



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

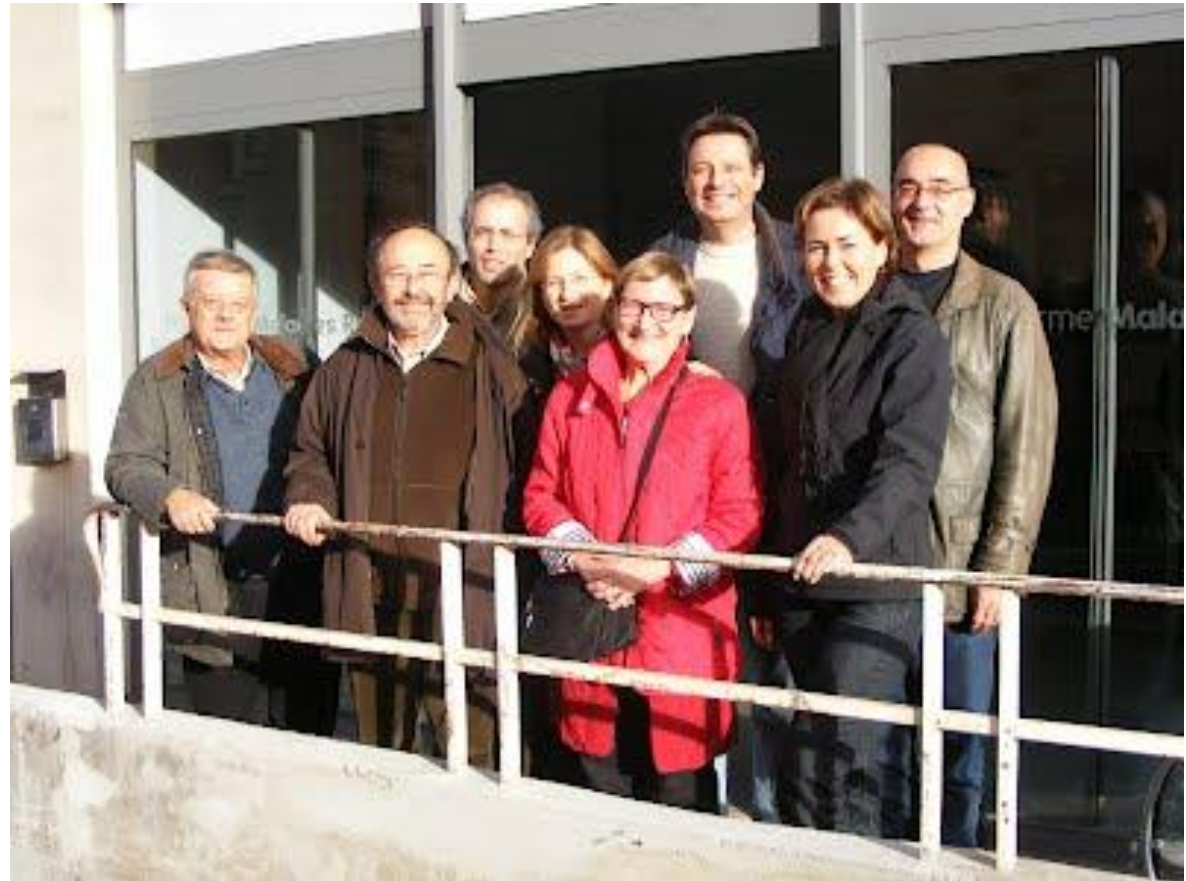
Rare!Together

- 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.



Rare!Together

- **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

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
- **Baurocracy** 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