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Editorial

By Ingunn Westerheim - OIFE President

Share, Care, Cure ... and?

The launch of the European Reference Networks (ERNs) took place in Vilnius, Lithuania in March 2017. And in Vilnius, Rebecca Tvedt Skarberg, was invited to share her vision on the future of the ERNs with politicians and professionals from all over Europe. Together with Avril Daly (vice president of EURORDIS), she was one of the two voices from the patient community at the kickoff. Rebecca is a patient representative (ePAG) in BOND - the network for rare bone diseases. She was suggested by the OIFE, but her mandate is to represent people with all kinds of rare bone diseases. I encourage you to check out her talk here: http://bit.ly/2tGsRkG

BOND - similar to the other networks for rare & complex diseases is still under construction. But it's becoming clearer for me (and hopefully for you) what BOND’s role is and how it can change the lives of people with rare bone diseases in Europe - if they succeed. In order to achieve this, BOND needs funding from the EU. And it worries us that EU-president Juncker is signalling less focus on health issues in European policies and programmes. This is why the OIFE has decided to support the initiative of the European patient organisations - where concern is expressed on the consequences this change in focus might have for the ERNs and other health projects in Europe: http://bit.ly/2sPf85Z
BOND had their official kickoff in Rome in June. Due to a fracture, Rebecca could not attend. But thanks to new technology and cooperative professionals, she attended via streaming from the hospital bed. What did we do before the Internet? Dagmar Mekking from Care4BB also attended the meeting, but in a slightly different role.

Is it still a bit unclear for you what these ERNs are and what they are going to do? We thought you might feel that way. But instead of attaching factsheets to this newsletter, we encourage you to visit the resource page of EURORDIS. There you can find a lot of information on the ERNs as well as the patient advocacy groups (ePAGs): http://bit.ly/2ut8lCQ.

The ERN slogan "Share.Care.Cure" is catchy. Sharing is important. One of the main goals of OIFE is to encourage more sharing of ideas, examples and tools between our members, between professionals and between the professional community and the patient community. Sharing is caring.

Care is also important. At OIFE AGM, May 2017, the delegates agreed on the following vision for the OIFE: "Children, youth and adults with OI living active independent lives worldwide - with access to competent healthcare, follow-up and social support.”

We have received some reactions to this vision in retrospect, but I still think it's a nice vision for OIFE. We are and will continue to be a European umbrella, with our main activities in Europe. But we also have associate members outside Europe. And I don't see a problem in wishing for a better life for people with OI - no matter where they live. What the OIFE must do to achieve it and what others need to contribute with is something else. Access to competent healthcare, follow-up and social support for people with OI is what OI-organisations strive to achieve all over the world. And if someone has figured it out in Europe...or the US, or in China - should we not share the ideas & tools in order to create better services all over? Sharing is Caring!

OIFE's main goal is not to provide services to individuals. We are not set up for that. Our goal & mission is to create networks and arenas - where sharing of good ideas and examples can happen. We will not provide care, wheelchairs or individual support. The local care providers need to do that, or the organisations in some countries. But we can encourage it and give advice on how it can be done. We are an umbrella organisation and our role is different. We can help people share ideas & information - whether it is physically (meetings and seminar) or virtually through our different networks.

Share. Care. Cure. Perhaps the cure is more important for some than others? Some adults with OI actually find it difficult when the main focus seems to be a cure. Maybe because they identify strongly with their OI as something that has shaped their personality and lives? Who would they be without the OI? Would they even consider the cure, if it existed?

Personally, I'm a pragmatic. Yes, OI has shaped my life to a great extent, and I wouldn't be without all the opportunities OI has given me. I've travelled, volunteered and met inspiring people all over the globe. But this doesn't mean that I don't want a cure. What does a cure mean? A quick fix or something that will wipe away OI? No, we are not
even close. Most of the research being done at the moment has another goal, which is reducing the severity of OI. And this is good, isn't it? Personally, I could do without some of the pain, discomfort and worries. Even if it has shaped my personality and made me more resilient...

