Editorial
By Ingunn Westerheim, OIFE President

Pain & pleasure
If you think this editorial is going to be an OI-version of "Fifty shades of grey", I have to disappoint you. It’s going to be about pain & pleasure in a non-sexual way. And how those two can sometimes affect each other.

Let’s start with the positive part. It was my great pleasure to take part in the celebrations of the Brittle Bone Society’s 50th anniversary and the 25th anniversary of OIFE. Together we went back to where it all started, in Dundee, Scotland. There Margaret Grant laid down the first bricks in what would later become a world wide OI-community. Two years later Gemma Geisman in the US followed in Margaret's footsteps by initiating the OI Foundation. 23 years after that, there was a tall Dutch guy called Rob who had the idea that people and groups in Europe would benefit from sharing experiences. He saw that people were doing the same mistakes and coming up with the same solutions in several countries. Only
without sharing them with each other. So that is what we aimed for at the OIFE AGM 2018: People from different countries and in different roles coming together to share experiences and ideas about running organizations and about OI-research. And it was a pleasure to be part of it. I must admit, I had dreaded five days of meetings in a row, with OIFE’s Annual General Meeting as the grand finale, but it went surprisingly well. The euphoria of meeting the OI-crowd covers the feeling of complete exhaustion. An amazing group of people! No wonder I have a passion for OI. It’s hard work a lot of the time, but it’s also a total pleasure.

But these marathon events also wear on my body. I don’t have the stamina I had before and sometimes I just have to take a break and lie down. Other people would say that they are tired. But I blame it on another thing...pain.

Pain can wear you completely out and sometimes I think I mistake it for tiredness. But keeping your mind occupied can be a good coping strategy for pain. As a good sarcastic American friend of mine said: "I go to work even with fractures. I just need something to take my mind off the negative. So I go to work and just get on with it."

So OI euphoria and work can be good painkillers. But stress is bad. It gets stuck in my body and increases the pain in my neck, in my hip or locations of old fractures. So in addition to keeping my mind busy against chronic pain, I must admit that I use painkillers.

But why should this be something to admit in the first place? Numerous times when I tell people with OI that I use prescription drugs every day, they often get ‘the look’. “Really...? Every day you say? Not only when you have fractures?”

Many people with OI never use any painkillers at all, by choice. Perhaps except when they have very severe fractures. Some use painkillers on bad days, some use them every day and some need strong stuff only to get out of bed. People are different. And pain is so difficult to measure. And talk about. It’s almost a taboo both among people with OI and professionals. But how do we get more knowledge on such an important issue if we don’t dare to talk about it?

I am all for prioritizing alternative ways of coping with pain. But we cannot pretend that many people don’t use and need painkillers in periods as well. The problem is that the knowledge is so scarce. What kind of methods should you use if your OI-pain is muscular, if it’s bone pain, if it’s neurological, if it’s stress related, fear related...whatever? Very different methods I guess. But many are not aware.

My hope is also that we judge each other less. Painkillers are perhaps not the right solution for you. But others might need them to be able to get out of bed or keep a job. Perhaps some need it only in rehab to become more active? Because exercise is probably the best painkiller of them all. But if you don’t get out of bed, it’s hard to reach the gym...

Coping mechanisms is something the new pain study from Spain is going to look at. Even if you don’t have chronic pain, the researcher Ruben still wants to hear from you if you have OI. The survey is available in both Spanish and English. You can read more about it in this magazine.

And to be honest, I think all people with OI have some level of chronic pain. But when you relate your pain to the worst femur fracture you had, it kind of makes the pain scale from 1-10 useless. Perhaps we need different tools? Or perhaps we just all need to move to Spain, where the climate is warmer?

Anyway, I hope you’ll enjoy the rest of the magazine and read it - with pleasure...

Ingunn
What is the OIFE doing?

An unusual summer has passed. Not only because it was the warmest in history in large parts of the world. But also because it offered several memorable events in the OI-community like the OIF National conference in Baltimore, USA, the 50th anniversary of the Brittle Bone Society and the 25th anniversary of OIFE in Dundee, Scotland. At the virtual OIFE office, the summer months was used for planning the 25th anniversary, but also to finish an important project for the OIFE - our brand new webpage. At the AGM we welcomed two new members into the Executive Committee - Dace Liepina from Latvia and Ida Männistö from Finland. And we got a new associate member organization OIF Nigeria in addition to Ukrainian Association of Crystal People, that was voted in as an ordinary earlier this summer. It was also a pleasure to meet Rageema and Suj from the South African organization, who joined the OIFE as associate members earlier this year. We are growing into the future!

Meetings and events

There has been many skypes with delegates and OIF, BBS & Care4BB to plan the OIFE AGM. There have also been meetings to prepare youth events and to finalize the new webpage. In addition there have been several meeting points with MereoBiopharma, to provide patient input and advice to the Asteroid study. Rebecca Tvedt Skarberg has as usual attended a substantial number of meetings in ERN BOND’s steering committee and working groups. An in addition we were represented here:

- Phone conference Alexion, June 26th (IW)
- Skype Luca Sangiorgi & Rebecca T. Skarberg on ERN-BOND July 5th (IW)
- BPS804 PRIME kick-off meeting at the European Medicines Agency (EMA), London, UK, July 23rd - Inger-Margrethe S. Paulsen represented the OIFE
- Meeting OIFE & Care4BB, Dundee, Scotland, Aug 16th (IW, TvW, IM & AR)
- Scientific Seminar BBS, August 17th (IW, IM & Rebecca T. Skarberg)
- BBS Family Conference & Gala Dinner, August 18th & 19th (IW, TvW, IM, DL & AR)
- Care4BB's meeting on Key4OI, August 18th (IW, IM & Rebecca T. Skarberg)
- OIFE AGM, August 19th & 20th (IW, TvW, AR, CB, IM and DL)
- MOCA-meeting, September 24th, Vienna, Austria (TvW)
- Steering Committee Meeting Care4BB, (IM)
OIFE has a new webpage!
OIFE's brand new webpage was launched at the OIFE AGM, and I'd like to use the opportunity to thank our two webmasters Ivar and André and Communication Manager Anna for their great effort during the summer months. Our goal with the new page is to provide clearer and more up to date information about who the OIFE is and what we do. We will also share news and events from our members and our brand new calendar provides updated information about bigger events and conferences going on in the OI-community. Check it out at www.oife.org

