



Osteogenesis Imperfecta
Federation Europe

Newsletter

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Editorial

Dear readers,

as all those who know me probably anticipated, I will continue to work in the OIFE and for the OIFE, but no longer in the most prominent position as president. Which suits me perfectly, thank you, Ingunn!

I am in regular and close contact with the new president, with OIFE's secretary and newsletter-editor Steffi and with many OI friends and as for many years I will continue to deal with and care for requests for information, help and advice from

the many individuals who contact the OIFE regularly and via email, Facebook or sometimes telephone.

Most of them are parents of OI children or adults with OI from all over the world (most recent requests came from Bangladesh, Jordan and Syria), but we are regularly contacted by doctors and researchers, physiotherapists or social workers on behalf of their patients or in order to create new alliances and for networking purposes.

The various OI foundations in the USA, Spain, the Netherlands and Germany, mainly the OIF, the BBS, AHUCE foundation, PadrinoS-OI and the OIFE cooperate closely in these cases.

In the past 20 years several of these first individual contacts have led to the creation of new OI treatment centers or national OI associations, and everyone is regarded as highly important and treated with care and interest for cooperation.

During the last 4 months a little accident with some pelvis fractures showed me again (and after several fracture-free years with „only“ non-skeletal OI issues like tendonitis's, muscular aches and pains) how suddenly OI-people can be thrown back and pulled out of all activities and too many daily routines.



Some weeks in bed, then wheelchair and in a nursing home taught me some essentials of life again. How important my many friends are to me (and how close through internet, fortunately!), how lucky I am to live in a country with good medical care and pain medication.

I had to spend two weeks in hospital and in bed most of the time, fortunately needed no surgery and now I am back on my two legs again and will soon return to work. During these first two weeks always my fear was the worst part. Not the real pain!

But: this time I never had a single moment, when my fears were not taken seriously. Everybody – from the cleaning lady to the professor in hospital and of course all my friends and visitors, was so nice, understanding and careful.

The doctors and physiotherapist did not always leave me alone when the fear would have kept me back. But they always accepted it, never took my lack of trust personal and helped me through the fear and out of bed. Without any damage to my fracture sites or soul! I am so grateful about this experience this time. Had much worse times in life! With these few fractures I had so far.

Thank you to all my OI-friends and: see you again!

Ute Wallentin

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What has the OIFE been doing?

By Ingunn Westerheim

Each year we ask our member organizations what they have been doing the last 12 months. Perhaps we are not that good at giving feedback in the other direction? Here are some headlines about what the OIFE has been spending time on the last 3 months.

Networking and collaboration

The first Friday each month the OIFE president (Ingunn) and Social coordinator (Ute) participate in phone conferences with the Osteogenesis Imperfecta Foundation USA (OIF), The Brittle Bone Society UK (BBS) and the Care4BrittleBones Foundation; The Netherlands. The purpose of these conferences is to exchange news about activities and research going on in Europe and the US. The OIFE has also initiated an informal collaboration with the International Osteoporosis Foundation (OIF).

The OIFE has attended several meetings/conferences the last 2 months:

- Council of EURORDIS (European Organization for Rare Diseases) in Paris, France
- Meeting with the Swiss organization SVOI in Bern about their 30th anniversary in 2016



Therese, Mark and André from SVOI having dinner with Ingunn from the OIFE

- European Patient Forum Regional Advocacy Seminar in Lund, Sweden
- ACHSE-seminar about "International Networking for Rare Disorders" in Berlin, Germany

We have also received positive news that the board of the Austrian OI-organization has decided to apply for membership in the OIFE for 2016, something we are really happy about.

Research and pharmaceutical industry

The OIFE has lately received an increasing amount of e-mails and requests about

collaboration with research projects and pharmaceutical companies. The quality and content of these requests vary to a great extent and it can be hard to know which projects we should support or not. At the moment the OIFE does not have a Medical Advisory Board of our own, but it is becoming more and more clear to us that this is something we will need the coming years.

European Reference Networks

European Reference Networks (ERNs) are supposed to create a clear governance structure for knowledge sharing and care coordination across the EU. They are networks of centres of expertise, healthcare providers and laboratories that are organised across borders. The European Commission will [launch a call](#) for applications from networks that want to become an ERN in early 2016. EURORDIS has developed a new [web section](#) with links to materials on how to prepare for this call.

