



Rare Disorders Denmark

Draft Programme

**Eurordis Membership Meeting 2008 Copenhagen
16 - 17 May 2008**

**Quality Hotel Hoje Taastrup
Carl Gustavs Gade 1
DK-2630 Taastrup**

Hosted by Rare Disorders Denmark

“Acting together for patient-centred care for rare diseases”

*A European workshop empowering patients, families and their organisations.
Towards multidisciplinary medical and social care
in Centres of Expertise and European Reference Networks for Rare Diseases*

Looking back on our progress over the last two years to promote policies on Centres of Expertise on Rare Diseases

EURORDIS Membership Meeting 2006 Berlin was dedicated to “Centres of Reference for Rare Diseases: How can we make it happen?”. This was a starting point for EURORDIS members to develop a common approach to the provision of healthcare services for rare disease patients. Based on participative debates we adopted a “Reflection Paper on Centres of Reference”.

Since then EURORDIS, national alliances and their members have worked together extensively on promoting the need of specialised healthcare services for rare disease patients and on facilitating a dialogue between all interested parties to develop common concepts, common language and common strategies. The core of these efforts was embodied in the Rare Disease Patient Solidarity project –RAPSODY- which commenced mid 2006 and will conclude mid 2008, supported by the European Commission and 10 partners.

11 national workshops organised in spring 2007, all based on the same agenda and background information, gathered over 270 patient representatives, healthcare professionals and policy makers to develop recommendations. The two-day European Workshop in July 2007 in Prague with 90 participants synthesised the outcomes of these 11 national workshops and brought together leading experts from the first European Reference Networks and representatives of the EU High Level Group on Health Services and Medical Care, DG SanCo and the Rare Disease Task Force.

In parallel, thanks to the participation of 137 patient organisations and 6 000 respondents, the EurordisCare 3 survey has led to the collection of solid data on the experience and expectations of rare disease patients and families across Europe based on 16 rare diseases and 23 countries.

Most recently, the European Conference on Rare Diseases 2007 Lisbon in November was the occasion to report and debate with a larger audience the positions of the policy makers in the EU High Level Group on Health Services and Medical Care, the outcomes of the RAPSODY national & European workshops and the preliminary results of EurordisCare 3 survey.

The state of play in 2008: a pivotal year to grasp the nettle

The rationale to address this theme with a European Workshop within the Membership Meeting 2008 is to conclude the cycle of internal efforts to conceptualise our needs and expectations and the external efforts to transform them into political advancements. The next cycle coming up is all about grass root work, sharing of experience and best practices, development of common tools and evaluation of concrete progress.

Today, in 2008, national Centres of Expertise and European Reference Networks for Rare Diseases have become a priority on the EU health political agenda. The future Directive on Health Services provides a base to establish European Reference Networks and specifically address the need to do so for rare diseases; it will also provide a new legal framework for the mobility of patients within the EU. The future Commission Communication on Rare Diseases – to be adopted later this year - clearly proposes to establish European Reference Networks for Rare Diseases in the coming years; it also encourages Member States to identify, select and support Centres of Expertise for Rare Diseases within the framework of National Plans for Rare Diseases.

EURORDIS and its members actively contribute to further promoting this policy at national and European levels. It is an essential tool to improve the quality of diagnosis and care across all rare diseases and all European countries. This has been illustrated by specific contributions from patient groups and the EURORDIS Position Paper “Centres of Expertise and European Reference Networks for Rare Diseases” in the context of the Public Consultation.

In addition, EURORDIS and its rare disease national alliances are promoting the adoption of Recommendations on rare diseases by the Council in order to strengthen European Commission and Member States policies with more binding commitments. Important elements of these strategies are: to adopt National Plans for Rare Diseases in a coordinated EU approach, to establish Centres of Expertise and European Reference Networks, to promote research, to gather expertise in order to

develop common guidelines, to improve access to orphan drugs and innovative therapies, to support patient groups empowerment.

