The changing role of patients
- from people in hospital to advocates & partners

Quality of Life 4 OI-conference
Amsterdam, November 22nd 2019

Ingunn Westerheim – OIFE president
## Disclosure of speaker's interests

<table>
<thead>
<tr>
<th>No (potential) conflict of interests</th>
<th>Company names</th>
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<tbody>
<tr>
<td>Relations that could be relevant for the meeting</td>
<td>OIFE has received support from the following companies in 2019:</td>
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<tr>
<td>● Sponsorship or research funds</td>
<td>● Alexion</td>
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<td>● Payment or other (financial) remuneration</td>
<td>● Mereo Biopharma</td>
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<td>● Shareholder</td>
<td>● Kyowa Kirin International</td>
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<td>● Other relation, viz. ...</td>
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The OIFE

- Osteogenesis Imperfecta Federation Europe (OIFE) is a European **umbrella organization** for organizations that deal with OI
- Our international network includes 35 organizations worldwide
  - 19 national groups in Europe
  - 11 national groups outside Europe incl. the OI Foundation
  - 5 supporting member organizations incl. Care4BrittleBones
Children and adults with OI living active and independent lives - with access to competent healthcare and necessary social support.
The mission of the OI Foundation (USA) is to improve the quality of life for those living with osteogenesis imperfecta through research, education, awareness and mutual support.
OIFE’s mission is to connect and empower organizations, professionals and individuals to improve lives of people with OI.
OIFE Magazine 1 - 2018

Editorial
By Ingaar Wiersenby, OIFE President

Dare to...

There is perhaps no consistent theme in this edition of the OIFE Magazine, like it was in the previous one: that maybe I just haven’t looked close enough. After thinking about it one more time, it occurred to me that maybe the theme of this newsletter is to dare? The Portuguese project you can read about in this edition was called “Dare to Live” or “Atrevete a viver” as they say in Portuguese. In the AIPO project people with OI challenged their fears and boundaries, either by swimming with dolphins or climbing walls.

Penny Ogilvie on the other hand is definitely a daredevil. Sometime she’s dangling outside!

OIFE Magazine 2 - 2018

The Voice of People with OI

Welcome to the first special edition of OIFE Magazine! The topic is research and I could have called this editorial “The patients’ voice.” But to be honest, I’m not too fond of the term patients. Patients belong in hospitals. The OIFE represents people with OI and families, who most of the time live active and meaningful lives outside hospital walls.

There are however many ongoing initiatives that include patients in one way or another. Patient involvement in research, patient centred outcome measures, patient reported data, patient priorities in research and I could go on and on. Many stakeholders want to hear our voice these days. Both because they are interested, but also to secure funding or to get approval from authorities.

OIFE Magazine 3 - 2018

Q for Quality

What is quality of life? I guess there are almost as many answers to that question as there are people on this planet. During one of the sessions at the CIOD conference, we were asked to use an app to create a wordcloud of what really mattered regarding quality of life. The words that got the top ranking were dignity, happiness, ability, autonomy, normality and participation. Many of them I can agree on. I’m not so into being normal now. But when I was younger it was very important to me. Autonomy and independence however are very important values for me. So is participation and happiness.

Speaking of happiness. I’m pretty happy with my quality of life at the moment. After the longest and iciest winter in 35 years, summer came as an explosion after a very short spring. May has been the sunniest month in 100 years in Oslo.
OIFE’s goals

- **Representing** our members and **be the voice** of people with OI and their families in Europe and on an international level;
- growing an **international network** between professionals, organizations, individuals and other stakeholders;
- **advocating for** access to competent **healthcare and social support**;
- encouraging scientific **research** on OI;
- **empowering our** member organizations by sharing information, knowledge and best practices;
- supporting **development** of OI organizations and support in more countries;
- **guiding individuals** towards information, healthcare and support.
SAVE THE DATE!
14TH INTERNATIONAL CONFERENCE ON OSTEOGENESIS IMPERFECTA

