

EKHA Accomplishments

EDITH

EU Pilot Project the 'Effect of Differing Kidney Disease Treatment Modalities and Organ Donation and Transplantation Practices on Health Expenditure and Patient Outcomes', comprising partners from 15 European countries.

2014

Conceived, drafted, and submitted the initial project description and proposal '*The Effect of Differing Kidney Disease Treatment Modalities and Organ Donation and Transplantation Practices on Health Expenditure and Patient Outcomes*' to the European Parliament, via MEP Karin Kadenbach, requesting to allocate 1M EUR in the 2015 Budget of the EU towards the pilot project.

Successfully lobbied all MEPs in the Environment and Public Health Committee, and the Budget Committee, for their support to pass the proposal through the multiple voting rounds on the budget in Plenary and be included in the General Budget of the EU 2015.

2015

Supported the formation of the multi-country/multi-centre consortium, including the ERA-EDTA, who would take on the project '*The Effect of Differing Kidney Disease Treatment Modalities and Organ Donation and Transplantation Practices on Health Expenditure and Patient Outcomes*' .

The project, now known as [EDITH](#), has two main objectives:

- To compare, from a macro-economic perspective, the various treatment modalities for CKD in EU countries, by investigating factors that influence treatment choice, and the impact on healthcare budgets
- To facilitate the setting up of EU-wide registries for the follow-up of transplant recipients and living donors

Desired outcomes:

- Recommendations for improving and harmonising treatment availability based on best-practice
- Strategies to improve the availability of transplantation across EU Member States
- EU wide registries to follow up transplant recipients and living donors

2016/2017

EKHA joined the [EDITH Consortium](#) as a ‘Collaborating Partner’ and attended the kick-off meeting in January 2016 in Brussels at the European Commission DG Santé premises.

Attended the partners’ meeting at the ERA-EDTA 2017 congress in Madrid in June.

The European Kidney Forum

In **2015**, EKHA launched the annual European Kidney Forum, held each Spring in Brussels. The Forum is hosted by EKHA and the European Parliament MEP Group for Kidney Health. Nephrologists, renal nurses, kidney patients, regulators, parliamentarians and health economists, come to Brussels to exchange views and find solutions to contemporary issues in sustainable kidney care. Participants have the opportunity to meet with MEPs and discuss European and national responses to kidney health and patient care in their country.

2015 – Sustainable Kidney Care: Is it possible?

2016 – Moving from Disease Care to Health Care: The Importance of Prevention

2017 – Improving Patients’ Choice of Treatment

2018 – Improving Access to Transplantation

Recommendations for Sustainable Kidney Care

In **2015**, building on its experience in the EU policy arena and its expertise in kidney health, EKHA developed and published a set of Recommendations aimed at helping European and national policy makers understand and design kidney health policies to continue to meet the needs of an increasing and aging population.

The EKHA Recommendations for Sustainable Kidney Care are built around 4 clusters:

- 1. Prevention and early detection**
- 2. Choice of treatment**
- 3. Increasing access to transplantation**
- 4. Treatment and reimbursement strategies**

The MEP Group for Kidney Health

The MEP Group for Kidney Health is the informal group of Members of the European Parliament committed to helping improve the policy response to the growing burden of kidney disease in Europe. The principal aim of the MEP Group for Kidney Health is to provide political impetus to improve policy on prevention, as well as improved access to best-practice care for all EU citizens.

EKHA manages the Secretariat of the MEP Group for Kidney Health. MEPs involved in the Group have access –through EKHA’s network of experts– to valuable information relevant to their work on health policy; in exchange, the MEP Group is instrumental to raising awareness on CKD amongst other policy makers and stakeholders.

Members of the MEP Group

- **Karin Kadenbach, Chair (Austria, S&D)**
- **Hilde Vautmans, Co-Chair (Belgium, EPP)**
- Brando Benifei (Italy, S&D)
- Mark Demesmaeker (Belgium, ECR)
- Peter Liese (Germany, EPP)
- Linda McAvan (UK, S&D)
- Miroslav Mikolasik (Slovakia, EPP)
- Sirpa Pietikäinen (Finland, EPP)
- Aldo Patriciello (Italy, EPP)
- Christel Schaldemose (Denmark, S&D)
- Annie Schreijer-Pierik (The Netherlands, EPP)
- Kay Swinburne (UK, ECR)

2015

Roundtable in the European Parliament

In addition to the annual European Kidney Forum hosted by the MEP group since 2015, EKHA and the group co-organised in October 2015 a policy conference in the European Parliament in Brussels on the topic of “Improving Prevention & Health Literacy - The quest to reduce the economic burden of chronic kidney disease in the EU”. Conclusions included the pressing need for improved prevention and health literacy amongst the general public and legal frameworks for industry commitments, in particular on salt reduction in processed food products.

