Editorial
By Ingunn Westerheim, OIFE President

Q for Quality
What is quality of life? I guess there are almost as many answers to that question as there are people on the planet. During one of the sessions at the ECRD conference, we were asked to use an app to create a wordcloud of what really mattered regarding quality of life. The words that got the top rating were dignity, happiness, ability, autonomy, normality and participation. Many of them I can agree on. I’m not so into being normal now. But when I was younger it was very important to me. Autonomy and independence however are very important values for me. So is participation and happiness.

Speaking of happiness. I’m pretty happy with my quality of life at the moment. After the longest and snowiest winter in 35 years, summer came as an explosion after a very short spring. May has been the warmest month in 100 years in Oslo.
Global warming should probably worry me more, but when I walked along the harbour last Saturday, I could feel nothing but pure happiness. While wearing my golden sandals, and experiencing 27 degrees celsius, sunshine and a mild warm breeze, I could see shiny happy people everywhere. Some of them jumped in the ocean for a refreshing swim. Some were enjoying a nice meal or a drink at one of the many new restaurants that have popped up at the Oslo waterfront Sørenga. And the normally reserved Norwegians were smiling, greeting and behaving euphoric after 3-4 weeks of amazing summer weather.

Yesterday I got a new manual wheelchair. It’s a brand new lightweight chair of the brand panthera - only 8 kg with wheels and specially adapted for my needs. Not too tippy, but still very light to push and maneuver. This reminds me how privileged I am to live in a country like Norway. If you are disabled, you get a wheelchair from the state without paying anything at all. We can get both a manual chair and a power chair, and we don’t have to choose between the two because of insurance.

Coming back to quality of life again - having a mobility aid that works for you, can be incredibly important for a person’s ability, autonomy and independence. Through OIFE I have become connected with hundreds of people with OI worldwide on Facebook. And I get sad when I see people who would have a complete other level of independence and mobility if they just had a better wheelchair. Some don’t have wheelchairs at all, which makes it impossible to get an education and a job and leads to isolation. Some have wheelchairs that are poorly adapted, which make them dangerous and easy to fall out of. Some of the worst cases of fractures I’ve heard of often comes from a fall from the wheelchair. With safer and better adapted chairs, many of these accidents could have been avoided. Having a better adapted and lighter chair would also make it easier for children to play independently with non-disabled children, for young people to hang with friends or to travel and for adults to keep a job and a social life.

So bisphosphonates, physiotherapy, orthopedic surgery are all very important. But I wish we could focus a little bit more on occupational therapy and how important daily living function (ADL) is both with and without mobility aids. If people have a nasty upper arm fracture, they can go from being totally independent to needing an assistant 24/7 because they cannot go to toilet by themselves. THIS is the kind of things that are affecting quality of life for people with OI. A severely disabled child who starts mobility training at an early age, can sometimes achieve small miracles when it comes to independence.

This is the kind of topics I hope the professionals involved in the Key4OI-project initiated by Care4BrittleBones (Care4BB) will address. OIFE is currently not in the steering committee of this project. The main reason is lack of resources. Research is not one of OIFE’s main priorities at the moment. But we will find ways to work together with Care4BB and the professionals, to make sure that the voice of people with OI are heard when discussions on outcome measures will take place. There will also be plenty of possibilities to interact at the planned conference about the same topic in November 2019, where OIFE will play a role. Until then you can read more about the topic in the report from Care4BB and from Claire Hill, who represented OIFE at OIF’s annual investigator meeting in Chicago.

I hope to see many of you in Dundee in August where we will celebrate the 25th anniversary of OIFE and the 50th anniversary of the Brittle Bone Society - the oldest OI-organization in the world! I wish you all a wonderful summer (or winter if you are down under).

Ingunn
What is the OIFE doing?

Summer is already here, but there is unfortunately little time to relax and enjoy the lovely weather. There are so many activities going on - including conferences, projects and networking with different stakeholders. With more visibility through our web, magazine and social media - we get more requests from different stakeholders who wants to collaborate or who are in need of information. OIFE has also initiated new connections on our own the last couple of months, because we are planning some new projects you will hear about soon.

When I look at my calendar, April was a very busy month. At the moment OIFE is run by volunteers only. Unfortunately this does not give us room to be represented all the places where we would like to be. This is an increasing challenge for OIFE. Since we are driven by busy volunteers, it's becoming inevitable that we need to hire staff if we want to reach the next level and be represented all the places we want. We also need to recruit more volunteers, who can help us out as patient representatives in research, help us out with web & social media and with different tasks.

Meetings and events
In addition to many meetings with OIFE member organisations and volunteers, the OIFE has organised/attended meetings with many stakeholders the last 3 months. Rebecca T. Skarberg has also attended a number of meetings in ERN BOND’s steering committee and working groups:

• Skype Mereo Biopharma, March 27th (IW)
• Phone conference with Alexion, April 4th (IW)
• ECTS Webinar Bone fragility in childhood - a complex and evolving subject - lecture with dr. Nick Bishop, April 5th (IW)
• EURORDIS Webinar on Community Advisory Boards (CABs), April 11th (IW)
• European Pediatric Orthopedic Society (EPOS)-conference, April 11th and 13th (IW)
• 18th Annual OIF Scientific Meeting, April 18th - 20th, Chicago, US (Claire Hill - OIFE MAB)
• Phone conference Kyowa Kirin, April 19th (IW)
• EC Skype April 24th, May 2nd, May 22nd and June 5th
• Rare Diseases International Membership meeting, Vienna, May 10th (IW)
• EURORDIS Annual General Meeting, Vienna, May 10th (IW & Rebecca T. Skarberg)
• ECRD-conference on rare diseases, Vienna, May 11th & 12th (IW & Rebecca T. Skarberg)
• Skype Janet Crompton (ICCBH & OI2020), April 25th (IW)
• Meeting about ERN BOND & OIFE, April 25th (IW and Rebecca Tvedt Skarberg)
• Phone conference with ECTS, May 2nd (IW)
• Skype with MAB-member Miguel R. Molina, May 23rd - OIFE MAB (IW)
• ECTS Rare Bone Diseases Patient Group Leaders Meeting, Valencia, Spain, May 25th (Miguel. R. Molina - OIFE MAB)
**OIFE's Medical Advisory Board (MAB)**

Our newly established Medical Advisory Board (MAB) has not been over occupied with requests from the OIFE yet, but some of MAB members have helped us out on various occasions. Claire Hill attended OIF’s investigator meeting in Chicago on behalf of OIFE. And Miguel R. Molina represented OIFE at the ECTS networking meeting in Valencia. Thank you so much to both of you for helping us out! And Lars Folkestad has done an interview for OIFE Magazine about his PHD project, where all the articles are open access. We encourage you to read his articles!

