



European network of paediatric research
at the European Medicines Agency



EUROPEAN MEDICINES AGENCY
SCIENCE MEDICINES HEALTH

29 January 2014
EMA/145659/2014

Minutes of the Enpr-EMA Coordinating Group (CG) meeting

Held by teleconference on 23 January 2014, 15:45-17:00 UK time

Attendees:

Enpr-EMA chair: Mark Turner

Enpr-EMA co-chair: Irmgard Eichler (EMA)

Enpr-EMA secretariat: Benjamin Pelle, Isabel Perez (EMA)

Coordinating Group Members: Anne Junker, Dirk Mentzer, Kalle Hoppu

Invited participant: Ralf Herold (EMA)

Apologies:

Gilles Vassal, Carlo Giaquinto, Gareth Veal, Tim Lee, Jose Drabwell, David Coghill, Christina Peters, Saskia de Wilt, Nicola Rupperto, Andrea Biondi, Adamos Hadjipanayis

Item	Summary of discussion	Action	
1	Apologies, adoption of minutes of last CG teleconference and CG meeting agenda	Attendance was noted, minutes and agenda were adopted without amendments.	N/A
2	Horizon 2020	No specific EC calls in Paediatrics but possibility to place a paediatric project within orphan call for instance To establish a roadmap to lobby the European Commission (EC) about the need to support medicines development in children (EMA meeting of 30/01/14) and get funding for paediatric clinical trials Enpr-EMA chair to write shared vision to EC and CG to comment on the document EMA to circulate current list of EU national MEPs so that CG can lobby in their national countries	EMA, Enpr-EMA Chair CG

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3	<p>Status update on emerging networks:</p> <ul style="list-style-type: none"> • Cardiology • Gastroenterology • Diabetes • New networks <p><u>Cardiology:</u></p> <p>Two ongoing projects: Scimitar syndrome register initiated by the Padova Group and contribution in the Cardiomyopathy register initiated by ESC.</p> <p>1 new project: participation in multicentre study on treatment by percutaneous ablation of supraventricular tachycardia in children less than 6 months of age</p> <p>Next meeting with the nucleus group in April (TBC) and AEPC business meeting in Helsinki, 22-24 May.</p> <p><u>Gastroenterology (PEDDCReN):</u></p> <p>6 weekly regular meetings of the steering group by TC.</p> <p>An online survey has been sent to UK contacts, Ireland and Holland. It will then be sent via ESPGHAN and BSPGHAN to rest of Europe, to identify potential investigators with interests in the network.</p> <p>Symposium at ESPGHAN annual conference in Jerusalem in June and an additional workshop to be planned.</p> <p><u>Endocrinology/Diabetes (EUCADET):</u></p> <p>Meeting of national representatives in September.</p> <p>Network meeting of representatives from Diabetes/Endocrine Societies throughout Europe planned for late April/early May 2014.</p> <p>Website in construction. European Children and Adolescent Diabetes and Endocrine Trials (EUCADET).</p> <p>Engagement with EFPIA around IMI call as part of Horizon 2020.</p> <p><u>Asthma network:</u></p> <p>EARIP http://earip.eu/ is a programme composed of 7 workpackages, with interests ranging from disease mechanisms and stratification to networking of clinical centres. One of the workpackages that is led by Dr Ratko Djukanovic, is called ERNAC (European Research Network of Asthma Clinical research facilities). Dr Djukanovic will be approaching academic centres, patient groups and charities, CROs and pharmaceutical companies to get their views on ERNAC.</p> <p>CG to ask to join the asthma network if they are interested and have expertise in pneumology</p> <p><u>Canadian network:</u></p> <p>Clinical trial networks of specialists establishing registry study groups (18 of these are in paediatrics)</p> <p>Business case: which matrix is used to show success? to compare</p>	<p>N/A</p> <p>N/A</p> <p>N/A</p> <p>CG</p> <p>N/A</p>

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	<p>experiences between Canada and EU</p> <p><u>Nordic network:</u></p> <p>Scandinavian countries (FIN, DK and SE): multi-country paediatric clinical trial network is being established</p> <p>In process of getting funding for the network</p>	N/A
4	<p>Enpr-EMA Resource Database</p> <p>The searchable resource database has now been published on the Enpr-EMA website and can be accessed here: Enpr-EMA Network Database</p> <p>Only 21 networks have submitted their updated self-assessments and are now included and searchable in the database.</p> <p>Those networks who have not yet submitted their updated self-assessments are invited to do it at their earliest convenience so they can be visible to external users when searching the resource database.</p> <p>All registered networks are however mentioned in the list of network members of Enpr-EMA and other networks not yet fulfilling all criteria which displays all networks with links to their network websites.</p>	Networks
5	<p>International Network Alignment Project</p> <p>Ongoing with the aim to build an Industry sponsored paediatric clinical trial network</p> <p>S. Maldonado / R. Portman are working on a consortium to link up with the American Academy of Paediatrics and to reach out to other members</p> <p>Anne Junker reported of the initiative of Mort Wasserman (American Academy of Pediatrics and head of the Pediatric Research in Office Settings (PROS) to bring together leaders of pediatric clinical research networks, and others (notably NIH institute leaders to sensitize them to the importance of networks/networking) and proposed to invite him to Enpr-EMA workshop, as it would be relevant to the work of Enpr-EMA, particularly WG9. Detailed proposals to be presented at Enpr-EMA June workshop</p>	N/A
6	<p>Worldwide involvement of children in clinical research</p> <p>C. Thompson (chair of Executive Committee of the American Academy of Paediatrics Section on Advances in Therapeutics and Technology) who has developed a young person advisory group (YPAG) in North America asked for possibility to link up EU established YPAGs and North American YPAGs into a Communicating International Network.</p> <p>Discussion of establishment of this worldwide involvement to take place at the Enpr-EMA June workshop.</p> <p>Charlie Thompson engaged Anne and Jenny Preston (UK-MCRN) to a teleconference they held last week to discuss a project on "Assent".</p> <p>A recently completed project was mentioned on palatability of paediatric formulations which involved a literature review and survey,</p>	N/A

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	http://pediatricinnovation.org/2013/02/ipi-launches-apt/	
7	Role and involvement of Industry in CG meetings Possibility of electing a member representing Industry, acting as an observer in CG meetings (similar as for ENCePP Steering Committee). Identified need for a SME representative will be explored by EMA.	EMA, CG
8	Topics at the Enpr-EMA annual workshop (26/06/14) Feedback from each WG on completed actions, Worldwide involvement of children in clinical research (possibility of presentation of the work done by KidsCan) Opportunities for public-private partnerships in research networks Network functions: sharing good practices, sustainable business plan and relationships between network investigators <u>Topic for CG meeting:</u> Promotion of the GRIP roadshow about Paediatric Clinical Pharmacology	N/A
9	A.O.B	None