EURORDIS, national alliances, European federations and all disease specific patient groups concerned have a key role to play to shape and further advocate for national and European policies on Centres of Expertise and European reference Networks for Rare Diseases.

Beyond this, we have a key role to play as equal actors, taking responsibilities at the local, national and European levels to implement these policies through quality collaboration with experts leading the Centres of Expertise and European Reference Networks as well as through our pro-active participation in the decision making process to identify, select and evaluate them.

We also share common concerns on the evaluation of patient outcomes, on a real multi-disciplinary approach, on good information sharing and networking between professionals to provide patient-centred services, on an integrated medical and social approach to provide comprehensive care, on the long term professional and financial sustainability of the infrastructures and essential tools - such as patient registries, biological resources repositories, patient electronic files - and on the good involvement of these networks in translational research to deliver eagerly awaited therapeutic advancements for our patients.

Looking forward to empower patient advocates and support groups

The objectives and expected outcomes of this European Workshop are to:

- Consolidate our common approach and share policy update, concrete experience gained through case studies, concerns and priorities
- Debate and first adoption of two new important tools:
 - o A “Declaration on Centres of Expertise and European Reference Networks for Rare Diseases”.
 - o A “Charter of Best Practice for Collaboration between Centres of Expertise and Patient Groups for Rare Diseases”.

Having a common agenda across European countries and across rare diseases increases dramatically the effectiveness of our advocacy efforts.

A Declaration officially adopted by our movement will provide a common political reference, a flag and sword to each rare disease patient group, each national alliance and each European federation.

A Charter officially adopted by our movement will provide a common framework to regulate the relationship between rare disease patient groups and their related Centres of Expertise and a tool box enabling patient groups to promote good practices and progressively build on them.

To achieve these objectives, the European Workshop will provide a policy update and will present a draft Declaration and Charter to be debated in small workshops. Throughout the meeting the results of the EurordisCare 3 survey and case studies will illustrate the reality of patient and families and the concrete practices between patient organisations and Centres of Expertise.

Draft Agenda

Thursday 15th of May:

Satellite workshops:

10.00-17.00 **6th Workshop of the Council of National Alliances:**

- Rare Disease Day 2008 & 2009
- National Plans for Rare Diseases, Commission Communication and Recommendations to the Council
- National Conferences on Rare Diseases

12.00-16.30 **European Help lines for Rare Diseases: New IT tools**

- Disease specific network meetings proposed to the 16 networks involved in EurordisCare:
 - Discuss the results of EurordisCare for your disease across Europe
 - Identify the key common issues
 - Develop essential common proposals improving access to diagnosis and care
- Disease specific network meetings organised by Danish patient organisations and their European partner organisations

Friday 16th of May

Conference: "Common actions to change day to day care"

09.30-10.00 Welcome messages

Terkel Andersen, President of Eurordis

Torben Gronnebaek, President of Rare Disorders Denmark

10.00-10.20 Update on the Commission Communication on Rare Diseases

Toni Montserrat, DG SANCO

10.20-10.35 Question & Answer

10.35-10.55 Key findings from the final analysis of the Eurordiscare surveys

Yann Le Cam, Chief Executive Officer, Eurordis

10.55-11.10 Question & Answer

11.10-11.40 Coffee break

11.40-12.00 Presentation of a draft **Declaration of common principles**, illustrated by results of the Eurordiscare surveys

Rosa Sanchez de Vega, President of FEDER, Spain

12.00-12.20 Presentation of a draft **Charter** on the relationship between patient organisations and Centres of Expertise, illustrated by results from the EurordisCare surveys

Christel Nourissier, Prader Willi France & Eurordis

12.20-12.45 Debate

12.45- 14.00 Lunch break

14.00-15.30 Parallel Workshops:

