Editorial

By Anna Rossi
OIFE Communication Manager

Safe & active in the OI community!

The last couple of months have been anything but easy. For all of us, this pandemic has arrived as some kind of storm, about which we heard something on the news, but never really thought would have arrived and jeopardized so much our daily, ordinary and chaotic days. I live in Italy, one of those countries where the COVID hit hard and caught us suddenly and unprepared, at first least.

As for me, I was busy enjoying a Powerchair Hockey International Tournament as technical delegate when we got the news about the first COVID cases in Italy. For me that meant I had to stop worrying about game rules, classifications, referees and matches and start worrying about making sure all those athletes and staff members could fly or travel back home safely and fast.
Coming back to an empty Milan was shocking, but necessary to realize that this was probably more serious than what we were told. In a few days, the complete lockdown was announced and our home became the only safe place to stay and be.

For someone who was used to being surrounded by people and having plenty of things to do and places to go, it was really complicated to realize that most of my upcoming plans were not going to happen. I remember thinking that I had never spent so much time grounded at home even with both legs in a plaster cast. Because even back then, I used to find a way to meet people, go out or plan small trips somewhere. On the other hand, as a reaction I bought a drawing album and some colouring pencils. This was the basics my mum made sure to have at home when I was a kid with a bad fracture, facing long hospitalizations or long periods at home.

So there was a part of me that made sure there would be stuff to do at home in order not to get bored after my work was done - without powerchair hockey training and matches, or without the chance to plan something last minute and go to meet friends. The three months of lockdown, in reality, turned out to be quite a busy period. Not only due to work stuff, but fortunately because many of the appointments and events I was afraid to lose, became virtual. So honestly, I think I have been part of many more events, educational seminars and classes than ever before. Also, I was positively surprised by how active the OI community was in those weeks, and how much it meant for me to see and be part of it.

There has been so much going on - from informational and medical webinars to recreational initiatives that brought us together and gave us the chance to meet and talk and get to know more about ourselves, about each other, about OI and, last but not least, to meet many new people. The OIFE Virus Workout was for me a big thing. For a while I was thinking I should find a way to keep myself fit. And I have always found it so hard to exercise in a way that did not have the taste or the look of the boring physiotherapy after a fracture. I wanted to find a more active and demanding opportunity to work out. Thanks to Virus Workout training by myself became fun, because I was not alone while doing it. Also everyone online had their very own way of facing the training and the very same struggles that I had with some of the exercises on the videos. Getting the chance to train in an adapted way lead me to look for more of those videos, and now I am training on a regular basis from home, following some videos and knowing better how much to push myself.

Also, the organization of the AGM took a lot of effort and time and it was great to see it succeed and to be part of it. I think OIFE never had so many people together in a meeting from all over the world. And as the OIFE Communication Manager, this switched on a light about the need to promote more of those kinds of activities, as they allow us to get in touch with larger groups of people than real-life events. One of the things that I loved the most was to see how many wishes arrived for the #Wish4OI campaign. It was the first time OIFE really had a "strategic" approach towards Wishbone Day, promoting an international campaign. It was somehow risky as we could not be sure it would work out. And this is why it was so good and satisfying to see how many people from so many different countries decided to share their wishes.

Being an active part of the OI Community in these last three months made me feel part of a world that, even with the utmost respect of the virus, not only did not stop completely, but kept going and went further beyond: growing stronger, establishing new relationships and looking forward for future adventures and meetings.
This COVID 19 will keep us company for a while more and will keep affecting our daily lives. So yes, we need to keep being cautious, we need to keep paying attention, doing social distancing, using masks and protections and following the rules we are given. But we should never give up our hopes.

Every one of us have their own safe harbours where we go when things go wrong or bad to find peace and comfort. I have been reminded, once more, that the OI community is one of those harbours for me.

What is the OIFE doing?

*By Ingunn Westerheim – OIFE President*

On May 5th the OIFE took over the social media channels of the magazine Rare Revolution Magazine under the hashtag #tuesdaytakeover. The purpose was to create awareness about OI and OIFE to a larger audience and to build up to Wishbone Day. On May 6th the OI-community came together and celebrated the International Day of OI with different social media activities. This year OIFE’s Communication manager Anna had created a campaign called #Wish4OI where people with OI, parents and professionals shared their wishes and hopes for OI in the widest sense. We gathered all the wishes in a video and in addition Anna also created two smaller animation videos about OIFE and about OI. You can find all the videos on our YouTube channel: [https://www.youtube.com/c/oifeORG](https://www.youtube.com/c/oifeORG)

OIFE AGM was planned for May 8th – 10th in Valencia, Spain. But the meeting moved online as so many other meetings. This included the EURORDIS AGM, the ECRD-conference and many more meetings. The OIFE Youth Event in Poland had to be cancelled, but a youth Zoom took place last week. Two successful Zooms with the OIFE MAB have also been organized. So there are more than enough things to report about, even if travel and physical events is out of the question for the moment. Make sure you follow our blog on our [www.oife.org](http://www.oife.org) for more recent news and keep following us on social media.

So stay tuned, enjoy the magazine and look forward to new OIFE initiatives!

Anna Rossi – OIFE Communication Manager
Meetings and events

Videocalls in the last months have included meetings related to Mereo Biopharma, OI2020 in Sheffield and the planned project connected to the EJP RD Challenge on measuring mobility in rare bone diseases. There have also been videocalls (VCs) with OIFE members, volunteers and members of OIFE MAB in addition to:

- EC-meetings on Zoom April 4\textsuperscript{th} and 5\textsuperscript{th}, April 21\textsuperscript{st}, April 29\textsuperscript{th}
- VC between OIFE EC & Mereo Biopharma April 21\textsuperscript{st}
- OIF Covid19 webinar, March 19\textsuperscript{th}
- OIF Mental Health & OI Webinar, March 26\textsuperscript{th}
- VC Chan Zuckerberg Initiative, April 7\textsuperscript{th} (IW)
- VC Kyowa Kirin International about collaboration project OI & XLH, April 20\textsuperscript{th} (IW)
- EURORDIS webinar on Covid19, April 22\textsuperscript{nd} (IW)
- EJPRD Research Challenges Workshop May 4\textsuperscript{th} (IW)
- Expert meeting on Key4OI hosted by Care4BB, May 6\textsuperscript{th} (IW)
- OIFE AGM part 1 and 2, May 9\textsuperscript{th}
- Webinar European Rare Bone Forum on patient engagement, May 11\textsuperscript{th} (IW)
- EURORDIS AGM, May 13\textsuperscript{th} (IW)
- ECRD-conference, May 14\textsuperscript{th} – 15th (IW, DL, RTS and TvW + more)
- MEDEV-MOCA-meeting, May 26\textsuperscript{th} (Taco van Welzenis)
- Brittle Bone Society Webinar on Covid19, May 28\textsuperscript{th}
- VC Walter Atzori (Alexion), June 5\textsuperscript{th} (IW)
- EURORDIS webinar on data strategy for the ERNs, June 18\textsuperscript{th} (IW)
- VCs with OIFE MAB on April 6\textsuperscript{th} and June 19\textsuperscript{th} (IW and CB)

