European Kidney Health Alliance
Activity Report 2018

April 2019
Monica Fontana
EKHA Membership

Full Members - **founding members of the Alliance**:

- **EKPF**: European Kidney Patients’ Federation
- **EDTNA/ERCA**: European Dialysis & Transplant Nurses Association/European Renal Care Association
- **DKF**: Dutch Kidney Foundation
- **ERA-EDTA**: European Renal Association – European Dialysis and Transplant Association
EKHA’s Growing Membership

Associate Members - European national and other non-profit kidney organisations:

1. Austria: Austrian Society of Nephrology
2. Bosnia: Society of Nephrology, Dialysis and Transplantation of Bosnia & Herzegovina
3. Estonia: Estonia Society of Nephrology
5. Germany: German Society of Nephrology
6. Georgia: Georgian Union of Dialysis, Nephrology and Transplantation
7. Italy: Italian Society of Nephrology
8. Netherlands: Dutch Kidney Patient Association
9. Portugal: Portuguese Society of Nephrology
10. Poland: Polish Kidney Association
11. Russia: Russian Dialysis Society
12. Slovenia: Slovenian Society of Nephrology
13. Spain: Sociedad Española de Diálisis y Trasplante
14. Spain: Spanish Dialysis Foundation
15. Spain: Spanish Society of Nephrology
16. Turkey: Turkish Society of Nephrology
17. UK: The Renal Association, UK
EKHA Management Committee

The activities of EKHA are conducted under the responsibility of its Management Committee, composed of two representatives from each full member organisation and a designated chairman.

EKHA Chairman: Professor Raymond Vanholder (Belgium)

- EKPF: Mr Mark Murphy (Ireland) *acting*
- EDTNA/ERCA: Ms Edita Noruišienė (Lithuania), Mr Alois Gorke (Germany)
- ERA-EDTA: Professor Carmine Zoccali (Italy), Ms Monica Fontana (Italy)
- DKF: Mr Tom Oostrom (The Netherlands), Mr Martijn Ubbink (The Netherlands)
EKHA Strategic Framework

Recommendations for Sustainable Care

Chronic kidney disease (CKD) is a major and growing health burden in Europe. One in 3 Europeans is at increased risk of developing CKD. A striking 3 in 10 already has impaired kidney function severe enough to affect their health status. The current rise in diabetes, obesity and aging will further worsen this situation unless there is greater focus and concerted action by European health policy-makers.

Being a ‘silent disease’ with few or no symptoms until it is too late, CKD receives little attention, particularly when compared with other chronic diseases. These Recommendations for Sustainable Kidney Care defined by the European Kidney Health Alliance (EKHA) are a common effort by stakeholders to propose solutions for the challenges of CKD in Europe through effective prevention and a more efficient care pathway intended to facilitate the provision of appropriate and affordable treatment to all Europeans equally, while promoting the highest quality of care.

**Burdern of CKD in Europe**

One in 3 Europeans has at least one clinical sign of existing CKD, such as the presence of protein in the urine—a sign of reduced kidney function. Perhaps even more startling is that an estimated 90% of these individuals are unaware they have early-stage CKD, and may experience few or no symptoms.

Nevertheless, from its early stages onwards, CKD is associated with an increased risk of complications and death, to a large extent attributable to an ensuing cardiovascular event. Diabetes is the leading cause of kidney disease, followed by high blood pressure (hypertension). The disease progresses fast by patients with CKD is linked with the effects of these concurrent diseases. Although progress has been made in recent years, end-stage kidney disease kills more people each year than breast cancer, prostate cancer or even road traffic accidents [1,2].

Globally, there was an 82% increase in the number of deaths from CKD between 1990 and 2017 [3].

Patients who eventually reach end-stage kidney disease need renal replacement therapy (RRT) via dialysis or kidney transplantation. Data from the European Renal Associations-European Dialysis and Transplant Association (ERA-EDTA) Registry shows that the prevalence of people on RRT across Europe increased by 5.3% from 2011 to 2012 to reach 736.7 per million population [4].