**OIFE AGM 2018 - "Back to the Future"**

The BBS turns 50 years in 2018 and we will celebrate OIFE's 25th anniversary & Annual General Meeting (AGM) at the same time. OIFE AGM will start Sunday morning and last until lunch Monday 20th of August. Do you have photos or documents from the OIFE history? Please help us out by sending an e-mail to office@oife.org

**EPOS conference**

The 37th Annual Meeting of the European Pediatric Orthopedic Society (EPOS) took place in Oslo in April. The conference annually gather more than 500 pediatric orthopedic surgeons, many of them working with OI. Since we knew both the international chair (dr. Darko Anticevic) and the national chair (dr. Terje Terjesen), we took the liberty of asking for free tickets for the welcome reception and the lectures related to OI. "We" were Inger-Margrethe Stavdal Paulsen (chair of NFOI) and myself, representing the OIFE. Fortunately we had a very positive reply. We felt truly welcome and it was a pleasure to network with the OI-doctors in the impressive Oslo Town Hall. Among others, we met dr. Wirth from OIFE's Medical Advisory Board and as dr. Kruse from Wilmington. Dr. Kruse told us he was interested in getting in touch with orthopedic surgeons with experience from operations on people with recessive OI-types. During the EPOS Study group (Genetic & Metbolic Group & Spine) session, we got to hear some interesting lectures. The two I remember the most came from dr. Cecilie Rustad, Norway ('Genes & OI - what is new?') and dr. Illka Helenius from Finland (Essentials of the C-Spine). The first was probably the easiest and most pedagogic lecture on genetics I've heard in a while, and got very good feedback from the surgeons. The second lecture had information on how to treat basilar invagination, something I've rarely heard anyone speak about in OI-conferences. More information about the programme can be found here: https://bit.ly/2xZvuAF
EURORDIS, RDI & ECRD

A few weeks later Inger-Margrethe and I were so lucky to be able to represent NFOI and OIFE again. This time around we met in beautiful Vienna, Austria where we were joined by Rebecca Tvedt Skarberg (OIFE/ERN BOND) and Dace Liepina (OI Latvia - LOIB). André Wittwer and Knut Erik T. Skarberg were also there to keep the ladies company.

OIFE is not a part of Rare Diseases International (RDI), although we have considered to apply for membership. After attending this meeting, I feel that they are working on a level where we might not belong at the moment. The meeting lasted only a few hours and we got to know how the different rare disease umbrellas in the world, work to influence the policy makers (United Nations and World Health Organization) on an international level.

The Annual General Meetings of the European rare disease umbrella EURORDIS, with more than 800 member organisations, is usually an efficient happening. Annual reports and financial reports are presented. Since the organization is very well run, there are usually very few comments to the reports. A new Board was elected, but this time around there were no candidates running against each other.
So the biggest news that came out of EURORDIS AGM this year was the change of fee system. It will still be based on the member's annual income - but in more categories than what they have today. I would say that OIFE benefits greatly from being part of EURORDIS - both through their events, but also their newsletters and educational opportunities. I would strongly encourage our members to get involved. It does not cost that much and you get a lot in return.

The European Conference on Rare Diseases & Orphan Products (ECRD) is a major event taking place every 2nd year in connection to EURORDIS AGMs. It's the largest multi-stakeholder gathering in Europe for the rare disease community covering research, development of new treatments, healthcare, social care, public health policies and support at European, national, regional and international levels. This year “Rare Diseases 360° – collaborative strategies to leave no-one behind” was the overarching theme of ECRD 2018. The theme was meant to illustrate the diversity of the different stakeholders in the rare disease community (NGOs, bureaucrats, pharma etc), and their need to work together to achieve progress in the rare disease community. At the previous ECRD conference in Edinburgh 2016, it was the European Reference Networks (ERNs) that was the hot topic. This year however, it was difficult to choose a certain track throughout the whole conference. I mostly chose to attend "Quality of Life" but I also attended the Digital Patient and Structuring the Research & Diagnosis Landscape. The first part was the best, so perhaps I should have stayed with QoL, which is also the topic of this magazine. For me, the networking part of ECRD 2018 became more important than the actual lectures. I got to catch up with several contacts I've had meetings with the last months and also got to know some new ones. It will be interesting to see what comes out of our new connections. Want to read more about the ECRD? Check out their webpage: https://bit.ly/2IHcxn7

Questions? Please e-mail president@oife.org
Who is Who?
OIFE’s Medical Advisory Board

Darko Antičević
I am senior consultant and paediatric orthopaedic surgeon at Zagreb University Children's Hospital in Zagreb, Croatia and I am adjunct professor of orthopaedic Surgery at Special Orthopaedic Hospital „St. Catherine“, in Zabok, Croatia. In both hospitals I work with paediatricians - medical geneticist and we offer a multi-disciplinary and personalized approach. We offer our services to patients living in Croatia as well as to patients from abroad including those living in Russia.

My experience with OI goes back for more than twenty years. In the year 1998 with group of my colleagues and OI patients’ parents, we founded Croatian Association of OI (CAOI) as patient and parents association. Since then, my experience has expanded to the treatment of the extra severe long bone deformities in neglected type III and IV OI patients who were on prolonged bisphosphonates treatment. In 2011, CAOI, scientific committee led by Joan Marini and myself organized the 11th International Conference on Osteogenesis Imperfecta in Dubrovnik, Croatia.

My job in both hospitals, is to take surgical care of patients (children and adults) suffering from OI and their related deformities/ fractures. We are using all spectrum of surgical equipment including the last generation of telescoping intramedullary rods.

The most important goal/task for the OIFE, as European organization of OI patients and parents, is to put forward all issues of advocacy for OIFE members to related European administrative bodies. The second goal/task is to connect all medical specialists who have professional interest in OI and working in Europe to enhance current knowledge and share the most novel scientific data on OI.

Miguel Rodríguez Molina
I am physiotherapist of AHUCE (the national association of OI in Spain) and it’s foundation Fundación AHUCE. I am specialist in different methods of neurological physiotherapy and I have been working the last years with many different rare diseases that affects the musculoskeletal system.

My last years have been all full time dedicated for OI, as I am the main responsible person of physiotherapy for OI in my country. Patients with OI have an incredible improvement potential with physical therapy, much more than neurological diseases. I have found their potential, but fear, lack of confidence, passivity and disinformation stops many with OI from developing their physical capacity, which affects their own health.