OIFE AGM

Our original plan for OIFE AGM 2020 was to meet in sunny Valencia from May 8\textsuperscript{th} to May 10\textsuperscript{th}. But the Corona virus put a stop to that, as it has done to so many other meetings and conferences. The EC decided to organize a two parts meeting on Zoom on May 9\textsuperscript{th} instead. Part one included approval of annual reports, budget and elections. We also presented our new financial policy. Part two included a webinar on new treatments in OI. Read more on page 7!

EURORDIS Events

EURORDIS AGM

On May 13\textsuperscript{th} Ingunn represented OIFE at the Annual General Meeting of EURORDIS on Zoom, which was scheduled to take place in Stockholm followed by the ECRD-conference. More than 240 people joined the first-ever virtual General Assembly of EURORDIS. A new Board was elected and we congratulate Alba Ancochea, Dorica Dan and Birthe Holm, who were all re-elected to the Board of EURORDIS. In addition two new members were elected to the Board of Directors: Alain Cornet, of Lupus Belgium & Maria Montefusco, Rare Diseases Sweden.
ECRD conference & Rare2030
On May 14th and 15th OIFE was well represented at the online European Conference on Rare Diseases (ECRD) with 5 representatives. In addition more than 5 people from the OIFE-community attended the event on behalf of other stakeholders. 1,500 people from 57 countries took part in the conference, which is recognized globally as the largest, patient-led rare disease event in which collaborative dialogue, learning and conversation takes place, forming the groundwork to shape future rare disease policies.

The Rare2030 - Foresight in Rare Disease Policy were among the central topics of the ECRD-conference. Rare2030 is a foresight study that gathers the input of a large group of patients, practitioners and key opinion leaders to propose policy recommendations that will lead us to improved policy and a better future for people living with a rare disease in Europe. Rare2030 is a two years project that will end in a presentation to the EU parliament at the end of 2020 with recommendations on the most critical areas needing sound policy. Rebecca T. Skarberg from OIFE and ERN BOND has been part of the expert panel of Rare2030 and gave several talks about the topic at the ECRD-conference.

With the information collected and trends identified the Panel of Experts has put together four possible future scenarios depicting what the world may be like for people living with a rare disease in 2030. Read more on the Rare2030 webpage: https://www.rare2030.eu/
**EURORDIS Digital School**
OIFE’s Communication Manager Anna Rossi has joined the EURORDIS Digital School, which takes place online this year. She has signed up for the entire Digital School 2020, which consists of webinars and eLearning and aims to empower rare disease patient advocates to use digital communication tools to improve the strategic outreach and community-building capacities of their organizations. Read more: [https://bit.ly/2V8vK9E](https://bit.ly/2V8vK9E)

**RDR Challenges Call**
Following the networking event in Paris in March, OIFE has attended 2-3 meetings a week related to the Rare Diseases Research (RDR) Challenges Call nr. 3 “Characterize Rare Bone Disorders (RBD) Mobility Challenges in Real World Setting” sponsored by the company IPSEN: [https://bit.ly/2JcRrPg](https://bit.ly/2JcRrPg)

The aim of the challenge is to develop full-body automated mobility assessment tool(s) to assess real-life mobility challenges in people living with rare bone disorders, to be compared vs available disease specific patient- and Health Care Professionals (HCP)-reported mobility assessments.

**MEDEV-MOCA-meeting**
Taco van Welzenis represented OIFE at the videoconference in the Medicine Evaluation Committee (MEDEV), where the setrusumab project was the topic (Mereo Biopharma). MEDEV represents an informal cooperation between 22 national authorities from 18 Member States and Switzerland responsible for the assessment, pricing and reimbursement of medicines in Europe. MEDEV members include national HTA agencies and social health insurers (payers).

**Launch of EuRR-BONE**
June 10th 2020 was the official launch & kickoff of the the European Registry for Rare Bone and Mineral Conditions (EuRR-Bone), which is funded by the European Union’s Health Programme. OIFE was represented by Rebecca Tvedt Skarberg (ERN BOND ePAG).

EuRR-Bone’s aim is to create a high-quality, patient-centered registry for rare bone and mineral conditions including OI in collaboration with the EuRRECa project (European Registries for Rare Endocrine Conditions).

EuRR-Bone will cover rare bone and mineral conditions the European Reference Network on Rare Endocrine Conditions (Endo-ERN) as well as the European Reference Network on Rare Bone Disorders (ERN BOND). EuRR-Bone will be of service to all patients, health care professionals and researchers involved in the care of people with rare bone and mineral conditions.

Read more about EuRR-Bone here: [https://eurr-bone.com/](https://eurr-bone.com/)
**OIFE AGM on Zoom – a success**

Each year all delegates are invited to the Annual General Meeting (AGM) of OIFE, which is normally the only time a year the whole Board comes together. At the AGM the Executive Committee (EC) accounts for OIFE’s activities in the past year, future plans and policies are discussed and members exchange news and ideas.

Our original plan for OIFE AGM 2020 was to meet in sunny Valencia from May 8th to May 10th. But the Corona virus put a stop to that, as it has done to so many other meetings and conferences. But we would not let it stop us from having our annual meeting. The EC therefore organized a two part meeting on Zoom on May 9th instead. Part one included approval of annual reports, budget and elections. And part two included a webinar on new treatments in OI.

![People from all continents took part](image)

**People from all continents took part**

62 participants attended part one of AGM 2020. 66 people attended the webinar (part 2) on new treatments. What was unique about this year’s event, was the record number of member organizations that were able to attend. We had all the national organizations from Europe except one attending. In addition to European organization and three supporting members, we had representatives from organizations and invited guests from all different continents including Peru, USA, Chile, Ghana, Nigeria, India and Australia. This year we had also invited people from Mereo Biopharma, our Medical Advisory Board as well as contributors from other rare bone communities, including XLH and HPP. Between 70-75 people attended the event in total

![Bruno elected as 2nd Vice President](image)

**Bruno elected as 2nd Vice President**

AGM part one included approval of annual reports, budget and elections. All proposals from OIFE EC were approved. We welcome Bruno van Dijck to the EC team, as the new 2nd Vice President of OIFE.
In addition to reports and elections, OIFE president and OIFE’s Communication Manager gave an update on current happenings and news and a summary from the national reports. The last part of OIFE AGM part one was dedicated to a presentation of a new collaboration on a planned global survey between OIFE, the OI Foundation and the company Mereo Biopharma.

