



Membership Meeting 2011

AMSTERDAM - 13 & 14 MAY



The patient's voice in National Plans for Rare Diseases

EURORDIS Membership Meeting 2011 AMSTERDAM

Thursday 12th of May

Satellite Meetings

10 h 00 - 11 h 30

ROOM : Oxford PlayDecide session (in Dutch)

11 h 30 - 17 h 00

ROOM : University of Amsterdam 1 & 2 Meeting of Dutch Patient Organisations
Zeldzaam, maar evenveel recht op zorg

17 h 00 - 17 h 45

ROOM : Heidelberg Dutch Press Conference

wgm



10 h 30 - 17 h 00

ROOM : Sorbonne Council of National Alliances

10 h 15 - 17 h 00

ROOM : Stellenbosch Online Patient Communities Workshop

13 h 00 - 17 h 00

ROOM : Harvard PlayDecide session

ROOM : Heidelberg PlayDecide session

Friday 13th of May

General Assembly and Conference - ROOM : University of Amsterdam 2, 3, 4

09 h 00 - 13 h 00

EURORDIS General Assembly (*EURORDIS Members only*)
- Business agenda & election of directors
- Debate: Enhancing our synergies on National Plans

13 h 00 - 14 h 00 Lunch

Conference : The patient's voice in National Plans

The concept of National Plans is much debated at a European level but not among patient organisations. What do National Plans mean for patient organisations and patients? How can patient organisations benefit from National Plans? How can they contribute to National Plans?

All of these important questions will be discussed and debated during two days in the conference, debates and capacity building workshops. All workshops are designed to provide useful information and/or sources of information to patient organisation representatives to help them in their own advocacy plans. These workshops will allow the exchange of ideas, best practice and experience across countries, with or without national strategies.

All workshops are elaborated in partnership with existing projects and/or organisations.

14 h 00 - 14 h 10 Welcome speech, *Terkel Andersen, EURORDIS*

14 h 10 - 14 h 20 Opening speech, *Dr. Frits Lekkerkerker, Dutch Steering Committee on Orphan Drugs, Netherlands*

14 h 20 - 14 h 50 EURORDIS' recommendations for National Plans, *Yann le Cam, EURORDIS*

14 h 50 - 15 h 10 EuroPlan: main outcomes and future directions, *Domenica Taruscio, ISS, Italy*

15 h 10 - 15 h 30 Outcomes of 15 National Conferences, *Avril Daly, Fighting Blindness, Ireland*

15 h 30 - 16 h 00 The patient's experience in the development and implementation of National Plans
The French Experience, *Christel Nourissier, EURORDIS, France*
The Portuguese Experience, *Paula Costa, Rarissimas, Portugal*

16 h 00 - 16 h 30 Coffee break

16 h 30 - 18 h 00

Round Table debate:
Speakers and *Mr. Antoni Montserrat, European Commission* will discuss and answer questions on:
- How can we push Ministries to implement National Plans?
- How can we monitor their implementation?
- What are the obstacles and how can we overcome them?
- How to adapt to national realities and the size of a country?

20 h 00 Welcome Dinner at the Rosarium

English to Dutch interpretation available for the conference only.

Saturday 14th of May

Workshops

All workshops are designed to provide useful information to patient advocates and to allow the exchange of ideas, best practices and experiences across countries, with or without national strategies. Patient representatives who have participated in National Conferences are invited to take an active part in the discussion and share the ideas and solutions discussed at the conferences they attended.

Full day workshop, 09 h 00 - 17 h 30
ROOM : University of Amsterdam 4

1) Newborn screening

in partnership with the Newborn Screening project of Istituto Superiore di Sanità (ISS)
Newborn screening is an important topic in the Council Recommendation on Rare Diseases and in National Plans. In this workshop, participants will be asked to express their views on the present practices in neonatal screening across Europe and to comment on what should be the future policies in this area and how newborn screening can be part of a national plan for rare diseases.

