Patients, people or partners?

OIFE believes that all clinical trials and research projects affecting OI directly, should have some kind of patient involvement. Patient involvement can happen in different ways and in different phases of a project. Sometimes advice from a new and unexperienced parent or a child is needed. Other times a person with OI, who can represent a larger group and speak on behalf of many, is needed. A so-called patient representative. Sometimes a project needs the experience of a patient expert and sometimes advice from a patient organization who knows the international OI-community is needed. Usually this is when OIFE comes into the picture. But we can also offer assistance to find people in all the roles described above.

Some organizations have been talking about involving the voice of the patients for 20 years already. But to some countries or groups, the concept is still relatively
new and even revolutionary. Fortunately concepts like patient involvement, patient empowerment and patient engagement have gradually become more commonly known. Especially in research and development, but also in policy work, development of new services and support.

And this is good! There is only one problem – we are not patients 24/7. We are not living our lives in hospitals or at the doctor’s offices. And thank goodness for that! We are living our lives out in the real world, with challenges and opportunities that are not connected to medical treatment. We are parents, employees, students, sisters, brothers, owners, friends, volunteers, athletes, artists, refugees and in short...people. People who want to influence the services we get and treatments that are being developed, but without defining ourselves as patients 100% of the time.

So, what can we do about this? We want to promote the concepts even more because patient involvement is important. But we don’t really like the terminology. And do we really have a good alternative? In Norway we say user involvement, because people are users or recipients of services. But to me that sounds more like drug users. Or abusers for that matter... What about patient and public involvement (PPI) as they say in the UK? Maybe? But I still feel something is missing. Where are the people? The individuals? How can we make sure that people’s voices are being listened to?

And what about the organizations? They can also play an important role in patient involvement. Sometimes as advisors, but more and more frequently as partners. Our voices are wanted in research projects, consortiums, and clinical trials. But is it on our terms or just to tick off a box in the grant applications? Is our input really wanted and taken into consideration both when prioritizing topics for research, developing a hypothesis, or creating project plans? Is our time and effort compensated and our knowledge and experience really appreciated? Does the researchers or companies really understand what we can bring to the table? Many times, the answer to this is no. But things are slowly changing. And only with our help and advice, can the situation improve.

I’m looking forward to a future where patient organizations are regarded as true partners and people with OI who knows a lot about OI and research, can be regarded as true experts. And where people with OI, who get involved or engaged in R&D can be regarded as people with complex lives and not just patients...

_Ingunn Westerheim, OIFE president_

**What is the OIFE doing?**

*By Ingunn Westerheim, OIFE President*

Since the last OIFE Magazine, we have used our time on various projects as well as preparing annual reports and other topics for the OIFE AGM. We had a successful kick-off of the Pain & OI-project in January. In March we had our establishing meeting of OIFE 2 under Belgian law. We are now waiting to hear back from Belgian authorities before we can continue our work. A lot of time and effort has been put into the process of getting a new bank account and developing new Statutes. In February we did a successful Rare Disease Day campaign with the overarching topic Equity. Now we are in the planning phase of Wishbone Day 2022 with the hashtag #1voice4OI. This year we have involved a number of activists with OI around the world to share important messages and amplify the strong voices from the OI-community. We are also working on the planning of a Topical Meeting in June 2023 in Stockholm, Sweden. Stay tuned for more information to come!
MEETINGS & WEBINARS
The last three months there has been a lot of meetings connected to different clinical trials & research projects. This includes several different meetings with the companies AMGEN/UCB and Ultragenyx/Mereo, to provide input from the patient perspective.

These are some of the other virtual meetings we have attended since the last OIFE-magazine:
- OIFE EC-meetings Jan 4th (postponed), Jan 18th, Feb 15th, March 1st (extra), March 15th
- OI-organization in South Korea & Korean professionals Jan 11th (IW)
- European Society for Pediatric Endocrinology ESPE (Amanda Helm), Jan 18th (IW)
- Care4BB Board & OIFE EC on how we can collaborate, Jan 18th (OIFE EC)
- Kyowa Kirin International, Jan 20th, Feb 14th (IW and BVD)
- Webinar Oslo Medicines Initiative – financing novel medicines, Jan 20th (IW)
- ERN BOND, Luca Sangiorgi Jan 26th (IW)
- ePAG education on guidelines Jan 31st (IW and RTS)
- PuREC (industry), Feb 3rd (IW)
- Webinar how to make videos with mobile phones Feb 9th (IW and AW)
- European Huntington Association Feb 10th (CK, BVD and IW)
- Quality of Life 4 OI-conference online, Feb 12th (several from OIFE)
- KAL Research Initiatives (Helen Hernandez), Feb 17th (IW)
- Webinar PEOF Patient Engagement on Market Value (IW)
- Program Committee OIFE Investigator Meeting Feb 28th (IW)
- EURORDIS Ukraine Emergency Meeting March 4th (IW and LZ)
- Formal establishment of OIFE 2 in Belgium, March 8th (OIFE EC + new founders)
- Pega Medical R&D, March 17th (IW)
- Webinar Aparito on video tools for measuring mobility, March 25th (IW)

REFUGEES FROM UKRAINE WITH OI
Another important activity has been the ad hoc project established to coordinate, advise, and support the refugees with OI who have fled Ukraine because of the Russian invasion, which the OIFE strongly condemns. We have established a resource group with national contact persons, which include representatives from the Ukrainian OI-organization. Through these contacts we try to assist families with OI who have fled Ukraine getting connected with organizations and volunteers in various European countries. Do you want to help? Send an email to office@oife.org with what you can contribute with (translations, housing, mobility aids, help to navigate the system or other types of support).

And read OIFE’s statement about what else you can do to help, on our webpage.

OIFE LEADERSHIP MEETING
OIFE’s 2nd Leadership Meeting took place on January 24th. More than 25 representatives from most of our European member organizations attended. Topics included among others, future events, restructuring of OIFE, IMPACT survey, news from research and clinical trials, the Pain & OI project, EU advocacy, ERN BOND and our upcoming campaigns for Rare Disease Day and Wishbone Day.
IMPACT SURVEY

The cleaning of the data from the IMPACT survey took a lot of time and resources, but it is now more or less finished. There are four scientific articles planned from the IMPACT survey in 2022 and 2023. One overarching article with the main findings, one article on OI’s impact on physical and mental aspects, one article on the patient journey (care pathways) and one about the economic impact on people with OI and the healthcare system. On February 18th we had the first official meeting in the data management committee of IMPACT. Stay updated on www.oife.org/impact

OIFE MAB & OIFE SUPPORT FOR R&D PROJECTS

OIFE Medical Advisory Board had their first 2022 meeting on January 26th. Topics included information from OIFE EC & OIFE MAB chair, a proposal from dr. Anticevic on minimum criteria for OI health care providers and guidance from OIFE MAB on how OIFE should deal with the increasing number of requests for support from research projects and consortiums preparing grant applications.

In January OIFE got many different requests to support grant applications for various research projects. After discussions with the OIFE MAB, we decided to support 3 applications by being a direct member of consortiums (CINDERELLA, DIAGSKEL & POC Tool). We also supported one other grant application with a support letter to the consortium.

We have also agreed to help with recruitment to a project about Patient Journeys for people with OI in Europe, run by the company Putnam Associated. We have attended 5 meetings connected to this project and provided input to question guides.

PAIN & OI PROJECT REESTABLISHED

On January 25th we organized the kick-off of the Pain & OI project, which is a collaboration between the OIFE and the OIF (USA) and a group of dedicated professionals who have experience on pain management, pain research and/or pain & OI. We had 21 participants from 10 different countries at the workshop. We agreed on the common goals:

1. Recommendations on how to measure pain in OI
2. Educational activities – OI & pain (incl. different types)
3. Recommendations on management of chronic pain for children and adults with pain

There have also been some smaller meetings connected to the project.
INTERNATIONAL RARE DISEASE SHOWCASE

The International Rare Disease Showcase was organized from February 1st – 3rd by the organization Beacon, formerly known as Findacure. It gathered over 430 attendees and over 70 speakers from 25 different countries. Ingunn took part in the Pitch & Mix Challenge with Jim Thomson from Pfizer and Elisa Ferrer from Aparate. Her talk was called “How the OI-community made an IMPACT” and received a lot of positive feedback. OIFE also had an exhibit at the showcase, which got us in touch with new companies and professionals interested in OI.

