Editorial

HOW DOES OI IMPACT OUR LIVES?
A retrospective study of medical and insurance records from the USA indicates that health care costs for people with a rare condition have been underestimated and are three to five times greater than the costs for people without a rare condition. Why are we not surprised? Finding out more about direct and indirect costs related to OI, was one of the aims behind the IMPACT survey, which closed on September 30th. With the tremendous help of organizations and individuals around the world, we reached our ambitious goal of more than 2000 responses worldwide. The final estimate says 2278 responses from more than 65 countries! More cleaning of data is needed before we can announce the exact numbers of responses and people included in the survey. As you know, one survey response can hold information on several people. So who knows how many people are actually included!

Some of the leading OI-researchers are now analysing the data and planning scientific articles about costs in OI and other questions the survey will help us fill different knowledge gaps on.
The knowledge gaps include what kind of medications adults with OI are taking today, which professionals people with OI are seeing, what worries people with OI have, if children with OI have problems accessing schools and whether there are differences between countries regarding this.

If we know more about the health-related costs (hospital bills, medications, rods etc) and the indirect costs (time away from work, adaptations, mobility aids etc) - we as OI-organizations can work with policy makers nationally and internationally to compensate some of these costs in a better way.

The data from the IMPACT survey can also be used when new medicines and advanced OI-treatments (for example gene therapies), hopefully passes the risk/benefit evaluation in EMA/FDA and becomes an object of cost/benefit evaluation (so-called health technology assessments or HTA) in X and Y country. Is improved quality of life for people with OI worth paying for? Of course, it is! Let’s hope the national health authorities agree with us when the time comes.

But let’s not forget that having OI impacts our lives in many more areas than health care. Quality of life in OI is about more than medicines, rehabilitation, and access to treatments. It's also about living full lives in an inclusive society - irrespective of our visible or invisible disabilities, which might come and go.

Quality of life is about getting a job, getting friends, getting laid and about getting out of the house without having to face discrimination and ableism. These are important questions that especially young people with OI care about. They are not so into care pathways, drugs, health politics and access to genetic testing. And we totally get that. This is why we have made psychosocial issues and ableism the main topic of this magazine.

Focusing on psychosocial aspects is important not only for people who have OI themselves, but also for parents of children with OI (with or without OI), for siblings without OI and for the whole community. We hope you enjoy this magazine and encourage your friends and contacts to read it!

By Ingunn Westerheim, OIFE president

What is the OIFE doing?

Since the last magazine, there has been one big project taking the time and energy of OIFE and all our member organizations – namely the IMPACT survey. The survey closed on September 30th after we expanded the deadline a little. Before that, OIFE was represented at many national meetings to promote and explain about the survey. This included the BBS-conference, family meetings in Finland, Switzerland, and Austria, adult meeting in Norway and an Italian webinar. We were also represented by Anna Rossi and Julia Piniella at several Spanish online meetings both for Latin America and in Spain. The final official numbers from the survey are not ready yet, but the final estimate says 2278 responses! This includes many more individuals, since many parents with OI answered both for themselves and for their children.

The IMPACT survey was a unique project which truly brought the OI-organizations around the world closer together. The OIFE EC would like to thank each and every OI-organization that contributed. Thank you to the OI Foundation, to Wickenstones and to Mereo Biopharma and Ultragenyx for your collaboration! And last but not least, thank you to every single person who shared your experiences, who spread awareness, who recruited, checked translations and who motivated other people to join. You are all amazing and we are so proud to say that the international OI-community have made an impressive and long-lasting impact together. Hopefully we will see the positive effects of this effort for many years to come.
In addition to activities and meetings connected to the IMPACT survey, we have had meetings with
different stakeholders and new collaborations have been established. More than ever is going on in OI-
research and the OIFE is getting more and more requests to provide support and input from the patient
perspective to different projects. Some projects and companies we contact ourselves, but more and
more stakeholders find us first, because we are more visible as the umbrella organization for OI.

Besides project meetings connected to the IMPACT survey, Rare Bone Mobility, XLH & OI, Pain & OI and
OIFE 2.0. these are some of the online meetings we have attended since the last OIFE-magazine:

- EC-meetings, June 8th, June 15th, July 5th, Aug 18th, Sep 21st and Oct 19th
- VC about the OI variant database, June 3rd (IW, TvW and Lida Zhytnik)
- EuRR-Bone Patient Plattform (IW, TW, RTS and Claudia Finis), June 7th and Sep 20th
- TOPAZ PPI Webinar, June 8th (IW and Patricia Osborne were speakers)
- EURACTIV webinar - "How to address the unmet needs of rare disease patients by transforming
the European OMP landscape", June 11th (IW)
- VC ICCBH & OI2020 – Janet Crompton, June 15th and Aug 16th (IW)
- Introduction meetings Sanofi, June 15th and July 1st (IW)
- Steering Committee meeting IMPACT, July 7th (IW and TvW)
- Findacure HTA webinar July 8th (IW)
- The MONITOR project, July 15th (IW)
- Clinical trial research update Ultragenyx, July 17th (IW)
- Programme committee, OIFE Investigator Meeting, Aug 27th and Oct 20th (IW)
- The Economist “Leaving the darkness, Tackling rare bone diseases”, Sep 22nd (IW)
- Key4OI Update Sep 28th (IW and more)
- Findacure, Webinar Measuring Quality of Life, Sep 30th (IW)
- EURORDIS Council of Federations WS led by OIFE & EHA, Oct14th (IW)
- Introduction Castle Creek Biosciences, Oct 18th (IW)
Our Annual General Meeting (AGM) 2021 took place on Zoom on June 19th. It was divided in 2 parts – the formal business part, for the OIFE delegates and part 2 “OIFE projects and collaborations” which included:

- Prelaunch of the IMPACT survey
- News from research (BOOSTB4, TOPAZ, SETRUSUMAB, EURR-BONE etc)
- OIFE projects & future events

In the second part, both delegates, OIFE MAB, clinicians, researchers and collaborators attended.

SAVE THE EUROPEAN HEALTH NGOS!

Large European health NGOs like EURORDIS and the European Patients’ Forum play a pivotal role in advocating for and communicating the needs of the most vulnerable in society, whilst continually pressing for greater action in health policy at the EU level. EURORDIS has been an invaluable support for OIFE both in policy work and educational activities. This is why the OIFE totally support the campaign #SaveEUHealthNGOs to restore the operating grants for health NGOs in the EU budget. We need EURORDIS and the health NGOs more than ever!
ORPHAN DRUG POLICY CONFERENCE

One June 11th OIFE attended a conference about European regulations on medicines for rare conditions (orphan drugs). The European Expert Group on Orphan Drug Incentives (OD Expert Group) started its work in 2020, bringing together representatives of the broad rare disease community. The group developed a report with 14 policy proposals with different ideas on how to address the unmet needs of rare disease patients by evolving the European orphan drugs landscape from research to access. The experts presented their recommendations in the light of the review on the EU legislation for rare diseases. Please contact president@oife.org if you are interested in the policy document or more information about the meeting!

