ESPN WG CAKUT/UTI/Bladder Dysfunction

Progress Report 2014/2015, September 1, 2015

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1. General issues:

a) A first ESPN WG Meeting had been held in Porto, Feb 3rd, 2014. Participants were both members of the WG and interested attendees of the ESPN Annual Meeting. A second ESPN WG Meeting will be held in Brussels, Sept 3rd, 2015 to introduce the EURECA Registry.
b) 5 new members were attracted to the WG CAKUT/UTI/Bladder Dysfunction since foundation.

2. CME and Educational Activities:

a) During the ESPN in Brussels 2015 a Symposium on Sept 4th, 2015 will be dedicated to research related to CAKUT: C. Bates (Pittsburgh, USA) will speak about the „ Genetic basis of ureter and bladder anomalies“, H. Reutter (Bonn, Germany) about the „ Genetic basis of VACTER anomalies “, S. Decramer (Toulouse, France) about „HNF1 beta in abnormal kidney development “ and M. Schreuder (Nijmegen, The Netherlands) about the „Role of epigenetics in development of CAKUT“ . The session will be chaired S. Weber (Essen, Germany) and F. Yalcinkaya (Ankara, Turkey).

b) Kjell Tullus (London, UK) has been elected as Education Officer for the ESPN WG CKUT/UTI/Bladder

Dysfunction.

c) On a three-monthly basis, novel research articles covering interesting topics related to CAKUT/ UTI/Bladder Dysfunction are uploaded to the WG web-site. Educational multiple-choice questions are prepared by dedicated speakers of symposia that are organized by the WG.

3. Registry Activities:

EURECA – European Registry for Familial CAKUT Cases

a) The EURECA Registry (European Registry for Familial CAKUT Cases) has been implemented as a web-based registry open to all members of the society (http://www.nefrokid.it/EURECA/v0/). This registy involves the most recent web technologies (AngularJS framework, responsive design, REST API pattern) and will be accessible by mobile devices. We expect to generate a comprehensive collection of familial CAKUT cases throughout Europe by the means of this Registry initiative. As CAKUT (in its overall presentation) is rather frequent we believe that the rate of success of identification of new causative genes will be much higher when restricting the study patients to familial cases. A multinational approach of experts in the field will further strengthen the outcome of the study. A web application will integrate pedigree draw in order to better understand the genetic implications of the disease. The registry will be supported by DNA collections and biobanking. An ESPN Research Grant to financially support this initiative has been approved and donated by the ESPN Council in September 2015.

b) ESPN/ERA-EDTA Registry data analysis on longterm outcomes in patients with Prune-Belly Syndrome (PBS) on renal replacement therapy has been performed by F. Yalcinkaya (University Children's Hospital, Ankara, Turkey) and Beyza Doğanay Erdoğan (Department of Biostatistics at Ankara University, Turkey) in collaboration with the ESPN/ERA-EDTA Registry team. 86 patients with PBS were compared to 1035 patients with congenital obstructive uropathy and 1905 patients with congenital renal hypodysplasia. The retrieved data is prepared for publication.

4. Clinical studies:

a) Link to the PREDICT-Trial (Initiators G. Montini, F. Schaefer). Giovanni Montini will present an up-date of the PREDICT-Trial at the ESPN Meeting in Porto (Sept 4th, 2015).

b) A questionnaire assessing the management of kidney dysplasia through-out Europe has been developed by Giovanni Montini for the WG. This questionnaire was presented and discussed at the ESPN WG Meeting in Porto on Sept 18th, 2014. After approval of the WG and the ESPN Council, the questionnaire was distributed to all ESPN members and via the ESPN mailing list of national societies. Two requests using MonkeySurvey were sent out in Nov 2014 and Jan 2015 and 246 answers were obtained. Currently, the data is prepared for publication.

5. Scientific studies:

a) Gene Identification Studies in CAKUT patients are a major focus of the ESPN WG, following set-up of the EURECA Registry.

b) Adrian Woolf (Manchester, UK) is planning a project within the WG focusing on “Renal tract malformations: from human genomics to novel therapies”. A project outline will be presented.

c) The German HNF1B Longitudinal Outcome Study, in the near future financially supported by the German National Ministry for Education and Research (BMBF) has been extended to international collaborating partners and the ESPN WG Inherited Kidney Disorders.

6. Website Educational Material/Experts to be asked:

a) Educational material has been posted on the ESPN website covering the following topics: UTI (G. Montini, F. Yalcinkaya), Bladder Dysfunction (A. Raes, A. Peco-Antic), CAKUT Genetics (S. Weber), Antenatal Management of CAKUT (K. Ismaili)

For the ESPN WG CAKUT/UTI/Bladder Dysfunction

Stefanie Weber

Essen, Aug 22nd, 2015