



Osteogenesis Imperfecta
Federation Europe

Newsletter

Issue 29, May 2016

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Editorial

Dear friends,

It is with great pleasure that I'm writing this editorial to you to bring you "fresh" news regarding OI and the OIFE's members activities.

As you all know, one of the OIFE's main tasks is to promote a strong international network that allows, not only patients organizations, but also doctors and other health care providers, to share knowledge and to cooperate, bringing highlight to OI and developing better strategies for treatments.

So, its with great pleasure that the OIFE, as partner of its Organizing Committee announce the Congress "**OI in 2016 – Latest Developments in Osteogenesis Imperfecta**", which will take place from Thursday, October 6th to Saturday, October 8th 2016, in Lisbon, Portugal.

Lisboa has long been amongst the most sought-after tourist destinations and still maintains its tradition in welcoming people from all over the world. The host city now welcomes you to discover everything it has to offer.

The event will be hosted just 5 minutes away from the city center, in the "Faculdade de Medicina de Lisboa", a partner of this project. This recognized center of expertise has traditionally provided health care with both academic and research services. Its facilities are integrated in the major hospital of the city and therefore ideally designed to meet every need of participants during the congress.

"OI in 2016" is organized by APOI (Portugal) and Fundación AHUCE (Spain), under the Iberian partnership seal "*UN*breakable Alliance". This alliance is aimed to stimulate the cooperation amongst patient organizations, health care providers and professionals, industries and families whose common objective is improving the quality of life of those living with OI.

The international scientific committee has prepared an exciting program aimed to highlight the new scientific knowledge and the latest developments in the field of Osteogenesis Imperfecta. Accordingly, we would like to invite you to actively contribute to this project advertising it to your scientific community. We expect that bringing experts from different countries together will allow for an enriching discussion of new strategies in the field and improve networking between specialists and patients organizations. Read more here: <http://oi2016.webs.com>

Additionally, the OIFE AGM will take place from October, 9th to 10th in Lisbon, near the Congress Center, in the hotels where we have already been for the AGM 2012.

We look forward to seeing you in Lisbon either for the OI in 2016 Congress or for the AGM, where I'll be waiting to host you and renew your Unbreakable Spirit of innovation to allow us to join hands to push the boundaries of Osteogenesis Imperfecta.

Kind Regards

Céu Barreiros
OIFE Treasurer
President APOI (Portugal)



Registrations NOW OPEN

OI in 2016

congress

Latest Developments in Osteogenesis Imperfecta

6th to 8th October **Lisbon Portugal**



UNbreakable Alliance



FUNDACIÓN **AHUCE**
Osteogénesis imperfecta

more information: info.fundacion@ahuce.org
comunicacao@apoi.pt

What is the OIFE doing?

OIFE Youth Event

A few weeks ago VOICE 2016 – OIFE Youth Event took place in London. There were 50 participants - with 25 from the UK and 25 from Europe. Please see the report "A weekend that I will never forget" page 8. We send a big "thank you" to the organizers in the BBS and to the author!

Networking and collaboration

The OIFE has attended the following meetings/conferences the last 1,5 months:

- EC-meeting – April 21st 2016
- Meeting Alexion – April 20th 2016 and Mereo Biopharma - April 16th
- "First Friday"-meeting with OIF& Care4BB – April 1st 2016
- Skype International Osteoporosis Foundation (IOF) – March 23rd

Trip to Scotland

In the end of May the OIFE will be represented at EURORDIS AGM and the ECRD-conference in Edinburgh, Scotland. We are also planning a visit to the Brittle Bone Society's headquarters. Read more about the ECRD-conference here: <http://www.rare-diseases.eu>

Trip to Switzerland

OIFE's president is attending the 30th anniversary of SVOI June 4th. In addition to celebrating their anniversary, SVOI will have their AGM and a seminar with the topic of the spine.