MEETINGS IN EURR-BONE & ERN BOND

OIFE was well represented at the annual meeting of the European registry for rare bone conditions (EuRR-Bone) on February 8th. We had 3 patient representatives and 2 MAB-members attending. It was a very informative meeting explaining the progress in the various parts of the project, including the development of a specific module for osteogenesis imperfecta (OI). On February 8th we were also represented at the annual meeting and 5 year conference of ERN BOND. In addition to these bigger meetings, we organized at least 3 informal meetings between OIFE and EuRR-Bone and ERN BOND during the last three months.

OIFE AT WINTER SCHOOL

March 21-25 the EURORDIS Winter School on Scientific Innovation and Translational Research took place online. This year OIFE was represented by our volunteer and MAB-member Lida Zhytnik. We’re proud to educate more and more patient experts who can represent the OI-community.

Meet the OIFE delegates

Diane Maroger, France

Who are you and what is your relationship to OI?
I am Diane Maroger, member of AOI board, born 55 years ago with OI type 3. I am a co-delegate, responding on behalf of the President of AOI Bénédicte Marie. For me OI means short stature, walking with sticks and I’m also very talkative. Hearing loss mild to severe started in my early 30s. I now benefit from a cochlear implant.

Tell us about your organization!
The French-OI-organization AOI (Association de l'Ostéogénèse imparfaite) was created in 1985 by Alain Diestch, Chantal Gatine and Pierre Bailly, all being people with OI. The medical board was headed by a leading European surgeon at the time, Dr Finidori. Early on, AOI created videos for parents to get tips about how to manage fractures and other questions related to OI. Our organization also advocated successfully for us to get most of our medical costs related to OI covered by social security. It publishes a magazine in French every term and holds an annual meeting open to all members.
Its medical board, now headed by geneticist Professor Valérie Cormier Daire, produced 2 webinars this year due to covid preventing us from meeting physically as we hoped. Website: https://www.aoi.asso.fr/

Currently we have around 190 members. This includes people with OI, parents and medical members. The board members are all volunteers. There used to be a professional secretary, but her contract ended in 2019.

Personally, I’ve been a patient representative for questions related to hearing loss and OI at AOI and OIFE since 2019. In 2021, I was a patient expert on that matter and ran patient-led Focus groups within the Key4Oi+ project framework run by Care4BB. The aim is to make sure key resources about hearing loss and OI are available to the OI community and to medical communities worldwide on the Key4O1 platform. In the process, we gathered a lot of patient feedback about what it is like to experience gradual hearing loss with OI, and what types of resources and support OI-ers with hearing loss would like to find. I hope this project can help us create safe spaces for people with hearing loss to speak up and feel supported inside the OI community. I am planning to make the videos from the Care4Bones’ Quality of Life conference on hearing loss accessible in French. I hope they will be disseminated in our national OI organizations and the OI federation.

What do you do when you’re not doing OI-work?
I have a Master’s degree in film. I was a professional film editor, but then I lost my hearing. Now I work in film production, script advising. I also have non profit activities related to disability and cinema (advocacy to improve the accessibility of film venues, TV and film programs, art schools, higher education and leadership in the cultural fields). I am also actively supporting environmental projects and educational or awareness projects welcoming refugees, countering all forms of discrimination.

In your opinion - what is the most important tasks for the national organizations?
- Representing OI people to improve our health management at all ages.
- Welcoming and advising parents when their child is suspected to have OI, or facing diagnosis.
- Making sure doctors and other medical staff are aware of OI in all areas of the country and have access to updated resources on how to treat fractures. This must include small provincial towns.
- Improving awareness about OI and quality of life issues especially regarding access to education, pain management, secondary effects such as hearing loss and dentinogenesis imperfecta.
- Creating resources and making support groups available to any person with OI (or parent concerned) needing to connect with a larger community of people facing similar challenges.
- Regularly assessing the needs and wishes of the country’s OI community to address other specific themes.

In your opinion - what is the most important job OIFE should focus on?
Making sure all the affiliate organizations get information about the latest drug development, clinical trials, and tools to evaluate if they should support such campaigns. Facilitating international meetings between people with OI and researchers in an accessible way, including those with OI who don’t hear well.

Do you have any other messages for the readers of OIFE magazine?
Keep going and keep connected! You are wonderful people!
OIFE Investigator Meeting 2022

SAVE THE DATE – 1st VIRTUAL OIFE INVESTIGATOR MEETING
November 18th 2022 14.00 – 19.00 CET

The umbrella association Osteogenesis Imperfecta Federation Europe (OIFE) is together with members from the Medical Advisory Board of OIFE inviting you to save the date for the very first European Investigator Meeting for osteogenesis imperfecta (OI).

This virtual one day meeting will take place on Zoom on November 18th 2022 from 2PM-7PM CET (8AM-1PM EST).

OUR AIM

Our aim is to present an overview of current OI-research (basic and clinical) in Europe and beyond. Presenters will include both experienced OI-researchers and new investigators. The event will be a supplement and a follow-up to the 14th International Conference on OI in Sheffield in September.

TARGET GROUP

The target group is primarily researchers and clinicians working with OI, but anyone interested in OI-research can join.

CONFIRMED SPEAKERS

The following invited speakers have been confirmed:
Frank Rauch (CA)
Brendan Lee (US)
Nick Bishop (UK)
Oliver Semler (DE)

FURTHER INFORMATION AND UPDATES

For further information, please contact the event coordinator Ingunn Westerheim on office@oife.org

More information about the event will be published on oife.org

To receive updates about the event – sign up here!
Cardiopulmonary risks in adults with OI

Interview with Robert A. Sandhaus, MD, PhD, FCCP, respirologist at National Jewish Health in Denver, Colorado

Who are you & what is your relationship to OI?
I’m Robert A. Sandhaus, MD, PhD, FCCP, although my patients call me Dr. Sandy. I’m a respirologist at National Jewish Health in Denver, Colorado where I lead a team of physicians and researchers who care for and study genetic influences on lung disease. I’m also the Medical Director of three non-profit organizations serving patients with the genetic lung and liver disease alpha-1 antitrypsin deficiency, the Alpha-1 Foundation, AlphaNet, and AlphaNet Canada.

I became involved with the OI community in 2005 when the U.S. Osteogenesis Imperfecta Foundation invited me to join their board of directors to help set up their linked clinical research centers. This because I had accomplished a similar mission with the Alpha-1 Foundation. I was welcomed by the OI community and was asked to help update some of the OIF’s educational materials about medical conditions other than orthopedic issues. I had to good fortune of meeting Dr. Joan Marini at the NIH and she pointed me to some of the literature about lung disease in OI published by herself and others. I started to explore the pulmonary issues in adults with OI and realized that collagen defects in OI can affect the lungs as well as bones. After rotating off the OIF board of directors, I became a member of the OIF Medical Advisory Council.

From the beginning of my studies, it was apparent that the lung issues associated with OI were not entirely due to scoliosis and fractures. Even individuals without abnormalities of chest wall architecture, such as adults with mild OI, have abnormalities of lung function.

Who was behind the pulmonary project?
The chairperson of the OIF board of directors, when I first became involved with OI, was Jamie Kendall. She was a wonderful person, leader, and legal scholar. Several years later, during a routine medical procedure, she went into respiratory failure and died. Her family and friends set up a research fund to learn more about the medical and social issues associated with OI in adults.