HOW TO FILL THE KNOWLEDGE GAPS IN OI

On September 14th the Brittle Bone Society (UK & Ireland) organized their annual conference online. OIFE was represented by Ingunn who gave a talk together with Dr Laura Tosi and Tracy Hart from the OI Foundation (USA) on how we can fill the many knowledge gaps we have in OI. The goal of the talk, was to explain how people with OI and parents of children with OI can contribute in different ways to filling some of the many knowledge gaps in OI, that makes it hard for clinicians and organizations to answer questions from the community:

- By taking part in natural history studies
- By taking part in clinical trials in OI
- By answering national and international surveys, like the IMPACT survey and similar
- By signing up for registries like the contact registry in the US and the RUDY study in the UK
- By contributing with patient reported data (PROMS) when visiting OI-clinics

Without the input from the patient community the clinicians and OI-organizations, will keep struggling to answer most of the questions from patients and members. We are aware that survey fatigue is a real problem, and we need to deal with it. Unfortunately, surveys are one of our main ways to wisdom, so we must find ways to make them less annoying. We also need to explain better how answering surveys will benefit each and everyone in the long run. You can watch a recording of the talk on OIFE’s webpage.
HEALTH TECHNOLOGY ASSESSMENTS (HTA) - WHAT IS IT?

OIFE have attended several educational webinars organized by Findacure on the topic health technology assessment (HTA). We try to summarize what we have learned below.

The IMPACT survey had several different purposes. One of them was to have better and bigger data for something called health technology assessments (HTA). This is a process where the authorities in a country look at the cost/benefit of paying for a new drug/surgery method versus continuing with existing treatments (if such exist). As you probably know there are many different treatments being investigated for OI at the moment. Some are in in a preclinical phase (animal research) and some are in clinical trials (where people take part in the trial): Stem cells, gene therapy, setrusumab, romosozumab and more.

When these potential new treatments hopefully reach the national approval processes in your country in the future - we will need data/documentation about the current situation for people OI, preferably for each and every country. We need data on what the physical and mental challenges for people with OI are (quality of life), how much we use healthcare services, which treatments we use today and how much we pay out of our own pockets for mobility aids, treatments, hospital visits and what kind of costs are covered by the welfare systems nationally.

WHY AND HOW TO MEASURE QUALITY OF LIFE IN OI

On September 30th we attended a webinar organized by Findacure, which explored ways to measure quality of life in rare diseases for the purpose of health technology assessment (HTA), and the ways patient organisations can get involved in the process, depending on the country they live in.

The webinar covered different kinds of tools to measure quality of life in OI (for instance pain scales or more general questionnaires like EQ-5D). They also explained that some rare conditions feel that the standardized tools are not relevant for their conditions and end up developing their own tools. This is however a very complex and costly process. Especially if you want the new tools scientifically validated and available in different languages.

One of the goals behind the project Key4OI initiated by Care4BrittleBones was to evaluate which tools would be most useful to measure the quality of life in people with OI and also suggest some standardizations. The project recommended a set of outcome measures to use in clinical work and research instead of developing disease specific measures.

One of the points from the webinar, was that HTA can also be a very powerful advocacy tool. Quote from an HTA agency: “When we are partnering with patient organizations in the early stages, we want them to understand that this is an opportunity for you to highlight the needs of your patient community, the policy priorities, things you need to change in terms of standards of care, where research needs to go for your group and how the research community should be thinking more broadly about your condition.”

These are some of the reasons why we need bigger and better data in rare conditions like OI.
WE NEED A EUROPEAN ACTION PLAN TO SOLVE THE CHALLENGES OF ERNS!

On October 19th Ingunn Westerheim represented all the rare disease patient organizations at a panel debate called the Patient Bio-Forum. This edition of the forum focused on the challenges and opportunities of the 24 European Reference Networks (ERNs). The panel consisted of experts representing patients, industry, EU and Member States. The entire panel agreed that the ERNs is a good and unique concept, but that there are different kinds of challenges that must be solved, before patients can have true access to expert advice in all European countries. Some challenges can be solved within each and every ERN or with improved national implementation, but other challenges need an overarching approach on a political level.

Our opinion is that a new European action plan, could be a good tool to address some of these overarching challenges. OIFE therefore supports EURORDIS in their call for a European action plan on rare diseases. Read more about the campaign #30millionreasons through this link!

Save the date OIFE investigator meeting 2022

SAVE THE DATE – 1st VIRTUAL OIFE INVESTIGATOR MEETING
November 11th 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 11th 2022 from 2PM-7PM CET (8AM- 1PM EST).

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.

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

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!
Meet the OIFE delegates

Teresia Harri, Finland

Who are you and what is your relationship to OI?
I am Teresia Harri and I’m the Finnish delegate for OIFE.

In what way does OI affect you personally?
I have OI type 1 myself. Its mild in my case, but still I have pain, more injuries and bruises and problems with seeing and hearing. On the other hand, it has given me strength and taught me to survive through almost anything.

In a few words - tell us a little bit about the organization you represent
The Finnish OI Association has around 300 members and the organization is entirely run by volunteers. The next activity is going to be the “little” Christmas party, which is popular party in Finland. It is celebrated around one month before Christmas.

What do you do when you’re not doing OI-work?
I am working as a research associate in finance. I also study cultural management. In my free time I do everything that is related to theatre; acting, producing and I’m also head of one small volunteer theatre. I also have a dog called Piki so I take that to walks, go to gym and if I have any free time left I like to read.

If you were the OIFE president for a week, what would you do/change?
I would like to arrange a big conference for the whole week for all OI people to attend.

In your opinion - what is the most important job for the national organizations?
I think it’s important to improve OI health by organising different courses, training, networking events etc. And we also need to educate the healthcare professionals to really know about OI so they can treat OI people more efficiently.

In your opinion - what is the most important task OIFE should focus on?
I think the Impact Survey was really good to start with, so we really get information on OI and in what different ways it affects people with OI. Improving knowledge is the main task that OIFE should focus on.

Do you have any other messages for the readers of OIFE magazine?
I’m glad to be part of the OIFE community. And hopefully the times will get easier, and we will meet in person soon!

Dana Andrei, Romania

I’m Dana Andrei (36) and I have OI, probably type IV. I never got tested. I’m still waiting and hoping for a testing program for rare diseases, free of charge! I live in a small town in the south of Romania and, I must confess, I find it pretty challenging most of the time, feeling frequently that OI is not my only disability.

I’ve learned to live with OI since my first fracture, soon after my very first steps. Same like in probably everyone’s case, OI took control of my childhood and wasn’t a year passing without at least one
fracture. How many? I couldn't say, probably around 20. I stopped counting after a while. I'm a wheelchair user from around 11 and the number of surgeries exceeds the number of fractures, possibly reaching 30. I haven't counted them either. I always have a bitter smile when I come across the saying "the diagnose doesn't define me". I don't know about others, but for me, OI remains the base of all the things I've done or couldn't do, of all my insecurities, fears, struggles but also of my small achievements. Everything started with OI and have been influenced by it along the way.

