

## Eurordis Membership Meeting 2009 Athens

Eugenides Foundation  
387 Syngrou Ave, 17564 P. Faliro

### Draft Agenda

#### Thursday 7 May – Pre-Meetings (*closed business meetings*)

10.30-18.00	8 <sup>th</sup> Workshop of the Council of National Alliances
10.30-18.00	1 <sup>st</sup> Workshop of the Council of European Rare Disease Federations
14.00-18.00	Help Line Network meeting

With the support of:



#### Friday 8 May

09.30-13.00	Eurordis General Assembly (Eurordis members only) Business agenda & election of directors
13.00-14.00	<i>Lunch at the Eugenides Foundation</i>
	<b>Awareness Conference “No policy without patients”</b> Chairpersons: Professor Antonios Trakatelis, MEP, Greece Marianna Lambrou, President of the Greek Alliance for Rare Diseases <i>Conference language : English, Greek translation provided Friday 14.00-17.45</i>
14.00-14.15	Welcome speech, <i>Marianna Lambrou, President of the Greek Alliance for Rare Diseases and Prof Antonios Trakatelis, MEP, Greece</i>
14.15-14.30	Opening speech by Ms Papoulia
14.30-15.00	What is patient empowerment and how to foster it? <i>Terkel Andersen, President of Eurordis</i>
15.00-15.30	Commission Communication & Council Recommendation: What’s in the new European legislation for patients? <i>Toni Montserrat, DG SANCO, European Commission</i>
15.30-16.00	National Plans for Rare Diseases: A pathway to improve RD patient’s quality of life? <i>Yann Le Cam, CEO Eurordis</i>
16.00-16.30	<i>Coffee break</i>
16.30-17.45	Roundtable debate: Sharing experience on National Plans <i>Chair: Rosa Sanchez de Vega, Spain</i> <i>Dorica Dan, Romania / Marianna Lambrou, Greece / Christel Nourissier, France / Mirjam Mann, Germany</i>
20.00	<i>Welcome dinner at the Aegli Restaurant</i>

Saturday 9 May – Parallel Workshops - morning

	<b>Workshop 1 – Online Communities Part I</b>	<b>Workshop 2 Registries Part I</b>	<b>Workshop 3 The Polka project to better empower patients in policy</b>
	<p><u>Moderator:</u> Denis Costello</p> <p><i>Online Social Networks of patients and carers are already having an effect on overcoming geographic isolation and helping to access quality information. Examples include blogging on quality of life issues, as well as patients &amp; carers supporting each other through shared experiences. This workshop will showcase success stories from Europe and the US and show how this phenomenon also has the potential to influence research.</i></p>	<p><u>Moderator:</u> Christel Nourissier</p> <p><i>Registries are a recurrent and vast topic. With this workshop, we aim at discussing collaboration, ownership and involvement of patient organisations, building on previous work.</i></p>	<p><u>Moderators:</u> Lene Jensen, François Houyez</p> <p><i>Patients' representatives who need to negotiate with policy makers will be trained with a new method developed by the network of European Science Museums: the Play Decide Sessions</i></p>
09.30-10.00	<p>Wisdom of the crowd &amp; social innovation in the RD Community <i>David Golub, Vice-President Mark Krueger &amp; Associates, Inc, USA</i></p>	<p>Different tools to answer different questions on research and public health issues for rare diseases, <i>Dr Ségolène Aymé, Orphanet</i></p>	<p>The Polka Project: A new approach to empower patient representatives, <i>Lene Jensen Rare Disorders Denmark</i></p>
10.00-10.30	<p>The Eurordis experience so far with online communities. The story behind the EURORDIS mailing lists. <i>Denis Costello, Eurordis</i></p>	<p>Round table: European databases – Different steps to build a European research network database, - Euro-Wilson, <i>Stuart Tanner, University of Sheffield, Uk</i> - European Huntington's Disease Network, <i>Jamie Levey</i></p>	<p>Presentation of a Play Decide session, <i>Aliki Giannakopoulou, Ecsite network of Science Museums</i></p>
10.30-11.00	<p>Learning from the Duchenne Community <i>Elizabeth Vroom, founder of duchenne-community.org Netherlands</i></p>	<p>Initiatives at National level: - <i>Stense Farholt, Centre for Rare Diseases, Hegby University Hospital Aarhus, Denmark</i></p>	<p>How patients' organisations can participate in 27 countries, <i>François Houyez, Polka Project Manager, Eurordis</i></p>
11.00-11.30	<p><i>Coffee break</i></p>		
11.30-12.30	<p>The Patients Like Me journey. <i>Paul Wicks, Head of R&amp;D patientslikeme.com</i></p>	<p>Discussion: Sharing data, benefits and challenges</p>	<p>Play Decide sessions Break out sessions, 6 to 7 groups</p>
12.00-12.30	<p>Experience gained by NORD with online communities at inspire.com. <i>Mary Dunkle, Vice-President Communications NORD</i></p>		
12.30-14.00	<p><i>Lunch at the Eugenides Foundation</i></p>		

## Saturday 9 May – Parallel Workshops - afternoon

14.00	<b>Workshop 1 – Part II Online Communities</b>	<b>Workshop 2 – Part II Registries</b>  Moderator: Tsveta Schyns, ENRAH	<b>Workshop 4 - The European Network of Rare Disease Help Lines.</b> <i>Find out how your patient organisation can gain by joining the network.</i>  Moderator: Vibeke Lubanski, Shane Lynam
14.00-14.30	Online communities as a vehicle for improving interactions between patients and medical professionals – a case study. <i>Dr. Manuel Armayones, Postdoctoral researcher, Open University of Barcelona.</i>	Outcomes of the EPPOSI workshop on registries, March 2009 <i>Stuart Tanner, University of Sheffield, UK</i>	How to go about setting up a help line? 3 testimonies <i>-Dorica Dan</i> <i>-Dr. Jan Traeger-Synodinos (tbc)</i>
14.30-15.00	What Eurordis is preparing. Presenting an online strategy incorporating patients and research <i>Denis Costello, Eurordis</i>	Input of families into the data base of the International Rett Syndrome Association, <i>Gérard Nguyen, Association Française du Syndrome de Rett</i>	Why my patient group should be interested in joining the network. What are the tools that have already been developed by the network? <i>Pam Davies (tbc), Marie-Claude Bergmann, MRIS</i>
15.00-15.30	How the patient conversation can impact on research directions. <i>Wikiprofessional.org</i> <i>Nickolas Barris, Netherlands</i>	Ownership of data and ethical issues <i>Dr Simon Woods, Treat NMD, UK</i>	What are the criteria for joining? What is the process? <i>François Houyez, Eurordis</i>
15.30-16.00	<i>Coffee break</i>		
16.00-16.30	Hand's on display of online community software for Rare Disease patients <i>Margaret Hanley, WTG Technology, UK</i>	Discussion: Involvement of patients in establishing and operating databases	Feedback from network business meeting and ongoing network initiatives
16.30-17.00	Conclusion of workshops in plenary session		
17.00-18.00	<i>Cocktail reception at the Eugenides Foundation</i>		

## Sunday 10 May

10.00-13.00 Visit of the Acropolis and the new Acropolis museum

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