Editorial
by Ida Männistö

About youth and hashtags

"I would so much like young people to have a sense of the gift that they are." – John Denver.

It took me a good while to find the perfect quote to start this editorial, because for some reason most quotes about youth I found were either bitter or condescending. Instead, I wanted to highlight the potential we have in our young volunteers and how we at OIFE appreciate the enthusiasm they bring every year to our activities. Every organization is dependent of the young talent as well as the seasoned veterans. There’s a constant cycle of getting new people involved. That’s probably why Ingunn asked me to write this editorial, as I am one of the newest members of the executive committee. Let’s get to work then.
January starts another new year for us at OIFE, which means a lot of planning and organizing for the executive committee. Luckily, not all is on our shoulders. There’s always a group of enthusiastic people to take charge of events and posts. I have been at two OIFE youth meetings to date, first one in Norway in 2012 and second time in The Netherlands in 2017. They both were very exciting, because ultimately you are going abroad and meeting people like you, who share the same experiences. So much fun! Organizing events for the youth is best done by the youth themselves. By giving them the reins, you get motivated volunteers and an event to remember. I know the Bilbao Youth meeting will be great!

Motivating volunteers is an art form. What works for one, doesn’t always work for another. I used to be involved in youth politics for several years and it was sometimes hard to get people committed and motivated to do the “duller” tasks. It is important to find out what motivates your team and assign the responsibility accordingly. What am I like as a volunteer? I am the kind who likes to invent and create new things at the start with high energy, but tend to leave it to the last day possible. That’s why it’s good to have different kind of people in organizations. It is good to sometimes take a step back to analyze how you like to work and try to match it to your team. Having to-do lists and schedules help!

The world is so much more open now, because of social media and Internet in general. Everything from important medical information to silly cat videos can be found with just a few clicks on the phone. The problem is that a lot of information is incorrect or is hard find or understand. If you look for research on OI online, you need a medical degree to fully understand it. That’s why it is important that we, as patient organizations and patient representatives, try to make that information easier to understand and digest for the wider audience.

Personally, I am trying my best to keep up with the latest tools and platforms, but it is a lot of work. There are a lot of good tools to create social media posts and free courses to make you a better writer.

That brings me back to our youth, who are fluent in so many apps and tech. Publishing stories on Instagram and Snapchat can teach a lot about creating meaningful content online. And for many, I think it translates to offline as well in self-confidence and presentation skills! These are often skills that you need when applying for work as well. So the bottom-line is, learn from your youth and teach them to become better at volunteer work. By the way, there are hashtags on Instagram like #OIcan and #UnbreakableSpirit, where people with OI around the world are declaring that hey, this is something I have, but I can do this. There is always a dash of #OIPride when I talk about OI, because even though it sometimes debilitates me, it has taught me perspective and resilience more than anything. You should check them out if you already haven’t. I wish you readers all a very good year 2019!

The editorial was written by Ida Männistö, 2nd VP of OIFE from Finland. You can reach her from Instagram @idscu and read her blog at idamannisto.com
What is the OIFE doing?

A busy autumn has passed. Busy both at the OIFE office, but also in the different lives of the members of the Executive Committee (EC). It has been difficult to find time to meet. But in November, the new EC of OIFE managed to get together for a 1,5 day meeting in Lisbon to get to know each other better and discuss how we can work together.

The last three months have also offered many videocalls and phone conferences between Ingunn and different stakeholders, who all want to collaborate with OIFE some way or another. It's exciting times, but also hard to know what to prioritize.

Through our website and social media, we try to share news and events from our members and our website calendar provides updated information about bigger events and conferences going on in the OI- and rare bone community. Check it out!

Meetings and events
As usual there have been several videocalls with delegates and member organizations. There have also been preparations of the youth event in 2019. We're still in touch with Mereo Biopharma, to provide patient input in the Asteroid study and we've been asked to find patient representatives to other research studies. Rebecca Tvedt Skarberg has also attended a substantial number of meetings in ERN BOND's steering committee and working groups and Ida Männistö has on behalf of OIFE attended a number of meetings in the steering committee of Key4OI.

- Webinar: Physical rehabilitation and OI, September 14th
- OIFE EC-meetings on Skype Oct 9th and Oct 23rd
- Phone conference Alexion, Oct 19th (IW)
- Skype Luca Sangiorgi about ERN-BOND, Oct 5th (IW and Rebecca Tvedt Skarberg)
- EURORDIS 27th ERTC workshop - EURORDIS Round Table of Companies (DL)
- ECTS conference call between rare bone stakeholders, Oct 17th (IW)
- Skype Cast Print (producer of 3D printed casts), Oct 23rd (IW)
- Skype Shriner’s Hospital (Cost in OI), Oct 24th (IW)
- Interview Students Voice, Nov 2nd (IW)
- Videocall programme committee See, Hear, Smile! (IW, DL, AR and TvW), Nov 5th and Jan 3rd
- OIFE EC-meeting in Lisbon, Nov 24th and 25th (the entire EC)
- Skype Janet Crompton, Nov 30th (IW)
- Phone conference, dr. Nick Bishop, Dec 19th (IW)
- Skype Inês Alves (ePAG ERN-BOND) about A stronger BOND between us, Dec 21st (IW)
OIFE AT EURORDIS MEETING
The 27th workshop of the EURORDIS Round Table of Companies took place October 16th in Barcelona. OIFE was represented by our Vice President Dace Liepina. Discussions focused on the importance of patient engagement in the development of medicinal products and the development of community advisory boards (CABs).

ERN-BOND
Rebecca Tvedt Skarberg (ePAG in ERN-BOND) attended the 4th Conference on European Reference Networks (ERNs) that took place in Brussels on November 22nd and 23rd 2018. "Think globally, act locally" was one of the messages from the conference. We all need to support and protect the networks to build sustainability and reach out to more rare disease experts and patients across Europe. Read more about the conference here: https://bit.ly/2BiMuS8
Watch the conference streaming here: https://bit.ly/2TF3fOy

Rebecca in Brussels together with Inês Alves from Portugal
One of the challenges that ERN-BOND and the other reference networks face, is the financial situation. This is because the EU has not yet provided a template of how the different European reference networks can interact with the industry. OIFE hopes these challenges will be solved, so ERN-BOND and the other networks can reach their full potential. The next technical meeting for BOND is February 13th - 14th in Brussels.