OIFE at the European Medicines Agency
The OIFE tries to be present in meetings that are relevant for OI. On July 23rd we had a representative attending a meeting on a potential treatment of OI in the European Medicines Agency (EMA) which is the European agency responsible for health through the scientific evaluation and supervision of medicines. Want to know more about the EMA? http://www.ema.europa.eu/

Webinar on patient involvement
On September 6th 2018 representatives from OIFE attended a webinar on patient engagement on medicines research and development. The webinar highlighted the important shift in the way patients are perceived, the great value of engaging them in the development of medicines and the diversity of methods and ways in which such engagement could happen. You can watch a recording of the webinar here: https://bit.ly/2NVZJjl

OIF's National Conference
The 2018 OIF National Conference, themed EXPLORE, gathered over 650 attendees and 50 speakers for a busy and memorable weekend in Baltimore, Maryland! The attendees of this summer’s conference represented seven countries and nearly forty US states. On behalf of the OIFE I thank the OIF for the kind invitation to take part in this great event together with my colleague from NFOI, Inger-Margrethe S. Paulsen.

The conference itself was enjoyable, with its many talks and sessions. But it was also great to meet Jacinta, the chair of the newly recovered Canadian OI-organization. COI is now a separate entity from the OIF, but receiving
administrative services from the OIF. I also met Lucia and Veronika, who's in the Board of the Equadorian OI-organization and Isis, who's in charge of the organization in Peru. It was also a pleasure to meet new and old professional contacts, like dr. Laura Tosi, dr. Raggio, professor Glorieux and dr. Jean M. Retrouvey. In the Get in Touch column, you can read that dr. Retrouvey is interested in setting up a network of dentists and orthodontists with special knowledge of OI around the world. Do you know a good OI-dentist? Let them know and we'll put them in touch!

**MOCA-meeting**

On September 24th OIFE's honorary member Taco van Welzenis attended a meeting in MOCA (Mechanism of Coordinated Access to Orphan Medicinal Products) in Vienna, Austria. MOCA aims at facilitating “early dialogue” between companies and national competent authorities (the payers) for pricing and reimbursement on specific orphan medicines. The purpose is to speed up access to orphan drugs in developments for patients in EU Member States. MOCA is open to:

- National competent authorities for pricing and reimbursement
- Patient representatives (coordinated by EURORDIS)
- Companies applying for market authorisation

At the moment there is only two therapies in OI that has socalled orphan drugs designation:

- Human allogeneic bone-marrow-derived osteoblastic cells (Bone Therapeutics SA)
- Recombinant humanised monoclonal IgG2 lambda antibody against human sclerostin (MereoBiopharma Ireland Ltd)

**The Dundee events**

From the moment we walked out of our overpriced wheelchair accessible shuttle on Thursday the 15th of August, a marathon of meetings started. Two of them were hosted by Care4BrittleBones, where OIFE & Care4BB talked about opportunities & challenges in future collaboration. Our new vice president Ida was appointed a role in the steering committee of the Key4OI-project, which is an umbrella of different subprojects aiming to improve the way we measure outcomes in OI. The main reason why we were in Dundee however, was to celebrate, celebrate, celebrate - ourselves and the Brittle Bone Society. And how that went down, you can read about in the text from our communication manager Anna Rossi.

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

Thomas Wirth
I am working as orthopaedic surgeon predominantly in the world of paediatric orthopaedics. My current position is Medical Director of the Department of Orthopaedics, Olgahospital, in Stuttgart, Germany.

I have a long-standing experience of more than 20 years of treating OI patients orthopaedically using the most actual version of telescopic nails. I was also involved in the surgical correction of bone deformities in adults, using all sorts of different, frequently custom-made nails. I have been treating a significant number of very severely involved patients and corrected a considerable number of forearm deformities.

We have a large OI clinic with about one hundred patients in our database. I see them clinically on a regular individual basis. I am also surgically treating their chronic problems such as deformity correction on all four limbs and their acute issues such as acute fracture treatment to what is needed. We have extended our indication and surgery for OI spine deformity correction and have become more courageous here.

OIFE is the binding member between the affected patients and all different people who work medically towards the well-being of OI patients. OIFE is creating the family background for all of them on an international basis. Internationalism is the second main task of OIFE, because international expert exchange and exchange between patients from different countries is making life much more interesting and offers many more perspectives.

Natalia Belova
I am a pediatric endocrinologist and clinical geneticist. Now I am head of Center of Inborn Pathology in GMS Clinic, Moscow. I have been involved in OI study for more than 30 years, when I started to work in Pediatric Research Institute. My first thesis was about possibility of treatment of OI with growth hormone.

My main goal was always to improve life quality of OI patients and to give them all possibilities for best medical care, education, personal and professional success. It was difficult to do so in government institutions. That is why in 2006 I organized Center of Inborn Pathology. OI is our main specialization, we have about 450 OI families under our supervision (about 50 new OI patients per year).

At present it is the only Center in former USSR, where OI patients have multidisciplinary approach and full cycle of diagnostics and treatment - from molecular diagnostics to bisphosphonates treatment, surgery, psychological and legal support.