I'm a member, volunteer and Facebook page manager of The Romanian OI Association "Fragile People" since 2018. That year I received the invitation from the president of the association to be one of the two delegates on the OIFE AGM, in Dundee, Scotland. I knew almost nothing about the OI world and the people committed to improve the lives of patients with OI. It was an overwhelming experience for me, but at the same time an inspiring and motivational one. I came across the our national organization through a reply from the OIFE social coordinator Ute, a few years earlier. She informed me of the organization's existence and gave me the contact details. So, I have to thank the OIFE for being a part of the community today.

In Romania we are around 20 members, all volunteers, together with two of the founders, with a database of 60 people (The Impact Survey helped me to add 5 more!). Our ongoing activity is focused on the transition from children to adults, trying to find specialists and make the national program for children available for adults too.

As strange as it might sound, my main and most important education is to be a patient in a Romanian hospital, for so many years. Unfortunately, after I graduated high school in mathematics and computer science, OI kept me pretty busy. I was having too many complications in my surgeries process that stopped me from following the same path as my colleagues, going to university. My last surgery was in 2016.

When I'm not doing OI work, I am a part-time assistant analyst in an audit company, I've tried the full-time programme but I realized I don't cope too well with fatigue, high workload and stress. It's probably related to OI.

I am passionate about art and design in many forms, especially interior design and graphic design which I practice from time to time for some websites and I like to consider myself a handmade artist, with more than 10 years of experience. In my free time I always play with all kinds of threads and beads using many knotting technics.

I'm not sure I can picture myself being the president of OIFE for a week. I'd need at least one month to be Ingunn's shadow before I could even know where to start or what to do. But it would certainly be as full of responsibilities as an honorary job! Congrats to Ingunn for keep doing it with so much passion!

Besides advocating for the community there are so many challenges for the national organizations, things to deal with and others to be done, maybe too many: dealing with the lack of resources, recruiting volunteers or raising funds, struggling to make treatments available for patients...and these are only a few. For us, by far, the most difficult is finding specialists who is willing to deal with OI adults, in every area of expertise.

I'm not sure I'm in the position to advise OIFE who's already doing so much for the OI community around the world. Personally, I think the adults' field is the most in need of improvements. Sharing every country's achievements about adults with OI would give others examples to follow or having at least a subject to discuss.

I'm really happy to be part of this beautiful community, the feeling of belonging and staying updated on OI is really helping me. And the fact that I can bring some contribution to the organization, gives me even more satisfaction. Stay safe and healthy and keep making the most out of your condition with the resources you have! I know, I will do my best!
Almost five years as an ePAG in ERN-BOND

Interview with Rebecca Tvedt Skarberg, member of European Patient Advocacy Group (ePAG)

The European Reference Networks (ERNs) are 24 virtual networks involving healthcare providers across Europe. They aim to facilitate discussion on rare diseases that require highly specialised treatment. One of these networks is the European Reference Network for Rare Bone Diseases (ERN-BOND).

ERN-BOND has selected osteogenesis imperfecta, as an area of focus, to understand the common challenges in diagnosing rare bone diseases and to provide recommendations for improving referrals, reducing diagnostic errors and shortening diagnostic delays. In February 2018 a White Paper on OI was presented at the EU Commission to present the existing challenges of diagnostics in OI.

Rebecca Tvedt Skarberg from Norway is a patient representative in ERN-BOND. She was suggested to BOND’s European Patient Advocacy Group (ePAG) from the OIFE and is now a member of BOND’s Steering Committee. She is also represented in many of the 10 working groups of ERN-BOND.

Who are you and what is your relationship to OI?
My name is Rebecca Tvedt Skarberg. I am 46 years old and live in Oslo, Norway. I have OI type 3 and I have had about 100 fractures. I have a small stature and use a wheelchair to get around.

How long have you been ePAG in ERN BOND?
I actually became involved in ERNs before they were «born». I took part in writing the application to form the network and was part of the establishment process. Inês Alves, from the achondroplasia community, and I worked together with rare bone specialists in Europe on setting up the network. EURORDIS held an ePag election in 2016 where I was nominated by OIFE and eventually elected ePag of ERN BOND. The ERNs were launched in 2017 at a memorable kick-off meeting in Vilnius, Lithuania. I was honoured to hold a plenary talk at that meeting. And looking back now, I do not think I understood what a giant step for rare conditions the ERNs were until afterwards. I sat on that stage looking out at health ministers, prime ministers, members of parliament (MEPs), medical experts, patient representatives, organizations and other stakeholders, talking about my hopes and dreams for the advancements the networks could bring. Everyone had come together to work towards creating better care for people with rare conditions. That day still gives me goosebumps.
What do you do as an ePAG in ERN BOND?

I think it is safe to say I have done a little bit of everything. From the get-go, the learning process has been steep. The networks were brand new and had to find their form and function. That alone feels like rowing a boat, while you are still building it. Our coordinator Luca Sangiorgi often compares ERN BOND to a newborn baby. Everything is new, it is still very dependent on TLC (tender, loving care) and people being hands on putting in the extra effort just to survive. It takes a while to learn how to crawl and eventually run! I am a member of the steering committee and have been in and out of several of the working groups. I attend video meetings where we map out next steps for building educational resources, for creating guidelines, for clinical trials etc. The last year I have invested a lot of time in understanding how registries work and how we best can build EuRR-Bone, our European registry on rare bone disorders. I have always advocated for patient representation and always looking for ways to make the patient voice heard.

How much time do you invest?

This is almost impossible to answer. If I wanted to, I could easily let BOND become my full-time job. However, for obvious reasons I still need my paid job, I do have family and friends, I have health issues and a life. Therefore, I try to balance my days as best I can. Sometimes, I must admit I am quite off balance, and find myself up half the night reading emails or polishing presentations. Luckily my husband is very supportive and never complains. He also has a bone condition, much rarer than OI, so we share the drive for more information and knowledge.

What kind of skills do you need to have to become an ePAG?

I think it is important to be interested in rare bone conditions, both your own and others. You should know the basics and be ok with having OI. If talking about OI puts you on an emotional roller coaster, it might be too tough becoming a patient representative. To help others, you need to help yourself first. Secondly, I think it is good to be able to speak, read and write English. The language barrier in Europe is real and to be able to contribute to discussions, English is essential. I wish this wasn’t that important and that translation technology was further developed, but this is where we are at today.

Also, it is good to have some insight into the eco system of rare disorders; research, pharma, data, authorities, structures, networks and organizations. How do they all fit in as pieces in the puzzle? Although it is good to have a clue about these topics, these are things you will learn as you go along. You don’t have to be an expert to get involved, you just have to be willing to get onboard. It is far more important that the organization you represent has your back and people you can turn to for advice and guidance. Being a patient representative is about representing a group or organization. It is not about private agendas and advocating for yourself. You must want to make a difference for your group and not be afraid to speak up about it.
What is the biggest challenge of being ePAG in ERN BOND?
Difficult question.... One challenge is the feeling that you never have enough time or that you don’t understand enough about the different topics or projects. In the beginning I had to read the same documents numerous times before I felt I understood anything. Being asked questions about research tools, about clinical pathways, PROMS and CROMS can almost wipe you out. Especially if you have just come home from work, or you are recovering from a fracture. Sometimes I wonder how I got myself into all of this. But then I remember all the people I get to meet and discuss rare bone conditions with. The world is becoming smaller and together we can make a difference for people with rare conditions. The thought of that is refuelling in itself.