Multi-Country Survey of Patient Choice of Treatment

2017

In 2017 EKHA launched a multi-country survey to explore and address the issue of kidney patient choice of treatment (or lack thereof) in different Member States and look at how it relates in the context of the sustainability of kidney care, economic

impact on health systems, and outcomes impact on the patient and his/her quality of life was the aim of the initiative which took place in 2017.

The survey was carried out in 9 countries (UK, France, Netherlands, Slovenia, Lithuania, Spain, Greece, Portugal and Poland) - in form of two online questionnaires, one for patients and one for healthcare professionals.

Main findings:

- Amongst transplantation options, living donation is often discriminated
- Low patient awareness of possible options due to the lack of patients education
- Free choice is hampered by financial drivers and lack of trained staff
- The opinions of the patients and their families are often neglected

The survey results were presented during the 2017 European Kidney Forum, and further discussed at the ERA/EDTA 2017 Congress in Madrid during the meeting of the EDITH project. Findings will feed into the EDITH project work. Data will also be submitted to further analysis for eventual publication by the team of the ERA-EDTA registry;

EU Events

2014

Participation in the European Commission's **EU Summit on Chronic Diseases** on 3 April 2014 with a keynote speech.

2015

Participation in the European Commission Conference "**Which priorities for a European policy on multimorbidity?**" in October 2015.

2016

Contribution to the event '**Improving organ donation and transplant across the EU: A cross-condition campaign**' held on the 18th of October 2016 in the European Parliament in recognition of the European Day for Organ Donation.

2017

Contribution to the EU Health Policy Platform Forum on the 27th of November 2017 in Brussels, organised by the European Commission. In his capacity as acting Chair of the European Chronic Disease Alliance (ECDA) - chaired by EKHA from 2017-2019, EKHA President Professor Raymond Vanholder presented a joint stakeholder statement on the employment of people with chronic diseases developed in partnership with fifteen EU organisations and led by the ECDA.

Publications

2017

The paper “**Reducing the costs of chronic kidney disease while delivering quality health care: a call to action**” co-authored by EKHA Chairman Prof. Raymond Vanholder and past Chairman Prof. Norbert Lameire, Prof. Lieven Annemans, Prof. Edwina Brown, Prof. Ron Gansevoort, Prof. Judith J. Gout-Zwart, Prof. Rachael L. Morton, Prof. Rainer Oberbauer, Prof. Maarten J. Postma, Prof. Marcello Tonelli, Prof. Wim Van Biesen and ERA-EDTA President Prof. Carmine Zoccali was published in *Nature Reviews Nephrology* (NRN) in May 2017.

Co-drafted several position papers of the European Chronic Disease Alliance calling for EU action on risk factors (salt, transfat, alcohol harm, tobacco use, physical inactivity)

Congresses

2015

EKHA participated at the **2015 US Kidney Organisations Summit during the American Society of Nephrology congress** presenting their work at European level and its model for advocacy cooperation and shared advice on how to enhance concerted action in the USA

2016

53rd Annual Congress of the European Renal Association – European Dialysis and Transplant Association (ERA-EDTA). Chairman Professor Raymond Vanholder gave the Plenary Lecture and the Opening Ceremony “From costs of kidney disease to a healthier society” and was awarded the **President’s Award for Outstanding Contributions to ERA-EDTA**.

ERA-EDTA National Societies Meeting during the Annual ERA-EDTA Congress, Vienna

Participation in the **Netherlands EU Presidency Conference** on food product improvement

Participation in a conference on stakeholders’ role in chronic disease policy formation, co-organised by **ECDA and WHO European Regional Office**

Collaboration with the **EU Joint Action CHRODIS** on prevention and treatment on chronic diseases

Participation in the meeting and position statement of the **European ADPKD Federation**

Participation in the annual meeting of the **International Federation of Kidney Foundations** in Malta in 2016



Participation in the meeting “The European response to chronic disease – the role of civil society.” Brussels

2017

ERA-EDTA National Societies Meeting during the Annual ERA-EDTA Congress, Madrid

46th EDTNA/ERCA International Conference, Krakow, full session devoted to the accomplishments of EKHA

13th European Peritoneal Dialysis Meeting

other

EKHA Chairman Prof Raymond Vanholder joined the meeting of the Dialysis, Nephrology and Transplantation Union of Georgia and **Deputy Health Minister Kvaratskhelia at the Ministry of Health in Georgia** (October 2015 & 2017) to discuss the European Recommendations for Sustainable Kidney Care.