I think that the most important goal for OIFE is to combine efforts of doctors, scientists and patients for the best life quality of OI patients of all ages and their families.
Research Interview - “Pain and OI”

Interview with Rubén Muñoz Cortés, psychologist of Fundación AHUCE

Who are you?
I am Rubén Muñoz Cortés. I live in Valencia, Spain. I am a psychologist with a Master’s Degree in Clinical Psychology and Neuropsychology. I am a PhD candidate in Clinical and Health Psychology at the University of Valencia. Throughout my career, I have been involved in clinical practice and since 2015 I have been working in the psychology department of Fundación AHUCE.

What is the project about?
The project aims to contribute to increase the knowledge on chronic pain experience in the adult population with OI. In order to do so, we will observe variables such as the frequency with which pain appears, its characteristics and the relationships it establishes with other important factors.

With this goal in mind, we first selected the most appropriate standardized questionnaires and created an anonymous 20-minute online survey, which can be filled out from a computer, tablet or mobile phone.

The second phase of the project, which we are currently in, consists of the dissemination of the survey by email, social media and through the OI-organizations. This is an international study, so anyone can participate regardless of his or her country of residence. The questionnaire is available in English and Spanish.

Later we will proceed to the statistical analysis of the data and publication of the results. This descriptive study is part of a doctoral thesis and a collaboration agreement between Fundación AHUCE and the University of Valencia.

PhD Jose F. Soriano, professor at the Faculty of Psychology of the University of Valencia, and Vicente Monsalve Dolz, psychologist at the Pain Unit of the General University Hospital of Valencia and professor at the University of Valencia, also participate as researchers in the project and co-directors of my thesis. Julia Piniella, technical
director of Fundación AHUCE, is involved in the organization, presentation and supervision of the project, as well as in the dissemination and distribution of the questionnaires and the cooperation with OI patients and groups.

**Why the topic Pain?**
In our daily work at the foundation, we observed that chronic pain is a reality in adults affected by OI. After reviewing the existing scientific literature, we realized that it was an important and under-researched topic. Although we are aware of the need for a multidisciplinary approach, we believe that a study from a psychological perspective will contribute to the knowledge about pain in OI and will potentially open new lines of research.

**What is the goal of the study?**
The main objective of the study is to evaluate the distribution of chronic pain in the adult population with OI and to observe how it relates to sociodemographic, clinical and psychological variables. Among other measures, we intend to observe the proportion of adults with OI affected by chronic pain in a large sample and the characteristics of this type of pain in relation to factors such as age, exercise or type of mutation. Furthermore, we are going to evaluate the role of psychological variables such as assessment, coping and personality. The study will also assess the impact of pain on day-to-day activities and perceived quality of life.

**Who is the target group?**
People with OI who are over 18 years of age, whether or not they have chronic pain and regardless of the country in which they live. The survey is available in Spanish and English in a simple language. With a minimum knowledge of one of the two languages, it is possible to answer the questions. The translation and validation of questionnaires into other languages is a very time-consuming and costly process. That is why we have chosen these two languages.

**What is the time frame?**
Initially the survey will remain open until December 31st 2018.

**How were patients involved in the planning?**
Working with patient associations is essential. They are a bridge between the academic world and the reality of people affected by OI. Through email or videoconference, we contact them to explain the project and ask for their collaboration in the dissemination of the survey. Without their help, it would not be possible to get a meaningful sample of people and the study would not be successful. As far as design is concerned, it has mainly emerged from the joint work of Fundación AHUCE and the University of Valencia, following scientific criteria and in line with other similar research projects. However, recognized professionals in the field of the OI have advised us and we are always open to suggestions and recommendations from other stakeholders. In fact, we have made some important changes thanks to them.

**Any messages to the readers of OIFE Magazine?**
First, we would like to thank all the people interested in this project, especially those who have participated by completing the survey and sharing it. We would also like to thank OIFE and the other associations and groups for their support and help in disseminating the study. Your participation is necessary to advance in research. Thank you very much!
Flashbacks from Baltimore  
by Ingunn Westerheim

The 2018 OIF National Conference, themed EXPLORE, gathered over 650 attendees and 50 speakers for a busy and memorable weekend in Baltimore, Maryland! The attendees of this summer’s conference represented seven countries and nearly forty US states. And on behalf of the OIFE I thank the OIF for the kind invitation to take part in this great event together with my colleague from NFOI, Inger-Margrethe S. Paulsen.

This was my second time at an OIF National Conference, which is quite different from other conferences I usually take part in. First and foremost it’s a family conference, bringing together OI-families and adults in order to provide updated information from professionals and OIF staff. But it’s also a very important arena for peer work. Valuable contacts and friendships are made across age groups. Another special aspect of this conference is the large number of professionals attending - not only to teach, but also to listen and learn from the OI-community.

I really like the sense of collaboration the OIF has managed to establish with the members of their Medical Advisory Board and other volunteer professionals. During the conference, the professionals give free medical consultations and some of the experts bring students or doctors in training to the consultations, in order to increase knowledge on OI. There is also a wide variety of sessions & talks - both plenary and with different tracks for various target groups. I was a little bit surprised to see how few participants there were at some of the interesting sessions, but I guess there’s just too much to choose from.

I must give credit to Program Director Petra Harvey and the OIF staff for constructing such an interesting program with something for all. For me some of the highlights were:

• The session about dental issues, with contributions from 3 different professionals, where one had OI himself. That was probably one of the funniest talks I've ever heard.

• The topic about basilar impression/invagination (BI) has not been addressed at many conferences. But this year I've heard two good lectures about it - one with dr. Suken Shah in Baltimore and the other with dr. Ilkka Helenius at the EPOS-conference. I think it's
important that both professionals and people with OI become more aware of BI, so they are able to spot the signals when a person is starting to have neurological issues because of this complication.

