ESPN WG CAKUT/UTI/Bladder Dysfunction Progress Report 2013/2014

1. General issues:

a) A first ESPN WG Board Meeting has been held in Leuven, Feb 3rd, 2014. Participants were Khalid Ismaili, Giovanni Montini, Karlijn van Stralen, Fatos Yalcinkaya and Stefanie Weber. Amira Peco-Antic and Ann Raes were excused. The minutes of the Meeting were send to the Secretary General Rosanna Coppo and the Assistant Secretary Elena Levtcheno.
b) 3 new members were attracted to the WG CAKUT/UTI/Bladder Dysfuntion.

2. CME Activities:

During the ESPN in Porto 2014 a Master class (CME 1, Sept 18th, 2014) will be dedicated to research related to CAKUT: Adrian WOOLF (UK) will speak about „*Genetics of Bladder Dysfunction Disorders",* Giovanni MONTINI (Italy) about,*Urinary Tract Infections in Children with CAKUT and Introduction of the PREDICT Trial*" and Karlijn VAN STRALEN (Netherlands) about the *„Progression of Renal Insufficiency in Children with CAKUT – Results of the ERA-EDTA Registry".* The session will be chaired Stefanie WEBER (Germany) and Giovanni MONTINI (Italy).

3. Registry Activities:

a) The development of a CAKUT Registry and Biobank has been intensively discussed at the WG Meeting in Leuven in Feb 2014 (initiative lead by F. Yalcinkaya and S. Weber). A ESPN Research Grant Proposal to financially support this initiative has been send to the ESPN Council in Mai 2014.

b) Link with ESPN/ERA-EDTA Registry: A Substudy of Outcome and Progression of Renal Insufficiency in Patients with Prune Belly Syndrome (PBS) has been performed by Fatos Yalcinkaya, Beyza Doğanay and Karlijn van Stralen(total of patients includd: 3,363 ; among these 70 patients with PBS and 3,293 patients with our diagnoses of CAKUT). The data will be presented at ESPN WG Meeting in Porto on Sept 18th, 2014.

c) Link with ESPN WG Inherited Disorders (Chair M. Konrad): a first meeting of the ESPN WG Inherited Disorders will be held in Porto on Sept 18th, 2014. Joint initiatives will be discussed there, e.g. Genetics of Cystic Kidney Diseasea and Living Donor Transplantation in Hereditary Kidney Disease.
S. Weber is member of the Board oft he ESPN WG Inherited Disorders and the Liason to the ESPN Council. She will report joint activities at the Council Meeting II in Porto.

4. Clinical studies:

a) Link to the PREDICT-Trial (Initiators G. Montini, F. Schaefer). Giovanni Montini will present an up-date oft he PREDICT-Trial at the ESPN Meeting in Porto (Sept 18th, 2014).

b) A questionnaire assessing the management of kidney dysplasia through-out Europe has been developed by Giovanni Montini for the WG. This questionnaire will be 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 will be distributed by email to all ESPN members. We expect that the questionnaires will be returned within a dead-line of 3 months (until the end of the year). Data analysis can then be performed in January 2015.

5. Scientific studies:

a) Gene Identification Studies in CAKUT patients are a major focus of the ESPN WG (following set-up of the Registry). The financial background of this reseach project will largely depend on the acceptance of scientific grants including the ESPN Research Grant.

6. Website Educational Material/Experts to be asked:

a) Extensive 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)

7**. ESPN WG Meetings**

a) A next WG Meeting with all members is planned on Sept 18th, 2014 in Porto (Arquivo Hall, 16-17:15). All members have been invited by email.