Minutes Brussels meeting of the CKD-MBD WG
Date: Friday, 4th September 2015, 1:30pm-2:30pm; Location: Silver Hall

Topics:

1. Education & guidelines activities; ESPN web page
   JB: web-page gets regularly updated including new interesting papers on CKD-MBD

2. Vitamin D pilot study
   DH presented the preliminary data of the pilot study using serum and clinical data from the
   4C-study (n=40, case-control study in vitamin D deficient patient with and without vitamin D
   supplementation) and the GOSH study (n=40; randomized vitamin D trial). As expected the
   4C-study population presented with a higher degree of CKD and consequently higher levels
   of P and PTH. Results: In both study cohorts vitamin D supplementation did not alter serum
   Ca, P, PTH, and bicarbonate levels. In the vitamin D supplemented patients of the 4C
   population a significant increase in FGF23 levels and a tendency for increased Klotho serum
   levels were noted, whereas sclerostin levels were not affected. By contrast, in the patients of
   the GOSH trial vitamin D supplementation resulted in a significant increase in klotho and
   sclerostin levels, whereas FGF23 levels were not altered. Our data suggest that vitamin D
   supplementation has an impact on FGF23, Klotho and sclerostin (indicator of osteocyte
   function) depended on the stage of CKD in children. It was agreed to focus on FGF23,
   Klotho, sclerostin and vitamin D (1,25 and 25 OHD) levels and their relationship to the clinical
   data in the further analysis. SDS values for all parameters need to be calculated. JB noted
   that she has left serum samples of about 100 healthy children for assessment of Klotho
   levels. RS will check the normal values for Klotho at GOSH. DH received additional sera
   from FS in order to complete vitamin D values (1,25 and 25 OHD) before and after initiation
   of vitamin D supplementation in the 4C-cohort. RS will do the same in the GOSH population.
   Aim: preparation of manuscript by the end of 2015.
   JB pointed out that it would be interesting to assess the effects of vitamin D on iron
   hemostasis in this population as well.

3. PEP study
   SB presented the protocol of the PEP study. It was feared that the Ethics committee might
   see the protocol in its current form as a full clinical study since we change the advice to
   phosphate management. Therefore, the protocol should be adapted to an observational
   study. SB will adapt the protocol with support of the other WG members. It was suggested to
   produce a CD and an online training version for PEP instead of an expensive book.
   Translation of PEP is still pending.

4. B4Bone study (RS)
   Unfortunately the EU grant application was not successful, although it received an excellent
   evaluation.

5. Future projects
   JG will send a proposal for a survey for standards of bone status assessment in children
   (indication for x-rays). New proposals for other projects are always welcome.

Dieter Haffner, 8th September 2015

CKD-MBD WG: Chair: D. Haffner; Board: S. Bakkaloglu, MA. Gamero, G. Reusz, R. Shroff;
Members: C. Pietrement, M.C. Matteucci, G. Di Zazzo, I. Guzzo, I. Dursun, E. Petrosyan, O. Ozkaya,
A. Anarat, F.L. Sever, G. Guido, G. Klaus, A. Prytula, J. Groothoff;
Liaison ESPN registry: M. Bonthuis, Liaison council: D. Haffner, Liaison ERA-EDTA: J. Bacchetta;
Liaison ESCAPE network/4C-Study: Franz Schaefer