- At the Women's Forum, only women with OI are allowed to attend, and I think this is a success criteria. It creates a safe space where women with OI can share their questions and worries regarding sensitive topics as menstruation, sexuality, contraception and menopause. This year it was 3 professionals providing advice in addition to peers - a physiotherapist, a gynecologist and an orthopedist.

The pain session was extremely popular, but a little bit disappointing because it mostly focused on various types of pain medication and not so much on the different kinds of pain that people with OI can struggle with. The use of strong opioids like oxycontin was really not problematized. This surprised me in the light of the ongoing opioid crisis in the US.

Another highlight was the keynote talk from paralympic gold medalist swimmer McKenzie Coan. A highlight that we actually missed was the concert with the famous violin player Gaelynn Lea, which I had been looking forward to attend.

But when you show up 35 people at a restaurant where the majority are wheelchair users, that dinner might take a while. No big surprise! The dinner was somehow connected to Tracy Mulroy's involvement in getting more focus on adult health in OI-research. For this she was awarded the OIF 2018 President's award, including her efforts in establishing the Jamie Kendall Fund, which is the first OI-community-directed and community funded research initiative. Jamie Kendall was a former board leader of the OIF, who died from pulmonary complications and her memorial fund is now being used to finance a pulmonary study on adults with OI.

So what did I forget? Oh, the Walk-n-Wheel! It's still a mystery to me, how walking a few hundred meters can bring in that amount of money. But yes we can! And then I didn't even mention the talent show and the advocacy day to Capitol Hill. We did not manage to take part in all the amazing activities. But we learned a lot and we got to speak to both new and old friends. We'll start saving up for the 50th anniversary soon. See you in Omaha, Nebraska in July 2020 everyone!
25 years of OIFE – how it all began
By Ute Wallentin

OI exists all over the world and the success-story of the international OI community and the OIFE started on three continents at the same time, more or less, but without the wonderful and easy exchange of knowledge and support that we can have today.

As we all heard many times this year, everything began in the UK, where in 1961 an OI baby was born to Margaret and David Grant. Maggie Grant has type I OI herself and – as she did not find any information during the following years – she placed an article in the Sunday Post newspaper and this was the start of the Brittle Bone Society and what is thought to be the world’s first support organization for people with OI.

Prior to this, in the USA Michael Geisman had been born in April 1956 and his mother Gemma shared Margaret Grant’s despair and her determination and founded the OIF in 1970.

The first Scientific OI-Conferences took place in 1981, 1984 and 1987 in Chicago/USA on initiative of very few American doctors and in cooperation with Gemma Geisman, founder of the US OI Foundation (OIF).

The idea to set up some kind of European Osteogenesis Imperfecta umbrella organisation was born in September 1990 in Salice Terme, Italy. A few OI families from several European countries (like Serbia and the Netherlands) had brought their children and accidentally met with some Italian families, observing the 4th International Scientific Conference on OI nearby Pavia.

Marcella Zingales (IT) and Rob van Welzenis (NL) had met there for the first time and were both so happy to exchange similar experiences with the “OI-vacuum” in their respective countries that they had the immediate idea to start a European network very soon. From the very beginning this was supported and encouraged by Margaret Grant and Dr. Colin Paterson from the BBS office here in Dundee!

In winter 1991 Rob & Lidy had invited 3 representatives from AOI (France) to their home in the Netherlands and they all discussed the necessary basic questions like a name for the federation, and its structure. Rob had created the OIFE logo and prepared a first draft for its future statutes.

And already in October 1992 the Dutch OI society VOI (*1983) organized a follow up meeting with 21 representatives from 9 international OI organizations (including the OIF from the US) in Woudschoten, near Utrecht,NL.
It was decided to set up a European Federation and a provisional Executive Committee, lead by Rob van Welzenis, was installed. After a busy year AGM 1 took place only one year later, on 31st Sept 1993 in Northampton/UK (while the 5th SC was held nearby Oxford).

The inauguration of the “Osteogenesis Imperfecta Federation Europe” (OIFE) became a fact. Delegates and observers from 9 countries discussed the structure and the future tasks of this new umbrella and delegates of six OI associations (NL, F; I, D, DK; UK) accepted and signed the foundation charter. An Executive Committee under the presidency of Rob van Welzenis was installed. The OIFE was legally established as a non-profit-society on May 31th 1994 in the Netherlands.

As many of you know and have experienced for years and again this past weekend with old and new friends from so many parts of Europe and the world, the OI-community has come a long way and we were and are successful and so important on many different levels.

Probably most of us feel that the OIFE has given them an extra huge and loving OI-family, where mutual support comes natural and overcomes limits and borders of all kinds – so much more is possible if you belong to this group full of solidarity and understanding.
The Dundee Events - Celebrate!
by Anna Rossi, Communication Manager OIFE

"An Anniversary is a time to celebrate the joys of today, the memories of yesterday and the hopes of tomorrow."

I would say this is pretty much what has happened in Dundee, Scotland from August 16th - 20th 2018, and not only for OIFE.

Actually the whole weekend was a celebration of happiness and of reunion or simply getting together and being able to share, tell, help, listen and learn...

This time a special aura was embracing the whole hotel and town...the 50th anniversary of Brittle Bone Society (BBS), the 25th anniversary of OIFE and last but not least - the Dundee Kiltwalk!

BBS 50th anniversary started the celebration with a scientific seminar on Friday the 16th followed by the opening of their History Bones exhibition. Saturday it was time for BBS's family conference & AGM with participants from UK & the republic of Ireland. OIFE's president Ingunn gave a shared talk during the conference about the value of national and international collaboration together with Tracy Hart from the OIF and Patricia Osborne from the BBS. On Saturday night we enjoyed an amazing gala dinner rich of entertainment, memories, stories and initiatives of which we will hear about also in the future.

