



Rare! Together

Creation, Operation and Management of
European Patient Federations

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Rare!Together

- **Creation, development, consolidation of federations**
 - Various European countries, different cultures, array of languages, different stages, no formal legality at an EC level
 - A ... movement of patients' organizations, ... with shared knowledge, skills and expertise worldwide (sharing best practices and practical strategies), will ensure effective impact at international, regional and national levels.

-IAPO

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- **WHY?**

- Healthcare issues cross national and regional borders:
 - **Public health issues are global**, i.e., infectious diseases...
 - The **health industry is increasingly multinational**, including pharmaceutical and medical device manufacturers, and managed care.
 - **Regulations and health care policies are debated internationally**, e.g., orphan drugs policy, clinical trial regulations, quality improvement approaches and clinical practice guidelines.
 - **Progress** in science, medicine and technology is international, i.e., ethical issues, new treatment choices, and funding questions, all of which affect national policies.
 - Other stakeholders are organized and influential internationally, from governments through the medical professions.
 - We need to keep patient concerns (funding, access, awareness, solidarity) on the map: R&D, Policy & Regulations, Access, Orphan designation, Genetic testing

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- **Mentoring topics**

- Structures and statutes (by-laws, etc)
- How to govern (General Assembly, BOD/EC, etc)
- Managing finances and administration
- Membership structure
- raretogether.eurordis.org

Resource development & Fundraising
- sustainability

Language concerns, cultural issues

Information sharing & Networking

Websites, mailing lists, blogs, newsletters

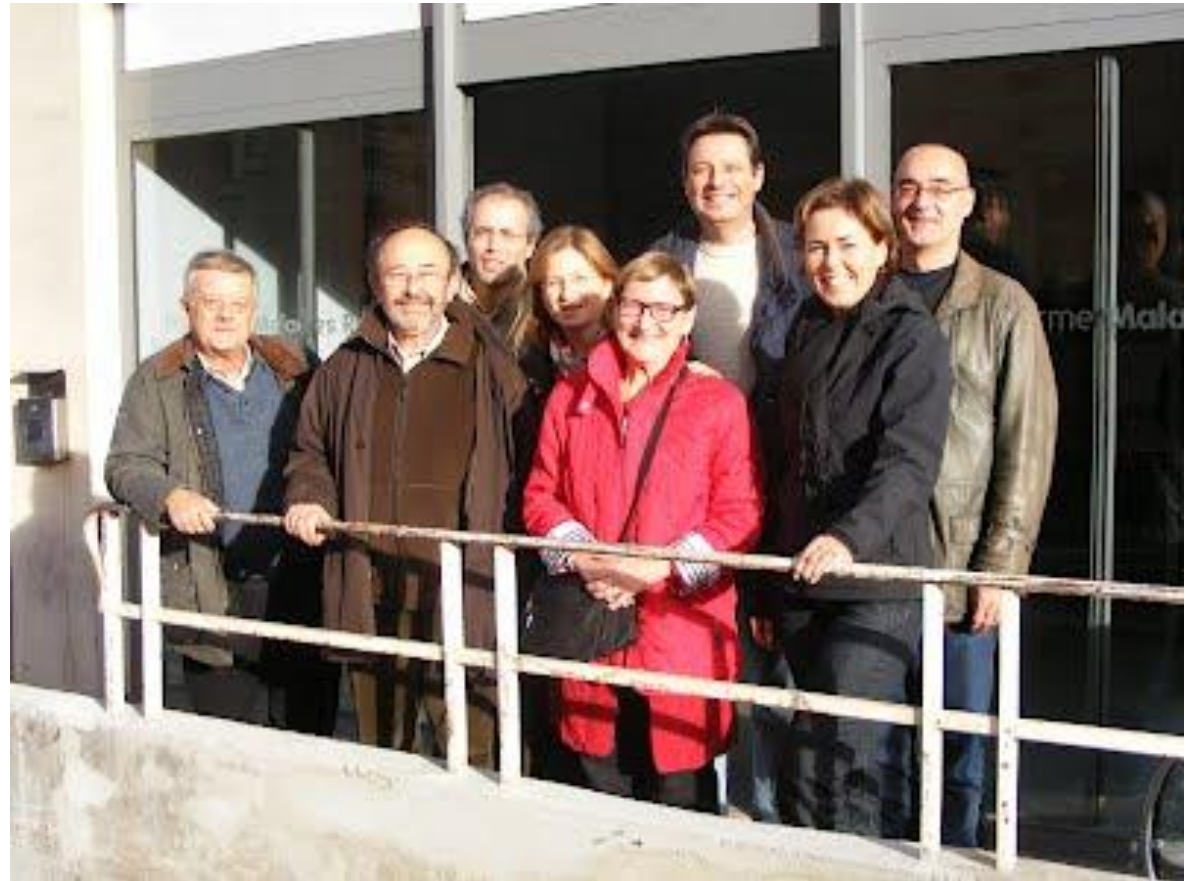
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- Advocacy at European level
 - Research, public health
- Collaboration with European Institutions
 - EMA, EC, EuroParl, EU Health Policy Forum
- Collaboration with other thinkers, other allied patient groups
 - Don't start from scratch, copy and edit whenever needed!
- **Responding to EC**
 - **Proposals, etc – Euro-HSP**
 - **NFPs can provide information in all countries**
 - Health programme 2008-2013 ***NEXT CALL FOR 2013 in July 2012**
 - Managed by EAHC; 365 million euros**
 - Fields: Health security, information, promotion**
 - Financing mechanisms: for projects**
 - Operating grants for NGOs***
 - Grants for conferences***
 - Tenders (do projects for, designed by, EC)**
 - Joint actions (together with states)**

