

Budapest, June 14, 2019

## **Nephrology and Public Policy Committee (NPPC) aims to intensify research activity**

**Epidemiological and clinical research and public policy in Europe are generally considered to be comprehensive and successful – and the European Renal Association-European Dialysis and Transplant Association (ERA-EDTA) is playing a key role in the field of nephrology research. But, of course, there is room for improvement. Therefore, the Nephrology and Public Policy Committee (NPPC) has been formed to strengthen the basis for a stronger research focus. Now, the NPPC has presented a five-year research plan to stimulate research collaboration in Europe.**

“Epidemiological and clinical research and public policy in Europe are generally considered to be comprehensive and successful, but there is potential for improvement and scope for new opportunities”, explains Professor Ziad A. Massy, Paris/France, Chair of the Nephrology and Public Policy Committee. “Especially in nephrology we have to further intensify our research activities. With 850 million people suffering from kidney diseases of any kind worldwide, nephrology has to be one of the main areas of medical research.”

In 2013 a paper [1] showed that of 40,970 trials overall, only 1,054 (2.6%) were classified as nephrology. The majority of nephrology trials were for treatment (75.4%) or prevention (15.7%), with very few diagnostic, screening, or health services research studies. “Although many trials in nephrology have been initiated within the last 5-8 years, we still have to catch up. In my view it is especially important to generate epidemiologic and health care data in order to sensitize the public as well as policy makers to kidney diseases. It is high time to put the global spread of kidney diseases into focus.”

To enhance research activities in nephrology, the NPPC worked out a research plan to be supported by the ERA-EDTA over the next five years. The main outline of the plan has been comprehensively described in a paper that was published in NDT yesterday [2]. Eight action points form the backbone of the plan and will stimulate research collaboration and grant applications in Europe under the umbrella of ERA EDTA:

- (1) to conduct collaborative research designed to discover non-invasive diagnostic tests or new predictive markers for kidney disease complications, aimed to further improve the

classification and prognosis of kidney diseases based on large scale omics data using available European patient cohorts;

- (2) to review the feasibility and relevance of the development of CKD stage 4-5 registries based on on-going experiences at national level, and explore if and how these can be brought together for quality assurance and research at the European level;
- (3) to plan a successful transition process from pediatric to adult care of CKD by active collaboration between pediatric and adult nephrologists and cohorts/registries;
- (4) to reinforce the collaboration between the European Renal Best Practice (ERBP) experts and ERA-EDTA registry staff in order to extend the number of indicators to include the thresholds of the ERBP recommendations as part of prospectively collected datasets stemming from different national or regional cohorts and from the ERA-EDTA registry and to adapt those as new recommendations are published;
- (5) to continue supporting the European Kidney Health Alliance (EKHA) with its established links with the EU, allowing it to target key nephrological topics prioritized by patients and professionals, such as better quality of life in renal replacement therapy (RRT) patients and improving kidney transplantation and home treatment modalities, which also include regenerative and personalized medicine;
- (6) to support the development of world-leading big data research in a number of ways including the creation of data networks and the development of educational programs;
- (7) to help the Eastern European nephrology community to optimize patient care and patient-oriented research in their countries by increasing public awareness, encouraging /supporting clinical nephrology and epidemiology studies and improving training in nephrology;
- (8) to create a European network of kidney units in order to extend our understanding of AKI progression and complications, including transition of AKI to CKD.

[1] Inrig JK, Califf, RM, Tasneem A et al. The Landscape of Clinical Trials in Nephrology: A Systematic Review of ClinicalTrials.gov. Am J Kidney Dis 2014; 63(5): 771–780

[2] Massy ZA. et al.. Nephrology and Public Policy Committee propositions to stimulate research collaboration in adults and children in Europe. NDT 2019, June 14 [epub]



### **About ERA-EDTA**

With more than 7,000 active members, the ERA-EDTA is one of the biggest nephrology associations worldwide leading European nephrology and one of the most important European Medical Associations. It organises annual congresses and a Scientific Education Interactive Day (SEID), it produces guidelines, it collects data and performs epidemiological studies through its Registry. It supports fellowships and research projects. Its publications are NDT and CKJ (this last journal is Open Access). The ERA-EDTA also has an online Educational platform: the European Nephrology Portal (ENP) which includes NDT-Educational@ENP. The 2020 Congress will be held June 6-9 in Milan (Italy). Visit the booth to receive more information!

Web site: [www.era-edta.org](http://www.era-edta.org)