OIFE Magazine 2 – 2020

Special edition on psychosocial issues

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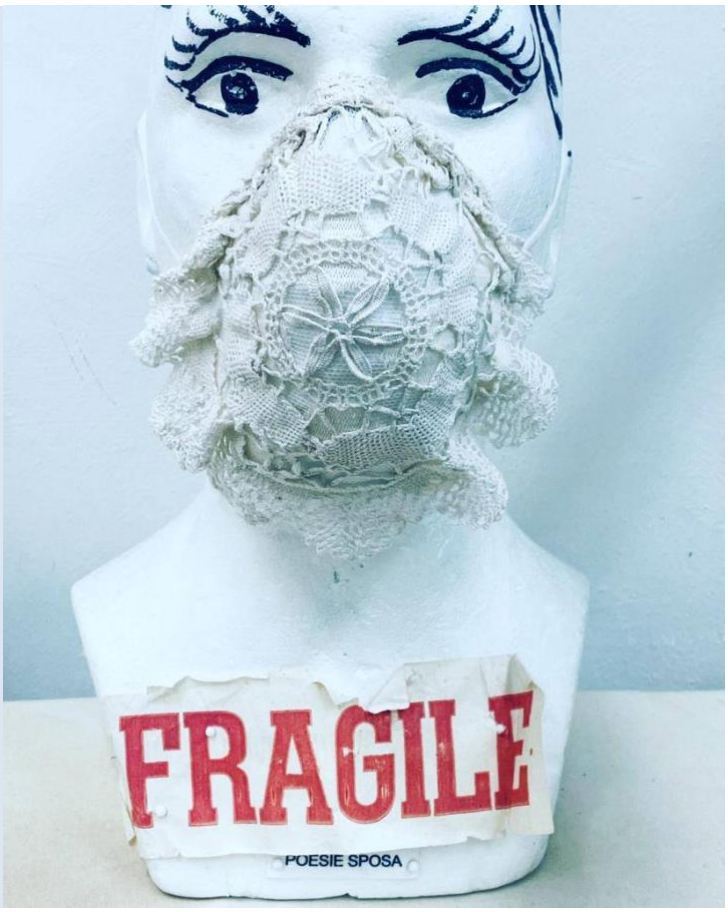

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It's a small world…

Fear is the path to the dark side, they said in Star Wars. Because fear can be used as a political tool to convince people to do their social distancing. But fear can also be destructive and cause anxiety. Especially for people who are part of the risk group of Covid-19. How tired we are of hearing that the virus is *"only"* dangerous for the elderly and sick! The artist Chiara Bersani from Italy wrote a blog about what kind of feelings these statements create. Check it out!

Unfortunately for people with rare diseases like OI, these are discussions we will have to endure the coming weeks and months. Because when are restrictions too dramatic? And what are the costs? Nobody knows. We are all moving in new and unknown landscapes, trying to adapt.

As the leader of an international organization it was both fascinating and scary to watch the situation develop so differently from country to country. What seemed unthinkable in one country (but not the other) was business as usual five days later. Dramatic changes from day to day. Hour to hour. "It's the end of the world as we know it." said R.E.M. How will the world will look like after this? We just know it will be different...

But there are also indirect positive consequences of the virus. The international OI-community has come together to help each other with advice, information and support. The OI Foundation (OIF) did a Q&A session with dr. Sandhaus and dr. Glorieux. And thanks to Zoom they were able to gather more than 250 participants from all parts of the world. Every Sunday evening, OIFE have invited people to "Virus Workout" on Zoom. Keeping active and doing some cardio is still important even if it has to happen in our own homes. But it's so much more fun to be active together! And laugh and joke a little as well, which is good for the mental health. Care4BrittleBones have invited people to virtual concerts, which has also contributed to keeping up the spirits.

OIF have also hosted a webinar about OI & mental health. One of the speakers were Kara Ayers – who is the coordinator of the network of people working with psychosocial health and OI. Some of you might have received an email about an "Expertise Finder Survey for psychosocial aspects of OI". It is issued by Care4BB and their goal is to improve quality of life of people with OI by learning about good practices, finding relevant research and identifying experienced professionals and patient experts interested in psychosocial issues & OI.

In fact, psychosocial issues is the main focus of this magazine, because the topic has been slightly ignored before. Maybe because people with OI have good coping skills? No matter how resilient we are, we all need some support from time to time. Especially in turbulent times like this, with a worldwide pandemic scaring even the toughest of us. My personal advice is to reduce the time spent on news and social media and use your time on something positive like volunteer work, hobbies, OIFE virus workout or virtual happy hour with friends or family.

If there is one thing that people with OI are good at – it's entertaining ourselves. Many of us have lots of practice from long hospital stays and time at home because of fractures. So we can do this! And with the help of Zoom & Skype – we can even do it together! Because it's a small world we are living in. For better and for worse. Stay safe everyone!

Kind greetings
Ingunn

What is the OIFE doing?

By Ingunn Westerheim - OIFE president

I can tell you about a lot of things we were *supposed* to be doing lately. But then COVID-19 came and turned the whole world upside down. OIFE volunteers are keeping busy anyway, by gathering information and hosting and attending virtual events in the OI-community, including webinars on COVID-19, Virus Workout and virtual concerts. OIFE AGM was planned for May 8th – 10th in Valencia, Spain. But the meeting has been moved to Zoom as many other meetings. We're still waiting to see what will happen with the OIFE Youth Event and OI2020 in Sheffield. Hopefully in a few months we will have more knowledge on how the situation develops. In the meantime - follow our blog on our **www.oife.org** for more recent news and keep following us on social media.