Can you mention an example where input from an ePAG changed the course of action in ERN BOND?
I try not to look at it like a «battle of wills» between patient representatives and health care professionals. It’s not a war, it’s a collaboration. My experience is that all members of BOND are very eager to hear what we have to say. Many times, there are no rights or wrongs. It’s more about putting priorities on the agenda. We all know that paediatric care is far better than adult care. Therefore it can be important to foster the adult perspective. OI is about more than broken bones, measuring height and straightening legs. Adults with OI face various challenges previously neglected in health care services or when new projects are funded. Lung dysfunction seems to be the main cause of death in OI, so why do we not have more focus on lung and pulmonary care? Hearing loss is a major contributor to feeling isolated and depressed, so why are there not more audiologists and psychologists onboard amongst our medical advisors?
There has been a lot of focus on bisphosphonates as if it has revolutionized OI, but the jury is still out on the long term effects of OI. Is counting fractures really a good measurement on how effective a drug is? And while talking about medical treatments, we still do not have access to treatment that affects the root cause of OI. We are still putting band aids on symptoms while in other disease areas they have come much further. Most importantly, I don’t think all Olers are on a hunt for The Cure. They value their lives just as they are, but want to help manage care, pain and everyday life as they grow older. These are some of the messages we try to get across.

What can a patient with a very complex case do to get access to expert advice from ERN BOND?
ERN BOND discusses complex cases through an IT platform called the clinical patient management system (CPMS). It is a form of second opinion you can ask for through your health care provider. Individuals cannot access CPMS themselves, but have to go through the doctor in charge of care. That doctor, if not already a member of BOND, has to access the ERN through a clinic in your country that is a part of the ERN structure. In CPMS the doctors can share x-rays or test results and discuss the findings and treatment options. The idea is that instead of the patient traveling to find the expertise the information «travels» through the secure IT structure. The system meets the requirements of GDPR and your data is shared only after you have given written consent. Please note that each country has specific rules and arrangements for the referral of patient cases to ERNs. (Editor’s note: Some countries are for instance not connected to ERN BOND via the CPMS system). See more info on ERN BOND’s website!

What are the most important activities ERN BOND is working on at the moment?
We will be seeing a major expansion of BOND from 2022 as we will be welcoming many more members onboard when the second call from the EU is finalized. We might even double in size if all applicants are accepted. This means a new boost, new people, establishing new working groups and distributing new roles. We are constantly talking about how to prepare and set the stage for this next step in developments. We also need more ePags onboard. We are constantly trying to reach out to rare bone patient organizations to spread the word.

Do you have any messages for the readers of OIFE Magazine?
I think my main message is to get engaged through your OI national organization and ask them how you can become involved. Progress does not happen by accident, and nothing is ever given. We have voices, our experiences are real and together OIFE will continue to create change in the field of OI.

Ingunn and Rebecca won the prestigious Black Pearl Award for their OI-work in 2021
Interview with Ida Vandsøe Madsen, student at the Department of Anthropology at University of Copenhagen, Denmark

Ida Vandsøe Madsen is a Ph.D.-student at the Department of Anthropology at the University of Copenhagen. Anthropology is the study of human biological and physiological characteristics and their evolution. She did her Master’s Thesis (final project) on OI as she was interested in how it is to live with chronic bodily fragility. Part of her thesis has been published as a research article titled ‘People Made of Glass: The Collapsing Temporalities of Chronic Conditions’.

Who are you and what is your relationship to OI?
My name is Ida Vandsøe Madsen. I am an anthropologist specialized in medical and psychological anthropology from the University of Copenhagen, Denmark. My relationship to OI is that I did my Master’s Thesis (final project) on OI. I chose to study OI as I was interested in how it is to live with chronic bodily fragility. Part of my thesis has been published as a research article titled ‘People Made of Glass: The Collapsing Temporalities of Chronic Conditions’ in the journal Anthropology of Consciousness. I am now a Ph.D.-student at the Department of Anthropology at the University of Copenhagen studying the relation between people with dementia and their relatives during the COVID-19 pandemic. I hope that I can work with OI again at some point.

What was your research project about?
I studied the social-psychological, bodily and existential aspects of living with OI in Denmark. I was interested in understanding how the physical environment is perceived when you live with OI, and how this is influenced by memories of past bone fractures and the prospect of future bone fractures. Finally, I studied how these perceptions, memories, fears and hopes change and persists over time.

The target group was medical professionals and researchers, mainly anthropologists, psychologists, sociologists and medical scientists working with OI or other conditions that entail aspects of bodily fragility. I do not live with OI myself, and therefore the people with OI I talked to were the experts. However, some of the people I talked to has told me that the study helped them find a new language for experiences they did not know how to describe. My goal is hence not to talk on the behalf of people with OI, but to offer an account based both on the stories I was told, and the vocabulary and analytical lenses anthropology has given me.

When it comes to the term “temporality”, I define it as lived time meaning time as it is experienced cognitively, emotionally and bodily by humans, i.e. not measurable time, clock-time or chronological time. I chose to focus on temporality, as I found that important aspects of living with OI have to do with lived time; memories from the past, sensations of bone fractures that never quite heal as well as fear and hope towards the future all shape actions and emotions in the present. In my approach to temporality, I was inspired by the philosophical tradition phenomenology, which deals with lived experience.

Who was behind the project and which methods were used? How was it financed?
I designed the project, gathered and analysed data, and wrote the thesis and the article with help and guidance from my supervisor Professor Tine Gammeltoft. In terms of methods, I conducted fieldwork
among people with OI in Denmark. Men and women aged 13 to 76 from all over Denmark participated. I had twelve main interlocutors who I interviewed. In five cases, I also conducted participant observation, meaning I followed their everyday lives. I received government financed education support as all Danish students do, but otherwise I financed the study myself.

**What were the most important findings?**
The most important finding is that life with OI, at least for the people I talked to, is greatly influenced by non-chronological memories of past bone fractures, incidents that could have led to bone fractures, and the fear of future bone fractures. Events of the past and images of the future can have great influence on actions and emotions in the present. Moreover, it seems that this is experienced as a constant bodily and mental weight, which is sometimes more explicit in the consciousness than other times. Small features of the physical environment evoke memories of past bone fractures or the fear of future bone fractures, and these memories and fears in turn influence how the physical environment is perceived. Whether this is more or less explicit in the mind, is often influenced socially, especially by family members.

**Were there any surprises?**
The types of memories that had great effect on the participants’ present actions and emotions surprised me. As an example, events that could have led to bone fractures, but did not, and events where other people (also people who do not live with OI) had been at risk of getting hurt affected some of the participants a lot. I had not thought about that before I started fieldwork, but it makes sense. Fear and trauma is not necessarily limited to actualized events or your individual body.

**In what ways was the patient organization or patient representatives involved?**
DFOI (Dansk Forening for Osteogenesis Imperfecta, The Danish OI Foundation) was informally involved. They were very helpful in terms of recruitment, answering questions, and providing network and contacts to other people working with OI.