Moderators:
Fabrizia Bignami, EURORDIS & Luciano Vittozzi, ISS, Italy

- PlayDecide session on Newborn Screening 2 hours deliberative debate in small groups
 - The EU tender on Newborn Screening for rare disorders in Europe, *Antoni Montserrat*
 - Organisation and practice of neonatal screening in Europe, *Eugénie Dekkers, Centre for Population Screening / RIVM, Netherlands*
 - Survey on European newborn screening programs: interaction between newborn screening laboratories, confirmatory diagnostic services and treatment units, *Peter Burgard, University of Heidelberg, Germany*
 - Patients involvement in newborn screening and practices, *Hanka Meutgeert, VKS, Netherlands*
Stephanie Weinreich, VU University Medical Centre, Netherlands
 - Governance of the European newborn screening systems. What framework for future newborn screening policies in the EU?, *Martina Cornel, Netherlands*
- Discussion with the audience about issues raised by the above presentations and on:
- Possible European policy in an international framework
 - Recommendations for National Plans and Strategies for Rare Diseases.

Same workshop to be held in the morning 09 h 00 - 12 h 30 and again in the afternoon 14 h 00 - 17 h 30
ROOM : University of Amsterdam 2

2) Centres of expertise & Networks of experts in collaboration with EU CERD

Centres of Expertise and European Reference Networks are a pillar of the Council Recommendation and national strategies on rare diseases. This session will revisit the basic concepts and will discuss the quality criteria reviewed by the EU CERD for Centres of Expertise (CoE) and define the best possible approach according to the size of the country population and the organisation of health care pathways by therapeutic areas. The discussion on CoE are also timely given the recent adoption of the Directive on Cross Border Health Care which will provide the legal instruments to implement such European reference networks for RD in the coming years. This workshop will discuss how to use and implement the concept in the development of National Plans for Rare Diseases.

Moderators:
Lene Jensen, Rare Disorders Denmark
and Aymeric Audiau, Alliance Maladies Rares, France

- Presentation of the concept, definitions and terminology *Samantha Parker, E-IMD, OrphanEurope*
 - EURORDIS Policy recommendations based on EURORDIS Declaration, Fact Sheets & Position Papers, *Birthe Holm, Rare Disorders Denmark*
 - Feedback from the 15 National Conferences on Centres of Expertise, *Simona Bellagambi, UNIAMO, Italy*
- Discussion with the audience around key questions.

Panel:
Speakers and Liesbeth Siderius, EAP
and Mirando Mrcic, Croatian Society for Rare Diseases

- 1) Difference of strategy according to country size,
- 2) Organisation of health care pathways by therapeutic areas,
- 3) How does this type of care impact patients in their everyday life?
- 4) Examples of good collaboration of Centres of Expertise and Patient Organisations,
- 5) Cross border access.

Workshops Programme Overview

	MORNING SESSIONS			AFTERNOON SESSIONS			
	9h	Coffee break 10 h 30 - 11 h	12 h 30	14h	Coffee break 15 h 30 - 16 h	17 h 30	19h
1	Workshop 1 - Newborn Screening Part 1 ROOM : University of Amsterdam 4		Lunch	Workshop 1 - Newborn Screening Part 2 ROOM : University of Amsterdam 4		Farewell cocktails Hotel Casa 400	
2	Workshop 2 - Centres of expertise ROOM : University of Amsterdam 2			Workshop 2 - Repeat of morning session ROOM : University of Amsterdam 2			
3	Workshop 3 - Registries ROOM : University of Amsterdam 1			Workshop 3 - Repeat of morning session ROOM : University of Amsterdam 1			
4	Workshop 4 - Research ROOM : University of Amsterdam 3						
5	Workshop 5 - Social aspects ROOM : Sorbonne						
6				Workshop 6 - Training of MDs ROOM : University of Amsterdam 3			
7				Workshop 7 - Prevention ROOM : Sorbonne			

Same workshop to be held in the morning 09 h 00 - 12 h 30 and again in the afternoon 14 h 00 - 17 h 30
ROOM : University of Amsterdam 1

3) Registries

in collaboration with the Epi-Rare project

Registries are an essential part of the Council Recommendation on Rare Diseases and of existing and future National Plans. The former EU Rare Disease Task Force and EPPOSI have already done a great deal of work on this topic, and now, with the EPI Rare project, patient organisations will be involved over 30 months in the process of defining best practices and policies for registries. This workshop aims at sharing experience and comparing different sorts of registries (disease specific, group of diseases, national etc) evaluating the outcomes of the EuroPlan conferences and elaborating recommendation for National Plans.

