Pain, Pink Elephants and Peer Support

I am going to start this editorial with a quote from the Australian physiotherapist Verity Pacey. You can read an interview with Verity in this OIFE Magazine, which is a special edition about OIFE around the world.

“Don’t wait for your healthcare team to ask you about pain and fatigue – tell them if you have these symptoms and ask for a referral to see someone to try and help. Every time you do this you will help your healthcare team learn more about managing daily activities when you have OI. Some of the best tips and strategies to make daily tasks easier are likely to come from your peers. Keep on supporting one another and advocating for your needs through organisations like the OIFE.”

Happy New Year we say, while we watch fireworks and listen to ABBA singing about confetti on the floor. Happy Schnappy... 2023 had an exceptionally bad start for me this year. It started with a very sore throat on New Year’s eve because of a cold I dragged back from Switzerland. It developed into a bad cough, which was the fourth one in 5 months.
But three days later I had a medical emergency of quite another character. Many people go around thinking that OI is all about brittle bones. But they couldn’t be more wrong. The IMPACT survey showed that the 3 top problems for adults with OI are pain (82%), fatigue (ca 70%) and soft tissue problems (ca 55%).

My biggest soft tissue problem besides muscle pain and inflammation has been too soft tissue in my so-called private parts. Yes, I am going to be explicit and personal now (maybe too personal for some) – but I already shared this information with 1260 people in the OIFE Adult Health group on Facebook, so I might as well share it with the rest of you.

On January 3rd a problem I’ve had for 6 - 7 years escalated and my uterus had a full prolapse. I simply could not get my body parts to stay where they were supposed to be, and it was causing a lot of pain. I was sent to hospital in an ambulance, where the gynecologists scratched their heads and looked concerned. This had never happened to a person in their 40s before. It ONLY happened with older women who had given birth to a lot of children. I told them that OI is a connective tissue disorder because of poor collagen and that this was probably a reason, something they agreed on.

The problem was that they didn’t know how to deal with it. My body was small, the internal organs were in strange places and full anesthesia wasn’t exactly something they wanted unless they really, really had to. So they first tried one procedure, which turned out to cause excruciating pain on my behind. Failure! The next day they tried another procedure, which caused intense pain in my bladder. Failure again! I will not go into all the gory details. But let’s just say that during these 48 hours I got to try all the pain killers in the catalogue – and most of them had more side effects than actual pain relief. But it was an “interesting experience” as some might choose to call it.

The doctors were weighing back and forth – hysterectomy or hysteria – that is the question. And how to do it? When? And if? So many questions, so few answers. But they actually agreed that they should probably listen a little bit more to the person with the problem: Me.
I decided to turn to the place I know best – the international OI-community. I asked a question in the OIFE Adult Health Group on Facebook, which is a group of 1260 people with OI (and nobody without) from more than 80 different countries! I asked if there were women with OI who have had the same procedure and what I should think about and not to forget - ask the doctors about. And I got a lot of response and good peer advice. As Verity said – some of the best tips and strategies are likely to come from your peers.

I am fortunately back home again and doing quite well for the time being. The doctors in Oslo University Hospital are still thinking. Surgery is postponed until March. I don’t have all the answers yet. But I feel incredibly grateful for this wonderful online community we have – where we can ask peers for advice based on lived lives and people with OI’s own medical experiences. On the contrary to what people think – it is NOT medical advice – because most of us are not doctors. But advice from peers can give people important things to consider when talking to professionals. And not to forget – emotional support.

You can read more about our peer group another place in the magazine. Join us if you are not already a member and tell your OI-friends you think might be interested as well!

And the Pink Elephants? What have they got to do with this? Join us for the conference “Balancing Life with OI” in Stockholm in June 2023! You will get to know...

Ingunn Westerheim – OIFE president

What is the OIFE doing?

By Ingunn Westerheim, OIFE President

Between October and February our time has to a large extent been used for planning events in 2022 and 2023. These events included the OIFE Investigator Meeting in November, OIFE Leadership Meeting in January and the upcoming events OIFE Youth Event in Italy in September and the Topical Meeting and AGM in Stockholm in June. We have also made an effort to continue activities in the OI & Pain project including the development of a survey together with the OI Foundation. In the end of November, the new Board also had the chance to get together face to face for the first time in Mechelen, Belgium.

OIFE have also been involved in two different grant applications for the European Programme on Rare Diseases (EJP RD). First and foremost a networking grant for our event in Stockholm. But OIFE has also made an effort to gather people for a consortium on natural history studies, which we hope will end up in a grant application and money for OI research.

MEETINGS & WEBINARS

In addition to a lot of internal meetings, we have had external meetings with our normal collaborators incl. the XLH Alliance, Mereo/Ultagenyx, other clinical trials and with various new stakeholders moving into the field of OI. We have also attended the following meetings:

- OIFE EC-meetings Oct 18, Nov 25-27 (Mechelen, Brussels), Dec 14, Jan 17
- OIFE Medical Advisory Board, Oct 12 and Jan 23
- Astra Zeneca about the “50 wheelchairs project” Oct 24 and Jan 27 (IW)
• XLH Alliance Oct 24, Dec 12, Jan 9, Jan 24 (IW)
• EJP RD networking grant meetings Nov 3, 7 and 28 (IW)
• Boost Pharma Nov 14 (IW)
• EURORDIS about Remedi4All Nov 23 (IW, CF and RTS)
• EuRR-Bone Nov 28, Jan 20 (IW, CF and RTS)
• Introduction Azafaros Dec 12 (IW)
• Isala clinic (NL), Dec 13 (IW)
• EJP RD Webinar Natural History Study grant Dec 15, Dec 21, Jan 10 (IW, RTS and CF)
• Angitia Bio, Dec 15 (IW)
• Kyowa Kirin International Dec 16 and Jan 26 (IW)
• ICD11 project - pain and OI in Norway, Jan 9 and 31 (IW and IMSP)
• Quince Therapeutics Jan 10 (IW)
• Alexion, Jan 12 (IW)

Pain and OI Project
Together with the OI Foundation we organized two more workshops in the Pain & OI project on October 12 and January 18. Workshop four was opened by pediatric rheumatologist Jacqui Clinch (photo), who works with OI and other conditions in a pain clinic in Bristol, UK. She gave a very good presentation called Bone pain, mechanisms and interventions. Dr. Clinch presented a “what” list which detailed the types of question to assist doctors in understanding pain:

• What types of pain are there
• What processes within bone can cause pain
• What aspects outside bone can influence bone pain and associated disability
• What pain assessment tools do you use
• What is your understanding of analgesics used in children
• What is your rehabilitation approach to cases

The second part of workshop 4 was used to provide input for the OIF and OIFE survey on pain and OI, which was also the main topic on workshop 5 in January. The survey (English language only) was launched at the OIFE Leadership Meeting on January 23 and will be open for at least one month. Many of the participants in the Pain and OI project are also contributing as speakers at the topical meeting in Stockholm.

