflicts and floods also pose substantial risks for kidney health [45]. While the EU has specific bodies to address emergency situations, it remains essential to

continually remind policymakers of the high-risk status of the CKD population in political conflicts and disasters.

Education

Awareness of kidney health and risk factors for kidney disease is disproportionately low among the general public [46–48]. Education and information initiatives are essential and should target not only people with kidney disease and their caregivers, but also the general public, school students, medical students, non-nephrology medical professionals and particularly general practitioners. Special approaches are needed to reach those who are difficult to engage through traditional channels like print and television, such as minorities, the poor and the less educated [23, 49].

Workforce shortage

The medical profession as a whole and particularly the group of nurses faces workforce shortages, due to unfavorable working conditions, unattractive remuneration, increasing demands and an ageing workforce without a sufficient inflow of younger candidates [50]. Nephrology, being highly specialized and technical, is particularly affected by this problem [51, 52]. In addition to workforce redistribution and redefining task responsibilities, prioritizing prevention, transplantation and home dialysis should also be supportive.

Personalized medicine

An important factor impacting quality of life is the need for tailored therapies for each individual. This includes expanding the range of and improving access to specific treatments for rare kidney diseases [53–55] and accommodating personal needs and preferences. Kidney care for children requires a highly personalized approach to minimize disruption in the lives of the child and its family. Likewise, minorities may benefit from culturally adapted approaches. Particularly when choosing KRT options or deciding between KRT and comprehensive conservative care, decision-making is facilitated by patient-centered care and shared decision-making [56].

Research and innovation

All the preceding subsections highlight the urgent need to advance innovations in kidney care, which have been too slow. Despite recent therapeutic breakthroughs [57–59], the progress remains notably behind that of other chronic diseases. Current therapeutic approaches do not address all causes of kidney disease and improvements in KRT have been lacking for decades, while promising improvements often are shelved before they reach the implementation stage. Investment in research and innovation should be proportional to the prevalence of CKD and its economic, ecological and outcome burdens. Particularly research on screening, prevention, inequities and health-economic and environmental impact should be favored.

TOOLS

Contact with different policy levels

EKHA maintains regular contact with all relevant EU policy levels, including the Commission, the Parliament and the Council of the European Union. This primarily involves directorates, sec-

tions and policymakers focused on health or related issues such as research, innovation or the environment. Contacts with Member States mainly occur through the rotating Presidencies of the Council of the EU and MEPs from various countries. EKHA's MEP group for kidney health supports EKHA in forwarding its policy asks to the European Parliament and Commission and ensuring political attention. For support at the national level, any parallel action by National Societies or individuals with local government contacts is unequivocally welcomed and will be supported by EKHA if needed.

Kidney Forum and other meetings

EKHA organizes an annual Kidney Forum in the European Parliament, hosted by the chairs of EKHA's MEP group, and focused on specific and timely issues in kidney care. The event brings together patients, professionals, policymakers, administrators, insurers, manufacturers and experts in health economy, environment, technology, research and innovation [60]. The 2025 Forum will focus on screening, prevention and the value of albuminuria as method to detect CKD and people at risk of CKD and cardiovascular disease. Table 3 reviews the topics of the last 10 Fora, illustrating the broad spectrum of kidney care issues covered.

EKHA also organizes or participates in other meetings, if the topics align with EKHA's standards and focus areas, take place within a European context and/or result in documents disseminated at EU level or promoting EKHA's focus issues [60].

World Kidney Day

WKD is an annual awareness initiative, usually happening in the second week of March, and coordinated by the International Society of Nephrology and the International Federation of Kidney Foundations [61]. Each year, EKHA aligns with WKD's central theme, though the format of EKHA's contribution varies, including sessions or questions on kidney diseases in the European Parliament, video messages from stakeholders, patients and politicians, and/or press communications. As an example, the EKHA "Show your Kidneys Love" campaign in collaboration with ERA and other kidney health organizations, was launched on WKD 2023 (see below) [62].