One of the first recipients of a research grant from the Jamie Kendall Fund for OI Adult Health was the Hospital for Special Surgery in New York City. Led by Dr. Cathleen Raggio, this project focused on the quality of life, pulmonary issues, and cardiovascular issues in adults with OI. Dr. Raggio, an orthopedic surgeon, asked me to join the project to help in the planning, execution, and analysis of the cardiopulmonary components of this study.

What is the project about? When did it start and for how long is it going?
The beginning of this project stated in 2016 when I was contacted to put together an educational brochure (The Guide to Medical Procedures for Adults with OI), a project initiated because of Jamie Kendall’s death. Through that project, Dr. Raggio and I started discussing ways to evaluate the cardiopulmonary risks of adults with OI. The cardiopulmonary project took off from there. It’s designed to identify the causes and risk factors associated with heart and lung problems in adults with an OI diagnosis.

We’ve currently enrolled almost 50 subjects in the study and are continuing to accept new volunteers. We’re also expanding the number of sites at which the study will be performed thanks to additional funding from the Brittle Bone Disease Consortium (BBDC) and the OI Foundation.
**Which methods were used?**

Individuals who enroll in the study and sign an informed consent are asked to complete questionnaires that gather general information about their vital statistic, sleep patterns, general quality of life, and respiratory quality of life. They undergo fairly extensive testing including blood work, arterial blood gas, lung function testing, EKG, echocardiogram, sleep study, spinal x-rays, and a CT scan of the lungs.

**What was your research project about?**

- **Topic/hypothesis:** Our overall hypothesis was that there are abnormalities of the heart and lungs due to OI that are underappreciated by the OI community and physicians. One specific hypothesis was that lung issues in OI are not due to scoliosis and chest wall abnormalities alone. We also wanted to evaluate what challenges to quality of life existed in adults with OI.

- **Target group/participants:** This study is what’s known as a pilot study, meaning that we may not get definitive answers to some of the questions we have, but we can identify what areas to concentrate upon in future studies. We are enrolling individuals with OI who are 18 years of age or older and who agree to the procedures involved. Any participant can refuse any particular procedure with which they are not comfortable.

- **Special challenges/problems:** One challenge we’ve had is enrolling male adults with OI. The overwhelming majority of the volunteers who have enrolled in the study are female. One of the charges to the new study sites being added (University of California Los Angeles (UCLA) and Kennedy Krieger Institute in Baltimore, Maryland) is to focus on enrollment of men. In addition, most participants have elected to avoid the blood gases and sleep study. Finally, the COVID pandemic has made enrollment of the last two years to be quite difficult.

**What have been your most interesting findings so far?**

Among the most interesting finding thus far have been the confirmation that the abnormalities in lung function in adults with OI appear to be independent of the degree of scoliosis, suggesting that abnormalities in the lungs themselves, rather than the chest wall, account for most of the pulmonary issues facing adults with OI. There have been a variety of cardiac abnormalities identified in the subjects thus far, but no single heart issue that stands out as most prominent. Additionally, we found that while the overall quality of life of adults with OI was relatively normal in adults with OI compared with the general population, while the pulmonary quality of life was significantly reduced.
The most surprising finding in this preliminary study is that almost all of individuals studied so far have abnormalities of the lungs’ bronchial tubes revealed on chest CT scans. The most prominent abnormality is bronchial wall thickening. In other words, the bronchial tubes that carry air in and out of the lungs have thickened walls that can potentially impede the movement of air in and out of the lungs and impair clearance of inhaled particles.

Based on these findings, and thanks to the Jamie Kendall fund, we have added the possibility of taking bronchoscopic biopsies. This means removing pieces of bronchial and lung tissue via a flexible scope inserted down the windpipe, to evaluate the cause of this bronchial wall thickening.

**What is the most important take home message for clinical work?**
I believe the most important take home message from this study and my nearly two decades of work with the OI community is that OI is not only a bone disease. It is important for all with OI to have their lung function evaluated on a regular basis.

**Did you have patient involvement?**
The direction and funding of this program was entirely directed by the adult OI patient community.

The debate has been going for quite a while about Covid-19, OI and risk. There seems to be some disagreement between doctors in the US and Europe. But perhaps it is only due to the different ways of doing risk assessments and the large number of complications due to Covid in the US? Would you say that the findings you have from the project also indicate that people with OI type I with normal lung capacity and no scoliosis have a higher risk of complications of Covid-19? Or would you just say that we need more research to advice on this?

This is an important question. While we don’t have specific research to definitively answer some of questions, we can apply data we know from other genetic conditions that affect the lungs. We know from several lung-affected communities that the risk of becoming infected with the SARS-CoV-2 virus (the virus that causes COVID-19) is usually not increased by these various lung conditions. What is affected is the severity of disease in those who contract COVID. Looking at Alpha-1 Antitrypsin Deficiency, one of the genetic conditions that has long term data on infection, hospitalization, and intensive care unit (ICU) stays during the pandemic, we see that patients with this condition did a better job of protecting themselves from infection compared to the general population. But in those who did get infected, they were more likely to be hospitalized or spend time in the ICU.

I would suggest that the same is likely true for the OI community, especially in view of the widespread lung abnormalities identified in our study. Therefore, in the OI community it is worth being a step or two more cautious than the recommendations to the general public. Maintain that social distancing and mask wearing somewhat longer than the rest of the population and be safe.

**Do you have any final messages for the readers of OIFE Magazine?**
The international OI community is better organized than most of the rare lung disease communities that I work with. I believe this is because of the grass roots support and involvement by patients and their families. It has been a pleasure to work in this medical area. My acceptance of the invitation to join the board of the OI Foundation was one of the best decisions of my life.
**Dental implants in OI**

*Interview with Dr. Ole Oelerich, Dentist at the Department for Prosthodontics and Biomaterials, University Hospital in Münster, Germany*

Who are you & what is your relationship to OI?
My name is Dr. Ole Oelerich, I am a Dentist at the Department for Prosthodontics and Biomaterials at the University Hospital in Münster, Germany. After completing my doctoral thesis on oral health-related quality of life (OHRQoL) of people with Ehlers-Danlos syndromes under the supervision of Dr. Marcel Hanisch, I wanted to expand my knowledge and focus my research on rare diseases and their impact on oral health. My goal is to provide scientific data to other researchers and advance the knowledge of rare diseases, because I think knowledge is one of the most important steps to improve the treatment and detection of rare diseases.

Who was behind the dental implant & OI project?
The project began when a patient with OI Type I needed an implant-supported prosthesis in 2019 and turned to Dr. Hanisch for help. He was able to treat the patient with a great outcome, but found that data on dental implants for people with OI was very sparse. You can find the case report here: [https://doi.org/10.3390/ijerph18084169](https://doi.org/10.3390/ijerph18084169) He asked me if I would be interested in conducting a systematic review on the topic, so I started to work on gathering data in August 2021.

Which methods were used and how was it financed?
I conducted a search in three of the largest scientific databases to find all case reports or studies in which people with OI were treated with dental implants. After collecting all the studies, we systematically analyzed each report to find out whether dental implants can be a safe and reliable method to replace missing teeth in people with OI. The research received no external funding and was entirely self-funded.

What was your research project about?
Since OI affects bone density and quality, we expect dental implants to have a lower survival rate compared to individuals not affected by OI. In addition, it must be considered that the usual therapy with bisphosphonates may further influence the survival rate of dental implants. Implant survival is defined as when the implant has fully healed after insertion into the bone, has formed a stable bond with the bone, and a crown or prosthesis can be placed on top of it.

We found a total of 12 case reports that dealt with the treatment of people with OI with dental implants. In all these scientific reports, 46 people with OI were treated with a total of 116 dental implants. In daily dental practice, the survival rate of implants is about 98%. Our systematic review found an implant survival rate of 94% in people with OI. This means that of the 116 implants placed, only 7 implants failed to integrate properly into the bone and could not be used for a crown or prosthesis. The whole systematic review can be accessed at [https://doi.org/10.3390/ijerph19031563](https://doi.org/10.3390/ijerph19031563).