OIFE 1st General Assembly under Belgian law
OIFE is now a legal entity in Belgium and assets & liabilities have been transferred to OIFE in Belgium. OIFE in Netherlands is dissolved and the German bank is closed.

On October 23 our member organizations came together to elect a new and expanded Board of seven people. There were in total 29 participants who attended, with 16 voting members. The OIFE Board gave a presentation about news and future activities of OIFE. The members were also informed that the process of re-establishing OIFE in Belgium has come to an end.

Some terminology changes to be aware off:
• The EC (executive committee) is now to be known as the Board
• The OIFE General Assembly will no longer be called the Board, but will still have the same power and mandate as before, except from decisions regarding associate membership.
• The contact persons of our member organizations will be called representatives, except when voting at our general assembly/annual meeting (where they are delegates).

Three new Board members were elected at the AGM - and you can read about two of them another place in the magazine. Our third new Board member Renata Hoes unfortunately had to resign from the Board in February 2023, because of personal reasons. At the October meeting, we also sent a big thank you to our vice president Dace Liepina who resigned after 4 years of service.

OIFE Investigator Meeting
On November 18th OIFE hosted our very first OIFE Investigator Meeting. More than 140 participants from Europe and beyond took part in the online event which included mainly researchers, clinicians, but also some industry representatives, patient representatives and students. The programme both included interesting talks about what is going on in European OI research (basic and clinical) as well as workshops on how we can collaborate more closely within European OI research. The event had very positive feedback and a large majority wanted the event repeated as an annual online event. A big thank you to the programme committee for their help and support!

Council of Federations in Paris
From November 8-9 Ingunn, Inger-Margrethe and Renata attended the EURORDIS Council of Federations meeting in Paris. Among the topics were access to treatments and the pharmaceutical legislation, information about Rare Disease Week and future funding options in research. There was also an update on the situation for people with rare diseases in Ukraine and a discussion about access to genetic testing in Europe.
EURORDIS BOARD MEETING
While OIFE’s new Board had a productive meeting in Mechelen, Belgium, Rebecca was attending the Board meeting of EURORDIS in Barcelona.

OIFE Leadership Meeting
On January 23rd the member organizations of OIFE were invited to the OIFE Leadership Meeting 2023. The purpose of the meeting was to inform the organizations about events and activities going on in the OIFE. The agenda included the following topics:

- News from OIFE incl. clinical trials
- Launch of OIF & OIFE pain survey
- EuRR-Bone registry – status and need for assistance from OIFE members
- How medicines are approved in your country and why you should know?
- OIFE campaigns 2023
- How and why collaborate with healthcare providers? Example from ZOI

Ca 35 participants took part from 18 different OIFE member organizations.

THE PAIN AND OI SURVEY
The OI Foundation and the OIFE have partnered on a new project investigating the experience of pain for people with OI. The survey is for anyone 18 years old or older and was written with input from the OI & Pain expert group. It is in English language only.

Through this survey, the international Pain and OI Project hopes to learn more about the different types of pain people experience, severity of pain and frequency, and how it is impacting people’s lives. Findings from this survey will be published online and presented at OIFE’s Topical Meeting, “Balancing Life with OI” in Stockholm, Sweden from June 9-10, 2023. Click here to fill in the survey – which takes less than 15 minutes.
Meet the new OIFE Board members

**Stephanie Claeys, Belgium**

Hello everyone, 35 years ago I was born in Bruges, Belgium with OI type 3. From birth, I was involved with the Belgian Patient Organization ZOI (www.zoi.be). In 2020 I got elected to the board of ZOI. I love to be with other people who have OI to share experiences, knowledge, advice both as a friend, but also as an experienced peer.

From 2016 to 2022 I was one of the two OIFE Youth coordinators. I was able to help coach the different host countries during that period and organized a youth event by myself in May 2022 in Belgium. I believe working to have inclusion of people with OI is extremely important, but it feels also very helpful to be around peers. I will always be a big supporter of (youth)meetings across borders.

Not only did I attend different youth meetings but I also attended different OI-related Conferences, organised by OIF and the OIFE. I have a Bachelor in Office Management with specialization as Medical Management assistant. Since 2008 I have worked in the general/public hospital in Bruges, Belgium as an administrative medical expert.

At the moment, I work for the Ethics Committee/Clinical Trial Center. Because of this, I have a good knowledge about the European Clinical Trial Regulation and I know how to look at clinical trials with a critical and ethical eye. I’m looking forward to contributing on the topics: research & development, patient involvement, peer work, youth activities and organizational management and event planning.

**Malene Sillas, Denmark**

My name is Malene Sillas. I’m 27 years old (soon to be 28) and I was born with OI type 1/4.

Since I was born, my family has attended the national OI meetings in Denmark, and through these meetings, I have made lifelong friendships that are still a very important part of my life today. Back in 2018, I became a board member of the Danish OI organization DFOI which I still am today. In the board, I’m in charge of our youth group and representing our national organization in OIFE.

In January 2022 I finished my master’s degree from Aarhus University, where I have been studying education science. During my time at the university, I was a student politician at the students’ council, where I mainly represented the students in political meetings, boards, etc., and advocated for better conditions for students’ wellbeing. Because of this, I have a deep understanding of different political systems and advocacy in general which I hope can be useful for the new OIFE Board. Since finishing my master’s degree I have been volunteering at the Danish children’s helpline, and I just did an internship as an educational consultant.

When I’m not working or doing OI-stuff I’m, what some might call, still stuck in lockdown trends because I knit an awful lot. I’m also the proud parent of a sourdough starter, that I made during the first lockdown, and named after the head of the Danish health authority. If you’re looking for sourdough tips, or just have other questions, don’t hesitate to contact me.
Meet our new OIFE Member COIS (Canada)

The Canadian OI-organization became an associated member organization of OIFE in October 2022 and we are very happy to welcome them to our international OI-community.

My name is Jacinta Whyte and I am the President and Chair of the Canadian Osteogenesis Imperfecta Society (COIS-SCOI). My 26-year-old daughter Rachel has Type IV OI and has been very lucky to have been a patient of Dr Glorieux and the team at the Shriners Hospital for Children in Montreal since a baby. It was through that association that I was asked to reactivate the COIS. So, I have been working for many years to achieve this goal and we finally re-established the COIS formally with full government registration in 2017.