Accomplishments

- **Euro-HSP** with 6 countries will have 2nd GA in Paris 26/27 May 2012.

- http://maps.google.es/maps/ms?client=firefox-a&hl=en&ie=UTF8&lr=lang_ca|lang_es|lang_en&oe=UTF8&msa=0&msid=104875227149697202159.00047af0843f4c3bbe04a



Accomplishments

- **ECHDO** will have its 2nd GA in Istanbul 26/27 May 2012.



Accomplishments

- **E-TSC** has a transitional BOD and plans on having its first GA in Naples in Sept 2012 with up to 16 members.



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- **Creation**
 - Relatively easy
 - 2 years, dedicated work and energy
- **Operation**
 - Meetings, action plan, growth
- **Management**
 - Dedication and commitment
 - Finances
 - Adaptation

Although a more direct say in shaping the organization and delivery of healthcare services by patients is a basic tenet of 21st century health reform, there is no sustainable modeling coming from the EC, so each European body makes up their own rules according to their needs. EC doesn't care where Patient Federations are set up or what they do or who they do it with.

Future?

- Continue to be *ad hoc* afterthoughts?
- There is an “increase in HCPOs across Europe (21,000 in Italy in 2003, 50% increase since 1997), increased engagement with policy makers and political institutions, and the creation of alliance organizations bringing together HCPOs across the sector.
- BUT, ‘variations between countries were observed, relating to different political, cultural and health system contexts’
- Representativeness, legitimacy, financial independence
- lack of capacity and resources, fragmentation and the power of more established interests mean we need to unite, but under a plan, not *ad hoc*.

Future?

- The European Alliance for the Statute of the European Association (civil societies) is a liaison to **The European Economic and Social Committee**
- **Why a statute for a European association?**
 - Building European active citizenship
 - Political recognition
 - Administrative simplification
 - Associations and NGO transparent functioning (public subsidies, coherence and sustainability)
 - Another way of being an economical actor
- European Civic Forum, anajmowicz@civic-forum.eu, + 33 1 43 14 39 53

Future

- **Sustainability of growing new Federations via Rare Together**
 - Live mentoring may not be possible
 - Website
 - Tandem mentoring (one group can help a new one)
 - Clear rules from EC

Back-up slides

PRO-federation

- Contact between people from different countries and various cultural backgrounds sharing the same disability
 - **learning from each other - for day to day living and other issues**
 - **giving advice and support**
 - **making friends**
- Collection and publication of information about the **disease** (both technical and practical) on an international level
- Raising awareness (politically and socially) and knowledge on an international level
- Collection of data (addresses, information on different structures or procedures of national organizations, etc.)
- Common website + networking – “together we’re stronger”! A united voice on a European level would have more impact (on regulatory authorities, etc).

PRO-federation

- Political representation of common interests on European (or international) level. Europe would officially recognize both the disease and the patients. This should include the ability to access EU grants.
- Setting up common projects (like youth exchange or summer camps, workshops and conferences)
- Cooperation with, networking for and training of medical professionals - patient networks can enhance the intra-cooperation of professionals who have not worked on common projects before
- Creation of common standards of care, rehabilitation + treatment
- Centers of expertise - on a national or European level
- Euro-groups can actively participate in policy development and decision-making

PRO-federation

- Promotion of research on all aspects of the disorder
- Transfer of knowledge and equipment, access to treatment and support for people with the rare disorder in less-developed countries
- Support for small national groups in the process of creating an organisation
- Exchange of “best practice examples” and guidelines for certain procedures (public relations, fundraising, organizing a conference....)
- When convenient, Euro-groups can partner with other stakeholders for a stronger advocacy toward governments
- These groups can then also advocate nationally for the implementation of EU rules and regulations in their favor
- Achieving these goals would all add up to improving health care and society

