

Current activities ESPN WG Renal Genetics (Sep 1st 2014)

Board Members:

Elena Levtchenko, Sevgi Mir, Detlef Böckenhauer, Carsten Bergmann, Martin Konrad

Additional members:

22 members from countries throughout Europe

Contact ESPN: Stefanie Weber

Contact EDTA WG: Francesco Emma, Olivier Devuyst

Past/present activities:

1. “best practise guidelines” for Gitelman syndrome
Initiative made by Olivier Devuyst, first meeting took place on Sept 25th 2013 in Brussels,
Group members include Elena, Detlef, Francesco, Martin, Dr. Bettinelli, Dr. Vargas, Dr. Karet
Current standing: first screening round finished, at the moment, retrieval of selected publications
2. “best practise guidelines” for Cystinosis
Initiative already taken before the establishment of the group, including Elena and Francesco,
Just published in NDT together with other articles on genetic kidney diseases, including several articles by active working group members.
Reference: *Nephrol Dial Transplant* (2014) 29
3. 1st official meeting of the ESPN Working Group will be held in Porto on Sep 18th, 10:30 a.m.
Aims:
Defining major goals and projects for the working group
current proposals:
 - Questionnaire-based study on Tx policies (living-related) in genetic diseases in Europe
 - Using the ESPN website for educational activities, e.g. slide presentations on genetic topics
 - others...
4. structured support of current activities of individual members:
ADPKiD study (F. Emma, F Schaefer), invitation on the website
LOWE syndrome, long term follow-up (M. Zaniew, M Ludwig), to be discussed
5. CME activities:
Symposium on genetics at the next ESPN meeting in Porto 2014 (see ESPN meeting program)
Symposium on genetics at the ESPN meeting in Brussels 2015 (proposals for topics received)