COIS do not operate on a membership model, meaning that we don’t have individual members. The OI population in Canada is still relatively small and we find it difficult to get hard numbers other than the population that the Shriners Hospital cares for, which is in the 700/1000 range. The assumption is that 80% of the OI population are typically more mild to moderate, therefore many go undiagnosed.

The general population in Canada are very fortunate as we have a public health system enshrined in law, so everyone has full access to medical care. For the OI population specifically, our child OI population are really lucky to have the great team at Shriners Hospital in Montreal leading the way in the fields of OI research, care and treatment of the ‘whole person’ in a family centered treatment model. So the whole family gets cared for! Adult OI care is more challenging, and COIS have commenced building a medical and treatment practitioners directory as we find professionals with experience in OI. This has become a top priority for COIS to make adult care more available and accessible.

We are a volunteer organisation and working with our eight board members we are slowly getting the OI Community connected and supported in Canada.
We are lucky to have a close association with the Shriners Hospital In Montreal, Quebec through Dr Francis Glorieux (COIS board member) and through a partnership with the OIF where we can leverage and share their great work. We are now also an OIFE associate member and look forward to building that relationship.

Our vision is to create one OI community without borders or barriers.

Our goals are:

• Awareness - to develop community and broader awareness of OI through targeted communications, ambassadors, digital outreach/website and events. We are also developing and implementing diversity and inclusion strategies to reach marginalized OI communities and people.
• Education - to develop educational and resource materials,
• To support research and academic OI development through the Francis Glorieux Fellowship program and to support medical research grant applications.
• Support - development of regional OI community support hubs, provide lifestyle advice and access to key OI care providers in Canada.

Together with fundraising for our Fellowship Program, our biggest challenge is finding volunteers who have the time to support COIS activities and build out our regional hubs. This is probably our key priority so we can get fully established.

Our biggest success was to get the COIS legally reactivated as a registered charity in Canada, (something we could not have done without the support of our partners at OIF.) We are also pleased to have launched our summer 'OICAN' family camp in partnership with a specialized summer wilderness camp provider, so the whole OI family can have summer fun at camp!

Our current major project is to fully launch the Francis Glorieux Medical Research Fellowship to support the development of academic research, skill and capability of young clinicians and physicians who will be contributors to the OI community over the short and longer term.

Our plans are to deliver on our strategic plan to achieve our goals and continue to build out our volunteering and fundraising base to enable many good things to happen! We also wish to connect more actively with other OI-organizations especially OIFE as given the diverse nature of Canada, we need to build a broader diverse community accessing multilingual capability that OIFE brings.

Many thanks,
Jacinta Whyte
President COIS-SCOI.
Meet our new OIFE Member OI Kazakhstan

In September 2022 we met two OI-professionals from Kazakhstan at the Sheffield OI conference. This was dr. Assem Dossanova and her husband professor Dossanov (photo on the right), who is one of the central orthopaedic surgeons in the Asian country, with a small percentage of the country situated in Europe. The couple told us that there was a relatively large OI-group in Kazakhstan, but that they struggled with lack of experience and were interested to join the OIFE to learn from other organizations and connect with the international OI-community. In October 2022 the group became an associate member of OIFE. With the assistance from dr. Dossanova, who is also the OIFE delegate, we have made an interview with Birzhan Sarzhanov, who is a volunteer in the organization.

Who are you and what is your relationship to OI?

My name is Birzhan Sarzhanov - a member of the Public Association "Patients with rare bone diseases", father of children suffering from OI. Currently we have registered more than 100 children between 3 months and 16 years with this diagnosis in Kazakhstan.

Nowadays the situation for patients with osteogenesis imperfecta in the Republic of Kazakhstan is improving. The first clinical guideline for diagnosis and treatment of Osteogenesis imperfecta was legalized in 2016. There are two centers of specialized care FC UMC “National Center of Motherhood and Childhood" and the Center for Diagnosis and Treatment of Rare Bone Diseases of Alanda clinic in our capital.

FC UMC provides genetic diagnostics, bisphosphonate therapy, surgical correction, rehabilitation, and psychological support.
A team of doctors conducting bisphosphonate therapy, surgical treatment, and rehabilitation works in the Center of Rare Bone Diseases under the leadership of Ass. Professor Dossanov B.A. Moreover, modern methods of surgical treatment are being developed and implemented here, and a clinical study of domestic telescopic implants has been started in collaboration with international experts. The Center regularly hosts master classes and seminars for doctors, including from the regions.

The patient organization "Patients with Rare Bone Diseases" is a relatively young organization. We registered with the justice authorities of the Republic of Kazakhstan in December 2021. 10 parents of patients with OI represent the main core of the organization.

Narbutina Almagul, a mother of two children with OI, is currently the President. Vice-President Bigalieva Ainamkoz, is also a mother of two children with OI. These two women carry out the main management of the organization «Patients with Rare Bone Diseases”.

The mission of the non-profit has been to improve the quality of life of patients with rare bone conditions. According to the fact that the main members of the organization are patients and parents of patients with OI, we decided to solve the challenges of diagnosis and treatment of this condition first. For this reason, we organized round tables with heads of healthcare organizations and parents; we initiated programs on television and we discussed financing problems even on social networks.

Today we can say that the key challenge has been solved. As many as two Centers provide medical care to children with OI. We have quotas from the State, and we can choose the best service in a private clinic. We work with charities to purchase medical devices privately. We also support clinical research organized by the scientific center of the Medical University.

However, the quality of a person's life cannot be assessed only by physical well-being, so we have big plans ahead to activate the social life of "brittle" children. The issue of accessibility of school education for wheelchair-bound children is still not solved. Not all municipal schools have ramps and elevators. Therefore, our children have to study remotely. This is the next issue on our agenda.
We would like to see our children active and happy. Using the example of other non profits, we are going to organize social projects like holidays/camps, so we can show children that a diagnosis is not a verdict. You can achieve a lot even if you have OI!

Among the active members of the patient organization, we have about 10 parents of patients with OI, as well as 5 adult patients. In fact, we are not actively recruiting new members yet. Since the foundation of the non profit, we have been more occupied with organizational issues.

Parents whose children have been diagnosed with OI, learn about us from doctors and medical staff, less from social networks. We have active messenger chats where we share relevant information and social networks in FB and Instagram.

Our biggest challenge and problem is our passiveness. If we want to change the attitudes of others to ourselves, we must first change ourselves. For a long time, people with disabilities have been positioned as recipients of care. In fact, each of us has unlimited opportunities and talents, the main aim is to show them. The biggest challenge is to step up our actions and implement our many plans.

