The time is now

By Ingunn Westerheim

For a number of years treatment of OI was mostly limited to bisphosphonates, surgical interventions and physiotherapy. Basically it still is, if you think of approved and standardized treatment. Bisphosphonates actually celebrated their 50th anniversary this year. For the last 25-30 years or so, it has been an important factor in OI. The same category of drugs with different names and labels, have given children growing up the last 20 years, a different start compared to people my age. We do however get on with our lives, even if we didn't receive the gold standard treatment, when we were young. The problem with bisphosphonates is that they only affect the quantity of bone and not really the quality. By slowing down osteoclasts, the body builds more bone of the same questionable quality as before. It helps, but it's far from a miracle cure.

But times are changing and new options are on the horizon. I think it's fair to say that there has never been so much research going on in OI and other rare bone diseases as today. Stem cells are being investigated in the project Boost Brittle Bones Before Birth (BOOSTB4). Mereo Biopharma has finished the first phases of the Asteroid trial, which is investigating the drug BPS804 (setrusumab) as a treatment for OI. The first results seem promising. BPS804 is approved as an orphan drug, which means that the drug is being developed specifically for a rare disease (in this case OI). This has generated the need for new knowledge in the OIFE and might later have consequences for our national organizations, when the drug potentially will be up for approval by the national health & pharma authorities & the payers. Another research project (MOI) lead by dr. Nick Bishop from the UK has received funding for an international study which will investigate repurposing of the drug Losartan in OI - a drug which is primarily used as a treatment for high blood pressure.
Don't ask me how that is going to work! But the experts have faith that it might have a positive effect on bone strength in people with OI. The study is connected to the international network C4C for pediatric trials and patient engagement.

An increasing challenge for researchers is to find enough people who are willing to take part in the different studies that are recruiting in different parts of the world. All of us want new treatments options to be developed, but not that many want to try out medicines that have not been approved or used for a long time. The challenge is - if nobody wants to go first, we will never have new knowledge. Certainly a dilemma that needs to be addressed...

Another increasing challenge for OIFE is to find enough people who can take on the role as patient representatives in different research projects. The demand for patient representatives has increased dramatically during the last four years. Paying attention to the voices of people with the disease, has become an increasingly important criteria when projects apply for funding and research grants. And the demand for OI-people with bright ideas and enough time to invest in various projects is huge.

OIFE and our member organizations really need to put our minds together and discuss how we can solve this challenge, which is basically a luxury problem. Why so? Because I truly believe that the outcomes of research & clinical development will be substantially better and more efficient if the people who will benefit from it are directly involved from A to Z. How can we as organizations find and recruit the right people? How can we train and educate patient experts when needed? Sometimes what’s needed is merely input from a person with OI/parent without that much knowledge about OI or how the system works. But sometimes the role as a patient representative is so demanding that you need knowledge about the system and organizational experience in addition to personal experience with OI. I’m talking about patient experts who can represent the OI-community in steering committees, in meetings in the European Medicines Agency (EMA), in health technology assessments nationally and internationally and people who can contribute as ePAGs in the European Reference Network for Rare Bone Diseases.

Fortunately the OI-community has solved great challenges before. The OI-organizations with its many engaged volunteers have a tradition for coming together and helping both each other and the professionals, when difficult questions needs to be answered and problems must be solved.

A good example of collaboration between engaged professionals and OIFE-volunteers was the topical meeting See, Hear, Smile! in Riga, Latvia. Together we created an interesting programme focusing on new and important topics - eyes, ears and teeth of people with OI. We managed to gather prominent lecturers from all over Europe and from Canada and the US. Between Riga and Amsterdam some of us met at the International Conference for Rare Bone Diseases (ICCBH) in Salzburg, where different stakeholders established a network between organizations, companies and other stakeholders interested in rare bone diseases, including OI.

In November we'll meet again in Amsterdam. The conference QualityofLife4OI will hopefully gather many researchers, clinicians and people with OI to discuss how quality of life of people with OI can be measured more systematically in order to make OI-research better and more efficient. The conference is initiated and organized by the foundation Care4BrittleBones and is a collaboration between the organizations OIFE, OIF and the European Reference Network for Rare Bone Diseases (ERN-BOND).

So much going on! Sometimes when my email explodes and my mind is spinning, it feels like too much. But the opposite would be worse, wouldn't it? What if nobody was interested in OI and no development was happening at all? This is certainly not the case at the moment. The time is now. And we have to use it wisely...
What is the OIFE doing?
By Ingunn Westerheim - OIFE president

A very busy spring has passed. It's already mid September and I wrote the editorial more than two months ago. But then conferences happened and the magazine had to wait. The topical meeting See, Hear, Smile! in Riga was followed by a constructive but packed and very busy OIFE AGM. And then I had 2-3 days at home to become human again, before I moved on to Salzburg and the ICCBH-conference. There my main task was to co-host the establishing meeting of a new multistakeholder European Rare Bone Forum. Unfortunately you will not be able to read about any of those events in this magazine. We are way overtime already, so we will mostly concentrate on what happened before OIFE AGM. OIFE Magazine 2-2019 is not hot news, but we hope you will enjoy the special edition about research anyhow. Want more up to date news? Check out our news section on our www.oife.org, where we try to publish more recent news and happenings.

Meetings and events
The months from January until June were mostly used for planning upcoming events, which generated numerous emails and videocalls. We provided input to Mereo Biopharma (Asteroid study) and we were asked to find patient representatives to other research studies. Rebecca Tvedt Skarberg also attended many meetings in ERN BOND's steering committee and working groups. And on behalf of OIFE, Ida Männistö attended meetings in the steering committee of Key4OI.