The EU has stated that it is unfeasible to create a separate ERN for every one of the over 6000 rare diseases that exist. ERNs will therefore be organised according to disease groupings. OI is likely to be placed in the group of rare bone diseases or rare connective tissues and musculoskeletal diseases. The OIFE is not directly involved in this, but please inform us by sending an e-mail to president@oife.org if you know of OI-related hospitals/centres that are interested in becoming part of ERNs.

Strategy work

If the OIFE is going to develop, we need a clearer vision and strategy. We are currently working on a draft for a long term and short term strategy plan. This will be one of the main topics at the next Annual General Meeting, which will probably take place the 2nd week of October 2016 in Salamanca, Spain. Mark the date! We will get back to you with more details.

OI Conference Oslo2017

The 13th International Conference (scientific) on Osteogenesis imperfecta will be held in Oslo, Norway - August 27th to 30th 2017. Please follow the webpage www.oioslo2017.org for more information.

Hit by OI – again...

by Rune Bang Mogensen, member of the Danish OI society and member of the Danish board, contact: rubm@dfoi.dk

The passage below is an article that I have written in the member magazine in the Danish OI-community. These series of articles gives the opportunity for our members to write about an experience, a holiday trip, or topic that means a lot to them. The purpose is that they pass on the baton to a new member after finishing their writing. In that way we, hopefully, get to know each other even closer.

By reading the previous articles I know that I'm now facing a serious job. I'll do my best to continue this high standard. Hopefully I wouldn't let you down!

Since Michael passed the baton on to me, I have been wondering a lot to find the exact topic, which should be worth writing about to continue the high standard. My article is going to get personal but I believe this baton should be that media that our members are able to use to get closer to each other – as peers, as 'family' and as human beings. By my contribution to this baton, I wish to get some human issues and psychological consequences into the debate about OI. Maybe 2015 is the year in which the Danish OI community starts talking about some of these topics that really hurts in an everyday life with OI.

As a 28-year old, I feel that I have been hit by OI again. The fractures, the persistent visits to the various hospitals and the temporary pain are now a part of my everyday life and I'm used to it. That's how it is and it would probably not get any better in the future. However, that would never get me down! Now I've reached a point in my life where I'm facing new challenges in my working

life as well as in my emotional life. A big part of my friends move in together with their girlfriends, buy houses, get pregnant (not the boys of course). They have found what most of us search for – love. Here, I sit as a 28-year-old single. Maybe I should be focusing on the fact that I graduated from my education as a social worker with good grades, my fine references from my temporary jobs, that I finally got a regular job, that I have absolutely no obligations to no one or the matter that all opportunities are lying open in front of me? However, I feel that I have been hit by OI again.

I clearly do remember when I was a kid and NEVER felt that I was any different from my friends because of OI. But then I became a teenager. All the girls were suddenly looking for the tall and broad-shouldered Brad Pitt look-a-like who was able to juggle a ball and dance with all the girls all night long. No matter how much I wanted to be like him, I wasn't able to meet the requirements as a boy with OI type 3 or 4. I remember that I was frustrated and used Mads, Michael and Morten to talk to. We were all in the same boat so to say. Only one of us needed to start a sentence and then the other three would end it.

After a couple of years the girls got smarter – finally. Now they were focusing on human values. Now I felt I was back in the game!

Now I feel that I have reached a point in my life where I feel different with some challenges my friends of the same age do not face. Despite my chase for the one and only at various dating sites with a lot of bold comments and by searching through a lot of parties I haven't found her yet. Sadly, the conclusion must be that OI and a wheelchair are bigger issues than I want it to be among the opposite sex. I don't understand why. I feel I have so infinitely much to offer. But I also do need to be realistic! I am not like the majority. What do you do with a young man who often gets a fracture? I do understand the mentality and maybe I would feel the same way if it were the opposite way - even though I find the mentality awkward and wrong.

I do know that it might sound as if I only blame OI for being the reason why I haven't found the one yet. That's not my intention – and that wouldn't however be a fair conclusion if you ask me. As with everyone else personality, views, manner, appearance and behaviour does play a role. Of course it does mean something to some girls that a boy is in a wheelchair – and that it might

prevent some girls from doing the next step. However, I do know that the reverse situation also is possible (thank you for that, girls!).