On Sunday the OIFE had their Annual General Meeting (AGM). In addition to the normal AGM business like annual reports and budgets, parts of the AGM consisted of a shared session with the BBS. The purpose was to try to uncover the priorities in research of people with OI. The session was lead by dr. Nick Bishop together with BBS-member Penny Clapcott. Reducing the numbers of fractures did not get a lot of votes and it is clear that quality of life is now the real key. Something which is also the topic of a conference taking place in 2019 - organized together by Care4BrittleBones, OIFE and the OIF.
In this line, the new OIFE strategy fits perfectly. The new vision, mission and goals were presented to the AGM delegates and approved unanimously as OIFE's strategy plan for 2018 - 2022.

The new OIFE webpage was launched, which will hopefully affect the whole communication, documents and identity of OIFE in the coming years.

This year we tried to focus less on formalities and more on sharing of ideas and experiences at the OIFE AGM. During the session called "A culture for sharing" the member organizations shared examples of concrete projects and different ways to fundraise for their organisations. It was followed by a workshop session to gather new ideas and ways to move forward. On Sunday - sharing of information and ideas were also in focus. This time the topic was OI-research and what is going on in Europe and the US.

Dundee was a milestone in OIFE history not only because of the number of candles on the super tasty cake. Dundee was finally the place in which the roots that were placed 25 years ago met the new principles and ideas of the current OIFE. A new start is also the time for welcomes and greetings. Nigeria and South Africa were welcomed in the OIFE network and member’s family.

The Executive Committee was also renewed during the meeting. Dace Liepina from Latvia and Ida Männistö from Finland replaced Vice-presidents Taco van Welzenis and Eero Nevalainen. And the EC now consists of only women, for the first time in history.

For our new honorary member Taco, it was an emotional moment to resign, since OIFE was so close to his heart. For Taco, Lidy and Rob, OIFE was not only an association. It was somehow a family member to take care of and help to grow. Rob was the one who started it all with his passion for OI, which he has clearly passed on to the new generation who is taking care of OIFE, its network and development.

We hope Taco will have more time for great new adventures with his brand new rucksack and that he will look back on good memories, while reading the old editions of the OIFE newsletters (that was in the backpack). And we look forward to meeting him again during the next AGMs because Taco will always be part of the OIFE family.

**So how was Dundee?**

It was an amazing mix of work, OI business, networking, powerpoints, sandwiches, chicken, haggis, meetings, but overall, after all, and most importantly **HAPPY PEOPLE.**
Impressions from Dundee

Anthony Hall
Therapeutic Area Head Orphan Diseases at Mereo

"The combination of the Scientific Symposium, BBS Family Conference and OIFE AGM over a long weekend was really fantastic. Every one of the meetings was hugely enjoyable and the opportunity to spend four days in close proximity with so many people from the international OI Community was both a privilege and a lot of fun."

The BBS 50th Anniversary celebration dinner was a particular highlight, especially with Margaret Grant attending. Everyone could see the immense amount of work that had gone into organising the event, and I particularly liked the excellent video detailing the history of the Society. The OIFE 25th Anniversary celebration was also great!

Tracy Hart
CEO of the OI Foundation

I represented the US OI Foundation and was joined by my board of directors president Ken Gudek and his wife Teresa, the chair of our Medical Advisory Council Dr. Francis Glorieux and the board president of the Canadian OI Society, Jacinta White.

I thought the Brittle Bone Society's scientific meeting and the family meeting were terrific. The information presented was very useful and I loved meeting new scientists that we could perhaps collaborate with in the US. I really enjoyed connecting with friends from all over the world during the BBS meeting and thought it was a very good idea to combine the OIFE's 25th anniversary celebration and AGM with the Brittle Bone Society's 50th Anniversary activities. I think it gave a feeling of unity and true friendship.

For me personally one of the highlights was sharing the stage with Patricia Osborne from the BBS and Ingunn - I think it showed people that we are actively working together and have a real commitment to each other. Another highlight was watching the Nigerian OI Foundation become an official member of the OIFE at the AGM...how wonderful!
Michał Daszkowski
Polish OIFE-delegate

Michał Daszkowski - I represented Polish OI Society (full name in Polish is "Stowarzyszenie Osób z Wrodzoną Łamliwością Kości (O.I.) - Polska". I am an NGO activist and I have OI myself.

The events in Dundee were very interesting. I'm impressed how perfectly and professionally the AGM was organized! I think many national organizations could learn a lot from the OIFE!

In my opinion, very interesting and important, is an idea of participating and partnering in research. Also sharing information and experience between people from different countries is very good. Especially in order to make living with OI more comfortable and safe.

Moments from Dundee
2 new faces in OIFE’s Executive Committee

Ida Männistö is a 29-year old Finnish patient advocate with OI type III and has been an active member of the Finnish OI association for around 10 years.

She was also active in the Social Democratic Youth in Espoo for 6 years, 3 of it as chair. Currently she is finishing her BBA studies.

**Ida:** “My motivation to get in to OIFE’s executive committee is that I know I have skills that could be useful to our community. I like to network and meet people, to make OI more known and to get useful information to spread.”

Ida took part in several trainings to learn more about leadership in patient advocacy, fundraising, organizing events, funding research and how to be ethically involved.

Dace Liepina from Latvia, mother of an 8 year old daughter with OI, has degrees in Service Management, Business Administration and Law.

Since 2011 she has her own accounting company, which allows her to combine work and taking care of her daughter.

**Dace:** “I believe my work experience and education in combination with interest in OI related activities, could make me a good vice-president for OIFE.”

Dace has been president of the Latvian OI Association for 3 years. Since then she has more and more become involved with OIFE and as delegate, having attended all AGMs and different OI related conferences.