There is an increasing focus on CPMS, the Clinical Patient Management System that is designed to allow the discussion of specific patients between experts in the networks - so the information travels, rather than the patient. A specific CPMS coordinator for ERN-BOND has been appointed, working in Bologna. Her name is Evelise Brizola and can be contacted on evelise.brizola@ior.it

OIFE is through our membership in EURORDIS, working to support ERN-BOND and the other networks where we can. A dedicated website for ERN-BOND is coming soon and OIFE will be one of the contributors. In the meantime you can read more about ERN-BOND on OIFE's webpage: https://oife.org/what-we-do/ern-bond/

Key4OI & Quality of Life
The conference QualityofLife4OI will take place for the first time in Amsterdam November 22-25 2019. QualityofLife4OI is initiated by Care4BrittleBones and the event is a collaboration between Care4BB, OIFE, OIF and ERN-BOND and central professionals in OI. It will bring together OI-professionals, OI-community and industry. OIFE is represented in the steering committee by Vice President Ida Männistö. Other members of the steering committee are Graham Marshall (chair) and Dagmar Mekking from Care4BB, Tracy Hart (OIF) and Luca Sangiorgi (ERN-BOND).

A stronger BOND between us
One of the goals of the OIFE project called "A stronger BOND between us" is to create an informal network between different stakeholders working on OI and other rare bone diseases (including rare skeletal bone dysplasias). OIFE sees the need to educate more patient representatives & volunteers in the rare bone community to:

- serve as volunteers
- run patient organizations
- be patient representatives in research, development and networks like ERN-BOND & BBDC

OIFE gets more and more requests for patient representatives to fill different roles in research projects, meetings at the European Medicines Agency and other regulatory bodies at an EU-level, but the challenge is that we don't have enough people with the right experience, expertise or background to fill these roles. Because of this we want to develop a capacity building programme to support rare bone organizations in recruiting and teaching patient representatives for

- ERN-BOND
- research projects & development of registries and guidelines
- European Medicines Agency (EMA) & FDA
- Health Technology Assessment – internationally and nationally

Our goal is not to compete with existing programmes as EUPATI and EURORDIS Summer School, but rather be a supplement and a first introduction for those who want to become patient experts. The OIFE project is currently in the phase of planning & networking. And we've been in touch with stakeholders like the European Calcified Tissue Society (ECTS), the industry, ERN-BOND, the International Conference on Children's Bone Health (ICCBH) and others.
Who is Who?
OIFE’s Medical Advisory Board

Lena Lande Wekre
I am working as a Senior Consultant in the Skeletal team at TRS National Resource Center of Rare Disorders in Norway. The center has registered 338 persons with OI, all ages.

My medical background is physical medicine and rehabilitation. I have been working in the field of rare disorders since 1999, especially with connective tissue disorders and skeletal dysplasias. I finished my PhD, “A population-based study on adults with OI” in 2012, and this study has formed the basis of follow-up routines for adults with OI in Norway. I have also participated in several other projects regarding OI. In 2006 I was involved in starting a multidisciplinary day clinic for children with OI at Oslo University Hospital.

I have always had a close relationship to the Norwegian patient organization on OI, NFOI, and we have collaborated on organizing several conferences. In 2017 I chaired the 13th international conference on OI (OIOslo2017).

As a clinician working in the field of rare disorders, I believe that one of the most important goals of a European patient association as the OIFE, will be to strengthen contacts and exchange among patients, clinicians and basic scientists from different countries. I do believe that international collaboration among us is fundamental to develop the best follow-up and treatment for people with OI.

Eva Åström
I am a paediatrician specialised in paediatric neurology and habilitation at the Astrid Lindgren Children’s Hospital at the Karolinska University Hospital in Stockholm, Sweden. Here I am a senior consultant and the leader of a multidisciplinary paediatric OI-team.

The paediatric OI-team was formed in 1991 and I have been a member from the start. We started the first intravenous Pamidronate treatment in 1991. I have a PhD from Karolinska Institutet (Thesis in 2007: Bisphosphonate treatment of children and adolescents with Osteogenesis Imperfecta).

I am the OI-physician for the Swedish children with OI. The team assess and treat children from all parts of Sweden from 0-18 years of age. In that age group we are following 150 children with OI. We collaborate with local health professionals in other parts of Sweden. We initiate and monitor bisphosphonate treatment and most of the orthopaedic surgery procedures are done here (incl. telescopic rods). The paediatric dentists in the team have a unique OI competence. My research is mainly about assessment/treatment of children with OI: bisphosphonates, MSC (mesenchymal stem cells), genetic and dental studies.

I believe that one of the most important goals for OIFE is international collaboration with clinicians, researchers and other patient organisations to strengthen patient input and patient oriented research to improve quality of life and equality.
What is the Transfer Tool?
The OI transfer tool is a portable, clinically meaningful, person-focused tool designed to help improve the transition experience for adolescents and young adults living with OI. Once completed, the tool summarizes the adolescents’ time spent receiving OI care in the paediatric setting, and is intended to be given to their receiving primary care physician or nurse practitioner in the adult health care system at the point of transfer. The tool covers a range of topics including: insurance information, psychosocial needs, activities of daily living, transportation, family history, immunization, major surgeries and hospitalizations, pain management, radiographies, medical equipment and follow-up needs.

The impetus for the project was derived from undergraduate nursing student Jaimie Carrier. Ms. Carrier experienced a difficult transition to adult care for her childhood onset condition. Meanwhile, Dr. Argerie Tsimicalis recognized the need to address the transition gaps for young adults with OI. Together, they mobilized the OI team to help create a tool to fulfil a gap in resources for young adults transitioning from the paediatric to adult care system.

