Editorial
By Ingunn Westerheim, OIFE President

Dare to...
There is perhaps no consistent theme in this edition of the OIFE Magazine, like it was in the previous one. But maybe I just haven’t looked close enough? After thinking about it one more time, it occurred to me that maybe the theme of this newsletter is to dare? The Portuguese project you can read about in this edition was called "Dare to live" or “Atreve-te a viver” as they say in Portuguese. In the APOI-project people with OI challenged their fears and boundaries, either by swimming with dolphins or climbing walls.

Penny Clapcott on the other hand is definitely a daredevil. Sometime she’s dangling outside
mountain cliffs from the hands of a nutty Norwegian. Other times she's hanging in straps from the ceiling at the opening of the Paralympics or other events. In the OIFE magazine you can also read that professionals have trusted us with their time and dared to become part of OIFE's new medical advisory board. And some would perhaps claim that editing our genome, like Fleur van Dijk is doing is a daring concept.

Our youth coordinator Stephanie, dared going on a desert safari in Jordan, but she did not dare to go camel back riding. That is totally ok! Fortunately for us the Dutch youth group dared to host the OIFE Youth Event and people from many European countries dared to attend. Some of us dare to run organizations and take on projects that we have never tried before. This can be pretty scary at times but very rewarding as well. And most people with OI dare to go on time and time again. Even after fractures, injuries, disappointments and frightening experiences. Perhaps we are the real daredevils?

We should dare to:

- dream
- ask for help when it's needed
- get an education and a dream job
- quit the same job when our bodies have had enough
- be sad and disappointed - we can still be positive people
- give our hearts to someone, even if they might not want it
- get up on the horse again, even if it's just a metaphoric one
- admit that we're sometimes over achievers
- take part in research projects
- aim for a cure, but strive for good quality lives in the meantime
- travel to foreign countries, but bring our OIFE passports in the pocket
- realize that all our problems doesn't relate to OI
- dive in to deep sometimes
- address the difficult topics - like depression, basilar invagination, child abuse, obesity, sexuality, anxiety and the feeling of loneliness
- share our experiences with others who need information and advice
- ask for a second opinion when we don't trust the medical advice we are given
- let our children be active and avoid wrapping them in cotton
- collaborate - sometimes we manage to get further together
- speak up when we don't agree
- do things differently
- let our children dare the same things as others...

Perhaps this was a wishywashy editorial. But I dared to write it, just like I dared to hold the alligator. I wish you all a Happy New Year in 2018. Dare to make it a good one!

Greetings from Ingunn - OIFE president
What is the OIFE doing?
By Ingunn Westerheim

A new year has begun, and we continue our common effort to improve the situation for people with OI. Now also together with China Dolls, who became an associate (non-European) member of the OIFE in December. In 2017 we reached our goal to establish a Medical Advisory Board for OIFE and do a revision of our signature document - the OIFE passport. Another goal was to share more examples and activities from our member organisations. You are now reading the first edition of the OIFE Magazine, that has evolved from a newsletter into a bigger format. Networking is one of OIFE's main tasks. And we want the magazine to mirror our contact with member organisations, researchers as well as other groups, networks or individuals who are doing interesting things related to OI. Among our goals for 2018 is to develop a new long-term strategy for the OIFE to help us prioritize better in a world with many tasks and few resources. We started the work at our AGM in 2017 and will hopefully finish it at our 25th anniversary (AGM 26) in Dundee, Scotland.

Meetings and events
We have not had a lot of meetings with external collaborators the last three months. Internally we've had three Skype-meetings within the Executive Committee as well as several other meetings with delegates or volunteers. In addition we have attended the following meetings:

- First Friday-meetings between OIF, BBS and Care4BB (IW and UW)
- EURORDIS-meeting Council of Federations (CEF) in Paris Oct 26th and 27th (IW)
- Teleconference with UCB pharma company December 8th (IW)

OIFE AGM 2018
The BBS turns 50 years in 2018 and what is more suitable than to celebrate OIFE's 25th anniversary & Annual General Meeting (AGM) at the same time? The event will start with a scientific seminar on Friday 17th of August followed by a family conference & celebration of BBS' 50th anniversary. See advertisement another place in the magazine! OIFE AGM will start Sunday morning/lunch and last until lunch Monday 20th of August.

