



Brussels, 7 January 2021

To: EU commissioner Health & Food Safety – Ms Stella Kyriakides
Regarding: Meeting request to discuss solutions for Chronic Kidney Diseases

Dear Ms Kyriakides,

Thank you very much for the opportunity to reach out to you. On behalf of the European kidney patients, represented by the European Kidney Patients Federation (EKPF) and supported by the European Kidney Health Alliance (EKHA), we want to point out an alarming message to you. Seventy-five years ago, the Dutch physician Kolff performed the first successful acute haemodialysis treatment, improved sixty years ago with a reusable blood access, enabling long term (chronic) haemodialysis. Unfortunately over the past six decades no further fundamental innovations for kidney patients were established. In the Bulletin of the World Health Organization, Chronic Kidney Disease (CKD) has even been described as [‘the most neglected chronic disease’¹](#).

Due to this negligence, CKD has become a silent killer with an increasing impact on patients and society as numbers keep rising and this is worsened by COVID-19. The pandemic disclosed how kidney patients were among the most vulnerable groups and showed the shortcomings in how treatments are delivered to them. CKD patients are more susceptible to COVID-19 (closed community for in-centre haemodialysis; immunosuppression in all kidney disease and kidney transplants) and have worse outcomes than other chronic diseases. This was acknowledged by EU Expert Panel on Effective Ways of Investing in Health, in its [opinion²](#) published on 7 December 2020. They mention CKD as a higher risk factor for COVID-19 infection and severe outcomes in comparison with other chronic diseases and the lower survival chance in case of infection.

With increasing demand for kidney replacement therapies, the associated high burden on quality of life and rising healthcare costs, there is an urgent need to improve treatments for CKD and kidney failure. Recent data showed that CKD entered the [World Health Organization³](#) top 10 of fatal diseases. By 2040, it will have risen to the 5th cause of death globally. Without adequate treatment, CKD culminates in advanced kidney failure with the need for kidney replacement therapy, i.e. transplantation or dialysis. Survival with dialysis is shorter than for many forms of cancer (but general awareness of this is very low). Treatment of kidney patients costs society at least as much as treating cancer, but investments to develop innovative kidney disease therapies are much lower than for cancer. The restrictions imposed by kidney disease therapies generate social exclusion, unemployment, and a decreased quality of life.

At this moment Kidney disease is not listed as one of the main focus points of the European Union for health-related research and innovation⁴. We are reaching out to you to help us change this. We need political support to raise CKD treatment to a higher level. Very soon EKHA will launch a call to action – named ‘the Decade of the Kidney’ – improving prevention, treatment & care of Chronic Kidney Disease in the aftermath of COVID-19’. Therefore, we would like to discuss the following topics with you:

¹ <https://pubmed.ncbi.nlm.nih.gov/29904224/>

² https://ec.europa.eu/health/sites/health/files/expert_panel/docs/o26_health_socialcare_covid19_en.pdf

³ <https://www.who.int/news-room/fact-sheets/detail/the-top-10-causes-of-death>

⁴ https://ec.europa.eu/info/research-and-innovation/research-area/health-research-and-innovation_en

1. **Call for an EU working group** (facilitated by EKHA) that will collaborate to design a plan (to be adopted by the EU Commission before the next European elections) to reduce the burden of CKD for patients and society by:
 - Awareness by education (prevention) and screening.
 - Better disease management, by facilitating home dialysis and research for new approaches to retard the development of CKD.
 - Funding for ground breaking innovations in Kidney Replacement Therapies allowing to prolong the survival of Kidney Patients significantly while improving their quality of life.
2. **Endorse a second EU Action Plan on Organ Donation and Transplantation** as a logical sequel of the [EKHA joint statement⁵](#) on this topic submitted to the European Commission in January 2020.
3. **Endorsement of our Decade of the Kidney initiative** (for instance on March 11, World Kidney Day). EKHA is at this moment building a strong collaboration that is focussed on lowering the socio-economic burden of CKD and create awareness for CKD as a neglected disease, because while lifesaving, dialysis is not the optimal therapy as it remains associated with high mortality, provides a relatively poor quality of life and is exceedingly expensive. We need better, more patient centred and innovative therapies which also need to be financially more sustainable. *The Decade of the Kidney* unites patients, doctors & innovators and hopefully politician's world-wide to accomplish this complex joint goal.

The points raised here were also notified in the EKHA open letter dd 22/09/2020 to the European policy makers (in attach), that your cabinet was so kind to support.

To provide more in-depth information on the problem we also attached the EKHA statement on resilient solutions for Chronic Kidney Disease patients. We would really appreciate if you would grant us a meeting to discuss possible solutions. Thank you very much for your attention and we hope that we can meet with you soon.

Kind regards,

Prof. Raymond Vanholder
EKHA President

Daniel Gallego
EKPF President



⁵ http://ekha.eu/wp-content/uploads/FINAL_Joint-Statement-of-the-Thematic-Network-on-Organ-Donation-and-Transplantation.pdf