Survey on the impact of OI
OIFE president presented the project, which is an initiative from Mereo Biopharma that is formally supported by OIFE and the OI Foundation. The plan is to do a global survey on the impact on OI to:

- understand the patient journey better in X & Y country
- to understand better what OI means for children and adults beyond fractures
- what the economic impact of OI is on people with OI and their families (direct and indirect costs)
- how we can measure quality of life in OI in the best possible way
- what kind of data we should collect and how

Three representatives from Mereo Biopharma were present at OIFE AGM to answer questions and comments from the participants. Mereo informed us that a steering committee will be established with members from OIFE, OIF and Mereo Biopharma in addition to 5 medical professionals from US and Europe, including both pediatricians and adult doctors.

Webinar on new treatments in OI
OIFE AGM part two took place on Zoom May 9th from 15.00 to 17.00 and included talks about:
- News on BOOSTB4 (Cecilia Götherström)
- News on setrumub project (Mereo Biopharma)
- Access to treatments for rare bone diseases (Oliver Gardiner & Paul Connor)
- Registries & patient data (Lena Lande Wekre)

Click here to download the agenda.
A talk with OIFE’s new Vice-President Bruno van Dijk

Interview by Stephanie Claeys – OIFE Youth Coordinator

Bruno, I have known you for several years, but can you please present yourself to the others?
Yes, of course! So my name is Bruno Van Dijck, chairman of the Belgian OI association. I graduated as an IT specialist and I’m currently working in the packaging industry. As the manager of both an IT company as a company on plastic production I’ve built a lot of experience in coaching people both in national and international environments.

You are also the chairman of ZOI, the Belgian OI association. How did you end up there?
Because I have OI myself (mild type 1), which is also the case of my daughter, I got in contact with ZOI. A dinner with someone from the board got me convinced to enter as a member many years ago. She was at that time the only OI-person I have ever met. During the first ZOI meeting I experienced a very warm welcome and acceptance from the other OI-people. It is a very nice feeling to be part of this community.

I completely agree. Since May 9th you are the 2nd vice president of the OIFE. What was your motivation to apply for this position?
Well, I did not really apply for this spot. Together with some of our Belgian delegates I went as the chairman of ZOI to some OIFE meetings in the past. Apparently, I must have left a good impression there, haha! On a certain moment I got the question from Ingunn, OIFE President, if I had someone in mind from ZOI who could fill the vacant position in the Executive Committee. During that conversation she let me know that my name was mentioned in the EC. So then she asked me if I was interested.

What is the thing which fascinates you the most about this function?
For me, the title itself is not that important. Getting together and see what we can do for each other sparks my interest. I still have to find my way in it, though I got already very well supported by the other members of the OIFE Executive Committee.

Do you have personal plans within OIFE?
It is important to feel good in the organization and to look to your own competencies. I believe this makes the wellbeing and the growth of an association like OIFE. My nose for opportunities can come in handy here. I would love to support projects and help where necessary. I think awareness is of great importance. Awareness makes a difference! I am convinced of this because of the know-how I can gather, or the contacts I can make, everyone will experience benefits, OIFE and ZOI. And that’s what it’s all about: briefing and supporting the OI community.

How was your first impression? Did you get a hearty welcome?
Yes! I felt very accepted immediately. Of course, I already knew the current members of the EC. But I never felt like a "newbie" and was immediately immersed in the association. Many new impressions, names, companies, colleagues and so on. In other words, it opens a whole new world to me.
Now it’s easy to fundraise for the OIFE!

OIFE has recently succeeded in getting accepted for the Fundraising Tools in Facebook and our Vice President Dace immediately decided to use the birthday fundraiser tool. For her birthday she invited friends and family to fundraise to support the projects and the activities of OIFE. And thanks to 24 donations, she managed to raise almost 900 euros for OIFE! We are extremely grateful. Thank you so much to all who contributed! We hope many more people will follow Dace’s example.

Do you want to fundraise for OIFE?
It’s very easy to create a fundraiser for OIFE on Facebook. You can create a birthday fundraiser or just a general fundraiser to help our cause. How to do it?
1. Go to https://www.facebook.com/fund/OIFEPAGE/
2. Click "Raise Money"
3. Choose "Osteogenesis Imperfecta Federation Europe"
4. Choose your goal in your local currency.
   You can increase the goal several times.
5. Choose the end date of the fundraiser
6. Click „next“
7. Choose a suitable title for your fundraiser
8. Write an explanation on why you have chosen to raise money for OIFE. The more personal you are, the more people might respond to it.
9. Choose a photo to go with the fundraiser (if you don’t add a personal one, it will use the header photo on OIFE’s Facebook page)
10. Publish it on Facebook!

NOTE! No fees to Facebook & tax deductions possible
Facebook does not charge any fees for donations to charities. 100% of donations goes directly to OIFE’s bank account. Donations to OIFE are eligible for tax credits or deductions in Europe. Please contact us for more information!
OIFE at the ECRD-conference

The European Conference on Rare Diseases (ECRD) was originally planned to take place in Stockholm in May. Because of the Corona virus, the conference was moved online to May 14th and 15th, which made it possible for more people from OIFE to attend. Five people represented OIFE specifically and you can read about their experiences below. In addition, six people from the OIFE-community attended representing other organizations or stakeholders. Rebecca Tvedt Skarberg (ePAG ERN-BOND) was invited as a speaker, and she gave one of the opening talks about Rare2030 as well as two talks in different sessions.

In total 1,500 people from 57 countries registered for the conference, which is recognized globally as the largest, patient-led rare disease event in which collaborative dialogue, learning and conversation takes place, forming the groundwork to shape future rare disease policies.

