



MINUTES

Ethics Working Group
European Academy of Paediatrics (EAP)
UEMS Section of Paediatrics

Bruxelles

Hotel Hilton, Hall A

December 2, 2016 at 09.00 – 10.30

1. Attendance and apologies
 - i) Attendance: at start: 8, thereafter: 11
 - ii) Apologies: Joe Brierley, Peter Hoyer, Stefan Grosek
2. Approval of the agenda
 - i) Approved, but with different order of points
3. Approval of the Minutes, Dublin, June 3, 2016
 - i) Approved
4. Manuscripts in preparation and topics for consideration:
 - i) **Sports and Arts in disabled children (presented by Liesbeth Siderius):**

This STATEMENT in preparation will be also asked to be supported by UNICEF (as before the paper on disability was supported by WHO) and Liesbeth is also waiting for the confirmation of support from EPA (which includes a lot of South-Eastern European paediatric societies). Robert Ross-Russell will check if there exist similar document within UK, and Francis Crawley will also work on further development of this document, while Liesbeth will try to link this to Rare Diseases WG.

- ii) **Health, Integrity, and Doping in Sports for Children and Young Adults (Proposal for European Academy of Paediatrics Resolution Ethics Working Group) (presented by Francis Crawley)**

This PAPER in preparation reflects the idea that sound competition in sports for children must be the sole issue and should be regarded only as a part of life, and to raise the awareness of huge influence of the industry, media, politics and parents'/society's expectations.

At this point Robert Ross-Russell started the discussion that EAP (WG Ethics) should write (as soon as possible) some statement or short paper on vulnerability of children in sports, because such a statement would also give EAP additional reputation and there should be an option to do such document to refer vulnerability and suggest adequate

protection for children in sports. Maybe it would also be possible to organize a kind of event (maybe here in Bruxelles) on this topic with interested partners/participants. Martin White and Tom Stiris also commented on such similar abuses in Ireland and Norway. Francis Crawley ment that the present paper should be kept as it is and just needs the introduction and the vulnerability of children in sports should be a separate topics, either as a short Commentary or Statement. Liesabeth Siderius commented that Statement (even if only on EAP website) have some meaning and aim that someone can always refer to it, when needed and suggest to have such statement as well, separated from the Francis' paper. Isabel Leiva proposed that this issue of vulnerability and abuse of children in sports should also be discussed within each National Society, while Armando Barillari supported the idea that such statement will increase the visibility of EAP.

Final decision was that the paper proposed by Francis Crawley be published as it is, with the introduction which Peter Hoyer will made, and as already decided in Dublin, no need to be accepted at GA. The first option proposed was The Lancet, or EJP (see minutes from Dublin).

(Comment: after the meeting the Introduction was sent by Peter Hoyer and David forwarded it to Francis, and members can comment on it – but, please, in a short time, let us say until New Year - see attachment)

Statement on vulnerability of children in sports and how to handle this problem will be outlined by Robert Ross Russell and Martin White, and the goal is to be published as a statement in EJP journal.

**iii) The performance enhancing drugs use in children in sport issue.
(prepared by Joe Brierley)**

This PAPER in preparation was shortly presented by David as Joe apologised. David suggested that everybody should read this first version (available at EAP website – Ethics WG – Documents under preparation) and to decide whether Joe should continue with this topic or not, especially because Joe expressed some hesitation as such similar paper was already published by AAP (the paper was sent to all members of Ethics WG before by David). However David commented his opinion that this first version is an excellent document (especially the proposed text in the Box) and should be further elaborated and published. The decision will be taken at next EAP (Spring) meeting.

iv) Obesity in children and adolescents (Artur Mazur)

This PAPER was presented by Artur Mazur and he just commented on some improvements (besides added 2 authors who contributed a lot to the paper), especially the Boxes on Recommendations for parents, paediatricians and teachers, as well as Conclusion part. Everybody congratulated Artur for this improvements and David just suggested that Francis Crawley do the revision of the English (similar as with the first version), and then it can be published (as already decided in Dublin) in a journal (?EJP).

v) Special lecture 10.00 – 10.30

mr. drs. Nicole U.N. Kien, attorney at law in Rotterdam, The Netherlands,
(specialized in legal matters in the Life Sciences & Health-industry)

Registries in Europe : Privacy Perspectives.

This was an excellent lecture on the approaching new legislation (in May 2018) on data protection, especially regarding the data in the registries (joint lecture of WG Ethics and WG Rare Diseases).

Extensive discussion followed and the consideration was discussed that such a lecture (together with some other topics, like ethical issues in research) could be presented as a workshop/symposium at one of the future congresses, together with rare disease WG (either in Ljubljana 2017 or Paris 2018).

Meeting ended at 10.45

D. N.