Meetings and events

All European meetings we were planning to attend between March and June have been cancelled. But most of the meetings have taken place in another format (usually Zoom). Videocalls in the last months have included meetings related to Mereo Biopharma, OI2020 in Sheffield and the planning of OIFE Youth Event in Poland. There have also been videocalls (VCs) with OIFE members, volunteers and members of OIFE MAB in addition to:

- EC-meetings on Zoom Jan 7th, Jan 21st, Feb 25th and March 17th
- Key4OI – final steering committee meeting, Jan 7th (IW)
- VC with Dr. Lena Lande Wekre about registries & real world evidence, Jan 24th (IW)
- Findacure Webinar – How to build an international patient registry, Jan 15th (IW)
- TC Cameron R. Penn (Board leader of OIF), Feb 27th (IW)
- VC Astri Arnesen, President European Huntington Association, March 10th and 20th (IW)
- Webinar Care4BB about plans for 2020, March 10th (IW)
- VC Pulse Infoframe March 16th (IW)

EURORDIS Events

EURORDIS 'Reframe Rare' Policy Event

On February 18th at the European Parliament, EURORDIS was relaunching the Network of Parliamentary Advocates for Rare Diseases, made up members of parliament (MEPs) advocating to improve the lives of the 30 million people with rare diseases in Europe. The EURORDIS 'Reframe Rare' Policy Event was held to mark the occasion of Rare Disease Day, the global campaign with events in 100+ countries around the world. Participants heard from members of the European Parliament (MEPs) who hosted conversations with patient representatives from across Europe including Rebecca T. Skarberg from OIFE, on topics including research and innovation, access to medicines, holistic care and cross-border health care and access to specialized care. OIFE Vice President Dace Liepina was also present as one of the participants.

Black Pearl Awards Ceremony

Later in the evening Rebecca T. Skarberg, Knut Erik T. Skarberg and Dace Liepina attended the Black Pearl Awards as invited guests by EURORDIS. Read more about this year's awardees and see a recording of the event here: https://bit.ly/2Ulyq3T

29th EURORDIS Round Table of Companies Workshop

On February 19th OIFE was again represented at an EURORDIS event in Brussels. Dace Liepina participated at the 29th EURORDIS Round Table of Companies Workshop "How to teach an old medicine new tricks – The importance of repurposing medicines for patients". The meeting is primarily for pharma companies, but also open for patient organizations. The workshop provided valuable information to its participants about repurposing of drugs including the STAMP initiative. From OIFE's perspective the workshop provided valuable insights as well as networking opportunities. You can read more and download the whole programme here: https://bit.ly/2QMndHb

EURORDIS Winter School

EURORDIS launched Winter School with the aim of deepening patient representatives' understanding of how pre-clinical research translates into real benefits for rare disease patients. The training equips participants with knowledge and skills so they are empowered to effectively participate in discussions with the researchers, policy makers and companies responsible for research or research infrastructures. The 2nd edition of training was planned held from 9-13 March 2020 in Paris. The event was moved to Zoom, and Claudia Finis from Germany represented the OIFE. The course covered topics including the history of genetics, diagnostics, new technologies in gene therapy and drug repurposing.

Paris Networking Event for the RDR Challenges Call

The European Joint Programme on Rare Diseases (EJP RD) brings over 130 institutions (including all 24 ERNs) from 35 countries. On March 3rd, Dace and Ingunn was supposed to attend a networking event in Paris related to the Rare Diseases Research (RDR) Challenges Call. We were particularly interested in challenge nr. 3 "Characterize Rare Bone Disorders (RBD) Mobility Challenges in Real World Setting" sponsored by the company IPSEN: https://bit.ly/2JcRrPg

The aim of the challenge is to develop full-body automated mobility assessment tool(s) to assess real-life mobility challenges in people living with rare bone disorders, to be compared vs available disease specific patient- and Health Care Professionals (HCP)-reported mobility assessments. Because of the increasing challenges connected to COVID-19 Dace & I decided to cancel our trip, but we have followed up with meetings on Zoom and TC with

- Dr. Luca Sangiorgi (Rizzoli Institute)
- Annabel Griffiths March 12th
- Sascha Fink, March 18th

Flashback from "Fragile Bones – Unbreakable Spirit?"

This is not the first time OIFE is concerned with psychosocial issues. Every third year, the OIFE organize topical meetings where professionals and people with OI come together to share ideas, learn about and discuss topics that have been neglected in the professional community. In 2012 we organized a topical meeting called "Fragile Bones – Unbreakable Spirit?" about the psychosocial aspects in OI. 55 participants from 16 countries came together in Lisbon, Portugal from October 26-28, 2012 to discuss issues like:

- Parenting / parenthood and the effects on non-affected siblings
- How to handle the fear of fractures?
- Partners, friendships and sexuality
- Achieving a positive self image
- Family tensions, overprotection, guilt
- Positive sides of life with OI
- Issues for adults
- Comparison between OI and other chronic diseases and healthy people
- Invisible problems
- Stigmatisation
- Support from within the OI community
- Social fear, fear of groups
- Pressure to achieve to your parents
- Letting go of your OI child
- Mental preparation for surgery

The abstract book can be downloaded here: https://bit.ly/2Jumwy4

On sexuality & relationships

"Can our association be a reference and listening point for pre adolescents, adults and parents of people with OI? We think so and thanks to our past experience both on our website and during our National Congresses, we experienced the importance to deconstruct our prejudices and concerns about sexuality thanks to comparison and meeting with people who told their stories and their lives that are unexpected and unique, as they are."

Alessandra Ciliberti

On stress related disorders

"*Considering the risk of anxiety disorders in populations with chronic medical illnesses and the unique symptoms of OI in terms of the recurrence of fracture experiences, proper treatment, prevention of PTSD symptoms in OI populations are necessary. Future research studies and methodology on PTSD identification and prevention among OI "sufferers" will be discussed."*

Katerina Kavalidou

To keep the momentum of this special edition, we will try to include one article/ contribution connected to psychosocial issues in every magazine from now.