Besides videocalls & teleconferences with OIFE volunteers and member organizations, these where the most important meetings from January - June:

• EC videocalls, Jan 15th, Feb 5th, Feb 12th, March 19th, April 23rd, May 21st, June 4th & 11th
• See, Hear, Smile! Programme committee, Jan 3rd, March 18th and May 20th
• Several meetings connected to A stronger BOND between us - ECTS, ICCBH & ad hoc management group Salzburg event (IW)
• George Reynolds, RareUrn (consultant Mereo Biopharma), March 27th (IW)
• European Hearing Instruments Manufacturers Association (EHIMA), April 9th (IW)
• Nick Bishop & Janet Crompton about OI2020, April 23rd (IW)
• Kyowa Kirin, May 16th (IW)
• Francois Houyes, EURORDIS about Drug Repurposing project STAMP, May 23rd (IW)
• Meeting ERN BOND ePAG Rebecca Tvedt Skarberg & NFOI, June 3rd (IW)
• Video lecture recording with Dr. Suken A. Shah, June 12th

ERN-BOND
On the February 13th-14th the second technical meeting of the European Reference Network for Rare Bone Disorders (ERN BOND) was held in Brussels. 27 members of BOND participated and among these all 4 of the ePAGs (patient representatives). In addition to Rebecca Tvedt Skarberg (OIFE) and Inês Alves from ANDO Portugal, the ePAGs now include Elisabeth Martin from France from the Association Olliers Mafucci and Tenna Toft Olsen from XLH Denmark.

Annual reports from all the working groups were presented at the technical meeting as well as the achievements of ERN BOND so far. Other topics that were discussed were the effects of Brexit and how BOND wants to continue to work together with the UK in the best possible way also after Brexit. Another topic was the new BOND website and social media pages on Facebook and Twitter. Hopefully these sites will grow and help communications within the rare bone disease community.
ERN BOND is looking forward to new projects and tasks and is slowly but steady finding its place in strengthening information, knowledge and treatment of rare bone diseases. Please follow the website [https://ernbond.eu](https://ernbond.eu) in addition to Facebook & Twitter for more updates.

**EURORDIS EVENTS IN BUCHAREST**

**Black Pearl Events**
The Black Pearl Events took place on the 12th of February and Rebecca Tvedt Skarberg and her husband Knut Erik attended. They had the pleasure of meeting the Princess of Romania and other royal guardians of the awards. The awards gather and pay tribute to people, organizations and companies who make outstanding efforts for people with rare diseases. After welcome drinks in the foyer of the Le Plaza Hotel in Brussels they enjoyed dinner while the awards were being presented. The rare disease field consists by people who think outside the box, who are willing to work hard and go the extra mile for raising awareness about their disease. The many testimonies from the prize winners underlined this fact. You can read more about the event here: [https://blackpearl.eurordis.org/about/](https://blackpearl.eurordis.org/about/)

**EURORDIS MEMBERSHIP MEETING**
Over 200 representatives of people living with a rare disease were present at the EURORDIS membership meeting in Bucharest from May 17th-18th. The meeting included the AGM of EURORDIS followed by workshops where various topics were discussed. The goal was to discuss next steps for implementation of the new position across Europe for the provision of holistic care for the 30 million Europeans living with a rare disease and their families. Romanian delegates Dana Andrei and Florenta Plugariu represented OIFE with the support of Rebecca Tvedt Skarberg.

**A stronger BOND between us - establishment of a European Rare Bone Network**
One of the goals of the OIFE project called “A stronger BOND between us” has been to create an informal network between different stakeholders working on OI and other rare bone diseases. In December/January we were part of forming an ad hoc working group consisting of OIFE (Ingunn Westerheim), Inês Alves (ANDO Portugal) and Gerald Brandt (HPP Deutschland). Our goal was to host an establishing meeting connected to the ICCBH-conference, for a multi stakeholder network. The purpose of the meeting was to discuss what the goals of such a network should be and how it could work. We were supported by the European Calcified Tissue Society (ECTS), different pharmaceutical companies, ERN-BOND, the International Conference on Children’s Bone Health (ICCBH) and others.

**OIFE at MOCA-meeting**
The European Medicines Agency and EU healthcare payers continued their cooperation on June 17th at a meeting in Diemen, the Netherlands, to help improve timely and affordable access for patients to new medicines (MOCA - Mechanism of Coordinated Access to Orphan Medicinal Products). Margriet Crezee from the Netherlands represented OIFE as a patient representative to talk about the patient perspective. Topics on the agenda included evidence generation for orphan medicines, unmet medical needs and horizon scanning for pharmaceuticals.
Who is Who?  
OIFE’s Medical Advisory Board

Fátima Godinho

My name is Fátima Godinho, 47 years old, married with 2 children.

I am a senior rheumatologist consultant working at a Hospital in Almada Portugal. I am also the Vice-President of the Portuguese Association of OI (APOI)

I have been a specialist in Rheumatology for 15 years and I follow adults of all ages with osteogenesis imperfecta (OI).

Rheumatology is a specialty dealing with musculoskeletal pathology of various etiologies. As we have a vast training in internal medicine, in addition to dealing with the musculoskeletal manifestations of the diseases. We also deal with the manifestations of OI in other organs or systems. We are the specialty responsible for the basic assessment of these patients, identifying their problems, treating them and directing them, when necessary, to other more specific specialties such as ophthalmology, ENT or orthopedics.

I also organize several meetings for patients, their families and other health professionals about OI.

The most important mission of OIFE is to improve the quality of life of OI patients. This implies the support of these patients in all medical and social areas. Support scientists in the area of research, dissemination and knowledge about new treatments and support to associations in other countries, centralizing the efforts so that all together can improve lives of people with OI.

Lidiia Zhytnik

My name is Lidiia Zhytnik. I obtained Bachelor’s degree in Gene Technology in 2012 and Master’s degree in Biomedicine in 2014. I am currently a PhD student and junior researcher in University of Tartu (Estonia), Department of Traumatology and Orthopedics.

I have mild OI and it encouraged me to study genetics and do research in the OI field. Since my Master studies in 2012, I joined the Estonian OI research team, under supervision of orthopedic surgeon Katre Maasalu. I continue to work with OI during my doctoral studies. It helped me to get in contact with other people with OI: Ukrainian Association of Crystal People, OIFE members and OIFE youth.

My PhD project is about OI genetics in Estonian, Ukrainian and Vietnamese populations. We have gathered a biobank of 237 OI families from three countries and currently analyse causative mutations in our cohort. In the future, I would like to continue with OI research and to focus more on causes of OI variety inside families.

I think that the most important task for the OIFE is to inform the research community about needs and interests of patients with rare disorders and to promote collaboration for benefits of OI patients.
New Study: Physical Function And Soft-Tissue Health in OI

Interview with Dr. Alex Ireland and Dr. Sergio Orlando,
both from Manchester Metropolitan University, United Kingdom

What is your profession and what is your relationship to OI?
My name is Dr Alex Ireland, Senior Lecturer in Physiology at Manchester Metropolitan University, UK. My research has previously focused on how the shape and structures of our bones and joints is affected by physical activity and disuse throughout life. I also examine factors which affect the size and strength of our muscles, as muscles are very important for maintaining bone and joint health. I became interested in OI, because there seemed to be little information on how muscle and movement was affected particularly in adults.