What have been your most interesting findings so far?
The main conclusion of our systematic review is that dental implants can be a safe and reliable method to replace missing teeth for people with OI and should definitely be considered by dentists.

Another interesting result of our investigation is the survival of all immediately loaded implants in the reports we found. This means that the implant receives a crown or prosthesis immediately after insertion and can thus immediately replace missing teeth.
Traditionally, implants were left without a restoration on them for the first months. Nowadays, more and more implants are loaded immediately, and it was nice to see that this treatment option seems to have great success also in people with OI.

**What is the most important take home message for clinical work?**
The most important message is that dentists should consider treating missing teeth with dental implants more often in people with OI. If they choose to do so, it is important that they publish their results to add to the available data on implant survival.

Of course, the individual risks must be carefully weighed in each case, but the data clearly show that dental implants can achieve great results.

**Did you have patient involvement?**
Our systematic review was solely a collection and statistical analysis of all existing articles dealing with dental implants for people with OI. No patients were involved in this part. However, we hope to assist dentists in deciding whether dental implants may be an option for treating their patients with OI with missing teeth.

**Do you have any final messages for the readers of OIFE Magazine?**
I am grateful for the opportunity you have given me to present our results, and I really hope that our research can help people with OI in the future when they are presented with the need to replace missing teeth. I will continue my research and hope that we can further improve the treatment of people affected by rare diseases.

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**Inclusion Project of Students with OI**

*Quote:*

“Dental implants can be a safe and reliable method to replace missing teeth for people with OI and should definitely be considered by dentists.”

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**Inclusion Project of Students with OI**

*Interview with Jessica Chemtov, Kinesiology student and Galil Osman, Occupational Therapy student; both at McGill University in Montreal, Canada*

We both came to learn about OI through our respective disciplines. We are research trainees of Dr. Argerie Tsimicalis who is an Associate Professor at McGill University and a Nurse Scientist at the Shriners Hospitals for Children, Canada.

**Who is behind the project?**
The Shriners Hospitals for Children (Canada), McGill University, Sunnaas Rehabilitation Hospital (Norway), George-Vanier School and Montreal School Services Center partnered on this project for a global view of the activities that children take part in throughout their school day and the adaptations and recommendations that could be made to optimize their schooling experiences.
How was it financed?
This project was financed by the in-kind contributions of each affiliation who permitted the clinicians to generate their time to providing feedback. Dr. Tsimicalis is personally supported by a Junior 1 Research Scholar Award from the FRQS. We are grateful to Tunis Shriners and Al Shamal for their ongoing support of research being conducted at Shriners Hospitals for Children – Canada.

Tell us a bit more about the tool itself!
This tool was created to ease the integration of the child or adolescent with OI into the school setting. This tool can be filled out by any healthcare professional who works in getting the child ready to go back to school. The final tool includes 16 sections supplying the student and school staff with a summary of the care the student should receive in all aspects of the school day.

Items included were: general information about the student, fracture response protocol, student inclusion recommendation, mobility considerations, transfer consideration, toileting protocol, physical education class recommendations, fieldtrip information, transportation considerations, evacuation plan, seating and scholarly considerations, consent and authorization forms and an annual renewal document. We show you an excerpt from the tool to highlight key features included in the school plan.

For example, there is a section about the student’s mobility requirements and a section for playground recommendations.

In addition, we have made a fillable PDF for the healthcare provider to individualize the program for the student as every child has unique needs when it comes to their learning environment.

What were the reasons for starting this project?
Rehabilitation specialists like physiotherapists and occupational therapists draft letters detailing recommendations for adaptations to the student’s schedule to optimize their learning environment. This tool allows healthcare professionals to share and communicate issues and solutions with the school in a more tailored and efficient way.

Do you think these recommendations are applicable also for other countries?
These recommendations are currently being translated into French for Shriners Canada. In addition, the recommendations are being translated into Norwegian by our partners on this project at the Sunnaas Rehabilitation Hospital. We will begin integrating the tool into practice. If others are interested in integrating the tool into practice as well, they may reach out to us. We are seeking to establish a process for evaluating the tool and welcome input from others.

Do you have a message for the readers of OIFE Magazine?
We welcome you to use the tool and do not hesitate to tell us what else is needed to optimize the experiences of children with OI.
The Quality of Life 4 OI conference took place online on February 12th and coincided with the 10th anniversary of the Foundation Care4BrittleBones. The six hour conference was very well organized and gathered more than 200 participants which included 55 speakers from many different countries. The opening session included introductory talks from the members of the steering committee in addition to overview talks about orthopedic surgery (by Dr. Franzone) and OI and medical treatment options for OI (by Dr. Rauch).

Parts of the conference was divided into parallel tracks which included: Key4OI, Hearing in OI, Teeth & Jaw in OI, Pulmonary function in OI and Basic science. The parallel sessions were planned based on the input from the projects Key4OI and Key4OIPlus. After the parallel sessions the insights from the survey on physical wellbeing of adults with OI were presented followed by a session on psychosocial aspects of OI. This included talks about an individualized school plan for optimal inclusion of students with OI, which you can read about on page 12-13 in the magazine. The session also included a very interesting talk about a multi-center study to evaluate pain characteristics in OI, by Mercedes Rodriguez Celin, who recently joined our Pain & OI project.

The abstract book can be downloaded here: https://bit.ly/3NslDpB. We have asked some of the participants to share their impressions and highlights from the conference with us.

**Mercedes Rodriguez Celin**
I am a pediatrician from Argentina with a specialty in Growth and Development. I worked for ten years at the Skeletal Dysplasia Clinic at Garrahan Pediatric Hospital, Buenos Aires. Since I moved to the US, I have been doing clinical research in OI at Shriners Hospital for Children, Chicago, for the last five years.

I enjoyed participating in the QoL4OI conference. The wide variety of topics presented and the cordial environment reflected the scientific excellence and the sense of community that was promoted. These characteristics are the perfect background for collaboration and teamwork.

I was impressed that despite the topics discussed being very different, the idea of having a multidisciplinary approach and building networks to improve the standard of care for individuals with OI, was present in all the sessions.
Ralph Sakkers
I work at a Pediatric Orthopedic Center and as a Coordinator of the Dutch national NFU-ERN center for children with OI. I was the first author of first placebo controlled randomized clinical trial with bisphosphonates in children with OI (Lancet 2004). I was also a co-organizer of the Key4OI project on outcome measurements and the first author of the Roadmap to Surgery in Osteogenesis Imperfecta.

I think the QualityofLife4OI-conference was a very well organized multidisciplinary conference with well-focused themes with the patient in a central position. The highlight for me was the interaction-cooperation with ERN BOND and EuRR-Bone.

Celine Disch
I am Celine. I have OI type 1 myself and I am vice-chairwoman for the board of Care4BrittleBones. I very much enjoyed the conference, from the preparations of the event to the reactions we received afterwards.

I love how all countries, nationalities and backgrounds came together to work together towards the same goal; improve quality of life for OI. For me, it was a great experience to moderate several sessions. The interesting talks and nice discussions were very valuable to me.

Jeanne M. Franzone
I am an orthopaedic surgeon at Nemours Children’s Hospital in Wilmington, DE, USA, where we follow OI patients and families from the prenatal period through the age of 35 years. I am the Co-Director of our Multidisciplinary Osteogenesis Imperfecta Program.

The QoL4OI conference in February 2022 was a wonderful virtual gathering of the international OI community. Many thanks to the tireless efforts of Dagmar and her Care4BrittleBones team for organizing such a tremendous event. Although it was virtual, the energy was palpable and the interactions were dynamic.

The interactions and collaboration for me were the highlight and the work that will come of these in the months and years to come. During the Key4OI session we discussed challenges of implementation in a constructive way. It was great to "see" such a great turnout. I can't wait for Sheffield in September 2022!

