Rare!Together
DOs and DON’Ts
How to create a disease specific European Patient Federation?

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Why create European Patient Federations?

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

European and international OIFE members

- Sweden
- The Netherlands
- Finland
- Denmark
- Norway
- Belgium
- Spain
- Georgia
- Russia
- Mexico
- Switzerland
- Croatia
- Russia - Moscow
- Ecuador
- Peru
- Poland
- Portugal
- Poland

USA
France
United Kingdom
Italy
Germany
Ecuador

Help OI foundation

Asociatia De Osteogeneza Imperfecta Imperfecta

EURORDIS

Rare Diseases Europe
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](http://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”

OIFE has still little resources, but: we did, do and ENJOY it …!!
The beginning of a European Federation

<table>
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<tr>
<th>30 or 20 years ago .....</th>
<th>lonesome struggle</th>
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<tbody>
<tr>
<td>- parallel national or regional activities for OI children</td>
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<td>- no knowledge about others, no interaction</td>
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<td>- little contact between doctors + patients families</td>
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<td>- travel and phone calls expensive – fax for quick communication</td>
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<td>- little accurate information available – difficult to find</td>
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<td>- no awareness about and for Rare disorders in general</td>
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<td>- huge differences between countries in standard of social support, treatment and care</td>
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<td>- considerable language and cultural barriers</td>
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<th>2012 .....</th>
<th>globalisation + communication</th>
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<td>- OIFE + worldwide OI-network (~ 50 associations)</td>
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<tr>
<td>- international cooperation</td>
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<td>- close international cooperation between patients and doctors/scientists</td>
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<td>- internet, inexpensive telephone + social media replace some travelling</td>
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<tr>
<td>- strong Rare disease umbrella = EURORDIS</td>
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<td>- worldwide communication and cooperation</td>
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<td>- reduced inequalities between countries inside EU</td>
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<td>- website: raretogether.eurordis.org</td>
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Far better conditions now than ever before! If “Rare go together”!
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 ……

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<th>DO</th>
<th>DON‘T</th>
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| - just DO it  
- please use and discuss this in your groups and get back to us  
- find support via EURORDIS or Rare!Together and look for partners on national and international level  
- Later join EURORDIS‘ Council of European Federations | - 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: raretogether.eurordis.org |

Further comments and questions very welcome!

Thank you!  

Ute Wallentin  
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DO  DO  DO  DO  DO  DO - just start and  DO!!!