Psychosocial network & patient centered outcomes research
Interview with dr. Kara Ayers

My name is Kara Ayers. I'm primarily connected to the OI community because I have OI (Type V) myself. My husband has OI as well and we were both fortunate to grow up with the benefits of being socially connected to others in our community. I completed my PhD in clinical psychology and focused my dissertation on the psychosocial aspects of growing up with OI. I'm completing my term as OI Foundation board member. I work in the disability field and serve on the Board of Governors for the Patient-Centered Research Outcomes Institute (PCORI).

One of the greatest advancements in the last decade of research related to OI, has been the recognition that much more than just our bones are impacted by OI. While not as heavily researched, more people are also realizing the psychosocial ramifications (both positive and negative) of our shared and unique lived experiences with OI. Just as psychosocial issues have often been overlooked in research, they are also sometimes overlooked in our treatment because acute issues, like fractures, surgeries, etc., seem to be more pressing needs. Psychosocial issues are also more variable and there's not as clear of a path for treatment. Some people with OI experience anxiety. Others may have difficulty managing their moods or struggle with fatigue.

There also seem to be positive aspects to growing up with OI, like the ability to repeatedly practice resiliency-building skills as we recover and relearn tasks over and over across our lifetimes. As a researcher, measuring quality or life or even coping skills can be challenging because OI is a unique and rare condition. As a community, some parts of the psychosocial experience have been unifying for some and dividing for others. Some people feel like descriptors like "unbreakable spirit" capture the fortitude of attitude and inner strength of people with OI while others feel like it's an unattainable expectation that further stigmatizes those who may feel at least temporarily broken. Better understanding our psychosocial experiences and deciding how we might best deal with them as a community is and will always be extremely complex. We are as vastly different as individuals as we are united as a community of at least some shared experiences.

One way we can begin to untangle this complexity is through the identification of psychosocial aspects of OI as important enough to be prioritized for research. Patient-centered outcomes prioritize the wishes of the patients in developing and carrying out new studies. The OI Foundation is exploring these priorities thanks to a grant from PCORI: https://bit.ly/2XbN0wn

This grant focuses on trying new ways to engage the OI community. Through this engagement, our community will determine what's most important to study. I'm eager to see if psychosocial issues are among those prioritized.

There's also international work in this area. Through a collaboration with Care for Brittle Bones, co-chairs Ute Wallentin, Claire Hill, and I are establishing a network of experts in psychosocial aspects of OI. The network aims to include professionals with and without OI and those who may not study OI but live with the condition and can provide rich information about the psychosocial experience. We'll leverage this network to build upon the work already done and identify new areas of research needed. If you'd like to contribute to the finder survey, complete the form here: https://bit.ly/39LOwYV

If you'd like to join the expert network but don't have time to upload publications, fill out the rest of the survey to be added to the group.

While we started these large-scale projects long before the COVID-19 pandemic, the relevance of understanding psychosocial aspects of living with OI seems more important than ever. Many of us are struggling with significant anxiety and greater isolation during this time. There's also hope in the growing number of connections I see beginning to form across my networks. For the last several weeks, I've looked forward to a weekend Zoom chat with a few of my close friends with OI from around the world. There are now ways to share a workout with other with OI from 12 countries! And there are educational opportunities for us to talk about mental health and self-care as adults with OI. It's my hope that everyone in our community can stay safe, healthy, and well during this time. Without overlooking the very difficult and frightening aspects of our shared experience, we can once again call on our resilience skills to carry us through together.

Kara B. Ayers, PhD - Kara.ayers@cchmc.org

Psychological Services:
Example from OIFE-Members AHUCE & Fundación AHUCE

How to handle anger, fear, guilt, sadness? Can I ever live an autonomous life? What about coping with pain and suffering? And how to find quick and professional help that is familiar with my condition? The Spanish AHUCE & Fundación AHUCE provides coping and adaptation strategies for psychosocial issues to people with OI. This free service is in Spanish language and open for all Spanish speaking countries. It can be carried out even via Skype!

Who is it for?

- People with OI and their families
- Professionals that require information and guidance

When is it necessary and useful?

- At the time of diagnosis
- Prior to hospital visits/surgery
- During consultations or hospital admissions
- In periods of convalescence
- In crisis situations
- In daily life

What kind of activities are carried out?

- Psychological care and scheduled consultations
- Training: workshops, presentations, courses
- Publications
- Networking: guidance to professionals, participation in rare disease groups
- Self-help groups for people with OI and their families
- Development of research project

AHUCE

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FUNDACIÓN AHUCE
Osteogénesis imperfecta

Laughter Yoga: Laughter is the best remedy

Laughter being the best remedy, has been scientifically proven in numerous studies. To laugh strengthens the immune system and the motion of the diaphragm massages the internal organs in a pleasurable way. Due to the intensive breathing process, that takes place while laughing, the body is increasingly supplied with valuable oxygen. Within moments your mood will improve. To receive the full health benefits of laughter, the Indian Physician Dr. Madan Kataria developed "Laughter Yoga" 25 years ago to implement and increase laughter in our daily life and schedule.

"Laughter Yoga" is a fun workout, which does not require any physical capability. It is therefore ideal for people with limited mobility in order to quickly and easily mend body, spirit and soul. I love self-determined laughter. Laughter is so enjoyable in a group but it is also possible and funny to laugh alone. For this reason, I developed an Online Course. The principle of "Laughter Yoga" is "fake it until you make it". Regardless of the circumstances, with "Laughter Yoga" you can directly influence your mood. Hoho Hahaha!

Susanna Patzel, OIFE-member from Austria
www.lachstern.at

Living with OI – Psychological consequences of OI

Increasingly people with OI and health care providers realize that living with OI can have an impact well beyond the physical. While everyone knows someone with OI who has struggled severely in a certain phase of his/her life, it often is not seen as an area that needs support.