The conference was divided into six different themes and we tried to spread out, so we had people from OIFE attending all themes:

Theme 1 – The future of diagnosis: new hopes, promises and challenges  
Theme 2 – Our values, our rights, our future: shifting paradigms towards inclusion  
Theme 3 – Share, Care, Cure: Transforming care for rare diseases by 2030  
Theme 4 – When therapies meet the needs: enabling a patient-centric approach to therapeutic development  
Theme 5 – Achieving the triple A’s by 2030: Accessible, Available and Affordable Treatments for people living with a rare disease  
Theme 6 – The digital health revolution: hype vs. reality
Taco van Welzenis (The Netherlands):
The ECRD was very professionally done and had optimal use of the technical possibilities. On the second day there were unfortunately some technical issues connected to sound and internet connections. But ironically, I think I was better able to hear the speakers at this online event, than in a full room with an audience. The highlight for me was the Swedish EU-politician David Lega who held several passionate talks.

Sandra Reis (Portugal):
It was the first time that I participated in the ECRD and it was a very positive surprise for me to see so many people interested in rare diseases. Before the conference, the “Rare 2030” seemed very complex and ambitious to me. After the conference, I understood much better the integration and connection between all the topics debated and the Rare 2030 project and agenda.

Many scientific studies and projects were described. It was clarified how scientific and technological developments are improving the diagnosis and knowledge of rare diseases, such as Next Generation Sequencing (NGS) and Artificial Intelligence (AI). The ECRD also demonstrated that in the EU, people with rare diseases and their families face social inclusion challenges every day. People with rare diseases are vulnerable because access to treatment, care, and opportunities is still not equal for all people. This reinforces the importance of these events to develop new strategies, regulatory practices, and policies at the national and global levels. The highlight for me, was the talk from Rebecca Tvedt Skarberg, which was very clarifying and inspiring.

Rita Santos (Portugal):
The opportunity to participate in ECRD arose because I am a student in pharmaceutical sciences who also happen to have OI. One of several topics that caught my attention at the ECRD was the importance of the users/patient’s opinion in the development of drugs and the fact that there are several different ways to include the user perspective in that same development. In general, the congress was a huge source of learning, where I was able to hear and share different opinions on all kinds of issues. Thank you OIFE!

Claudia Finis (Germany):
At the conference I heard talks about many different topics, including adaptive trials according to a baysian modell. In this model you can make interim analyses to see if there is a benefit. On one hand the pharmaceutical company may stop the study earlier if the drug shows no benefit but on the other hand if a drug shows at this early stage a benefit, it will get to regulatory agencies much earlier and therefore earlier to the patient. It is possible but with doubts and uncertainties. Another highlight for me was to learn about the work of the AKU Society. Alkaptonuria (AKU) is a ultra-rare disease (only one in 500.000 people is affected) which also affects the bones. The AKU Society carried out a drug repurposing project from a mouse model to apply for market authorisation in only 10 years! They recruited 138 patients in Europe and raised about 20 million pounds in order to get the study done! Amazing!
Meetings in OIFE’s Medical Advisory Board (MAB)

April 6th 2020 the OIFE MAB came together for their first meeting since it was established in 2018. OIFE’s MAB has been revised and two new members have been added, which includes dr. Heidi Arponen from Finland and dr. Ralph Sakkers from the Netherlands. The first MAB-meeting was mainly to give the MAB an introduction about what the OIFE is working on. But on Friday the 19th the MAB came together for their 2nd meeting. The topics included Key4OI and the new rare bone registry EuRR-Bone. In addition to the OIFE MAB, we had invited the OIFE EC, our resource group on registries and Tracy Hart from the OI Foundation. In total, 18 people took part.

The agenda included:
- Status on Key4OI - Dagmar Mekking
- Information on EuRRBone - Natasha Appelman-Dijkstra
- Other news from OIFE – Ingunn Westerheim

Standard set of outcome measures
Dagmar Mekking from Care4BrittleBones gave a short introduction about the project Key4OI, which is a standard set of outcome measures for OI. It is not a registry and not a set of guidelines! The standard set has been developed through a process involving an international group of experts and focus groups, where children and adults have provided their input from the patient perspective. More information on Key4OI can be found here: [https://bit.ly/2CyTEot](https://bit.ly/2CyTEot)
See also explanatory video on YouTube: [https://youtu.be/xj7MQqqXA1Q](https://youtu.be/xj7MQqqXA1Q)

Information on EuRR-Bone
Natasha Appelman-Dijkstra, from Leiden University, gave a presentation on the brand new EuRR-Bone registry, while being stuck in traffic. Talk about passion for OI! EuRR-Bone’s aim is to create a high-quality, patient-centered registry for rare bone and mineral conditions including OI in collaboration with the EuRRECa project (European Registries for Rare Endocrine Conditions).

The introductions were followed by questions from the participants and a very constructive discussions which included questions on:
- How we can develop better guidelines for OI
- How the patients can help the professionals to provide data
- How different registries in different countries can work together
- How patient organizations and other stakeholder can come together to work to achieve more standardized and regular follow-up of people with OI in all age groups
Who is Who in OIFE MAB?

Ralph Sakkers
I am one of the paediatric orthopaedic surgeons at the Wilhelmina Childrens Hospital of the University Medical Centre Utrecht in the Netherlands. We are the national centre for children with Osteogenesis Imperfecta (OI) in the Netherlands, and we are treating more than 250 children with OI. The multidisciplinary team for OI started in the early nineties and currently has 25 members covering the specialties paediatric orthopaedic surgery, spine surgery, paediatric rehabilitation medicine, paediatric physiotherapy, paediatrics, paediatric neurology, pediatric radiology, genetics, paediatric ENT, paediatric ophthalmology, psychology, occupational health, social care services, pediatric dentistry, and also has dedicated cast technicians. I have now been the coordinator of this team for the last 20 years. We built a multidisciplinary team for adults with OI with befriended colleagues in 2007 and have transition clinics together with the multidisciplinary team for adults with OI since that date. We have a close collaboration with the Amsterdam University Genetic Center.

One of my focus areas in research is OI, with scientific publications on both basic and clinical research outcomes. One of the most important papers was the first randomized controlled trial on bisphosphonates in children with OI published in the Lancet. Currently, I am one of the principal investigators in the BOOSTB4 consortium on stem cell transplantation in osteogenesis imperfecta and coordinating the consensus paper Roadmap to Surgery in OI in the Key4OI project together with dr. Richard Kruse.

On an international level, I am currently the chair of the Study Group Genetics and Metabolic Diseases of the European Paediatric Orthopaedic Society. This study group focuses on international collaboration in education and research in musculoskeletal genetic and metabolic diseases including osteogenesis imperfecta.

The most important task for OIFE in my view is to be the voice of the patient with OI. This voice should lead doctors, researchers and politicians in the direction of the most important needs of the patients with OI, not only on a medical level but also in the context of function and participation. Networking should be an important task, including connecting different groups involved in the quality of life for patients with OI. Another important issue should be providing adequate information. Not only scientific, but on all areas concerning OI. The recent conference QoL4OI was a beautiful example of how organizations can have a major role in bringing together all those involved with care for patients with OI.