Who was behind the project? What kind of methods were used?
At the Shriners Hospitals for Children®-Canada, an interprofessional expert task force (Task Force) with expertise in OI was convened to create the transfer tool. We followed the methods used to create evidence-based practice guidelines, which is a type of knowledge synthesis study. Our Task Force was composed of 9 members including: a primary care nurse practitioner and clinical nurse specialist who practices in the child and adult healthcare systems, a paediatrician scientist, a clinical nurse specialist, two registered nurses, two physiotherapists, an occupational therapist, a social worker, an administrative decision maker, and two former patients of the child healthcare system including one with OI and one with a different childhood-onset chronic illness.

The first draft of the transfer tool was created using information retrieved from published research and transition tools available in North America (published and unpublished). Over a one-year period, the draft was refined by the Task Force until consensus was reached, ensuring all components deemed essential for a successful transition to adult health care were included.
Why is there a need for a transfer tool? And what is the purpose behind it?
Having a portable and comprehensive summary of the adolescent’s key information plays a significant role in a successful transition. It empowers adolescents to take charge of their own health by encouraging them to fill it out *with* – and not by – the interprofessional health care team. By equipping patients with a concise summary of their OI history, we are also hoping to reduce the apprehension some health care professionals may experience when having to care for adult patients with a childhood-onset chronic condition.

Who is the target group?
The tool was created for adolescents and young adults living with OI who are transitioning from the paediatric to the adult health care system. Surprisingly, these portable transfer summary tools, if appropriate, are difficult to obtain. Thus, we urge the community to share. This tool serves as a complement to the one developed by the Osteogenesis Imperfecta Foundation (OIF), and may be easily adaptable to fit the needs of other adolescents and young adults with a chronic condition. The tool developed by the OIF can be found here: https://bit.ly/2Dd7lqS

How were the patients involved?
Two former paediatric patients with a childhood-onset chronic condition were part of the Task Force (Carrier and Chougui). They also attended the Collaborative Care Transitions Symposium in Toronto to inform the creation of the tool (See Picture). Our Task Force also gathered feedback from the patients and their families who receive care at the Shriners Hospitals for Children®-Canada and those who attended the OIF National Conference 2016. We received valuable feedback from patients and families that was integrated at various stages of development and collectively reflect the final version.

Can other countries use this/translate this to their language?
The tool, which can be downloaded for free on the OIFE website, is intended to be widely distributed. We encourage the translation into other languages, and we’re available for consult on the translation process. We would appreciate if you could acknowledge the original creators, and share the translated version, so we may share with others. You may contact Dr. Argerie Tsimicalis at: argerie.tsimicalis@mcgill.ca

Other messages to the readers of OIFE Magazine?
The process of creating guidelines and tools is iterative, ongoing and subject to change with more information. We welcome feedback from the global community, so we may enhance the tool, and would love to hear how the tool is being used in practice.
From October 25th to 28th 2018 Kristian and I traveled from Norway to Århus in Denmark to attend the annual OIFE Youth event. The traditional youth event took place in the Pindstrup Centre and was organized by the Danish girls Malene, Ninna, Matilde and Marie, who’s one of OIFE's youth coordinators. The girls had put in a lot of effort to make the event as successful, nice and useful as possible. Actually they had planned the event for a whole year, from when we left the 2017 event in the Netherlands.

The 2018 event had people with OI between 16 and 35 as a target group and welcomed as many as 42 participants from eight different nations: Norway, Sweden, Denmark, Germany, the Netherlands, Belgium, UK and Spain. The increase in number of participants was mostly due to a big delegation of 12 people from Spain, with Tamara from Ahuce as the coordinator. The Spanish participated with four people in 2017, which was their first OIFE Youth Event.

After being collected at Copenhagen and Aarhus airport, the accessible bus took us to the Pindstrup Centre, which is a holiday centre adapted for disabled people. It has a bigger building in the middle and is surrounded by three houses, which can accommodate around fifty people in rooms for 2-5 people.

The first day was used for getting to know new people and relaxing, after what was for several rather strenuous travels. Some of the Spanish had been spending the night on Tamara's couch in Madrid, due to long stopovers with Ryan Air both in Madrid, London and Copenhagen. Another adventurer was Qusai from the Netherlands who started with a delayed train in Amsterdam followed by a missing ramp in Hamburg. There Qusai and his powerchair had to be lifted out of the train by the local firesquad! This was followed by a four hours taxi trip to Århus, because all the trains had left for the night. Around half past 10 in the evening, most people had arrived though, and the long week-end could start.
The Danish girls had organized activities, with the goal that everyone should get to know each other irrespectable of nationalities and type of OI, and they had been very creative in their programme planning. Speed-befriending, naked painting and baking with a set of special ingredients was only some of the many activities we tried during the first whole day. The baking ingredients could be won in contests consisting of liquorice eating, humming or beer pong.

Day three we visited Århus city, where we got to spend time in ARoS art museum, the old town and the dome church. We finished of with a great meal at Jensen's Steakhouse.

The last day we painted t-shirts, had a sit down aerobics class and a neon dance party in our newly painted t-shirts.

Both Kristian and I were very happy and content with this year's youth event. International contacts and friendships were made and we exchanged ideas and experiences on how it's like to live in different countries regarding healthcare, car support etc. The differences between the countries are huge.

The event was very amusing and something the participants will surely remember for a very long time. Everything was very well organized. Even a water pipe breaking, causing us to be without water for 15 hours, was handled. The girls mastered the logistics perfectly, especially considering that we were around twenty wheelchair users. The Danish organizers therefore deserve a great THANK YOU! I'm sure the way the OIFE Youth Event 2018 was organized, will inspire future organizers. We're already looking forward to Bilbao in 2019.

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**OIFE YOUTH EVENT**
**BILBAO SPAIN**

**OCTOBER 23 – 27, 2019**
**BBK BILBAO GOOD HOSTEL**

**REGISTRATION WILL OPEN APRIL 1ST**
**AGE 18-35**
Youth Weekend – some reflections

Stephanie Claeys, 31, Belgium
"The best thing about the OIFE youth events is the feeling that you're not alone. It sounds a bit sad, but for me it's really nice to talk to others who feel the same about so many things. This year the activities were also very original and creative. But I just notice that there is a lack of youngsters from the southern part of Europe. Many don't speak English. I think those youngsters are willing to learn it, but they don't have the tools. Maybe an online English course could help?"