This is why, Care4BrittleBones has funded a 2-year project looking into psychosocial consequences of OI in collaboration with the VOI (Dutch OI Association), the UMC Utrecht (expertise center for children with OI) and the Isala (Expertise Center for adults with OI) in the Netherlands.
You can read more about the project on this page: https://bit.ly/2V4yK5X

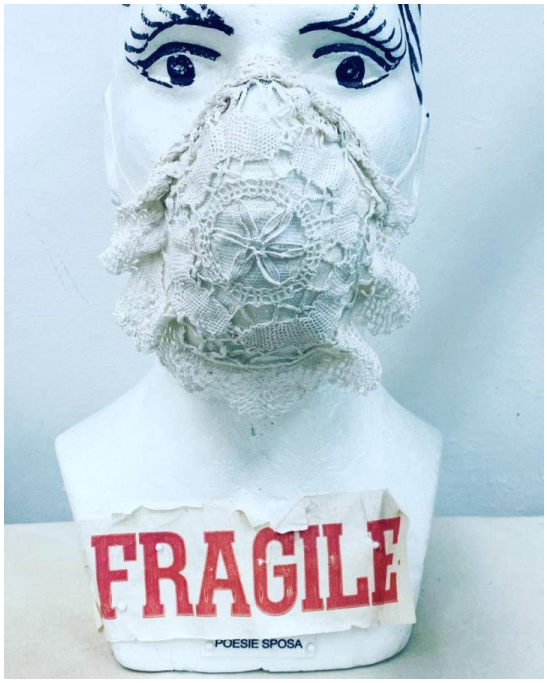
OIFE's resource page on OI & COVID-19

The OIFE will try to keep a dedicated section on our webpage updated with links to resources about COVID-19 and osteogenesis imperfecta. We have created a shortlink to this page to make it easier to remember. If you type in the following in your browser, you will be redirected to our resource page:

https://oife.org/covid19

Coronavirus and the toxic narrative of disability

By Chiara Bersani, Italy (translation Anna Rossi)



Every catastrophic film, every war novel, every graphic novel about dystopian futures is for me an opportunity for an imaginative exercise on my death. If you have been a kid with a disability and then a girl with a disability, to finally become a woman with a disability, then you have grown up with the request to remain rational.

During evacuation drills they teach you to stay in your place, not to hinder the escape of others and to wait for rescuers to come to save you. On the plane you will always be on the side of the window so that the people next to you can escape without having to step over you.

And no, you can't get angry. You can't even get too sad.

Emergency management is a science and you, aware of your physical condition, must understand that society is something complex and in every emergency the goal is to save the largest number of people who can then survive.

Embracing your limits is your duty, rejoicing in what you have, for the time you have it, is good practice.

Aiming for survival during a zombie epidemic would therefore be a foolish waste of time, better cultivating fantasies of heroic deaths in which your legacy will be the survival of your loved one rather than an entire community or group of children ...

Coronavirus: How to reinforce a toxic narrative?

Then comes the coronavirus and you live a few km away from that town that everyone talks about because it is the epicentre of the Italian version of the contamination. And find out that no, now that we are at that point all that exercise done in your first 35 years of life is not going well for you.

Dearest world, dear television, dear journalist, dear expert in the most disparate scientific subjects, however praiseworthy your attempt to say that the coronavirus Covid-19 is a disease that is only lethal only for a low percentage of the population, you every time conclude, by saying that I will die.

«Coronavirus is dangerous for weak people ... elderly people ... people with previous respiratory diseases ... cancer patients»

I didn't understand it right away. At the first interviews it seemed to me that their words calmed me too. Or maybe I just wanted to be comforted. Also be considered a subject to comfort.

But we are not. I am not, nor are the older people, nor the cancer ones. We, all of us, are the examples that comforts others. We are so when we are called to be examples of life, endurance and wisdom (read under ableism).

We are such when we are asked to accept the fatal percentage of an illness in our ranks.

After all, we live so far from the idea of immortality and so in confidence with that of death, that it will certainly not be a great effort to accept the role of borderline cases in a collective narrative aimed at not questioning the power of the healthy.

A wasted opportunity

This moment could be used in many ways. This virus, its easy movement in the world, could become an occasion to remind us that we are human and as such we are fragile. We could have accepted all together that we are not immortal, not only we weak subjects but also that 40-year-old who feels the eternal power flowing in his bones.

It would have been nice for once to seek a more noble sense in a truly special moment. Perhaps an enlightened precedent would have been created, perhaps caring for oneself and others would have truly occupied the center of the world for some time. And since I'm playing a fantasy game, I like to go further and think that perhaps capitalism would have trembled, seeing its fake immortal and performing bodies waver.

We would all have been fragile. And we, who have always known fragility, swear that we would take care of you. But none of this happened...

We could have sailed together. Instead each one remained anchored to its reef and collective reflection preferred the more immediate consolation.

Maybe I will get sick and if the TV happens, he told me that I will most likely occupy that small percentage of hopeless. So since I have been organizing death since I was a child, I decided to write this article. I won't be able to save anyone with my passing. And if it happens as they say, it will be lonely and far from heroic. But I want to tell you that while the virus sneaks around a few kilometers away from me, I read Laura Pugno who in her "In the wild" says:

"The savage is decided by us, it does not exist in nature, it is created when we close the front door, we define an inside and an outside (...) It comes by itself, from the wild, that it is dangerous".

Youth Colum: The art of being unhappy

By Stephanie Claeys, OIFE Youth Coordinator

Can we be unhappy or do we keep on with that unbreakable spirit which people with OI all seem to have? Why do we want to be so happy? Think about this with me for a while!

Imagine: you were a 2 year old toddler and your mother or father asks you to draw something simple like a tree on a piece of paper? Right, you grab a pencil and start to move the pencil over the paper making scratches while you look your mother or father into the eyes waiting for their affirmation…

How did your mother or father react? Of course she or he put on the high pitched voice and produced some words like: "Wow, what a nice tree you just designed! That's amazing!". Nothing on the piece of paper has the shape of a tree…

But that's what happened right?

