Hello over there!

My name is Stephanie Claeys (29) and together with Marie Holm Laursen (19), we are the new OIFE Youth coordinators.

I do have OI, type 3 and have had many many fractures since I was born. Now I have only one severe fracture every 5 years or so. In October it was 5 years! Boeboehoew...

Since 2013 I live on my own in Bruges. Bruges is a very nice absolutely NOT accessible city in the North-West of Belgium, not so far from the North Sea.

Although as I mentioned not accessible, since it's a city from the Middle Ages, it's a very beautiful city! If you ever want to visit it, just let me know. I do know all the exceptional accessible places ;-)
activities.

So don’t hesitate to let us know if you want to organize a weekend in your country. We can give advice on how to do it. In 2010 I helped organize a youth event in Belgium which was superfun!

Stephanie

Hello!

My name is Marie Holm Laursen and I am 19 years old. I live in Denmark in the city Aarhus. In my everyday life I go to college. Otherwise I love to swim and have fun with friends. I am working as a public speaker. My lecture is called “RulleMarlies Roadshow” and it is based on my everyday life with OI. My main points are happiness and prejudices. In continuation of that I have opened a lifestyle blog where I write about everything that is going on in my life. I have a big interest in communication and PR.

I have OI and I have probably broken my bones 500 times. I used to break something almost every month, but I have not broken anything in a year. So I am pretty excited about that! But having OI kind of sucks, sometimes I wish I could be without it. In spite of that it is not all bad to have OI, and that is of course because of all the nice people I have met because of my OI. People I never would have met if I did not have OI. I just love to go to all the cool events through the OI society and get together and have a lot of fun. Now I have become one of the OIFE Youth coordinators, which is so cool! I am sure that it is going to be fun, and I am really looking forward to it.

Marie

OIFE’s new Youth Coordinators Stephanie Claeys (Belgium) and Marie Holm Laursen (Denmark)
What is the OIFE doing?

By Ingunn Westerheim

A lot has happened at the virtual OIFE office the last 3 months and we have also had our Annual General Meeting (AGM) in addition to many other meetings and networking activities. In this article you can read about some of the highlights.

Meetings and events

The OIFE has attended the following meetings/conferences the last 3 months:

- OIFE Annual General Meetings, Lisbon – Oct 9th – 10th
- OI in 2016 – New Developments in OI, Lisbon - Oct 7th – 8th
- Networking meeting about Rare Skeletal Disorders with International Osteoporosis Foundation and other stakeholders, Lisbon - Oct 6th
- 2 Skype-meetings with MereoBiopharma, Sep 26th and Oct 28th
- Skype-meetings with the Polish OI-organization
- Skype-meeting with the Osteogenesis Imperfecta Foundation (US), Sep 28th
- Skype-meeting with Dr. Aliaksei Pachkaila from Belarus Oct 26th
- EURORDIS-meeting in Council of Federations, Paris, Nov 3rd
- EURORDIS workshop on genome editing, Paris, Nov 4th

Situation in the former Soviet countries

The OI-organization in Ukraine (Association of Crystal People – UACP) continues to work hard on the approval of medical treatment of children with Osteogenesis Imperfecta by the Ministry of Health - so far without big success. The reason is that in the former Soviet countries, you have to have a protocol approved by the health authorities – in order to use a pharmaceutical drug. Russia has similar challenges and it is not always easy getting treatment with bisphosphonates if you are a child with OI in Russia. Belarus had the same problem for many years, but they solved it some years ago and got the necessary approval from the health authorities. Currently, medical, orthopaedic treatment and rehabilitation of patients with OI in Belarus is available and paid by the state. We hope that a closer collaboration with the OIFE and our international network, will contribute to solve this difficult challenge in the former Soviet countries. Do you have tips on how we can help? Please contact office@oife.org.

Youth Event 2017

The Youth Event 2017 will take place in the Netherlands. We will be back with more information about date and deadlines in our next newsletter. Stay tuned via our Youth Group on Facebook:
OIFE AGM 2017

The AGM 2017 will take place in Warszawa, Poland from May 26th – 28th. The venue will be Best Western Hotel Portos, ca 9km from the international airport. Mark the date!

Need for photos!

The OIFE needs illustrative photos for our webpage and printed material. We are especially interested in photos of people with OI doing everyday activities. Do you want to help us with this? Please send us your high resolution photos to secretary@oife.org and give us the permission to use them for our material!