01 2020
5-8 SEPTEMBER 2020

SHEFFIELD, UK

For further information contact
Nick Bishop (Sheffield, UK)
Local Organising Committee Chair
Email: iccbh@ectsoc.org
Website: www.iccbh.org
Who are the patients?
People with OI in hospital
Who are the patients?
The patient organizations
Who are the patients?
People with OI & their families

“Patients are experts by lived experience, whose perspective on disease and care is unique.”
Who are the patients?
The patient experts
Who are the patients?
KOL - The key opinion leaders
Person in hospital

Parent of person with OI

Person with OI

Patient representative

Patient expert

Person seen by doctor

OI-organizations

Staff member?

Volunteer of OI-org.
Empowerment

• The European Patient’s Forum has the following definition of empowerment:
  – Empowerment is “a multi-dimensional process that helps people gain control over their own lives and increases their capacity to act on issues that they themselves define as important.”
  – Collective empowerment is “a process through which individuals and communities are able to express their needs, present their concerns, devise strategies for involvement in decision-making, and take political, social, and cultural action to meet those needs.”
Only once a person is empowered, can a person be engaged...
How can we be empowered?

1. **Support to self-care and self-management**
   The ability to deal with all that OI entails, including symptoms, treatment, physical and social consequences, and lifestyle changes.

2. **Shared decision-making**
   Process by which a clinician and a patient jointly make a health decision after discussing options, potential benefits and harms, and considering the patient's values and preferences.

3. **Health literacy, education and capacity-building**
   Patient organisations often fulfil the task of ensuring education for patients and healthcare professionals through helplines, information, and ad hoc trainings.
OIF Podcast Series

Leaders in the OI Field on New Advances in Research and Treatment

The OIF’s monthly podcast series, Leaders in the OI Field on New Advances in Research and Treatment, is a part of the OI Foundation’s campaign to increase outreach and educate medical professionals who treat individuals with osteogenesis imperfecta.

Clinical Research in the area of OI
Dr. Brendan Lee, M.D., Ph.D.

Identifying New OI Genes and what they mean to Understanding OI
Eric Rush, M.D.

Multidisciplinary Care for the Pediatric Patient with OI
Cathleen Raggio, MD

Surgical Updates on Treating Children with OI
Richard W. Kruse, DO, MBA

Pregnancy and OI
Deborah Krakow, MD

Gaps in Care and Information in Treating Adults with OI
Laura Tosi, MD

Click here to listen!

Click here to listen!
WORKSHOP
A GENÉTICA DAS DISPLASIAS ÓSSEAS
19 OUTUBRO 2019
Dr André Travessa

HORÁRIO: 09H30 – 12H30
LOCAL: RUA MANUEL MENDES, LOTE 10 – L 4
8ª QUINTA DAS LARANJEIRAS – PARQUE DAS NAÇÕES – LISBOA

Sócios 5€; Não-sócios 10€

Um projeto da APOI
Com apoio da ANDO Portugal
Topical Meetings

Orthopaedic aspects
Physiotherapy and rehabilitation (2009)
Psychosocial aspects in OI (2012)
See, Hear, Smile! (2019)
Where is our voice needed?

Micro/individual level

Macro/service level

Policy level
Patients role in research

Patient participation

the TOPaZ trial

Key4OI

MOI-study (LOSARTAN)

Patient engagement
It's YOU!

We need YOU.

YOU have to help us.

And if YOU cannot do it,

YOU have to help us to find someone who can...
You can’t just tick off the box...

• Lack of awareness about patient engagement among researchers and patients themselves
• Lack of knowledge & guts!
• Unclear requirements and roles
• The 25th hour problem
• We have OI!
• And what’s in it for us…?
And guess what?

We have OI!
Patient education!
The A to Z of medicines development
Join us...

We have almost 3000 followers on Facebook, but we would love to have more...

www.oife.org

E-mail: office@oife.org

Facebook: @OIFE_PAGE

Twitter: @OIFE_OI

Youtube: oifeORG

LinkedIn: www.linkedin.com/company/oife