In Europe, 1 in 3 adults has some degree of kidney disease, but many people don’t know they have it, or that they are even at risk.

**What does kidney disease cost?**

The cost of treating CKD is formidable. Hospital-based haemodialysis—the most common form of dialysis—alone costs up to €60,000 per year per patient. Moreover, this does not take into account the lost productivity caused when CKD interferes with job or work, or prevents patients from working altogether.

Dialysis is resource-heavy, costing up to €80,000 per year, per patient, depending on the country and method.

In general, RRT consumes 2% of overall healthcare expenditure in Europe, for only 0.2% of the population. The total direct cost of RRT across Europe is unknown, but one estimate put it at up to €50 billion per year. There are additional healthcare costs of co-interventions needed to sustain RRT and to treat its complications, indirect costs associated with the time patients are absent from work while undergoing treatment, and ancillary costs such as transportation to and from the clinic.

These figures also exclude the medical costs incurred before patients reach end-stage CKD—a population estimated to be around 30 times larger than the population on RRT.

In England, for example, the cost of CKD to the healthcare system was estimated at £1.66 to £1.49 billion (2008-2010) at 2010 prices, representing 1.3% of all spending. Importantly, more than half this sum was spent on RRT provided for only 2% of the CKD population. Illustrating the high cost of RRT. High costs were also associated with the cardiovascular complications associated with CKD. It was estimated that in one year in England, approximately 7000 excess strokes and 12,000 excess heart attacks occurred in the CKD population, as compared with matched individuals without CKD.

[1,2,3,4]
EKHA supports policies, which reduce the variation across the EU in access to organ donation and transplantation.

Key asks:

1. Promotion of **equitable access to kidney transplantation** for all valid candidates, informed by EU–wide strategies

2. Improving **living donor transplantation**, through donor exchange programmes and supportive compensation and legislation

3. Increased awareness of the need to **optimize deceased organ retrieval processes**, through opt out schemes and expanded donation criteria

4. Provision of **appropriate support to Member States**, reflecting the multi-speed and multi-level patchwork that exists across the EU

➢ **Continued Focus in 2019 EU Kidney Forum**
2018 EU Kidney Forum
26th April, Brussels
2018 EU Kidney Forum
Kidney Donation and Transplantation—
*The Gift of Life*

*European Parliament, Brussels, 26 April 2018*

- **Annual event** hosted by the MEP Group for Kidney Health
- Goal: Increase awareness and discuss approaches to address the differences in *practices and access to Kidney Transplantation in Europe*—“*the gift of life*”, to improve the situation for the benefit of patients.
- Gathered **54 delegates**
- Organ Donation & Transplantation across the EU, presentation by Stefaan Van der Spiegel, Head of Unit, DG Santé
- Showcased early results from the **EDITH project**
- High level representation from **the European Parliament and the European Commission**
- Sponsorship – Support from: **Baxter, Amgen, B.Braun, Novartis and CSL Behring**
Impressions: 2018 EU Kidney Forum

The European Kidney Forum 2018 Report can be found here

Conclusions:
• Develop awareness raising activities, dissemination plans and monitoring and evaluation strategies in collaboration with professionals
• Informed decision making when assessing access to the most suitable and cost-effective treatment modalities
• Harmonised access to transplantation is needed.
Annual Welcome Meeting of Associate Members
Presentations about progress, successes & challenges

Hans Bart
Director/psychologist/donor
Dutch Kidney Patients Association

Main NVN goals for 2018

Fiona Loud
Policy Director
Kidney Care UK

Update on activities Kidney Care UK
EKHA Policy Actions in 2018
Driving the debate around Chronic Diseases

Key leadership roles  EKHA again holds the Chairmanship and Secretariat of the ECDA
ECDA Highlights from 2018