OIFE passport new edition
Thanks to support from Mereo Biopharma, we have revised and printed a new edition of our signature document - the OIFE passport. The OIFE passport is a personal document in the format of a passport. It is meant as a travelling companion and a guide to local OI assistance in foreign countries. It contains the statement that the bearer has OI, a brief explanation of what that means and how a person with OI should be treated (in 22 languages). Precautions to be taken with X-ray examinations are explained. Members of OIFE member societies can obtain a copy from their national OI society. Others can contact secretary@oife.org
OIFE Youth Event 2018
Denmark will host next year’s youth event from October 25th – 28th 2018 in Aarhus, Denmark. Stay tuned via our new Youth Group on Facebook: https://www.facebook.com/groups/OIFEYouthONLY

BOND & OIFE
The OIFE has volunteered to assist the European Reference Network for rare bone disorders (BOND) in spreading information to patient representatives in countries who have health care providers (HCP) in BOND. This includes OIFE-members Belgium, France, Germany, Italy, The Netherlands, Portugal and United Kingdom. We have also reached out to our contact persons in Sweden, Estonia and Czech Republic. OIFE has spread requests to provide BOND with existing guidelines for treatment of OI from different countries. In addition we have spread a request to recruit individual patients/parents of children with OI who could answer a query about diagnostic challenges in OI. Are you interested in joining the group of patient representatives who receives more extensive information about BOND through Facebook Workspace (not the same as Facebook)? Then please contact president@oife.org

Collecting data about 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 in people who have OI. Do you have experience or knowledge about this topic? Please send an e-mail to Diane: dmaroger@gmail.com

Rare Disease Day 2018 - topic Research (again)
Rare Disease Day 2018 is an opportunity to call upon researchers, universities, students, companies, policy makers and clinicians to do more research about OI. On February 28th 2018, the 11th Rare Disease Day will see thousands of people from all over the world come together to advocate for more research on rare diseases: www.rarediseaseday.org Are you and/or your organisation going to be part of the event? Do you have creative ideas? Send them to office@oife.org

Questions? Please e-mail president@oife.org

New OIFE member: “China Dolls”
We are happy to announce that China Dolls have decided to join the OIFE as an associate member. We are happy to have our Chinese colleagues formally included in our big international network!
China Dolls’ President and OIFE delegate Sun Yue says, there are about one hundred thousand people with OI in China. In 2008, the OI association was established with following goals: To provide care and help for people with OI and other rare disorders, to promote public understanding and respect, to eliminate discrimination, to protect equal rights to medical treatment, education, and employment, and to urge governments to set and implement policies.

Since then, there have been two National Conference For OI Patients. Furthermore, “China-Dolls Rare Disorders Care Foundation” was established and the Shandong Jinan China-Dolls Home of Care started to provide service for Shandong patients. You can find more information here: www.chinadolls.org.cn

**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
New OIFE Medical Advisory Board (MAB)
By Ingunn Westerheim

It has become clear to us that the OIFE more and more often need advice from medical professionals. We have many informal contacts today, but in 2017 we decided to establish a more formal advisory team of OI-knowledgeable professionals - a Medical Advisory Board for OIFE. Our ambitions did not include a forum where every European country and every profession was represented. We have asked people from different professions (both clinicians and researchers) based on previous knowledge and an interest for OIFE and patient organisations in general.

Dr. Oliver Semler has served as OIFE's Medical Advisor for several years and he has kindly agreed to chair the Medical Advisory Board for the first period from January 2018 - December 2019.