Heidi Arponen
I'm a dentist specialized in orthodontics. I work at University of Helsinki, Finland and at a healthcare center in my home town. I’ve been doing OI-related research since 2006, first focusing on basilar impression and related conditions, and later on teeth, fatigue, and sleep. I work as an orthodontic clinical consultant participating in treatment planning of individuals with and without OI. I’ve had the privilege of co-operating with the wonderful people of the Finnish OI Association for a number of years. In my opinion, one of the most important tasks of OIFE is to support and connect people. Social connections bring us happiness and wellbeing. The joy of having someone who gets our jokes or helps us deal with hard times. Helping others is a key to happiness. I admire OIFE team for the important mission of raising awareness and bringing joy.
Dr. Richard W. Kruse recently published a new book on surgery in OI. OIFE was one of the consultants in the writing of the book, to secure that the voices of people with OI were represented. But dr. Kruse is not only a writer. He’s a busy doctor involved in many different projects and activities both nationally and internationally – including developing a new delivery clinic for babies with severe diseases and the international expert group connected to Key4OI. Because of all these activities, we thought it was time for a conversation.

Who are you and what is your relationship to OI?
I’m Richard W. Kruse - a Professor of surgery, pediatric orthopedic surgeon, and codirector of the osteogenesis imperfecta clinic with Dr. Michael Bober MD PhD pediatric geneticist at the Nemours Alfred I DuPont hospital for children in Wilmington, DE USA. I have a subspecialty in the surgical treatment of OI and see children and adults with OI as part of my daily clinical and research work. I am a member of the Medical Advisory Council of the Osteogenesis Imperfecta Foundation in the United States. I co-chair an international task force working on a consensus paper in the surgical treatment of OI with Dr. Ralph Sakers in the Netherlands. I have recently finished producing a textbook on OI for surgeons.

I have been working as an OI subspecialist for 26 years. We see OI patients daily. We are fortunate to be able to follow patients fracture care in our extensive fracture clinic, which I supervise. We have a large multidisciplinary team and have a formal team meeting and multidisciplinary clinic twice a month. We, as a team, and with international collaborators, are all involved in clinical research.

In addition we have a comprehensive multidisciplinary team caring for both children and adults up to age 35 with OI. We are all in the same clinical location, so we find interdisciplinary communication to be a strong part of our program.
Could you say something about your involvement in the Key4OI project?
The Key4OI project an international group of OI experts organized and led under project manager Dagmar Mekking, CEO of Care4BrittleBones. The goal is to identify and achieve outcomes of treatment that matter to patients with OI throughout their lifetime. The project involves worldwide representatives and seeks to improve OI care in patients of all cultures and socioeconomic status.

The key question is:
“What data should be collected, evaluated and compared taking into account both patient reported outcome measures and clinically reported outcome measures to drive sustainable insights for healthcare improvement and research into both. The primary objective is to reach multidisciplinary and international consensus for a standard set of outcomes in OI care and research.”

You told us about your new delivery unit for babies, can you explain what it is?
Our advanced delivery centre is designed to help healthy expectant mothers deliver their baby who will require immediate and complex care after delivery. The deliveries will be scheduled inductions or scheduled C-sections. The baby will receive comprehensive coordinated care from pediatric subspecialties immediately after birth and mom will get to be in the same hospital. We have had one delivery of a patient with OI who was subsequently cared for in our NICU and continues to receive ongoing follow up by our subspecialty team after discharge.

Who can come to the clinic?
We welcome patients from all over the US and even outside the US. If patients are not local, the mother will need to transfer her OB/prenatal care to our adult hospital partner, Christiana Care, in the event that she develop conditions that preclude her from delivery at Nemours (pre-eclampsia, for example) and delivery would have to occur at our neighbouring medical centre with postnatal transfer to Nemours of the baby. Insurance needs to be vetted as well prior to acceptance for delivery at Nemours.

I've heard someone say that OI type II is lethal, but that some are "just too stubborn to die". What are your thoughts on this?
This is a very complex situation. The difference between type II and type III OI is not absolute. If one is to use radiographic criteria to make this distinction, there is no doubt that there are some infants with radiographic type II OI who have survived with aggressive care. There have also been infants with type III OI by radiograph who did not survive despite interventions. Some physicians have considered making the distinction between type II and type III OI based upon survival itself and not radiograph. Our belief is that the type of care and support to be provided to an infant should be based on the wishes of the family after extensive discussions about possible outcomes. While there are some children who may not survive despite intervention, there are others who surpass prognostic expectations, and this can be hard to discern from radiograph alone.
Are there any special recommendations on birth of a baby with mild or severe OI?

There does not appear to be a significant benefit for the numbers of fractures seen at birth based on method of delivery. Decision should be made on a case-by-case basis and determined by obstetrical and maternal factors such as previous delivery method and whether or not the mother has OI.

There are not clear clinical guidelines regarding the mode of delivery for a patient with OI. While theoretically delivery by cesarean is potentially less traumatic, evidence suggests that cesarean delivery does not decrease fracture rates at birth in infants with nonlethal forms of OI, nor does it prolong survival for those with lethal forms.

In one study, most deliveries still occurred by cesarean for the sole reason that the fetus had OI. Overall, this decision should be individualized and made jointly by OB and neonatology/pediatric specialists. In addition to fetal and maternal considerations, other factors important to the decision include timing and ability of resources for a controlled delivery and postnatal stabilization.

These kinds of programmes cannot be developed in all hospitals/countries. How can we make the birth of an OI-child in any country as good as possible?

If it is known that a child will be born with OI, having a medical care team in place and having family and team discussions about care and interventions before delivery is best practice. We here are working closely with colleagues worldwide as mentioned above to begin to address the disparities of care available to patients and families with OI. It is a total group effort requiring extensive international collaboration to not only understand and address cultural and socioeconomic aspects but to keep the patient’s view at the forefront in addressing barriers.

And finally - congratulations on your new book! Do you have any messages for OIFE Magazine?

My answer to this is a thank you to OIFE for leadership in advancing patient care and research. It is absolutely critical that patient driven organizations lead the effort. We as health care providers need to more completely understand how our actions and decisions affect your lives. Also we need to thoroughly understand the priorities of your individual situations to provide you optimal outcomes. Additionally things will not improve without all our voices being heard by governments, insurance providers, and communities.

