



# MEMBERSHIP MEETING 2016

Edinburgh | 26 May

EURORDIS.ORG | #EMM2016



Romanian National Alliance for Rare Diseases - Rare Disease Day 2016

With the support of



Co-funded by  
the Health Programme  
of the European Union

# EMM 2016 Edinburgh

## Edinburgh International Conference Centre

- 09.30-13.00 **EURORDIS Extraordinary & Ordinary General Assembly** Room: Sidlaw
- 13.00-14.00 **Lunch**
- 14.00-17.30 **Four parallel workshops :**
- 1 European Reference Networks (ERN) and ePAGs Room: Tinto
  - 2 RareConnect Room: Moorfoot
  - 3 Social policy and social innovation Room: Kilsyth
  - 4 Good clinical practice in the context of ERN Room: Harris 1 & 2
- 18.00-19.00 **Welcome Reception for Patient Groups** Strathblane Hall

## Workshops Program

### 1. European Reference Networks (ERN) and ePAGs

start at  
14.00

**Moderators: Yann Le Cam, Matt Johnson, EURORDIS**

*An overview of the development of ERN applications and patient engagement in the emerging networks.*

- 14.00-14.30 ● **ERN State of the Art** *Yann Le Cam, Matt Johnson, EURORDIS*
- > First ERN applications, grouping & scope
  - > 1st lessons learned, what's next? Opportunities? Challenges?
- 14.30-15.30 ● **European Patient Advocacy Groups (ePAG)** *Matt Johnson, Lenja Wiehe, EURORDIS*
- > How do patient advocates participate? What is their role?
  - > ePAG Terms of references, Common principles, Common objectives
  - > ePAG communication via RareConnect, *Denis Costello, EURORDIS*
- 15.30-16.00 ● **Coffee break**
- 16.00-17.00 ● **Discussion with elected ePAG representatives and all participants: Goals & objectives, difficulties & successes, challenges and vision of ideal patient engagement**
- > *Daniel Renault, Federation of European associations of patients affected by renal diseases, France*
  - > *Anne-Sophie Lapointe, Vaincre les Maladies Lysosomales, France*
  - > *Richard West, Behcets International, UK*
- 17.00-17.30 ● **Conclusions & way forward**, *Yann Le Cam, EURORDIS*

### 2. RareConnect

start at  
14.00

**Moderators: Denis Costello, Rob Pleticha, EURORDIS**

*An update on the RareConnect social network's activities and learn about new projects being planned that enhance the capacity of rare disease patients to connect with one and other on a global level*

- 14.00-15.00 ● **RareConnect update** *Robert Pleticha, EURORDIS*
- 15.00-15.30 ● **RareConnect Discussion Groups** *Denis Costello, EURORDIS*
- 15.30-16.00 ● **Coffee break**
- 16.00-17.30 ● **PhenomeCentral and the MatchMaker Exchange: an introduction to rare disease matchmaking for discovery of novel disease genes by clinicians and patients**  
*Michael Brudno, Sick Children's Hospital, Toronto, Canada*

### 3. Social policy and social innovation

start at  
14.00

**Moderator: Maria Montefusco, EURORDIS Social Policy Advisory Group & Nordic Centre for Welfare and Social Issues**

*A toolkit and inspiring case studies to help you take action to support the integration of rare diseases into social services and policies*

- 14.00–15.00 ● **Advocacy toolkit to integrate rare diseases into social services and policies**
- > Available tools: fact sheets, guiding principles and case studies *Raquel Castro, EURORDIS*
  - > Make your voice stronger: INNOVCare/Rare Barometer survey on daily needs of people living with a rare disease and their families *Sandra Courbier, EURORDIS*
  - > Advocate for health services to play an active role: European Commission Expert Group Recommendations *Dorica Dan, Romanian National Alliance for Rare Diseases & EURORDIS*
- 15.00–15.30 ● **Inspiring integrated care models**
- > INNOVCare project: holistic care pathway facilitates the coordination of care between health, social and local support services *Raquel Castro, EURORDIS*
  - > Navigators project: volunteers support people living with a rare disease to navigate the Danish health care and social systems *Stephanie Jøker Nielsen, Rare Diseases Denmark*
- 15.30–16.00 ● **Coffee break**
- 16.00–17.30 ● **Social innovation: what is it and how can it be an opportunity?**
- Anette Scopetta, Head of Work, Wealth and Welfare, Deputy Director, European Centre for Social Welfare Policy and Research, Austria*
- > The basics of social innovation
  - > Can social innovation be an opportunity for your patient organisation?
  - > Funding opportunities for social innovation projects
  - > Inspiring social innovation projects to support patients with complex conditions  
*Open discussion, learning from each other*

### 4. Good clinical practice in the context of European Reference Networks

start at  
14.00

**Moderators: Geske Wehr, Selbsthilfe Ichthyose e.V., Germany & EURORDIS Board of Directors and Juliette Senecat, EURORDIS**

*A presentation of the use of best practice guidelines and tools available in the context of ERN and a discussion on patient engagement in this field.*

- 14.00–15.30 ● **Rare diseases guidelines and useful tools in the perspective of rare disease ERNS**
- > Best practice guidelines in the context of rare disease ERNs. *Domenica Taruscio, RARE-Bestpractices Project Leader, Istituto Superiore di Sanità, Italy*
  - > Presentation of the tools developed by the RARE-Bestpractices project, funded by the European Commission, to appraise clinical guidelines for rare diseases. *Karen Ritchie, Lorna Thompson, Jenny Harbour, Healthcare Improvement Scotland, United Kingdom.*
- 15.30–16.00 ● **Coffee break**
- 16.00–17.30 ● **Patient involvement in rare disease guidelines: case studies and discussion**
- > Contribution of the rare disease patient community in the identification, appraisal and dissemination of best practice guidelines for rare diseases and in the promotion of their use in the context of ERNs. *Avril Kennan, DEBRA Ireland; Silvia van Breukelen, VSOP, Netherlands.*
  - > Discussion: principles for the engagement of people living with a rare disease in translational activities bringing healthcare evidence into practice, including clinical guideline development. *Discussion led by Karen Ritchie, Lorna Thompson, Jenny Harbour, Healthcare Improvement Scotland, United Kingdom.*



### EMM 2016 Edinburgh

Edinburgh International Conference Centre  
The Exchange Edinburgh, 150 Morrison St,  
Edinburgh EH3 8EE, United Kingdom

#### Paris Office

EURORDIS

Plateforme Maladies Rares  
96, rue Didot  
75014 Paris, France  
Tel: +33 (0) 1 56 53 52 10  
eurordis@eurordis.org

#### Brussels Office

EURORDIS

Avenue Louise 149/24  
1050 Brussels, Belgium  
Tel: + 32 (0) 2 535 75 26

#### Barcelona Office

EURORDIS

Recinte Modernista Sant Pau  
Pabellón de Santa Apolonia  
Calle Sant Antoni M<sup>a</sup> Claret 167  
08041 Barcelona, Spain

[eurordis.org](http://eurordis.org)  
#EMM2016

With the support of



Co-funded by  
the Health Programme  
of the European Union