New OIFE-database of professionals

The OIFE has created a new and more expansive contact list of professionals. The purpose of the database is to spread our general newsletter (4 times a year) as well as information about scientific events and research grants. We will not use the list for other purposes or share it with anyone outside the OIFE secretariat. Do you know a professional, who should be included in the list? Tell them to contact office@oife.org

Questions? Please e-mail president@oife.org

OI Congress 2016 – Deep scientific insights and collaboration powered by the UNbreakable Alliance!

By Dagmar Mekking

Lisboa, a town that has shaped the history! People, who are thinking of Lisboa may mostly think about the ancient times... around 16th century, where Lisbon was the European hub of trade with Africa, India, the Far East and Brazil. The atmosphere of the old town surely still radiates the rich history, which has made the city UNESCO World Heritage!

But it was not the history that brought us to Lisboa this time. The scientific and non-scientific OI – Community came to Lisboa on 6-8th October 2016 to reflect on latest developments in Osteogenesis Imperfecta and think about the future.

An UNbreakable Alliance of many partners

The Conference came up as a result of a project organized by the Portuguese OI Association, APOI, called Unbreakable Alliance. The organisation of the Congress was
carefully planned by this OI organization and Fundacion AHUCE, an organization closely linked to the Spanish OI-Association AHUCE and responsible for Research in Spain. They set up an Iberian Partnership with the name of “UNbreakable Alliance” to stimulate cooperation amongst the OI communities, Health Care Professionals and many other stakeholders for a better quality of life of people with OI. They surely achieved this goal in an extraordinary way.

Working with a scientific committee composed of Portuguese and Spanish scientists as well as Prof Francis Glorieux from Montreal, Canada, they composed an inspiring agenda which provided insights on the very latest developments for OI. I was really impressed by the nice balance that was struck:

- On the first day, APOI prepared a Pre Congress Course, with Portuguese Professionals using Portuguese language, making sure there was low threshold access to information for anyone supporting people with OI in Portugal. A platform for the top of the international OI professional world was also provided. Many of them made their way to Lisbon, so the congress became a true high caliber international scientific event.

- Days 2 and 3 were prepared by the Unbreakable Alliance Partnership (APOI and Fundación AHUCE). The conference featured 30 presentations covering a very broad spectrum of topics -from dental issues to genetics to pain management and physiotherapy. The topics chosen enabled insights into the most innovative approaches in OI, providing an opportunity for professionals to advance their knowledge.

- The conference brought very different perspectives together, as the attendance consisted of Researchers and Health care providers (50%), medical students (25), the OI Community itself (25%) and also representatives from the Pharmaceutical industry. This way topics could be looked at from very different angles.

Diverse conference program
The Conference was held in the prestigious Aula Magna of the Medical University of Lisbon, just 5 minutes from the old City Center. The university has been a committed partner of the event from day 1. The Organising Committee was extremely friendly and helpful, providing every participant with an especially made conference bag with information on the conference, sponsors and other partnerships that had been created. Every request was picked up and responded upon in a true unbreakable alliance – way!

The congress organisers ensured a very diverse program, like short deepdives into themes (eg the theme “Beyond fractures” presenting insights into ocular, oral and hearing challenges related to OI), presentations from subject matter experts, facilitated panel discussions and poster talks. Various OI Communities were invited to add an extra spark of energy and inspiration to the discussion by presenting their ideas and goals for the OI Community. This was the first time that such a platform was provided to the OI Community. A courageous choice from the organisers, which got extremely positive feedback by all conference participants. Clearly a best practice for other conferences in the future to build on!

A springboard for more collaboration

The best part about the conference was the open atmosphere amongst all participants. Scientific and OI Community participants engaged in lively conversations during the entire day.

Each lunch and coffee break was intensely used to connect and the Aula Magna was buzzing from the strong relationships between colleagues and friends who had not seen each other for some time. A special atmosphere that the OI World is known for as it has a couple of life long dedicated OI Professionals that don’t shy away to connect with the OI Community on a very personal level.

A wonderful gift to the OI Community as many of our researchers really know how the
daily life of someone with OI looks like.

But also it is a gift to the OI Professionals, who are able to receive ideas and a stronger sense of purpose by experiencing the needs of families with OI first hand and seeing how they can add value to their lives.

The conference ended in a festive mode. Prof. Francis Glorieux received a well deserved lifetime achievement award. He was clearly very moved by the initiative and received the award with great pride and humbleness at the same time.

All conference participants also took a group picture, which will be a great memory for everyone.

A huge thank you to the “UNbreakable Alliance” for organizing such an exquisite conference, open for everyone to contribute! Whilst Lisbon is famous for its past, this was a very unique and innovative conference which has set an example for many other conferences in the future. And even more importantly, no doubt you have helped to make the future for people with OI a bit better. THANKS A LOT!
Impressions from Lisboa congress

OIFE was curious to know a bit more about some of the participants. So three of them kindly gave information about their connection to OI and how they heard about the congress, as well as what their highlight was:

**Anthony Hall, UK:** “I am working for a company that is developing a potential new treatment for OI and heard about the congress from people in the OI community.