**What was the most important take home message?**
I think it could be helpful to be aware of patients’ lived experience of OI. OI is so much more than preventing bone fractures. To most of the people I talked to the main goal is not to prevent bone fractures. It is to live a full and fulfilling life by balancing the risk of bone fractures and the risk of missing out on life.

I also think it is important to be aware of the mental stress and trauma that OI can cause. What might seem like unpredictable future scenarios or events of the past can have very real effects on life quality in the present. Finally, I think it is important to be aware of the social aspects, as the way OI is talked about and handled in families, friendships and professional settings matters and has great consequence on the lived experience of the illness.
OL at the Paralympics

Before the Paralympic Games in Tokyo, the Spanish organizations have identified seven people with OI who were competing in the Paralympics. The athletes came from Spain, Greece, The Dominican Republic, USA, Germany, Japan and Great Britain.

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**CONGRATULATIONS MCKENZIE COAN!**
Before the Paralympics, McKenzie Coan from the US joined Dr. Kara Ayers to discuss her experiences as a US Paralympic Gold Medalist and OI community member preparing to head to Tokyo for the 2020 Summer Paralympics! Watch the recording of the event at the YouTube channel of the OIF: [https://youtu.be/rUnbfhxDe0k](https://youtu.be/rUnbfhxDe0k)

She has also published a book about her experiences.

We congratulate McKenzie Coan for winning the gold medal in 400 freestyle S7!

**CONGRATULATIONS VALENTIN!**
We congratulate Germany’s Valentin Baus with his gold medal in table tennis!

**CONGRATULATIONS JORDANNE!**
We congratulate Jordanne Whiley from the UK with silver (tennis doubles) and bronze (tennis singles) in the Tokyo Paralympics.
What is ableism and why does it matter to you?
Ableism turns disabled people into "others" - and helps non-disabled people stay "normal".

Through the hashtag #AbleismTellsMe different disabled people told their stories about discrimination. What exactly is Ableism? And what is the difference between that and hostility to disabled people? This is what Rebecca Maskos, from Germany, tries to explain in this article. It was originally published on October 26th in the magazine “Die Neue Norm” (The New Norm), which has kindly allowed us to republish. The magazine The New Norm wants to put the topic of disability into new contexts – from charity and welfare to being part of the mainstream society.

Rebecca Maskos was born in 1975 and lives in Berlin. She studied psychology in Bremen and disability studies in the USA. She was an editor at "Mondkalb", co-founder of Leidemedien.de, worked on projects on disability and feminism and publishes as a freelance journalist on disability issues. She is currently writing her dissertation on ableism, autonomy, and the use of mobility aids. Rebecca has OI herself.

Able-what? Is Ableism (Ableismus in German) just another fancy word in social media? The term ableism originated from the English-speaking disability movement. It is connected to the word “ability”, and has also been used in Germany the last 10 years or so. With the Twitter hashtag #AbleismTellsMe, the term Ableism also made it into German mainstream media. In the beginning of September 2020, the American disabled student Kayle Hill tweeted about her experiences with discrimination under #AbleismTellsMe. And after this happened, the hashtag went through the roof, especially in Germany. In hundreds of tweets, people reported some blatant experiences of exclusion and disadvantage, an expression of how society deals with disabilities.

IS ABLEISM THE SAME AS HOSTILITY TOWARDS DISABLED?
But does this really require a new Anglicism? Is ableism something new, different or does it refer to experiences that we disabled people know well enough - summarized under the term hostility towards or discrimination of disabled people? Yes and no. Ableism is nothing new at first glance. Ableism shows itself when we do not appear as a competent subject at eye level, when we seem invisible and when decisions about ourselves are made over our head. When our friends and partners are addressed as our "guardians". Ableist thought patterns attribute everything we do back to our disabilities: We are in a bad mood, grumpy and lonely or curious, friendly and nice, supposedly because we are disabled. Or we do everything despite our disabilities - our lives are solely directed towards overcoming our disabilities.

Ableism makes us as complex persons, disappear behind a wall of stereotypical assumptions. For example, that our disability makes us bitter and depressed, and that it therefore takes a lot of courage to lead a "completely normal life". Or that we are helpless and incapable in all areas of life. Ableist is the recognition that when it rains, we “go out anyway”, “we’re also at the party”, “don’t let our handicap hold us back”, or “stand up to it”. However, the envy/resentment we get for disabled parking spaces, ID cards for the severely disabled and additional vacation days is also a form of ableism. It also includes questions of whether our life is worth living at all and whether we are not primarily a burden for our families.
A broad spectrum of ideas and thoughts come together under the catchphrase ableism. The overlap with
disability discrimination/hostility is evident. The hatred and violence that people with disabilities then and
now face, are in fact hostility to the disabled. Also the question of how many “care cases” a society wants to
afford, or whether, in times of scarce resources in the health care system, one does not have to prioritize
which lives we save and which we don’t. The term hostility towards the disabled hits the devaluation of
disabled lives in all its sharpness. And yet it makes sense if the term ableism stands by its side.

ABLEISM IN EVERYDAY LIFE

Firstly, the practice of how people deal with disability is not always hostile. Often it comes across as rather
friendly, as congratulations on the "courage to face life", as the exuberant, not always helpful help in
everyday life or in the form of well-meant tips on how to easily get rid of chronic pain or allergies and asthma.
Secondly, ableism is broader than hostility towards disabled people. Like racism and sexism, the term not
only depicts the practice in dealing with a group, but also the social conditions and structures that produce
this practice. Ableism is not only evident in weird comments or in petting a person on the head, but also in
the stairs without a ramp, in the missing elevator, in the funds that organizers simply do not want to raise
for sign language interpretation, live streaming or plain language. The term hostility towards disabled people
can also suggest that it is sufficient to simply change your own attitude - namely into one that is “disabled-
friendly”.

It is no coincidence that terms such as “misogyny” or “xenophobia” are used less often. Because, like ableism,
racism and sexism, they are not only patterns of thought and action, but also an expression of relations of
social power that affect all people - in very different ways. White men, for example, hardly ever need to deal
with the unreasonable demands from a racist and sexist society and therefore often find it difficult to
recognize these mechanisms at all. Also non-disabled people, can appear privileged in this context: They are
spared for the energy-consuming struggle with barriers and prejudices. Disabled people, on the other hand,
don’t just have to deal with the other’s ableism. In addition, there is also the risk of internalizing the ableism
that comes from the outside. The risk exists, that at some point you will see yourself as inferior, as a burden
for society.
CONNECTIONS TO OTHER -ISMS
There are a lot of parallels between ableism, sexism, racism and similar "-isms". But there are also differences. An identity as a non-disabled person is fragile. In old age, at the latest, we are all right in the middle of a disabled life: No life ends without impairments. And in the vast majority of cases, we all have temporary minor and major impairments in the course of life. We all must face experiences with impairments - with illnesses, with dependencies on others, with the need for help, but without being automatically disabled as a result. Nevertheless: A serious accident is enough, and then you are suddenly part of the "Disabled People's Club".