My name is Dr Giorgio Orlando, Research Associate at Manchester Metropolitan University working with Alex. During my PhD, I carried out research into the effects of diabetes on muscles. Currently, I am working on the impact of OI (type I) on muscle, bone, and tendon health. During this time, I have become particularly passionate about this topic and have understood that my research activity must be centred on helping people affected by this severely debilitating condition.

Can you tell us about your research project?
We know that OI affects bones, but soft tissues (muscle/tendons/ligaments) also contain a high proportion of the type of collagen affected by OI. Many people with OI also report clinical problems with soft tissues such as joint hypermobility, dislocations and muscle or tendon injuries. Muscle/tendon weakness could also lead to impaired balance and mobility, which affects daily living and contributes to fall and fracture risk. Studies by Prof Frank Rauch and colleagues in Montreal have shown that children with OI tend to have smaller, weaker muscles and be less
physically active. However, there are no studies describing muscle or tendon health or physical function (balance, mobility, etc.) in adults with OI of any type.

Our research project (http://brittlebone.org/physical-function-and-soft-tissue-health-in-oi/) aims to examine the size and function of muscles and tendons in young adults with OI type I. This work is being completed in collaboration with Prof Peter Selby from Manchester Royal Infirmary. We are still recruiting young adults aged 18-35 with osteogenesis imperfecta type I, this will involve a 2-hour visit to our central Manchester laboratory for which travel expenses will be covered. If you appear eligible for this study and would like to participate, please click the link above for further details.

In addition, we are using some existing questionnaire data from the Rudy Study to find out how mobility and other activities of daily living differ in people with different types of OI, and how that impacts on their lives. We are collaborating with Dr Kassim Javaid from the University of Oxford on this work. For individuals in the UK with OI, you can sign up via this link to take part in the study, which investigates different aspects of health and function in people with OI and other rare conditions through questionnaires: https://research.ndorms.ox.ac.uk/rudy/

How is the project financed?
The project has been supported by a Research Grant from the Brittle Bone Society (BBS) a charity supporting people in the UK and Republic Ireland with OI and their families. Additional support has been provided by our university.

Do you have patient involvement (organizations or people with OI) in your project? How?
The BBS have been very supportive throughout this project. We attended their Family Conference to discuss our project, and got some very helpful and supportive feedback from individuals with OI and their families. We also discussed the project with medical colleagues with experience of working with individuals with OI at the BBS Annual Scientific Symposium, which also gave us encouragement and some helpful suggestions.

Do you have a message for the readers of OIFE Magazine?
As researchers new to working in OI, we have been very grateful for the support and encouragement for our work both from individuals and organisations within the OI community. We are keen to develop this initial work to encompass adults of different ages and OI types in future projects, and we will keep you posted!

**Identifying Gaps in OI Research – Report from OIF Scientific Meeting**

*By Dr. Antonella Forlino, member of OIFE’s Medical Advisory Board*

It was a great pleasure to be sponsored by OIFE to participate at the 19th Annual OI Foundation (OIF) Scientific Meeting held in Chicago on April 10-12 and co-chaired by Dr. Marini and Dr. Raggio. The American Scientific Community involved in OI research met together to discuss on the extremely stimulating topic “Identifying Gaps in OI Research”.

Basic, translational and clinical researchers were present. It was a great opportunity to deeply discuss various OI related questions in a friendly and stimulating environment. Dr. Marini opened the Meeting with a brilliant overview on our current understanding of the disease in terms of different OI types, their molecular basis and clinical manifestation.
The first Session on “The Role of Cellular Metabolism and ER stress” moderated by Peter H. Byers provided an exciting update on the relevance of cell homeostasis as modulator for OI bone phenotype. The accumulation of mutant collagen type I in many OI types has been demonstrated in several studies and the modulation of its intracellular fate has been pointed out as possible target for novel treatments. To stimulate protein folding using chemical chaperones as well as to enhance protein degradation by favoring autophagy have both been considered valid approaches.


Finally, Dr. Phillips illustrated an interesting and novel link between muscle weakness and mitochondrial dysfunction in OI using the oim murine model (Gremminger VL, et al. J Bone Miner Res. 2019).

Session 2 “OI Type VI and Atypical OI Type VI and the pathway connecting them” chaired by Dr. Schwarze, was focused on the recessive OI forms type V and VI caused by mutation in IFTIM5 and PEDF genes, coding for the protein BRIL and Pigment Epithelium Derived Factor, respectively. Interestingly, a specific mutation in BRIL (S40L) generates in human a clinical outcome resembling mutation in PEDF, but the biochemical bases are still uncertain. A cross talk between PEDF and TGFβ in modulating PPARγ expression during osteogenic differentiation was proposed by Dr. Kang. The role of PEDF in osteoblasts differentiation and the potential use of a PEDF mimetic peptide was presented by Dr. Niyibizi. The very peculiar phenotype associated to overexpression in mice of the protein BRIL carrying the human S40L mutation, responsible for the unusual OI type VI phenotype presented by Dr. Moffatt and the new knock-in model carrying the S42L mutation generated by Dr. Guterman-Ram will open new possibility to understand the role of BRIL in osteoblasts function.
In session 3 “Bone cells and transplant” chaired by Dr. Nagamani, an update on the potentiality of local transplantation of skeletal progenitor in murine model was provided by Dr. Sinder and Dr. Morello presented new RNAseq data that will help to dissect the role of osteocytes in the OI disease development.

Session 4 was focused on the “Response of Murine Models to therapeutic antibodies” and chaired by Dr. Glorieux. Dr. Kozloff presented data on the effect of anti-sclerostin on cranial bone in a murine model of OI, further confirming the goodness of the therapy. A novel system based on the use of patient’ bone chips subcutaneously implanted in nude mice, followed by local antibody injection, has been presented as tool to evaluate the patient specific effect of the drug. Dr. Rauch reported interesting data on the limited effect of anti-TGFβ antibody treatment in the severe OI model Col1a1<sup>trt/+</sup> mice (Tauer JT, et al., J Bone Miner Res. 2019;34(2):207-214).