My intention by this baton is not to cry, making people feel sorry for me or give up because that will never happen. My intention is just to highlight an issue that might hit the generations to come and at the same time tell them "that you are not alone with your thoughts and frustrations". I also do want to shout out and say that these thoughts and frustrations are completely natural. Life is tough no matter what. It doesn't matter if you have OI or not. It's a fact that that some ingredients is added to the hotchpotch when you have OI. I think that it is important that the

Danish OI community (and the OI communities in all countries) are responsive to these topics – to funny topics as well as the less funny topics. In that way we would be able to back each other up.

Looking back maybe that would have been a benefit to my generation and me if the generations above us have been focusing on that and would have told us about human issues/challenges that we might face later in our twenties (hurray for belated wisdom!).

I think it would be absolutely amazing if the Danish OI community in the future were able to get a psychologist attached in one way or the other. This psychologist needs to have basic knowledge about the aspects and consequences regarding OI. In that way, the members would have the opportunity to contact the psychologist when some of the different psychological OI-issues hit us. In that way the psychologist has the opportunity to give a piece of professional advice to whom it may concern. Another solution could be that the psychologist would help by guiding the member where to find the right answer or how a member should relate to starting up a more intense psychological treatment. This is just an idea to a future initiative, which could be discussed among our members as well as in the board.

Refugees with OI – “Qusai on his way”

OIFE is not only addressed by OI-people in need of advice concerning their physical problems. Years ago a young Syrian from Damascus had contacted us and asked for help, because after a „visit“ from Syrian police, he was so injured and afraid that he could no longer stay in his country and asked for advice where to go and how to reach a European country with good healthcare for OI. Then he fled to Turkey, where his sister lives in Istanbul and tried to find a way to safety from there.

First we could not help him, but when he addressed us again in spring 2015, we were at least able to bring him in contact with UNHCR in Turkey.

Over the last months his situation got more and more desperate and finally, after a last telephone contact to UNHCR in October without immediate consequences, Qusai could no longer wait. He found another young man who wanted to try the escape over these a before winter and sent an email to his friends: „I’m on my way!“.

Two days later we received the announcement through one of Qusai’s many friends (a lady from Canada this time) that Qusai and his friend and personal assistant Ahmed

had survived the night on a boat between Turkey and Greece, had landed on a Greek island and were heading to Athens by ferry.

The next morning they would arrive in Athens – without wheelchair, warm clothes and freezing, but alive.

Qusai's friend desperately asked for someone to go to Athens harbour the next morning with a wheelchair and to make sure that Qusai would be seen by a doctor immediately and would be brought somewhere safe – his goal was to travel on through Macedonia, Serbia and so many other countries and to reach the Netherlands, where his cousins live for some months already.

After an email to our three contacts in Greece, a series of many wonderful started, because our friend Katerina Kavalidou, the founder of a small Greek OI society and psychologist, immediately and overnight found volunteers working with immigrants in Greece and one of them, a young medical doctor, really went to Athen Harbour the next morning and found Qusai and Ahmed after some hours.



Qusai had three new fractures from his adventurous escape on that boat, had lost his glasses and had almost drowned in the cold water, but he was alive. Meanwhile he has been shortly treated in two hospitals, does now live in a Greek refugee camp and is waiting for the official permission to be flown to Amsterdam soon.

He is supported by almost 7000 supporters over an online-petition, got a wheelchair and new glasses with the help of Greek volunteers, a toilet chair was brought for him to the camp and a ramp built, so he can leave the container he lives in. Not only Katerina in Greece, but many OI-friends in Germany, Canada and the Netherlands plus some officials from EURORDIS in Paris are supporting his urgent request for relocation to his family in the Netherlands – we will report again....

Read more and sign the petition here: <http://bit.ly/qusraf>

Ute Wallentin, socialnetwork@oife.org – or email Qusai: koosycool6@yahoo.com

OIFE youth weekend in Berlin 2015

By Lars Nettet Romundstad

Arrival

Three excited young Norwegians named Kristian, Simen and Lars got up at an inhumanly early hour in three different towns one morning in September. We all met at Oslo Airport Gardermoen with one common target; Berlin. We were on our way to the international OI Youth Weekend in the German capital. The last Norwegian Fatima arrived later the same evening.

