



EURORDIS
Rare Diseases Europe



Rare! Together *DOs and DON'Ts*

How to create a disease specific European Patient Federation?



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PRO-federation



- Exchange and combination of experience and knowledge (effective!!)
- representation of common interests on European (or international) level.
Europe will officially recognize both the disease and the patients. This may eventually 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 - together we're strong!

- Promotion of research on all aspects of the disorder
- For studies and research a higher number of patients can be reached
- 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



OIFE = Osteogenesis Imperfecta Federation Europe



OIFE

- founded in 1993 by 7 national OI-societies
- each member is represented by a delegate
- the delegates form the OIFE-Board
- and choose the Executive Committee



OIFE development 1993 – 2012

from 7 to 26 member organisations

- ▶ regular contact to over 25 further national OI associations and groups
- ▶ today representing over 8000 OI people in Europe
- ▶ recommendations and support for new OI-groups and young associations
- ▶ membership in EURORDIS = Rare-disorder-cooperation worldwide

OIFE – Osteogenesis imperfecta Federation Europe

OIFE development 1993 – 2012

- ▶ **close cooperation with OI specialists + medical advisors**
 - Topical meetings on special aspects
 - Patients representatives as observers + speakers at medical conferences
- ▶ **support for OI individuals in many countries**
- ▶ **fundraising for special projects (“youth weekends, students exchange, flying OI-experts)**
- ▶ **information and contact network for OI people and professionals**
- ▶ **collection and publication of information material**
- ▶ **OIFE – newsletter (4 x per year)**



OIFE - after almost 20 years

USA
OSTEOGENESIS IMPERFECTA FOUNDATION

France
aoi

Poland
Logo with a pink wheel and a sun

Portugal
apoi

Sweden
RBU Riksförbundet för rörelsehindrade barn och ungdomar

Australia
Logo with a blue stylized figure

The Netherlands
voii vereniging osteogenesis imperfecta

Denmark
Logo with a blue stylized figure

Norway
Logo with a blue stylized figure

Georgia
GLASSY CHILDREN

Belgium
Logo with a green diamond

Spain
AHUCE ASOCIACION HUECOS DE CRISTAL DE ESPAÑA OSTEOGENESIS IMPERFECTA

Germany
Goii

Mexico
angelitos de cristal, i.a.p. Fundación mexicana para la atención de personas con Osteogénesis Imperfecta

Switzerland
Logo with a grid of letters A, S, V, OI

Croatia
Logo with a map of Croatia and the text 'Hrvatska Osteogenesis Imperfecta'

Russia - Moscow
Артучкие Дети региональная общественная организация мам Зюга!

Asociatia De Osteogeneza Imperfecta Romania
Logo with a blue stylized figure

United Kingdom
BRITTLE BONE SOCIETY

Perú
ASOCIACIÓN OSTEOGÉNESIS IMPERFECTA DEL PERÚ

Italy
Logo with a black and white figure

Help OI foundation
Logo with a red flower

Ecuador
Logo with a colorful figure and the text 'FEI'

OIFE - success story after 20 years

OIFE activities and special projects

- OIFE OI-pass - emergency travel document
- OIFE recommendations “How to set up an OI association”
- OIFE Topical meetings:
 - - 2009 OI-in-Motion-Conference on rehabilitation, Germany
 - - 2012 Psychosocial aspects of OI – October, Portugal
- Making friends project
- OIFE website – www.oife.org and facebook site
- OIFE – international youth weekends and contact
- OIFE project fund – i.e. “flying OI-experts”
- Support for individuals – in cooperation with HOI and PadrinoS-OI
 - No office in Brussels, no director, no staff –
But: valuable connections worldwide, knowledge,
experience - OI-people are no longer “alone”



The beginning of a European Federation

30 or 20 years ago lonesome struggle

- parallel national or regional activities for OI children
- no knowledge about others, no interaction
- little contact between doctors + patients families
- travel and phone calls expensive – fax for quick communication
- little accurate information available – difficult to find
- no awareness about and for Rare disorders in general
- huge differences between countries in standard of social support, treatment and care
- considerable language and cultural barriers

2012 globalisation + communication

- OIFE + worldwide OI-network (~ 50 associations)
- international cooperation
- close international cooperation between patients and doctors/scientists
- internet, inexpensive telephone + social media replace some travelling
- strong Rare disease umbrella = EURORDIS
- worldwide communication and cooperation
- reduced inequalities between countries inside EU
- website: raretogether.eurordis.org

How you can do it?!



How to get started

- Contact between representatives from different countries and various cultural backgrounds sharing the same disability
- Definition of common goals
- Discussion + agreement about structure, country for legal seat + registration
- Public relation + raising of awareness (politically and socially) on national and international level
- Collection of data (addresses, information on different structures or procedures of national organizations, etc.)
- Common website + networking – “together we’re stronger”!

raretogether.eurordis.org + cooperation with mentor/

or tandem-partner-organisation



Initiated by EURORDIS, started in Athens in May 2009, the Council of European Rare Disease Federations, CEF

provides a platform for exchanging experience and information across federations working for specific diseases or groups of diseases.

- The Council enables European Rare Disease Federations to:
- Share at the European level information and experience relevant to common activities and issues concerning specific rare diseases,
- Discuss and implement common activities within EURORDIS,
- Enhance or build capacities as European federations to gather patient groups from different countries for specific diseases or group of diseases,
- Foster a voice at the European level for respective diseases,
- Directly or indirectly reduce the impact on the lives of those living with the rare diseases addressed by European federations.

So far we had 5 very inspiring CEF – workshops - come and join us!

And now

DO	DON'T
<ul style="list-style-type: none">- just DO it- please use and discuss this in your groups and get back to us- find support via EURORDIS or <i>Rare!Together</i> and look for partners on national and international level- Later join EURORDIS' Council of European Federations	<ul style="list-style-type: none">- don't hesitate, it is worth while- try to go the long way alone – we offer support and know what may lie ahead of you- stay behind alone and desperate you ARE not alone!- forget: <p><u><i>raretogether.eurordis.org</i></u></p>

Further comments and questions very welcome!

Thank you!

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