European Reference Networks (ERNs)

OI will be placed in the «Rare bone disorders» group». This is based on professional decisions from the different health care providers in Europe. It is important to stress, that this does not mean that challenges regarding connective tissue will be disregarded.

There is an initiative to form an ERN for rare bone disorders lead by Dr. Luca Sangiorgi from Bologna, Italy. They are currently developing one ERN with two different sections (skeletal dysplasias and metabolic bone disorders).

Patients will be involved via patient advocacy groups (ePAGS). ePAGSs will work together with the ERNs representing the patient interests on a general level. There are two representatives related to OI in the ePAG of "Rare Bone"- Jean Moitry from France and Rebecca Tvedt Skarberg from Norway. Read more here: www.eurordis.org/content/epags

Each health care provider (HCP) might also ask you as a patient organization for your support regarding their application to become part of an ERN.

OIFE webpages were hacked!

We are working on restoring www.oife.org after the pages were hacked. Let us know if you see wrong information or bugs in the webpage!

OIFE AGM

We remind you to save the date for the next OIFEAGM taking place in Lisbon from October 9th–10th (meeting on Sunday AND the entire Monday) after the 1stHispanoluso Congress about OI (OI in 2016 – Latest Developments in OI).

Other news

- We have been contacted by Rare Diseases South Africa
- We have been in touch with Rare Diseases International and European Patients Forum regarding membership for OIFE.

Questions? Please e-mail president@oife.org

New OIFE member

We are very happy to welcome OIA Austria as new OIFE member. The association was founded in 2007 - you can find more information here: www.glasknochen.at. We also welcome SteffyGründler as the Austrian delegate!

"My name is Steffy, and I live in in Tirol. My flat is next to my parents' house, so they can help me, that is very good, because with one hand, pushing the wheelchair is crazy. I am 33 years old, can walk for 3 meters, but the rest of the time I need a wheelchair. I broke my bones more than a hundred timesbecause I was a very wild child, did not understand the word "no", you should not ☺! I have a younger sister – no one else in my family is affected.

I work in an office 30 hours per week. It is ok, and my colleagues help me if I need something. On weekends I like to go outside with friends, watch Game of Thrones ☺ and go on vacation, maybe to Croatia this year."



OI-conference in India – June 26th 2016
2nd National Meeting on OI and Metabolic Bone Diseases



at the Dr. RN Cooper Municipal Hospital, Mumbai, India. Free registration.
For more information please contact office@oife.org

Interview: Diving with OI

By Ingunn Westerheim

In 2015 you took over as the Polish delegate in the OIFE. Can you tell us a little bit about yourself and your relation to OI?

My name is Aneta Gałazka, I am 25 years old. I have OI type IV. I used to walk, but after nonunion of femoral neck fracture, I use wheelchair on a daily basis. Most of my day jobs keep me busy, I am an English teacher in language school and companies and student of Applied Linguistics.

Would it also be possible to say a few words about the Polish organization? How many members do they have? What are their main activities?

For the time being the organization numbers about 180 members. Every year we organize rehabilitation camp, usually by the Baltic Sea. Professional healthcare is provided by our consistent group of physical therapists, who are leading specialists in rehabilitation of people suffering from brittle bone disease in Poland.

I have seen on Facebook that you have a special hobby – scuba diving! Can you tell us a little bit about this?

Yes I am a scuba diver in HSA system (Handicapped Scuba Association). I have started it because I am passionate about water sports, I swim and sail as well. I did the scuba diving certificate called OWD (Open Water Diver) in June 2015 in Croatia. This is the last step of training, after few workshops in a swimming pool and lectures concerning physics, safety and equipment. As far as I know, it is not popular sport among people with OI because of some fears concerning fractures. Of course, at the beginning I was a little bit scared about weight of equipment. Fortunately, it occurs that below the water the weight is not noticeable. It is also worth to mention that this is sport based on partnership, so there is always a companion, mostly trained in diving with disabled.

How was it to dive in the Red Sea?