I try to improve movement and functionality through different techniques and therapeutic exercises. In addition I work with other PTs in our national network of physiotherapists. I also create a lot of information materials about OI where I try to highlight aspects that are usually less in focus than fractures: soft tissue, fatigue, normal development, proper handling, pain etc.

Every year we organize a little congress of physiotherapy in OI in Spain. I teach about OI in various contexts and I am also present in social networks where I try to help people with OI and their families, even outside Spain, such as South America or even Africa.

I think that OIFE has the exciting opportunity to change lot of things, being the bridge between patients and clinicians. Usually we talk a lot about fractures and treatments. But there are many more complex questions in OI. It is necessary to empower people with OI and to talk more about “secondary problems” such as pregnancy, sexuality, pain, growth, functionality, daily life, self-knowledge…in a few words: quality of life.
How was the investigator meeting?
This was a fantastic and informative meeting, bringing together clinicians (including some allied health professionals), researchers and patients. It ran over two days, and also offered opportunity to meet with other professionals and exchange ideas. There was also a poster session, which provided further chance to gain insight into current research. Several health professionals with an interest in quality of life measurement were also attending the meeting, and this enabled me to have some excellent discussion and plan future collaboration.

What was the main topic this year?
The main topic this year was outcome measures and the relevance of these to patients. An outcome measure is a tool, questionnaire or test that is used to capture data. Within healthcare and research this data can be clinically relevant (BMD, vertebral fractures) functional relevant (walking/wheeling distance, dressing) or patient relevant (quality of life, pain, fatigue, participation); the latter are more subjective and where possible reported by the patient. An end point is an outcome or event that is measured objectively to determine whether an intervention being studied is beneficial.

Were patients included in the meeting?
Three patients and a parent led a session entitled ‘Patient perspectives on Outcome Measures’; this launched the first day of the meeting. Each presented their background experience and thoughts in relation to this topic, a panel discussion followed, with questions from the audience. Lara Alders highlighted outcomes such as realistic functional mobility and psychological outcomes such as pain, mood and anxiety. Caroline Tipton spoke of outcomes in relation to mildly affected individuals and those related to aging. Patients and members of involved in the care of patients and families with OI to consider outcomes from the patient perspective. Outcomes need to be more relevant to patients, clinicians and researchers need to measure outcomes that patients feel are important to them, and where possible patients should report their own outcomes (PROs)
OIF were actively contributing to the overall conference within the audience and asking questions. Kara Ayers, a psychology professor and person with OI, gave an excellent talk about measuring psychosocial outcomes in chronic rare diseases.

**What was the main take home message?**
The take home message...that’s a difficult concept to put concisely into words. In the final presentation Joan Marini pulled together the broad spectrum of outcome measures that were discussed at the meeting, highlighting; radiographs, DXA, HRpQCT, scoliosis, basilar invagination, pulmonary structure and function, muscle weakness and muscle bone crosstalk, growth, fatigue, pain and pain tolerance, mobility, resilience and anxiety. The need for more patient relevant outcome measures was acknowledged, alongside the need to encourage agencies such as the FDA and EMA to think likewise, and to facilitate the move to considering improvement in outcomes such as QoL as a primary outcome.

**Were there news about medical treatment?**
As a physiotherapist I found the science behind muscle bone crosstalk very interesting. It motivated me to more frequently describe, to my patients, how bones and muscles work, and how having stronger muscles protects osteocytes within bone. As everyone is aware, physiotherapy exercises are often boring, but the knowledge that maintaining muscle strength can be a long term protective measure, may be useful to motivate my patients. Well, I can hope...

From a potential medical treatment perspective I found the presentation by Ken Kozloff very interesting. Their group had treated mice with pamidronate followed by a sclerostin antibody. They suggested that the bisphosphonate treatment would increase trabecular number and then the addition of a sclerostin antibody to increase new bone formation; creating an architecture on which to make new bone. Additional cycles of combined treatment demonstrated gains in trabecular mass and vertebral stiffness.

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**What is Quality of Life Assessment?**
Patient and caregiver perspectives are collected through a number of techniques

- **Open Interviews**
  - In person
  - By phone
  - Focus groups
  - Web discussion groups

- **Structured Surveys**
  - Paper and pencil
  - Computer, tablet, or smartphone
  - Phone interviews
  - Personal interviews
  - Ratings by caregivers or clinicians

- **Momentary Assessment**
  - Smartphone: “What is your level of pain right now?”

- **Registers**
  - Uniform, clinically rich data

**A combination of approaches often provides the best results**

From the lecture of Jakob Bjorner – Overview of Traditional Quality of Life Assessment Methodologies
Many are talking about patient reported outcome measures? Why?
I think finally almost all stakeholders have realised that in order to demonstrate improved healthcare in their patients, it is important to ask the patient’s themselves. Assessing whether an intervention has improved the health and well-being of patients, such as reduced their pain and fatigue, improved their self-reported functional ability and enabled them to live well with a chronic condition is now vital.

Can you tell us about the project you are planning on QoL?
This is not premature, the proposal for round two is due in tomorrow. I am planning to undertake multicentre international focus groups with children and adults who have OI. I have previously developed the OIQoL, a questionnaire to examine quality of life and well-being in children with OI. It was developed using interviews and focus groups with individuals in the UK, I now want to make sure its content is valid in other countries around the world.

For example - are the items within the questionnaire relevant to individuals with OI in other countries? I will be leading on the children’s focus groups and the team in Isala will be leading on the adults.

Any message to the Magazine readers?
Oh, that’s tricky...I would like to encourage people to get involved in research. Not necessarily by participating in trials, but by making healthcare professionals aware of what you would like them to research. What is important to you? What would improve your quality of life? There has been a shift over the last few years, acknowledging a need for patient relevant and patient reported outcomes. We now need to know what those outcomes are. Without the lived experience and knowledge from individuals with OI, this will not be possible. Research is often fun, particularly qualitative research, such as focus groups and interviews. There are no right or wrong answers, just opinions, and they are all important.
Mortality & Morbidity in Patients with OI in Denmark

Interview with Dr. Lars Folkestad, MD, PhD

Who is Lars Folkestad in private and as professional?
I am a 38 (and a half) year old staff specialist in Endocrinology, currently working at the department of endocrinology at Odense University hospital. I see a wide range of patients with different endocrine diseases. My main interests are metabolic bone and calcium diseases, such as OI, and thyroid disease. More importantly I am a father of 3, Thomas aged 8 and my twins Johannes and Sofie aged 5. Safe to say, I have my hands full with them.

I started my phd scholarship in 2010, at the same time as I started my postgraduate specialist training. During this time I was a part-time phd student and part-time clinician. This allowed me to do OI related research for my entire postgraduate training. As a specialist I was fortunate enough to be hired at Odense University hospital, my alma mater – and where my research have been conducted. The department of Endocrinology is one of three centres in Denmark that see adult patients with OI. I am now a part of the OI team at our department.