In Session 5 “Surgical Fractures and healing” chaired by Dr. Kruse, Dr. Smith, Dr. Zieba, Dr. Franzone, Dr. Robinson addressed the questions of OI fracture healing using OI murine model and OI patients observation. A better understanding of fracture repair in OI is necessary to improve the treatment of OI fractures, also considering rodding and bisphosphonate treatments.

Session 6 focused on the “Clinical Natural History” of OI was chaired by Dr. Rush. Dr. Raggio, who suggested cardio-pulmonary screening for all patients, discussed the cardiac and pulmonary complications in adults affected by OI. Dr. Marini presented a standardized chart for growth/BMI in classical OI (Barber LA, et al. Genet Med. 2018). The session closed with an innovative study on the OI cornea presented by Dr. Moroi.

Session 7, chaired by Dr. Rauch was focused on the “Updates on Treatment Protocols”. A preliminary update of the status of the two clinical trials: Mereo trial (Setrusumab, anti-sclerostin antibody) and Fresoluminab trial (Anti-TGFβ antibody) was provided by Dr. Nicoal and Dr. Nagamani, respectively. Dr. Shapiro closed the meeting with a discussion on the current treatment for OI.
Welcome to OIFE China Dolls!
Interview with Zhou Shuang, director of China Dolls

Who are you and what is your relationship to OI?
Zhou Shuang, not affected by OI, is the director of China-dolls center for rare disorders, and she works here more than five years.

How many people with OI does China have?
There are approximately one hundred thousand people with OI in China according to the incidence rate of one in 10,000 - 15000 people.

Can you tell us about the situation for people with OI in China?
People with OI face a lot of challenges in China such as economy, treatments, social inclusion, education and employment. Treatments: there are very few hospitals where doctors can give correct treatments to OI patients. A lot of patients had experienced error diagnosis, error treatments or partial treatments, all these problems leads to serious deformities, high disability rate and high financial burden.

Can you tell us about your organization?
China-Dolls Center for Rare Disorders (CCRD), formerly known as China-Dolls Care and Support Association, was founded by individuals with Osteogenesis Imperfecta (OI) and various rare disorders in May of 2008. CCRD was registered under Beijing Civil Affairs Bureau in 2011. Jinan China-Dolls Center for Rare Disorders was founded and registered in 2015. Currently, CCRD has 2 offices in Beijing and Jinan, Shandong.
As a non-profit and non-government organization, CCRD works with and for people with OI on local medical promotion, medical aid, peer mutual support by empowerment, policy advocacy and public engagement. We aim to raise public awareness of OI, to eliminate discrimination and prejudices, to secure equal rights of people with OI on healthcare, education, employment and other areas, and to promote related policies to benefit people with OI.

Our Vision & Mission:
We work together with and for people with OI and their families, through peer supports, multi-stakeholder engagement, OI community awareness raising, public education, medical research, multidisciplinary treatment promotion, health and education policy advocacy. To create an equal, inclusive and barrier-free society.

You recently celebrated the 10th anniversary of China-Dolls. Please tell us about the event
Inadvertently, China-Dolls Center for Rare Disorders has gone through a decade, the establishment of the Illness Challenge Foundation has been nearly three years. So we held the 10th anniversary of the event of China-Dolls Center for Rare Disorders. More than 400 people who were OI people, volunteers, partners, media and lots of friends from various backgrounds enjoyed this evening. Special guests gave fantastic performances, keynote speeches helped listeners know CCRD deeper, and the charity auction showed people’s great support.

A fantastic evening with many performances celebrating 10 years China-Dolls

Together, we maximize the capabilities and possibilities to help a considerable numbers of people. With so many people’s help, we boost our confidence to channel more support to the rare disease community.
Who are you? What is your profession and what is your relationship to OI?

Cecilia Götherström:
I’m a researcher who have explored the potential use of stem cells for treatment of OI and other diseases for almost 20 years. My “relationship” with OI started in 2002, and since then it has been closest to my heart.

Eva Åström:
I’m a pediatrician and pediatric neurologist and leader of the Swedish multidisciplinary pediatric OI-team and the main principal investigator of the clinical trial BOOSTB4. I am also a member of the OIFE’s medical advisory board.

Can you tell us about your research project?
We have previously treated a few unborn babies and children with OI with stem cells, which has shown promising results. The Boost Brittle Bones Before Birth (BOOSTB4) project is a European network centred around four clinical hubs in Stockholm, London, Cologne and Leiden/Utrecht. We will investigate if stem cell transplantation before and/or soon after birth is a safe, feasible and effective treatment of OI. We hope that an early treatment of OI will result in a better effect and that maybe less treatment is needed later in life. If we see a good effect of the stem cells, we will explore their use in older people with OI. The project will also evaluate the acceptability of this type of stem cell therapy, both from the patient and family perspective as well as from health professional in the area, and from an ethical perspective. Finally, we will develop a method for non-invasive diagnosis of OI. This means that for diagnosis of OI during pregnancy one could take a blood sample from the pregnant woman instead of taking a sample from the fetus.

If you are interested in participating in the BOOSTB4 trial, you are welcome to contact us (BOOSTB4@clintec.ki.se). Children under the age of one year diagnosed with OI type III or severe type IV with a collagen type 1 mutation may participate in the trial.

How is the project financed?
The BOOSTB4 project is financed by the European Union's Horizon 2020 research and innovation programme (grant agreement 681045) and by the Swedish Research Council. We have also received funding from Care 4 Brittle Bones for studies of the previously treated children with OI.

Do you have patient involvement (organizations or people with OI) in your project? How?
When we in 2015 wrote the research application to the European Union, we wanted to incorporate the views of patient organisations on the project. OIFE gave input on the project and kindly wrote a support letter that was included in the application. Since then the project has investigated
stakeholders’ views to understand the believed benefits or concerns, identify ethical issues and establish protocols for support and counselling. This study involved adults affected with OI, with and without children affected with OI and parents of children affected and patient advocates from relevant patient support groups. You can read the report on OIFE's webpage. We have also asked for input on the trial participant information and other trial documents from patient organisations.

Do you have a message for the readers of OIFE Magazine?

Cecilia: I have a motto that comes from Pippi Longstocking: “I have never tried that before, so I think I should definitely be able to do that!”