Perhaps the Share.Care.Cure is missing a Q for Quality? Because who are these patients they all talk about? At the ICCBH-conference in June, I tried to remind the allied health professionals that we are primarily people with OI - not patients! When you are in hospital, you regard yourself as a patient. But the rest of the time - a sister, lawyer, traveller, mother, party animal, nerd and whatever other qualities your personality might include. We are patients in medical care, but this is not where we live our lives. And my wish would be even more focus on this space in our lives.

And even if we're not patients, we still have our challenges. We have pain, fractures, mysterious symptoms, too little energy and worries about the future. Regarding ourselves but also because of our kids. Please give us tools to handle our lives as people with OI - and not only as patients! Good **quality** of life is possible to achieve for most - if we only have access to the right care, follow-up and social support (mobility aids, assistance, financial support, education etc). And this care & support should be accessible whether you are a child with OI, a young person, an adult or an old person. And no matter where in the world you live. In my vision...

*Ingunn Westerheim, OIFE President*
What is the OIFE doing?

By Ingunn Westerheim

News in brief from the OIFE

Summer is still here, but holiday has to wait. Just as you had to do for the OIFE newsletter. We're sorry for that. At the OIFE virtual office, we're trying to catch up after the AGM in Poland. What must be followed up and how? Below you can get a short glance about what the OIFE has been working on since last edition. In addition to the topics mentioned - we have also worked on supporting the countries who are still struggling to get bisphosphonates "accepted" as treatment for children with OI. Still without major breakthroughs unfortunately.

OIFE Annual General Meeting in Poland

The 25th OIFE AGM took place in Warszawa, Poland from May 26-28. We were very warmly welcomed by the Polish OI-organisation. Thank you so much for that! We had constructive discussions about OIFE's strategy - short and long term, which was the main topic. We also welcomed OI Latvia (LOIB) as a new ordinary member of OIFE. The minutes from the meeting will be made available at our webpages when they are finally approved by the delegates.

Group picture with OIFE delegates and members of the Polish OI-association
Other meetings and events

Representatives from OIFE have attended a number of meetings the last 4 months. In addition to the most important ones below, there have also been numerous Skype-meetings with Care4BB, with OIFE members and volunteers:

- Phone conference with research project Rare Commons - February (IW)
- EC-meeting in Milan, Italy - Feb 24-26 (all members of the EC)
- Course on patient participation in research, Oslo, Norway - March 9 (IW)
- Kickoff for the European Reference Networks in Vilnius, Lithuania - March 9-10 (Rebecca T. Skarberg)
- Phone conf. with Patient Primary - March 24th (IW)
- Skype with Q&A session between OIFE's president and Russian children & youth attending Russian OI-camp - April 18
- Eurordis AGM, Budapest, Hungary - May 19-20 (Céu Barreiros)
- Kickoff for the European Reference Network for rare bone disorders (BOND), Rome, Italy - May 22-24 (Rebecca T. Skarberg followed the meeting via streaming - Dagmar Mekking from Care4BB was present)
- Skype with dr. Luca Sangiorgi (BOND ERN) - June 16 (IW)

Russian children with OI having fun during their OI-camp in April this year. Ingunn (photo in the right bottom corner) talked with the young people via Skype.

In the OIFE newsletter you can read about the international study Asteroid, by the company Mereo Biopharma. The European kickoff took place in Copenhagen from May 3-5. The investigator meeting gathered researchers from Denmark, UK and France and OIFE's president gave a talk about the OI-community, patient organisations and challenges and opportunities on patient recruitment.
Ingunn gave a talk about the role of the patient organisations. Care4BrittleBones presented their consensus project on Rehabilitation for children with OI.