CON-federation

- **Economic concerns:** a European Federation will need financial resources, and access to subsidies is difficult, especially at the beginning. This will result in the need to ask national members for economic support of the Federation's operational costs, e.g., an annual membership fee that might be a burden for small national organizations. Also, costs to attend annual meetings, workshops or European conferences are high and may be too high for certain groups.
- **Language barriers:** problems in using a common cross-border language and to find national representatives with adequate language skills.
- **Lack of human resources:** as volunteers are rare, the foundation of a European Federation might be difficult due to the lack of a competent and capable representatives
- **Beaurocracy** for organisations that already do not have a lot of time.
- The local/national group may be able to make decisions quicker than through the European federation.

Future

- **The economic crisis is re-defining everything**
- **It is going to get worse before it gets better**
- **BUT the science of biotechnology and genetics is a continuing growth area**
- **Patients need to be a part of that growth**
 - In defining what needs to be studied as well as making sure there is enough money for that
 - Patients need to underline their own importance
 - Groups/collectives will be more necessary than ever vs. individual voices
“Together we’re stronger!”
 - Social causes as well need to be pushed by us
 - Patients are an added value – without patients, there’s minimal rx

What I need from you

- **Looking at the web-site**
 - Can it be made better or more friendly?

Still to do...

- **Looking for groups – Orphanet**
- **Action Plans (document your case – facts & testimonies)**
- **Funding; fundraising**
- **Languages**
- **Online Communities**
 - Almost real-time translations

- **Fragile X**
- **Bechet's**

- **Keep website up-to-date (weekly reminders?)**
- long-term fundraising, workload maintenance, communication methods, understanding other cultures and systems

Remember...

- **Build partnerships (no need to do it alone)**
- **We are rare citizens and consumers – build that into an advantage**

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- **Existing patient groups**

- DEBRA, EAND, Euro-Ataxia, FEWS, Myeloma Platform, OIFE, CFE
- Epidermolysis Bullosa (EB), European Alliance of Neuromuscular Disorders, Fed of Euro-Williams Syndrome, Myeloma is bone lesions/tumors, Osteogenesis Imperfecta (brittle bones), Cystic Fibrosis
- <http://www.cfww.org/cfe/>
- www.hsp-selbsthilfegruppe.de
- <http://www.debra.org.uk/>
- <http://www.williams-syndrome.org.uk/>
- <http://www.emp-myeloma.eu/>
- <http://www.oife.org/home/home.html>
- <http://www.cfe.org>

Rare! Together



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- **Focus Groups**

- European
- Fledgling
 - Already have informal ties with groups in other countries
- Leadership

- **Outreach**

- Overall outreach
 - Raretogether.eurordis.org
 - 3 “organisations” with between 6 and 24 groups

Rare!Together

- **Developed by Eurordis**
- **Funded by the Medtronic Foundation, USA (www.medtronic.com)**
 - (With new additional funding from EC)
 - Medtronic
 - “When life depends on medical technology”
 - “Contributing to human welfare by the application of biomedical engineering to alleviate pain, restore health and extend life.”

Medtronic products - spinal and bone therapies, pain relief, neurostimulators - movement disorders and pain conditions

Rare!Together

- **Mentor**

- Guide to Establishing & Developing a European Rare Disease Patient Network
 - long-distance - emails, telephones, dedicated listserv

- **Additional experts**

- Advocacy experts, media whizzes, legal & financial experts
 - **Face-to-face meetings** and **workshops**

- **Steering Committee**

- 1 rep from each Patient Network (ECHDO, Euro-HSP)
- The Mentor
- The Project Manager (Eurordis)
- Rep from DEBRA
- Rep from OIFE
- Rep from CFE

Rare!Together

Building a Federation

8 basic steps to setting up a
European Federation

Action Plans

Creating the structure

Is there a best country to register
a Federation?

Look for other national groups

Membership

Pro's & Contra's of European
Federations

Sharing Experience

Governance

Board of directors

By-laws

Employees & Volunteers

General Assembly

Good international practices

Statutes

- Eurordis RareTogether Knowledge Base -
Capacity Building for Networks of Rare
Disease Patient Organisations

Advocacy & Communication

Advocacy at a European level

Advocacy tools

Blogs

Language issues

Rare Disease Communities

Rare Disease Day

Surveys

Websites

Funding

Code of Good Practice

Cross border tax relief

European Commission Calls for
Proposals

Financial management

Financial support by commercial
companies

Fundraising

Resources

Transparency