Eva: Always try to improve treatment options without causing harm, and remember that every individual is unique.

OI-Symposium in India
By Eva Åström, OIFE Medical Advisory Board

The Centre for Stem Cell Research at the Christian Medical Collage in Vellore, India arranged a two day symposium on OI and stem cell treatment the 6th-7th of February 2019. The aim was to provide a platform for scientist and physicians working in this field of research to come together and discuss the recent developments for better diagnosis and management of OI. Invited speakers from Australia, India, Sweden, UK and USA were participating in person, by video link or recorded video lecture followed by skype discussion.

The main focus for the first day was “Translational research in OI & Cell Therapy” with the main topics: prenatal diagnosis (Suresh), clinical assessment and management (Åström), radiological assessment (Gibikote), update on OI classification (Sillence), molecular diagnosis (Shah), surgical management (Fernandez), medical management (Åström/Sillence), Quality of Life, physiotherapy (Hill), cell therapy (Horwitz) fetal MSC therapy (Götherström), BOOST2B collaboration (Madhuri) and role of DXA (Paul).
The theme for day 2 was “Current Regulatory and Ethical Requirements for Conducting Cell Therapy Based Clinical Trials/Research”. Main topics were the need of dialogue between regulators and investigators and industry (Srivavtava), current challenges in regulations of production, distributing end export/import (Hedenskog), regulations in India (Gopta) and Europe (Franzén), regulatory changes in India (Nair), manufacture and quality assurance of MSC (Walther-Jallow), requirements for reconstitution (Goos), graft manipulations for allogenic SC-transplantation (Mathews), requirements for a new cell-scaffold product trial in India and clinical trials using them (John/Madhuri) and finally clinical concerns and regulatory strategies for implementation (Walther-Jallow).

During two intense but extremely well-organised days in beautiful surroundings and an outdoor temperature of 35 degrees we connected and learnt from each other.

EURORDIS Meetings 2019
By Dana Andrei & Rebecca Tvedt Skarberg

Black Pearl Events
The Black Pearl Events took place on the 12th of February and Rebecca Tvedt Skarberg and her husband Knut Erik were invited to attend. They had the pleasure of meeting the Princess of Romania and other royal guardians of the awards. The awards gather and pay tribute to people, organizations and companies who make outstanding efforts for people with rare diseases. After welcome drinks in the foyer of the Le Plaza Hotel in Brussels they enjoyed a three course meal while the awards were being presented. The rare disease field consists by people who think outside the box, who are willing to work hard and go the extra mile for raising awareness about their disease. The many testimonies from the prize winners underlined this fact. You can read more about the event here: https://blackpearl.eurordis.org/about/

EURORDIS AGM 2019
Over 200 representatives of people living with a rare disease were present at the EURORDIS Membership Meeting in Bucharest from May 17th – 18th 2019. The meeting included the Annual General Meeting of EURORDIS followed by workshops where various topics were discussed. Romanian delegates Dana Andrei and Florenta Plugariu represented OIFE with the support of Rebecca Tvedt Skarberg.
The goal was to discuss next steps for implementation of the new position across Europe for the provision of holistic care for the 30 million Europeans living with a rare disease and their families by 2030 structured around three pillars that were explored in detail:

- Quality and adequate social services and policies
- Integrated care: bridging health and social care
- Equity of rights and opportunities

EURORDIS and its members are calling upon the EU, all European countries and all stakeholders within the health and social sector, to disseminate the new position about holistic care and to take action based on its recommendations.

The Panel Discussion covered:

- Five targets that will allow to achieve holistic care for by people living with a rare disease in Europe and their carers 2030 Europe and their carers 2030
- How to start and promote integrated/holistic care at national level
- What achievements/services do we already have that can be used for integrated holistic care for rare disease patients and the wider community

You can find all the presentations from the workshops here: [https://bit.ly/2mqNRZV](https://bit.ly/2mqNRZV)

For me as both representative not only of OIFE but also of the Romanian OI-association it was a very useful meeting to get new knowledge. I could collect a lot of helpful information to improve the collaboration between the Romanian OI-association OIROM and the Romanian National Alliance for Rare Diseases. Many thanks to OIFE for allowing me to represent them in this meeting!

**Rare 2030**

Rare2030 is a first-of-its-kind project created to carry out a foresight study on the future of rare disease policy. Led by EURORDIS in cooperation with seven other partners, Rare2030’s end goal is to propose policy recommendations that will lead to a better future for people living with a rare disease in Europe.
The partners have already brought together nearly 180 key opinion leaders in a new Panel of Experts and started building a knowledge base of new trends that will drive future rare disease policy. This panel has met online through several webinars and will convene on 7 November in Brussels to validate these identified trends and consider future policy scenarios that could form the Rare2030 concluding recommendations.

OIFE will contribute to the process through our ERN BOND ePAG Rebecca Tvedt Skarberg. Rebecca and Dana already participated by attending the Rare2030 workshop held during the EURORDIS Membership Meeting 2019 where participants brainstormed future trends and drivers of change in rare disease policy. The information from that meeting is being brought together in a series of steps of consultation that will inform the final recommendations, to be presented at the European Parliament in late 2020.

**Marie’s Youth Corner**

*By Marie Holm Laursen, OIFE youth coordinator*

I have been participating in the Asteroid study since September 2018. It is a study where they will investigate in a new drug called BPS804. Hopefully this drug can improve the strength and flexibility of the bones so they won’t break as often. I get an injection every month on the hospital and each injection takes about an hour. It was really difficult for me to participate in the study because I didn’t fit the criteria’s. You have to be able to get your arm and leg in a scanner and if you have rods in your bones you can’t use the scanner. I have rods in all my bones but lucky my rods were short so they could get a small picture of my bones without any rods in the scanner. The short rods are not good for my bones but I was just so happy that I could participate in the study!

The doctors are not able to give a lot of information about the drug which is of course because it is a study. It is so weird to get some medicine injected into your veins every month and you have no idea if it is working or what the extent of effect could be. I haven’t had any side effects, which is really good.

