

Eurordis Membership Meeting 2009 Athens

Eugenides Foundation
387 Syngrou Ave, 17564 P. Faliro

Draft Agenda

Thursday 7 May –Satellite Meetings (*closed meetings*)

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| 10.00-18.00 | 8 th Workshop of the Council of National Rare Disease Alliances |
| 10.00-17.00 | 1 st Workshop of the Council of European Rare Disease Federations |
| 14.00-18.00 | Help Line Network meeting |

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Friday 8 May

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| 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> |
| 14.00 | Awareness Conference “No Rare Disease policy without patients”
Chairpersons: Prof. Antonios Trakatelis, MEP, Greece
Marianna Lambrou, President of the Greek Alliance for Rare Diseases |
| 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 May Papoulia, Wife of the President of the Hellenic Republic |
| 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>Nick Fahy, DG SANCO, European Commission</i> |
| 15.30-16.00 | National Plans for Rare Diseases: A pathway to improve RD patient’s care and quality of life? <i>Yann Le Cam, CEO Eurordis</i> |
| 16.00-16.30 | <i>Coffee break</i> |
| 16.30-17.45 | Roundtable debate: National Plans – From words to action?
<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

	Workshop 1 – Online Communities Part I <i>Moderator: Denis Costello</i> <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 & 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>	Workshop 2 Patient Databases and Registries Part I <i>Moderator: Christel Nourissier</i> <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>	Workshop 3 The Polka project to better empower patients in policy <i>Moderators: Lene Jensen, François Houyez</i> <i>Patient representatives who need to negotiate with policy makers will be trained in a new method developed by the network of European Science Museums: the Play Decide Sessions</i>
09.30-10.00	Wisdom of the crowd & social innovation in the Rare Disease Community <i>David Golub, Vice-President Mark Krueger & Associates, Inc, USA</i>	Different tools to answer different questions on research and public health issues for rare diseases, <i>Dr Florence Suzan, Institut National de Veille Sanitaire, France</i>	The Polka Project: A new approach to empower patient representatives, <i>Lene Jensen Rare Disorders Denmark</i>
10.00-11.00	Learning from the Duchenne Community A European story: <i>Elizabeth Vroom, founder of duchenne-community.org Netherlands</i> A US story: <i>Pat Furlong, founder of duchenneconnect.org</i>	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, France</i>	Presentation of a Play Decide session, <i>Aliki Giannakopoulou, Ecsite network of Science Museums</i> How patient organisations can participate in 27 countries, <i>François Houyez, Polka Project Manager, Eurordis</i>
11.00-11.30	<i>Coffee break</i>		
11.30-12.00	The Patients Like Me journey, <i>Paul Wicks, Head of R&D patientslikeme.com</i>	Initiatives at Nordic level: <i>Stense Farholt, Centre for Rare Diseases, Aarhus University Hospital Skejby, Denmark</i>	Play Decide sessions Break out sessions, 6 to 7 groups
12.00-12.30	Experience gained by NORD with online communities at inspire.com., <i>Mary Dunkle, Vice-President Communications NORD</i>	Discussion: Sharing data, benefits and challenges	
12.30-14.00	<i>Lunch at the Eugenides Foundation</i>		

Saturday 9 May – Parallel Workshops - afternoon

14.00	Workshop 1 – Part II Online Communities Moderator: Mary Dunkle, <i>NORD, USA</i>	Workshop 2 – Part II Patient Databases and Registries Moderator: Tsveta Schyns, ENRAH	Workshop 4 - The European Network of Rare Disease Help Lines. The workshop will be a chance to present how patient organisations can gain by joining the network and to discuss the new governance plan, which tries to ensure that the expertise of the more advance members is shared with the more recent services. Moderator: Shane Lynam, Eurordis
14.00-14.30	Online communities as a vehicle for improving interactions between patients and medical professionals – a case study, <i>Dr. Manuel Armayones, Internet Interdisciplinary Institute, Open University of Catalonia.</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? 2 testimonies - <i>Dorica Dan, Romanian, National Alliance for Rare Diseases</i> - <i>Dr. Jan Traeger-Synodinos, University of Athens / Greek Alliance for Rare Diseases</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 database of the International Rett Syndrome Association, <i>Gérard Nguyen, Association Française du Syndrome de Rett, France</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>Marie-Claude Bergmann, Maladie Rare Info Service</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 Houÿez, Eurordis</i>
15.30-16.00	<i>Coffee break</i>		
16.00-16.30	Hands-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 Moderator: <i>Torben Gronnebaek, Rare Disorders Denmark</i>		
17.00-18.00	<i>Cocktail reception at the Eugenides Foundation</i>		
18.30-19.10	Show at the Eugenides Planetarium		

Sunday 10 May

10.00-13.00 Visit of the Acropolis

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