Patient voice

EKHA actively involves people affected by kidney disease in its decision process and in all its initiatives. This personal experience with a disease that impacts personal, social and familial lives is seen as vital. Such communications resonate with the general public and policymakers, complementing the theoretical insights provided by experts on the clinical, health-economic, environmental and societal burden of CKD.

Awareness creation

Many communications and appeals by those involved in kidney care assume that the issue is well-known to the general public and policymakers. However, one of the key obstacles to effective advocacy for kidney care is the widespread lack of knowledge about kidney functions and about kidney diseases, their relation to other diseases and their treatments [47]. A survey in the UK revealed that most people were uninformed about kidney functions and risk factors [48]. Every EKHA initiative includes a plain-language explanation of the basics, the issue at hand and

Table 3: Annual EKHA Kidney Fora since 2014.

Date	Title	Notes
2 April 2014	Integrated action needed to tackle health inequalities in European kidney care	
30 March 2015	Sustainable kidney care: is it possible?	
19 April 2016	Moving from disease care to health care	Organized outside the European Parliament in the aftermath of the Brussels terrorist attacks of March 22
11 April 2017	Patient choice of treatment	Organized outside the European Parliament
26 April 2018	Kidney donation and transplantation—the gift of life	Organized outside the European Parliament
25 June 2019	Organ donation and transplantation in Europe—can we meet the needs of patients?	
11 March 2020	A shared vision for improving organ donation and transplantation in the EU beyond 2020	Originally planned as a live event (scheduled on March 3), but then postponed and reformatted into an online webinar because of the onset of the COVID-19 pandemic
18 June 2021	Unmet needs and challenges in access to treatments in Europe—the case of chronic kidney disease	Online webinar because of the COVID-19 pandemic
15 June 2022	The Decade of the Kidney™—10 years to bring innovative and green treatments to kidney patients in Europe	
26 June 2023	The future of kidney care—investing in green nephrology to meet the European Green deal targets	
2024		Not organized because of the European elections in June; to be replaced by an event early in 2025

its implications. While some of these messages may be repetitive, awareness is not achieved through one single action.

EKHA's most successful awareness campaign to date has been "Show your Kidneys Love," in which Tina Turner shared her experience of developing CKD due to neglecting her hypertension [62]. Identifying and engaging with other willing and notable people with any stage of CKD would be beneficial in supporting similar future EKHA campaigns.

Publications, position statements and presentations

For effective policy action, consolidating supporting ideas in publications is crucial. To date, 46 papers have been published with EKHA's support or under its umbrella, often involving external experts, and addressing key topics essential for sustainable kidney care. Table 4 lists some of the most representative papers and their covered topics [6, 9, 14, 23, 26, 27, 35, 36, 43, 55, 63–80]. For the complete list of EKHA publications, the reader is referred to the EKHA website [7] (<http://ekha.eu/>). These publications help to shape arguments for future discussions with policymakers and stakeholders, provides scientific information supporting EKHA's asks, and are a source of information for other materials such as infographics, posters, open letters or manifestos. They also provide officially published documents to distribute at relevant meetings.

EKHA also publishes and contributes to position statements, white papers and open letters [81], which help raise awareness in a clear and accessible manner, integrating various concepts, concerns and potential solutions. Table 5 highlights some of the most relevant EKHA documents published in the past decade.

One of the most recent examples is the EKHA Manifesto [37], published in the context of the latest European Parliament elections in June 2024. It emphasizes the need for more and better-organized organ donation and transplantation as well as the creation of a second EU action plan on organ donation and transplantation. The Manifesto also calls for a harmonized screening and prevention program and advancements in therapeutic innovation for CKD.

Finally, EKHA representatives regularly deliver EKHA-branded presentations at national and international meetings on topics aligned with EKHA's focus points and activities.