The following people have confirmed to volunteer as our advisors the coming two years:

- Oliver Semler, Germany (chair of OIFE MAB)
- Darko Anticevic, Croatia
- Eva Åström, Sweden
- Natalia Belova, Russia
- Marijn Creton, the Netherlands
- Lars Folkestad, Denmark
- Antonella Forlino, Italy
- Fátima Godinho, Portugal
- Aliaksei Pachkaila, Belarus
- Miguel Molina Rodriguez, Spain
- Lena Lande Wekre, Norway
- Thomas Wirth, Germany
- Liidia Zhytnik, Estonia

A more detailed presentation will be included in later edition of OIFE Magazine.

It is important for us to stress that the purpose of OIFE's new advisory board is NOT to give advice regarding specific medical problems concerning groups or individuals with OI. Our wish is that the MAB-members will be speaking partners & advisors to the Executive Committee in more strategic questions - for instance:

- Policy planning where this has a medical component
- Discussions about new scientific developments
- When to support, promote or inform about research

We will do a revision every 2nd year in an attempt to secure that different fields of expertise and networks of OI-specialists will be represented.
Genome Editing in OI: Interview with Fleur van Dijk

Who are you, what is your job/profession and what is your relationship with OI?
My name is Fleur van Dijk and I am a clinical geneticist. A clinical geneticist is a medical specialist who sees people with (suspicion on) hereditary disorders in clinic. During my paediatric internships I met a clinical geneticist who was examining a baby at the neonatal unit and when I talked to him and later did my internship at the genetic department I knew for certain that I wanted to become one too!

During my clinical genetic training in Amsterdam I also did a PhD programme focussed on clinical and genetic aspects of OI. This led for example to the discovery of new OI causing genes and a publication of international guidelines on laboratory analysis in OI.

The most rewarding for me was that when I became a clinical geneticist in 2012, I also became part of the multidisciplinary adult OI expert clinic in Isala, Zwolle, the Netherlands. This has enabled me to meet many people with OI, which has been very insightful for me as to what they report to be their main problems and what kind of questions they have.

In 2016, I left the Netherlands and accepted a position in London as clinical geneticist and lead of an expert center specialised in diagnosing rare types of Ehlers-Danlos syndrome (a group of other hereditary connective tissue disorders whose features can sometimes overlap with OI). However, I am also still part of the adult OI team in the Netherlands and I take the plane every month to be there when the clinic starts!

Can you tell us about your research project? What is your goal? Who are you working/collaborating with?
My research project is ultimately aimed at establishing new and improved therapy for OI. More than 90% of people with OI have a mutation in either the COL1A1 or the COL1A2 gene. These genes make a protein called collagen type 1 which is among others produced in bones and ligaments. A reduction in the amount of collagen type 1 and/or production of abnormal collagen type 1 by the bone forming cells (osteoblasts), leads to OI. The current golden standard regarding pharmaceutical therapy for OI is bisphosphonate therapy. However, bisphosphonates are aimed at reducing activity of bone degrading cells (osteoclasts) and do not address the primary problem in OI which is abnormal/decreased production of collagen type 1 by bone forming cells.

To make a long story short, we are working on a safe strategy to correct the specific genetic defect in the cells of a person with OI. We will use protocols to create induced pluripotent stem cells (iPSC), a powerful gene modification technique called CRISPR/CAS9 and protocols to differentiate corrected iPSC to bone forming cells that ultimately can be brought back in
the circulation of people with OI. When this strategy works, it needs to be tested in mouse models of OI before it can ever be applied to people with OI. I am working with several parties which consist of the University Medical Center Groningen, the Netherlands, the iPSC-CRISPR facility, the department of Isala hospital, Zwolle, the Netherlands and of course with the funders of our research: care4brittlebones (scientific OI organisation) and ZZF (foundation for rare disorders located in Netherlands). However, we also aim to collaborate internationally and first steps are being taken.