We are a young organization that has not yet been able to express ourselves completely. Nevertheless, already today, we have the opportunity to choose a doctor and a medical center – and this is one of the main achievements of our team.

On February 28, we are planning a TV story dedicated to Rare bone conditions, including OI. On May 6, on the International Day of "OI", we will do an activity to raise awareness about this serious and rare disease.

In the near future, we will begin preparations for the organization of the event "Children's Day", which we celebrate annually on June 1.
Meet the OIFE Representatives – from Associate Members

ANDREA MEDINA, CHILE

Who are you and what is your relationship to OI?
I’m the founder and chairwoman of the board of Fundación de Osteogénesis Imperfecta Chile (FOICH). I have OI myself, and that is why my interest was born in creating an organization that brings together people with OI in the country.

In what way does OI affect you personally?
I’m a woman with OI and OI is part of my life. From a very young age I’ve been aware of my condition, and to a large extent, it defines who I am. I’m fortunate to be able to do the things I’ve wanted, always considering the OI as an important part of me, of my essence.

Can you tell us a little about how and where you live?
I live in Santiago, the capital of Chile, but I was born and raised in Rancagua, a city 90 km south of Santiago. I moved for my university studies and stayed here for work and for its accessibility, which is the best in the entire country (although there is still a long way to go). I live in the heart of the city, a place full of buildings, offices and businesses. It suits me because from this place I can easily get to any point in the city. It may be a little noisy, but it suits me quite a bit.

What do you do when you’re not doing OI-work?
I’m a journalist and I have a Master’s in communication. I’ve developed my career in the digital area and social networks. I’ve specialized in issues of diversity, equity and inclusion, with an emphasis on promoting the rights of people with disabilities, access to information, independent living and accessibility. Currently, I divide my time between FOICH and my media channel Integrados, www.integradoschile.cl. The channel was founded by me and is focused on disability. Among my hobbies, I love reading, watching series and traveling.
Are there things you have to struggle with in daily life?
Life after the start of the pandemic has changed a lot. Before, I worked in an office near my apartment, I walked to the office every day, I also went out to do some small purchases and met with friends. With the pandemic I started working at home and I don't go out much anymore. I have had to adjust my routine, because only last October, the last Covid measures were lifted in Chile, such as the use of masks in public places and the limit on capacity in public places.

All of this has meant that I have changed my routine and decided to make changes in my life, leaving my job to dedicate myself completely to OI and people with disabilities. Because of all of the social consequences caused by COVID-19, we must add that in Chile people with OI must fight for the lack of accessibility in different areas and above all, for the lack of social security. This influences the quality of life that people with OI have, since basic things for our development are not guaranteed. This includes access to medical treatment, mobility aids (for example wheelchairs, canes, etc.), personal assistance and more.

In a few words - tell us a little bit about the organization you represent:
The Fundación de Osteogénesis Imperfecta Chile, FOICH, was created in 2017, due to the interest of five adults with OI and two of their relatives, since there was no organization in the country that brought together people with OI and their families. Today FOICH represents 145 people with OI and is run only by volunteers.

Ongoing projects/activities which might be of interest to readers of OIFE magazine
We want to make up for the time lost due to the pandemic, which affected every person in the organization and made our constant work weaker. The long quarantines and sanitary measures that limited capacity, as well as the same personal precautions to avoid the virus, meant that we did not have a constant job and now we see that things are changing for the better. Now we want to take advantage of the time by organizing various initiatives for 2023.
In your opinion - what is the most important job/task/area for national OI organizations?
We have the huge task of bringing together people with OI from our countries and representing their needs and requirements before public opinion, generating links beyond our borders, and finding new initiatives and opportunities that can help us. We are the voice of people with OI and our responsibility is to ensure a better quality of life.

Do you have any other messages for the readers of OIFE magazine?
We are very grateful for the reception from the OIFE to our organization. Personally, I had the opportunity to travel to Sheffield for the OI 2022 conference (see photo) and I was able to share with you, meet you in person, beyond video conferences and emails. The work and commitment of all the people who are part of OIFE is vital for us, you teach us with your years of experience and encourage us to continue working for the rights of people with OI.

RAGEEMA LIVINGSTONE, SOUTH AFRICA

Who are you and what is your relationship to OI?
My name is Rageema Livingstone and I live with my husband and 3 kids in a suburban area of Cape Town South Africa. I have a 16 year old daughter with type 3 OI. I am also the chair and founder of Brittle Bones South Africa (SA).

Are there things you must struggle with in daily life? Can you give an example?
I would say the most challenging areas in day-to-day life is worrying about my daughter’s safety travelling to and from school as well as the financial impact of special needs schools and medical treatments, medical equipment and being a mum of a teenager with OI which includes her own emotional struggles of daily life living with OI.

What do you do when you’re not doing OI-work?
When I am not busy with OI I work and spend time with family and friends. I love baking with the kids and playing board games. I also volunteer in community outreach programmes in impoverished /disadvantaged areas.
Tell us a little bit about the organization you represent

The organisation is called Brittle Bones SA and was founded in 2015 due to a lack of support and information regarding OI in South Africa. Currently there are over 300 members across South Africa most of which are people with OI. Brittle Bones SA is mainly run by volunteers.

Professor Shahida Moosa is the Head of Medical Genetics at Tygerberg Hospital in Cape Town. She has a special interest in the inherited disorders of bone, especially OI, and she discovered 2 new genes for OI during her PhD studies in Germany. Upon returning to South Africa, she established the Rare Disease Genomics research group at Stellenbosch University.

One of her first projects was to study the underlying genetic basis of OI in South African patients. Her MSc student, Kimberly Coetzer, was able to use the latest in genetic and genomic testing techniques to diagnose 48 South African patients with OI at Tygerberg Hospital. The study formed part of the group’s Undiagnosed Disease Programme, which includes all undiagnosed patients with suspected rare diseases, including OI. Prof Moosa believes that every person with OI needs a confirmed genetic diagnosis, and that this will increasingly become more important as newer therapies become available. She is an ardent supporter and advisor to Brittle Bones SA. Community engagement and education are vital, according to Moosa, and having support groups such as Brittle Bones SA as an integral partner in research and diagnostics is at the core of what drives the Rare Disease Genomics group.

In your opinion - what is the most important job/task/area for national OI organizations?

The most significant role of a national OI organisation is to assist communities in getting the proper support and education regarding OI and to also bring about awareness of this rare disease. Also to assist people to improve quality of life through education and proper treatment and medical devices needed.
JENNIFER COWLEY, AUSTRALIA

My name is Jennifer (Jenny Cowley). I have Type 1 OI and so have 13 of my family members. I represent the Osteogenesis Imperfecta Society of Australia as the newly elected President. OI affects me personally by slowing me down when I get older. When I don’t do OI-work, I like cooking, gardening, art and spending time near the beach.