Large projects supported by the EU

EKHA successfully advocated for EU funding of the EDITH project (Differing Kidney Disease Treatment Modalities and Organ Donation and Transplantation Practices on Health Expenditure and Patient Outcomes), supporting a multistakeholder assessment of the reasons behind the significant differences in uptake of KRTs among EU countries [82]. This project produced several seminal reports clarifying key factors both from the patient and the professional perspective [72, 73, 83].

EKHA was also commissioned by the EU to coordinate a thematic network on formulating recommendations to enhance organ donation and transplantation in Europe. This resulted in a joint statement [84], to be elaborated further in a later publication [36], in which EKHA for the first time expressed the need for a second EU action plan on organ donation and transplantation.

PREVENTCKD is another EU-supported project to map prevention practices in Member States and to formulate recommendations for improvement and harmonization of CKD prevention across Europe [85]. Deliverables are recommendations for kidney health, optimal outcomes and quality of life with kidney diseases, updated data on prevalence, suggestions for screening and a collection of best practices for CKD prevention across the EU.

EUROPEAN VERSUS NATIONAL LEVEL

EKHA's advocacy approach is driven by a strategy at influencing decision making within the European Commission, with the expectation that these ideas will be cascaded down to member states. However, one of the weaknesses of this approach lies in the Commission's low competence in health issues, meaning governments might still pursue diverging courses. Therefore, a

Table 4: Most relevant EKHA publications and the discussed key areas.

Author	Reference	Reference number	Weblink	Main areas discussed
Vanholder et al.	<i>Nat Rev Nephrol</i> 2017;13:393–409	[14]	https://www.nature.com/articles/nrneph.2017.136	Prevention, screening, health economy
Vanholder et al.	<i>Nephrol Dial Transplant</i> 2019;34:1254–61	[9]	https://pubmed.ncbi.nlm.nih.gov/30629203	Transplantation, education
Himmelfarb et al.	<i>Nat Rev Nephrol</i> 2020;16:573–85	[78]	https://www.nature.com/articles/s41581-020-0315-4	Research and innovation, home dialysis, quality of life, health economy
van der Tol et al.	<i>Nephrol Dial Transplant</i> 2020;35:979–86	[77]	https://pubmed.ncbi.nlm.nih.gov/32227227	Health economy, home dialysis
Zoccali et al.	<i>Nephrol Dial Transplant</i> 2021;37:21–8	[76]	https://academic.oup.com/ndt/advance-article/doi/10.1093/ndt/gfaa163/5901672	Research and innovation
Stel et al.	<i>Kidney Int</i> 2021;100:182–95	[35]	https://www.kidney-international.org/article/S0085-2538(20)31529-5/abstract	Home dialysis, transplantation
Vanholder and Lameire	<i>Nephrol Dial Transplant</i> 2021;36:8–11	[75]	https://pubmed.ncbi.nlm.nih.gov/33377168	Education, crisis management, prevention, home dialysis, health economy, quality of life
Vlahou et al.	<i>Hypertension</i> 2021;77:1029–35	[74]	https://www.ncbi.nlm.nih.gov/pubmed/33583200	Research and innovation
de Jong et al.	<i>Nephrol Dial Transplant</i> 2021;37:126–38	[73]	https://www.ncbi.nlm.nih.gov/pubmed/33486525	Home dialysis, transplantation, education, health economy, workforce shortage
de Jong et al.	<i>Nephrol Dial Transplant</i> 2022;37:477–88	[72]	https://www.ncbi.nlm.nih.gov/pubmed/33677544	Home dialysis, transplantation, education, quality of life
Vanholder et al.	<i>Clin Kidney J</i> 2021;14:1719–30	[6]	https://www.ncbi.nlm.nih.gov/pubmed/34221379	Quality of life, health economy, environment, research and innovation
Vanholder et al.	<i>Nat Rev Nephrol</i> 2021;17:554–68	[36]	https://www.ncbi.nlm.nih.gov/pubmed/33953367	Transplantation, education
Mendu et al.	<i>Kidney Med</i> 2021;3:635–43	[71]	https://www.ncbi.nlm.nih.gov/pubmed/34401729	Home dialysis, education
Lameire and Vanholder	<i>Nephrol Dial Transplant</i> 2021;36:1155–7	[70]	https://www.ncbi.nlm.nih.gov/pubmed/33450003	Education
Vanholder et al.	<i>Nat Rev Nephrol</i> 2022;18:479–80	[68]	https://www.ncbi.nlm.nih.gov/pubmed/35637382	Crisis management
Vanholder et al.	<i>Nephrol Dial Transplant</i> 2023;38:1080–8	[26]	https://www.ncbi.nlm.nih.gov/pubmed/35481547	Environment, home dialysis, prevention, transplantation
Sever et al.	<i>Nephrol Dial Transplant</i> 2023;38:300–8	[80]	https://www.ncbi.nlm.nih.gov/pubmed/36066915	Crisis management, transplantation
Stigant et al.	<i>Kidney Int</i> 2023;104:12–15	[27]	https://www.ncbi.nlm.nih.gov/pubmed/36642093	Environment
Boenink et al.	<i>Nephrol Dial Transplant</i> 2023;38:1540–51	[66]	https://www.ncbi.nlm.nih.gov/pubmed/36626928	Transplantation, education
Vanholder et al.	<i>Clin J Am Soc Nephrol</i> 2023;18:1510–8	[55]	https://www.ncbi.nlm.nih.gov/pubmed/37294578	Prevention, screening, education
Pawlowicz-Szlarska et al.	<i>Nephrol Dial Transplant</i> 2023;38:2407–15	[69]	https://www.ncbi.nlm.nih.gov/pubmed/37326036	Crisis preparedness
Sever et al.	<i>Nat Rev Nephrol</i> 2023;19:672–86	[65]	https://www.ncbi.nlm.nih.gov/pubmed/37479903	Crisis preparedness
Vanholder et al.	<i>Nat Rev Nephrol</i> 2023;19:694–708	[23]	https://www.ncbi.nlm.nih.gov/pubmed/37580571	Inequities, education, transplantation, home dialysis, prevention