Can you explain more about iPSC, gene modification and differentiation to bone forming cells?

iPSC are induced pluripotent stem cells. They can be created from human tissue such as skin cells and urinary cells and they have the capacity to differentiate in different cell types. In order to have iPSC 6 people with OI type 1 and 3 due to a known genetic cause donated skin cells and urinary cells and we established iPSC lines from these patients. CRISPR/CAS9 is a novel technique for gene modification and can also correct the genetic cause. It is adapted from a system that was used by bacteria to get rid of DNA from invading viruses. It essentially consists of two components: a guide that aims to find a specific DNA sequence and an enzyme that can cut this specific DNA sequence.

Do you see any ethical challenges with changing the genes of a person? What about future generations?

We aim to correct a disease causing mutation in a person with OI. Because of that I do not see a specific ethical challenge but I do see a challenge to make sure that the correction is safe and does not cause problems in other parts of the DNA. We have thought of this a lot and will test this extensively.

What is the most rewarding working on this project?

The fact that we are working on a project in which the newest techniques are used to try to improve treatment for people with OI.

What are your thoughts on patient involvement in research?

A new development that is not to be stopped and should be promoted. Patients are of course the main stakeholders in research projects and they should have a say in how their data are being used.

Do you have a message to the readers of OIFE magaziner?

Thank you for your patience, support and participation regarding OI research. It may seem that progress is only made very slowly but I know that a dedicated international OI research community exists that works on improving the situation for people with OI in many ways!

Youth Event 2017 in The Netherlands

by Stephanie Claeys

Today it’s Monday the 6th of November...

Yesterday I had the feeling that I’ve never been that tired ever, but it was so worth it. Every moment of the weekend I’ve enjoyed, definitely no dull moment!
Wednesday the 1st of November we met in the city of Marknesse, where after settling in our room in “de strandhoeve”, it all started from there. It was very nice to see the people I’ve met before, though some of them I haven’t seen for 6 years; but to be honest nobody changed!

It was also amazing how the new people for me were immediately talking and eager to get to know each other. The first night was already very short but at that time I didn’t know the nights that had to come.

So I had a great time. What did we do?

- A visit to Zwolle, a city around 40 km from where we spent the weekend. This was also the place where some of us took the train to on Wednesday. We were divided in groups of 4-5 people and played a very funny game which was a treasure hunt. We got some papers with tasks to fulfill during that afternoon. We laughed our heads off. Every time a task was fulfilled, we had to send a WhatsApp to the organizers of the game. Then they gave us points. After a while the weather changed so we had to take shelter in one of the cafés. After the rain we continued our game and around 17.30 we went to a restaurant where we had a nice meal all together.

- We had a great Boys against Girls game organized at the place we stayed. We got different questions in which we had to guess the right answer. Everyone got the chance to participate to this very dynamic quiz. It was a neck-to-neck race, but of course, the girls won ;-)

- On Saturday we took a trip to Amsterdam. We had to leave very early (after only a few hours of sleep) with the bus. In the morning we visited the Van Gogh museum and after that we had some free time. After lunch it started to rain and we had to split up, because getting in somewhere with the whole group in Amsterdam was not possible. But we had a great time. I don’t know what the others did, but I went with the Dutch people to a bar, and after that we connected with the Norwegian guys and had some sushi for dinner.

- We had great nights with a lot of joy, laughter, interesting talks, very nice people, good drinks and so much happiness.
I was thinking about this the whole weekend: Integration and inclusion into society is so important. But even now and then... it’s so important to be just surrounded by people with your own disability to feel just “normal”. It gave me the strength and the energy to go back into my own society and kick some ass.

Because that’s what we do, people with OI, we often kick some ass. And I love that.

On those weekends we don’t break our bones, but break through our limits, and that is so important to do.

Thank you guys for this great weekend, this great opportunity. I loved it the most.