Moderators:
Gérard Nguyen, Rett Syndrome Europe
and Lut de Baere, Rare Disease Organisation Belgium

- Presentation of the concept, definitions and terminology, *Ulrike Pypops, CF Belgium*
 - Outcome of the RD Task Force and EPPOSI Workshop on registries, *Tsveta Schyns, ENRAH*
 - Presentation of the Epi-Rare project, *Yann le Cam, EURORDIS*
 - Feedback from the 15 National Conferences on Registries, *Gabor Pogany, HUFERDIS, Hungary*
- Discussion on possible policy recommendations

Half day workshop, 09 h 00 - 12 h 30
ROOM : University of Amsterdam 3

4) Research

EURORDIS has produced a Fact sheet on Research as well as a reference paper entitled "Why RD Research" that will be presented, along with surveys on the role of patient organisations in research and trends and determinants of RD research. Based on this information, a second Reflection paper on Research will be discussed with the participants, which will contribute to the development of recommendations on research for National Plans.

Moderator:
Terkel Andersen, EURORDIS

- EURORDIS Research Policy recommendation, *Béatrice de Montleau, AFM / EURORDIS*
 - Results of Survey on the role of Patient Groups in Research and their priorities for the future, *Florence Paterson, Ecole des Mines, France*
 - Presentation of the RD Platform fact finding study on the trends and determinants of rare disease research, *Virginie Hivert, Orphanet, France*
 - Feedback from the 15 National Conferences on Research policy, *Avril Daly, GRDO, Ireland*
- Discussion of the EURORDIS 2nd Reflection Paper on Research based on key questions

Half day workshop, 09 h 00 - 12 h 30

ROOM : Sorbonne

5) Brainstorming & Policy Development session: Social aspects

Social aspects have been much discussed at EuroPlan conferences and form an important part of National Strategies. The future Joint Action on Rare Diseases (JARD) will integrate specialised social services and integration of rare diseases into existing and future social policies and services at EU level. This brainstorming session will discuss how best to integrate social aspects into national strategies.

Moderators:

John Dart, Debra International and EURORDIS

- Feedback from the 15 National Conferences on social aspects, *Britta Berglund, Ehlers Danlos, Sweden*
- Presentation of Social Challenges of RD patients in the Joint Action on Rare Diseases, *Dorica Dan, Romanian National Alliance*
- The Norwegian Model, *Lisen Mohr, Frambu, Norway*
- ▶ Discussion:
 - What are the social aspects discussed in the context of National Plans?
 - What are the actions planned to address social challenges of rare disease patients.
 - What is the added value of a European action?

Half day workshop, 14 h 00 - 17 h 30

ROOM : University of Amsterdam 3

6) Brainstorming & Policy Development session: Training, information and education of MDs

The training of medical doctors and other health care professionals is a new hot topic that emerged from the 15 EuroPlan conferences. Some experience has been gained by patient organisations directly involved in the training of medical students as part of university degrees or of continuous education. This brainstorming session will try to find a way of placing the training of medical professionals into national strategies.

Moderator:

Mirjam Mann, ACHSE, Germany

- Feedback from the 15 National Conferences *Christel Nourissier, EURORDIS*
- Training package on RD for medical students, *Bernd Quadder, Deutsche Sarkoidose Vereinigung, Germany*
- Case study: Italian Training for MDs, *Renza Galluppi, UNIAMO, Italy*
- Sharing expertise: transfer of experience from patient organizations to doctors and between patient organisations *Rainald von Gizycki, Retina Europe, Germany*
- ▶ Discussion: How can the training of MDs and medical students be integrated into National Plans?