For a while I started to think that the drug was working. When I started the study I was in a really bad period and my bones were very fragile at this moment. I had about 4 broken bones in a row and they happened out of nowhere. Then after I started getting the drug I didn’t break anything for a long time. Unfortunately I broke my leg in February and it happened when I moved from my bed to my wheelchair. This is something I do every day with no problems but this day my bone just broke. It was not because I put a lot weight on it so it was very weird. After this I wasn’t so sure that the drug was working but I still really hope that this drug can do miracles, but I just have to wait and see. They can’t tell me when I will get the results so I can only cross my fingers and hope for the best!
Volunteering for OIFE

Interview with Julien Delaye

Who are you and what is your connection to OI?
I am Julien Delaye, 26 years old, living in Belgium. Over the past seven years, I studied marketing, European Public Health, and more recently Public Policy and Administration, which took me to several places such as Denmark, the Netherlands, Finland and Ireland. A few months ago, I got introduced to Ingunn Westerheim as I had finished my studies in Dublin and was then actively looking for a first job.

Why did you decide to volunteer as an intern for OIFE?
Over my academic journey, I have developed a strong interest in rare diseases, with a clear emphasis on how patients and patient communities could contribute to future developments in healthcare. After meeting with Ingunn via Skype and being offered an intern position, I though working with OIFE was most definitely in line with my personal interests and motivations, as well as a great starting point for my career. What contributed to my decision to become an intern for OIFE is that I had – and of course still have – the feeling that, while acquiring some experience, I could make myself useful at the same time, and apply my personal skills to a good and important cause. I believe it is a win-win collaboration and, as a first job, I think it really helps me connecting with the rare disease world in a truly stimulating and human way.

What are your main interests professionally?
My main professional interests encompass rare disease policies in Europe and the roles patient associations could fill in various stages of policy and/or treatment developments. Having a quite political and public health background, I am especially interested in the European and national projects that could benefit from patients’ expertise and experience. In the future, I would like to work as a patient advocate in policy making, ideally at the European level, which is why the mission and activities of OIFE deeply appeals to me.

And hobbies?
In my free time, I am a great fan of traveling, mostly when it takes me to unusual places where most tourists don’t go. I also never say no to opportunities to try local food specialties while traveling, the fermented shark in Iceland and indescribable dishes in Cambodia being my most memorable experiences in that regard! I also love reading, writing novels or poems, and I recently developed a true fascination for Scandinavia. So I try to immerse myself in the Scandinavian culture through music and art. And of course, as Belgian, I must mention my love for beers and microbreweries from all over the world.

Do you have an advice to others who might consider volunteering for a non profit?
While I had never really thought about it before finishing my studies, I truly enjoy being a volunteer for OIFE. I believe it is the kind of experience that helps you shape your career in a perhaps more human and ethical way. I don’t really have specific advice for whoever is thinking about volunteering, except that you should be motivated to bring something, even if it may seem a small thing, to the non-profit your are applying at. If you are, then find the domain you are interested in and start looking for that kind of organization. Any organization that appeals to you for a certain reason is always a good choice.
Join the conference Quality of Life 4 OI, taking place from 22-25 November 2019 in Amsterdam!

The Conference organized by Foundation Care4BrittleBones together with OIFE, OIF, ERN-BOND and BBDC will provide a platform to engage on clinical practice and research aimed at increasing quality of life for people with OI. The conference discusses topics like surgery and rehabilitation, medical treatment options including stem cell treatment and gene therapy, diagnosis and psychosocial aspects like fatigue, pain and mental health. The conference takes a multidisciplinary approach and is focused on children as well as adults with OI. Key questions are: How do we measure outcomes in people with OI and what should the standard of good clinical care be in these areas?

This conference is for you, if you are:

- a health care provider or allied health care professional (Genetics, Internists, Pediatricians, Endocrinologists, Rheumatologists, Radiologists, Nephrologists, Orthopedic Surgeons, Nurses / Physician Assistants, Physiotherapists, Occupational therapists, Psychologists, Dentists…)
- a person with OI or closely related to someone with OI. We will do our very best to ensure we can accommodate the needs of every person with OI. Please be in touch to learn about accessible rooms and daily living support. A helpdesk has been established just for you (OI@qualityoflife4oi.org)! Don’t hesitate to ask!
- an industry representative interested in OI (pharmaceutical or other industry)
- an other representative, eg from EMA (European Medicines Agency), ERN-BOND, BBDC etc.

For more information and registration, go to www.qualityoflife4oi.org.

Contact: dagmar.mekking@care4brittlebones.org

Call for Late Breaking Abstracts

Don't miss the deadline 1st October
More therapies for rare diseases! - 3rd EURORDIS Multi-Stakeholder Symposium February 2019 in Brussels

By Taco van Welzenis, OIFE

Relevance for OI
EURORDIS, an alliance of 851 rare disease organizations, including OIFE, was the organizer of this event. The purpose was to discuss how more new therapies can be made available to rare disease patients. Many stakeholders like pharma companies, policy makers, politicians and rare disease patients were present. The 500 “most common” rare diseases constitute 98% of rare disease patients, the other 6500 “ultra rare” diagnoses are just 2% of patients. At this moment 95% of rare disease patients do not have a therapy available for their condition.

EURORDIS has therefore set the ambitious goal to get 3 to 5 times more new therapies approved per year for 3 to 5 times less of the cost by 2025. In 1999 the EU Orphan Drug Regulation (ODR) came into force, under the ODR 143 new products have been approved so far. The ODR attracts development of new medicines to Europe, thereby speeding up availability to the European market of the resulting products. OI is a relatively rare diagnosis with several new drugs for it in the pipeline - and possibly more in the near future – so the question of availability of new therapies is fully relevant to our community.

New therapies do not always reach the patient
But why is this such an issue? That becomes clear when we look at the chain of events that has to take place before a new therapy becomes available; Investment – Research – Authorization (EU level) – Assessment (mostly supranational) - Price negotiation, Allowance and Reimbursement (national level). Many complications can arise along this chain. Sadly this means potential good therapies sometimes fail to reach the patient. It can be because no agreement can be reached about the price, (very unsatisfying!), or the number of patients is too small to statistically prove efficacy. When an effective therapy exists but is not available for patients this can give rise to – illegal - production of the medication by hospitals, mistrust between parties and most importantly, huge frustration for patients.

The chain of events to reach a new therapy
Investors only want to give money when they expect a good return on their investment, the same for pharma companies (industry), who have to make a profit. Tests have to be done for effectiveness, safety and dosage. Rare disease therapies are a niche market and often smaller companies with less economic resources specialize in them. In Europe a central body decides about market authorization of therapies, the European Medicine Agency (EMA). When a product
fulfils some strict criteria EMA can give it “orphan drug designation”. This is highly desired because this also means that for the first years a company gets exclusive access to the EU market.