Stephanie

Examples from OIFE Members:
Project “Dare to live” in Portugal
By Céu M. Barreiros, president APOI

Have you ever thought that some things are just too difficult for you to do by yourself?
Have you ever felt like OI is just in the way? Then don’t! Just Dare to Live!

These are the thoughts behind a Project organized by the Portuguese OI association. Many of us realize that people with OI live their lives fearing another fracture, stress and pain. Kids grow up with the sense of “not being able to do the same things that other kids do” because they might hurt themselves. This might lead to limitations in life and normal routines, influencing social and emotional development and causing strong impacts on individuals and their families.

The Portuguese OI Association was created in 2006 by the will of several OI patients and parents, supported by medical doctors. It’s an organisation open to everybody interested in OI, that identifies itself with the Mission of the organisation - “promote a better quality of life for people with OI through information, education, awareness, joined actions with other organisations and encouraging and cooperating in research”.

Although the impact of the disease may vary in function of the clinical type, most children with OI experience complex psychosocial difficulties associated with the disease, the pain and functional limitations. OI is recognized as a very stressful condition severely affecting daily routines, self-care and functionality, with the consequent decrease in autonomy and negative effects in self-efficacy, self-image and social integration

Margarida Custódio Santos
Family experience with osteogenesis imperfecta type 1: the most distressing situations
DISABILITY AND REHABILITATION, 2017
Taylor&Francis
Growing slowly but consistent, APOI has now 173 members (69% OI patients and their families and 31% professionals and others), and has been working with the OIFE since 2009. Its major goal is to promote patient empowerment and capacity building, in order to help people with OI achieve better self-efficacy, self-image and social integration and also help parents adapt to the disorder (including the need to find an appropriate balance between protecting their children and encouraging them to be actively involved in developing appropriate activities).

Having all these concerns and thoughts in mind, APOI developed the Project “Dare to Live”. Aiming to highlight the value of patients, the goal is to promote a “special” day/weekend where people with OI and their families can participate in activities that might be difficult or risky for them to do by themselves. These are organized with the help of professionals and
volunteers prepared to deal with OI and usually include educational programmes and capacity and team building projects to create strong bonds between the participants.

The aim is to challenge OI and its limitations to be able to say “I CAN DO IT” in the end! So instead of assuming something is just too dangerous for OI people to do, we try to tear down the wall that exists between OI and the adventure world. And the key is very simple. Just create secure conditions that allow people to have equal access.

It always reminds me of a story where a kid with OI decided he wanted to climb a tree, and his mother kept saying “no you can’t”, “no, you’re different”, “no, you’ll hurt yourself”, but the problem was that the stubborn kid was 6 years old and he had decided he wanted to climb the tree, so if his mother wouldn’t allow it then he would do it by himself in secret – and that could have very bad consequences.

Wouldn’t it be better if his mother had said “Do you want to climb the tree? Ok, come along, I’ll help you and we will do it just until the first brunch. What do you think?” – this way she would be not only assuring the safe conditions for him to achieve his goal, but also reinforcing his self-esteem.

This is our thought regarding this project: if we assure the safe conditions, then we can do it. So, risk prevention and control is our major priority. The Project “Dare to Live” has already taken place 3 times and it is a major success, becoming one of the most important moments of APOI’s yearly activities.

On its first edition we went to a horse riding school and had the opportunity to experience wonderful horse riding adapted to each person’s conditions. In 2016 the programme gained a new dimension when 25 OI families joined on a marvellous summer weekend on the south of the country and had a day in a thematic park where the biggest challenge was a swim with the dolphins. And this year the challenge was an adventure camp where we could develop orientation skills, team building capacities and experience river canoeing and slide.

These are usually wonderful weekends with very positive impacts on children and adults, where we have time to learn, time to play, time to make friends and time to hear OI people say “yes, I DARE and I CAN” and parents say “Yes, THEY CAN”! Our biggest challenge for the future is to have new ideas for new adventures, so if you think of something wonderfully interesting, please share it with us!

