

First Announcement – Topical Meeting

Fragile Bones – Unbreakable Spirits?

Psychosocial aspects of
Osteogenesis Imperfecta

April 20-22 2012



**Trinity Hotel & Conference Center,
Snoghøj, Fredericia, Denmark**

**We will keep you updated if you
send a message to the chair of the
organizing team at**

Netherlands@oife.org

**You can also pre-register on the
OIFE website if you follow the link
at the top of this page:**

**[www.oife.org/projects/unbreakable_spirits/
unbreakable-spirits.html](http://www.oife.org/projects/unbreakable_spirits/unbreakable-spirits.html)**

A lot of focus has been on the treatment and prevention of fractures and the biochemical backgrounds of OI, much less attention has been given to the psychosocial aspects. OIFE thinks many such issues can potentially arise, both for the individual with OI as for his or her family. These deserve more attention and we have therefore decided to organize a special Topical Meeting on this subject.

The meeting is aimed at psychologists, social workers, nurses, physicians, people with OI and their families and everyone else interested. One goal will be to think of strategies to cooperate

and encourage further research in this field.



Preliminary program

We have secured several speakers already, however as only little research has been done we will probably not have a full program with research outcomes. We want to include other interesting elements such as personal experiences and discussions. Details are to be announced. We hope this meeting will be a stimulating and inspiring event for all.

Topics

There are many topics we would like to include in the program – don't hesitate to contact us if you can contribute with a poster or want to suggest a speaker on one of the topics below:

- “Euphoria” and OI – true or fake? Are people with OI allowed to be sad?
- Influence of childhood experiences, signs of posttraumatic stress?
- Parenting / parenthood and the effects on non-affected siblings
- How to handle the fear of fractures?
- Measuring the quality of life in OI
- Partners, friendships and sexuality
- Achieving a positive self image
- Family tensions, overprotection, guilt
- Positive sides of life with OI
- Issues for adults
- Comparison between OI and other chronic diseases and healthy people
- Invisible problems
- Stigmatisation
- Support from within the OI community
- Inventory of studies so far
- Somatisation
- Social fear, fear of groups
- Pressure to achieve to your parents
- Letting go of your OI child
- Mental preparation for surgery