Perhaps that is the reason why disability creates so much fear and insecurity? All of us, are actually closer to a life with disabilities than most people would like to think about. Acting ableist can be an attempt to keep an uncomfortable truth at a distance: Nobody is inviolable. Ableism can turn disabled people into “the others” and keep them at a distance. The supposedly safe normalcy does not have to be shaken in the first place...

Unsolicited advice for non-disabled parents of disabled children
By Haley Brown, blogger and creative artist from the US

Unsolicited parenting advice from someone who isn't even a parent is...everyone's favourite thing, right? I know, I know, it can be really rude and annoying. But I wrote this from a place of deep love - for disabled kids AND our parents. For all kids and parents. SO here we go!

Before I get going on my unsolicited advice, you might be like, 'ok Haley, but who the heck are you and what are your credentials for speaking on this topic?' And that would be entirely reasonable. I am not a child psychologist. I'm an OI (type V) adult who's worked with children for 17 years, and I have non-disabled parents. I'm 30 years old.

Ok let's start with 10 points in no particular order...

1. Stop praising your disabled kid (directly or to other people) for being positive!
Especially around medical procedures or painful experiences. While it may seem harmless to you, it trains your kid to suppress their extremely valid responses to pain for other people's comfort. Your kid should get to feel however they feel about whatever medical trauma they're going through. Validate all feelings are coming up for them instead of constantly asking them to stay positive or be brave.

Anecdote: a kiddo I was babysitting for, cut his finger open when we were doing a project, and he was absolutely freaking out. After we handled it and he was feeling better, I said to him "I'm so glad you're feeling better. You were super brave." He said: “Because I didn’t cry... that much?” (He cried a lot). I said “No! It’s still brave if you cry! You were brave for getting through it, and for sharing how you felt about it. You were brave for crying. It was scary and it makes sense to cry when you're scared.”
2. Protect your kid from other people relentlessly praising them for their positivity!
I have a lot to say about my own experiences with strangers, acquaintances, and well-meaning adults in my life praising me teary-eyed for being so inspiring and positive when I was actually in a lot of emotional distress. It created a cognitive dissonance that I’m still working though as an adult. Along these lines, look up the late Oier Stella Young’s talk “I’m not your inspiration, thank you very much”. Allow your kid the dignity of being a complex human being with lots of different feelings, and also the dignity of being ordinary.

3. Think twice before posting on social media!
I see a lot of social media posts in the inspiration realm, where parents post pictures of their disabled kid in the hospital with an inspiring caption. I get that this might help you process your feelings, but ask yourself how it would feel to be in your kid’s position. How would it feel if your body was photographed at its most vulnerable, and your trauma was posted on social media for all to comment on?

Having a kid go through medical procedures is a traumatic experience for grown-ups too, and sharing is probably cathartic for you. I get that, so try sharing with a private text thread of close friends and family, instead of... literally everyone.

4. Seek support from peers or professionals!
You, grown-up, are going through the ongoing traumatizing experience of having to fight for your kid in the medical realm and coordinate their care. It’s a lot. Your feelings are valid too! AND...I truly believe that it will serve both yours and your kid’s well-being for you to process that in therapy or peer support, if you have access to that. It should be a top priority.

5. Get to know diverse adults with disabilities!
Do you have disabled adults in your life? Do you have disabled friends? Do you follow disabled activists and organizers on social media? Do you and your kids watch shows and movies with disabled characters played by disabled actors, read books by disabled authors? If so, that’s amazing! Do the disabled people in your life span across other intersections of identity? Are you in relationships with black, queer, poor disabled folks, for example? Do you recognize that disability intersects with other facets of identity in complex ways? Does the advocacy groups, charities and organizations you follow and participate in have leadership from disabled people themselves? If no, ask why not and seek out those kind of groups!

6. Value disabled adults in YOUR life and prevent internalization of ableism!
Some non-disabled grown-ups of disabled kiddos do their best to find a disabled ‘mentor’ for their kid. Which is an amazing start at getting them the positive representation they desperately need! But, unfortunately, if you don’t model that you cherish and value disabled adults in your life, that mentorship is likely to fall flat once your kid starts to internalize the ableism that the culture is constantly throwing at them.
7. **Work on your own ableism!**
Examine and work to uproot your own Ableism. We all have it. Google “Disability Justice”!

8. **Recognize that pain can be hidden!**
Recognize that your kid might be experiencing physical pain even if they aren't naming it. I think a lot of my tantrums and my resistance to bedtime (which are also just normal for all kids) involved the additional layer of physical pain or not wanting to be alone with my pain.

9. **Resist body shaming in all forms!**
Fiercely resist body-shaming in all forms, and start with yourself! Model what it is like to heal your own body-shame and develop a respectful and loving relationship with your own body. Model that all bodies are different, all bodies have needs, all bodies are worthy.

10. **Help your kid develop curiosity, joy within, and agency around their own body!**
Help them name what is happening in their body in positive moments as well as more painful/negative ones. Express to them that their body is theirs. Practice consent! When consent is breached (as it almost always is in medical settings with children), honour the trauma of that.

If you read to the end... **congratulations!** Even just having the courage to consider advice about your parenting from a disabled adult you don’t know, is a big deal. And I don't mean that in a sarcastic or condescending way. I get that parenting is the hardest job in the world, and I know that you love your kid so fiercely. Love from Haley!

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**Parenting a child when you have OI**

*By Claudia Finis, DOIG (German OI-association)*

I got an inquiry if I could write something about parenting with OI of a child with OI. Gladly, I thought. However, I am not the measure of all things. So I asked two other OI-affected parents if they could talk to me about this topic and if I could translate this into an article. Both immediately agreed. Sven has a son affected by OI and Janina has a daughter affected by OI, while I was the only one in this group to have two children, a son without and a daughter with OI. Many topics came up in our conversation. Some of our thoughts and experiences are given below.

We chose to have a child or children. We do not believe that a happy life is only possible without disability. It takes a lot for a happy life. However, the absence of a disability is not absolutely necessary.
We probably all know people who seem to have so much, and are still unhappy. For Janina, it means looking at everyday life, with or without a disability, in a way that includes all possibilities. You will always find ways and approaches that others are trying to find in vain, or that they may not yet be ready for.

A basic assumption of some people is, according to my feeling, that all disabled people always suffer, never rejoice, and if they do it’s short-lived and half-heartedly, because then the suffering immediately strikes again unavoidably. That’s not the case. Really! In fact, there are people who feel that way. But they exist among the disabled and not disabled. Really!

**How did it all begin?**

For all of us, the decision to have a child was a conscious one. The notification that our child has OI, however, occurred differently for everyone. While Sven’s baby was diagnosed with a fracture during a prenatal examination, I had a strange finding (I thought at the time) that did not match my own OI as a child. With Janina it was completely different, because she thought her baby would not be affected for months until she found out after an atypical fracture and a genetic diagnosis.

Therefore, Sven was the only one in our group who had this one moment of recognition. He reported that he needed some time to digest this back then. But he is sure that the shock was different for him than for non-disabled parents. Perhaps one of the first thoughts of parents without disabilities is: "How should my child with brittle bones lead an independent life?"