We do this all the time towards toddlers because it makes them happy. And we as humans want to make others happy. Even if what they do is not good or correct.

Happiness is imprinted from the moment we start to communicate with each other. Since we are born: Baby don't cry, be happy! We believe that when we feel happy, we feel better. These days, everybody has a pressure to be very happy. We are all on social media, seeing how everyone else is so happy.

But to be honest, if I look around me, I see a lot of the opposite. Especially in the age group between 15 and 35. The ones who have spent their youth on social media. A lot of friends my age and even a lot younger are suffering from alcohol and drug addictions, depressions and burn-out. And it starts a lot earlier than it used to.

We all want so much. We want good grades in school, and good scores on the sports team, and the boy- or girlfriend who is the most popular and perfect parties!

When we graduate and look for a job, we want the best job we can get. With all the extra bonuses we can get, like a car, a phone and a laptop. We want flexible hours, so we can arrive and leave work when we can. And it goes on. To get that job, we need to search for a long time, and I see that young people just stay home waiting for that job to come along. Instead of doing something else which is not that perfect, we can't handle the fact that we would be a little unhappy with that temporary job.

Maybe, for young people with OI it's different? Because we have our relatively severe disability, we can't expect things to go so smoothly. Like finding the best girl- or boyfriend, or the best job we can get? We are resilient enough to fight against things that doesn't go so well in our lives.

Are we…?

In 2016 I was in Orlando, Florida attending the national American OI-conference. I was there with around 350 others with OI. I'll never forget the first evening when we did a "walk" in the hotel complex we stayed in. For me it was very weird to go out and shout about how great it was to have OI. I was a little bit shocked because of the enormous amount of other people with OI and the extreme positive approach towards OI.

But to be honest. After 3 days being there, hearing all those positive ideas about having OI, I started to believe it a bit. And I understood that it is a lot easier to cope if you can regard OI as a kind of a blessing. However weird that might sound…

So yes, it is possible that we can "get up again" more easily after a negative life experience than people without OI. Because we have learnt how to do it since an early age.

But when you have to do this many times during your lifetime, sometimes it all becomes too much. And then we have to be aware and allow ourselves and others to feel unhappy. It is not a blessing to have OI after fracture number 142 or so. OI can really be a pain in the ass, or let's say in the bone…

Maybe we need to learn the art of being unhappy in order to better understand our own feelings…?

MESSAGE FROM ORGANIZERS OF OIFE YOUTH EVENT 2020

We hope that you are safe and healthy.

We are looking forward to organize this amazing OIFE youth event in Krynica Morska, Poland, but due to this unstable situation related to pandemic of COVID-19, we cannot guarantee that it will come to happen.

We are waiting with any announcements until the 1st of June, 2020. If then, there will be possibilities to travel, book a ticket and organize international meetings, we will organize the best meeting ever. Let's keep our fingers crossed!

For this reason we are extending deadline to apply until 1st of June, 2020:
https://forms.gle/Jb7mqrK7GHjzjkj76

Let's wait patiently with hope!
Aneta, Karol & Piotr

How Apple Watch helps me stay healthy

By Jacob O. Wittorff, OIFE-member Denmark

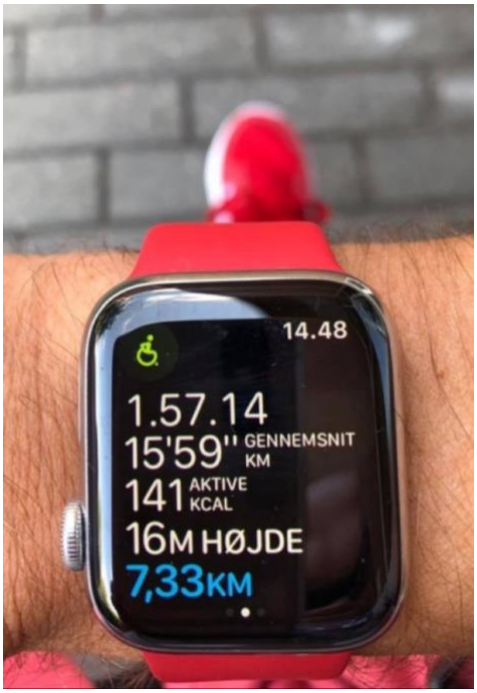
"Jacob Wittorff has called the alarm center after Apple Watch detected a bad fall."

That message lands late at night on May day 2019 on my parents 'and brothers' phones. Shortly before, I was pushed home in my wheelchair from the football cup final at the stadium. However, the evening comes to an abrupt end. I was slightly drunk, on my way through the rainy streets and I didn't notice the curb; suddenly my wheelchair is upside down. At the crash, I break one of the tibias and hit my head, but my Apple Watch instantly detects the fall, automatically dials the alarm center and sends the text message to relatives whom I have specified as contacts in advance.

Apple calls this fall detection feature, and it's available on the two latest Apple Watch models (Apple Watch Series 4 and Apple Watch Series 5). Fall registration is one of the reasons why I, as a wheelchair user, do not want to manage without my Apple Watch. I live alone in my apartment on Nørrebro, Copenhagen, and one of the things I fear most is that one day I fall and am unable to even get up or call for help. But I don't have that fear when I have my Apple Watch on my arm.

Special features for people in wheelchairs

Fall registration, however, is far from the only feature of the watch that can benefit wheelchair users. Since launching the first edition of Apple Watch in April 2015, Apple has equipped the watch with ever-increasing features that appeal to people trying to live an active life in a wheelchair.



For example, the clock will notify you if you have been passive for too long in the last hour. In the first edition of Apple Watch, the message read: 'It's time to get up and walk.' But as I said with a laugh to a friend when I got my first Apple Watch in 2015: "I feel a little like my watch is trolling me when I get that message".

