



Rare Disease Working Group (EAP, UEMS Section of Paediatrics) Friday December 5th, 2014 Brussels 9.00-9.30

Minutes

1. - Attendance and apologies: Jola Wierzba. Agenda approved

2. - Minutes, Meeting Rzesow, May 2014: no comments

3. - Report on FP7 Rare Best Practice (see presentation enclosed)

- Guideline appraisals- RBP WP 4 request

Paediatricians are asked to help appraising rare disease guidelines according to the AGREE method: Congenital cataract; Cystic fibrosis; Epidermolysis bullosa ; Noonan syndrome;

Wolfram disease: contact: jenny.harbour@nhs.net

- Pilot Guideline WP 3 "catastrophic antiphospholipid syndrome"

This guideline was selected among 44 others as presented (slide 5).

- Coordination and Dissemination : networking and meetings.

During meetings such a paediatric rare disease meeting in Moldavia as the EAPS we address the need of guidelines and e- health. Availability of guidelines in an open resource webbased environment helps less well developed countries.

Proposed is a session/ workshop at meeting in Oslo on the appraisal of rare disease guidelines.

4. - Report on EU Commission Expert Group on Rare Diseases

EAP is represented in the EU expert group.

- EAP has supported the use of ICD, orphacodes, SNOMED and ICF. At the last meeting November 2014 the group adopted 'Recommendation on Ways to Improve Codification for Rare Diseases in Health Systems'.

http://ec.europa.eu/health/rare_diseases/docs/ev_20141112_flash_en.pdf

Discussion: M . Katz asked about EAP involvement in ICD11? Apparently there is none.

- There was a proposal for grouping of rare diseases (see presentation slide 10). Question is what can be expected of paediatric subspecialists when it comes to management of complex chronic and disabling conditions. And how would that fit into the EAP statements on medical home / integrated care? Some of the colleagues present offer their assistance to an EAP opinion on this proposal.

5. -Next steps and meetings

- EAP September meeting : AGREE method and rare disease guidelines?

6.- Any other business

Attention is asked for resolution of World Health Assembly endorsing the *WHO global disability action plan 2014–2021: Better health for all people with disability.*

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