OIFE’s new Executive Committee (EC) from left to right:

Anna Rossi, Communication Manager, Italy
Dace Liepina, Vice President, Latvia
Ingunn Westerheim, President, Norway
Céu Barreiros, Treasurer, Portugal
Ida Männistö, Vice President, Finland
International conference QualityofLife4OI in 2019

Make sure you mark the date November 22nd - 25th 2019, when the international conference QualityofLife4OI will take place in Amsterdam. The conference is an initiative from Care4Brittle Bones and is hosted by a coalition of OI-organizations (Care4BB, OIFE and OIF), Medical professionals (ERN – BOND) and the Industry. It is coordinated by Foundation Care4BrittleBones, who has the financial risk.

The Conference provides a platform to engage about clinical practice and research for people affected by OI. What is the expert opinion on good clinical practice in diagnostics, clinical assessment and treatment of OI today? What do people with OI need most to have good quality of life? What research needs are currently unmet? How can the efficacy of a trial of clinical treatment be evaluated with metrics that make sense for regulatory authorities as well as people with OI? Both qualitative and quantitative aspects will be discussed in an interactive and international setting.

The Conference aims to bring together professionals and people from the OI-community:
- clinicians of all disciplines supporting OI,
- researchers working on OI-related projects
- anyone from the OI-community with an interest in research beyond the personal level
- representatives from industry supporting OI
- other stakeholders interested in OI

It will provide an opportunity to meet, learn, network and get inspired to improve quality of life for people with OI across borders, professions and boundaries.

Interested to hear more and potentially attend? Subscribe to the Conference Newsletter via this link: https://bit.ly/2ON4A6i
Stephanie’s Youth Corner
by Stephanie Claeys, OIFE youth coordinator

B ’e deireadh-seachdainsog a bh’ ann! Or... it was a nice weekend! ... this is KelticScottish.

I used Google translator so I have no clue if this is correct. My apologies to the Scottish people if this sounds horrible!

But what in my experience is correct, is that it was a very very very nice weekend!

I’m so happy that I could be there as the representative of the OIFE Youth.

My friend Laurence and I started our journey in Belgium on Friday very early in the morning. After a train to Brussels, the Eurostar to London and the train from London to Dundee we had been traveling for 12 hours. The last part, the train from London to Dundee was very long... But hey, we made it, and we met some OI people on the train which was fun. The advantage of the OI-recognition makes you have no dull moment when you have to kill time.

Immediately after entering the Hotel Apex in Dundee it was clear that we entered the right hotel. Everybody was chatting together and having a nice time.

Some of the people attending the weekend I knew from previous but recent youngster weekends, but some of them I haven’t seen since about 15 years.

The weekend was full of interesting topics, great talks, nice dinners and vibrant people. I almost had the feeling that I was in the USA, like 2 years ago. Then I was in Orlando organised by the OIF. This was a little smaller, but I think with even more different countries than then.

It was very nice to know that from almost every country of the European map, there were people present. And even from the USA and Africa!

The difference between these adult meetings and the youth meetings is that there are more moments that you should listen to the one who is speaking in front, and having a more formal schedule. But just as the youngster weekends the evenings are with a lot of joy, talks, happiness and party!

Again, Thank you OIFE! I had a blast. I can’t wait to see you again another time, and to the young people out there: Don’t hesitate to attend a youth meeting! You won’t regret.
Who are you and what do you do?
My name is I Ketut Budiarsa. I am a Balinese man from Kedewatan, Ubud, Bali, Indonesia. I am the head of Yayasan Cahaya Mutiara Ubud which is a foundation run by people with disabilities, for people with disabilities. I am an accomplished artist and an activist for the rights of people with disabilities. I also have Osteogenesis Imperfecta as do my two brothers.

In what way has OI affected your art?
Even though my artwork has, at times, been perceived as reflecting sadness, I am always at my happiest when brushing paint on canvas. Painting is a therapeutic outlet and a pressure release for me. It is a natural form of self-expression that allows me to express my life experiences, memories and emotions. Being able to focus what I feel inside to the outside by using acrylic and oils I can freely project my emotions onto canvas. Osteogenesis Imperfecta has inspired my work just as much as it has limited my life. It has allowed me to express my individuality on a level that is certainly not ordinary and for that I am truly thankful.

What projects are you currently working on?
I am currently working on hosting an OI Seminar here in Indonesia. We wish to bring together international and Indonesian medical professionals to share knowledge about OI so that we can improve the quality of life for Indonesian people living with OI.
Why do you do what you do?
Having a disability in Indonesia is difficult. Life is complicated and we have limited access to opportunities and life experiences. Whilst we may not allow our disabilities to define us, our society certainly confines us. My OI has given me an insight into the suffering of others. It allows me to feel empathy for their position and compassion for those who are vulnerable and at risk. That is why I pursue my work with Yayasan Cahaya Mutiara and try to reach out to other people with disabilities who have no help or support.

What themes do you pursue in your art?
When we were children, my brothers and I decided that our shared natural talent and passion for art into a possible occupation, into a reality that would empower us to be considered valued community members. We were fortunate to meet Balinese artist I Gusti Murniasih whilst we were at school, and we were drawn to her style of using traditional Balinese techniques with a modern twist. The works for our first exhibition were produced in her honour and showcased her iconic style. This exhibition was opened by Maestro Kartika Affandi, a very famous Indonesian artist. After the exhibition, Maestro Kartika became our art mentor and guide. Today, I would say that the main theme for my work emanates from the emotions surrounding and connected to my life and living with OI. The style of my work is shaped from the teachings I have been lucky enough to receive.

What kind of work do you most enjoy doing?
I enjoy working with oils and acrylics on canvas.

What’s your scariest experience related to your work?
The opening of our first exhibition and being afraid that people would not accept or like our work because of our disabilities. This was a critical moment.