By 2016, Apple launched a new approach specifically for people in wheelchairs. Now, in the Apple Watch app, you can indicate that you are a wheelchair user, and instead you will receive a message that reads, "It's time to wheel around." The message is a call to make you move and get your blood flow going. I use it myself as an opportunity to roll out and grab a glass of water or a cup of coffee as I sit in front of the computer at my work. If you use an electric wheelchair, you will hardly benefit from rolling a small ride, but you may instead see it as a call to do a few quick stretching exercises.

Special exercise programs
Apple has also designed a number of exercise programs specifically for wheelchair users, which I use myself when going around Copenhagen. The exercise programs for wheelchair users do not count steps but pushes you make with your arms. In this connection, the calculation for burning calories has also been adjusted so that it is now adapted for wheelchair use instead of walking, running or cycling.

A piece of advanced electronics
Apple Watch also contains some technology that you won't find in your phone. This applies, among other things, to the watch's heart rate monitor, which continuously measures your heart rate. It doesn't just happen when you exercise. It also measures your heart rate during the day. Therefore, in the Apple Health app, you can also constantly find your ongoing heart rate measurements, as well as your resting heart rate and your heart rate variance.

The clock also gives you alerts if your heart rate becomes very high without being physically active at the same time, and it also warns you if your heart rate becomes very low. At the same time, the two latest editions of Apple Watch also have a built-in ECG that enables the watch to take a cardiogram and thus identify irregular heartbeats. However, it is worth noting here that the ECG built into the Apple Watch has only a single built-in electrode, while the cardiograms made in the hospital use 12 whole electrodes located at different locations on the body. Therefore, Apple also emphasizes that the ECG meter in an Apple Watch cannot be used as a replacement for a professional ECG.

Helped me to better health
For me, over the past many years, Apple Watch has helped me take better care of my health. But if you are tempted to buy an Apple Watch, there are a number of things to keep in mind. First, the watch requires that you also have an iPhone. For example, if you have an Android phone, you will not be able to use the watch. In addition, you should also be aware that the fall detection feature only works if you have an Apple Watch Series 4 or the latest Series 5, and if you are under 65, you must also actively choose to turn it on in the provided app.

OIFE VIRUS WORKOUT EVERY SUNDAY

Are you stuck in your home because of COVID-19? Are you bored? Can't go to the gym or swimming pool? Don't worry, OIFE is inviting you to a virtual wheelchair aerobic session every Sunday!

Time: Every Sunday
- 18.00 Central European Time (CET)
- 12.00 Eastern Time (EST)

Place: ZOOM - https://zoom.us/j/944443892

The exercise lasts approximately 30-45 minutes. Make sure you have light weights/manuals available.

Join our Facebook-event and invite your friends as well:
https://www.facebook.com/events/649959332447113/
We have space for 100 people in our virtual gym - so first come first served!

A Question of Survival

By Ute Wallentin

"This is my last chance, I don't have any other choice to make. If I survive tonight, it is because of my lucky charm. And if not, I really don't care anymore". These were Qusai's thoughts on a stormy and rainy night on his escape from Syria. The young man with OI faced extreme fears, sufferings and pain. Ute Wallentin has been in contact with Qusai from the beginning and this is the story:

Qusai Al Rifai and I never met personally until November 2019 in Utrecht, The Netherlands where he now lives and studies. But we have known each other virtually for more than 10 years. We met on the internet. He described his situation and his activities working as a volunteer translator of scientific texts from English into Arabic. After that we kept in touch on email, and it was very exciting and heart-warming to finally sit at the same table together after so many years!

Qusai was born in Damaskus, Syria in 1986 and lived with his family, OI (and many fractures) and without any support from any kind of health system or government in an apartment on the 4th floor in the capital. He was forced to leave his country in 2010, 4 years after the death of his father and main carer.

First he went to live with his sister and her husband in Istanbul, Turkey. But when he lost his refugee status and residence permit there two years later, he searched for a possibility to flee to Europe, where he knew that OI treatment would be available. UNHCR tried to help him, but in the end there was no hope left to be brought to a safe country and the way back to Syria was blocked.

In 2016 we wrote about Qusai's dangerous escape from the Turkish coast to first Greece and the time there until finally the official resettlement from there to the Netherlands:
https://oife.org/docs/newsletter/newsletter30.pdf

Now I was very curious to meet him in person and interested to hear how he now lives in his new home country. It was so good to finally be together and talk sitting at the same table. And I am sure that this was only the first of many more meetings to come.

See you again soon, Qusai!

Ute

Artists with OI: Ditte Johansen

Can you tell us a little about yourself?
My name is Ditte, and I'm a 25-year-old woman, that is born – and still living – in Denmark. I'm working as a writer, and besides my ordinary and boring adult life, I'm filling my days with lots and lots of hobbies; I'm an actor, an author and "a public person" in some ways when the opportunity presents itself. I love having a lot on my plate, so I'm always busy, busy, busy!

When did you decide to publish a poetry book?
Well, that simply wasn't a decision I had to make. I'm born with a creative nature and an artist's soul, so writing has always been an innate interest. And if you love books and is writing yourself, it is my conviction that you will cross the poetry genre minimum once in your life.

How did you do the publishing?
Since I was 18 years old, I've tried to publish my stuff at all costs. But all the profiled publishing companies wouldn't touch any of my scripts even from a distance. I knew what kind of authors they wanted, but that wasn't me. And instead of changing my personal touch and risking to lose myself in the process, I simply gave up. My integrity has always been my first priority, so I just locked my scripts away in a drawer and forgot all about my dreams. Until the day, when my boss introduced me to one of her friends; a publisher who was only interested in poetry. So I took the chance, and he LOVED my script! And the rest is – well – history…

Why do you deal with psychosocial aspects and OI in your poems?
As I see it, OI and psychosocial aspects are just two sides of the same coin. If you – as a person with OI – are telling everyone that you can't acquaint yourself with some kind of psychosocially related problem, you're lying. Being different; being a minority will always create some frustrations associated with having OI, be in a lot of pain, etc. I wanted to tell an honest story from a disabled person's perspective. There's a huge lack of honesty associated with being disabled. The stories you'll probably find nowadays will generally be these nauseating heart-warming stories, that aren't even telling the (whole) truth.

