

ePAG f2f meeting 2019

16 May 2019

Crowne Plaza Bucharest (Crown A, Crown B and Primavera)

During the meeting participants will explore a selection of good practices that ePAG patient advocates will present and discuss with their peers. As such, this meeting will be an opportunity to learn from each other and build your network with patient advocates working in other European Reference Networks.

Good practices:

1. *Clinical Practice Guidelines narrative review (CPG.1)*
2. *Patient Journeys (PJ.2)*
3. *Patient involvement in the ENDO ERN Registry (RE.3)*
4. *Governance (Gov.4)*
5. *Development of Rare Eye Disease (RED) Ontology using Orphanet and HPO base (Ont.5)*

09.00-09.30 Registration and allocation of group

09.30-9.40 Welcome and introduction to the meeting by facilitators (EURORDIS staff and ePAG patient advocates).

09.40-11.00 Group discussion on 2 ePAG good practices.

30 min presentation of good practices (15 per good practice), 40 min group discussion (20 per practice), 10 min wrap-up by facilitators (5 per good practice).

Group 1 Crown A: Good Practices CPG.1 and PJ.2

- *Charissa Frank, 9.40 - 10.20*
- *Sue Routledge and Ammi Sundqvist, 10.20 – 11.00*

Group 2 Crown B: Good Practices RE.3 and Ont.5

- *Johan de Graaf, 9.40-10.20*
- *Russell Wheeler, 10.20-11.00*

Group 3 Primavera: Good Practices Gov.4 and CPG.1

- *Loris Brunetta, 9.40-10.20*
- *Ilaria Galetti, 10.20 – 11.00*

11.00 -11.30 Coffee break

11.30-12.30 Group discussion on 1 ePAG good practice.

15 min presentation of good practice, 35 min group discussion, 10 min wrap-up by facilitators

Group 1 Crown A: RE.3, *Johan de Graaf*



Group 2 Crown B: Gov.4, *Loris Brunetta*

Group 3 Primavera: PJ.2, *Sue Routledge and Ammi Sundqvist*

12.30-13.30 Lunch

13.30-15.00 Group discussion on 2 ePAG good practices.

30 min presentation of good practices (15 per good practice), 50 min group discussion (25 per practice), 10 min wrap-up by facilitators (5 per good practice).

Group 1 Crown A: Good Practice Gov.4 and Ont.5

- *Loris Brunetta, 13.30 - 14.15*
- *Russell Wheeler, 14.15-15.00*

Group 2 Crown B: CPG.1 and PJ.2

- *Ilaria Galetti, 13.30-14.15*
- *Sue Routledge and Ammi Sundqvist, 14.15-15.00*

Group 3 Primavera: RE.3 and Ont.5

- *Johan de Graaf, 13.30-14.15*
- *Russell Wheeler, 14.15-15.00*

15.00- 15.30 Recap of the day (participants coming together per ePAG group to reflect on main take-aways and all facilitators to meet to discuss conclusions).

15.30-16.00 Summary and conclusions by facilitators

16.00-16.30 Coffee

20:00 Dinner CNA and ePAG patient advocates

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