Lidia Zhytnik
I have OI type 1. And I am also a researcher and work as a postdoc in Amsterdam UMC on a project developing a therapy for OI. I am a member of OIFE MAB and the Care4BB board.

The QoL4OI conference was dedicated to the 10th anniversary of Care4BB. The conference gathered OI friends from both the research and patient community to talk about challenges, successes and concerns in our work. The conference became a platform for a fruitful discussion between clinical specialists, basic science researchers and patient advocates. And we expect initiation of many follow up OI projects in the upcoming months, which will strengthen our collaboration and bring us closer to our desired goal - improved quality of life for OI people all over the world.

I was very inspired by talks, research presentations and also by comments and feedback from OI people. How many dedicated people there are on both the patient and also professional side of the OI-community! How much willingness there is in our people to work together and improve our lives.

I would like to thank all participants and speakers, who joined the conference and who shared their knowledge and experiences. Also, many thanks to the Care4BB board and conference team who organized such a wonderful event.
New multidisciplinary OI-Clinic in Ghana

Interview with Justina Yiadom-Boakye, President and Founder of the Osteogenesis Imperfecta Foundation-Ghana (OIF Ghana)

Who are you and what is your relationship with OI?
I am Mrs Justina Yiadom-Boakye, a mother of three wonderful girls. My first child has Osteogenesis Imperfecta, also called Brittle Bone Disease. Having had this experience, having seen what I went through, I had the desire to set up a foundation and help other mothers of children with this condition.

What is the situation for children with OI in Ghana?
As with every child with sickness, they don’t have it all rosy. There is a challenge with raising nationwide awareness of the condition OI. Then again, management of such children at home and at some facilities poses a problem due to little or no knowledge about the condition and its management. Some OI children also die at the early phases of life from varied causes, especially pulmonary complications.

OIF Ghana works in collaboration with Cape Coast Teaching Hospital and most of the activities in terms of healthcare are centred around this hospital. For patients to receive health care from OIF Ghana, patients have to travel to this city from wherever they are to access healthcare. This is a major challenge for patients depending on the distance. Another major challenge is funding, as resources are limited, to help push objectives of the foundation for the benefit of the OI children we cater for.

Tell us about your new MDT clinic!
It’s dubbed the Osteogenesis Imperfecta (OI) Clinic set up in collaboration with Cape Coast Teaching Hospital. The team of specialists have been put together to ascertain and manage the psychosocial and medical needs of these children. We are in the first year and have already had the first edition of the clinic in January. It’s now established to be run on a quarterly basis per year. It’s a day clinic after which a round table discussion is done to discuss each patient and the necessary treatment modalities to be done.

Professionals involved are Consultant Paediatrician, Specialist Paediatrician, Specialist Orthopaedic Surgeon, Specialist Ophthalmologist, Specialist ENT, Specialist Dental Surgeon, Specialist Radiologist, Physiotherapist, Occupational Therapist, and Clinical Psychologist.

Alongside this clinic, patients are scheduled to have their bisphosphonate therapy, which is done a day before the clinic day.

As such, patients are housed privately and are transported to the hospital for their bisphosphonate therapy. They are taken back to the foundation’s facility and then taken back the next day for the clinic.
How did you establish it?
Having a child with OI, I have had the privilege of having medical care from Shriners Hospital for Children in Canada. Having observed proceedings as we were being attended to, I had the desire to replicate that in Ghana, my mother nation, having seen the effectiveness of having been subject to the system. Due to that, we had a lot of discussions with the leaders of the Cape Coast Teaching Hospital over a period of time. Finally, we were able to set it up and even have our first clinic in 2022.

How do you educate your new professionals in OI?
The foundation has international collaboration with sister western stakeholders like Shriners Hospital for Children, OIFE, OIF USA, Care4Bones and others. Through these contacts we established links for in service training for these professionals, especially towards the management of OI and its comorbidities.

How do you spread awareness about the clinic?
The clinic is yet to be publicised with plans to formally unveil it on Wishbone Day here in Ghana, publicising in on TV, radio and Internet nationwide.

Any messages to the OIFE Magazine?
I’m grateful for this interview to talk about this new initiative and I’m grateful to the team and leaders of Cape Coast Teaching Hospital, Cape Coast, Ghana for helping establish this initiative. It’s my hope that it stays, and I would also take this opportunity to make an appeal to the international community for funding to help push this initiative and help in its sustainability for the benefit of the OI kids we cater for.
Get to know Padrinos-OI!

**Who are you and what is your relationship to OI?**
My name is María Barbero. I am the mother of an already adult son who has OI. I was also the founder of the first Spanish OI site and the first Spanish-speaking OI network.

**Are you involved in OI-organizations?**
Although I am a Spaniard, as I have lived in Germany for many years, I joined the German OI organization early in 1995. I have also been a member of the Spanish OI organization Ahuce since 1996, where I presided the board from 2011 until 2013, and was able to act as a founding member of Fundación Ahuce, the Spanish Research Organization for OI. In 2006 I had the honor to be appointed as an honorary member of the Ecuadorian OI organization, FEOI. I have been the president of Padrinos-OI since its foundation in 2006. Padrinos-OI has been a supporting member of the OIFE for some years now, and I am its official representant there. At this point I am also the second delegate in the OIFE for Fundación Ahuce and for the national Spanish OI organization Ahuce.

**Tell us about Padrinos!**
As I said before, I was the founder of the first Spanish OI site and the first Spanish-speaking OI network. The site started functioning in 1997, and with the contacts I made through my website, from people from Ecuador, Perú, Cuba, Spain, México, Panamá, Venezuela, Brazil and Argentina in 1998 we initiated an OI mailing list which had members from most of the Spanish speaking countries which were connected to the world wide web in those early Internet-times. We had our first personal Spanish meeting during the international OI conference which took place in Montreal in 1999. Our list soon grew to be a very useful instrument of contact between OI families and the very few medical specialists on OI who would devote time to offer online insight and treatment tips. I would like to specifically mention Dr. Horacio Plotkin and Dr. José Ignacio Parra, who always answered consultations from their respective offices in Montreal/Omaha and Madrid, and who were the corner stone of our small OI community.

This mailing list kept functioning until 2010, when we moved to the more up-to-date form of a Facebook group. And through these channels, I had direct contact with country OI-organizations that made me aware of the acute treatment need of OI children and adults living in countries without a satisfying health infrastructure. To cope with these needs, in the year 2003, I initiated a private network of contributors among my friends and colleagues. Some of them offered their support to pay for the medical treatment of OI children in Ecuador and Perú. To increase the transparency of this growing private network, in the year 2006, with the help of some other engaged German and Spanish OI people, I founded in Germany the charity OI-Paten/Padrinos-OI, an official and legally constituted non-profit organization whose aim is to cover the medical treatment of OI people around the world.
We are a small charity that raises between 15,000 and 20,000 Euros a year. Therefore, we cannot pay for expensive surgeries. However, we are effective enough to be able to cover OI specific medicines (Pamidronate and Zoledronate, and clinical supplies) as well as orthopedic equipment in countries where these treatments would otherwise not be available for children and adults who couldn’t afford them.

**What kind of work is Padrinos doing?**
The work we do can be divided into three areas:

- We regularly cover the medical treatment for people with OI in the countries where we are active. These treatments take place in coordination with the local organizations. What we cover are mostly medicines (bisphosphonates, vitamins, and calcium supplements), but we also pay for the basic material needed to apply the treatments: needles, disinfection supplies, cotton, x-rays, blood work, bone densitometries. We also pay for physical therapy treatments.

- We provide people with OI with medical equipment: wheelchairs, crutches, and walkers.

- Our third special field of action is the organization of teaching surgeries and medical workshops on OI in third world countries. We send medical specialists to perform teaching surgeries that help the patients locally in their country and serve to teach surgeons and other medical specialist about the treatment of OI. In those cases, we pay for rods, x-rays, surgical material, for the transport of specialists who perform these surgeries and for the material needed for the patient treatment.