What projects are you currently working on?
As I said before, I love having *a lot* on my plate, so I've currently got three projects that I'm working on. I just signed a new contract with my publisher for my next poetry collection, which will be a follow-up to my first one. I've also finished the English translation of my first book – "Puppet Infirmary". Both of them are getting (re)published by the end of the year. So all you English-reading people – there's a lot in store for you! Meanwhile I'm working on a novel, but that project may not happen for a long time. But it will come sooner or later. I'm stubborn and hard-working.

What role does the artist have in society?
I don't think that art should be art, just because it could be. Or that you should be an artist because you can. Art is like air – even though you'll never see it, you can't live without it. If society was a big vase, art would be the glue that's sticking all the broken pieces together over and over again. If we eliminate all kinds of art – the society would corrode and crumble away. Being an artist is an important job – maybe one of the most important ones, because you're the voice of other people. Whether you paint or write, you are channelling emotions through your book or painting, that they may not be able to express themselves. You're telling their stories for them, so to speak. And that's why artists are so important to society – because they're expressing all your personal feelings, even when you can't do it yourself.

Is there anything you like to tell our readers?
Please be honest, with yourself and with others! The stories you tell, may be other people's guidelines. And if what you say isn't true, you'll mislead them. If life is hard – tell them! If life is freaking awesome – tell them! We all have the responsibility to teach the next generations what life is about and how you live it. With or without OI - that doesn't matter. No one is satisfied with a soothing lie.

New OIFE Member: FOICH CHILE

Interview with Andrea Medina, FOICH President

FUNDACIÓN DE OSTEOGÉNESIS IMPERFECTA CHILE

Who are you and what is your relationship to OI?
I am Andrea Medina, founder and president of the board of the Fundación de Osteogénesis Imperfecta Chile, FOICH. I have OI for this my interest is generating actions that allow other people with OI to develop in their lives, just as I have. I am a journalist and I have a master's degree in communication from the University of Santiago de Chile.

How many people with OI does Chile have?
According to our register, we have 113 people with OI in the country. However, we estimate that there are more than 250 people.

Can you tell us about the situation for people with OI in Chile?
People with OI in Chile live a very different reality depending on their access to health, their economic situation and their place of residence. People who live in Santiago, the capital of the country, have more access to medical benefits and social inclusion, compared to people who live in other regions of the country.

Can you tell us about your organization?
FOICH was founded on December 18, 2017 as a non-profit organization. But we started working almost two years before. It was founded by seven people, of whom five have OI and the other two people are direct relatives of people with OI.

Our main objective is to generate actions for the social inclusion of people with OI, through collaborative work with family, professionals and other national and international organizations.

Our management is focused on the directory, which determines the actions and initiatives that are carried out, as well as the planning of the foundation.

How many members do you have? How do you recruit more members?
We have registered 113 people with OI, who participate in our actions together with their families. To incorporate more people, we ask that they sign up for our register, which has response options for people with OI and without OI.

What are the biggest challenges for your organization?
Our first and greatest challenge is to know the number of people with OI in Chile, to know where they live and what their reality is. Chile does not have official figures of people with OI from government organizations, so it is very important to be able to establish this number in order to trace the next steps.

Another important challenge is to create links with the doctors and institutions that care for people with OI, because the treatments differ from where they live and, in addition, the health services do not have a unified protocol for the application of bisphosphonate in people with OI. There are also problems of access to certain medical supplies, such as nails for operations.

Do you have projects you want to tell us about? What is your biggest success?
Our greatest success is knowing that there are at least 113 people with OI in Chile thanks to our Cadastre (database). This is a permanent initiative and we will not stop having it until we know of all the existing cases in the country.

The current reality of Chile has changed our projects lately. First the social outbreak (politicial protests) of October 2019 affected us in our plans to meet and now the Coronavirus Covid-19 is making us rethink our plans for this 2020.

What are your plans for the future?
We want to strengthen ties with doctors and health professionals to help us improve the quality of life of people with OI, as well as we want to take the necessary steps to incorporate OI treatment into the benefits of the Ministry of Health, to increase access to these and decrease their costs.

In addition, we have a big job to make OI visible in the country, so that the rest of the community becomes aware of our condition. Last but not least, we must continue to strengthen our FOICH community, in order to have greater ties between us in the whole country.

HEARING LOSS PROJECT IN CHILE
We are happy to inform you that our new OIFE-member Fundación de Osteogénesis Imperfeta are currently part of a project to investigate prevalence of hearing loss in people with OI in Chile. The first project on hearing loss & OI we have heard about for quite some years now.

News in brief

ERN BOND - FUNDING FOR RARE BONE REGISTRY

Good news from ERN BOND today. The European Commission has decided to support the development of EuRR-Bone - a European Registry for Rare Bone and Mineral Conditions. The OIFE is looking forward to working together with ERN BOND to make the registry as good as possible from the patients perspective. Read more on http://ernbond.eu/

RESULTS FROM SURVEY ADULT HEALTH & OI

The Adult Health survey done in the UK have had over 200 responses and the survey is now closed. The Medical Advisory Board of the Brittle Bone Society, which includes people living with OI and leading NHS healthcare professionals, have reviewed the preliminary findings which demonstrate significant care gaps around mental well-being and fatigue. They are now updating the BBS factsheets to cover some of these areas, e.g. 'Best Contraception for your Bones' and one for 'Hypermobility'.

