Minutes ESPN WG Board Meeting, Feb 3, 2014, Leuven, 10:30-12:00

Participants:

Khalid Ismaili, Giovanni Montini, Karlijn van Stralen, Stefanie Weber, Fatos Yalcinkaya

Excused:

Amira Peco-Antic, Ann Raes

Welcome (SW), short introduction of all board members. SW summarizes recent activities. A welcome email has been sent to all WG members, material for the webpage has been collected (WG program, WG introductory text, educational material), CME Courses CAKUT have been proposed for the ESPN 2014 in Porto and the ESPN 2015 in Belgium .

Issues of how to enhance the number of active WG members were discussed (circulate WG membership application via ESPN Registry mailing list (KvS), activate personal contacts, e.g. including pediatric urologists (KI) – **important:** all WG members have to ESPN members except non-pediatric nephrologists)

Educational material/guidelines were provided for the following topics: prenatal ultrasound and perinatal management (KI), enuresis (AR), urinary tract infection(GM), management of hydronephrosis (FY), genetic testing (SW). Other topics of interest can be added to this list and to the website at any time, please contact the WG Board.

Important: all WGs are asked to also provide patient educational material!

Training possibilities to offer in specialized pediatric nephrology centers (4-weeks-stay) were discussed, e.g. training in perinatal/postnatal management of CAKUT patients.

1-**3 ESPN fellowships** are supported by the ESPN (for 1-3 months), for fellowship application see ESPN website (to announce in ESPN newsletter).

CME Course, ESPN Porto 2014: Speakers Adrian Woolf (Genetics of Bladder Dysfunction), Giovanni Montini (PREDICT Trial), Karlijn van Stralen (CRI in children with CAKUT, Results of the ERA-EDTA/ESPN Registry).

CME Course, ESPN Belgium 2015: Suggested topics High-throughput Screening of CAKUT associated genes, The role of microRNAs in regulating kidney development, Phenotypic spectrum of HNF1B-relate disease.

Linking to the ERA-EDTA/ESPN Registry: Topics and modalities of application for a substudy involving aspects of CAKUT were discussed with KvS. WG members are invited to contribute ideas related to aspects of life-long disease/adult data.

Clinical studies: the PREDICT Trial (a study of the ESCAPE group) is introduced by GM, information about the study will be posted as a link on the webpage.

Other initiatives are discussed, e.g. the launch of a questionnaire-based survey of how pediatric nephrologists in Europe manage patients with renal dysplasia (GM, KvS).

Research trials: SW introduces the national initiative of a questionnaire-based evaluation of disease progression in HNF1B-asscoiated nephropathy. Other pediatric nephrology centers throughout Europe might be interested to participate. For more information or protocol contact SW or Christine.Okorn@uk-essen.de. Subsequently, it is discussed that it might be useful to contact the French HNF1B study.

Registry: a Registry of Familial CAKUT in Europe is proposed (SW). Aim of the registry is the collection of clinical data of familial cases of CAKUT throughout Europe (siblings affected or CAKUT in several generations; consanguineous families) and whole exome sequencing (Wes) in selected cases. The outline of the registry, a grant application and ethical issues concerning DNA collections will have to be discussed.

Varia: proposals for a ESPN WG symbol/icon and additional ideas for the WG website are very welcome.

The next **WG Board Meeting** will be held in Porto Sept 18-20, 2014.