New book about surgery in OI

The book written by Dr. Richard E. Kruse from Wilmington, US, will help guide decision-making in surgery using biologic and surgical principles to assist the planning and execution of surgery with available resources. It will then provide the surgeon with background knowledge of the genetic, medical and surgical principles necessary to formulate a comprehensive treatment plan, illustrated by varied and complex patient cases from experienced surgeons and clinicians worldwide. Beginning with an introduction to osteogenesis imperfecta and the general care of the patient, the book is divided into thematic sections covering general surgical considerations, principles of extremity surgery, and surgical cases on the pelvis, upper and lower extremities, and the spine, it will incorporate aspects of surgical decision-making, including cultural and geographic factors, to give a truly global perspective on the care of these complex patients.

You can purchase the book here: https://bit.ly/3eJXDMQ
**TeleECHO series on rare bone diseases**

The Osteogenesis Imperfecta Foundation and the Rare Bone Disease Alliance are the hosts of the Rare Bone Disease TeleECHO Clinic Series. The goal of this educational program, a partnership with Project ECHO™ (Extension for Community Healthcare Outcomes), is to build capacity to safely and effectively diagnose and treat rare bone diseases and disorders.

This series uses Zoom videoconferencing, and will take place on the first Thursday of every month at 3pm EST (9PM CET). In each monthly session, faculty members or guest speakers will present a brief didactic presentation, followed by participant-led case presentations and group discussion of the presented cases. The faculty encourages participants to present case studies related to rare bone diseases at each session. No cost AMA PRE Category 1 CME credits are available for participants.

Project ECHO is an innovative educational program developed at the University of New Mexico Health Sciences Center. This collaboration will assist in expanding access to specialty care by increasing capabilities of primary care providers, improve the health of the beneficiary population, decrease cost associated with rare bone disease care, and ensure a ready medical force.

The interdisciplinary faculty in the Rare Bone Disease TeleECHO includes:
- Michael Collins, MD National Institutes of Health, NIDCR
- Michael Lewiecki, MD University of New Mexico
- Eric Rush, MD University of Kansas Hospital
- Jay Shapiro, MD Uniformed Services University of Health Sciences
- Dolores Shoback, MD University of California San Francisco
- Laura Tosi, MD Children’s National Health System

Previous sessions can be watched online, including:
- Genetic Testing in the Diagnosis of Rare Bone Disease
- OI Dominant vs Recessive: Impact on Treatment
- Non-Accidental Trauma

Link to the TeleECHO page of the OI Foundation here: [https://oif.org/research/echo/](https://oif.org/research/echo/)

The OI Foundation is considering creating a specific TeleECHO series about osteogenesis imperfecta (OI) during the autumn of 2020, where professionals from both US, Europe and other parts of the world will be invited to contribute and attend. Please contact office@oife.org if you have questions on this.

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**TUNE IN JULY 2ND 2020**

**9PM CET (3PM EST)**

Management of Pregnancy & Delivery in the Patient with a Skeletal Disorder

– Deborah Krakow MD

*Chair of the Department of Obstetrics and Gynecology, Professor of Orthopaedic Surgery, and Professor of Human Genetics at University of California Los Angeles (UCLA) Health*
Examples from OIFE Members: ZOI Hospital Agreements

Most of the patients with OI are diagnosed in a hospital. They leave hospital with many questions, fear or just feel left alone. So ZOI (Belgian OI-association) has entered a cooperation agreement with 10 regional hospitals in order to support OI patients with information directly after diagnosis. The infographic below shows how an agreement with self-help friendly hospital could look like.
Who are you and what do you do?
My name is Chiara and I am a writer/creator and a performer with a disability. I am Italian and I am 35 years old. I work in different fields like performing arts, contemporary theatre and contemporary dance.

In what way has OI affected your art?
Honestly, I am not sure if I would have chosen to do this as a profession, if I didn’t have OI. I was 19 when I moved to another city in order to attend University (Psychology). During the school year I enjoyed participating in theatre groups and it was therefore quite logical for me to seek some kind of course to attend in order to do something nice and enjoyable and to meet new people. The meeting with the Scuola di Formazione dell’Attore of Lenz Rifrazioni theatre company changed all the rules for me. That was the place where, for the first time in my life, a very physical teaching method was offered and proposed also to me and to my body. And my fragility was never used as an excuse to be excluded from the practice or lessons. I was asked the very same commitment and discipline as all the other students. The only difference was that I had to translate the instructions of the teachers into my own possibilities and range of movements. I started also, quite early, to work without the wheelchair both during rehearsals and on the stage and that was the place and time where my revolution happened.

In many years of school, in hours of physical activities, that I attended only as a bored observer or during which I was asked to study the theory while my class-mates’ bodies were sweating and flourishing; in many years of physiotherapy, rehabilitation, swimming pool, passive gymnastics and static tables/standing benches...no one had ever recognized my body as an entity that could be something else than a sick body to look after, take care of and possible make better. The day someone saw an expressive potential in my body, it felt for me like looking out into a new endless archipelago of possibilities.

My body and its history have influenced and keep influencing my entire career. Sometimes I accepted it, sometimes I haven’t, every now and then I asked loudly the right to talk about something else. It is something constantly present in my work, with which as it happens in life, I start a negotiation at each new beginning, and every time it ends in a different way.

What projects are you currently working on?
For years I have been asking myself about the concept of the Political Body, which is what the shape of our body reflects when it enters society and how we can change the image of it. I have always considered this concept applicable to every human being, even though I knew that for people with an eccentric body like mine the question was even more evident and therefore easier to delimit.
For this reason, the first works that dealt with this theme have always involved very significant bodies (old bodies, my body, etc.). In my latest work however, called “The Whales Song”, I wanted to try to face the same reflection but starting from a more common and canonical body: the one of the performer Matteo Ramponi.

**Why do you do what you do?**
Initially I did it for pure, deep, essential personal pleasure. I wanted to discover this incredible world from which I was always excluded. Then I started, almost without asking myself any questions, to answer the first job offers as an actress. One day I realized that the company I worked for was starting to feel a bit too small for me, I realize that I wanted to study and work in other contexts too. This would have meant abandoning the city where I lived and making investments in time and energy that hardly could go together with the project of getting a degree in psychology. There are many of my colleagues who have done both, a degree and an actor training but at that time I realized that I could not.

Living with OI also means living with different timings. The time to go to the bathroom, the time to take a train, to get dressed, to clean the house ... studying and working in the theatre both required a time and concentration that for me, with my amount of energy, was not sustainable. That was the moment of choice. 4 exams from graduation I left university and moved to central Italy to work. From there it all really started.

