Newsletter
Issue 26

In This Issue:

<table>
<thead>
<tr>
<th>Editorial</th>
<th>P. 1-3</th>
</tr>
</thead>
<tbody>
<tr>
<td>Please welcome...!</td>
<td>P. 3-4</td>
</tr>
<tr>
<td>New role of Ute</td>
<td>P. 4</td>
</tr>
<tr>
<td>Remember ...</td>
<td>P. 5</td>
</tr>
<tr>
<td>Seminar “Issues 2015” - a Success</td>
<td>P. 5-7</td>
</tr>
<tr>
<td>News in brief</td>
<td>P. 7-8</td>
</tr>
</tbody>
</table>

Editorial
“A passion for OI”

Dear OI-friends around the world! First of all, I need to say thank you for the trust you have showed by electing me as the new President of Osteogenesis Imperfecta Federation Europe (OIFE). And thank you for your brilliant job Ute Wallentin! Nothing less than 14 years as the former President of the OIFE! Can you imagine? I can assure you that it will be hard to fill your shoes, even if I have been your ‘trainee’ for the last 12 months.

Like Ute, I have for many years been interested in this mysterious condition called Osteogenesis imperfecta, brittle bones or OI. Not that surprising, since I’ve had the diagnosis myself for more than 40 years.

But maybe my interest is a little bit over the average. Because I think you must be a little bit crazy to take over this job. And the reason why I volunteered, is probably because I have a passion for OI. For 14,5 years I have been the chairperson in the Norwegian OI association (NFOI). I have learned a lot from these years and gotten to know a lot of interesting people. And some of my best friends I have met in the OI-community both nationally and internationally...

Now I am looking forward to collaborating with a huge international network of professionals and people with OI - all of them interested in improving the lives of people with OI. And I don’t know where I heard the expression “passion for OI” the first time. But I think it must be from professor Glorieux or dr. Fassier– two giants in the OI universe.

The strange thing is – no matter where you travel in the world – there are quite a lot of similarities between people who have OI. The financial situation can be completely different from country to country. I admit that I am privileged to come from Norway where we get free health care, free mobility aids and government support for our organizations. I will try to be conscious of this in my new position. Because I am fully aware that OI-organizations in other countries struggle to provide people with wheelchairs, bisphosphonates and medical treatment. Others are more into peer work and raising awareness about OI, combined with different kinds of fundraising.
But whatever the situation might be and wherever you go – you will find the unique OI-spirit. I don’t really know how to describe it. And I don’t want to sound all ‘inspirational’, because I hate that. But I think the OI-spirit is all about survival and having a positive attitude despite a lot of challenges in life. Dark humour also helps when life is playing tricks on us. Children with OI are born with a rare condition that involves a lot of pain and disappointments – especially in the younger years. And I think this does something to us. It makes us good at coping with different challenges. A lot of time is spent in hospital with books and pedagogic toys, which perhaps give OI-children an advantage in school compared to the children who spend all their time on more physical activities. They also get used to dealing with tricky choices and professionals at an early age. Perhaps this makes children with OI more verbal than other children?

Because I honestly don’t believe people with OI are born smarter than others. And I have met some pretty stupid people with OI. But their upbringing and challenges have perhaps made us tackle our life in another manner than other people? As a famous geneticist in Norway said about the type II children: “Some of the children with OI type II are just too stubborn to die…”

I doubt if people with OI have the opportunity to have a higher education in all countries. But my impression is that it’s not only in Norway that people with OI are overrepresented regarding higher education. Then it depends on the disability access and welfare system in the country if you are able to get and keep a job. I’m not saying that all people with OI have to work or take a higher education – but from my point of view these are important factors in achieving an independent life. My advice to young people with OI would therefore be – move out from your parents’ house as soon as possible (if possible)! Your life will be so much better after that...

And I think this is one of the main duties of the OI-organisations around the world. In Norway – children, youngsters, parents and adults with OI have met in big family meetings for years. I think this has created an arena where the different generations can ask each other questions – but also learn from examples and have good role models. Children with severe OI can see that Maria or Robin with severe OI has gone to university, moved out from their parents (maybe a little bit later) and gotten a job. Or maybe they are just active in a political party, a sports team or a patient organization? Sometimes a job is not the answer, but keeping active is the important issue...

In the family meetings, worried parents can also observe that parents of other OI-children dare to let their OI-children participate in ‘dangerous’ activities. And most of the time it works out well. Overprotection is in my opinion one of the worst dangers for children and young people with OI.

And the young people who attend the meetings have the opportunity to ask the adults. When did your hearing go bad? How did you get your first job? And how was it to start dating? Well, I will not lie to you – dating with a disability is NOT easy. But sometimes it’s easy to blame the disability too much. Many non-disabled people are single as well. And if you don’t go out there and try – it’s never going to happen. That’s for sure...
Hmm...how did I end up here? From talking about a passion for OI –to ending up talking about dating! This is probably not the area where I should give any advice at all. So I stop it right here...