The OI-community was also well represented at the International Conference on Children’s Bone Health (ICCBH) with representatives from Norway, Germany, Estonia, UK and the Netherlands. Ingunn Westerheim and Ute Wallentin, (second from left) represented the OIFE, and OIFE’s medical advisor Dr. Oliver Semler had an active role during the conference.
“Flying OI-Experts”

On June 29th OIFE's own Medical Advisor Oliver Semler gave a talk about rehabilitation of OI-children at The First Eurasian Orthopedic Forum in Moscow, Russia

http://eoforum.ru/forum

The conference had more than 3000 participants and was a good opportunity to create awareness about OI among Russian professionals.

After the conference, Oliver visited several clinics in Moscow - where he met children with OI and their doctors/physiotherapists. Oliver's travel was financed with the support of the OIFE-project "Flying OI-Experts".

OIOslo2017 - Pre Conference seminar on Patient Participation

On the 26th of August, the Norwegian OI-organisation NFOI is inviting OI-delegates to a pre-conference seminar about "Patient participation in OI-research". It is open for representatives from OI-organisations who are attending the OIOslo2017-conference. See www.oioslo2017.org for more information.

Questions? Please e-mail president@oife.org
Some Reflexions on AGM 25

By OIFE honorary President Rob van Welzenis, The Netherlands

Dear friends,

My wife Lidy and I were very happy to be able to (partly) attend AGM 25 and we enjoyed it very much. Our aim was not as much to participate in the discussions, but more so to meet old and new friends.

I also wanted to experience the first AGM in an eastern European country. Poland announced its intention to join the OIFE already some 20 years ago, so it was good to see that they had succeeded to do so. I have the feeling that they felt welcome and will be actively participating in the OIFE from now on. This once more proved the value of the principle that the OIFE AGM is held together with a meeting of the OI society in the host country.

It was good to see that the OIFE is still very much alive after these 25 years. I could never have imagined that it would have grown to such an important and established institution as it now is. Most of that development is of course due to the previous president Ute Wallentin.

For Lidy and myself it was a very emotional meeting, because it was our farewell to the OIFE and the many friends involved.

I can be proud of being your honorary president

Rob van Welzenis

New OIFE member: Welcome Latvia!

Since May 26th 2017 OIFE has Latvia as new member. It is the first member country of the Baltic states (former Soviet Union states) and we welcome Dace Liepina as official OIFE delegate from Latvia’s OI association called LOIB. In the following interview you can find out more about LOIB and the situation in Latvia.
Who are you and what is your relationship to OI?

My name is Dace and I am mother to a 7 year old lady with OI type 4. We live in Riga, which is capital city of Latvia.

Can you tell us a few words about Latvia?

Latvia is in the centre of Baltic states. Country borders with Estonia, Russia, Belarus, Lithuania and Baltic Sea. It’s population is 1,978,000 according to last population count on 2015.

Latvia has a huge capital relative to its tiny population, with over one third of the population living in Riga. Riga is well known for its Art Nouveau buildings. Since Latvia is located by Baltic sea, we are very lucky to have great sandy beaches, all of which are accessible to public. Although Christianity is dominating now, we are still holding to our pagan roots and celebrate midsummer and other pagan celebrations, by trying to stick to original ways they have been celebrated. So don't be surprised if you come to Latvia on 23rd of June and see across all countryside fireplaces and people gathering around them, singing, dancing and jumping over them.

Can you tell us about your organisation?

The organisation was founded on January 2011, so it is 6 years old already. At this point we are reactivating membership so by the end of summer we will be able to tell more precise amount of members. So far we have been in touch with 13 persons with OI.

These are our goals and activities:

• Gathering people with Osteogenesis imperfecta (OI) and their families into Association and database compilation;
• Informative support for members of the Association, exchange of experience with OI related matters, and in situations where people with OI and their families feel lonely;
• Informing public and health care responsible government institutions about needs and problems of people with OI and their families;
• collecting information and publication in mass media about OI;
• Medical database compilation of doctors and medical professionals who have experience in treatment of patients with OI

How do you recruit members/promote the organisation?