Next health technology assessment (HTA) bodies look how well the effect and safety have been proven, what the value is to the patient, what the side effects are and how this compares to the price that industry is asking. Often HTA assessment is done for several countries combined. Finally the national health care authority of each state negotiates with industry about the price and decide about allowance on the market and conditions for reimbursement at the national level. Besides the HTA assessment also the national healthcare budget plays a role here, which is both an economic and a political issue. Some of the wealthier states still spend relatively little on healthcare. A government can decide to prioritize care for rare diseases. Budgets and policies may change with each new government. Some people argue that rare disease therapies are very expensive, while some are indeed, most are not overly expensive. Because of the small number of patients the total costs amount to only 3-5 % of the total healthcare budget. Recently costs have received renewed attention because research into rare diseases also gives us therapies for common diseases, some of these innovative therapies are expensive which is a budget issue.

Possible solutions
The EU is supposed to function as a single market. But for medications this does not hold true. The reality is that we deal with some medium sized markets like France and Germany and over 20 small markets. This leads to higher prices and inequality within Europe when it comes to access. A real single market would seem the best way forward. If the EU could go to the negotiating table as one, representing perhaps hundreds or thousands of patients per rare diagnosis - it would be in a stronger position to negotiate a good deal with industry. EU wide transparency is easier for investors and pharma too, instead of negotiating 28 times about (ultra) small numbers of patients and dealing with many different HTA bodies. It would undoubtedly boost investment and therapy development. United the EU could also try to tackle some issues like industries trying to make huge profits with repurposing existing medications or massive increases in price once a drug has been proven effective.
In order to harmonize policies in Europe however, countries have to be prepared to give up some control over their budgets and policies, and it also demands economic solidarity between EU members. Patients with a rare disease have an equal right to care and new therapies. This point has been made at the EU level but it has not been translated into policy enough yet. If we adhere to this ethical standard it follows that we should be prepared to invest in rare disease therapies until the same level of care has been achieved as for more common conditions. Patient outcomes and all aspects of value should be taken into account when deciding about acceptable price levels. If we apply less strict rules for proof of effectiveness (not safety) at the point of market authorization that will speed up availability too. This can be done if the EU sets aside some money for evaluation of the effect at a later stage. As OIFE we can advocate for a fairer, more transparent sustainable system, encourage a Europe wide OI registry, further cooperation between the national healthcare systems, challenge misconceptions about orphan drugs, support EURORDIS and take part as patient experts at as many levels of the process as possible.

Research Announcement

The Swedish University Karolinska Institutet sponsors an academic multicentre clinical trial to study the safety (the primary outcome) and efficacy of the investigational drug BOOST cells (fetal mesenchymal stem cells) on fracture occurrence, growth, bone mineral density and biochemical bone turnover in children who have OI.

The BOOSTB4 trial will initially open to eligible children up to 12 months of age who have a diagnosis of OI Type III or severe Type IV with a collagen type 1 mutation. All 15 participants will receive four doses of BOOST cells four months apart. A second trial group is also planned, in which one dose of BOOST cells will be given to 15 affected fetuses before birth, followed by three doses of BOOST cells four months apart after birth. The trial is divided into two periods where the first period runs over two years, and the second period follows the child at his/her routine OI visits over an additional eight years.

The trial will take place in four countries: Stockholm in Sweden, London in the United Kingdom, Cologne in Germany and Utrecht and Leiden in the Netherlands. Please note that trial sites are not yet open, with recruitment anticipated to commence after summer 2019. Participants from other European countries are welcome to join the trial and travel to a trial site.

For more information and a complete list of trial locations visit the website www.BOOSTB4.eu. If you have any additional questions, please contact us via the email address BOOSTB4@clintec.ki.se.
**News in Brief**

**OI-Congress in Ecuador**
Do you live in South America? Then you should check out the OI-congress from October 16-17 in Quito, Equador. It is hosted by Fundación FEOI with support from OIFE & the OIF and professionals from Spain & Canada. Click here for more information & to register: [https://www.feo.org.ec/page/congreso2019](https://www.feo.org.ec/page/congreso2019)

**In Memoriam**
Sean Stephenson from the USA was probably one of the most famous people with OI worldwide. We’re sorry to hear about his passing, that was due to a head injury, according to his wife Mindie Kniss. May he rest in peace.

**Presentations from See, Hear, Smile!**
From June 14th – 15th around 85 people from 22 countries met in Riga, Latvia for the topical meeting “See, Hear, Smile!”. The participants were a mix between professionals, people with OI and others interested in the topic.

The goal of the meeting was to create an arena to present newer research and treatment methods related to eyes, ears and teeth of people with OI. The topic also included neurological issues affecting the head/brain (basilar invagination).

You can now download the presentations from the event from our new subpage about topical meetings: [https://oife.org/what-we-do/events/topicalmeetings/](https://oife.org/what-we-do/events/topicalmeetings/)

**Publish Clinical Trials!**
Did you know that all sponsors of clinical trials conducted in the European Union have an obligation to make summaries of results of concluded trials publicly available in the EU Clinical Trials Database (EudraCT)? Unfortunately many stakeholders don’t fulfill their obligation, which makes the database incomplete.

Why is publication important? Because transparency and public access to clinical trial results, whether positive or negative, are fundamental for the protection and promotion of public health. Transparency also enhances scientific knowledge and helps to advance clinical research and support more efficient medicine development programmes.

WEB BASED RARE BONE CLINICS
The OI Foundation and the Rare Bone Disease Alliance are excited to kick-off the Rare Bone Disease TeleECHO Clinic Series tomorrow! Professionals from outside the USA can also join! For more information or to register, visit www.oif.org/ECHO.

NEW VIDEO EXPLAINING OI
Check out the educational video about OI that the Swiss OI-organization Schweizerische Vereinigung Osteogenesis Imperfecta has created. The video explains the basics about OI as a collagen defect, diagnosis and treatment. It’s available in 2 languages:

German: https://youtu.be/i44KElsuaPs
French: https://youtu.be/GVZ_L1No7pg

WE NEED THE UK IN ERN BOND
OIFE is supporting the Genetic Alliance UK’s #ProtectERNs campaign that calls on the UK government and the EU to secure the sustained involvement of the UK in European Reference Networks (ERNs) post Brexit. This is especially important for the network for rare bone disorders (ERN BOND), because they have a substantial number of UK healthcare providers actively involved in the network.