The scientific content was extremely interesting and useful, with great topics and engaging speakers. Plus it was especially nice to have the opportunity to meet many people with OI from a lot of different countries:”

**Yasser Elbatrawy, Egypt:** “I am an Orthopedic professor in AlAzhar university in Cairo, Egypt and I treat patients with OI and heard about the congress via e-mails.

It was a great to meet different specialists not only in Orthopedics but in other specialities that deal with the OI patient. I regret that there is no center or hospital in my country that is specialized in OI only. The patient go to the different specialities solely! There should be a center in every city with doctors and specialists all together in one place to plan for every patient individual treatment plan. I am happy to know you all and I hope we have improvement in the future for treating OI patients.”
**Brittle Bone Society (BBS) Family Conference August 2016 in Reading, UK**

By Ute Wallentin

When I decided in early spring that I would spend my summer holidays this year in England with old friends, my second thought was how nice it would be to combine this with the annual BBS-conference. My last participation ten years back was almost history, but I remembered well, how the OIFE had been founded with the support of the BBS and in Northampton in 1993 and that in 2001 I had been elected second OIFE president again in the UK, in Birmingham.

So in mid August I arrived late Friday evening in Reading, west of London; this time without any „official mission“, but as a private person and an OI-woman. I enjoyed two lovely days with some old and many new OI-friends in the Hilton Hotel.

The BBS Family Conference was in many ways very similar to all the other OI conferences in many different countries and settings I have participated in during the last 32 years: the unique atmosphere a mixture of „family-feeling" and excitement plus anticipation.
The fact to meet old friends again after so many years is always heart-warming, but the weekend was as well full with new acquaintances and fascinating presentations of so many different speakers.

Not to mention the accompanying program for children, a talent show for kids on Saturday evening and a delicious Gala dinner.

But one outstanding difference to other national conferences was in my impression the surprisingly large number of adult OI people present, especially on Saturday, when probably more day guests had come to meet old friends and to learn about the latest news.

Some highlights from the numerous interesting and impressive on Saturday were:

- a planned trial called „TOPAZ“ that from January 2017 will compare the effects of „PTH (teriparatide) versus Zoledronic acid“ for OI adults. The goal is to follow 400 adults in 25 different treatment centers, unfortunately (from my point of view) only on a national level. But as we all know how difficult it often is to bring just two local clinics to cooperate, we can certainly all benefit in the end from this study’s results. (presented by Prof. Stuart Ralston)

- the growing importance of genetic tests for OI patients of all ages and severity was explained and a new possibility for English OI people to receive genetic testing without extra costs was presented by Dr. Kassim Javaid.

- The same speaker gave a fascinating overview about the RUDY Study, that brings not only OI patients, but several different rare disorders and researchers together and seems to me a very interesting and promising tool that should later be probably brought to use in a wider, international frame. See https://research.ndorms.ox.ac.uk/rudy/

- I learned a completely new word: „designability“ – where creativity and cooperation can lead to new, innovative and useful (even trendy, good-looking) household amenities and custom-made equipment for disabled people.

- Finally Dr. Richard Keen gave a presentation about the situation of OI adults that was not only entertaining, but at the same time shocking in some ways. He stated that obviously 30 % of OI adults had never seen an OI specialist.
Finally Maria Barbero had been invited to present a number of very encouraging examples of international collaboration between the small PadrinoS-OI-organization and the “Flying OI experts” program of the OIFE and other small foundations and organizations in Spain, the Netherlands, the USA, etc. They resulted in new and successful OI treatment units in countries like El Salvador, Honduras, but as well for OI patients in Nepal and the Sahara, that have been life-changing for OI families in different countries, where no OI treatment was available before.

Thank you very much for these two days full of nice new encounters, meetings with old friends and interesting, inspiring news – hope to meet again soon!

OIFE’s AGM – new phases and new faces

By Ingunn Westerheim

From October 9th to 10th OIFE’s Board (the delegates) came together in our Annual General Meeting (AGM) after the congress in Lisbon. We were 21 participants from 13 different member organisations present as well as guests from the German HPP-organisation and the new Latvian OI-organization.