At Tegel airport we were met by someone of the German OI society, but had to wait for three more hours on a delayed flight from Rotterdam carrying Dutch participants. Waiting was going to be the theme of this weekend...



We could finally head on to the Hotel4Youth, where we met up with just under 30 other excited young people from across Europe. Apart from us Norwegians there were participants from Denmark, Finland, the Netherlands, England, Wales and the host nation Germany, all with various types of OI, spanning the ages 16 to 25.

We spent the first night at a local restaurant where we could taste the local dish Currywurst, an Indian-inspired variant of the German sausage Bratwurst. It is particularly popular in Berlin, and the Germans almost made it an ultimatum that we tasted it during our stay. It tasted better than it perhaps sounds.

Day 2

Early next morning we rose to blue skies and temperatures resembling a nice Norwegian summer day. Renate Rey from the German OI Society was in charge of the happenings, and she had ordered a sightseeing bus with room for 17 wheelchair users and the able rest. In the following 2.5 hours we were overwhelmed by a hyper-enthusiastic guide sharing all what was to know about Berlin.

We had lunch at Alexanderplatz near the iconic television tower, and we had a walk/roll towards the Brandenburger Gate. We went on to Potsdamer Platz and visited the enormous Berlin Mall. This was an elegant multi-story shopping centre with all you could wish for in all price levels. After another meal the project of transporting 17 wheelchairs (among which four were electric) from Alexanderplatz to the Reichstag (Parliament) started. It took half an hour to get everyone up one level to the U-Bahn platform only to be rejected by the train drivers who had orders to carry only two wheelchair users on each train. The 9-minute train journey thus took us one and a half hour in total... Then after visiting the Globe at the top of the Reichstag where we had a good view over the city we got on with the two-hour return to the hotel.

Day 3

We had a more serious start this day with a sitting at the hotel where all shared what the concept "self determination" meant to them. Many stressed that asking for assistance was no problem and that a disability obviously limits what other people would call independence and freedom. Most participants felt that freedom to control your own life and make your own decisions in everyday life is what matters, and this is decisive for life quality. We moved on to discuss health insurance and aid systems in various countries.

After a long but informative meeting we had some time off. Some went to see the well-known "Uhr der fließenden Zeit" while others relaxed at the hotel. Later we all met up at a nice bar downtown for some good food and what they called Diesel (beer and coke). We hung out until closing time, and even the staff joined us when the other guests had left.

Day 4

Saturday was the last whole day in this beautiful city. We went to a museum called Story of Berlin. Informative, but we quickly realized that this museum was probably for a older group of people than us. Soon after we went back to the Berlin Mall to go for more shopping. As day became night we steered our wheels towards the Sony Centre. This is a very fashionable neighbourhood with new, high-rise buildings and a slightly futuristic ambience.



We had yet another good meal and the mood was very good now as everyone had gotten to know each other quite well. One electric wheelchair user had a chair breakdown on the way home, and this resulted in the journey taking close to three hours! Nothing could break our stride though; we were even expelled from the hotel restaurant due to an ostensibly loud mood, so we took to a playground nearby where we stayed until the early hours.

Return home

Sadly the last day had arrived and people started their journeys home after a big hugging session in the hotel lobby. While the other Norwegians returned with direct flights I had booked a journey via Copenhagen to Oslo for my friend and assistant Simen and me. Bad decision. A delayed flight from Copenhagen resulted in us having to spend the night at Oslo airport having just missed the last flight home from there. Oh well, we did catch the first flight the next morning though.

Summary

The OI Youth Weekend 2015 in Berlin was a huge success. Good planning and engaged and enterprising organizers made this weekend into a great experience. The only downside was the logistics of transporting this many wheelchair users in one go.

Thank you to the German OI Society and thanks to everyone else who contributed to making this a jolly good trip!

Calendar

2016

February 29th : Rare Disease Day <http://www.rarediseaseday.org>

May 6th :Wishbone Day (international awareness day for Osteogenesis Imperfecta)

June 4-5th : 30th anniversary of the Swiss OI-Association (SVOI)

November: OIFE annual general meeting in Salamanca, Spain

2017

August 27th – 30th : 13th Conference on Osteogenesis imperfecta in Oslo, Norway

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