Lars Nesset Romundstad, 23, Norway
"The best thing about the OIFE events is the bond with young people across borders and languages. Another highlight were extremely well organized social games. To better engage young people one should create more vivid youth events in each individual country, and make sure more people want to join the international youth weekends."

Qusai Al Rifai, 32, the Netherlands
"It was great to have the opportunity to meet and getting to know each other. Everything was amazing and special. To better engage young people one should organize more events every year."

Louise Vidlund, 28, Sweden
"The best thing about OIFE Youth Events is to meet other like-minded friends and that everyone has one thing in common. Best place to meet new people and connect contacts! The highlight of this year was that you once again got to know new people. My advice to OIFE: continue as you did before!"

Lucía, 28, Spain
"At OIFE Youth Event not only you do meet people from Europe but, best of all, we share experiences and do realize the huge abilities we all have. In my opinion, the most remarkable thing about such an event is the ability of the organizers to create this amazing meeting on a voluntary basis, and the purpose of these people who travel for hours with this clear objective: the union. On the other hand, a good way for attracting young people every day might be to create more activities related to games and competition, as well as to effectively implement the announcements of the event and the search for additional funding. In conclusion, It's been a great experience and I look forward to meeting everyone again soon."
"The Transformation" and "The Course of Success" – Psychological Programs for OI-Children in Russia
By Aleksandra Romanycheva

In December 2018 the Russian Charitable Foundation “Brittle People” started its most outstanding online-project “The Transformation”, focused on children and teenagers with OI and their professional skills and psychological health.

Inspired by “The Transformation” programme’s success, our Fund’s psychologist Aleksandr Kharitonov decided to run another one – “The Course of Success, which started in September 2018. Both projects are financially supported by the Presidential Grants Foundation.

“The Transformation” was a one-year project based on weekly training in groups and has two breaks for spring and summer camps. Children watched webinars in ZOOM platform, made homework and participated in discussions of personal development, studying their own and other people’s place in the world and their future profession. Motivational speakers talked to children about their experiences, profession and unlimited opportunities of life. With the help of “The Transformation” project, participants became more socially active, learned to show their leadership skills and saw how many “fragile” children live in Russia. Most importantly, they realized that they are not alone. In total 62 children from 34 federal regions of Russia participated in “Transformation” program, and 74 children – in “The Course of Success”.

The main goal of “The Course of Success” program was to provide children with career guidance, to develop their knowledge and skills in a professional area they chose for themselves. Children were offered to choose professions in three areas: “Creativity”, “Business” and “Digital”. After finishing the program, each participant would present his own project.
Traditionally, all online training is supported by live-meetings in spring and summer camps for OI-children and their families. As a result of the project, Charitable Foundation “Brittle People” expects that children with Osteogenesis Imperfecta will improve the basic skills and competences, will get career-oriented (according to their capabilities and age), and become more adaptive to the modern labor market conditions.

These projects are very important steps towards making children with brittle bones independent and self-confident members of the society. Also an unplanned effect was that children’s intellectual and emotional improvements led to the physical one. Some of project’s participants, who previously used a wheelchair not only because of real necessity, but mostly because of the feeling that they walk weirdly, gradually began to walk.

**Thank you, Rob!**

We are happy and grateful to announce that Rob van Welzenis, founder and first president of the OIFE, left an amount of 10,000 euros to the OIFE in his testament. We are particularly touched by his legacy as it shows how Rob regarded the OIFE as close to his heart until his last days and wanted us to have an extra amount for our important work ahead in his sense!
The Portuguese OI association (APOI) has existed for 12 years now. However, one of its main difficulties has been catching young people’s interest and involving them in the community. This year we finally made it! The trick? Very simple - we asked them to organize the activities they wanted themselves and be project assistants.

Health education is one of the main goals of our association. We believe that by giving families educational tools, it will allow them to better understand their disorder and health conditions and develop strategies to cope with OI, and consequently better integration.

The project “Learn+” is a good example of this. During the year we organize several educational sessions or practical workshops about topics like: OI in general, cardiology aspects, first aid in fractures, school integration, psychological support…and this year, also about youth. So, Mariana, Marta and Tiago, the Youth Team, proposed to organize a whole week of activities just for young people. It was awesome!

Most of the teenagers didn’t know each other beforehand. But by spending time together, at the end of the second day they felt as best friends.

For the educational programme we organized several activities. One was a very fun Video Conference, of Q&A for them to ask all the doubts they had in their day by day living with OI, which they felt uncomfortable to ask their own doctors or their parents. Playing around in the swimming pool was also a way to introduce several hydrotherapy concepts they can also apply on a regular basis. Cultural activities included a visit to an interactive museum, a visit to the city annual fair and a boat trip in Douro River. But the most important activity for them was practical workshops about anxiety and fears conducted by APOI’s psychologist.

After five marvellous days without parents, they came home absolute sure that this was only the beginning of a strong connection and the Portuguese Youth Meetings are here to grow and stay!

See you next year - we are already planning!
New OIFE member: Ukrainian Organization Crystal People

Interview with Karina Prokopiuk

Who are you and what is your relationship to OI?
My name is Karina and I am mother to 8 year old girl with OI type 3. We live in Rovno, which is located in Western Ukraine.

Can you tell us a few words about Ukraine?
Ukraine is a country in Eastern Europe. It has a population of about 42.5 million, making it the 32nd most populated country in the world. It is the second-largest country in Europe. Capital and biggest city is Kiev. Ukrainian is the official language and its alphabet is Cyrillic. The country shares borders with Russia, Belarus, Poland, Hungary, Moldova, Slovakia and Romania.