Half day workshop, 14 h 00 - 17 h 30

ROOM : Sorbonne

7) Brainstorming & Policy Development session: Prevention

in collaboration with the International Federation for Spina Bifida and Hydrocephalus

Prevention is another rather new topic on the Rare Disease agenda that has not yet found its place in national strategies. However there is more than one Rare Disease for which prevention strategies are possible! We hope this first meeting on prevention will prompt discussions on the scope and specific measure on prevention to be integrated in National Plans.

Moderator:

Dorica Dan, Romanian National Alliance

- Presentation of the International Federation for Spina Bifida and Hydrocephalus' primary prevention study, *Pierre Mertens, International Federation for Spina Bifida and Hydrocephalus (IF)*
- Folic acid prevents neural tubes defect., *Mrs Eli Skattebu, Norwegian Association for Spina Bifida and Hydrocephalus (RHF), Kim Hannisdal, BayerAB, Sweden*
- Presentation of the Eurocat study on prevention of Congenital Anomalies, *Dr. Domenica Taruscio, ISS Italy*
- Prevention in the Spanish National Plan for Rare Diseases, *Evanina de Morcillo Makow, Debra Spain*
- ▶ Discussion:
 - How can Prevention be integrated into National Plans?
 - How to identify other diseases where prevention is possible.
 - How to gather more information?

SOCIAL PROGRAMME

Welcome Dinner

Friday, 13 May, from 20 h 00

A Welcome Dinner will be held for all participants of the EURORDIS Membership Meeting at the following venue:

Rosarium : Amstelpark 1, Europaboulevard 1083 HZ Amsterdam Tel: +31(0)20 64 44 085

COACHES

Coaches will be provided to take all participants to and from the Rosarium.

19 h 00 - 19 h 15 In front of the Victoria Hotel (Damrak 1-5) 5 minutes walk from the Centraal Station in downtown Amsterdam.

19 h 30 - 19 h 45 Hotel Casa 400

20 h 00 Arrival at Rosarium

22 h 30 - 22 h 45 Return to Hotel Casa 400 and Victoria Hotel

For those of you who wish to make your own way to the Rosarium, a direct metro line from the Centraal Station or Amstel Station runs to the RAI stop.

The Rosarium is a 5 minute walk from the metro stop.

It is also possible to take bus 62 from the Amstel train station.

This bus drives past the RAI station and stops just before Weerdestein Rosarium.

The Rosarium is located along the ring road of Amsterdam, near the southern axis and the RAI Conference Centre.

There are always parking spaces in the evenings and at weekends for those travelling by car. Parking is free. The Rosarium has adapted facilities to welcome wheelchair users.

Amsterdam City Canal Cruise

Sunday, 15 May, 10 h 00 - 11 h 30

A canal boat cruise with the Blue Boat Company has been organised for all participants of the EURORDIS Membership Meeting.

The boat has an extensive audio system which will inform you about all the interesting, beautiful and funny landmarks. English and Dutch are standard, other languages are on request. The vessel is wheelchair friendly, equipped with a wheelchair lift which allows you to board without leaving your wheelchair. **The on-board toilets are not adapted for wheelchair users.**

The boat will leave at 10 h 00 from Stadhouderskade 30, opposite the Hard Rock Café and will return to the same place at 11 h 15.

Directions:

From the Hotel Casa 400
Walk to the Amstel Station from the Hotel Casa 400 (5 minute walk). Take tram line 12. Get off at the Van Baerlestraat stop. The dock is a 5 minute walk from the tram stop.

From the Centraal Station
Take tram line 1, 2 or 5 from the Centraal Station. Get off at the Leidseplein stop. The dock is a 3 minute walk from the tram stop.

EURORDIS

Membership Meeting 2011 Amsterdam

In collaboration with :



With the support of :



And :



EURORDIS

Plateforme Maladies Rares
96 rue Didot, 75014 Paris, France
Tel : 33 1 56 53 52 10
Fax : 33 1 56 53 52 15
eurordis@eurordis.org

www.eurordis.org