After Croatia it was totally marvelous experience! Diversity and richness of coral reefs made me extremely delighted. Moreover, it was diving safari so I spent one week on the boat diving twice a day for six days. Each diving lasted about 40-50 minutes depending on the water conditions. I acquired totally new skills as : diving in the night, diving from ponton called 'Zodiac' and diving in the currents. I have seen butterflyfish, clownfish (known from the movie 'Finding Nemo'), turtle, morays and most importantly..... amazing reef shark.

Have you been to other diving destinations?

As I mentioned before I was in Croatia, but I have lots of diving plans including Mexico and Galapagos Islands.



Is this something you would recommend to others with OI? What are the possibilities and challenges? I have always thought the equipment is very heavy

to carry?

I am not a doctor or physical therapist, but after diving training I have noticed better capacity of lungs. Moreover, this sport involves muscle effort which is perfect workout for me. Even training with snorkel is beneficial for the organism. The only challenge which I saw is inflated jacket which can be harmful for our ribs. Anyway, I haven't got injured so far. Instead I have improved my physical endurance, you know I prefer to break my limits not bones ☺

I really would like to recommend trying scuba diving for many reasons: 70% of world is covered by water so there is so much to explore, breathtaking views give you unforgettable experience, you can increase the circle of friends sharing the common interest and passion, possibility to breathe as a fish is totally new experience for your body, crossing the borders between



the terrestrial and submarine world gives you a sense of euphoria and all worries have no meaning. There is just absolute peace and even more than that, there is this absolute harmony with nature.

Thank you very much for the interview!

A weekend that I will never forget

By ThinesGaneshamoorthy

It's where I met my OsteogenesisImperfecta (OI) family (not literally, but you'll get what I mean) for the first time. This has been 22 years in the making but finally I had the opportunity and the courage to meet with others people with OI. It must have been my lucky day because it also happened to be the occasion where the Brittle Bone Society (BBS) teamed up with the OsteogenesisImperfecta Federation Europe (OIFE) teamed up for the first time to host this event together. And what a weekend it was... partying, sporting and general craziness in one bundle of a weekend!

The BBS defines the Youth events focus as being:

The Brittle Bone Society hold this annual event, in April or March each year, for 16 to 30 year olds with Osteogenesis Imperfecta. This is an opportunity for our youth members to meet and socialise with each other, learn new skills, hear talks from healthcare professionals, and to take part in forums and workshops.

And to their credit, OIFE and BBS delivered on all counts! Below you will find a brief summary of the days and my thoughts.

Friday

The day of arrival!

I was a bit of a nervous wreck, anxious before we had even started the journey. Even Kasia has started to experience the overflow of my nerves. While this event had been months in preparation, I don't think I fully anticipated how much this would affect me.

Questions started flowing around my head, will they like me? will I fit in? was I ready to meet a whole group of fellow individuals with OI?

This feeling had been perpetuated by my parents always sheltering me from people from OI in my past. While they had their reasons, which they never disclosed to me, it worried me what their reasons were. Was it because they believed I was not emotionally ready to understand the full gravitas of my condition and the variety that exists within it?

As we pulled into the hotel, we were welcomed by the massive wine tower in the heart of the hotel (to do this justice you really do need to Google it!). After checking in, Kasia and I had intended to go and chill out until the program of events began at 7pm that evening. However, after we moved into the hotel room and I went downstairs to register with the BBS team I got sucked into the OI Community. When the stories and drinks started flowing I could have not felt more comfortable within the group. The bunch were friendly, inviting and banter-ific. Then I knew, they were going to become a part of my life.



Hours passed by and eventually it was time for dinner and pub quiz. The buffet style food

was magnificent and the pub quiz which followed which was meant to be a mixer activity went a storm. 'The Smashers' team, which I was a part of, failed to win (we did come a respectful 4th and did mark the winning teams answers) but we will be back again next year!