Can you tell us about your organization?
The organization “Ukrainian Organization Crystal People” (UOCP) was created on June 2014. So far we have been in touch with 200 persons with OI. These are our goals and activities:

- Gathering people with OI and their families into the Association and database compilation;
- Our organization is funded by private donors, which helps to cover at least some expenses, that patients with OI have (medical support, surgeries, rehabilitation and genetic tests);
- Informative support for members of the Association, exchange of experience with OI related matters, and in situations where people with OI and their families feel lonely;
- Informing public and health care responsible government institutions about needs and problems of people with OI and their families;
- Collecting information and spreading information in mass media about OI;
- Medical database compilation of doctors and medical professionals who have experience in treatment of patients with OI

How do you recruit members/promote the organization?
Information about the organization has been sent out to main hospitals, genetic doctors, rehabilitation doctors and other health care professionals in Ukraine. We also have a website and Facebook-group:
Website http://ostimperfecta.wixsite.com/oiua
Facebook group https://www.facebook.com/groups/1665289700364209/

Biggest challenges in Ukraine
Unfortunately there are a lot of challenges for patients with OI. Currently the biggest challenges for Ukrainian patients with OI are:

- the absence of diagnostics (genetic analysis)
- the absence of protocol for OI surgery and treatment, approved by the government and Ministry of health.
- too little professionals for kids/adult health care, who know about European protocol for OI surgery and treatment.
- expenses, that patients with OI have (medical treatment support, surgeries, rehabilitation and genetic tests).
Plan for the future.

Our goal is to have protocols for OI surgery and treatment, approved by the government and Ministry of health and free medical treatment for patients with OI. We want to collaborate more with doctor's associations in Ukraine and other countries to get OI more visible among doctors in order to get the best health care as possible. To share information about OI and help those who are having OI and their families.

FOXP2 - European Network for international mobility of disabled youth

FOXP2 aims to be the first European mobility network for young people with disabilities and their families. Their goal is to facilitate international mobility, learning, and the discovery of other cultures. FOXP2 is based on a digital solution developed in partnership with Capgemini.

The network can be used for student or work-related exchanges (as internships for example), but also for holidays or to simply communicate with other families in order to get advice and information.

Our platform integrates a matching engine that allows families with the same difficulties to contact each other. The project is based on two guiding principles: cooperation between families and openness to all disabilities. See video presentation for more information: [https://www.youtube.com/watch?v=03v3_R2wMH8](https://www.youtube.com/watch?v=03v3_R2wMH8)

FOXP2 cooperates with Assurinco, an insurance company that offers professional assistance and answers to specific questions. The repatriation insurance provided by Assurinco can be subscribed for 29 euros and covers all the costs related to the trip back home in case of medical needs (like airplane tickets).

We are currently developing the network in Europe and we wish to inform more particularly directed towards the young people with OI. We have already some teens with OI in our network who are looking for host family. For further information please contact [alix.paulmier@foxp2.eu](mailto:alix.paulmier@foxp2.eu)
Access to international mobility in higher education for disabled people

By Freyja Haraldsdóttir

My name is Freyja Haraldsdóttir and I’m an adjunct in the Department of Education in the University of Iceland, a PhD student and a feminist disability activist. I want to share my experience as a disabled student studying abroad, discuss some recommendations for change and finally stress why access to international mobility in higher education is essential for disabled students.

Personal experience
The year 2015 I went, together with my friend Embla, who is also disabled, as an exchange student for 7 months to Manchester Metropolitan University in England while working on my MA degree in gender studies. Overall, my experience was positive, and with support from the international office at the University of Iceland, and Erasmus+ and Manchester Metropolitan University, most of the barriers were sorted out. I got additional funding through Erasmus+ that was absolutely necessary to make this happen. But. There’s always the but.

First of all it is important to address my privilege. I’m one of the very few disabled persons in Iceland who receive individual budgets for personal assistance services, but I need 24h assistance. Without that kind of services I would not have been able to go – I think I can state that. Also, I have been able work alongside my studies so financially I was more stable than many disabled people who have to rely on the benefit system in Iceland. I was also able to have support from my family to some extent. In addition to this, Embla and I, who had support from each other in this process, are both experienced travellers, speak fluent English and are very much used to dealing with complicated systems of oppression and ‘computer says no’ scenarios. Also, we have a network of friends in Manchester that was very welcoming and supportive. This is not something that we can be sure of in disabled students lives.

What I found personally to be lacking, was a dedicated person, who could follow me through this process and hold on to all the loose ends, instead of me needing to run between different offices and people to keep things afloat. I did not get any formal support in finding accessible accommodation, which I think was one of the biggest stressful parts. Embla and I found an apartment for rent three days before we left Manchester and we were not 100 % sure it would be accessible. It turned out to be ok-ish, but for 7 months I had to walk to university a few times a week to take a shower. I did it, and it was worth it, but it is a ridiculous situation to be in.

Access to international mobility in higher education for disabled people
I believe, as with anything else, disabled students access to international mobility in higher education, needs to be approached and thought about, in context with other areas of our lives:
• disabled students need to know that they can study abroad and that they will be supported in their process, both financially and practically
• disabled students who have already studied abroad need to be representing student mobility programs and recruited for work in this area (so disabled students have rolemodels and can seek advice and guidance from someone who has similar experiences)
• access to housing that meets their needs and is situated in places that are reachable and possibly located centrally
• accessible public transport
• The cost of transferring mobility aid (e.g. wheelchairs, beds) from one country to another or renting mobility aid needs to be covered.
• the opportunity to have a contact person, staff or student (or both), both in the university at home and in the new country, to prevent complications and isolation
• in relation to healthcare, disabled students need to be supported in making connections, e.g. doctors and physiotherapists, if needed in the new country.