• Together with ECDA, launched the **EU Manifesto calling on the European Commission to recognise health as an objective in its own right in its next 2019-2024 workplan**, with specific targets on chronic diseases, and to scale up related investment in prevention of CDs to achieve the UN Sustainable Development Goals (SDGs)

• Contributed to **EU advocacy related to the UN High-Level meeting on NCDs** and participated in **EU Joint Action CHRODIS Plus Work Package 8 “Chronic diseases and employment”**

• Produced position papers on: salt reduction, tobacco, trans-fats elimination, alcohol use and air pollution
Congresses & Publications 2018

- Presentation by Prof Vanholder at the Annual ERA-EDTA Congress, Copenhagen, 2018
- Presentation by Prof Vanholder at the EDTNA/ERCA, Genoa 2018
- Nephrology Dialysis Transplantation: How to increase kidney transplant activity throughout Europe—an advocacy review by the European Kidney Health Alliance by Prof Vanholder et al. Authored in 2018
Development of an EU kidney research agenda begun in 2018, starting with the progress made to date and leveraging the work underway in the Netherlands in developing the national agenda.

The Dutch Kidney Foundation, the Dutch Kidney Patients Association, and the Dutch Federation for Nephrology, led the development of ‘Nierziekte de Baas’ (‘Beating Kidney Disease’), which will be repurposed to reflect the EU context.

The Dutch project has 3 key characteristics:

- Born out of multi-stakeholder engagement
- Mission orientated
- Aligned with Dutch national science agenda
The Gift of Life: Campaign on Organ Donation & Transplantation

• Launched at the 2018 Kidney Forum, to engage EKHA’s partners on transplantation, give MEPs a tool to engage their constituencies and to disseminate EKHA’s messages to the broader stakeholder audience.

• Highlights need for a coordinated approach to organ donation & transplantation at EU level, and appropriate legal, structural and cultural frameworks at Member State level to boost donation and transplantation.
  – A visual identity for the campaign was developed, along with key messages and an infographic that were tweeted and posted to the website
  – Promotional materials distributed at EU Kidney Forum and ERA-EDTA Congress

• A Call to Action was also launched during the Forum, which served as the basis for the policy paper by Prof Vanholder, eventually published in NDT.
“Effect of Differing Kidney Disease Treatment Modalities and Organ Donation and Transplantation Practices on Health Expenditure and Patient Outcomes”

• **Aim:** Examine the effect of
  
  – differing kidney disease treatment modalities
  
  – organ donation
  
  – transplant practices

  on health expenditure and patient outcomes

• **EC-funded:** 3rd Health Programme

• **3 years:** 1 January 2017–1 January 2020
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<td>Hospital Clínic de Barcelona as Affiliated Entity of Beneficiary</td>
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EDITH work packages

WP4: Treatment modalities choices, outcomes and costs for ESKD in EU Member States and associated countries

WP5: European Living Donor Registry (ELDR): Supranational data sharing tool

WP6: Follow-up registry for kidney transplant patients in all EU Member States

Work on-going, first results to be released by end 2019
EU Thematic Network

Organ Donation and Transplantation in the EU

• EKHA proposal for an EU Thematic network on Organ Donation and Transplantation accepted in 2018
• Thematic Network kick-off on 6 February 2019
• Thematic Network to publish Joint Statement on Organ Donation and Transplantation, including:
  • Clustering of countries for implementation of strategic plans, depending on their strengths/weaknesses (one-size fits all is not the approach recommended even though countries can learn from each other)
  • Striving towards general European opting-out
  • Stimulate expanded cadaveric donorship and living donation
  • Eliminate financial barriers for (living) donors and hospitals
  • Improve patient information

A key policy ask would be to call for a 2nd EU Action Plan on Organ Donation & Transplantation.
EKHA’s Online Presence

- Regular updates to **website with EU policy news**, linked to **monthly eNewsletter** highlighting EU and national news
- **Twitter account** with growing number of followers
- **Gift of Life campaign** with campaign materials and guidance
thank you!