



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 appologies
- 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://eapaediatrics.eu/wp-content/uploads/2016/11/Performance-enhancing-drugs-Brierly.pdf

- ii) Sports in disabled children (Siderius Liesbeth) Please read outline at: http://eapaediatrics.eu/wp-content/uploads/2016/11/Sports-and-art-in-disabled-children.pdf
- 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 word (attached). Everybody will look on it and make his own comments and sggestions. Francis commented that these are the rights of the children that go hand in hand with other rights, such are how we are dealing with the rights of migrannts and those with disability so we cam 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	christine@aebi.ca	Switzerland
Ines Azevedo	inesfazevedo@clix.pt;	Portugal
	inesaguedaazevedo@gmail.com	

Francis Crawley	fpc@gcpalliance.org	Belgium
Peter Hoyer	peter.hoyer@uk-essen.de;	Germany
	pfhoyer@gmail.com	
Manuel Katz	katzmanuel@gmail.com;	Israel
	manuel.katz@bsh.health.gov.il	
Jean-Christophe Mercier	jean-	France
	christophe.mercier@rdb.aphp.fr	
David Neubauer	David.neubauer@mf.uni-lj.si	Slovenia
Vladimir Pilossoff	vpilossoff@mail.hearthospital.bg	Bulgaria
Robert Ross Russell	robert.ross-	United Kingdom
	russell@addenbrookes.nhs.uk;	
	rir20@cam.ac.uk	
Liesbeth Siderius	e.siderius@kpnplanet.nl	The Netherlands
Ahmed Soliman	asoliman1@nhs.net	United Kingdom
Tom Stiris	tom.stiris@medisin.uio.no	Norway
Martin J White	mjmjwhite@gmail.com	Ireland