Table 4: Continued

Author	Reference	Reference number	Weblink	Main areas discussed
Sever et al.	<i>Nephrol Dial Transplant</i> 2024;39:1218–20	[64]	https://www.ncbi.nlm.nih.gov/pubmed/38366137	Transplantation
Zoccali et al.	<i>Nat Rev Nephrol</i> 2024;20:460–72	[63]	https://www.ncbi.nlm.nih.gov/pubmed/38575770	Research and innovation
Vanholder et al.	<i>Nephrol Dial Transplant</i> 2024;39:1741–3	[79]	https://www.ncbi.nlm.nih.gov/pubmed/38754992	Home dialysis, workforce shortage, education
Vanholder et al.	<i>Nephrol Dial Transplant</i> 2024; available online	[43]	https://www.ncbi.nlm.nih.gov/pubmed/39251399	Home dialysis, workforce shortage, education

Table 5: Titles of main EKHA position statements of the last five years.

Year	Topic	Notes
2020	EKHA infographic Position paper ahead of the hearing of the expert panel on effective ways of investing in health Five key recommendations to improve prevention, treatment and care in the aftermath of the COVID-19 pandemic Resolve the urgent needs of kidney patients in the “Decade of the Kidney™”	Visual summarizing the main issues regarding CKD A contribution to a framework for resilient organization of health and social care following the COVID-19 pandemic Open letter to EU policymakers EKHA position paper on the new EU pharma strategy
2021	EKHA call to action to improve CKD prevention, treatment and care EKHA open letter to EU policymakers: life after COVID-19	Position paper published in the aftermath of COVID-19 Call for second action plan on organ donation and transplantation
2022	Self-management in CKD	EKHA intern thesis
2023	Call for renewed EU action plan on organ donation and transplantation Improving care and awareness of CKD A stitch in time; early intervention to tackle Europe’s NCD crisis	Open letter Publication in Public Health Europe Quarterly Document issued by PHSSR EU expert advisory group, with involvement of EKHA/ECDA leadership
2024	Kidney Manifesto	Document issued before the European elections of June 2024 in preparation of the new European Commission mandate 2024–29 to promote transplantation, and prevention and innovative treatment of CKD. Adapted version issued at the beginning of 2025