What topic/topics does the PhD thesis cover?
My thesis cover 4 different topics, mortality and causes of death in OI, fracture risk and fracture rates in OI, bone-mass, -structure and -geometry of OI bone and risk of cardiovascular disease in OI. The thesis itself was written as 4 systematic search and narrative reviews covering the current literature. Included in the reviews I included the 4 publications from the 4 research projects that comprise the phd scholarship.

1) Mortality and Causes of Death in Patients With Osteogenesis Imperfecta: A Register-Based Nationwide Cohort Study. J Bone Miner Res. 2016 Dec;31(12):2159-2166

2) Fracture Rates and Fracture Sites in Patients With Osteogenesis Imperfecta: A Nationwide Register-Based Cohort Study. J Bone Miner Res. 2017 Jan;32(1):125-134

3) Bone geometry, density, and microarchitecture in the distal radius and tibia in adults with osteogenesis imperfecta type I assessed by high-resolution pQCT. J Bone Miner Res. 2012 Jun;27(6):1405-12

All the publications are open access, and can be accessed for free through the journals’ homepages or pubmed.

**Why mortality and morbidity?**
My experience with patients with OI was from adult patients. And we had observed that in patients with OI there are challenges that are related to OI but also due to ageing. We were wondering how having OI would influence the life-expectancy in the Danish patients with OI. As the collagen deficiency is an important part of OI, we hypothesized that some disease might be more prevalent in the OI cohort than in the general population. Due to the way the Danish healthcare system is organized, there is registered individual level data on all inhabitants in the Danish health registers. An unique personal identifier enables record linkage across different registers. Furthermore, seeing that the registers are made for governance they all have high coverage and are high in quality. This enabled us to run nationwide register-based cohort studies including all patients with OI in Denmark. We could now evaluate the burden of disease in the Danish OI cohort, or the morbidity so to speak.

![Image](image.png)

**What was the most interesting findings?**
The most interesting finding was that patients with OI had increased risk of death compared to the reference population, comprised of non-OI individuals. Patients with OI had a higher risk of death from respiratory diseases, gastrointestinal diseases, and trauma.

When evaluating the fracture rates we saw that patients with OI have peak fracture rate during the toddler and adolescent years, fewer fractures during adulthood and increased fracture rates especially in older women.
In patients with type I OI we found altered bone geometry (lower total bone area in the radius), altered bone microstructure (decreased trabecular number, increased trabecular spacing, and greater trabecular inhomogeneity), and lower bone mass (decreased areal and volumetric BMD) compared to healthy controls. Our results suggest that the increased risk of fractures in patients with type I OI is a combined result of altered bone matrix quality, low bone mass, and altered bone microstructure and geometry.

Patients with OI have increased risk of cardiovascular disease. The risk of heart failure, mitral valve regurgitation, aortic valve regurgitation, and atrial fibrillation or flutter seemed to increase from the age of 50 years in the OI cohort.

What was most surprising?
It was surprising that even though we found increased risk of cardiovascular disease in the OI cohort. There were no increased risk of death from cardiovascular causes. This may be due to the fact that death due to cardiovascular diseases are the second most common cause of death in the general population.

In what way did you work with the patient organization?
I have been fortunate to work closely with the Danish OI Society (DFOI) and all my projects have been discussed (at length) with the board at many different time points in the research process. I am confident that my projects have become better from these discussions. Early in my phd scholarship I was invited to present my phd protocol at both the national patient society annual meeting and at the Nordic OI patient society (OI Norden). As a novice this was somewhat nerve wrecking, but as always the OI community was very helpful and understanding. Later in my studies I was invited to present preliminary data at the Norwegian OI society's annual meeting. I feel very honoured to be invited to these meetings, as this is where the real experts are.

What are your future plans?
As a newly educated specialist I am still trying to find my feet. But I am hoping that I will be able to continue to work with OI both in the outpatient clinic and as a researcher. I firmly believe that the combination of research and clinical work is the best way to increase my OI knowledge and the level of care that I can provide. I have many questions that I cannot find the answer to, so there are almost unlimited research projects to start. The challenge is funding and finding the time. Hopefully I will have new data out during the next months, continuing the work started in my phd.

Any message to the OIFE Magazine readers?
I would like to thank OIFE for giving me the opportunity to elaborate a little on my research. I know that the title of my thesis is a bit loom and gloom. But identifying challenges is the first step on the way to better treatment and care. To be honest, I find many positives in the data as I thought the differences between the OI cohort and the reference population would be much larger. If you have any questions, or want to discuss my studies, please do not hesitate to contact me. I am not promising I am able to answer them all, but I will try.
Examples from OIFE Members: Pain Clinic Rehabilitation

Interview with Ute Wallentin, German OI-delegate

We heard that you went to a 5-weeks-pain-clinic recently. Please tell us about it!

Yes, it was very interesting and so far quite successful. I went to that day clinic for 4 weeks from Monday to Friday in February and have (had) a one-week-follow-up „booster week“ in June, after having tried to introduce what I learned during the course into my daily life for 3 months.

I had only got into the program after two intense days of very detailed „assessment“ in November of last year. During those two days I had various examinations and had been asked many questions concerning my physical and mental/psychological status and my life and attitude towards my disability, my body and its „challenges“.

The program (financed by my health insurance) is offered to groups of eight adult patients with different causes of their chronic pain and they are treated by 11 professionals over those 5 weeks: medical doctors, nurses, physiotherapists, psychologists and psychotherapists - each with special extra training for patients with chronic pain and many had pretty special extra qualifications.

It was very impressive, how close the team worked together. Each morning they had a short meeting where they exchanged information about every one of us eight patients. So all of them were always on the same level of information concerning our „progress“ and struggles, and we were really closely supervised by them all.

What are the goals of such a program?
The main goals are:
- to confirm or further develop the diagnosis of „pain“ and to understand its individual causes;
- to reduce or optimize pain medication;
- to teach us understanding of chronic pain and its components;
- to minimize our individual pain and to help us better deal with the inevitable pain in our life;
- to improve quality of life and to encourage more activity and social integration;
- to diminish fear and depression that do increase pain;
- prevention of a further chronification of pain;
- introduction of the individually developed program into the daily life and private circumstances of every patient.
- unnecessary further examinations, surgeries and other activities shall be avoided.
So what are the main components of the program?
The program I did is mainly focused on information, cautious exercises, learning of „mindfulness“ and to take better care of myself. We were taught a better balance between rest, lots of movement and the adaptation of one’s individual goals to the needs and limits of our bodies.