ERNs connect patients, clinicians and researchers, allowing knowledge and expertise on rare diseases to be shared across Europe and in turn provide patients with access to diagnosis and transformative care without the burden of long-distance travel.

Support the campaign by signing up here: https://protect-erns.eu/showyoursupport/

NEW EUROPEAN RARE BONE FORUM
On June 23rd OIFE was happy to co-host the establishing meeting of a multistakeholder rare bone network together with Hypophosphatasie Deutschland e.V. and ANDO Portugal with the kind support of the European Calcified Tissue Society - ECTS and ICCBH. Patient involvement in research & development and educational activites for patients, professionals and industry representatives were mentioned as some of the top priorities for future collaboration.

CONECT4CHILDREN
New conect4children Consortium will include a study on Losartan as a treatment for osteogenesis imperfecta in children and young people. Losartan is a drug that is normally used to treat high blood pressure. The study aims to recruit 30 children. Study is lead by Prof. Nick Bishop of the University of Sheffield. The conect4children (c4c) consortium announced on April 29th the selection of its first portfolio of pan-European paediatric studies aimed at advancing the
understanding of high priority medicines commonly used in babies, children and young people in Europe. Read more here: https://bit.ly/2lAib3F

DISABILITY MINISTER
We congratulate Rick Brink with being elected as ‘Disability Minister’ in The Netherlands. The appointment of a special minister for the disabled is the award of a campaign by Lucille Werner.

She thought that there was far too little attention for the two million disabled people in the Netherlands. Through his informal position Brink has to lobby for the disabled people in the Netherlands as the new ‘minister’. Also, from his position he will question legislation and implement new ideas.

WEBINAR ON REGISTRIES
Registries was one of the main topics at OIFE AGM. Mr. George Reynolds gave a talk about the status on OI-registries in Europe and what will be needed in the future.

EURORDIS hosted a webinar June 25th where you could hear from experts Julian Isla (EURORDIS volunteer and Foundation 29), George Reynolds (RareUrn) and Luca Sangiorgi (ERN-Bond) about opportunities to create or become engaged in existing patient registries: Click here to watch the recording of the webinar: https://youtu.be/kbtsZxdGKhY

VIDEO LECTURE BI
The video lecture of Dr. Suken A. Shah’s talk about basilar invagination has now been published on OIFE’s YouTube channel. It was first presented at the topical meeting See, Hear, Smile on June 14th in Riga, Latvia. https://www.youtube.com/watch?v=KJA_3T9Ng

OIFE EXECUTIVE COMMITTEE:
Ingunn Westerheim and Ida Männistö have been re-elected as President and 2nd Vice President of OIFE for the next 4 years.

NEWS ON ASTEROID STUDY
Mereo BioPharma has announced encouraging 6 month data from the open label arm of its phase 2b dose-ranging clinical study in adults with Type I, III or IV osteogenesis imperfecta (OI) treated with BPS-804 (setrusumab), the “ASTEROID” Study.

OI AROUND THE WORLD
We congratulate «our man» in Bali, Ketut Budiarsa on his wedding day. Let love rule!

OI & HISTORY
Did you know that at the British Museum the ancient Egyptian mummy of a child with Osteogenesis Imperfecta is on display?

OI IN TAIWAN
Greetings from Taiwan where the OI-community have hosted a three day rehabilitation camp (Fish in water) for children with OI and their parents. Great job!

INVESTIGATOR AWARD
Today we send our congratulations to Lida Zhytnik from Estonia who’s a member of OIFE’s medical advisory board. This summer she was one of the winners of the New Investigator Award at the big ECTS-conference in Budapest. She won with a poster titled “Interfamilial variability in collagen-related Osteogenesis Imperfecta”.

STATISTICS IN CHILE
One year ago the OI-organization Fundación de Osteogénesis Imperfecta Chile created their national OI-registry. Now they are sharing their first statistics about the 93 people with OI they have collected data on.

Según el Catastro de personas con osteogénesis imperfecta (OI) en Chile de 2019, a mayo de 2019

93 personas con OI en 14 regiones

73% dice saber que tipo de OI tiene
50% ha recibido bifortunado
35% está estudiando
36% está trabajando
27% no estudia ni trabaja
44% está inscrito en el Registro Nacional de Discapacidad
67% está en Fonasa
27% está en Isapre
# Calendar OI-events

## 2019

<table>
<thead>
<tr>
<th>Date</th>
<th>Event Description</th>
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<tbody>
<tr>
<td>Sep 28-29</td>
<td>40th anniversary of Finland OI, Vierumäki, Finland</td>
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<tr>
<td>Oct 16-18</td>
<td>3rd Ibero-American congress on OI, Quito, Equador</td>
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<tr>
<td>Oct, 23-27</td>
<td>OIFE YouthEvent, Bilbao, Spain</td>
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<tr>
<td>Nov 22-25</td>
<td>Conference Quality of Life4OI, Amsterdam, The Netherlands</td>
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## 2020

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<tr>
<th>Date</th>
<th>Event Description</th>
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<tr>
<td>Apr 4th</td>
<td>AOI Journées Nationales 2020, Montpellier, France</td>
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<tr>
<td>May 1-3</td>
<td>NFOI AGM &amp; Family Meeting, Oslo, Norway</td>
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<td>May 8-10</td>
<td>OIFE Annual General Meeting, Valencia, Spain</td>
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<td>Jul 9-12</td>
<td>OIF National Conference &amp; 50th anniversary, Omaha, Nebraska, US</td>
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<tr>
<td>Aug 28-31</td>
<td>OIFE Youth Event, Krynica Morska (Gdansk), Poland</td>
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<tr>
<td>Sep 4</td>
<td>OI2020 - Pre-conference seminar for OI-organizations, Sheffield, UK</td>
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<tr>
<td>Sep 4-6</td>
<td>OI Austria Annual Meeting, Stubenberg, Austria</td>
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For updated list of scientific events & conferences - see OIFE's calendar: [https://oife.org/news-resources/calendar/](https://oife.org/news-resources/calendar/)

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