



European Academy of Paediatrics
Paediatric Section of U.E.M.S (European Union of Medical Specialists)



Ethics Working Group

European Academy of Paediatrics (EAP)
UEMS Section of Paediatrics

Minutes WG Ethics

Rzeszow, Poland

Friday, May 30, 2014; 10.15-12.00

1. Attendance and apologies

There were 17 members attending, apologies from Azovedo, Crawley and Grosek

2. Approval of the agenda

3. Approval of the minutes from Brussels, December 13, 2013

Both approved

4. Manuscripts in preparation:

- a. Update and finalization of the EAP EWG paper: 'Determining bone age in asylum seekers' (A Nicholson and P Sauer)

There was no feedback from Pieter Sauer regarding the possible EJP publication

- b. Update and further developments regarding the the 'EAP Response to the WHO Discussion Paper on Early Childhood development and Disability': WHO response; Co-operation with the European Commission Expert Group on Rare Diseases and the European Commission project (Liesbeth Siderius)

There was no feedback from WHO – After discussion there has been decision made:

A final sentence/question should be added: "Let us know what we can do further to help, support and expertise on this topic"?

Liesbeth will add this sentence and resent it again to WHO.

- c. Update on the EAP EWG project on 'Ethical issues concerning medical records and electronic files' (D Neubauer, FP Crawley). David explained that this topic has been »on board« for quite a long time. The members were positive that this topic should continue, maybe we should get in **contact with EAPRASnet and sort out some ethical issues regarding their questionnaire on: Electronic Health Record Survey and we should get some IT professional view on the technical issue of electronic data protection.**

Also F. Crawley promised to send a kind of framework on this topic!

- d. Update on the project 'Ethical issues with regard to minor parents providing informed consent for their child in a vaccine trial' (D Neubauer)

David reported on meeting in Wavre (Belgium) organized by GSK Vaccine group (Tatjana Poplazarova & Veronique Delpire) + representatives from North America (Mary Ott and Susan Rosenthal), Ghana (S Owusu-Agyei), Panama (X Saez-Llorens) and D Neubauer and F Crawley, on May 22 – 23, 2014. There was a proposal to write a manuscript and maybe thereafter a guideline on **'Ethical issues with regard to minor parents providing informed consent for their child in a vaccine trial'** ***All the attending members were very much against this topic to be discussed***



within the EAP, and the president (Tom Stiris, Norway) thought it should not be further developed, and that it has ethically questionable issues as the pharmaceutical company is involved.

Everybody agreed that there should not be support of EAP on this topic.

- i. Short presentation of Rare Diseases & Parent project (L Siderius).

Liesbeth presented key issues on this topic and it has been agreed to proceed with this project.

- e. Future papers under consideration:

- i. 'Vaccination problems and communication with parents: side effects'

There are actually 2 problems: one is the parental refusal and the other one is that health care providers are often quite reluctant to support vaccinations in children adequately

(Laszlo Kovacs will prepare an outline for next meeting discussion)

- ii. 'Ethical issues on how to communicate with children with disabilities and their families' (attached)

David will resent this manuscript again to all the members of EAP 3 months before the Bruxelles meeting, asking ALL the members to give their final comments on this paper, which finally should be realized in Bruxelles

5. Any other business

A) Ines Azuvedo (P) proposed a future topic on:

»Futility of respiratory support in severely disabled children«

David will ask her to prepare a kind of framework for this topic.

B) Francis Crawley proposed a position paper/manuscript on

»Ethical issues regarding Phase 0/I Microdosing in Paediatric Research«.

This has been accepted for further evaluation, if Francis will provide some more details on this topic.

Looking forward to meet you in Bruxelles, December 5 – 6, 2014

David