The OI Society of Australia was founded in 1977 by parents and friends of those with OI in order to create a point of contact for newly diagnosed families. Today it is representing 139 members. It is run entirely by volunteers. We have a biannual conference for our members. It is held over 2 days and all members are welcome to attend. Our biggest challenge so far, was Covid which excluded us from having our face to face conference.

Our Conference in 2022 was held from 30th September - 2nd October in Sydney. Our 45 years celebration coincided with our conference and was a huge hit. There was a variety of speakers including guest speakers incl. Dylan Alcott and Samantha Bloom. The gala dinner was a wonderful time had by all. Lots of catchup chats, new friendships formed, networking, and most of all information. Professor Sillence, which you probably all know, with the assistance of Ms Alison Senn, has played a role since 1975. Over the years there has been more than 22 genetic types of OI diagnosed. He has worked with his colleague Dr Jenny Aunt for many years.

Our plans for the future are to provide members with a database of medical professionals in Australia. We will continue planning a biannual conference for members to attend and to assist members where we can. I think the most important task for a national OI-organization is to have updated information and resources on hand for our members. My message to the readers of the OIFE Magazine is: Reach out when you need it! You never have to face OI alone.
I’m Natalie and I’m an elder millennial (born in 1981). I live in Tennessee with my husband, Justin, and our three spoiled dogs. In college, I studied journalism, but creative writing was always my first love. I feel very blessed to be able to say writing is my job now, and that I make books for kids. When I’m not writing, I love reading on the porch, long dinners with my family, lazy movie nights, and roadtrips up into the mountains.

At what age and how did you find out you want to become an author?
I can’t remember a time when I didn’t love stories. When I was very little, I loved listening to my parents read stories to me - or even make up bedtime stories. I realized early on that my imagination was limitless regardless of the physical limits pushing against me. I think, for most of us who love books, we can remember the story that made us feel “book magic” for the first time. I’m talking about the story that was written so well you felt like you were inside it. For me, that book was The Lion, The Witch, and The Wardrobe by CS Lewis. It’s like I could feel the same icy wind Lucy felt when she pushed the wardrobe door open. I felt her fear sometimes, and I also felt her courage — and that was huge for me. Books helped me realize how brave I could be — the story was fictional, but the courage I found was so wonderfully real.

Writing felt like a very natural extension of that story-love. I absolutely was not a kid-prodigy writing novels in third grade. I started by writing pretty terrible poems (that my parents still have), some short short stories, and I think I tried to start classroom newspapers every other week. But writing is like any other art — you really do get better the more you do it, no matter how old you are. I never stopped doing it. As an adult, I realized that if I actually wanted to be an author ... I needed to finish writing a novel. I did ... and lots of rejection followed. But then I sent my work to an incredible agent who loved it, and she connected me with my editor at Scholastic. Scholastic published some of my favorite books as a kid, so it’s a big honor to be a little part of what they do. I was always hopeful I’d get to write one novel. But my seventh book, Hummingbird, just came out and I’m so grateful.

What themes do you pursue in general?
I think the number one theme that seems to surface in my novels is that we’re forever connected to the people we love. All of my novels also have a little fantasy and magic in them, but they’re usually anchored in realistic towns. I’m very inspired by Roald Dahl and Dolly Parton — they both write in such lyrical, imaginative ways and have such fantastic characters in their songs and stories.
It might sound cheesy, but I think everything I write is a love story, even though there’s no romance in a book for young readers. I write a lot about the people I love and miss, the big questions I still have about life, faith and doubt, and wonder and hope — everything that goes through the blender of my brain somehow ends up in the stories. There’s just a little shimmer of magic in there, too. Because I believe there’s so much magic in the world.

**Do you have a favorite book/role model?**

If you mean my favorite heroine in a book, it’s hands down Anne Shirley from the *Anne of Green Gables* series. The thing that still amazes me about those books, especially reading them as an adult, is that there’s no magic or fantasy element. If there’s a quest, it’s sweet and bucolic. Mostly, it’s just the story of a girl growing up. And I love that she’s actually allowed to grow up - to make mistakes, and to discover the world. I like how she pushes against her quirky-weirdness until she realizes, herself, that she’s actually pretty great. That her unique way of seeing the world is kind of magical. As far as author role models, Ann M. Martin was one of my most favorite authors as a kid. I still love her books. Moreover, I love that she’s still - this many years into her career - writing such relevant, timely, beautiful work. Her books are evergreen.

**Do you have a particular target group? Why?**

Right now, my novels are all for middle grade readers — so around ages 8 to 12. Middle school was a very memorable time for me. So when I write from that place, I think it feels authentic. It’s a very open-hearted place to write from, emotions are more raw, but - for me - there wasn’t this veneer of skepticism just yet. I think those experiences we had as kids shape so much of who we are as adults - for bad but also for good. Plus, I know I’m biased, but middle grade literature is so lyrical and lovely. I just got an email from a 65-year-old woman who told me she loved the books - and that made my day. I really feel like middle grade novels are for everybody, no matter the age.

**What is the most tricky part when writing a book?**

For me, it’s remembering - every single time - that it takes time for the story to percolate. I’ve yet to write a first draft that’s very good. Or even kind of good. It’s all a mess at first, and that can be frustrating. But once I get that first, messy draft out — I can finally see a little bit of a landscape forming. I can get back into it and really tease out the elements I’m excited to tell. Sometimes when I’m drafting - or even at the finish line of that first janky draft - I want to quit and write something else. But the more I stay with a story and work to craft it, the better it gets.

**Tell us how you came about to write a book about a girl with brittle bones!**

Thanks for asking this! Like Olive, the main character in *Hummingbird*, I also have OI. I broke my leg for the first time when I was ten weeks old. That’s a whole other story in itself - one I know lots of people in this community would be familiar with. But eventually, I was diagnosed with OI. Because my type is mild, my doctors always encouraged me to start walking again after fractures healed. At school, I used a wheelchair or walker so I wouldn’t get accidentally pushed over by classmates. My childhood was full of joy and fun. It also had lots of broken bones it it.
I vividly remember a time walking from my bedroom door into the hallway and hearing my leg snap. Just snap, for seemingly no reason. I think I was in 7th grade when I was able to walk without a walker. I’m able to do that now unless, of course, I’m recovering from a fracture.