The list is not exhaustive. For the complete list and for the documents *per se*, please use <http://ekha.eu> (reference [7]).

PHSSR: Partnership for Health System sustainability and Resilience; EKHA: European Kidney Health Alliance; ECDA: European Chronic Disease Alliance.

parallel approach is crucial, where national or regional nephrology organizations align with EKHA’s methodology, particularly regarding patient involvement, coalitions with other organ specialties, and sharing EKHA’s principles with local authorities. To achieve these goals, these societies are encouraged to utilize the documents available through the EKHA communications network and website. Advocacy for any disease cannot be effective if carried out by only one or a few organizations. It is a responsibility shared by all those involved.

EU HEALTH POLICY IN A GLOBAL PERSPECTIVE

Although health policy remains primarily within the competence of individual Member States, the EU’s health policy aims to promote harmonization, uniform strategies and the sharing of best practices across Member States. This was very well illustrated by the EU Beating Cancer Plan [86] and the EU Council

Conclusions on cardiovascular health [87], and the Council Conclusions on organ donation and transplantation [88] (December 2024). Issued at the end of the Hungarian Presidency, these conclusions contain several references to kidney diseases. Similarly, the Mission Letter to the newly appointed Hungarian EU Commissioner for Health (December 2024) calls for a unified approach across the EU in areas such as prevention and cardiovascular disease [89].

While constitutionally and structurally different, the US Federation of 50 states shares some similarities with the EU model. However, in healthcare, a decentralized model is applied that sometimes conducts to marked legislative inconsistencies such as for abortion laws [90], protective legislation for living organ donors [91] or the approach to life-saving dialysis provision for undocumented migrants [92], which all are inconsistent among individual states. Those inter-state differences became particularly evident during the COVID-19 pandemic, when US states issued varying messages regarding the severity of the pandemic and on public health approaches like vaccination [93],

contributing to disparate outcomes between individual US states [94] and a significantly higher mortality than in EU countries with an economic status comparable to that of the USA [95, 96]. Similarly, in the early months of the Russian–Ukrainian conflict, EU humanitarian support to Ukraine (including healthcare) was effectively coordinated by the EU’s Directorate-General for European Civil Protection and Humanitarian Aid Organizations [97] (ECHO), and the decision to offer Ukrainian refugees the same access to healthcare provision and reimbursement rights as EU citizens was implemented across all EU Member States [98].

Other collectives around the world also work towards coordination of health policy and programs. The Council of Ministers of Health of Central America and the Dominican Republic (COMISCA) was formed in 1991 to address health issues of regional relevance [99]. COMISCA cooperates with the Consortium for the Epidemic of Nephropathy in Central America and Mexico [100] (CENCAM). Similarly, the African Centers for Disease Control were established in 2016 to strengthen the capacity and capability of public health institutions in the region [101]. Other regional bodies [102] include the Association of Southeast Asian Nations (OASEAN), the Southern African Development Community (SADC) and the Union of South American Nations (USAN). Though initial focus of many of these regional health coordination bodies has been on surveillance and control of infectious disease threats, some of them are developing strategies to tackle NCDs [103].

However, despite these initiatives, many countries across the world still act individually in health matters.

EKHA IN A GLOBAL PERSPECTIVE

The International Society of Nephrology [104] (ISN), a member of EKHA, leads global kidney health advocacy, collaborating closely as non-state actor in official relations with the World Health Organization (WHO), to elevate kidney health as a focus area [105]. Furthermore, ISN provides feedback on technical packages for cardiovascular health and is developing a joint framework for integrating CKD care into primary care. The ISN also collaborates with WHO to support kidney care during emergencies.