Saturday

The day I took 12000 'steps'! More on that later though Saturday was the main part of the VOICE event. It was packed with talks from healthcare professional and workshops followed by a fancy 3 course meal and of course, all good 3 course meals are followed by a DISCO!

We had the pleasure of hearing from:

- Dr Richard Keen; Progress in OI Services
- Dr Lydia Zhang; The RUDY Study
- Chris Clark; Transition
- Claire Hill; Quality of Life
- CoreenKelday; General Discussion

Each of these sessions were so innovatively different and interactive in ways that I am not used to at youth events/ conferences. Not only was I able to see familiar speakers from my past speak on what was going on in the world of OI and Rare Disease, it was great to learn new things about OI and about the experiences of others with OI.

Some interesting things I picked up from it were:

- *Online Patient Passports being created through the RUDY study;*
- *That there is great examples of transition services for those with rare diseases and other chronic health conditions in foreign nations such as the Netherlands;*
- *There is no OI specialist for OI Adult Services in England & UK;*
- *OI Passport created by OIFE, useful for people with OI who want to travel!*

The experiences and expertise I found from these sessions I will be sure to share far and wide when I go out on my advocacy tours!

Once the workshops and talks had passed there was some free time to chill,



I took advantage of the hotel's comfortable sleeping arrangements to catch up on some

Zzz's before the big night

The three course fancy dinner was stunning, what was more impressive and delightful to see what how well turned out and in yellow the other young people were!



Right: ThinesGaneshamoorthy, author of this report

Post - dinner, the lights dimmed, the smoke flowed and the dancing consumed the floor and we danced into the early hours of the morning while sipping on delightful drinks from the bar.

When I retired to my room in the early hours of the morning I was shocked to see that I'd taken over 12,000 steps through the

days rigorous activities and lost over 800 calories. What a way to close off a perfect night!

Sunday

Sunday began quite abruptly and the haunting realisation that this would be my last day with my OI Family was gloomy and heart wrenching and the fact the first call of the day of sports somehow made my heart sink more...

While the sports sessions started off rather slow and lacklustre we all soon got into the spirit of things thanks to the energy and spirit bought by Darren Rees, our instructor. We started off with various warm up leading up to a inventive spin on 'musical chairs' followed by a rather competitive game of baseball. It was an energetic morning and I have never wanted to get more involved with sport than just after this session. I have a new passion to explore disabled sports and to see what I can get involved in!

Then the inevitable soon came! The Goodbyes! This was the hardest part of the weekend for me. I had become so close to this group of people, I felt as though I was leaving a part of me behind. Fighting back the tears, I said my goodbyes in the knowledge while this maybe be it for now we will all meet again at the BBS AGM in August or at the next VOICE.

This weekend had been a wonderful experience for me, I have managed to find a whole new community of whom I never want to part from, a group of people whose banter is second to none and a community to whom I can relate to and get support from. A truly international community bound by an unbreakable spirit.

I would like to thank the BBS and OIFE for organising and for giving me and my girlfriend

a chance to attend. Until the next time, stay awesome.

Calendar

2016

May 26-29: AGMwith OI Conference DOIGin Duderstadt, Germany
May 27-29: National Meeting of As.It.OI (Italian OI-Association) in Bari, South Italy
June 4-5: 30th anniversary SVOI (Swiss OI-Association)
July 23-30: Family Camp DFOI (Denmark)
July 22-24: OIF National Conference, Walt Disney World Swan and Dolphin Resort, Orlando, Florida www.oif.org/conference
July 28-31: Family camp at Geilo (Norwegian OI association NFOI)
Sept 9-11: National Meeting of OIA (Austria) in Salzkammergut, Austria
Sept 22-25: OI-meeting adults NFOI with medical TRS-seminar
Oct 7-10: OIFE AGMand 1stHispanolusoOI Congress in Lisbon, Portugal
Oct 23: Medical meeting in Leuven, Belgium (ZOI – Belgium)

2017

Aug 27 – 30: 13th International Conference on OI in Oslo, Norway – www.ioslo2017.org

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