



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



## Agenda

Rare diseases/Ethics Working Group  
European Academy of Paediatrics (EAP)  
UEMS Section of Paediatrics  
Domus Medica, Bruxelles  
**December 1, 2017: 09.30 – 11.30**

1. Attendance and apologies
2. Approval of the agenda
3. Approval of the Minutes, Hotel Tivoli Vilamura, Portugal <http://eapaediatrics.eu/wp-content/uploads/2017/05/Minutes-WG-Ethics-Vilamura-May-12-2017.pdf>
4. Manuscripts in press:
  - i) Obesity in children and adolescents (Acta Paediatrica) – accepted
  - ii) Health, Integrity, and Doping in Sports for Children and Young Adults (Resolution of European Academy of Paediatrics

Ethics Working Group) (published in EJP see at:

<http://link.springer.com/article/10.1007/s00431-017-2894-z>

Still waiting for translations

We should attempt to achieve translations into major European and International Languages:

- German (Peter)
- French (Jean-Christophe)
- Spanish (Manuel) - **DONE**
- Portugese (Ines)
- Italian (? Francis will forward)
- Russian (? Francis will forward)
- Arabic (Ahmed)
- Chinese (Jean-Christophe will forward)

**Decision: The translations will be done by ethics WG members (in brackets) as soon as possible.**

### 5. Manuscripts in preparation:

- i) The performance enhancing drugs use in children in sport issue.

(Brierley Joe) Please read outline at: <http://capaediatrics.eu/wp-content/uploads/2016/11/Performance-enhancing-drugs-Brierly.pdf>

- ii) Sports in disabled children (Siderius Liesbeth) Please read outline at: <http://capaediatrics.eu/wp-content/uploads/2016/11/Sports-and-art-in-disabled-children.pdf>
- iii) Statement of vulnerability in sports (Robert Ross-Russell, Martin White)  
RRR has proposed to start with the table on Rights of the children and how they are really respected in the real world (attached). Everybody will look on it and make his own comments and suggestions. Francis commented that these are the rights of the children that go hand in hand with other rights, such as how we are dealing with the rights of migrants and those with disability – so we can maybe merge the three manuscripts in prep somehow together. It should also be stated somewhere that US never ratified the Declaration of Rights!  
**Decision: everybody will write the comments to the table and send them either to Rob and Martin or to David to complete it and then decide whether to write a statement or a manuscript out of the data.**
  
- iv) First-in-children Clinical studies of Medicines (Francis Crawley), Microdosing in children (Francis Crawley), Migrant children and young adults in Europe: ethical view on research, participation in studies and ethical guidances for medical work (Crawley, Neubauer) – *postponed*

- 5. AOB (Declaration of Geneva) Revised version (October 14, 2017)  
<https://www.wma.net/policies-post/wma-declaration-of-geneva/>

***Presentations:***

- 1. ***Klaus Rose, Medical Science, Klaus Rose Consulting, Switzerland: Do we still need PIPs – 20 minutes and 10 minutes discussion***

Welcome to EAP Ethics WG  
David

List of attending members from last meeting (**please, check the e-mail addresses**):

Christine Aebi	<a href="mailto:christine@aebi.ca">christine@aebi.ca</a>	Switzerland
Ines Azevedo	<a href="mailto:inesfazevedo@clix.pt">inesfazevedo@clix.pt</a> ; <a href="mailto:inesaguedaazevedo@gmail.com">inesaguedaazevedo@gmail.com</a>	Portugal

Francis Crawley	<a href="mailto:fpc@gcpalliance.org">fpc@gcpalliance.org</a>	Belgium
Peter Hoyer	<a href="mailto:peter.hoyer@uk-essen.de">peter.hoyer@uk-essen.de</a> ; <a href="mailto:pfhoyer@gmail.com">pfhoyer@gmail.com</a>	Germany
Manuel Katz	<a href="mailto:katzmanuel@gmail.com">katzmanuel@gmail.com</a> ; <a href="mailto:manuel.katz@bsh.health.gov.il">manuel.katz@bsh.health.gov.il</a>	Israel
Jean-Christophe Mercier	<a href="mailto:jean-christophe.mercier@rdb.aphp.fr">jean-christophe.mercier@rdb.aphp.fr</a>	France
David Neubauer	<a href="mailto:David.neubauer@mf.uni-lj.si">David.neubauer@mf.uni-lj.si</a>	Slovenia
Vladimir Pilosoff	<a href="mailto:vpilosoff@mail.hearthospital.bg">vpilosoff@mail.hearthospital.bg</a>	Bulgaria
Robert Ross Russell	<a href="mailto:robert.ross-russell@addenbrookes.nhs.uk">robert.ross-russell@addenbrookes.nhs.uk</a> ; <a href="mailto:rjr20@cam.ac.uk">rjr20@cam.ac.uk</a>	United Kingdom
Liesbeth Siderius	<a href="mailto:e.siderius@kpnplanet.nl">e.siderius@kpnplanet.nl</a>	The Netherlands
Ahmed Soliman	<a href="mailto:asoliman1@nhs.net">asoliman1@nhs.net</a>	United Kingdom
Tom Stiris	<a href="mailto:tom.stiris@medisin.uio.no">tom.stiris@medisin.uio.no</a>	Norway
Martin J White	<a href="mailto:mjmjwhite@gmail.com">mjmjwhite@gmail.com</a>	Ireland