Regarding the countries we are active in, we have been working since 2006 without interruption with Ecuador and Perú. In a sporadic manner we have offered support in El Salvador, Honduras, Cuba or Panamá. We also develop individual projects to support treatment for single individuals in other countries. One of such projects is currently working in Nepal. We had one of those in Afghanistan (child is now happily living in the US) and in Turkey, Mongolia and Yemen.

**How is Padrinos managed?**
We have an extremely lean organization, with only five members in our board (president, treasurer, secretary and two speakers) and two more liaison members, who respectively sit in Perú and Ecuador. We also have some supporting paying members who support our activity but are not involved in the decision-making. And then we have sponsors that send us money, monthly or yearly, to cover the treatment expenses of the OI people we support.

The whole organization functions on a volunteer, non-paid basis. Our two members in South America inform us about the upcoming treatments and necessities to be covered in the local organizations. We regularly (bi-monthly) send money to Perú and Ecuador, and our counterparts there organize the treatment and send us the invoices, the pictures taken during treatment and the letters or messages from the OI people we help to treat.

For the countries where bisphosphonates are not available, we buy the medicines elsewhere and send them to our counterpart in the country. It is important to say that we always have a local counterpart who has a medical background. We work basically only with long established OI organizations, not with private persons. In case there is no
functioning organization in the country, we need an application from an interested party (parent or medical specialist) who does not only seek the interest of his own child, but who tries to help a group of OI patients. The counterpart in the country needs to make sure that a local medical specialist gets in touch with our OI specialists in Spain to get advice and medical protocols. We do not provide any kind of medical advice, and we only send medicines when the contact with a responsible medical professional has been made.

What have been the biggest challenges and successes?
The biggest successes have been our collaboration with local entities, like the FEOI, for the regular treatment of OI patients. Every three months at the beginning of our activity, twice a year now, with the new drug therapies. Also, I need to mention the organization of two teaching surgeries and conferences for medical professionals in Ecuador. These two events took place in 2006 and 2011 and there we could reach out to the medical professionals and take direct contact with children, adults and families we had been supporting since 2003. The medical events have constituted a before and an after regarding the OI treatment in Ecuador. Doctors from other South American countries also joined the conference to get an insight in OI from well-known international medical specialists.

We tried to do the same in Cuba in 2014, but the response from the medical side was not so satisfying. Nevertheless, through contact with the Cuban patient community, we got some very needed surgeries were performed. And those patients have had a much better fracture-free live since then.

Another big challenge was the attempt to organize a first Central American OI conference in Honduras in 2016. This was not possible due to internal problems with the local organization. We hope that this long overdue Central American OI Teaching Seminar can be made reality at some point in the future.

Are there any personal connections between the sponsors and the supported?
The main idea in the private network that originated in Padrinos-OI was to keep a personal contact between the sponsors and the families of the children and adults who were receiving the donations. This ended up being extreme difficult for two reasons:
• The private contact too many times led to high expectations from the families of OI patients. They would often misuse the contact to ask for further financial support for non-OI related issues.
• As the circle of supported OI patients grew bigger, it became increasingly difficult for our very small organization to keep the many sponsors informed about the individualized highlights of every patient. With over one hundred OI patients receiving medical care through Padrinos-OI, the number of letters, e-mails, pictures and emergency information that needed to be sent to the different sponsors grew exponentially and made it impossible to keep up with the personal contact. Especially since some OI children and adults have more than one single sponsor.

Now the collected funds we receive are not personalized for a concrete patient, but sent as a whole amount to the organization, that uses it to cover the general needs of all patients. The sponsors receive a yearly newsletter about the project with information about the work that has been done. We also have a small private Padrinos-OI Facebook group where we regularly post information about the treatments that take place. In case that a sponsor wishes concrete information about a child he has been sponsoring, he can address our local counterpart organization and ask for information on that person. The local families never get the private contact nor the information of the person who sponsors them.

How can people support the work you do?
For any information about financial support, you can write to padrinos@oife.org. We accept one-time donations, as well as regular financial support. As we are a legally registered charity in Germany, we can provide our donors with tax relevant certificates of donation.

The other kind of volunteering we could use would be somebody who could help us make an easy maintenance webpage for Padrinos-OI. We used to have one, which became obsolete some years ago, and we never had the time nor the skills to prepare a new one.

Have you worked together with OIFE’s Flying OI Experts Project?
Yes! We enthusiastically support the idea of the Flying OI Experts OIFE project. We have worked together both for our Ecuador Conference project as well as for the Cuba Medical Workshop project, and we had the chance to bring people from Honduras to the OI Conference in Lisbon thanks to the Flying OI Experts project. We could never have gone so far in our efforts to educate the medical community without the OIFE support, and I would like to underline that this is one of the most beneficial OI projects for people with OI who don’t have access to a solid health infrastructure. Bringing OI specialists to the countries where they are needed and having those specialists showing local doctors and medical personnel how to treat OI people is the most relevant action that needs to be performed, in order to consolidate effective OI treatment all around the globe.

Any message for the readers of OIFE Magazine?
Thank you for reading these words. And thank you to all of you that work to create a more informed, more proactive and healthier OI community worldwide!
Activists with OI: Giorgia Meneghesso

Who are you and what is your relationship to OI?
My name is Giorgia Meneghesso, I have type IV OI, with a little bit of overlapping genes with Ehlers Danlos. I am the regional representative of the Italian OI-association (As.it.OI) in Lombardia, and the third OIFE delegate for the Italian OI-organization As.it.OI.

What do you do as an activist?
As an activist I try to make people aware of ableism and all the discriminations it carries with it through my Instagram page giorgia_meneghesso Incantiamoci. I created this page years ago, to share contents as I am a singer. I’m also a singing teacher making singing exercises suitable for all body types, and I’m also concerned about accessibility of concerts venues. During the first lockdown in Italy, I decided to start conveying information about ableism and being an activist. I started being contacted by associations and other influencers. Last summer, I had the chance to participate in a festival in Italy called “Festival of the beautiful things” done by the Collective “Aware - resilient beauty”. I did different Instagram directs, on accessible tourism, the importance of language and of using the right terms regarding disability, on being an ally etc. Now I am proposing myself as disability consultant for schools, companies, associations etc. Soon my website will be online, and I will start a collaboration with my municipality.

Which topics are you engaged in?
Ableism is the root cause of all the other topics, so in the last months I’ve spoken about all of them. Recently I had the chance to do an interesting Instagram direct with a Vanity Fair Italy online journalist about sex and disability, maternity, and the double discrimination to which women with disabilities are subjected. We will continue this soon. After that, I have been contacted by other influencers involved in the fight for the recognition of invisible disabilities and we did an Instagram direct about this theme and about diseases like vulvodynia, or pudendal neuralgia. I am writing an article for a group of feminist disabled women, so in the future, my Instagram page might be focusing more on feminist topics and sexuality.

How or why did you get involved as an activist?
I grew up in a very discriminating context. I’ve always felt a sense of discomfort, and I’ve always thought the problem was me. I was taught by my family that I had a different body to be ashamed of, that I will not be able to go to the university, have a decent job, live on my own etc... Over the years I’ve understood that the problem was me facing a society that wasn’t offering me all the instruments I needed to live my life completely and to have the freedom to decide for myself. But I didn’t understand that this feeling was due to something that wasn’t depending on me. During the first pandemic lockdown in Italy, I had the time and the chance to study Disability Studies, which is a recent study discipline that analyzes disability as a social, political, historical and
cultural phenomenon. I started to follow different activists in Italy and all over the world. I thus became aware that the monster I had been fighting against during my whole life, has a name: Ableism. I studied a lot, and during the last year, I decided it was time for me to express my voice.

**What are you fighting for?**
I think that we will never be completely overcome ableism, at least in my lifetime. But many things are changing thanks to all the activists fighting all over the world. Change is also thanks to the opportunities of social media, that helps spreading information from activists. I believe that awareness, knowledge and sharing are the keys to the solution, and I am fighting to spread them.