The sun has set over Oslo now. Autumn has arrived and today I had to turn on my extra heating for the very first time since May. I think I will spend the rest of the evening trying to find cheap plane tickets to a warmer place.

No matter what you are passionate about – I wish you all a pleasant autumn. I am looking forward to doing an effort – trying to make the world a better place for people with OI. Hopefully with your help...

Ingunn Westerheim
OIFE President since Sept. 18, 2015
Norway

Please welcome with me: Ingunn Westerheim, new OIFE president since September 2015

By Ute Wallentin

I have the immeasureable pleasure to present to you my successor in this demanding volunteer's position.

Ingunn Westerheim just turned 40, lives in Norway´s capital Oslo for many years, but she grew up in a small town on an island called Stord on the Norwegian West Coast. Ingunn speaks Norwegian and English – and read a little bit of German, French, Spanish and Dutch. She lives with OI type III (has never been tested) and had around 40-50 fractures.

She uses a manual wheelchair inside + when traveling and a "Permobil" outside (in Norway you really need one). Despite her job she has been the board leader in NFOI for the last 14,5 years, and instead of only retiring from this work, she volunteered to be a candidate for the OIFE presidency (and is planning to retire as Norwegian OI-leader soon).

Ingunn works 50% as a legal advisor in the Labour and Welfare directorate in Norway and has a 50% disability pension (for the last 4 years). From March 1st 2015 (until March 1st 2016) she is actually on an annual leave from her legal work to travel and do OI-work on a national and international level. Since 2014 she is also the project manager of the 13th international conference on OI – www.oioslo2017.org . She says she has a "passion for OI", but in her private life she spends time with traveling, attends rock music and other concerts, tries to spend enough time with friends.
and to read books - she communicates a lot via the internet.

Her travel blog is interesting to read and gives first-hand-information about wheelchair accessible destinations: https://wheeltheworld.wordpress.com

Ingunn was and is the best choice as new OIFE president, competent, sensitive and intelligent, fun to be with, an excellent team-worker, but with obvious leader-skills, I am extremely grateful that I could "pass on" the OIFE and the tremendous and exciting tasks that lie ahead for all of us (the OIFE in the US; the BBS, United Kingdom, our huge international OIFE-network including parents, OI adults and excellent, dedicated health professionals) on to her recently! "OI (and now we all with Ingunn) can do!!"

Ute Wallentin
OIFE - retired second and Ex-president of the OIFE (2001 - 2015)
now German OIFE delegate and responsible for "networking & social projects"

New role of Ute – coordinator of OIFE’s social network

The OIFE is an umbrella organisation for OI-organisations and we don’t have individual membership. But from time to time, the OIFE receives inquiries from people with OI or their relatives from different countries around the world. People ask for information, financial support, where to find doctors with OI experience, advice regarding medical treatment or other issues.

What we usually do in these situations:

- Ask the person to contact their local OI-organization (if there is one)
- Give the person advice (which doctor to contact, where to find info etc)
- Put the person in contact with one of OIFE’s member organisations who provide support for individuals (for instance Padrinos)
- Put the person in contact with other OI-people in the area so they can give each other mutual support.

Sometimes putting people in touch with each other locally can lead to the establishment of an OI-group in a new country. In these situations the OIFE might give advice on how to start an OI-organisation.

If the OIFE office gets inquiries like the ones above – we will forward them to our new coordinator of our social network: socialnetwork@oife.org

The name of the new coordinator is Ute Wallentin, and you all know her well from before. We are happy you are still willing to support the OIFE with your volunteer work Ute!
Remember to update your contact info!

Since Ute Wallentin has been the president of the OIFE for 14 years, many people have gotten used to the fact that contacting the OIFE is the same as contacting Ute. The former President of the OIFE has been extremely good at networking and she has a lot of contacts around the world. We therefore need your help. Please update your contact information as soon as possible!

**president@oife.org**: President (Ingunn Westerheim)  
**info@oife.org**: President (Ingunn Westerheim) and Secretary (Steffi Wagner)  
**office@oife.org**: President (Ingunn Westerheim) and Secretary (Steffi Wagner)  
**socialnetwork@oife.org**: Social Network co-ordinator (Ute Wallentin)

And perhaps Ute’s e-mail is not the only one you are not 100% certain of?

**delegates@oife.org**: All the OIFE-delegates  
**youth-coordinator@oife.org**: Anna Rossi  
**Webmaster@oife.org**: Ivar Troost + Rob van Welzenis  
**Ass-webmaster@oife.org**: Rob van Welzenis + Ivar Troost

**ISSUES 2015 A SUCCESS – “OIFE is pushing the Envelope on organising Medical Conferences”**

A topical seminar about Osteogenesis Imperfecta - saw 73 delegates from 21 different countries attend the ‘Soft Tissues & Soft Issues’ event hosted and arranged by the Norwegian OI-organisation (NFOI) together with the umbrella organisations OI-Norden and the OIFE. The event took place in Oslo from September 16th – 18th 2015.

