Dear Friends,

It's late one evening. Most things I wanted to get done today are done, or at least I gave it a good try. Time to relax, OI and OIFE couldn't be further away in my mind. On Facebook I see a post from my friend M., an OI-mom with a young child who also has OI. M. writes that she has fallen yesterday, a femur fracture is the result. I really feel for her, she was walking so well and now this happens! Immediately OI is back in my mind. I remember similar accidents, only a few weeks ago another of my walking OI friends broke his hip and another one his arm in a very nasty way.

At the same time knowing so many people with OI has been a great comfort. I remember very well when the Dutch OI organization started back in 1983. At that time I did not know anyone with OI. Finally hearing stories that compared to my own - often crazy – life, was an overwhelming experience. I realized how I had always felt alone with OI until then. But now I had found a community I wanted to belong and contribute to. After being active in the Dutch and later also the German OI association I joined the OIFE.

Hearing OI stories from so many countries made me realize how much they had in common. Of course there are differences as well, due to culture, economics and attitude towards disabled people – but the similarities are striking. A lack of knowledgeable doctors, people wondering about the future of their child or of themselves when they age. Dealing with the invisible and psychosocial aspects of OI. At the same time the positive experience that children and young people often achieve a lot in terms of education, family life and independence, even when circumstances are tough. In the past years our world has changed a lot, internet has lessened isolation, advice can sometimes be a mere mouse click away. I don't think it can replace the personal contact at OI meetings though. At the same time bisphosphonates, FD rods and a better understanding of OI at the molecular level mean that there is more to inform and answer questions about. OIFE plays a crucial role in this, we are the proverbial spider in the information web, connecting OI societies, scientists and individuals often from places were no OI association exists.

Those serious injuries put my almost healed rib fracture in perspective. A month ago I tried to connect my laptop to a socket on the wall behind me, leaning over the armrest caused my rib to crack. Perhaps it is the downside of doing OIFE work, there is always someone you know who is seriously injured. As if you work in the emergency room of a hospital next to a ski slope. Only these people are not my patients but my friends, these are not people who had a massive accident while racing down a mountain, these are people who had their 10th, 20th, perhaps 100th break doing something utterly mundane. These are people like me.

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At the same time several of my friends had fractures, other OI friends told me about knee-replacement surgery, about hearing loss and heart valve issues. How they deal with fatigue and pain. But also how their lives improved from oxygen therapy or fitness programs. It is obvious that OI is so much more than just the fracture side of things. Our previous topical meeting in Lisbon in 2012 dealt with psychosocial aspects of OI, our next Topical Meeting in Oslo in September 2015 will focus on the soft tissue involvement, think muscles, lungs, fatigue and such. Often as much of a problem to adults than fractures so I think an excellent topic for us this coming year. With that I hope we continue to be a strong community, I wish all of you happy holidays and good health in the year to come!

Taco van Welzenis, 1st vice-president, Dutch delegate

**Announcement: Topical meeting 2015 in Oslo, Norway: Osteogenesis Imperfecta “Soft tissues & soft issues – OI is more than fractures”**

At OI conferences we hear a lot about genetics, surgery and bisphosphonates. The focus is often on treatment strategies for children with OI. But what happens when the child grows up, fractures less and the pediatrician is no longer around? At this seminar we will focus on the health issues of adult people with OI, especially the non-skeletal problems. Perhaps it will leave us with more questions than answers, but we hope the seminar will spark an interest in the matter and stimulate further research.

Everyone interested in the topics is welcome to attend. Previous topical meetings have turned out to be excellent arenas for international exchange between doctors, nurses, psychologists, physiotherapists, occupational therapists and people with OI.

The main topic will be soft tissues; the tissues that connect, support, or surround other structures and organs of the body, not being bone. This includes tendons, ligaments, fascia, skin, fibrous tissues, fat, synovial membranes, muscles, nerves and blood vessels.

Potential questions regarding this topic can be:

- How do loose joints affect pain and ADL?
- Should you operate on a ruptured OI muscle? How?
- What are the results of joint replacement when people with OI replace hip/knee?
- What kind of OI-pain is related to muscles and/or nerves?