The agenda was long, and we did not succeed in covering everything. But that’s how it is when we have a lot of information to share and strategies to discuss. In addition to the annual report from the Executive Committee (EC), these reports were presented:

a. Report from “OI in 2016 - Lisbon” (for those who were not present)
b. Report from social network coordinator Ute Wallentin
c. Report from webmaster IvarTroost
d. Status on European Reference Networks (ERN) and EURORDIS-meetings
e. Report from Skeletal Rare Diseases Coalition of Supporting Partners (IOF)
This year it was particularly nice to have the Russian OI-organization present, since the agenda included a proposal to change their status from associate to ordinary members. The Russian delegate gave an overview of the situation. And as you could read in another column – there are challenges regarding treatment for children with OI in Russia. The Board voted to include Russia as an ordinary member and from 2017 OIFE will have 17 ordinary members (European), 7 associate (non-European) and 5 supporting members.

Collaboration in research was one of the central topics. Dagmar Mekking (Care4BB) presented ideas on how we can work together for better research in the OI-community – both as individuals and as OI-organisations. She encouraged the member organisations to go into full or partial alliance with Care4BB regarding fundraising for OI-research.

During the AGM there were four parallel workshops with the following topics:

1) OIFE-passport – need for changes?
2) Further development of the OIFE webpage
3) Social media & the need to develop guidelines for this
4) Collaboration in research

Focus was on PR & communication, and this was not accidental. During the months before the AGM we realized the need for more force in the administration of the OIFE. Especially in the area of communication & information, which is one of OIFE’s most important tasks. The Board decided to expand the Executive Committee (EC) and welcomed Anna Rossi as OIFE’s Communication Manager and 5th member of the EC. A few days earlier she had resigned from the position of OIFE’s Youth Coordinator. As you could read in the editorial – we are happy to welcome Stephanie from Belgium and Marie from Denmark, as the new youth coordinators.

Another important decision was OIFE’s language policy. With a rapidly changing world, it’s a struggle to keep information up to date. On these grounds the Board decided that English and Spanish exclusively will be OIFE’s languages on the web. Each national organization must promote OIFE and our work in their webpages and newsletters.

During the meeting, we had the long awaited celebration of Ute Wallentin for her 15
years effort as the OIFE president. Because of a fracture she could not attend the AGM in 2015, but this year she got a small celebration and a well deserved present. Thank you Ute and thank you to all who made the OIFE AGM 2016 a constructive event! For those who are interested - we will publish the final version of the minutes on our webpage.

**Networking meeting about OI & SRDs**

OI is one of the most common rare bone diseases or “skeletal rare disorders (SRDs)” as the International Osteoporosis Foundation (IOF) call them. Since SRDs are in the mandate of the IOF, the OIFE initiated a conversation with the foundation two years ago to discuss possible collaborations. We decided to do a joint networking meeting October 6th, since many stakeholders were already present in Lisbon. OIFE’s president (Ingunn Westerheim) and medical advisor (Oliver Semler) represented the OIFE and from the OI-community we welcomed APOI (Céu Barreiros), Padrinos (Maria Barbero), Care4BB (Dagmar Mekking), the Brittle Bone Society (Patricia Osborne & Coreen Kelday) as well as Professor Glorieux and Tracy Hart from the OIF. Arjan Harsevoort represented the Isala clinic.

Dr. Maria Luisa Brandi and Dr. Kassim Javaid represented the IOF as well as Communications & Advocacy Manager Catherine Laverty who lead the meeting. Representatives from the HPP-community (Gerald Brandt & Gráinne Crowley) and skeletal dysplasias (Inês Alves) were also present. Inês is also one of the patient representatives in the BOND ePAG.

There were constructive and good discussions, but there were no clear conclusions drawn from the meeting. One of the areas described as potential collaboration was training of GPs/local doctors in order to better diagnose a rare bone disease (like OI and HPP) compared to other more common bone diseases.
Announcement

OIOslo2017 - Save the date!
The 13th International Conference on Osteogenesis Imperfecta will take place in Oslo, Norway from August 27 - 30, 2017.

www.oioslo2017.org

Questions? post@oioslo2017.org

Calendar

2017
February 24th: The 1st BBS Scientific Symposium, London, UK
February 28th: Rare Disease Day (international event)
April 28th – 30th: AGM & family meeting NFOI, Oslo, Norway
April 30th – May 7th: OI: Awareness Week (OIF)
May 6th: Wishbone Day (international event)
May 19th – 20th: EURORDIS Membership Meeting
May 20th – 21st: SVOI Annual Meeting, Nottwil, Switzerland
May 26th – 28th: OIFE AGM, Poland
June 15th – 18th: DOIG Annual Meeting, Duderstadt, Germany
September 1st – 3rd: OI Austria 10 year anniversary, Wien, Austria
2018
July 13\textsuperscript{th} – 15\textsuperscript{th}: OIF National Conference, Baltimore, US

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