What about pain killers? Did they prescribe the „right ones“ for you?
Not in my case, although I learned a lot about different ways to treat pain. Not only using different kinds of pain medication (if really necessary), but by learning to use a small TENS-unit (electrical nerve stimulation through the skin to relax muscles), several kinds of treatment with cold or warm patches (little sacks filled with beans or spelt etc.) or different relaxation techniques. We do meanwhile have such „pain management programs“ all over the country in Germany and some do focus mainly on better pain medication etc., but our program here has the philosophy to use pain medication when necessary to enable the patient to „get up and move again“, be more active and enjoy life, but they mainly teach other ways how to deal with pain, mentally and physically.

What did a typical day in clinic look like?
Well, we did have different kinds of physical exercises every day, in groups and individually with our „own“ physio-therapist. Then each day they held some kind of „lecture“, information about pain, psychological and physical reasons and interaction between „body & soul“, knowledge about painkillers, healthy food, stress factors and many other topics from different perspectives and disciplines. We learned various relaxation techniques, Chi Gong, Tai Chi, meditation and others. But we were also introduced to aroma therapy and treated with natural essential oils. Twice a week we went „outdoors“ and were taught to take regular pauses and not to continuously overexert ourselves, but to better listen to the individual needs of our body. We had group sessions and individual therapy sessions with psychologists and could discuss our attitude towards life, our personal goals and the balance between activity and rest etc. with the other group-members and with the therapists - as far as we wanted. Nobody was ever forced to do or say more that he or she wanted!

Meeting with Rob Camp from EURORDIS
„OIFE’s work is not only and always centered on topics and essential content of projects around Rare disorders. But often the relation to people do play an important role and last longer than the actual project.

Ten years ago Rob Camp from EURORDIS (as project manager of the RARE-TOGETHER!-project) and Ute Wallentin (then OIFE president) met first and cooperated regularly over several years.

This May Ute went to Spain for a private holiday and had the pleasure to meet Rob Camp during his lunch break near the new EURORDIS office in Barcelona. Afterwards she got a tour inside the spectacular building of the „Hospital de la Santa Creu and San Pau“
**What did you learn and how has your situation changed?**

I had much time to consider (not for the first time, but with excellent support and a group of people with similar problems) what I really want for the rest of my life and what really matters for me. So I understood that it is not possible to stay healthy and active, IF I continue to be far too active in my daily life, and if I will not begin now to take better care of myself and to accept how my aging body will need more rest and peace, sleep and consequent better „care“ in future.

I am pretty successful so far, and have developed a whole „set“ of measures how to better organize daily life, so I do have more „quality time“ for myself. I gave up on the old conviction that I should always do everything NOW that came to my mind and seemed important for the benefit of my clients at work or my many friends. That attitude has caused lots of stress during my adult life, as I understood!

On the other hand I am physically more active and moving every day and more consequent in doing my daily exercises at home or in the gym. And that should help me reduce my pain, I guess! But I got aware again that a certain level of pain is just „normal“ for many people at my age and especially for someone with OI. And that it is better for me to just accept this fact than to feel too sorry for myself and to focus too much on my pain and less on other positive aspects of my life.

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**Announcement from the Brittle Bone Society, UK: We are turning 50 in 2018!**

We are delighted to announce our 2018 conference to mark our 50th Anniversary will be in Dundee at the fantastic Apex Hotel at City Quay on a beautiful riverside location, right beside the train station and minutes from the airport.

From 17th - 20th August 2018 we will host a series of events: a Scientific Symposium; the History Bones exhibition; talks; consultation meetings with delegates; and some serious work with our PPI groups about our OI Adult campaign and patient involvement in research.

There will also be old favourites like our gala awards celebration, and this not to be missed weekend will close with the OIFE AGM on Sunday and Monday.

Registration is now open – this includes registration for OIFE AGM 2018. OIFE delegates must contact secretary@oife.org to get a password for registration.

Accommodation and conference registration bookings must be placed separately. Full details, including registration, can be found on the conference website: http://bit.ly/2ASA68H
Marie's Youth Corner

In that moment when you hear the bone break, it affects all of us. In a fraction of a second unpleasant emotions arrives. We have been here before. We will definitely be here again. We have become experts in a life with a disability. My disability.

Each of us have our own ways to handle the situation when the bone break. Each have a role. My mom is very practical “Where's the pain?” “How many painkillers do you need?” “Do you need to go to the emergency?” She is energetic and so cool! My sister backs out of the situation if someone else is taking over. No doubt that I would have done the same thing if it was the other way around. My dad shares his exceptional calmness he always has on him. I myself try to cut off the emotional part of the situation. Sometimes I succeed in cutting the emotions off and sometimes I don't. And that's okay. I find it much easier to handle the situation if I just focus on the actual circumstances instead of all the frustrations.

Frustrations that involves powerlessness over the fact that once again I am in this situation. There will be room for the frustrations later and they usually sets in when emergency has calmed down. I am very aware of the reaction it causes in my family, when I announce that I have broken a bone. Discomfort. It is the worst partykiller. All the attention turns towards me. I always try to tell them very calmly that “I broke a bone”, so it will reduce the reaction that happens in them. So hopefully they won't get so affected by the situation. After all it doesn’t matter how I tell them. They can see right through me, and they are not in doubt of the seriousness in the situation.

I have always said that I am happy that it is me who has the brittle bone disease in this family. There is a big difference from being the person who has the broken bones, or the person who stands on the side line. None of the situations are fun. I find it difficult to be on the side line if someone in my family are feeling pain or sad. It is easier to handle it when I am the one who is in pain. But luckily we get use to any position we are in. We find our own ways to be in the situations. But it is definitely not easy for any of us.

I did not cry in the moment when I broke my pelvis! But I cried when I saw how much it affected my family. I could have been without this fracture. My family could have been without this situation once again. I am sitting with a broken pelvis because I chose to take the risk with my project to try to walk.

When I broke my pelvis it hurt so bad and during the night the pain got worse. The bad energy I am sending out in my home because of the pain will spread to the rest of the family. The day after I broke my pelvis we called the hospital because the pain got unbearable. They send an ambulance
and I got admitted. I wasn’t supposed to go to the hospital before the day after because I needed to wait until there was a doctor who had knowledge in OI. But because of the pain we went to the hospital a day before. My dad went to the hospital with me, so that day got torn out of his calendar and replaced with hospital. And my mom took the day after. I know that no matter what happens, they will always be ready to help me. Then we will create the best of the situation. But there is no doubt, that they could easily find so many other things that would be more interesting and fun than taking me to the hospital.