We have a Facebook group and information about the organisation has been sent out to genetic doctors, rehabilitation doctors and other health care professionals.
Emilija and her friend Alesa (both affected by OI) enjoying summer in Latvia

Biggest challenges in Latvia

Currently the biggest challenge is to find medical professionals for adult health care. For children everything more or less is set and there are treatment possibilities, but once the child is over 18, it all stops. So our plan is to get in touch with doctors who would be willing to take care of adult OI patients and make a good communication with them, so that if an adult with OI comes to us, we would know, whom to refer to.

Plans for the future

Short term internal plan is to organize a meeting with OI families. It will be in the end of July and aim is to finally meet and get to know each other and discuss further plans of action for the organization.

However priority task is to send out letters with hope to collaborate with doctor associations to get OI more visible among doctors in order to get the best health care possible.

We are still developing and trying to understand how we can use the organization at its best to help those who are having OI and their families. We are setting up Facebook page for OI organization in Latvia to be able to share information and to inform about OI related topics in Latvia.

New OIFE Youth Group on Facebook

Since the original OIFE Youth group on Facebook was established so many years ago, we’ve been having some technical problems with it lately. It was lacking many of the functions of a normal Facebook-group, and this made it difficult for our Youth Coordinators to accept new
members. We have decided to close the old group and create a new one: https://www.facebook.com/groups/OIFEYouthONLY

OIFE Youth Only is OIFE's closed Facebook-group for young people with OI aged 16-35. A closed group, means that only people who are part of the group can read what's being posted on the wall.

In the group you can share news, thoughts and experiences about being young with OI. Joining the group will also give you an opportunity get to know young people in other countries than your own.

The group is ONLY open for young people (16-35 years old) who have OI themselves. Parents or professionals are not allowed to enter. You don't have to belong to one of OIFE's member organizations to be part of the group.

OIFE has two Youth Coordinators: - Stephanie Clayes &- Marie Holm Laursen. If you have questions about the group you can contact them on Facebook or send an e-mail to youth-coordinator@oife.org

Announcements

Come join us for OIOslo2017!

The 13th International Conference on Osteogenesis Imperfecta will take place in Oslo, Norway from August 27 - 30, 2017.

Register at www.oioslo2017.org

Questions? post@oioslo2017.org

Quality Hotel Expo, Oslo, Norway
Research Announcement

The OIFE would like to bring your attention to a clinical research study investigating the effect of anti-sclerostin therapy in osteogenesis imperfecta (OI).

Mereo BioPharma is sponsoring a multicenter clinical trial to study the effect of anti-sclerostin therapy drug BPS804 on the strength and quality of bone. Multiple sites in Europe, the United States and Canada will be recruiting study participants. Adults ages 18 years and older who have a diagnosis of OI Types I, III, or IV are eligible for this 1 year clinical research study.

Visit their Clinical Trials Website or their Study Website (www.asteroidstudy.com) to learn more, find your nearest study location, and register your interest in participation. If you have any additional questions, please email asteroidstudy@mereobiopharma.com. Their study contacts will be able to tell you more about the clinical research study, review eligibility criteria, and find a site near you.

Disclaimer: The OIFE is not involved in the design or management of this research, and as such, is neither endorsing nor supporting this study. The mission of the OIFE is to keep the OI community informed of all relevant studies. This information is made available as a service to the OI community. We are available to answer questions on this or any other research announcement. Please contact the OIFE at office@oife.org if you have any questions.

Life with OI in Turkey

Original text in Turkish by Elif Gamze Bozo
English translation: Volkan Serin

Dear Readers,

First of all I want to start writing by mentioning myself. I was born in Ankara in 1984. I came to life with brittle bone disease. Due to my situation at the beginning of elementary school, I have not asked to be taken to school. After all, I was taken to the school with great effort of my family. I have completed the courses with distance education.
because of the obstacles of transportation for disabled people in Turkey and my health problems. And then I graduated by completing Anadolu University Public Relations Publicity and Journalism department on the same way. I am a documentary photographer as a member of the Turkish Photography Art Federation and also a call center assistant at the leader customer services of a telecommunication company in Turkey. Rare diseases are not fully known in Turkey. In my childhood, my doctor did not have enough information about OI. Following studies abroad about OI disease by my father, we could get some knowledge. In my school years we had so much difficulty because school management and teachers did not want to take responsibility with fear of breaking my bones in any case. Rare diseases are still not known in Turkey and patients with these diseases are not well informed by many doctors. In short, the awareness about OI is at the lowest level.