**If you woke up tomorrow and the world had changed for the better - how would it look like?**
I think we are living in a very complex world, with so many facets, and that thanks to the social media we are becoming more aware of them. Our society is changing but we are still going through a period of transition. This will perhaps lead to a better world and a more evolved humanity with no need to ask for accessibility information, with easier access to health care, education, job careers, and in which also bodies like mine will be considered sexy.

**What can we as OI-organizations contribute with to make the situation improve?**
It will be useful to talk more about ableism. I realized that many disabled people do not know about its existence and do not recognize the subtle discriminations to which they are subjected. Many are accepting them passively, but at the same time, feeling that something is wrong. I am receiving messages in which people thank me for giving a name to their feelings. I therefore know that this is the right way to follow.

**And what can we do as individuals?**
We all have so many things to deal with in everyday life and we cannot fight against everything. Sometimes it seems as if we are fighting against windmills. I think the best way is to try to explain as much as possible to non-disabled people, to educate them, to be aware of the discriminations that are still existing and to explain to them how they can become an ally. This includes the easiest things as avoid parking in places reserved to the disabled and avoid using mental illness as jokes. It also includes understanding the difference between looking at a disabled person and considering him/her for what she/he is in reality, without pietism or heroism. And last but not least, to recognize and fight with us against violence and denied rights.
Sammi loves weird silly toys and takes whatever her current favorite is with her everywhere. She has OI Type III and uses a wheelchair. She has broken hundreds of bones from simple things like tossing and turning too much when asleep (when she was younger) or sneezing too hard. At the age of 11 she got the role of Esperanza Jimenez, a sassy little girl with pink glasses, on Netflix’s Original Series *Raising Dion*.

Please tell us a bit about Sammi!
Sammi Haney is 11 years and lives in San Antonio, Texas. She has Osteogenesis Imperfecta Type III (severe). Her hobbies included reading (“Warriors” Series about cats), playing video games (Minecraft), gardening and learning to crochet.

In what way is OI affecting everyday life in your family?
Sammi does Physical Therapy twice a week, so we have to schedule things around it. If we are going somewhere as a family, we have to preplan to see if everything is accessible for Sammi.

How did you discover Sammi’s talent for acting?
We really didn’t know she could act until we started to prepare for her Raising Dion audition for the role of Esperanza. She was able to quickly remember the script and had a unique way of bringing her sassy personality into the delivery.

Is Raising Dion the first project Sammi has been involved in?
Netflix asked Nikki Young, who used to work in casting, but was now the Entertainment Director at Morgan’s Wonderland if she knew any kids who were a good fit for the role of Esperanza. She recommended 3 kids, 1 of which was Sammi. Sammi had never acted before, but she was in a commercial for Morgan’s Wonderland. This is the world’s first fully accessible and inclusive theme park, which Sammi goes to.

How does OI affect Sammi’s acting career?
I (dad) read through all the scripts before they started filming and suggested changes for things that weren’t safe for Sammi to do. This could be picking up a heavy backpack, having multiple actors take her in and out of a car seat, or going really fast over gravel. And they changed and accommodated everything I mentioned to them. On the first day on set we found out that the normal transportation vans for actors were not safe for her to get in and out of, so we told Netflix we needed a special van with a ramp so she could wheel her powered chair into the van. And within 2 hours they had one on set and ended up using it in the show too. When Sammi is on set, they always make sure that they stop everything and clear a path for Sammi, so nobody carrying heavy equipment around, bumps into her. Netflix has been extremely accommodating, and we have always felt Sammi’s safety came first.
What was the scariest experience Sammi was involved in from her perspective?
The scariest part did not involve filming Raising Dion. She has a fear of long ramps. When she was younger, at water therapy, when Mom went to do something, Sammi snuck away and tried to go up a long ramp by herself to prove that she could do it on her own. But she ended up tipping over in her wheelchair. Thankfully she didn’t get hurt. Her trailer at base camp for Raising Dion has a ramp on it (which we think is safe), and for Season 1 she hesitantly did go up and down the ramp with help. For season 2 she was just too scared to even do it with help, so we would pick her up and carry her into the trailer.

Do you see Sammi as a role model?
We hope so. She is trying to break down walls and show Hollywood that people with disabilities have a lot to add to a show and should not be left out. When Sammi got the role of Esperanza, we were told by an ally, that people high up in the industry (I don’t know who) that knew about the role, said to this ally, “There is no such thing as a funny 8 year old girl who uses a wheelchair, you are going to have to get an 11 or 12 year old girl and have her fake using a wheelchair.” Sammi proved them wrong, and we hope she helps pave the way for many more actors with disabilities to prove others wrong. When people see people like them on the TV screen, they realize there is no reason they cannot do the same thing.

What are Sammi’s dreams/dream projects?
Sammi: I love the Star Wars universe, and especially the recent shows like “The Mandalorian” and “The Book of Boba Fett”. I would love to work on those shows or similar ones.

Do you have any messages for the readers of OIFE Magazine?
We need more people with disabilities representing us in the entertainment industry. For that to happen, we need to challenge the ableism still in the entertainment industry, but we also need more people with OI who dream about being in the entertainment industry, to pursue that dream and actually give it a try!
Yoga & OI

Report by Archana Ravindra Palahalli, President of the Indian OI Foundation (IOIF)

What exactly does yoga mean? Can anyone with OI practice yoga, no matter how limited their movement is? How can yoga help in everyday life? Archana, the President of OIFE’s member association in India, is affected by OI herself and has been practicing yoga for a long time. In the following report, she gives insights into the topic and talks about her positive experiences. She also has helpful tips for anyone who would like to practice yoga themselves.

Introduction to Yoga

Yoga is a holistic approach in bringing the body and mind to work in unison. It is both a science as well as an art of healthy and sound living. Yoga is effective to bring self-awareness, improve breathing and relaxing the mind through relaxation techniques. This can be achieved through regular practice of various pranayamas (breathing techniques), yoga asanas (yoga postures and stretches) and yoga nidra (deep relaxation) and meditation.

The word ‘Yoga’ is derived from the Sanskrit word ‘Yuj’, signifying, to unite to bring a perfect harmony between the mind and body, man and nature. Yoga originated in ancient India over 5,000 years ago. Patanjali, known as the father of yoga; 2000 years ago, authored several Sanskrit texts and systematised the practise of yoga. His documented work is called ‘Yoga Sutras’ allows us to follow his work with ease.

My experience with Yoga

I have OI type 4 and I’ve been practicing yoga for six years. Practicing Yoga helps me to handle my daily physical and mental stress along with keeping my body flexible to handle the challenges of OI. Yoga has enabled me to be mindful of my inner bodily sensations such as pain, discomfort and ease. Yoga brings awareness to your breathing, thoughts, anxiety, and concerns so you can work towards calmness.

Do you offer it to the members of IOIF?

We gently suggest Yoga practice to our members after consulting with their doctors. In the near future, we plan to conduct online gentle yoga sessions for those interested.

Which are the challenges?

OI affects individuals at different levels of severity. It is important to develop yoga practices modifying asanas to enable all OIers to practice at their comfort levels after consulting with their doctor. It is very important to practice with the guidance of an experienced and knowledgeable yoga therapist who understands the limitations of your condition.

How do you solve this?

The best and most beneficial way to introduce yoga to the OI community is through pranayamas, relaxation practices, or meditation.
What effects can yoga have?
Along with a relaxed, balanced state of mind, the psychological equilibrium is necessary for everyone in all different environments and situations. Yoga is one of the most gentle ways of developing awareness and calmness not just at the physical level, but also psychologically as well. The inner strength gives the innate capacity to handle pain better.

The different breathing exercises (Pranayama Yoga) helps with developing efficient use of abdominal and diaphragmatic muscles and improve the respiratory system. Good health equates to a better quality of life. The different yoga techniques aide in stimulating one’s psychological state and research has indicated that yoga and meditation have helped adults with reducing depression, stress, anxiety levels and posttraumatic disorders.