My dad and my sister had made it clear to me, that they were not fans of my walking project. I didn’t listen to them, because I have never held back because of the risk of a fracture. Now I can suddenly see what they meant. It is not because they just say “Too bad. Have a good trip to the hospital!” and live their lives. No - their lives gets affected by it too. Very much so. Plans sets aside. Worries fill their mind. The energy in the house gets affected when I am in a lot of pain.

I know for sure that they always will support me and they will always have my back, no matter what kind of things I decide to do in life. But I also know that it is hard to be a relative to a person with a disability. It took almost 16 years before the fractures finally decreased. My family and I cold finally have some relief from the unpredictability my disability brought into our lives. The unpredictability still kicks in with broken bones nowadays, but not as much as it used to.

We can be the best experts in broken bones, but it will never be fun. So when is enough enough? I don’t have the answer but if you are on the side line of the person with the disability it can also be tough and we need to show respect for that!

Key4OI – an update from Care4BrittleBones
by Dagmar Mekking, Executive director C4BB

OIFE: Care4BB has important news about Quality of Life, right?
Key4OI is the name of a new project, which we have recently decided to support with Foundation Care4BrittleBones. It is focusing on what is key for people with OI regarding research and treatment and enables consistent measures for these key areas. This is important because OI is not just “one disease”. There is huge variability in how OI plays out. It differs for example across types of OI and across age groups. Up to 15 different medical disciplines can be involved. What aspects of OI are most important to Quality of Life of people with OI? Nobody knows today. Also, each country and each hospital is treating OI differently at the moment. Often there is no scientific evidence (yet), and because we don’t measure the success of treatment consistently, we don’t know what works best.
Let me give you two examples of the differences we have today: In some countries children are treated with a telescopic rod whilst in others only firm rods are being used. What works better? We don’t know. Another example is bisphosphonate treatment. There are no countries that follow the same protocol. What is the right standard for which patient?

In Key4OI we have a great coalition with representatives from Health Care Providers and OI-organisations who will co-create and suggest a minimum set of measures and promote their use across countries. This will not standardize the treatment, but at least it will give us clarity on what the outcome of the treatment is. Indirectly it may lead to changing the treatment to what leads to best results and it may trigger research in areas that are confirmed as important for people with OI. The project will take up to 3-5 years. You can read more about parts of the project in the interview with Claire Hill, in this magazine.

**OIFE: Why is Quality of Life (QoL) so important to you?**
I have learned a lot about OI since my daughter Sophie was born with OI 12 years ago. I used to think of OI in terms of fractures. Now I know that OI has so many different aspects! We need to create a broader view on what matters to people with OI at all ages to focus treatment and research on the key areas for many people. Measuring QoL is important, for a variety of reasons:

1. I believe that you can only improve what you can measure in some way. Also I believe “what get’s measured, get’s done”. It simply focuses the attention of the many people/institutions working with OI.
2. Research is generally focusing on areas that are not yet scientifically proven and can be measured with strong objective criteria (eg the height of people with OI, or bone mineral density). This is certainly understandable, but it may not address what is most impactful to improve QoL. We would like to help focus research on areas that make the biggest difference to people with OI.
3. Given the variability of OI and the many different genetic mutations that have found to be causing OI, we need to be able to create big data from many people with OI to enable strong research. Defining an international set of common data will give us new insights that we currently don’t have.

**OIFE: What is your vision regarding this topic?**
Together with many other partners who work with OI every day, we would like to improve the Quality of life of people with OI. This can be done in two very different ways: First by helping to find “a new treatment” for OI in an area that is felt as very impactful by people with OI. This can be new medication, but also the application of a new genetic technique, better rehabilitation and improved support to psychosocial issues. Secondly, a better QoL can be achieved by enabling a better “ecosystem” for research and treatment and enabling quicker learning.

**OIFE: Is there other important news from the last application round?**
There are many really interesting proposals we would like to support in this round. We are in the final stages of discussions around projects related to the following:

- investigating the Weight Bearing Shoulder in OI
- the oldest and largest database for OI Mutations, which is crucial for geneticists and prenatal diagnostics.
- the use of special elastic orthoses for children with OI
• the development of an international expert opinion paper on good clinical practice of OI and
• we are investigating the feasibility of a conference to discuss the topic of Patient Outcomes in Amsterdam (22-25 November 2019). This in collaboration with our Care4BrittleBones Network Partners (VOI, ASITO, ZOI, SVOI, AOI, DOIG) as well as OIF, ERN BOND, OIFE and many other parties including pharmaceutical industry. It would be a conference that needs to be interesting for both professionals, people with OI with an interest in research and pharma.

OIFE: How will people with OI/parents be included in the Key4OI project?
We are at the beginning and have not discussed this with our key partners yet. The view of Care4BrittleBones is always: It is important that we have the OI community “at the table” and participating on an equal level with everyone else. Because we are not a patient organization with individual members, we would rely on the advice of the OI-organizations to suggest the right people. Generally we will be looking for people who are super motivated regarding the topic of Patient Outcomes, have time available in their lives to do this, are willing and able to learn fast and are able to think strategically and beyond their own individual needs. Interested individuals are more than welcome to get in touch using conference@care4brittlebones.org

OIFE: Why should the patient community take the lead in this and not the professionals?
Interesting question! I think it is neither patient community nor the professional community in the lead. I strongly believe all progress for OI requires both! It really doesn’t matter who takes the lead, as long as somebody helps all parties to move forward together. What matters is that we have a mature dialogue where all parties are able to bring their unique insights to the table. A practical example: Each medical conference I have been to in the last few years had one or more presentations about the “height of people with OI”. Should we not talk more about fatigue and pain instead? I am absolutely convinced that researchers and industry and even institutions like the European Medicines Agency (EMA) are willing to listen and respond to the needs of people with OI, if they are able to form an opinion what their key priorities are.

OIFE: What is quality of life to you personally?
“Quality of Life” for me is to make the most out of any moment in my life. I think it is important to add something to the world around me in a lasting way, no matter how small the difference may be. In 2017 I made the decision to leave my current employer to work fulltime for Foundation Care4BrittleBones. Being able to spend my life working together with many others to improve OI makes me profoundly happy and satisfied.

The illustration is taken from the ECRD conference and the lecture of Jakob Bjorner – Overview of Traditional Quality of Life Assessment Methodologies

Challenges of Implementing QOL Measures in Rare Disease Clinical Trials

1. Understanding the disease or condition
   - What is known about the condition?
   - How is it treated?
   - How does condition impact patient and caregivers?