Workshop 1: European reference networks for rare diseases	Workshop 2: Innovative partnerships between patient organisations and National centres of expertise
<p><u>Moderator:</u> <i>Soren Lildal, Danish Apert Syndrome Association</i></p> <p>European Centres of Reference Networks for Cystic Fibrosis (ECORN-CF)</p> <ul style="list-style-type: none"> ▪ The patients perspective <i>Karleen de Rijcke Cystic Fibrosis Europe</i> <p>GENESKIN</p> <ul style="list-style-type: none"> ▪ The professional's perspective: <i>Dr. Marina D'Alessio, Istituto Dermopatico dell'Immacolata, Italy</i> ▪ The patients perspective <i>John Dart, DEBRA Europe</i> 	<p><u>Moderator:</u> <i>to be appointed</i></p> <p>Multidisciplinary clinics for Alström Syndrome initiated by a patient organisation,</p> <ul style="list-style-type: none"> ▪ <i>Dr Richard Paisey, Alstrom clinics at Torbay Hospital, United Kingdom</i> ▪ <i>Johanne Foster, Astrom Syndrome UK (tbc)</i> <p>Marfan Sweden centre of expertise, initiated by a patient organisation</p> <p><i>Lise Murphy, Svenska Marfanföreningen, Sweden</i></p>
<p>After each presentation, time for Q&A will be allowed. The objective of these workshops is to share best practices in partnerships between patient organisation and European reference networks or national centres of expertise and to learn from the case studies presented.</p>	

15.30-16.00 *Coffee break*

16.00-17.30 Parallel Workshops:

Workshop 3:	Workshop 4:	Workshop 5:
<p>Debate on the draft Charter on relationships between patient organisations and centres of expertise</p>	<p>Debate on the patient's Declaration on common principles</p>	<p>Get the most out of the Eurordiscare survey <i>Workshop limited to 15 participants</i></p>
<p><u>Moderators:</u> <i>Birthe Holm, Danish Osteogenesis Imperfecta Society</i></p> <p><i>Flaminia Macchia, Eurordis</i></p>	<p><u>Moderators:</u> <i>Lene Jensen, Rare Disorders Denmark</i></p> <p><i>Dorica Dan, Romanian National Alliance for Rare Diseases</i></p>	<p><u>Moderator:</u> <i>François Houyez, Eurordis</i></p> <p>How to use, adapt and present the Eurordiscare 3 results to your members and other stakeholders and use it for advocacy purposes. <i>François Faurisson</i></p>

17.30-19.00 *Screening of short films related to rare diseases (optional)*

19.00 ***Welcome Dinner at the Conference venue***

Saturday 17th of May

09.00-11.00 Parallel Workshops:

Workshop 6: Challenges & expectations for future Networks of Reference for rare diseases	Workshop 7: Psycho-social methods and travelling teams
<p><u>Moderator:</u> Toni Montserrat, DG SANCO</p> <p>Key lessons learned from the first networks <i>Laura Fregonese, Leiden University, Netherlands</i></p> <p>European Network of Reference for Rare Paediatric Neurological Diseases launched by a patient organisation <i>Tsveta Schyns, ENRAH, Austria</i></p> <p>Our vision for a European Dysmelia Network <i>Alan Summerside, Thalidomide Trust, UK, (tbc)</i></p>	<p><u>Moderator:</u> Flavio Minelli, Unione Italiana Ittiosi & Eurordis</p> <ul style="list-style-type: none">- Social Guidelines for Rare Diseases in Denmark, <i>Torben Grønnebak RDD</i>- The Norwegian training and resource centre TRS, <i>Per Frydenborg CEO (tbc)</i>- The Danish Spielmeier-Vogt team (Batten disease), <i>Anne Hamann Coordinator (tbc)</i> <i>Merete Staureby, Danish Batten Disease association</i>

11.00-11.30 *Coffee break*

11.30-12.30 Plenary discussion on the Declaration and Charter

12.30-14.00 *Lunch*

14.00-17.00 Eurordis General Assembly (members only)
Business Agenda & Election of Directors

17.00-18.00 *Farewell cocktail at the conference venue*

Sunday 18th of May: Optional Copenhagen Boat Cruise in the morning

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