We, brittlebone patients are living away from education, health and employment rights. The Ministry of Health does not count the number of brittlebone patients anyway. When I sent a letter to the Ministry of Health a few years ago, "I like to know the number of brittle bone patients in Turkey", the answer was "We are not separating the disabled groups. And we do not know the specific numbers". In response to the answer, I regretfully asked the question to myself, "How can I reach brittle bone patients and help them?". Due to the inaction of the Ministry of Health on regulation of the health committee report on health reports, brittlebone patients are given the same health reports like all other orthopedic disabled people. Because of these reports, we get mistaken for other disabled people else and this causes medical malpractice on us. Medical expenses and needs of a patient with brittle bone are not the same like spinal cord paralyzed patient. There are no water therapy and physical therapy centers available for brittle bone patients in Turkey. In addition, brittle bone patients do not know what kind of treatments are applied and which medicines are used. Brittle bone patients are restricted to participate in social life by their parents with the fear of the bones will break.
In order to change this perception, we organized a conference on May 10, 2017 with the students of the Faculty of Political Sciences of Ankara University to work on awareness. The aim was to give the right message to the community with public service announcement.

My purpose was as a director to tell the patients with brittle bone and their families our disease more accurately and raise the awareness of the society. The conference brought the voice of awareness with the participation of OI patients and the national press. Our aim was to change the perception of the disease that the parents are wrong about and we have succeeded on our own hook.

Yes I know! There is no cure for this disease! However, medical treatments and water therapies can raise the our quality of life. We can join social life with the help of these.

My only chance was the support of my family in every aspect. I hope that rarerly seen diseases will become known by the society and they will not remain as orphan diseases.

Elif Gamze Bozo
News in brief

OI in South Africa: We congratulate Brittle Bones South Africa with their official launch. This is the link to their Facebook-page:
https://www.facebook.com/brittlebonessa

Their webpage you find here:
http://www.brittlebones.co.za

Ghana launches OI Foundation

The program started with a mammoth float that attracted the attention of market women and the ordinary person on the streets of Cape Coast, the central region of Ghana. The program also saw parents with children with OI coming all over Ghana, including a parent from Nigeria with her OI child.

Branded OI T-shirts were distributed freely to the over 200 participants who joined the celebration on 6th May, 2017. Mrs. Justina Yiadom-Boakye, the founder of OI-Ghana called for government and individual support for people with such conditions so that they could live their full potential. She sent a clear message to parents all over Africa, especially in countries where such children are banished to desist from such evil practises and called on stakeholders to make a difference by creating the awareness on the opportunities available to OI children.

www.oifghana.org

Justina Yiadom-Boakye, the founder of the OI Foundation Ghana with two supporters
Calendar & Contact

2017
August 11-13: BBS UK Family Conference & AGM in Newcastle
August 19: ZOI Belgium summer tour: boat trip in Antwerp
   Including:
   • August 26: OI-Community Seminar-Patient participation in OI-research
   • August 27: Physiotherapy Seminar
September 1–3: OI Austria 10 year anniversary, Wien, Austria
September 19: VOI The Netherlands “Aftersummer dive” with BBQ
October 5-7: OIF Clinical Meeting on OI, Baltimore, USA
October 7: VOI The Netherlands General autumn meeting
October 15: ZOI Belgium family meeting with guest speaker
October 21: VOI The Netherlands Adult meeting
November 1- 5: OIFE/VOI Youth Event in the Netherlands

2018
January: First Central American OI Congress in Honduras

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