At first, because my experience with OI was so personal, I was only going to make it ... kind of an afterthought for Olive. Like, yes, she has OI. But I also wanted to make sure she had an epic, full life of adventure and wonder and friendships and first crushes. She’s not everybody’s shining inspiration. She’s a girl, just trying to grow up. Then I broke my femur while writing the book. And I knew I’d glossed over the full truth of my experience. She still has a story full of adventure. She also has a disability that’s really frustrating sometimes. I tried to stay as true to my experience as possible, and writing from a very real place.

Did you get feedback on this book?
I work with a brilliant editor. Her name is Mallory Kass, and she’s actually written some incredible novels of her own (under the name Kass Morgan). I heard an author say once that an editor’s job is to hold a flashlight while you dig for buried treasure. I do a LOT of digging but Mallory’s flashlight never waivers. She helps me bring out new story-threads and themes. She’s incredibly thoughtful, smart, and creative. I love making stories with her. I also send drafts to my mom, still, just like I’ve done since middle school.

What do you do when you are not writing?
If I’m not writing, I’m usually spending time with my husband and dogs, our families, road-tripping, or reading. Or ordering coffee at my favorite spot. Or binge-watching The Great British Bake-Off.

Do you have a message for the readers of OIFE magazine?
Mostly, I would just say thanks for making this community such a welcoming and authentic space. As I was writing HUMMINGBIRD, I had the stark realization that my parents raised two kids with OI with no internet. They couldn’t google treatments, they couldn’t get the kind of resources you can get here and on oif.org. Most of all - they couldn’t connect with other people who were experiencing this. It’s great that this space exists for all of those reasons and more. I would also say that if you - like me - ever want to share your experience with OI through your art, don’t hold back! And do it how you want to do it. Every single person’s experience with disability is so unique - so however you choose to share it (or not share it at all) is totally up to you. I’m excited to see more and more disability representation in books, movies, and television. I believe the world needs to see all kinds of bodies doing all kinds of things. And I believe we need more disabled creators in those spaces making art, too.
My name is Ole Rasmus, and I am a 39-year-old dentist from Norway. My relationship with OI stems back from working with researchers who have studied OI extensively as well as seeing some patients. My role includes writing reviews about oral health in rare disorders, including OI. I am fascinated by how rare disorders demand us clinicians understand more about everything from clinical set-up, materials used and the underlying biology. Rare diagnoses may point in what direction we ought to aim to do better for all.

You and your work experience?
I was educated in Norway, Denmark and South Africa. Before the pandemic and two small children, I organised regular dental missions to East Africa, and I have also worked for several years in Finland. My passion is to improve clinical work. I love how dentistry merges knowledge about medicine, biomaterials and procedural techniques with a spectrum of personalities and lives. I am also developing a web-based database and clinical support tool for dentists. It will allow for an easy assessment of rare findings in the oral cavity and the rest of the body. We hope to aid dentists in making the first step towards a diagnosis and provide information and links to more resources for dental personnel seeing anyone with a known diagnosis. The prototype is undergoing user feedback at the moment, and it will be available in Norwegian and English in 2023. The project is financed by the Norwegian national advisory unit for rare disorders.

Tell us a little bit about the TAKO centre!
The TAKO-centre is a national resource centre for oral health in rare disorders. It was established in 1993 and is situated at the Lovisenberg Diaconal Hospital in Oslo. Our mandate is to build experience by seeing patients with rare disorders and oral findings, through clinical work and research. The centre communicates with dental and medical personnel in all of Norway. Our team is multidisciplinary, which is essential to manage the variety of disorders we see. Patients with more than 600 diagnoses have been assessed at our clinic.
What was the review of OI about?
It is about OI, oral health and dental management for clinicians and patients. We used the published literature and referred to research done at the TAKO-centre and globally. We also included clinical experiences from our centre and from colleagues abroad.

What are the dental problems of people with OI?
Dental issues vary a lot between individuals. The severity of the condition in general is not always linked to the severity of the oral findings. The main issues in OI are dentinogenesis imperfecta (DI) and malocclusions (misalignment between the teeth or jaws). Some may miss one or more teeth. The malocclusions are more severe in OI types III and IV. The most difficult malocclusion to manage is when the posterior teeth don’t occlude.

Were there any surprising findings?
Temporomandibular joint problems (jaw joint-related pain) also called TMJ affect the quality of life no more for people with OI when compared to the general population, contradicting expectations. This problem is often linked to stress in the general population. Perhaps people with OI could teach us all something about coping mechanisms?

What effect does bisphosphonates have on teeth in OI?
Bisphosphonates do not affect teeth, but may affect the risk of osteonecrosis («dead» bone) following oral surgery. The dosage, administration method (intravenously or tablets) and period of administration matter. However, not a single case of osteonecrosis has been reported in OI patients. This does not mean there is no risk, but in the short term, it seems low.

Can a person have dental problems due to OI without having DI?
Teeth are mainly composed of hard enamel, dentin and soft pulp tissue. In terms of volume, the most significant tissue component is dentin. Dentin protects the neurovascular pulp tissue from oral bacteria. DI means dentinogenesis imperfecta, weak dentin. The weak dentin provides less protection against potential bacterial infections and may lead to abscesses in untreated teeth without visible cavities. The teeth may be discoloured bluish-grey or brownish-yellow. The weak dentin provides weak support for the enamel, leading to fractures and rapid tooth wear if dentin is exposed. This is especially relevant for primary (baby) teeth, which are usually more affected by DI than permanent teeth. DI can also be «hidden» in OI, as microscopic images have revealed unstructured dentin in teeth without visible DI clinically.
What is the most important take home message for clinical work?
The dentist must know OI/DI before embarking on any treatment. It is not sufficient to know how to do a treatment, they also need to know what treatment is suitable and when to do it. In dentistry, a myriad of different materials and methods may be used, each with its own strengths and weaknesses. The clinic should allow for wheelchair access and systems to work clinically around these. Dentistry is a precise field, one millimeter may determine success or failure. It is important that the dentist can see well.

Were patients/patient organizations involved in your research?  
Our text was reviewed by NFOI before publishing. I really appreciated the feedback from the OI-community. You are the experts.

How often should a person with OI see a dentist?  
Children with OI should be seen when the first tooth erupts and frequently in childhood. Adult intervals are individualised and vary from four exams per year to one every two years. The number of formal dental sub-specialities varies from none to thirteen between EU countries. Dentistry is a clinical speciality in its own right. It is always wise to consult an experienced clinician updated on the current best practices. It is important that he/she demonstrates concern and interest in you as a patient, has relevant clinical experience and a network of colleagues to consult, so they can manage potential challenges. The most relevant dental specialists for OI patients are pediatric dentists, oral surgeons, orthodontists and endodontists.