What’s your favourite art work?
My favourite works continue to be those of my first teacher and mentor, I Gusti Murniasih.

What role does the artist have in society?
In Bali art is deeply entwined with our culture. It is a way of life. The artist is both story teller and a story keeper.

What is your dream project?
To help many people with Osteogenesis Imperfecta and to open the minds of all people about this rare disease. To develop a large community to help Indonesian’s living with OI.
New OIFE member: OIF Nigeria
By Tarela Aghanti, chair of OIF Nigeria

The OI Foundation Nigeria, founded by Tarela Aghanti in March 2016, is the sole organization set up to address the needs of people born with Osteogenesis Imperfecta (OI) in Nigeria and are working with other African and international OI-organizations.

“Our charity is working towards achieving a society in which the needs of people living with Osteogenesis Imperfecta (brittle bone disease) in Nigeria and around the world are understood, respected and fully met.

We will work towards improving the quality of life for people diagnosed with OI in the country by providing advice, raising awareness and providing information. We also provide treatment, surgeries, wheelchairs and mobility equipment needed for comfortable and independent lives with good quality.”

OIF Nigeria is now in contact with children and their families in Nigeria identified with OI in Lagos State, Enugu, Abuja and Oyo State, Porth Court, Delta State and we believe there are more in other states. We are presently in communication with these families, connecting OI patients together, sharing experience, lifting each other up, encouraging and supporting each other. We are connecting patients with OI professionals and connecting interested OI health professionals in Nigeria with international OI experts. We are also providing Zoledronic acid medication for people affected.

Currently, OIF Nigeria is working really hard towards changing the beliefs of individuals as this condition and disability as a whole is spiritualized and can be associated with witchcraft, Evil Spirit and shame. In some parts of Nigeria, it could be said that a disabled child is cursed, which leads to many children being abandoned by their families, which is one of the biggest challenges that we face in our country.
OI also known as brittle bone condition is a rare condition. This is why we are committed to raising awareness on OI to help change the mindset, understanding and beliefs of our people so these children could be accepted, loved and cared for, as this will also help with inclusion in our society. We believe awareness is the key to change, so we go on air (TV, Radio, social media etc) through which we have been contacted for support and help by parents whose children are having symptoms and features of OI.

In the future we would love to create and raise more OI awareness in remote villages in Nigeria to find more OI patients and families, to be able to support them with treatments, equipment and surgeries to help improve quality of life.

From the 16th to 22nd of November we are having a five days distribution of wheelchairs & mobility aids, for both OI children and adults and people with physically challenges. This in order to support, promote independence and improve the quality of life each person can live.

OIF Nigeria National Annual Conference is on the 17th November 2018. We hope to see as many people there as possible, both from Nigeria, but also from other African countries if they are interested.

OIF Nigeria can be found online at www.oifnigeria.com and on Facebook.
Dr. Jean-Marc Retrouvey is a Canadian orthodontist and is the Director of the orthodontic division in the Faculty of Dentistry at McGill University. He works in close collaboration with Dr. Glorieux and Dr. Rauch at the Shriners Hospital in Montreal to assess the dental condition of people with OI. Over 350 patients have been examined in his clinic for dental issues and also for orthodontic consultations.

The craniofacial and dental aspects of OI have been studied for many years but thanks to the Brittle Bone Disease Consortium (BBDC), a consortium supported by the National Institute of Health, a longitudinal study of the effect of OI on the craniofacial complex is now underway. The BBDC now follows the largest sample of OI individuals in the world.

As the research project also involved more in depth investigations, the Canadian team is now using state of the art digital imaging to get more information on the whole craniofacial complex, simulate and quantify treatment needs and hope to start a prospective study on the use of clear aligners to improve dental occlusion in people with OI type III and IV.

Are you interested in collaborating with dr. Retrouvey and in being part of an international network of dentists and orthodontists working on OI? Please contact office@oife.org and we will put you in touch.

Searching professional volunteers
Did you know that there are many ways you as an OI-professional can help the OIFE:

- Providing expert advice on certain topics
- Becoming part of our worldwide list of clinicians & researchers that can be contacted for local advice and support
- Contributing with talks or other contributions on one of our events
- Volunteering as a Flying OI Expert
Our support programme Flying OI Experts enables professionals to travel to less developed countries to teach and improve knowledge, treatment and social support in these countries. This can also lead to new initiatives in starting local OI-groups, that can provide support to more individuals and families.

Interested in helping us improve knowledge on OI? Please contact office@oife.org

**ERNs searching affiliated partners**

Now is the time to recommend healthcare providers (HCP) in your country to become an affiliated partner within a European Reference Network (ERNs). ERNs are virtual networks that connect healthcare providers (centres of expertise) across Europe, so that rare disease medical expertise travels, rather than the patient. You can read more about the ERN for rare bone disorders (ERN-BOND) at [www.oife.org](http://www.oife.org).

ERNs are currently seeking new affiliated partners (healthcare providers with a special link to a given ERN). If you know of a healthcare provider that you think could become an affiliated partner within the ERN relevant to your disease, you can contact your ministry of health to learn more about the process they are putting in place to designate affiliated partners.

Questions on ERNs? Contact EURORDIS ERN& Healthcare Director Ines Hernando: ines.hernando@eurordis.org

**OI India - searching members**

The Indian Osteogenesis Imperfecta Foundation (IOIF) was established recently and is chaired by Mrs. Archana Ravindra Palahalli, who has OI herself. The goal of IOIF is to reach the whole country of India, but due to limited funds, they will begin their activities from Bangalore and gradually reach out to other regions of the country.