The seminar is thought to be the first of its kind covering the topic of OI and non-skeletal issues. The participants consisted of a variety of healthcare professionals including doctors, nurses, physiotherapists, occupational therapists, psychologists and others. Among the contributors was Professor Francis Glorieux of the Shriners Hospitals in Montreal. 40 per cent of the participants were delegates from European OI-organisations. Organisers were pleased to gain assisted funding for the meeting from Alexion Pharmaceuticals.

**Seminar topics**

Seminar talks focused on the physical challenges adults with OI face, excluding fractures being the most known consequence of OI. But OI can also involve challenges regarding soft tissue as well as lung-, cardiac and gastric issues. This can cause pain and fatigue and other complications for people with OI. The goal was to increase the knowledge and encourage more research in non-skeletal issues as well as development of services for adults with OI. Examples from adult clinics in the
Netherlands, Denmark and UK (Birmingham) were presented and well received. Another goal was to discuss how complications can be prevented by follow-up routines. During the final session a proposal of follow-up routines were presented by dr. Lena Lande Wekre, based on the PHD "A Population-based Study of Osteogenesis Imperfecta in Adults – Clinical and social aspects". You can download the abstract book:  [http://nfoi.no/issues2015/Topics.aspx](http://nfoi.no/issues2015/Topics.aspx)

**Delegates from the OIFE**

Delegates with OI themselves presented testimonies and joined a panel discussion where professionals could ask them about life as an adult with OI. There were several sessions that allowed discussion between people with OI and the different healthcare professionals. The seminar also covered news on research, registries and collaboration between researchers and patients.

**Positive feedback**

During the seminar, we came over several positive Tweets from dr. Lars Folkestad using the hashtag #Issues2015.

**OIFE:** Thank you for calling our seminar ‘Soft Tissues & Soft Issues’ the best organized conference you have ever come across! We were so happy to hear that. What were you particularly satisfied with?

**Dr. Lars Folkestad:** First of all I would like to say that from a participant’s point of view the meeting went flawlessly. There were no major slips in a tight program and we were on time through out. All communication was sent out in good time and with the information we needed.

**OIFE:** During the seminar you tweeted that the organizers were pushing the envelope on how to organize medical conferences. Would you like to elaborate on this?

**Dr. Lars Folkestad:** Well, most conferences are by researchers for researchers about whatever the researchers find important. I have been to a lot of meetings, but never been to one where the patient organizations decided what were important topics and primed the researchers with questions they wanted answered. This is a new way of thinking and it was a great experience. I have been to another conference where a big pharmaceutical company had hired actors to play patients in order for us to hear the ‘patient’s like stories’. At Issues2015 we got to hear real stories and listen to real problems. I had feared that it would decrease the level of science, but I don’t think it did.
OIFE AGM
The seminar was followed by OIFE’s annual general meeting, where new President Ms Ingunn Westerheim was unanimously elected to the Board. Romania and Portugal changed status from associate to ordinary member organisation and the OIFE also welcomed Fundación Niños de Christal de Panamá as a new associate member organisation.

News in brief

Romanian OI programme in 2014
Following lobby efforts of patients’ organizations, the year 2014 witnessed the introduction of telescopic rods within the OI national health programme for rare diseases. In this way, both the drug component and orthopedic component of the OI treatment protocol are entirely financed from the state budget for healthcare.

According to the official information received from National Health Insurance House (the authority in charge with the implementation of the healthcare services) in 2014:

- 29 children received drug treatment (pamidronate infusions). The actual budgetary expenses were 18,950 lei, while the projected budgetary expenses 43,000 lei;
- 9 children received telescopic rods. The actual budgetary expenses were 247,000 lei, while the projected budgetary expenses 800,000 lei. (The average exchange rate of the national currency (leu) is 4,5 lei /1 euro.)
The national programme for rare diseases – OI section is implemented within 2 children’s hospitals in Bucharest and one county hospital in Târgu – Mureș. Also, pamidronate infusions are made in other general or children hospitals all around Romania, but the corresponding expenses are not known and are not included in the above figures. As one can see, there is a lot of budgetary „room”, therefore we are confident that more and more OI children will benefit from the best available OI treatment options.

Series of documentary films on rare diseases (in french): Igor Pejic is currently working on a documentary film about Osteogenesis imperfecta and is still looking for persons to participate. For more information, please see www.ulule.com/unepersonnerare or contact Igor directly: ipejic@lasocietedespossibles.com.

Visit OIFE at:
Website: www.oife.org
Facebook: : https://www.facebook.com/OIFEPAGE
Twitter: @OIFE_OI