



European network of paediatric research  
at the European Medicines Agency



EUROPEAN MEDICINES AGENCY  
SCIENCE MEDICINES HEALTH

30 November 2017  
EMA/785044/2017  
Human Medicines Research & Development Support Division

## Minutes - Enpr-EMA Coordinating Group meeting

Wednesday 22 November 2017, EMA room 03-H and via Adobe Connect;  
15.00 to 16:00 UK time

Chairpersons: Mark Turner / Irmgard Eichler

Agenda	Topic leader	Minutes
Adoption of agenda	Mark Turner	Adopted
Maximum number of working group members	Pirkko Lepola	<p>A maximum of 10 members with a limit of 1 representative for each company or organisation as well as an equal representation of the various stakeholders was proposed to ensure efficient working. While this proposal was endorsed in principle, it was also stressed that the number and composition should be based on the actual needs and tasks of the working group on an ad-hoc basis; therefore, some flexibility should be possible. It was agreed to recommend, but not to enforce the proposal in the mandate of the working groups.</p> <p>Finally it was agreed that members retired from their organisations but willing to continue contributing to the work of Enpr-EMA working groups are welcome to do so, as long as they no longer use their previous affiliation and their status is clearly indicated.</p> <p>The mandate of the working groups will be revised and circulated.</p>
Renewal of the Coordinating Group	Isabel Perez	<p>All coordinating group members are reminded to express their interest for renewal for the next 3 years (by e-mail) to the Enpr-EMA secretariat.</p> <p>2 members confirmed verbally their interest to represent their 2 networks :</p>



Agenda	Topic leader	Minutes
		<p>Ruth Ladenstein (OKIDS)</p> <p>Ian Wong (EUNETHYDIS)</p>
<p>Endorsement of newly received or updated applications for Enpr-EMA membership</p>	<p>Irmgard Eichler</p>	<p>The membership of NETSTAP e.V. as category 3 network was endorsed.</p>
<p>AOB</p>	<p>Irmgard Eichler / Mark Turner</p>	<p>Suggestion topics for next year workshop:</p> <p>Review activities of various working groups on areas where there may be overlapping projects with the objective of sharing information/work, to avoid duplication and increase collaboration between networks and other stakeholders.</p> <p>Challenges in clinical trials in ultra-rare diseases: a holistic approach is considered necessary; there is the need to identify and reach out to other organisations/networks (e.g. European Reference Networks, learned societies, HTA bodies, etc.). This approach will, hopefully, encourage possible synergies among networks and organisations as well as prevent overlay of activities.</p> <p>Current Enpr-EMA network representatives are asked to reach out to affiliated organisations (e.g. networks, learned societies) to identify groups with activities similar to those of the various Enpr-EMA working groups) who might provide synergies and to send relevant contact details to Enpr-EMA secretariat in preparation for the 2018 face to face workshop.</p> <p>Deadline: 19 January 2018</p>