2. Conceptualizing treatment benefit
   - What constitutes a meaningful treatment benefit?
   - How will the clinical study be designed, i.e., the context of use?
   - Which types of tools are needed?

3. Selecting / Developing Outcome Measure
   - Can any existing measure do the job?
   - How to develop or adapt a measure for this context?
Artists with OI: Mira Thompson

Who are you and what do you do?
My name is Mira Thompson and I’m a singer.

In what way has OI affected your art?
As much as I want to say it hasn’t, I also know it completely affects the way I look at life in general. Which does not mean every song I write is directly connected to disability or ableism, but I also don’t avoid those subjects. But to me they are as important as writing a beautiful song about heartbreak, to name an original subject. I do, however, feel responsible for using my voice (quite literally) to advocate for disability rights. Music can be a powerful way of doing that. I recently released a song that I made with my friend Femke Smit using sounds my power chair makes. The lyrics are meant to be a bit confrontational. I’ve used what I see as some of the thoughtless statements and questions posed to those with visible disabilities. I dubbed the lyrics over the wheelchair sounds. Although the lyrics might seem to be a bit cynical, it was important for me to radically ban sentimental emotions about this subject. My friend Feline Hjermind, who is a video-artist, made a video clip to accompany the song. Interested parties can find it under the title ‘Tiny Shoes’ (Mira Thompson) on YouTube: https://bit.ly/2Hlrjsm

What themes do you pursue?
Just about anything that captures my imagination can become a theme for my music. For example I am now working on a song inspired by my own shadow. I found the idea of a shadow of something (or someone) very small taking on large proportions as a shadow. Fascinating!

What role does the artist have in society?
I don’t think I get to decide what role an artist has in society. An artist can fulfill so many roles and functions in society. One of my hopes is to be able to provide a sense of connectedness for people. Although I definitely don’t think art has to be political, I do think that is one of it’s possible functions. For example, I strongly believe that it is a political act in itself for a woman with a visible disability to perform on stage. If my music reaches lots of different people on lots of different levels, then I have succeeded.

What is quality of life for you?
For me, quality of life is being able to keep developing in every aspect of my life. This means not being held back by social and/or physical barriers or restraints. That can range from simple accessibility issues to access to education and openness in all kinds of social situations.
Who are you and what is your relationship to OI?
My relationship with OI started nearly 12 years ago when my daughter was born with the condition. She is diagnosed as type 3 and currently wheelchair bound as she is experiencing bone thinning to the extent that her left femur is nearly completely gone. At birth she was misdiagnosed as type 2 and I was told she would pass away. After being diagnosed through the Red Cross as type 3 I became a sort of counsellor to new parents with OI kids this sparked the idea of starting a support group with has grown into a NPO: https://www.facebook.com/brittlebonessa/

How many people with OI does South Africa have?
At this stage I cannot give you an answer to how many OI people is in SA as hospitals cannot give me statistics as no one has been keeping a record and I am in the process of getting information from government hospitals so I can compile my own statistics.

Can you tell us about the situation for people with OI in SA?
Not many people are aware of the condition. My daughter attends the Red Cross Hospital here however most doctors have not dealt with the condition so they do not easily recognize it. There is currently only research into genetics as far as I am aware. Currently a case study is being done on my daughter by dentists as they have never dealt with dentogenesis before at government hospitals. I have not done research into private dentists as it is very costly and majority of patients cannot afford it.
Can you tell us about your organization? When was it founded? How is it managed?
My organisation has been around for about 5 years however it was only officially registered through government last year. I manage most of the day to day queries as well as setting up events and fundraisers. I have help through my family and friends. It is a struggle to get people involved sometimes, as most people expect a salary or money to be allocated to them if they assist in fundraising, which makes it very difficult.

How many members do you have? How do you recruit more members?
Currently we have over 100 members in our support group. We do posts on social media and through events and advertising on local media such as newspapers and radio stations we have managed to get into contact with more members.

What are the biggest challenge for your organization?
Our biggest challenge is funding which enables us to provide wheelchairs and medical equipment to families with OI as well as day to day costs of running the organisation. Another challenge is lack of education on the condition as members have many questions that doctors cannot always provide us with.

Do you have projects you want to tell us about? What is your biggest success?
I have lots of projects which I am working on, such as providing our patients with special personalised blankets. One of the local orthopaedic hospitals is close to my heart as my daughter had her rod put in there and I have regular drives to provide the hospital and patients with items they may need. In the past year we have helped 3 children with wheelchairs and I am currently busy with raising funds for another little girl to receive her chair. We have also assisted with families that could not meet the yearly fee of special needs school which is a bit costly here. I work with my daughter's school in providing equipment to learners such as kaye walkers, splints and wheelchairs.

What are your plans for the future?
My future plans is to establish a better quality of life for OI in SA and Africa as a whole by helping to educating families and making medical professionals aware of this condition. Through projects I am working on I would like to create employment for special needs parents struggling and not able to go out and work.
Dr, Jeanne Franzone MD is also an orthopaedic surgeon at Nemours specializing in OI with a particular interest in the correction of limb length inequality and deformity correction to include growth modulation techniques in OI.

Dr. Kruse current research interests include:
- the upper extremity, particularly the shoulder in OI and
- surgical care of patients with recessive and non-collagen I mutations.

His team is very interested in expanding international collaboration to better understand the impact of upper extremity pain or functional limitations on the day to day life of patients with OI. He can be contacted at rkruse@nemours.org and Dr. Franzone at jeanne.franzone@nemours.org and they would be interested in hearing patient stories or furthering collaboration with other professionals.

Patient representative in Key4OI
Do you have OI yourself or do you have children with OI? Would you like to be involved in a global international OI improvement project organized by Care4BrittleBones? Are you curious to meet other people interested in research from all parts of the international OI community and researchers? Do you have time to spend 3 hours a week on the project for 1-2 years? Please get in touch with office@oife.org before July 10th 2018 to find out more!

ePAGs in ERN BOND
Are you a person with OI interested in improving clinical treatment for people with OI? Do you have knowledge or interest about the European Reference Network for rare bone disorders (ERN-BOND)? If you are interested in being a patient representative or would like to learn more on ERN-BOND - please contact Rebecca Tvedt Skarberg on rebecca@nfoi.no

Surgery of shoulder in OI & surgery in rare OI types
Richard W. Kruse, DO, MBA is a paediatric orthopaedic surgeon at the Nemours Alfred I., DuPont Hospital for Children, Wilmington, Delaware, USA. He holds appointment as Clinical Professor at the Uniformed Services University School of Medicine in Bethesda, Maryland, USA. He and his orthopaedic colleague Jeanne Franzone MD specialize in the surgical treatment of osteogenesis imperfecta and and Dr. Kruse is co-director of The Osteogenesis Imperfecta program at Nemours.