**What themes do you pursue?**
The issue of the Politically Body is certainly central, but there are other topics as well moving around it such as The Society, the alliances between bodies, the relationship between human and landscape, the fragility.

**What kind of work do you most enjoy doing?**
As an author I like to do a constant exercise of dis-affection to languages. I am not the kind of person that overthink about scenic language, I think about the emotional waves I want to ride. Emotions has unpredictable rules that only listening can allow you understand. As an interpreter I like to experiment with different languages as well.

In Italy the life of an actress with disabilities is very complex because we are a professional category that does not exist. There are no roles for us, nor there are other authors with disabilities who created worlds in which to move. This is why I listen a lot, I talk a lot with directors, both male and female, and whenever one of them opens a chance of collaboration I go for it no matter which is the language he or she is looking or asking for. Being trained as a contemporary actress fortunately makes me quite versatile and if my body is not considered such, then it is my skills that remind the world that I am, like any other trained and competent actress.
What’s your scariest experience related to your work?
Getting hurt on the stage. It has never happened to me, but I am perfectly aware that it can happen and that statistically, if my work continues at the current pace, it will happen. It is scary mainly in the solos, when you know that no colleague will be able to intervene and help you leave the scene without excessive trauma and maybe even without interrupting the performance. If one day I get hurt during a solo I will have to stop it. Declare it. Create a bubble of terror and accept that my fragility gets exposed. This is, working-wise speaking, my worst nightmare.

What is your dream project?
I have two, and neither of them concerns a piece of work. I would like the role of artist with a disability to be recognized in Italy and all the protection and associations of reference to be created. We are working in this direction but we are only few and it could take years ... but I would like to retire, one day, knowing that a 19 years-old girl in the future will be able to dream of becoming a dancer, actress, director or screenwriter regardless of her fitness.

The other dream project concerns the training system for artists in Italy. I would like it to be open to every type of body as are compulsory schools. We boast one of the most inclusive school systems in the world, yet this wonderful facility crumbles down as soon as we leave the high schools and it completely disappear if we talk about artistic training.

With other colleagues we are working to bring the matter afloat until we get to the art academies that receive state grants to become by the law truly accessible for all.
E-soccer: Niklas lives his dream

Can you tell a little about yourself?
My name is Niklas Luginsland, 24 years old. Currently I live at home in Germany with my parents and my brother. One year ago I finished my Bachelor in Public Management. During my studies I lived together with 3 other students. I have type 3 OI, need a wheelchair all the time. But I feel good at the moment doing a lot of physical sport.

How did you get to E-Sports, in soccer in particular?
I am playing FIFA since 2002, when I was 6 years old. I really love soccer, but I had no opportunity to play. That’s why I started to play E-soccer. For 4 years I have played at a high level that means a lot of offline and online tournaments around the world. Since 2018 I am a professional player for VfB Stuttgart Esports.

Please tell us about your recent championship!
My last big tournament was the Bundesliga Home Challenge. Nearly all Clubs of the Bundesliga have professional FIFA players. Before Corona we played together with soccer players from our club against the other Bundesliga.

What are the requirements for people who want to do this kind of sports?
It’s very important to have quick reactions. Because you have to make a lot of decisions within a short time. You also need a very high concentration during the matches. Moreover the mentality of a player is really important. But besides the E-sports training I do a lot of physical sports and healthy food is also important to feel good.

How do you manage training?
At the weekends I often play a lot FIFA. Normally about 12 hours, because we have a lot of competitions. During the week I have to share my time with my master study Leadership and Sports management. In average I play about 1-2 hours a day.

What are the most challenging issues in this kind of sports?
To be concentrated during the long time of matches. For instance I have to play 30 matches from Friday to Saturday in Fut Champions Weekend League.

What is/was the most exciting moment for you?
Of course the start of my career in August 2018. It was a fantastic feeling to be introduced in the Mercedes-Benz-Arena in Stuttgart, Germany.

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E-sports is a form of sport competition using video games. E-sports often takes the form of organized, multiplayer video game competitions, particularly between professional players, individually or as teams.
What would you recommend to people with OI who are interested in doing soccer e-Sports?
Follow your dreams and never give up! If you have fun to play FIFA, do it! Train a lot and learn from better players. For instance watch the gameplay of them.

What are your future plans?
I am not sure what will happen in the future, but first I want to finish my master study next year. My dream is also to play FIFA for the next few years on this high level. After that I strive for a management position in sports- or public sector.

Read more about Niklas and e-sports here: https://bit.ly/2YDEXSl

Wheelchair Curling: Interview with Michal Daszkowski

Can you tell a little about yourself?
I’m 47 years old and live in Warsaw, Poland. At the moment I’m living alone in my pretty accessible flat. I am using wheelchair for almost my every daily activity. I am working as a freelancer (IT - system and network administrator).

How did you get into wheelchair curling?
Some time ago my old friend invited me to come and watch him exercise wheelchair curling. I was not sure if it will be interesting for me, but I was curious enough, so I decided to see. I met some nice people who were seriously involved. And the coach was a very special person: friendly, wise and with perfect attitude to other people. She showed us how much fun curling can be!
Please tell us about the world championship in Finland!
The championships took place in December 2019 in Lohja (Finland). These were the championships of group B - it's the 'second' group, because in curling rules are a bit similar to ice hockey. In group A there are the strongest teams. So after championships of group B, three best teams will be promoted to group A.

In group B currently there are 15 teams. All information, including teams and schedule you can find here: [https://worldcurling.org/events/wwhc2019/](https://worldcurling.org/events/wwhc2019/)

What is very important, I am not the only OI person in our team! Together with me is also Joanna Kozakiewicz, so 40% of current Polish National Team in wheelchair curling are people with OI.

Unfortunatelly, this competition was not very successful for us, but we expected that. For almost the entire team it was the first time in World Championships - very stressful and a real challenge. Additionally, we had two really strong teams in our group: Sweden and Canada. Especially Canada was an extremely tough competitor - three members of their team are Paralympic champions!

But it was a really great experience and we learned a lot. People playing curling are very friendly and this is some kind of big "family", so it was a lot of fun. Despite of our results, we returned in very good mood. Now we know what to change and improve, and hopefully next year will be much better!

What are the requirements for people who want to do this kind of sports?
This is very good question! Because, unlike many other sports, it's not very demanding in terms of physical fitness. Of course, you must have arms strong enough to push the stone on ice, so probably not for people, who need an electric wheelchair to move. But I believe that almost every person, who is using a manual wheelchair, is able to play wheelchair curling!