They have asked the OIFE and our contacts worldwide to encourage both OI-families and professional we know in India to get in touch with them:

Indian Osteogenesis Imperfecta Foundation (IOIF)  
No. 17, 15th Main Road, 16th Cross,  
Padmanabhanagar,  
Bangalore - 560070  
India

Email: info@ioif.org or archipr917@gmail.com  
Website: [www.ioif.org](http://www.ioif.org)  
Telephone: +91 80 26390901, +91 9980761683
Announcements

Update on the Asteroid study
Mereo BioPharma is sponsoring a multicentre international clinical trial to study the effects of the anti-sclerostin therapy drug setrusumab on bone in OI.

The study recently successfully completed patient enrolment, 112 patients were enrolled at multiple sites in Europe and North America. Adults between 18 and 75 years old who had a diagnosis of OI Types I, III, or IV were eligible for this clinical research study.

Visit the clinicaltrial.gov listing Clinical Trials Website http://bit.ly/2F3inxO or the company’s Study Website www.asteroidstudy.com to learn more.
SAVE THE DATES IN 2019
Please note that the dates for next year’s OIFE events have been settled:

• OIFE Annual General Meeting, June 14th - 16th in Riga, Latvia
• OIFE Youth Event, October 23rd - 27th, Bilbao, Spain

Also check out the International Conference QualityofLife4OI that will take place from November 22-25 in Amsterdam, The Netherlands. The conference is open for both professionals and people with OI and is a collaboration between Care4BrittleBones, OIFE, OIF&ERN-BOND.

CONSENSUS PAPER PUBLISHED
At the conference OIOslo2017 an expert panel was convened to develop an international consensus paper regarding physical rehabilitation in children and adolescents with OI.

The project was initiated by OIFE’s supporting member Care4BrittleBones, but OIFE assisted with spreading information about the project and connecting with potential professionals. The experts were chosen based on their clinical experience with children with OI and were identified by sending out questionnaires to specialized centers and patient organizations in 26 different countries.

The final expert-group included 16 representatives (12 physiotherapists, two occupational therapists and two medical doctors) from 14 countries. Within the framework of a collation of personal experiences and the results of a literature search, the participating physiotherapists, occupational therapists and medical doctors formulated 17 expert-statements on physical rehabilitation in patients aged 0–18 years with Osteogenesis imperfecta. The paper has now been published. Read more and download the paper on www.oife.org

THE STUDENT VOICE
We have signed up as volunteers. Let’s see if there are any students who wants to interview someone with OI. The Student Voice essay competition of Findacure highlights the importance of rare diseases and patient engagement to the doctors and researchers of the future. The competition is open to undergraduate and master students around the world in all subjects, though it is most applicable to medical and biosciences students. A winning essay will be selected for each question, with one essay chosen as the overall winner and securing a publication in a respected journal. Read more here: https://bit.ly/2J1PPqP

OI IN CANADA
We congratulate all our contacts in Canada with the return of the Canadian OI Society (COIS)! In partnership with the Osteogenesis Imperfecta (OI) Foundation, who will provide administrative support, the COIS has been revitalized and is ready to begin providing services and resources to Canadian members.
**OI IN MALAYSIA**

Awareness raising about OI to professionals and the public is important, especially in countries where there is not so much expertise on OI. *Jeans for Genes Malaysia* did an awareness day in September, where OI was one of the diagnoses in focus. There were three adults with OI sharing their experiences.

**OI IN CHILE**

On September 26th representatives from the OI-organization in Chile *Fundación de Osteogénesis Imperfecta Chile* met with Teletón Chile to address topics about OI. They talked to the National Medical Director and the director of social and community development on various topics related to the care of children and adolescents with OI in their institutes. Teletón also promised to spread information about the OI-registry in Chile to patients, businesses and the Ministry of Health.

**OI & EDUCATION**

We congratulate OIFE’s second youth coordinator Marie Holm Laursen - Pigen med knoglerafglas with her graduation. Education is the key to independence. Hooray!

**NEW FACTSHEET**

OIF has created a new factsheet: *Overview of Bisphosphonate Use in Children Living with OI*. The document explains the difference between various types of treatment and answers common questions from community members and providers. To view or download the new fact sheet, visit [http://ow.ly/iznF30kBtcE](http://ow.ly/iznF30kBtcE)

**NEW CROWDFUNDING PAGE**

To enable families with OI around the world to raise funds and awareness for OI-research, Care4BrittleBones has created a brand new fundraising page on [research4oi.org](http://research4oi.org). Since June they have already collected about 350 donations! Are you interested in crowd-funding? Care4BrittleBones will hold a webinar shortly to explain how it works. Please email Dagmar to get an invite: [dagmar.mekking@care4brittlebones.org](mailto:dagmar.mekking@care4brittlebones.org)
### Calendar OI-events

**2018**
- Oct. 25 - 28: OIFE Youth week-end, Aarhus, Denmark
- Oct 26 - 28: NFOI Week-end for adults with OI, Oslo, Norway
- Oct 9 - 11: Familiekursus, Fredericia, Denmark
- Nov 17: OIF Nigeria National Conference, Lagos, Nigeria

**2019**
- May 10-12: NFOI AGM & 40th anniversary, Oslo, Norway
- May 16 – 18: EURORDIS Membership Meeting & AGM, Bucharest, Romania
- June 14-15: See, Hear, Smile! Topical Meeting OIFE, Riga, Latvia - *not 100% confirmed*
- June 14 – 16: OIFE AGM, Riga, Latvia
- Oct, 23 – 27: OIFE Youth Event, Bilbao, Spain

**2020**
- July 9-12: OIF National Conference & 50th anniversary, Omaha, Nebraska, US

### Calendar scientific conferences

**2018**
- 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
- Sep 11-14: International Skeletal Dysplasia Society (ISDS) 2019, Oslo, Norway
- Nov 22-25: International conference QualityofLife4OI, Amsterdam, NL

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

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