A regional advocacy model similar to that of EKHA is the US Kidney Health Initiative [106] (KHI). This public–private partnership, formed between the American Society of Nephrology and the US Food and Drug Administration [107], focuses on innovation in biological, pharmacological and technological fields, clinical trials, and improving patient quality of life, particularly for children and transplant recipients. The strategies employed by KHI closely align with those of EKHA.

The US National Kidney Foundation [108] advocates for kidney disease legislation and resources across the USA, engaging with the Congress, the Administration and individual US states to develop supportive strategies. Similarly, the AAKP [109] plays a prominent role in coordinating patient advocacy, with a focus on education, empowerment and innovation in kidney care.

Finally, also several organizations in Australia and the UK are advocating for a brighter future allowing every individual to enjoy optimal kidney health [110–112].

CONCLUSIONS

Despite significant progress in recent years, awareness about kidney health and kidney care remains insufficient among the general population and policymakers in Europe. Until 2021 the terms “kidney” or “CKD” were absent from official EU docu-

ments, but CKD now is regularly referred to and EKHA consulted. The COVID-19 crisis marked a turning point, drawing more attention to health issues and highlighting the severe risks faced by people with kidney disease. This momentum should not be lost.

To raise awareness, the EKHA team, along with its growing network of stakeholder organizations, makes persistent efforts to draw the attention of EU policymakers to the escalating CKD problem. However, much more needs to be done for the world to recognize that kidney disease is a major public health problem deserving attention and investment in proportion to its prevalence and its financial, environmental and human burden.

The large but largely invisible group of people with kidney diseases deserves full commitment of the entire kidney health community to decrease the impact of this challenging and insufficiently recognized condition. EKHA strives to increase awareness, ensure access to the spectrum of quality care, and to call for innovation in therapeutics and green kidney care, to enhance the lives and wellbeing of all those affected by kidney disease.

SUPPLEMENTARY DATA

Supplementary data are available at [Clinical Kidney Journal](#) online.

ACKNOWLEDGEMENTS

The members of the EKHA Board of Directors are: R. Vanholder, President; T. Oostrom, Dutch Kidney Foundation (DKF); R. Torra Balcells, European Renal Association (ERA); I. De Barbieri, European Dialysis and Transplantation Nurses Association—European Renal Care Association (EDTNA-ERCA); D. Gallego, European Kidney Patient Federation (EKPF); F. Schaefer, European Rare Kidney Diseases Reference Network (ERKNET); G. Oniscu, European Society of Organ Transplantation (ESOT); D. Haffner, European Society of Pediatric Nephrology (ESPN); M. Nangaku, International Society of Nephrology (ISN).

EKHA was supported through unrestricted grants from AstraZeneca, Novartis, Astellas, Baxter Healthcare, Fresenius Medical Care, GSK, Hansa Biopharma, B Braun, CSL Vifor, Bayer, Mozarc Medical, Novo Nordisk, SOBI (year 2024). The European Kidney Health Alliance is the recipient of support by the European Union in the context of the Annual Work Program 2022 on prevention of non-communicable diseases of EU4Health, topic ID EU4H-2022-PJ02, project # 101101220 PREVENTCKD. All current EKHA actions would be impossible without the organizational assistance of Greta Bitante (until June 2024), Serena Cristiani, Nina Gabatan (from June 2024) and Dominique Dubru (Triumph).

DATA AVAILABILITY STATEMENT

No new data were generated or analyzed in support of this research.

CONFLICT OF INTEREST STATEMENT

R.V. is advisor to AstraZeneca, Glaxo Smith Kline, Fresenius Kabi, Novartis, Baxter, Nipro, Fresenius Medical Care and Nextkidney. No other author declared a conflict of interest.

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