Our own experience of a successful life with a disability may help here. For me and Janina it was more like sliding into certainty.

**What changes?**

Regardless of a disability, every child is a surprise package. The first child in particular, changes life tremendously. This disability-related “more” adds not as much weight as it does for non-disabled parents. Many things that non-disabled parents have to learn, are already a natural part of our lives. Submit applications, take accessible detours, visit experts and therapists…. all of this is familiar to us. It is just nothing special. We are now also doing this for and with our child, just as non-disabled parents do their things. Things that were already part of their lives before, they now do this with their non-disabled children as well.

**What people without disabilities ask about!**

All three of us were surprised to hear that we were asked independently of one another how we, as disabled parents, wanted to manage to care for the children, since we couldn't run after them. I was very surprised at this. For me it means that people who ask like this, always raise their children with the help of physical superiority and power. But this was never my pedagogical approach.

Janina (photo), sitting in an electric wheelchair, went to the zoo alone with her daughter when she was little. And her daughter, who was very mildly affected by OI, did not run away from her. At that time, I was also alone on excursions with my 2-3 year old son, who was not affected, even on very rough terrain. I wasn’t afraid he might run away from me, and neither is he. I have often been on the road with both children or just one of the two without any other, non-disabled adult. I never had this problem with any of my children.
According to my parenting style, I never intended to run after my child. And this is regardless of my disability. I often get the impression that many of the supposed problems that non-disabled people see for disabled parents only exist because of their rigid, not always meaningful ideas.

**Do you need special aids?**
Janina and I both had something built according to our needs. We used creativity to handle things differently than usual when it was necessary. Janina had the first baby bed converted according to her needs. I myself had my father-in-law build me a board attachment for the bathtub for changing.

The things that are needed in this situation can often not be found in the catalogue of equipment for disabled. In this case the help of proud, technically gifted grandparents is very welcome.

**How do I teach masculinity?**
As the only father in our group, Sven was and is constantly confronted with the question of male role models. How can you teach a son to be a man if you can't do all the body-related things that seem so important to manhood? Sven (photo) himself also has an affected son, but sees no problem for himself. In some points he fulfils the classic male role requirements, in others not. He is quite relaxed about this. Perhaps with this attitude he is fulfilling contemporary demands on men more naturally that other men could use as an example. Just a thought from my perspective...

**We are role models**
Every day we show our children how to lead a fulfilled, happy, special, sad, exhausting, funny, normal ... life with a disability. We demonstrate how to deal with difficulties, whether they are related to OI or not. Just like everyone else, we are mostly successful in doing this. And just like for everyone else, it sometimes doesn't work out so well. Then we talk to our children, straighten the crown and continue walking or rolling...

Janina also emphasized the equal partnership based on eye level, whether with or without a disability, as a very important basis for children. This especially for children with a disability, to be the best possible role model and to strengthen them at all times on their way into life.

That leads to the last point:

**We are not alone!**
Our partners have to be mentioned. None of us did get our children alone, cared for or raised them alone. This influenced our decision to have children. Our three families are lived inclusion!
Life as a “shadow child”  
By Kristine Holm Laursen

Often siblings of children with a chronic illness are called "shadow children" because they live in the blind spot of their parents. They are often alone with their grief and put their own needs aside for their siblings' needs.

My name is Kristine Holm Laursen, but just call me Krisser. I am now 26 years old, studying to be a physiotherapist, working in a running club. My "coping strategy" is running, so I run quite a lot.

I am a shadow child and can relate to many of the things mentioned. When it's written down in black and white, it doesn't sound very fun. Life as a shadow child is often described as something negative, a situation where you will always end up being number 2 and often failure or being let down is one of the big emotions.

Personally, I think that's a shame! Because of course I will always wish that my sister was healthy and that I would never have to see her in pain again. BUT I am proud to be a shadow child. It has made me who I am today. It has made me strong and it has made me special!

When I think back to my childhood life with a sister with a rare disease, I first remember all the good things. I remember when we went to Disney Land with the Wish Fund, when we got money for an aquarium and all the good times we had together. Then all the other thoughts arrive. One particular childhood memory takes a lot of space. Or actually it's not one memory, but several memories from the same situation. I remember clearly all the times my mother came into my room happy and with joy in her voice told me that now my sister was discharged early and that now they would all be home. I hated it! I knew very well that it was too early to be discharged. AGAIN! Because this wasn't the first time my sister had been discharged early and taken all the worry and pain home with her, to my safe space. Often, she was still very much in pain and there was always a depressed atmosphere at home. I still feel a lump in my throat when I think about it. Because for me it suddenly wasn't "my home" as it didn't feel as a safe place anymore. My sister was never the type to scream or cry in pain. She was strong. Yet there was always a definite atmosphere that is hard to describe as anything other than tense.

Time and again my sister was also re-admitted quickly, because she became ill again, or the pain increased. It was always a dilemma, because I understood perfectly well that my parents and sister did not want to stay in hospital. But at the same time, it was far beyond my limit to handle the pain, the worry and the tense atmosphere in what was also my home.
Personally, I have developed a very specific coping strategy, namely running. I guess it's a form of denial where I try to escape or simply run from reality. Still, I would recommend all shadow children to find a hobby, something they are passionate about and a place where they can be themselves and not "Marie's sister". I have definitely used running in a dangerous way for many years, running from my worries and feelings without addressing why I was doing it. It wasn't until I learned about coping strategies in a class, that I realized what I was running from. After I became aware of it, it has really been an eye opener.

For me, the most important thing is that at races I am seen as "Krisser" and not "Marie's sister". People know me for who I am and not from my sister's story. People recognize me for my efforts and not for my sister's. Through running I feel that I am me and not in the shadow of anyone! This is not to say that I think everyone should start running, but that immersing myself in something and learning new skills has been very important in how I have dealt with and coped with bad days.

Even though I'm now doing well and thriving, it's not always easy to see loved ones in pain or being sad. I still recall those situations where you feel incredibly powerless and inadequate as a relative. It is terrible to be a bystander without the power to do something. Sometimes I wish I could take just a portion of the pain. Not only do you have to stand by and watch your sibling in pain, but it always hurts beyond belief to see your parents worry and be sad about it. As a sister, I always tried to maintain the facade at home when my sister was hospitalized. I was often looked after by my grandparents, but when I got old enough to be home alone, my parents would take turns coming home and to share meals with me. At those occasions I always tried to cook for them and be positive, but that was just playing to the gallery. Because of course I was also broken inside because my sister was hospitalized. I hated the uncertainty, the doubt and the worry.

Fortunately, my sister and I have always had a special bond. We have been able to read each other without saying anything and we have always been able to infect each other with good energy and good humour. I am extremely proud of my sister Marie. Today she is one of my best friends. I could never "blame" her for anything. And I know that she will always be there for me if one day I get sick or hurt.
INTOI 2020+1 CONFERENCE
Several people from the Medical Advisory Board of OIFE attended the IntOI 2020+1: Virtual International Meeting Early Stage Investigators Symposium. The event was chaired by dr. Joan Marini and hosted by the OI Foundation. You can find a recording of the event here: https://youtu.be/jLMhU8N1QSE

OIFE HAS ITS FIRST EUPATI FELLOW
We congratulate Leonardo Panzeri (one of the Italian OIFE delegates) with graduating from the European Patients’ Academy on Therapeutic Innovation (EUPATI).