Artists with OI: Penny Clapcott or: With OI against gravity
By Penny Clapcott

Hi I’m Penny Clapcott and I’m 29 years old from the UK with type 3 OI. I have always been into sport and being active from a young age. I was lucky that I went to an inclusive school where I attended mainstream lessons but I also had a place to go for additional support with hydro- and physiotherapy. My secondary school (from the age of 11) encouraged me to take up competitive swimming. I started to take training seriously around the age of 12 where my swimming career took off very quickly. By the age of 15 I had broken 4 World Records and
was swimming for GB. Unfortunately I had classification issues in the lead up to Athens Paralympics so I wasn’t able to go which was devastating, having had sacrificed to much and putting my heart and soul into training to be in the peak of my condition. However having done all this training and learning how to be extremely disciplined I was ended up going to university to study sports development and concentrate on studying without distractions. During my time studying at University I found a circus company offering training to disabled people. I thought I’d give it a go but honestly thinking I wouldn’t be able to do it because it’s dangerous, I could fracture.

I went to my first session and within the first 10 minutes I was hanging upside down which was the weirdest sensation having never been upside in my life. Everything we did was slow, done at a low level and with 1 to 1 support. I couldn’t believe I was doing something so adventurous but the feeling of letting go and just pushing my body once again to the extreme was incredible. I had a lot of upper body strength from my previous swimming training and my teacher from Cirque Nova saw I had so much potential to become an aerial circus performer. I took my shine to cocoons in the beginning, which are like a material hammock hung up from a single point. It was a great way for me to be up in the air but always having something to sit and hold on to. We developed a little routine and I first performed for the first time at a disability arts festival in London at Trafalgar Square. From that show onwards I never looked back. I developed my skills further, trying out different equipment but always things that I was able to sit and hold on to and started to perform regularly at various events.

I absolutely love being in the air and gives me so much freedom that I can’t have when I’m back on the ground using my wheelchair. When I’m in the air performing, people see me as a person doing cool things rather than the stereotypical view of a ‘poor disabled person’. It has allowed me to travel and perform all over the place. In 2012 I did the biggest gig of my life, which was at the Paralympic Opening Ceremony for London 2012. Each aerialist had a disability and it was incredible to have so many various disabilities working together to create such a large artistic performance.

I have always been cautious of doing aerial circus with my OI, luckily I’ve never had any accidents or fractures from training or performing. I built great trust with my teachers who understand that if I said something didn’t ‘feel’ right then we would stop straight away and try something different. I always worked within my own limits and actually found my OI helped me in many ways such as having bowed arms meant I could have better grips with some things and having my spine rodded meant my abs were strong because I couldn’t slouch. Leading up to big performances such as the Paralympic Opening Ceremony and
performing many shows in Los Angeles I did feel anxious that I would fracture and I would let down my co-workers. I feel that anxiety is just part and parcel of having OI and it’s just learning to cope with it and understanding/reading your body. There were times when something didn’t feel right so I would miss out that particular move and replace it with something easier or sometimes I felt great and would be able to try out other things in training.

