Plan of the activities of the ESPN DIALYSIS WG in 2017

Next meeting of the Group: Helsinki, 9th of June 2017.

<u>Educational activities</u>: Basics in Pediatric Dialysis (T. Holtta as organising person), Helsinki, 9th of June 2016. The program will be posted in the ESPN website in Spring 2017.

Dialysis Master Class (R. Shroff for the ESPN Dialysis WG) during the 50th Anniversary Congress of the ESPN to be held in Glasgow in 2017.

Research activities: 1. With the ESPN/ERA-EDTA Registry:

- Topic accepted by the Registry: Time of initiation of dialysis and outcome in children in Europe (S. Bakkaloglu, C.Stefanidis): full data analysis by dr E. Preka on behalf of the Registry is in progress.
 - Topic discussed with the Registry representative (M.Bonthuis):
- European survey on standards of pediatric dialysis care: (A.Edefonti, M.Bonthuis): the importance of such data for research and political purposes is recognized and the hypothesis of a common European form to be distributed to national registries will be considered.

2. Other research activities:

- European survey on vaccination policies in pediatric dialysis units (S. Bakkaloglu): Data from 17 countries from the EPDWG and ESPN Dialysis WG centers were collected and a first draft of the article will soon be available.
- Preliminary questionnaire on extra-corporeal modalities of desensitization of hyperimmunised children waiting for renal transplantation (F. Paglialonga, C. Schmitt): forms submitted to the ESPNDWG and EPDWG centers, waiting for all centers completing the answers.
- European survey on dialysis treatment modalities of children with Congenital Nephrotic Syndrome (R.Shroff, T.Holtta): the ESPN Dialysis WG and EPDWG centers collaborated in data collection and a first draft of the article will soon be available.
- European survey on hospitalization in pediatric dialysis units (S. Bakkaloglu): waiting for the modified version of the protocol after the discussion within the Group.

- 3H Study: 28 centers in 10 European countries contributed to data collection and the number of patients needed for the study (190) has been reached; follow-up is coming to a close by mid-2017.
- The article "Considering Renal Replacement Therapy in Children with Severe Mental Disability: Results of a Worldwide Survey on The Opinion of Caregivers" by L. Willem **has** been very recently sent for publication and is waiting for approval/revision in 2017.
- The study "Assessing calcium balance in children with CKD to optimize treatment strategies", proposed by R. Shroff, sponsored by an ESPN grant, is going on in five European units.

Guidelines

- Two Guidelines, one on native, one on active Vitamin D use in CKD and dialysis (in collaboration with the ESPN CKD-MBD group) were completed (R. Shroff and C. Schmitt as main authors). The two manuscripts have been submitted for publication to NDT and are waiting for approval/revision in 2017.
- The Guideline on rhGH treatment in CKD and dialysis was recently started, with selected members of the ESPN CKD-MBD and Dialysis WGs participating and further members of the ESPN Transplantation WG joining the initiative.
- The update of the EPDWG guidelines/recommendations posted in the ESPN website is seen as one of the aims of the group and will be done with the aid of an expert trained in the Cochrane Library and with the collaboration of the European Best Practice Guidelines Group. Due to the present engagement with the CKD-MBD Group and the Transplantation WG in preparing the rhGH guidelines, the first guideline will be chosen and revised in 2017.
- Other guidelines:
- Clinical practice guidelines on vascular access for hemodialysis. An outline of the guideline has been developed (C. Stefanidis and R Shroff) and a guideline working group appointed.

Synergies

- 1. Synergy between the ESPN Dialysis WG and the European Pediatric Dialysis Working Group (EPDWG): three collaborative studies are in progress: the survey on vaccination policies, that on dialysis treatment of Congenital Nephrotic Syndrome and that on extra-corporeal modalities of desensitization of hyperimmunised children waiting for renal transplantation.
- 2. Collaboration between the ESPN Dialysis WG and the ESPN/ERA-EDTA Registry: one topic will be finalized in 2017:" Time to initiation of dialysis and outcome". C. Stefanidis (in the Board of the Scientific Committee of the Registry and of the ESPN Dialysis WG) and E. Verrina (in the Board of the ESPN Dialysis WG) received the mandate to interact with M. Bonthuis to identify future projects in 2017.

3. Synergy between the ESPN DialysisWG, the ESPN CKD-MBD WG and the ESPN Transplantation WG will continue in 2017 by developing the Guideline on rhGH treatment in CKD, Dialysis and Transplant periods, due to the common data regarding the same ESRD patients.

Budget

Part of the budget of 1000 Euros for 2017 has been anticipated by the ESPN Treasurer to pay the expenses of the first meeting on rhGH treatment guidelines in November 2016.

ESPN Regulations

Replacement of one member of the Board of the Dialysis WG will take place at the beginning of 2017 and will be done by voting, according to the ESPN Council instructions.