For more information please follow our webpage [www.nfoi.no/issues2015.aspx](http://www.nfoi.no/issues2015.aspx)
We are looking for speakers

We are currently in the process of putting together a preliminary program and we are looking for speakers, especially from outside Scandinavia. If you are interested in speaking at the seminar please send an e-mail to post@nfoi.no with the following information:

- What topic you would like to speak about – an abstract would be nice (but not necessary yet)!
- What topics are you currently working with and/or a CV showing your experience with OI?
- Are you working with children and/or adults with OI?
- Would your employer be willing to cover some/all of the costs of your participation?
- How much time would you need for the presentation?
- Would you also be willing to participate in a panel discussion about one of the topics (which one)?

We are both interested in medical professionals and speakers who have OI themselves. See also our FAQ for speakers at [http://nfoi.no/issues2015/speakers.aspx](http://nfoi.no/issues2015/speakers.aspx). Thank you very much!

OIFE AGM 2014 in Helsinki, Finland

Impressions from two new OIFE-delegates

Coreen Kelday, UK

As delegate for the UK Charity Brittle Bone Society I was delighted to attend the OIFE AGM. This was my first time attending an OIFE meeting. It was great to meet so many inspirational people from around Europe and to feel part of a larger OI community, where we can share information and ideas.

Since my visit to Helsinki in September I am happy to say we have been able to work more closely with OIFE in various ways: Patricia Osborne our CEO regularly holds telephone conferences with president Ute Wallentin and Dagmar Mekking of Care for Brittle Bones to ensure that we are all working more closely together.

A meeting was held at our Annual Conference in London in August between the BBS, OIFE and Care4BrittleBones to look into the possibility of developing plans for work surrounding the building of an ERN (European Reference Networks) for OI.

The ERNs are collaboration networks across all 28 European Union member states to share expertise and data for rare disorders to achieve better outcomes.

Like the OIFE and some of its members, we at the BBS are also currently seeking to share our knowledge with other Rare Bone Groups, especially the HPP community whom have many similar traits to OI.

The Brittle Bone Society are currently liaising with Rare Connect, [https://www.rareconnect.org/en](https://www.rareconnect.org/en). This is an online platform where you can meet and interact with others who share your condition in a supportive and friendly environment. This is an excellent way for everyone in Europe to stay connected with each other, and we hope once the OI community on Rare Connect is up and running, people from all around Europe will use this, and upload their stories.

We benefitted from having European representatives attend our annual conference from OIFE
(Taco van Welzenis) and Care for Brittle Bones (Dagmar Mekking) and other groups within the UK and we will continue in this theme next year and hope for more delegates from mainland UK and also Europe attending our events. For me the experience I gained by attending OIFE was invaluable. The BBS will continue to work closely with OIFE and I very much hope to meet everyone again in Oslo in 2015.

From left to right: Annelies Martens Belgium; Leonardo Panzeri, Italy; Anna Rossi, Italy; Taco van Welzenis, The Netherlands; Ingunn Westerheim, Norway; Ivar Troost, The Netherlands; Ute Wallentin, Germany; Rebecca Tvedt, Norway; Trond Gården, Norway; Laurette Paravano, France; Maria Barbero, Spain; Olga Witthauer, Finland/Germany; André Wittwer, Switzerland; Coreen Kelday, UK; Eero Nevalainen, Finland. Not on the photo: Mads Dyreberg Haldrup, Denmark; Stefanie Wagner, Germany

André Wittwer, Switzerland

The 22nd OIFE AGM was my first meeting. So I was very excited to participate as the Swiss delegate. I already arrived some days earlier in Helsinki, as my goal was to do a city trip before the OIFE AGM starts. Usually I do not travel alone so before the departure I was a bit nervous. I had no clue how easy or hard it is going be to travel alone with the manual wheelchair and the baggage.

Helsinki is really worth a visit. On my city trip I enjoyed the warm and nice weather with 20 degree celsius. The highlights of the trip were the boat trip around Helsinki and the different islands, the marketplace with the market hall, the rock-hewn church, the music centre, the Uspenski cathedral, the dom, the island Suomenlinna and of course the delicious food in various restaurants. Suomenlinna was very challenging with the wheelchair. Although they had a dedicated map showing routes for people in wheelchairs. But some paths were so steep, that I had to get out the chair and push it up or down the cobblestone paths. On Wednesday afternoon I travelled further to Vantaa by taxi for the OIFE meeting.

