

!! Invitation to Friday, May 17th, Lunchtime Meeting on Promoting an Active International Porphyria Patient & Healthcare Professional Network !!

Dear Porphyria Patient Representatives,

we would like to use the opportunity of the P&P conference and the Porphyria Patient Day to meet as a group, propose to enhance the international network across patient organizations and between them and the healthcare professional community, and discuss opportunities to realize these objectives.

The core of the proposal is to use the recently launched RareConnect Porphyria Community as the foundation for an international patient and medical expert network. We will encourage a strong active participation and propose a concrete project that we would like to promote through the RareConnect network – An international awareness campaign for hepatic porphyrias supported by OrphanEurope.

To set the stage, the meeting will start with brief presentations on RareConnect and RareTogether, EURORDIS' platforms to network patients across national boundaries, and by OrphanEurope on the Porphyria Awareness Campaign. The presentations will be followed by Q&A and a round-table discussion on the proposal and other ideas to promote an international network. The meeting will then end with a follow-up action plan and hopefully set the course for a strong international network that will contribute to advancing knowledge on porphyrias, improve the well-being of individuals and families affected by porphyria and promote their interests. Please, find the detailed agenda below and in the attachment.

Please, confirm your attendance at this meeting by April 29th. If you cannot attend, please do also let us know by responding to this Email. This will allow us to organize the lunch packets according to number of participants.

The same invitation has been sent out to key national porphyria medical experts and we are looking forward to having a good discussion between patient representatives and professionals.

Best regards,

Jasmin & Rocco – Porphyria Patient Day Organizers

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See agenda overleaf

Agenda

12:30-12:35	Introduction, distribution of lunch packets	Jasmin/Rocco
12:35-12:50	RareTogether – Helping in the creation, operation and management of European Rare Disease Federations	Anja Helm, EURORDIS
12:50-13:05	RareConnect Porphyria Community	Robert Pleticha, EURORDIS
13:05-13:20	Porphyria Awareness Campaign	Margueritta Abou Hanna, OrphanEurope
13:20-13:45	Q&A, Round-table discussion	All
13:45-14:00	Follow-up actions & wrap-up	All

Tentative target – Patient representatives and professionals from:

1. Argentina
2. Australia
3. Belgium
4. Canada
5. Denmark
6. France
7. Germany
8. Italy
9. Netherlands
10. Norway
11. South Africa
12. Spain
13. Sweden
14. Switzerland
15. UK
16. USA