I have been doing aerial circus for around 8 years but unfortunately last year I have developed an issue with the base of my spine and pelvis which has put my aerial circus career on pause. I do feel privileged that I had 8 successful years that OI didn’t stop me from going on one big adventure with my circus buddies and if I can’t return to circus I will be disappointed but I know it’s better to quit whilst you’re ahead and not to push my body when my body is saying no. I find it incredible that the last thing I did was balance over the edge of a mountain, which had been a dream for such a long time to work with Eskil Ronningsbakken. Eskil is a famous hand balancer from Norway and when I met him in the early days of my circus career I knew that one day I really wanted to do something with him as he inspired me so much. He was pushing the boundaries, but in a completely different way. Just the way I felt being an aerialist with a disability, but never knew if it would be possible. In 2016 we made it happen and we did a balance over the edge of a mountain. It was incredible. People often ask me if I was nervous doing it. But actually doing the balance was so much fun and I loved it. You’re so focused on what you’re doing and making sure you’re listening to your body, you don’t have time for being nervous. The thing that made me nervous was going up the mountain on Eskil’s back. We weren’t sure how we were going to do it but the joy of being so small, he just tied me onto a backpack and took me up the mountain on his back. We had such a laugh together and if you’re going to trust anyone to carry you up a mountain, it’s going to be someone who balances for a living! (watch the video here: **https://www.youtube.com/watch?v=1xBhe2u4ouY**
I really hope in the future I can get back to circus but I know that might not be possible. It’s hard to accept your body isn’t doing what you know it is capable of doing but you just have to move on and try something different. I’m not exactly sure what I can replace circus with that will give me the same adrenaline rush but I’m sure something will come along. In the meantime I’m carrying on with my day job, which is in the fitness industry, working in a gym as a fitness advisor. I am also training to become a wheelchair dance teacher, which will hopefully give me some creative outlet.

New OI-organization in Chile

The inaugural meeting of Fundacion OI Chile took place in Santiago de Chile on September 30th 2017. Laurette Paravano (OIFE-delegate nr. 2 from France), is travelling in South America this autumn and she sent us the following report:

"I participated in an OI meeting in Santiago de Chile. This meeting was organized by the newly founded Fundacion OI Chile and its board members, a group of 7 people. The inauguration has still to be approved by authorities.

70 adults and children with OI and their families attended the meeting, and also 3 doctors (MD Aro, MD Reyes and MD Pamela Trejo Param). Others could see and hear the presentations via Facebook streaming.

The meeting aimed at presenting the foundation and the board team as well as listening to families’ expectations. There were round tables on 7 topics: health, family, education, gender, professional life, accessibility and human rights. I also presented the OIFE and shared some experiences from European OI-organizations.

The meeting was a huge success for both organizers and participants. People had a big need to talk to each other and they were happy to meet other families. The board was interested in sharing information with the OIFE and becoming an associate member.

The President of Fundacion OI Chile is called Andrea Medina and can be contacted on andreamedina@gmail.com"
In the beginning of 2017 I received the brochure of Hannibal VZW. Hannibal VZW is a Belgian organization that offers vacations for people with and without a disability. Since 2006 it brought me to different places in Europe. The age limit is between 18 and 30, so hitting 30 this year meant it was my last chance.

In the brochure there were 3 options: Lisbon, London and Jordan. Of course Jordan was immediately blowing my mind. Lisbon I’ve visited with that organization 6 years ago, and London would have been my 5th time. Although I love those cities a lot, I was not so enthusiastic about visiting those another time…

But Jordan… is that possible with OI type 3? I knew from the beginning that traveling to Jordan with an electric wheelchair would be kind of impossible. Me without my electric wheelchair? Without any freedom? For sure I would have a lot of back pain because the manual wheelchair is never used more than 3 times a year, and has not been adapted since my childhood…

But Google, the tour leader, my sister, and the OIFE Facebook page made me push through. The journey included a jeep ride in the desert. So I asked if there was anyone who had done this before, and also if there were people with OI from Jordan. Both of my questions I got answers to and so in March I made de decision to go.

September 2nd we took the flight to Istanbul/Turkey and then to Amman/Jordan. I have always taken flights before with my electric wheelchair and I must say I am less worried now, though we had to hurry to catch the flight to Amman in time.
We arrived in Amman and so our adventure could begin. We had a personal guide and driver all the time with us, which was fantastic. Without them our trip would have been different, that’s for sure. The driver knew he had to drive calmly and he really did that. And thanks to the guide we could visit Petra by electric golf car (without this it would have been very hard to get to the treasury or Al Khazneh), he gave me and the other wheelchair user the opportunity to be at Petra by night because his cousins had to set up the candles, so we could get there with his pick-up truck. He was the extra assistant which helped by pushing the wheelchairs and carrying us around when it was hard to get somewhere with the wheelchair which was an added bonus.