Any other important aspects?
Regular practice develops into better control and channeling of your thoughts. Strong discipline with yoga practice leads to better success to reach goals.

“Yoga is a light, which once lit will never dim. The better your practice, the brighter the flame”.
-B.K.S. Iyengar (Yoga Guru)

Get in touch!

PROFESSIONALS WHO WANTS TO WRITE ABOUT OI
Dr. Atul Bhaskar from India is one of the editors of the International Journal of Paediatric Orthopaedics.

Dr. Bhaskar has been commissioned to write a brief symposium on OI for the journal. And he has asked for OIFE’s help to get in touch with professionals who would like to write/or have already written about different aspects of OI. He says such a symposium has never been written in the Indian Orthopaedic Literature. Anyone can contribute an article 3-4 pages on the various topics:

- Genetics in OI
- Bone Biology
- Medical Treatment
- Surgical Treatment
- Rehabilitation
- Caregiver challenges
- Newer Frontiers
- Non-orthopaedics issues in OI patients and their management

All contributions will be duly acknowledged. If any authors from the international OI-community is interested, they should contact dr. Bhaskar as soon as possible: arb_25@yahoo.com
**News in brief**

**ERNs for Ukraine**
The 24 European Reference Networks incl. ERN BOND - European Reference Network on Rare Bone Diseases have created a resource page for patients from Ukraine, to make it easier for them to find expert centres and urgent expert care in other countries: [https://erncare4ua.com](https://erncare4ua.com)

**WILL YOU ATTEND THE ECRD?**
Registrations to attend the European Conference on Rare Diseases are now open! The conference is one of the biggest of its kind and a great place to learn what is going on in the rare disease community about research, registries, orphan drugs, patient engagement and much more. More info on [https://www.rarediseases.eu](https://www.rarediseases.eu)

**REGISTRY TRAINING COURSE**
Are you interested in becoming a patient expert on the topic of rare disease registries? Sign up for the 5-day EJP Rare Diseases training on Rare Disease Registries and FAIRification of data taking place in Rome, Italy on 26-30 September. Registration deadline: 13 April: [https://cutt.ly/QAUCetv](https://cutt.ly/QAUCetv)

**Survey on Pregnancy**
Do you think there should be more information or education on contraception & OI, on pregnancy & OI, on preimplantation genetic diagnosis (PGD), on breastfeeding or other issues related to pregnancy or family planning? Then now is your chance to tell the decision makers!

**News from Bone Research**
Pascale V Guillot, Associate Professor at University College London, investigates the possibility of exosome therapy for those living with OI.

Exosome therapy presents several advantageous characteristics compared to live cell therapy. Exosomes are not alive, and although they have the capacity to migrate to a variety of target cells, they are not engrafting in target tissues and not contributing to tissue formation. In addition, it is possible to engineer exosomes to direct them to specific target cell types and modify their cargo to deliver proteins of interest. Read more: [https://bit.ly/3IteGkx](https://bit.ly/3IteGkx)
The European Reference Networks including ERN BOND, is doing a survey in all the networks about which challenges people with rare conditions including OI face regarding pregnancy and family planning. Deadline: 15th April 2022. Link to survey can be found here in 7 languages.

NEW EMA INFORMATION SYSTEM ON CLINICAL TRIALS
The European Medicines Agency’s (EMA) Clinical Trials Information System (CTIS) has gone live as of January 31st. CTIS is the backbone of the Clinical Trials Regulation that will harmonise the assessment and supervision of clinical trials in the European Union. Sponsors, patients, healthcare professionals and the general public can visit the public Clinical Trials website at https://euclinicaltrials.eu/home

DATA SHARING - THE KEY TO PROGRESS
Experts in the field say that inadequate infrastructure for data sharing and international collaboration on research is the main obstacle to progress. Rare diseases are difficult to study as scientists must first find patients, who can only be found if they have been diagnosed. Yet, without sufficient research, many are not. However, if countries share data, then patients can be studied and effective treatments developed. OIFE is working on gathering information on where data on OI is being developed and how we can promote more sharing of data between European countries. Read this interesting article from Financial Times about the topic here: https://on.ft.com/3L377T8

GAELYNN ON BROADWAY
The ethereal vocals and soulful fiddle playing of Gaelynn Lea (artist with OI) have made her a rising star in America’s folk music scene. She has toured the country for the past five years and opened for The Decemberists and Wilco, but Broadway was never on Lea’s radar until she got an unexpected call from Tony Award–winning director Sam Gold. Would she be interested, he asked, in composing original music for his forthcoming revival of Macbeth, starring Daniel Craig and Ruth Negga? Of course she said yes. Read more here: https://bit.ly/3CXGn3E

TIPS & TOOLS
Maybe the inflatable shampoo bowl is a tool that could help people with OI who cannot easily transfer or are in bed due to a fracture? Check out the inflatable shampoo bowl: guidebook.ifopa.org/inflatable-shampoo-bowl
BBS/OIF/OIFE

Awards

Announcement and invitation to apply

The international osteogenesis imperfecta conference brings together scientists and clinicians from a wide range of disciplines, presenting updates on developments in scientific research, medical and surgical treatment options, and discussions around topics such as rehabilitation, quality of life, pain, mental health and service development.

The delayed 14th edition takes place in Sheffield, UK, on 30 August – 2 September 2022. The multidisciplinary nature of the conference provides a networking opportunity for specialists from many different fields including geneticists, internists, endocrinologists, orthopaedic surgeons, dentists, radiologists, paediatricians, physiotherapists, nurses as well as patient and industry representatives.

The Brittle Bone Society, Osteogenesis Imperfecta Foundation and Osteogenesis Imperfecta Foundation Europe are delighted to offer a number of awards to healthcare professionals and researchers working in a low-or middle-income country to come to the conference with all costs covered. The awards will be administered through the OI2022 meeting organisation.

Deadline for nominations: 25 April 2022

The Award

Award winners will be offered costs associated with joining the 14th International Conference on Osteogenesis Imperfecta, 30 August – 2 September 2022, in Sheffield, UK, including free registration, accommodation and travel.

www.oj2022.org
ICCBH
Maria Luisa Bianchi Award Winner

Congratulations to Aashima Dabas, from New Delhi, India, winner of the first ICCBH Maria Luisa Bianchi Award for a female working to improve bone health in children in a low or middle income country. Aashima will be presented with her award in Dublin at ICCBH.

3rd INTERNATIONAL SYMPOSIUM ON MUSCLE-BONE INTERACTION IN DUCHENNE MUSCULAR DYSTROPHY

Online meetings:
October/November 2022
Dates and programme announced shortly
Enquiries to jared.wong@glasgow.ac.uk.

ICCBH Bone School

www.iccbboneschool.org
30 JUNE – 1 JULY 2022
DUBLIN, IRELAND

Who should attend?
- Clinical paediatric, adult and endocrine trainees and fellows with an interest in bone disease
- Clinical and translational researchers

See the Bone School website above for more information

For further information please see www.iccbh.org or email us at iccbh@ectsoc.org
ERN-Workshop:
Translational Research on bone-impairment in rare diseases

The workshop is aimed at giving an update on translational research on bone impairment in rare diseases and bringing together experts and trainees to facilitate collaborations. The in-person event will take place over two days on June 9th – 10th at the Faculty of Medicine of Lyon in Lyon, France.

The workshop is open by prior registration and selection to senior scientists, senior physicians, postdocs, medical fellows, and PhD students who are employees of or affiliated to an ERN Full Member or affiliated Partner institution.

The training workshop is free of charge and consists of interactive presentations and discussions on different areas of interest. On the second day, a “meet the experts” session will encourage small group talks, exchanges, and networking.

Registration closes on March 27th.
Further information can be found here

OIFE Calendar
For an updated list of events & conferences - see OIFE's web calendar: http://bit.ly/36A6mw8

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