What should people with OI do to take care of their teeth?  
I like the 2x2x2 rule: 2 minutes of brushing with 2 cm toothpaste 2 times a day. Electric toothbrushes are great. Flossing the areas of the teeth from the point of contact to below the gums allows for the removal of bacterial plaque. Toothpaste with a higher content of fluoride or mouth rinses may be advantageous. I recommend consulting your dentist about which fluoride concentration is right for you, as this will vary.

Is Osteonecrosis a problem in OI?  
With the available data, it does not seem so, but long-term follow-up of individuals who have started early with bisphosphonate therapy is necessary to evaluate properly before concluding.

In Norway dental treatment is mostly covered by the government if you have OI - can you briefly share how this works? Does it matter if you see a public or private dentist?  
Dental services in Norway are provided by the public dental service and private clinics. The public dental service employs approximately 25 percent of all dentists and is responsible for treating the young and frail in the population according to the law. Three quarters of dentists work in private practice. An OI diagnosis entitles you to partial coverage from the Norwegian Health Economics Administration (HELFO) for dental treatment irrespective of the severity of OI. The price of the treatment is usually higher than the coverage. The patient has to pay the difference themselves.

Any final words for the readers of OIFE Magazine?
I am impressed by the strong spirit held by many with osteogenesis imperfecta. It seems the physical challenges you have to go through makes for some tough, optimistic and forward-looking individuals. Quite the opposite of brittle.
My name is Verity Pacey and I’m a physiotherapist from Sydney, Australia. I began working with children with OI around 20 years ago now. I had the privilege to work in a specialist multidisciplinary clinic for children with OI – the only one in Australia at the time. I worked clinically in this service as the physiotherapist initially, then as the service coordinator for the children with bone and mineral disorders. During this time, I was doing my PhD focused on management of joint hypermobility in children. I moved to a full-time academic position in 2018 with my research then expanding out to have a focus on initially children, but now people of all ages, with OI and other skeletal dysplasias as well as hypermobility disorders. I collaborate with people both nationally and internationally and work closely with patient advocacy groups when planning and conducting research studies, and supporting education initiatives for patients and health professionals.

Tell us about your current project!
The current project was developed with Dr Penny Ireland, a physiotherapist in Queensland, another state of Australia. We’re also working closely with key Australian clinicians in both New South Wales and Queensland (Australian states) including an endocrinologist, rehabilitation physician and physiotherapist. We have also worked closely with individuals with skeletal dysplasias, including the Short Statured Peoples of Australia (SSPA) while planning and running the project. For the first 12 months we had no funding. We ran the project with the support of 5 final year Doctor of Physiotherapy students (DPT) at Macquarie University (where I teach) as part of their research studies. We now have another 4 DPT students involved and were lucky enough to receive a small grant from the Connected Foundation, a patient charity group associated with the multidisciplinary clinic where I used to work. That grant is paying for two of last years students to remain working on the project as research assistants.

The project focuses on the functional performance of individuals in their everyday activities. This includes, mobility, self-care activities, using public transport, leisure activities and communication.

There is a survey first which captures current challenges with functional activities at home, work/school and out in the community, including symptoms such as pain and fatigue, and the strategies people successfully use to overcome these challenges. Following the survey, we perform a standardised functional assessment over the phone or zoom. This assessment is performed via interview and covers self-care, mobility and cognition. We then provide a report combining the survey responses and the assessment scores back to each participant. But, surveys and standardised assessments only give us so much information. So, we are then undertaking interviews in key topic areas.
The first one we focused on was the barriers, facilitators and experience of accessing and using the National Disability Insurance Scheme (NDIS), our government support for people with disabilities here in Australia. It hasn’t been running for a very long time and still has some teething issues, so it was so important to hear the voices of participants to establish what was and wasn’t going well. Next up we are focusing on challenges and strategies for self-care activities, and barriers and facilitators to school participation with the plan to be providing individuals and healthcare professionals with top tips on strategies and equipment to make everyday tasks easier.

The project is for anyone with a skeletal dysplasia, any age. We have almost 100 people who have taken part so far, many of whom have OI! We would always love to have more people with OI involved, so if you are interested you can access the information sheet and the survey here - https://redcap.mq.edu.au/surveys/?s=8YT4N3P98X

What were your most interesting findings?
The project is still running so we don’t have final conclusions yet, but we are finding that a high proportion of people have pain and/or fatigue (up to half) during daily tasks such as self-care or mobilising. Many people report useful strategies to overcome these challenges, and the interviews we have coming up will delve into this detail a bit more, particularly in understanding the impact of pain on daily activities and the ways in which people currently manage this.

The interviews that we have completed about the NDIS access were really interesting. We referred to it as “consistently inconsistent” for people to access and use our Australian disability funding system. The role of advocates, whether parents, partners, professional advocates or friends, seemed to be one of the most successful strategies to help work through these inconsistencies with the system.

What is the most important take home message for clinical work?
I’m sure that we will be able to say more when the study is complete, but for now the main message to clinicians is to ask about pain and fatigue and to explore this in depth. This isn’t just asking your patient to rate their pain from 0 to 10, but having a conversation about the impact of pain and fatigue on daily activities, and the impact of daily activities on pain and fatigue.

We need to consider different environments (home, work/school and the community) as experiences can vary in each. If we don’t know what’s happening, we have no way to try and assist our patients – so make sure that you ask!
Were patients/patient organizations involved in your research (patient involvement)?
Yes, in lots of different parts of the project - the initial design of the questionnaire, appropriate recruitment strategies, and educating the DPT students about living with a skeletal dysplasia. We have been lucky enough to be able to present our project plans and our findings so far at patient conferences here in Australia, and have recruited through these conferences as well.

Please tell us a little bit about the other project with pain diaries!
I am working with an amazing PhD student from Belgium, Marie Coussens, who has almost completed her PhD now. We have recruited adults with OI from Australia and Belgium, and part of her study includes measuring pain with daily diaries. There are such little amounts of research on adults with OI compared to children. Part of this study will help with understanding adults pain experiences better.

Any messages for the readers of OIFE Magazine?
Don’t wait for your healthcare team to ask you about pain and fatigue – tell them if you have these symptoms and ask for a referral to see someone to try and help. Every time you do this you will help your healthcare team learn more about managing daily activities when you have OI. Some of the best tips and strategies to make daily tasks easier are likely to come from your peers. Keep on supporting one another and advocating for your needs through organisations like OIFE.

News in brief

NEW REPORT ABOUT IMPACT ON SIBLINGS
A rare condition diagnosis affects not just the individual but the whole family. It inevitably alters family dynamics and can completely change the life path a family had planned and set out on. The impact is felt by all.