Jordan is so extremely beautiful. I’ve never seen such beautiful sunrises, starry skies and landscapes before. But what made my trip perfect was the fact that I had hardly any back pain. Maybe it was because of the heat, it was almost between 30 and 40 degrees; or was it the adapted wheelchair seat, or a combination of both? I have no idea, but my back really did very well, even after the very bumpy jeep tours in the desert I had no pain.

So going to Jordan with OI, of course! Why not? The people are very generous and always keen to help you. We haven’t noticed anything from the problems in the neighbor countries, the food is very nice and the starry skies are just to dream about. My personal conclusion of this trip: You’ll never know, until you go...

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**Research Announcements**

**Disclaimer:**
The OIFE is not involved in the design or management of the following research, and as such, is neither endorsing nor supporting these studies. The mission of the OIFE is to keep the OI community informed of all relevant studies. This information is made available as a service to the OI community. We are available to answer questions on this or any other research announcement. Please contact the OIFE at office@oife.org if you have any questions.
Mereo BioPharma is sponsoring a multicenter international clinical trial to study the effects of anti-sclerostin therapy drug setrusumab (previously called BPS804) on bone in OI. The study is now open to recruiting patients at multiple sites in United Kingdom, France, Denmark, 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 1 year clinical research study, which aims to enroll up to 140 patients.

Visit theclinicaltrial.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 you have any additional questions, please email AsteroidStudy@mereobiopharma.com. Their study contacts will be able to tell you more about the clinical research study, review eligibility criteria, and find a site near you.

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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 7-17 who have a diagnosis of OI Type I through IV. **In late January 2018 Amgen anticipates opening the study to eligible children 2-6 years of age.**

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/2kLfg3l](http://bit.ly/2kLfg3l)

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.
## Contact

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## Website

Website: [http://www.oife.org](http://www.oife.org)
Facebook: [https://www.facebook.com/OIFE](https://www.facebook.com/OIFE)
Twitter: [@OIFE_OI](https://twitter.com/OIFE_OI)

## Calendar

### 2018

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<thead>
<tr>
<th>Date</th>
<th>Event</th>
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<tbody>
<tr>
<td>February 28th</td>
<td>Rare Disease Day (worldwide)</td>
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<tr>
<td>March 9th - 11th</td>
<td>Executive Committee meeting OIFE (place not settled)</td>
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<tr>
<td>March 17th - 18th</td>
<td>Journées Nationales de l'AOI, Reims, France</td>
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<tr>
<td>April 13th - 15th</td>
<td>Annual Meeting DFOI, Copenhagen, Denmark</td>
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<tr>
<td>April 27th - 29th</td>
<td>Annual Meeting NFOI, Oslo, Norway</td>
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<tr>
<td>May 6th</td>
<td>Wishbone Day (International Day of OI)</td>
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<tr>
<td>May 10-12</td>
<td>EURORDIS AGM &amp; ECRD conference, Vienna, Austria</td>
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<tr>
<td>May 30th-June 3rd</td>
<td>Annual Meeting DOIG Duderstadt, Germany</td>
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<tr>
<td>August 17th</td>
<td>BBS - Scientific Symposium, Dundee Scotland</td>
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<td>August 18th - 19th</td>
<td>BBS 50th anniversary, Dundee, Scotland</td>
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<td>August 19th - 20th</td>
<td>OIFE AGM, Dundee, Scotland</td>
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<td>Aug. 31 - Sep 1st</td>
<td>Family Meeting OI Austria, Tirol</td>
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<tr>
<td>October 6th</td>
<td>Jubileumsviering VOI (35 years), Utrecht, The Netherlands</td>
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<tr>
<td>Oct. 25th - 28th</td>
<td>OIFE Youth week-end, Aarhus, Denmark</td>
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