

2015 SUMMIT OF US KIDNEY ORGANIZATIONS – SAN DIEGO, NOVEMBER 4, 2015

EKHA as a model for multi-stakeholder collaboration

Indeed, EKHA was invited by the American Society of Nephrology (ASN) to attend the 2015 Summit of US Kidney Organizations, which took place during the annual ASN Kidney Week, to present EKHA's work at European level, EKHA's model for advocacy cooperation and to share advice on how to enhance concerted action in the USA. Prof Raymond Vanholder, EKHA Chairman, Prof Andrzej Wiecek, President of the European Dialysis and Transplant Association – European Renal Association (ERA-EDTA) and Ms Monica Fontana, Executive Manager of ERA-EDTA attended on behalf of EKHA.

Prof Vanholder presented EKHA, particularly emphasizing the current composition of the alliance. He outlined the importance of the composition, which allows an open and facilitated discussion, but does not reduce each member's role to report back to its Association. The board, which is made of the four full EKHA members, actually represents several thousands of European individuals, and counts on the involvement of Associate Members, which are national kidney-related societies.

Prof Vanholder then laid out different aspects of EKHA's recently-launched recommendations on sustainable kidney care, as well as the actions that being undertaken or planned at EU level as well as with the national Governments:

- *Prevention and early detection:* control and appropriate treatment of diabetes and hypertension, education (not only of nephrologists, but also of the general public, nurses and primary care physicians), life-style measures (combat obesity, smoking, lack of exercise, high salt and phosphate diet), early detection.
- *Patient choice of treatment:* focus on home treatment for dialysis, conservative care in case of comorbidities.
- *Transplantation:* activation of both living and deceased donation programs, opting out for deceased donation.
- *More rational reimbursement strategies:* reimbursement favoring patient choice of care and in proportion to real costs.

He also summarized the set of strategies that are being considered for implementing the recommendations. These include dissemination through personal networks, endorsement by sister societies such as ASN or ISN, involvement of other stakeholders such as the WHO, and support from MEPs (especially EKHA-related working groups) and national societies.

Prof Vanholder also highlighted the importance and the purpose of the partnership with the European Chronic Disease Alliance (ECDA). As EKHA, together with several other chronic disease societies is a member of ECDA, all disorders are linked in a partnership and a common approach can be adopted. This facilitates exchanges with EU policy-makers, who indeed favor discussion with organizations that are grouped into one. EKHA's actions thus rely on four different levels: national societies, the European professional societies such as ERA-EDTA, EKHA itself and the ECDA.

To conclude, Prof Vanholder highlighted the benefits of a reduced group, which prevents from having confused discussion and enables to identify a common interest.

EKHA US counterparts welcome EKHA's focus on research and prevention

The open discussion following EKHA's presentation revealed that EKHA's American counterparts experience similar problems in their interaction with political representatives. However, differences were also highlighted on specific aspects. The overall debate demonstrated goodwill from US organizations to adopt a similar structural approach as EKHA's, with emphasis on prevention and research.

On this positive note, Ms Fontana encouraged the organisations to stepwise action into building cooperation, as this process could take a while.

The Summit of US Kidney Organizations is an annual meeting during ASN's Kidney Week, gathering representatives of the major societies and foundations representing kidney patients and health professionals of the USA. The 2015 meeting had the aim of fomenting coordination and joint action between US groups devoted to kidney patients and health professionals, in their relations with the policy-makers in Washington DC.