In more general terms, student mobility programs need to be flexible and offer various ways of studying abroad, short or long term. We need to be mindful of the history of oppression in disabled people’s lives and the cost of it for our empowerment and wellbeing. I believe we also need to acknowledge intersectional structures of oppression and be aware that disability is not a single issue struggle. Disability does not exist in a vacuum but is interrelated to gender, class, sexuality, gender identity and expression, race and other identities that can in one way or another influence the opportunities of disabled people to study abroad. Disability is not a one size fits all category and there are also disability related hierarchies. People with visible and invisible impairment will not in all aspects experience barriers and prejudice the same way. The same goes for people with different impairments or multiple impairments. We need to think about the diversity of the group and be aware that certain groups, e.g. people with learning disabilities, will most likely be subjected to higher degrees of oppression and discrimination in higher education, than people with physical impairments. While advocating for international student mobility this is something we must never forget.

The feeling of control and empowerment
We know from research and history that disabled people have not had equal opportunities when it comes to education and the labor market. The Convention on the Rights of Persons with Disabilities stress the importance of securing the right to education on all levels, as well as access to participation on the open labor market. Moving to another country and experiencing new academic environment widens people’s horizon, disabled or not, and offers greater opportunities for growth. It can also be beneficial for further studies and job opportunities. It’s also a time where we often expend our social networks and build new relationships.

Finally, on a more personal note. Studying abroad for me was one of the most important things I have ever done. The planning and organising was challenging but it was worth every second. The seven months I spent in England were liberating because I had space and time to just think about my own work and take care of myself which is not an easy task for a disability activist. It was also extremely empowering because a few years earlier, due to internalised ableism, I had not believed I could do this, and also because stepping outside your comfort zone, if that even exists for disabled people, fuels your self confidence, gives you a feeling of control over your own life and a sense of selfworth and autonomy.
My voluntary work in Ghana

I am Stefanie Ritzrow. I'm 19 years old and I just graduated from school this year. I have OI type IV and I use a wheelchair, since I cannot walk. My biggest passion is traveling, and I always wanted to combine that with being a helpful hand and experiencing more than a normal holiday.

In December 2017 the framework of the “weltwärts everyone inclusive!” – a project for inclusive volunteer services, grabbed my attention. So I applied – first without any expectations. Then everything went really fast. I passed two preparational seminars where close friendships got established and since 26th of September I have lived in Ho, Ghana, West Africa!

I am working for VOICE GHANA, an NGO managed for and by people with disabilities. Voice Ghana's focus is to promote access to quality education for children with disabilities. My placement is primarily in Ho Anglican School, Unit for Special Needs Children (mental retardation and psychological disabilities), where I assist the staff during the lessons and sometimes overtake a class of about eight pupils for a short period to realize own ideas and projects. This school is a role model and very unique in this area.

Together with my co-volunteer and two other short-term roommates, we are having a good time together and I am really enjoying my stay. Even though there are good and bad moments and sometimes I am full of worries, I always try to focus on how cool it actually is that I am here at all! Of course I also made some risky trips and had some dangerous situations. In the end it was at fine and I could laugh about what I just set myself up to do again!

Unfortunately I am pretty dependent here. I often have to get carried, pushed or assisted. However this is still not a big problem for me, as I have a private taxi driver, an assistant for household and I am never really alone. I also have physiotherapy here, twice a week.
Apart from the volunteer work, my biggest highlights so far, were the Wli Waterfalls in a mountain-like tropical forest, coming from Togo (for a couple of minutes my nerves lost control and I thought I could never make it since I was scared to literally fall down the mountains), a traditional Ewe-Festival in a beautiful forest located 10m below street level without any chance to get down (and up) there with a wheelchair. But I made it! Together with German and local friends we had a really fantastic day and night.

Apart from that, I had my first trotro ride as well, where I can only advise to be careful with OI! Moreover, you should not take a tuctuc bike for long distances if you are with more than five people AND have a non-foldable wheelchair. Haha.

At first, a lot of things were new for me and I probably had a little „culture shock“, but if you really open your eyes and observe, ask questions, stay sensitive for potential backgrounds and meanings you might not understand right from the start, you will surely have a great time and take part in a personal and global movement. I always knew that neither my wheelchair nor my OI could discourage me from doing so. Volunteering is not only spending time in a country “far away” and being a saviour in a protectory or nursing home. It is rather about changing your perspective, exchanging cultural aspects, ways of life, thoughts, opinions, and so much more. Then when you go back to your home country with all your new experiences, you will also bring something back home to share. So what I think is, that the connection that gets build up is full of profit for everyone. Especially people with disabilities should be taken into development cooperation more.

If you are interested or feel encouraged, do not hesitate to email me or send a message on Facebook! I would love to hear some of your experiences or just to share more of mine!

stefanies_mail@web.de
ritzroads.wordpress.com
News in brief

NEWS FROM RESEARCH
Mereo BioPharma Group, a UK-based specialty biopharma company, has completed patient enrollment for a phase 2b clinical trial of BPS-804 (Setrusumab) for the treatment of osteogenesis imperfecta (OI). Its multi-centre, randomized, double-blind, dose-finding phase 2b study dubbed ASTEROID will evaluate it in a total of 112 adult patients across the US and Europe, said MereoBioPharma. Read more about the study here: https://www.asteroidstudy.com/

EAT, BREATHE & SLEEP!
This is the key words of a research project supported by the Italian OI-organization. Eating, breathing and sleeping are three fundamental aspects for people's quality of our life. The goals of the study include evaluating if people with OI have special nutritional needs and an analysis of how nutrition (and obesity) affects breathing, sleeping and mobility. The project is currently recruiting participants in Italy. We're looking forward to hearing about the results, which we will present in the OIFE Magazine in a later edition. Stay tuned!