While the effects on the individual and the parents are perhaps more apparent, siblings also carry the weight of rare condition on their shoulders, and their lives are impacted in many ways by the challenges of living in a rare family.

They regularly have plans changed, miss out on opportunities and have to respond to a barrage of questions and often unkind comments from their peers, all while accepting the responsibility of caring for, and worrying about, a sibling. This project, supported by Alexion, AstraZeneca Rare Disease, aims to give a voice to RARE siblings. To find out what impacts them most, understand their individual and collective experiences and determine their unmet needs: https://bit.ly/3HF4Oal
TOOLKIT ADVOCACY
Are you interested in patient advocacy - or changing the world for the better for people with OI or other rare conditions? Then check out this toolkit from Share4Rare!

2ND OPINION
Did you know that the Spanish organization Ahuce organized a 2nd opinion service, where people with OI can get a 2nd opinion from an OI expert (orthopaedic surgeon)?

NEWS FROM OI RESEARCH
A Belgian project has been looking into muscles in OI type 1. The Belgian researchers concluded that adults with OI type I have smaller bones, lower trabecular bone mass, lower estimates of bone strength, and higher cortical density in comparison with controls and that there are some indications of a disturbed biomechanical muscle-bone relationship in adults with OI type I:
http://ow.ly/U5zT5OLbV1C

FACTSHEETS ABOUT OI
Check out the new factsheets from the Brittle Bone Society in the UK & Ireland.
Some of them can also have relevant information and tips for people with OI and their families in other countries:
PROJECT FOR OI CHILDREN
In Italy ASITOI is organizing a project called #PlayingTogether - laboratory for psycho-motoric skills for children with OI. It includes both farm visits and fun in the pool.

OIF NEW DIAGNOSIS TOOLKIT IN SPANISH
This widely used resource from the OIF is now available in both English and Spanish. The toolkit provides medically verified information for parents and medical professionals on topics important for the care of OI babies.

TREATMENT OF HEARING LOSS & OI - A SYSTEMATIC REVIEW
Many people with OI experience hearing loss. Therapies to ameliorate hearing loss rely on conventional treatments for hearing loss in the general population. The success rate of these treatments in the OI population with poor collagenous tissues is still unclear. In this open access article, researchers have conducted a systematic review and meta-analysis on the efficacy of treatments addressing hearing loss in OI:
https://www.nature.com/articles/s41598-022-20169-9

IMPACT IN ITALY (OCT 16)
Thank you to Leonardo from ASITOI who on October 16 represented the international OI-community at an Italian conference in October. Our poster about the IMPACT survey presented findings from the Impact survey at a scientific conference in Italy.

Issues covered in this resource include pregnancy, diagnosing OI and types, handling, feeding and dressing, pain management and a section to “Share with Your Doctor”. The toolkit is available to download here:
https://bit.ly/3WMHThA
**Join OIFE’s OI & Adult Health peer group**

OIFE’s peer group Adult Health & OI is a closed Facebook-group for adults who have OI (English language only). We welcome participants from all countries, as long as you can communicate in English. A closed group means that only people who have been accepted by the moderators and who are part of the group can read what’s being posted on the wall. In the group you can share experiences about living with OI and getting older with others who might have similar experiences. Questions of various kinds can be asked and answered, such as:

- medical issues or concerns
- personal experiences related to a life with OI
- seeking & giving emotional or psychosocial support
- practical hints and possible solutions
- personal advice from the experience of peers
- helpful adaptations for the daily life with OI

The group is ONLY open for people who have OI themselves. You don’t have to belong to one of OIFE’s member organizations to be part of the group.

**Research announcement**

**SURVEY TO IMPROVE CLINICAL TRIALS IN OI STILL OPEN**

In clinical trials - the regulatory authorities are for counting fractures. But this doesn't always make sense for adults with OI, because we don’t fracture that often. Researchers and the organizations are interested in finding out in which way we can measure progress/changes in clinical trials, in addition to counting fractures: Measuring pain, mobility, mental health, overall health etc?

In this survey which is both for adults with OI and parents of OI-children - you will first be asked to answer a standardized set of questions on clinical impact on physical and mental health. After that you will be asked to complete two different short questionnaires, to evaluate which of the two is better and more relevant for people with OI. Are you interested? Please email OI@patientinterviews.com

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*Group by Osteogenesis Imperfecta Federation Europe*
BALANCING LIFE WITH OI
9-10 June 2023 / Stockholm

Topical meeting on the impact of pain in osteogenesis imperfecta (OI)

Lack of understanding and poor management of pain severely impacts the quality of life of children and adults with osteogenesis imperfecta (OI).

Under the title “Balancing life with OI” we are organising a topical meeting on the neglected subject of the causes, assessment and management of pain and its impact on physical and mental health, sleep, fatigue, mobility, relationships/families and work/life balance for people living with OI.

The topical meeting will offer the opportunity to present and discuss current research, treatment methods and other updates on OI-related pain.

The meeting format will comprise a mix of longer talks from invited speakers, shorter talks based on submitted abstracts, workshops, panel discussions and poster presentations.

Parts of the programme will be relevant for people working with other rare bone diseases.
TARGET GROUPS

Anyone interested in the topics is welcome to attend:

- Clinicians and researchers with an interest in OI in general
- Clinicians and researchers with an interest in pain, fatigue, sleep and mobility etc
- OI-community (people with OI, family members, staff and volunteers)
- Professionals and people connected to other rare bone diseases
- Industry representatives

GENERAL INFO

From Friday 9 June 09:00 to Saturday 10 June 2023 16:00

Scandic Continental
Stockholm City Centre
Walking distance from airport express

45 wheelchair accessible rooms

Language: English

COLLABORATIONS

The conference will be a cooperation between the OIFE and the Swedish OI-organization SFOI.

We will also involve OIFE's medical advisory board and our international resource group on pain and OI in the planning process.

OSTEOGENESIS IMPERFECTA FEDERATION EUROPE
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+47 9064 3867  www.oife.org  office@oife.org

REGISTER HERE
SCAN ME
We are happy to announce that the OIFE Youth Meeting will be hosted by As.It.O.I. – the Italian OI organization from the 7th to the 10th of September 2023. The location will be Jesolo, a stunning place by the seaside and near the beautiful city of Venice! A 4-day experience filled with fun, relaxation, and many interesting and interactive activities. Don’t miss out on the chance of making new friends, of enjoying Italian cuisine, and of visiting the amazing surroundings Jesolo and Venice can offer! Contact youth@oife.org if you have questions about the upcoming event!

**OIFE Calendar**

**Contact**

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