Main necessary skills are: intelligence (!), ability to concentrate and perfection in movements. And you don't need to be very young - this is sport both for teenagers and people 70+

You are member of the Polish national team. How do you manage training?
Unfortunately during last year we had very serious problems with covering costs of our trainings. So we were able to exercise usually only once a week. It's not enough. I hope it will change in the next months and years.

What are the most challenging issues in this kind of sports?
Money and lack of places to play and exercise. In Poland there is only one professional curling hall which is in Lodz, more than 100 km from Warsaw (most of us are from Warsaw). There are some other places, but usually not so good - ice surface for curling must be very special: perfectly flat and smooth. It's really hard to prepare it and costs a lot.

Do you get any subsidy (for instance for travelling to events)?
This is the main problem for us! The situation in the Polish Curling Association is horrible for several years. Currently the association has really huge debts and no money at all. So we had no help from them. Not only for wheelchair curling - all Polish teams need to collect money for participation in competitions.
We get some money from sponsors, some directly from Polish Ministry of Sports and the rest from crowdfunding. It was amazing that people are so helpful, but it shouldn't work in this way. This is an Olympic and paralympic sport!

**Which was the most exciting moment for you?**

In October 2019 we had very important competitions in Poland. First (unofficial) Polish Championships. And it was decided that the winning team will be nominated as Polish National Team for World Championships. In the final match, we met with the oldest and Polish wheelchair curling team "Culani". We had never won against them before. This time was our day: we were playing very calmly and finally we won 6:3. It was a really great moment for all of us and me personally. But I do believe that there will be a lot of similar and better moments in the future!

**What would you recommend to people with OI who are interested in doing this?**

Quickly check where is the nearest curling club in your country, contact them and ask when you can come and try! And just do it! In my opinion, this is absolutely perfect discipline for many people with OI.

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**WHEELING A MARATHON WITH OI**

![Wheeling a marathon with OI](image)

Natalia Sobota from Poland, affected by OI, took the second place in the 20th PKO Poznań Marathon 2019 covering a distance of 42.195 km in 04:40:04 in the category "Woman, direct wheelchair". Congratulations!
News in Brief

OIF CONFERENCE ONLINE
In place of the in-person OIF National Conference this year, the Osteogenesis Imperfecta Foundation will host a Virtual Conference on July 10-12, 2020. The Virtual OIF Conference will provide live online versions of some of the most popular informational and social sessions at the biennial OIF National Conference.

OIF Virtual Conference is free of charge, but you must register for each session you would like to attend: https://bit.ly/2AdR6v1

WEBINARS ABOUT COVID-19
There have been several webinars lately connected to the Corona virus and its consequences for people with OI and rare bone diseases. We have updated OIFE’s resource page on Covid-19 and OI, and you can find link to the most relevant recordings there including the webinars from the OI Foundation, Brittle Bone Society and the EU Commission/ERN BOND:
www.oife.org/covid19

R.I.P. GEMMA GEISMAN
It with great sadness we received the news from the Osteogenesis Imperfecta Foundation in the USA, that their founder Mrs. Gemma Geisman has passed away. We send our sincere condolences on behalf of the international OI-community. We are extremely grateful for the very important initiative that Mrs. Geisman did 50 years ago. Without her the OI-world might look different. May she rest in peace.

NEWS FROM OI RESEARCH IN THE US
Check out this very interesting newsletter (target group people with OI and their families) from the Brittle Bone Disorders Consortium (BBDC) about clinical OI-research currently happening in the USA:
EXERCISES FOR CHILDREN WITH OI
The Sheffield Children’s Hospital in the UK have put together a series of instructional exercise videos about keeping active during the isolation. To view them, please click here: https://bit.ly/3cZIPbW

OI IN PHARMA TIMES
PharmaTimes is the UK’s leading pharmaceutical magazine with more than 23,000 readers, which include 8,000 healthcare professionals in the UK. The April edition includes an interview with OIFE’s president Ingunn - about how it's like to live a life with OI: https://bit.ly/3fNOHpX

OI2020 MOVED TO 2021
We inform you that the 14th International Conference on Osteogenesis Imperfecta scheduled for 5-8 Sept in Sheffield, UK, will be postponed to 1-4 Sept next year. Hope to see you there! http://ow.ly/Fmrr30qOP1y

NEWS ABOUT EUROPEAN REFERENCE NETWORKS
The EU Commission publishes a newsletter about what is happening in the different European Reference Networks (ERNs). We bring you direct links to two of the topics we think might be most relevant for professionals working with OI:

- New membership applications for ERNs – the approval process has been delayed because of the Corona virus: https://bit.ly/2XJS9vP
- The project to develop OI guidelines (ERN BOND) is also delayed because the EU wants to develop a joint method to develop guidelines across the different ERNs: https://bit.ly/2UjsRSY

Full ERN newsletter from the EU Commission: https://bit.ly/2Y8WaZA

REPRODUCTIVE OPTIONS & OI
Lida Zhytnik (member of OIFE MAB) and her colleagues from Estonia has published an open access review article about reproductive options for families at risk of OI.

The review article provides a comprehensive overview of possible reproductive options for people with OI and for unaffected carriers of OI pathogenic genetic variants. The review considers reproductive options across all phases of family planning, including pre-pregnancy, fertilisation, pregnancy, and post-pregnancy.

The complex process of decision-making around OI reproductive options is also discussed from an ethical perspective. https://bit.ly/3g7HL78

IRDIRC GUIDEBOOK TO DRUG DEVELOPMENT
We recommend to check out the new guidebook on drug development from the International Rare Diseases Research Consortium (IRDIRC) https://bit.ly/2XG4uRC
PATIENT ENGAGEMENT FORUM
PARADIGM, PFMD and EUPATI welcome you to the Patient Engagement Open forum – a series of virtual events where we will work together, in a multi-stakeholder context, to turn patient engagement into reality.

The Forum aims to provide a holistic perspective of patient engagement, the landscape and actors, and foster collaboration and co-creation while breaking down fragmentation and silos that are often present in patient engagement work.

Topics range from tools and recommendations for effective patient engagement, methods for monitoring and evaluation of impact and outcomes in patient engagement activities, and fair market compensation for patient input to interactive sessions on assessing good practices in patient engagement and more.

Read more here: https://bit.ly/30yURGh

NEW OI SONG
Check out the new OI-song «Count on Me» performed by 21 singers from the OI-community in 10 different countries! The project was initiated by Stichting Care4BrittleBones. Well done!

https://youtu.be/Vkx0VgWVqyw

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OIFE Calendar
For an updated list of events & conferences - see OIFE’s web calendar:

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