ESPN CKD-MBD Working Group
Coordinator: D. Haffner
Board members: J. Groothoff, R. Shroff, R. Bacchetta, S. Bakkaloglu

Minutes Venice meeting

19 October 2019 (11:00-13:00 / Sala Zorzi Room)

(Coordinators of the projects are given in brackets)

Attendees

Dieter Haffner: Haffner.Dieter@mh-hannover.de
Stella Stabouli: sstaboul@auth.gr
Maren Leifheit-Nestler: leifheit-nestler.maren@mh-hannover.de
Anne Schon : schoen.anne@mh-hannover.de
Enrico Vidal : enrico.vidal@inwind.it
Agnieszka Prytula : agnieszka.prytula@uzgent.be
Julie Bernardor : bernardor.j@chu-nice.fr
Claus Schmitt: clauspeter.schmitt@med-uni-heidelberg.de
Rukshana Shroff: rukshana.shroff@gosh.nhs.uk
Sevcan Bakkaloglu: sevcan@gazi.edu.tr
Dorota Drozdz: dadrozdz@cm-uj.krakow.pl
Justine Bacchetta : justine.bacchetta@chu-lyon.fr

1- Educational Projects (JB)

2- Phosphate Education Program (PEP) (SB)

New strategies in hyperphosphatemia management
ESPN research grant 2014
High protein/medium protein/low protein
Concept: to adapt the dose of binder to the content of phosphate in the meal
To develop an app for teenagers with pictures?
RS: app already existing in GOSH with pictures and small games => maybe to adapt for the Turkish diet?
Agenda for early 2020 in Sevcan's unit

3- New guidelines and best practice recommendations (all)

- Clinical practice recommendations for use of GH in children with CKD, published

- Clinical practice recommendations on the use of cinacalcet in children on dialysis, Epub
Question: the cinacalcet is not open-access => how can we do to put them on the ESPN website?

- Clinical practice recommendation for bone evaluation in pediatric CKD
The content of recommendations is OK, problem = the word count
Max 3500 words, currently 5800 => negotiation with NDT => not really the scope
Summarize all the recommendations in a Table (clinical + bio), and put the grading in a column
Grade the recommendations; grade X is possible

Check whether there are contradictions with the other guidelines => each coordinator will double-check
Abstract GOSH => no link between DXA and biomarkers
Make a list what is “suspected uncontrolled renal bone disease”
Introduction: patients with metabolic bone disease are not considered in this consensus such as cystinosis and PH1 (refer to the specific guidelines)
Next round => JB and RS then DH and then the entire group
Table 2: to re-think… + develop the legend of the table => begin from the labs

- Renal nutrition taskforce => calcium and phosphate Epub Pediatr Nephrol / protein-energy management submitted / vitamin and mineral requirements / nutritional prescription / potassium / obesity and cardiovascular risk (Stella Stabouli)

- Guideline to start in 2020:
Option 1: management of CKD-MBD post Tx => A Prytula, but consensus now or should we wait to have data from Certain and TRANSOS (prospective study in Lyon)? => fall 2020 for beginning the consensus

Option 2: diagnosis and management of infants with CKD-MBD => JB, RS, CPS, EV, SS, AP, SB, Majein, DH. The challenge will be to prepare it before. PICO + questions. June 2020 in Leuven or in Lyon? JB will evaluate the two locations and prepare the PICO, literature review and working groups before

4- Clinical studies
- Active vit D study and collaboration with 4C (MLN) => cf poster (N=19 pairs)
- CALBAL study => cf oral R Shroff
- GH treatment and CV outcomes in CKD children (SS) => primary outcome parameter? Case control study; the impact of CKD stage on the heart is enormous. Check the Plos 4C paper. Check with FS which analyses have already been performed on the topic.

- Study on mineral bone metabolism after renal Tx => A Prytula; retrospective study within Certain. Risk factors, management strategies. Main contributors pre-existing CKD-MBD, immunosuppressive therapies. Largest study so far: Bonthuis cJASN2015, 1237 patients, SHPT still 41% at 1 year (pre-emptive Tx: lower risk); Guzzo Pediatr Nephrol 2011 post Tx SHPT in children; Grenda Am J Transplant 2010; Prytula Pharmacogenomic 2016 and Pediatr Nephrol 2018
Objective(s): to analyse the long-term evolution of SHPT and other parameters of bone mineral metabolism after renal Tx
Role of hypoMg?
De novo pediatric renal Tx patients / at least 1 year of follow-up
Exclusion: PTX, graft loss within the first 3 months
Follow-up yearly until 5 years
Data: underlying renal disease, dialysis, donor source, RRF, height and BW + rhGH + native vit D + active D analogs + calcimimetics
Labs: PTH (to express as xx-ULN and double-check with all the centers what are their local normal ranges)
Add everolimus (+ levels) + bicarbonate + ALP

5- Board
December 2019: 1 SB leaves and SS arrives (each year one person should be exchanged)

6- Miscellaneous
SS will take a look to the ESPN website and our dedicated webpage
Next year => there will be an ESPN research call