COVID-19 WEBINAR NOW ON YOUTUBE

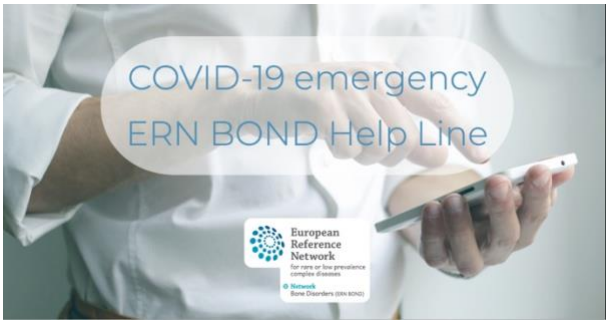
Did you miss the great Q&A webinar with Dr. Robert Sandhaus (pulmonologist) and Dr. Francis Glorieux about COVID-19 and OI? If you were not able to attend the call, please watch the recording here: https://youtu.be/QQmjtcaTO_Y

ERN BOND COVID-19 HELP LINE

ERN BOND - European Reference Network on Rare Bone Diseases has created a 24-hour Help Line for COVID-19. The purpose behind it is to give advice in cases where a person with a rare bone disease (incl. OI) has contracted COVID-19 or there is a strong suspicion that they have it.

You can contact the Help Line by calling or sending a whatsapp message to the number: (+39) 331 1728796

For now, the network is primarily for Italy (the country in which the emergency is most acute), but ERN BOND is encouraging similar helplines in other countries.



MULTIDISCIPLINARY OI-CLINICS

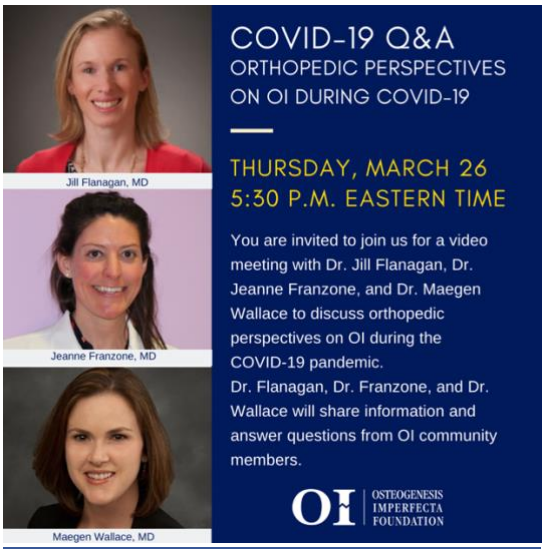
Every second Tuesday of the month for more than four years, the OI-community in Spain has gathered professionals at Sant Joan de Déu Hospital in Barcelona for multidisciplinary OI-clinics to evaluate children with OI. Professionals from different specialities (rheumatology, trauma, rehabilitation, social work, genetics, psychology) take part in the clinics including the pscyhologist from the OI-organization Ahuce.

COVID-19 MENTAL HEALTH Q&A
On Thursday, March 26 The OI Foundation hosted a video meeting to connect OI community members with Dr. Kara Ayers and Dr. Michelle Fynan to discuss mental health and self-care considerations during the COVID-19 pandemic. You can watch the recording of this session at https://youtu.be/I6TfpT_-OKE

Kara Ayers, PHD

Michelle Fynan, PhD, LMHC

COVID-19 ORTHOPEDIC Q&A
Jill Flanagan, MD, Jeanne Franzone, MD, and Maegen Wallace, MD joined OI community members to discuss orthopedic perspectives on OI during the COVID-19 Pandemic. Watch the recording of this video at https://youtu.be/ha1glBIgejI



TIPS & TRICKS FOR DAILY LIVING FOR CHILDREN WITH OI
Have you seen this webinar called "Tips & Tricks for daily living for children with OI" that was produced by Care4BrittleBones in 2019? If not, we recommend you to do so. Occupational therapist Kathleen Montpetit and Marie Elaine Lafrance from Shriners Hospital for Children Canada are sharing tips and tricks to support daily living for children and adolescents with Osteogenesis Imperfecta (OI). See https://bit.ly/2QTXrka

LECTURES FROM SEE, HEAR, SMILE
Did you know that most of the presentations from the topical meeting #SeeHearSmile are published on the OIFE webpage? You can download the powerpoint files through the link below:

1. OI-related hearing loss in OI overview (Freya Swinnen)
2. OI-related hearing follow up & treatment (Freya Swinnen)
3. Otological and audiological findings from the Danish study (Christer Swan)
4. Surgical treatment options of hearing loss in OI (Ulrik Pedersen)
5. Cochlear implant surgery (Gunta Sumeraga)
6. Inner ear deafness & OI – a solitary journey with a possible positive outcome (Diane Maroger)
7. OI & hearing loss – how does it affect quality of life? (Tamara Fernandez)
8. Hearing loss – psychological consequences & coping teqhniques (Hege Saltnes)
9. Hearing aids improve hearing and a lot more – what users report (Max Niebling)

See: https://bit.ly/2WQjTyE

CHECK OUT CRIP CAMP!

The documentary movie Crip Camp premiered on Netflix on March 25th. The film is about a summer camp for disabled youth in the Woodstock era. But it's more than that. It is also a film about a group of teenagers who kept in touch after camp and started the fight for disability civil rights in the US, which later inspired disability activists all over the world. It's one of the first documentaries produced by President Barack Obama and Michelle Obama.

TOOLKIT FOR ORGANIZATIONS

Take a look at the recently published toolkit on Empowering Leadership and Positive Organisational Governance created by the European Patients Forum.

It aims at strengthening patient organisations by enhancing leaders' leadership skills, which consequently enables positive governance in their daily work.
https://bit.ly/2wO0ZO9

OIFE Calendar

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

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