METAMIZOLE IN PREGNANCY
Following a review of medicines containing the painkiller metamizole, European Medicines Agency (EMA) is recommending that the maximum daily dose of the medicine and the contraindications to its use in pregnancy or women who are breastfeeding should be harmonised for all products on the EU market. Metamizole-containing medicines are available in Austria, Belgium, Bulgaria, Croatia, Czech Republic, Finland, Germany, Hungary, Italy, Latvia, Lithuania, Luxembourg, Netherlands, Poland, Portugal, Romania, Slovakia, Slovenia and Spain. Read more in this link: https://bit.ly/2THEOPN

CHINA DOLLS 10 YEARS!
We congratulate our associate members with their 10 yearanniversary, that was celebrated on December 23rd 2018. You can still watch the streaming of their 10th anniversary celebration now: https://bit.ly/2ARd4kG

FOLLOW OIFE (@oioife) on INSTAGRAM!
You can now follow OIFE on Instagram @oioife

CONGRATULATIONS
We congratulate OI activist Dhanya Rhavi from India with National Award for Empowerment of People with Disability - under the category 'Role Model.' She was nominated by the Ministry of Social Justice and Empowerment, Government of India. Keep up the good work & spreading awareness on OI!
OI IN TAIWAN
In the beginning of December the OI-organization in Taiwan opened a photo exhibition about living with OI.

GOOD NEWS FROM RUSSIA
Thanks to the theatre play "Sea of trees" in Гоголь-Центр / Gogol-Center the Russian OI-organization managed to collect 218 thousand rubles! All the money from the event will go to treatment, rehabilitation and costs arising from the transport of children with OI, from different cities of Russia and neighbour countries.

RESEARCH AWARD
We congratulate researcher Argerie Tsimicalis, who's the recipient of the Rosemary Wedderburn Brown Prize. The award recognizes individuals with outstanding scholarly potential and who demonstrated research excellence in the early stages of their career.

JOIN OUR GROUP FOR ADULTS WITH OI!
Did you know that OIFE has a Facebook-group (in English) for adults with OI where you can seek advice on health related questions by experienced peers? The group is ONLY open for people who have OI themselves and you have to confirm this before being accepted in the group. You don't have to belong to one of OIFE's member organizations to be part of the group, but you must be able to read and write English.

In the group you can share experiences and ask questions about health related topics connected to OI such as:
- medical issues or concerns;
- personal experiences related to a life with OI;
- seeking & giving emotional or psychosocial support
- practical hints and possible solutions
- personal advice from the experience of peers
- information on individual rights
- helpful adaptations for the daily life with OI
**OI & POWER**

Congratulations to Samantha Renke, Lord Kevin Shinkwin, and Shani Dhanda for being included on the Shaw Trust #DisabilityPower100 list, celebrating Britain's most influential disabled people. People with OI can and know how to influence. And we do!

**WEBINAR DAILY LIVING WITH OI**

Care4BrittleBones is hosting a webinar directed to occupational therapists and physical therapists. Kathleen Montpetit will share her findings from a survey about "Tips and Trips for daily living with OI", which was done amongst the OT community. The webinar is for professionals primarily, but interested people with OI and their families may also participate. Upfront registration is required (limited places): https://bit.ly/2TCJNRp

Date: Thursday 21 February at 2 pm CET, 8 am EST, 9 pmCST

**WEBINAR: Fundraising for OI research**

Care4BrittleBones will be holding a Fundraising webcast with lots of useful tips how to effectively fundraise for research for OI. They are inviting the worldwide OI community in particular, but also researchers, clinicians and anyone else who is interested in this topic. They will discuss many different aspects of fundraising. The focus will be on crowdfunding. Upfront registration is required (limited places): https://bit.ly/2SJvDht

Date: Friday, 8 February at 2 pm CET, 8 am EST, 9 pmCST
Get in touch!

In this column professionals, organizations or volunteers can make small announcements that they are interested in getting in touch with people who are interested in the same topic and/or have experiences to share. Do you want to get in touch with people working in your field? Send us a short bio & the topic you are working on to office@oife.org

Searching professionals interested in psychosocial aspects of OI

In 2019 Care4BB would like to build up a network to foster knowledge exchange around psychosocial aspects of OI. The network will be led by Dr. Kara Ayers (photo) from Cincinnati children’s hospital, USA and Dr. Claire Hill from Sheffield’s children hospital, UK. The purpose of the network is to explore key topics of shared interest, foster scientific research and best practice exchange in this area with the overall aim to improve quality of life for people with OI. If you are a professional working with people with OI (children or adults) in relation to psychosocial topics and interested to share your experience and learn from others, please sign up to the community to be kept informed about their upcoming meetings and any educational activities. This professional network is open to people from all disciplines including allied health professionals. Sign up here: https://bit.ly/2RsatYs

Questions? Please contact dagmar.mekking@care4brittlebones.org

Patient representatives - research & development

Are you interested in research & development in OI? Do you have OI yourself or do you have children with OI? Are you interested in getting involved as a patient representative and represent OIFE in:

- research projects related to development of new medicines & treatments for OI
- other kind of research projects related to OI
- providing advice to OIFE and our member organizations on priorities in OI-research
- development of registries & guidelines
- meetings in the European Medicines Agency (EMA) or the FDA (USA)
- Health Technology Assessment - influencing what kind of drugs are approved and paid for for OI?

Or are you just interested in learning more about the topic before you get involved? Whatever alternative that suits you - please get in touch with us by sending an email to president@oife.org

ePAGs in ERN BOND

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

SURVEY ON RESPIRATORY FUNCTION & OI

The OIFE would like to bring your attention to a research study investigating cardiopulmonary outcomes and quality of life in adults with OI. The clinical examination part is only recruiting people from the USA. But the internet based questionnaire/survey is open for any person with OI 18 years of age or older as long as he/she can write/read English.

You can find the survey here: http://j.mp/2SUjerF

ABOUT THE PROJECT

Hospital for Special Surgery (HSS) in New York, USA, is sponsoring a pilot study in which researchers are exploring respiratory function and its relation to quality of life, type of OI, presence of scoliosis/chest wall deformity, and other factors such as age or co-existing co-morbidities.

We hope that you will take the time to complete the St. George’s Respiratory Questionnaire and Additional Questions so that we can learn more about the relationship between respiratory function and quality of life in adults with OI.

HSS is committed to protecting the privacy of your information, and wants you to understand how information you provide will be used and protected. All the information you provide in the questionnaires will be shared only with others who are participating in or sponsoring this study, or who have administrative or regulatory oversight of this study. Everyone who sees your information has agreed to protect it. Published study results will not contain information that could identify you. Whenever possible, all information that identifies you will be removed before your information is shared. If you do not agree to participate in this study, it will not affect the health care you receive. You may revoke your permission to use your information in this study by writing to the study contact. If you have any questions about how your information will be used and protected, please contact Elizabeth Yonko (see below).

