

Minutes of WG Ethics
(EAP, UEMS Section of Paediatrics)
Bratislava, Hotel Devin
Saturday, May 30, 2015; Hall B
08.30 - 10.00

1. Attendance and apologies

There were 15 members attending this WG session, apologies from Ines Azuvedo, Portugal, Francis Crawley, Belgium and Štefan Grosek, Slovenia.

2. Approval of the agenda

Agenda was approved

3. Approval of the minutes from Brussels, Winter joint Meeting

Brussels minutes (December 2014) was approved

4. Manuscripts in preparation:

a. Finalization of the EAP EWG paper: 'Determining bone age in asylum seekers' (new version available on website – under: *Papers waiting for publication*)

David informed the group that the reviewers from EJP made some comments and corrections were made, however there was no further reply from the editor yet.

Francis proposed a Position paper on this topic (presented at the meeting), but members were rather reluctant for such a type, as position papers actually never hit the right target.

Instead there was solution made that it should be a little bit shortened and just main points should remain, with primary point stating “that bone age is not correlating with chronological age, and that as the paediatricians we believe that this is a completely wrong assumption”. The position paper is well written, English is perfect and it would be great if this statements are published, e.g. The Lancet.

David will ask Francis if he is ready to do it.

b. 'Ethical issues on how to communicate with children with disabilities and their families' (see at website) – is it still actual?

After a discussion there was a decision taken, that the topic should be abandoned as such and a new version should be made, like for example: What is the attitude towards children with disabilities and their families (from the medical institutions standpoint view). For such a survey the best would be to perform a questionnaire to be sent to all the members of EAP. Manuel Katz promised that he will send to David ESSOP Children's Rights Global Questionnaire and from that one David will make points for the disabled children, and Artur will also help.

c. Futility of respiratory support in severely disabled children (an outline of the manuscript will be prepared by Ines Azuvedo) – follow soon

d. Ethical issues regarding microdosing in Paediatric Research (an outline of the manuscript will be prepared by Francis Crawley) – follow soon.

David did not receive the frameworks for these two topics, and most probably will be postponed for he Brussels meeting.

e. Manuscript on Neonatal Male circumcision (new outline of the manuscript was sent and different opinions were received, one from Zachi and Shimon was presented to all members in paper form on the table)

At the discussion of all pros and cons David presented 3 solutions: to completely change the paper and add ethical and law points as well (Shimon and Zachi), to rewrite it with

the accentuation on ethical view only (Francis) or to abandon it and withdraw it completely because:

- it is difficult to achieve all nuances and all aspects of this problem
- already until now there was a lot of misplaced, unwarranted discussions, and
- and that comments are too many and too complicated to be placed on the website. *Ad hominem* arguments are also inappropriately placed in the public.

Finally everybody agreed that it should be abandoned, however Francis can go on and present ethical views of this problematic topics.

There were also some general aspects of this problem told from different angles/countries and from different members of EAP.

Israel: freedom of the religion and practices

Germany: fundamental human rights are above all rights

Canada: there is position paper on this topic from Canadian Paediatric Association (1996): circumcision can be done, depending on culture and religion and the number of newborn circumcisions in USA is probably dropping due to the fact that before it was free of cost, now the parents should pay (around 250 to 300 USD)

Ireland: obstetricians are reluctant to do the circumcision, also paediatric surgeons are rather reluctant and if you do not offer this service, parents will seek help in their own communities which is risky.

Turkey: female circumcision is forbidden, male circumcision is performed at age of around 8 years, rarely in newborns. Always performed by surgeons in the hospitals.

f. Position paper on Early Development & Disability - ?

This position paper was well written and adopted by GA, but there was no response from the WHO authorities.

5. Any other business

a) Some new proposals were discussed:

Obesity in children (will be further elaborated by Artur and David)

Doping and sports (David and Artur will try to find relevant references on this topic)

Ethical issues of presenting children (especially handicapped and those with rare diseases) in public (There exists Broadcast code for children)

b) Peter presented new publication on Making decisions to limit treatment, just published in ADC supplement (Larcher V, et al. Arch Dis Child 2015;100(Suppl 2):s1-s26. doi:10.1136/archdischild-2014-306666) and Millenium development goals progress report (ADC, February 2015)

c) David presented Nuffield Council of Bioethics - Children and clinical research: ethical issues

All the three will be put in PDF form on our site (other documents)

d) It has also been proposed that maybe it would be useful to send the important links to all the members, or to include them in Newsletter

David