Almost all participants arrived on Wednesday evening and we had dinner together. I was so excited to get to know everybody. This year the Finland OI association SOIY hosted the OIFE delegates and guests from all over Europe who came to the OIFE AGM. After the first day of the parallel OIFE and SOIY meetings we were invited to celebrate the 35th anniversary of SOIY with a delicious dinner.
The OIFE meeting covered a big range of topics to be presented, discussed and decided. Reports, plans for future projects, votes on important policy-issues and decisions on volunteer’s tasks and distribution of responsibilities. Too much to describe here, but ask for details, if interested!

I’m looking forward to meet you all again in Norway 2015!

There and back again or Father and Child Journeys…
By Nils Fastenrath, Germany

Once upon a time there were some men. All of them had kids, at least one with brittle bones. But with unbreakable spirits.

So fearlessly they decided to go out into the wildest and unknown territories of ancient Germany. Their wives and mothers were anxious: "Oh, my son, my darling! Stay at home please. It's a safer place to be...!" But boldly responded their husbands and sons: "Do not be afraid, my dear! Whatever the circumstances, whatever the physical condition - a man must do what a man must do."

So they went out, for the first time in the year of the Lord 2013. Six Fathers and six sons with brittle bones.

Not to forget brave young lady Sarah who slipped into the van unobserved by her parents. When she was detected far from home her father could not send her back, so she joined the men on their dangerous journey.

After endless hours on the rough roads of Germany they finally reached the "Walderholungsstätte für Männer", a scary hostel for tired adventurers in the gloomy woods near the town of Wuppertal which was founded in 1886. So there they resided for two days.
They fed themselves with everything their eyes and hands could discover on the ground.

After they had drawn strength from the plants and insects they moved out to a hilly place in Wuppertal which was inhabited by many kinds of wild and dreadful animals. The people of Wuppertal have been plagued for centuries by huge elephants, nearly invisible lions hiding in the grass and attacking suddenly, as well as hundreds of malicious penguins. They fought with all their might and rode their wheelchairs like never before.

In the end they prevailed and freed the people of Wuppertal.
As thanks the young heroes were allowed to cross the wild waters of the Wupper river by using the legendary Schwebebahn.

After returning to their hostel they celebrated like men, sitting at the fireplace with bread, meat and beer and telling heroic stories until the stars began to shine on this young band of brothers.

In their homes the mothers were waiting and how joyful they were to welcome back their men! They all were unharmed but full of pride and ready for new adventures...

But almost a year went by until a reinforced crowd moved out again in March of 2014. Encouraged by past victories new men with their kids joined them from all parts of Germany.

So eleven men with their OI children went to the Spessart forest and stayed in the "Schullandheim" (school youth hostel) of Biebergemünd.
In the night druid Christian Lang prepared a magic meal for the heroes. He had recently rediscovered his famous crêpe machine and showed his skills so that all participants were filled with strength for the dangers to come.

On Saturday they went to the Wildpark "Alte Fasanerie" in Hanau. There they were confronted with huge owls and fearful eagles. But they did not flee and stood firm, one of them even sleeping while an eagle flew close to him. Finally the birds of prey were tamed and the young men fed them with their own hands.

After returning to their base camp pizza man Johann provided them with enough pizza to feed a whole army.

So the first two Father-and-Child journeys were a great success and will be continued in the years to come! New young heroes are welcomed!

**International OI-calendar**

**2015**

March 14-15 Denmark: OI Nordic meeting in Copenhagen  
March 21-22 France: National OI meeting and 30 years French OI association in Eurodisney (Mame-la-Vallée)  
April 30-May 3 Norway: National OI meeting in Oslo  
May 6 WORLDWIDE: Wishbone Day  
May 8-10 Denmark: National OI meeting in in Fredericia, Jylland  
June 4–7 Germany: National OI meeting in Duderstadt/Göttingen  
June 6-7 Switzerland: National OI spring meeting  
July 3–5 Australia: National OI Conference in Brisbane, Queensland  
July 18-25 Denmark: Family Summer Week  
Sept 17-18 Norway: Topical Meeting "Soft tissues & soft issues – OI is more than fractures”, Oslo  
Sept 18-20 Norway: Peer meeting for adults, Oslo

Visitors are welcome to all events – please contact OIFE  
Visit OIFE at Facebook!