ONLY FOR PEOPLE LIVING IN THE US:

Individuals 18 years of age or older who have a diagnosis of OI are eligible for this single-visit research study, which aims to enroll 50 participants. If you have any questions about the study or your eligibility, please reach out to Elizabeth Yonko. Your completion of the above questionnaires will not impact your participation in the pilot study.

If you have any interest in enrolling in the pilot research study, Hospital for Special Surgery in New York City is actively recruiting study participants. Contact information for the study site is listed below.

Elizabeth Yonko
Research Technician
Hospital for Special Surgery
535 East 70th Street Research Institute, 4th Floor
New York, NY

10021 (212) 774-2355

Disclaimer:

The OIFE is not involved in the design or management of this research, and as such, is neither endorsing nor supporting this study. 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.
See, Hear, Smile!
Topical Meeting on Osteogenesis Imperfecta

14TH - 15TH OF JUNE 2019
TALLINK HOTEL
RIGA - LATVIA 2019

At OI conferences we hear a lot about long bones, spine and bisphosphonates, but what about the rest of the body?

More than 50% of people with OI suffer from hearing loss. Many don’t even know they have it.

Several have so severe problems with their teeth that it affects their ability to chew, eat and smile.

And did you know that OI can also affect eyes & vision?

This seminar will create an arena to present newer research and treatment methods related to eyes, ears and teeth of people with OI

Recommendations of follow up of both children and adults with OI related to the topic will also be discussed.

Programme committee:
Kristofer Andersson, DDS, PhD - Sweden
Jannie Dahl Hald, MD, PhD - Denmark
Lars Folkestad, MD, PhD - Denmark
Kaija Kuurila-Svahn, MD, PhD - Finland
Christer Swan, Associate professor, MD, PhD - Denmark
Dace Liepina, OIFE - Latvia
Anna Rossi, OIFE - Italy
Taco van Welzenis, OIFE - The Netherlands
Ingunn Westerheim, OIFE - Norway

Target group
- Dentists, orthodontists and other professionals working with teeth & jaws
- Clinicians & researchers with an interest in eyes & ears in OI
- Clinicians & researchers with an interest in OI in general
- OI-community (people with OI, family members, staff and volunteers)

Visit https://oife.org/seehearsmile for more information about conference fee, registration and practical information.
The European Patient Forum is happy to share with you an exciting opportunity for the 3rd edition of the Summer Training for Young Patients Advocates. The theme of 2019 is ‘Shaping the Future of Patient Advocacy’.

Over the course of four days, young people will be expanding their skills and maximize their leadership potential. The dedicated sessions will focus on topics such as representativeness, transparency, ethics and the importance of building trust. Patient advocacy may take different pathways, through individual patient advocates, emerging online patient communities and more formalised entities such as patient organisations. The Summer Training Course will look at how uniquely they can contribute to patient advocacy and do complement each other.

The training will take place on 7-10 July 2019, in Vienna Austria. Deadline for applications is 1st March 2019. EPF offers support of travel costs and accommodation.


Testimony from Penny Clapcott (in the front row to the right):

"Last year I was accepted onto a training programme with the European Patient Forum (EPF). Last year’s focus for the training course was based on becoming a better patient advocate and learning key campaign skills to promote your rare disease/health condition.

I applied because I have been on a patient forum for a big research project based in the UK called The RUDY study, which is an online based research project. I am interested in the key concept of ‘nothing about us without us’ campaign as I feel that is vital for OI. At the Brittle Bone Conference I was able to share a little bit about my experience and speak with other health professionals that what we want as patients is very different to what clinical trials aims to improve.

For the EPF course we attend a 5 day course in Vienna, Austria with incredible tutors and access to many other health professionals
such as the European Medicine Agency staff member and head of the European Patient Forum CEO. We did a lot of practical work to develop our own campaigns which we then launched after the 5 days training. We were put into teams where we had monthly skype calls to check in with each other, discuss any barriers we’re facing with our campaigns and offer solutions and creative ideas to move forward individually and as a group.

I really felt it improved my confidence and broke what feels like a huge unrealistic end goal into much more manageable goals. My campaign was based on quality of life for people with OI. I want doctors and researchers to listen to us patients that we want to have a good quality of life and that isn’t always about reducing fractures, more often it’s about better pain management and strategies to help prevent and reduce fatigue. Since finishing the summer course I have been invited onto a medical research board as a patient within the Brittle Bone Society and still heavily involved with the RUDY study.

I highly recommend anyone who is interested in patient advocacy to apply for this year’s course. I promise that you’ll meet some great people from all backgrounds and health conditions. It was a great chance to learn from professionals as well as peers in a similar position to you."

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**International conference**

for OI-professionals, OI-community and industry supporting OI on

**Quality of Life 4 OI**

**22-25 November 2019**

Amsterdam, The Netherlands

**SUBSCRIBE NOW TO THE NEWSLETTER** [http://eepurl.com/dDRPen](http://eepurl.com/dDRPen)
## Calendar OI-events

### 2019
- **February 28**: Rare Disease Day
- **March 16-17**: Annual Meeting AOI, Paris, France
- **May 6**: Wishbone Day [www.wishboneday.com/](http://www.wishboneday.com/)
- **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
- **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

### 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
- **Sep 20-23**: ASMBR Annual Meeting, Orlando, Florida, US
- **Nov 22-25**: International conference QualityofLife4OI, Amsterdam, NL

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

## Contact

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Ute Wallentin (Coord. Social Network): [socialnetwork@oife.org](mailto:socialnetwork@oife.org)

Stefanie Wagner (newsletter editor and secretary): [secretary@oife.org](mailto:secretary@oife.org)

Stephanie Claeyts and Marie Holm Laursen (Youth Coordinators): [youth-coordinator@oife.org](mailto:youth-coordinator@oife.org)

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