Cochlea Implants & OI
The OIFE has been working together with our new volunteer Diane Maroger from France, to collect data, articles, professional advice and personal experiences on Cochlea Implants (CI) in people who have OI. Do you have experience or knowledge about this topic? Have you performed CI surgery on a patient with OI? Please send an e-mail to Diane: dmaroger@gmail.com
Mereo BioPharma is sponsoring a multicentre international clinical trial to study the effects of the anti-sclerostin therapy drug setrumab on bone in OI. The study is open to recruiting patients at multiple sites in Denmark, France, United Kingdom, Canada and the United States. Adults between 18 and 75 years old who have a diagnosis of OI Types I, III, or IV are eligible for this clinical research study, which aims to enrol up to approximately 140 patients.

The most important inclusion criteria are:

- Genetic confirmation of COL1A1 / COL1A2 defect (can be obtained in the study)
- Previous bone fractures

Visit the clinicaltrial.gov listing Clinical Trials Website [http://bit.ly/2F3inxO](http://bit.ly/2F3inxO) or the company’s Study Website [www.asteroidstudy.com](http://www.asteroidstudy.com) to learn more, find your nearest study location, and register your interest in participation.

If required the study provides patient travel support services for all visits to hospital.

If you have any additional questions, please email AsteroidStudy@mereobiopharma.com

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Research announcement update: Denosumab Trial

The company Amgen sponsors a multicenter 3 year clinical trial to study the safety and efficacy of the investigational drug Denosumab on bone mineral and fracture occurrence in children who have OI.

Currently the study is open to eligible children ages 2-17 who have a diagnosis of OI Type I through IV.

The study has 38 sites participating in this clinical research study in the following countries: Australia, Belgium, Bulgaria, Canada, Czech Republic, France, Germany, Hungary, Italy, Poland, Spain, United Kingdom and, United States.

For more information and a complete list of study locations visit the Clinical Trials website [http://bit.ly/2kLfg3I](http://bit.ly/2kLfg3I)

If you have any additional questions, please contact the Amgen Call Center at 001 (866) 572-6436. Their Customer Service Representative will be able to find a site near you and provide you with the Site Study Contacts; who will tell you more about the clinical research Study.
News in brief

**OI Registry In Chile**
On May 10th the newly established Chilean OI-organization Fundación de Osteogénesis Imperfecta Chile announced the establishment of a National OI-registry in Chile. You can find the organization on Facebook now: [https://www.facebook.com/SomosFoich](https://www.facebook.com/SomosFoich)

**Exercise & OI**
Do you understand Spanish? Check out the book «Osteogenesis Imperfecta - Exercises at home». Created with support from the Spanish OI-organizations Ahuce and Fundación Ahuce.

**Bone Pain Ambassadors**
The research group "Bone Pain Ambassadors" is interested in getting in touch with patients with OI who have experience with bonepain who wants to volunteer for their section on Patient Testimonials (interviews) on this website: [http://bonepain.eu/patient-stories/](http://bonepain.eu/patient-stories/)
See the attached photo for more information. Please contact president@oife.org or the project directly if you want to volunteer for the project.

**Research Award**
The Care-for-Rare Foundation for children with rare diseases – in conjunction with the Werner-Reichenberger Foundation – invites applications for the Care-for-Rare Science Award 2018 endowed with 50,000.00 Euro. The award should give scientists the chance to initiate a basic of clinical research project in the field of rare diseases. Deadline is July 31st 2018. Read more at their webpage [https://bit.ly/2t36OI7](https://bit.ly/2t36OI7)

**Fun For Flying OI Experts**
The participants of the Annual General Meeting in the Norwegian OI organisation NFOI bought lottery tickets for 10.234 NOK (1058 EUR) during their family dinner. 100% of the money will be donated to OIFE’s project Flying OI Experts. Way to go!

**Do you want to donate to Flying OI Experts?**
THE LOST TABLECLOTH
Did you know - in 1982, the first OI International Conference was held in Edinburgh with representatives from 14 different countries in attendance? This was many years before the OIFE was established (1993). Many of the delegates signed this tablecloth which was later embroidered. Will you help the Brittle Bone Society share to find out if anyone still has it?

O2020 IN SHEFFIELD
The 14th international conference on OI will take place in Sheffield, UK from September 5 - 8, 2020. There will most likely be a pre-conference event for patient representatives (or similar) connected to it. Please mark the date!

SAVE THE DATE!
14TH INTERNATIONAL CONFERENCE ON OSTEOGENESIS IMPERFECTA
O2020
5-8 SEPTEMBER 2020
SHEFFIELD, UK

For further information contact
Nick Bishop (Sheffield, UK)
Local Organising Committee Chair
Email: n.j.bishop@sheffield.ac.uk
Calendar OI-events

2018
August 18 - 19  BBS 50th anniversary, Dundee, Scotland
August 19 - 20  OIFE AGM, Dundee, Scotland
Aug. 31 - Sep 1st Family Meeting OI Austria, Tirol
Sep 7 th - 9th   NFOI Urban Youth Camp, Oslo, Norway
October 6th    Jubileumsviering VOI (35 years), Utrecht, The Netherlands
Oct. 25th - 28th OIFE Youth week-end, Aarhus, Denmark
Oct 26th - 28th NFOI Week-end for adults with OI, Oslo, Norway
Oct 9 - 11      Familiekursus, Fredericia, Denmark

Calendar scientific conferences

2018
Aug 17    BBS - Scientific Symposium, Dundee Scotland
Sep.     Multidisciplinary Expert Forum (China Dolls), Beijing, China
Sep. 26 - 27 Mechanistic & Therapeutic Advances in Rare Skeletal Diseases, Montreal, Canada
Sep 27-29 European Society for Paediatric Endocrinology, Athens, Greece
Sep 28 - Oct1 ASMBR 2018 Annual Meeting, Montreal Canada
Dec 1-4 International Congress of Endocrinology, Cape Town, South Africa

2019
April 4-7 World Congress on Osteoporosis, Osteoarthritis & Musculoskeletal Diseases, Paris, France
May 11-14 46th European Calcified Tissue Society Congress, Budapest, Hungary
May 18-21 European Society for Endocrinology, Lyon, France
June 22-25 9th International Conference on Children's Bone Health, Salzburg, Austria
July 15-17 Bisphosphonates 2019: Celebrating 50 years, Sheffield UK
Nov 22-25 Key4OI - Patient Outcomes, Amsterdam, NL - not confirmed

2020
Sep 5-8 OI2020: 14th International conference on OI, Sheffield, UK

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