EUPATI offers a lot of different educational activities, both on a European and national level. The topics are research, development, patient engagement and more. Learn more at: https://eupati.eu/training/

STUDENT VOICE
Once again, the OIFE has joined the Student Voice-project to create awareness about OI among medical students. On Friday 22nd of October we will be speaking to a medical student from the UK about benefits and barriers in patient participation in research.

APPLY FOR EURORDIS SUMMER SCHOOL!
The deadline to apply for the 2022 edition of EURORDIS Summer School is November 15th! OIFE have at least five people who attended Summer School before and who graduated as patient experts. Take your patient advocacy to the next level, and learn with EURORDIS about an exciting range of topics - including clinical research, ethics in medicines development and health technology! openacademy.eurordis.org/summerschool

ERN BOND HAS A NEW WEBPAGE
We congratulate one of our important collaborators ERN BOND – the European Reference Network on Rare Bone Diseases with their new webpage: https://ernbond.eu/
SOCIAL MEDIA COURSE
Do you want to lead your patient organisation to social media success? Plan & Create for Social Media Success with OpenAcademy online FREE interactive course hosted by EURORDIS: l.eurordis.org/Nek3

SISOM OI
The research team at Shriners Hospital for Children Canada just published "Experiences of Children with Osteogenesis Imperfecta in the Co-design of the Interactive Assessment and Communication Tool Sisom OI: Secondary Analysis of Qualitative Design Sessions" in the JMIR Pediatrics and Parenting.

The people behind the article were Maia Siedlikowski, Lianna Curiale, Dr. Frank Rauch and Argerie Tsimicalis.

Read the article here: http://dx.doi.org/10.2196/22784

THE TOPAZ TRIAL IS RECRUTING ADULTS WITH OI
The TOPAZ Trial is recruiting adults with OI in UK, Ireland, Netherlands, France and Denmark. The trial is designed to determine if anabolic therapy with Teriparatide (TPTD) followed by a single infusion of zoledronic acid (ZA) is superior to standard care in adults with OI. The trial is open to anyone over 18 years with OI whether or not they have previously been treated. The only exception is people who have received anabolic therapies in the past two years.

If you are interested in taking part in the study please feel free to email the study team on topaz.trial@ed.ac.uk or Professor Stuart H Ralston, the Chief Investigator on stuart.ralston@ed.ac.uk for further information. Read more in OIFE Magazine: https://oife.org/2020/11/17/the-topaz-trial/

GREETINGS FROM CANADA
It’s not only Russia who are doing summer camps. The Canadian Osteogenesis Imperfecta Society (COIS) has been working with a larger camp for kids to make it accessible for children with OI. You can find COIS here: https://www.cois-scoi.ca/
GREETINGS FROM RUSSIA
The Russian OI-organization has organized a new edition of their famous youth & family camps. This time it was once again by the sea and the main topic was stereotypes and how to fight them.

The title of the camp was «Aliens in wheelchairs». Five delegations from other planets landed on Earth, and during the first meeting, representatives of Earth’s civilization told them about the most popular stereotypes on Earth.

CELEBRATE WITH OIFE!
Help us reach our vision of children and adults with OI living active and independent lives by creating a fundraiser for OIFE on Facebook! 100% of donations goes to OIFE. We assure you that Facebook charges no fees.

Go to www.facebook.com/fund/OIFEPAGE/ and follow the instructions to create a normal fundraiser or a birthday fundraiser. You can use a personal photo and a personal text with a connection to OI/OIFE to make it more impactful. Thank you for your support!

Research announcements

Romosozumab Trial for OI
The company Amgen is sponsoring a multicenter clinical trial to study the safety, pharmacokinetics, and pharmacodynamics of the investigational drug romosozumab in children and adolescents who have OI. Currently the study is open to eligible children ages 5 to less than 18 years of age who have a diagnosis of OI Type I through IV. The study has sites participating in this clinical research in the following countries: Germany, Hungary, Italy, Spain, Greece, Turkey, Russia, Austria, Netherlands and Switzerland. For more information, please visit the clinical trial registry page at: https://www.amgentrials.com/study/?id=20160227

If you have any additional questions, please contact the Amgen Call Center at +1 (866) 572-6436 or send email to medinfo@amgen.com. A Customer Service Representative will be able to find a study site near you and provide you with the site study contacts who can tell you more about the clinical research study.
Announcement on the clinical trial BOOSTB4

In Sweden, the Karolinska Institutet and the Karolinska University Hospital are leading the academic clinical trial BOOSTB4 where we are looking for subjects who have a diagnosis of OI Type III or severe Type IV with a specific collagen mutation. The aim of the clinical trial is to study the safety and efficacy of the investigational drug BOOST cells (fetal mesenchymal stem cells) on fracture occurrence, growth, bone mineral density, biochemical bone turnover and quality of life in children who have OI.

The BOOSTB4 trial includes 2 groups of children, the postnatal group (15 children) and prenatal group (5 children), who will receive 4 doses of BOOST cells. Currently, 9 children from several European countries have received between 1 and 4 doses of the BOOST cells and 13 children have been included in the postnatal group. No significant side effects have been detected during the trial so far.

**The postnatal group** is open to children up to 18 months of age who have a diagnosis of OI Type III or severe Type IV with a collagen mutation (glycine substitution in COL1A1 or COL1A2). All 15 participants receive 4 doses of BOOST cells 4 months apart.

**The prenatal group** is open since June 2021. In this group 1 dose of BOOST cells will be administered to affected fetuses before birth, followed by 3 doses of BOOST cells four months apart after birth.

The trial welcomes children and pregnant women from within Europe to Karolinska University Hospital in Stockholm, Sweden. The trial can include new participants until February 2022. Dr Eva Åström is the Principal Investigator for the clinical trial.

For more information, such as the inclusion and exclusion criteria, please visit the website [www.BOOSTB4.eu](http://www.BOOSTB4.eu).

If you have any additional questions, please contact us via the email address [BOOSTB4@clintec.ki.se](mailto:BOOSTB4@clintec.ki.se).

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**DISCLAIMER**

The OIFE is not involved in the design or management of research studies we announce and as such, is neither endorsing nor supporting these studies. The mission of the OIFE is to keep the OI community informed of all relevant studies. This information is made available as a service to the OI community. We are available to answer questions on this or any other research announcements. Please contact the OIFE at office@oife.org if you have any questions.
Announcement and invitation to nominate

MARIA-LUISA BIANCHI AWARD 2022

The Maria-Luisa Bianchi Award has been established by ICCBH to honour the memory of Professor Maria-Luisa Bianchi for her role in establishing and developing ICCBH and for her significant impact on the field of paediatric bone disease through her research and clinical work. The Award reflects on her commitment to the development of the field and her unstinting willingness to contribute her time and effort for the benefit of all.

The goal of this nominated award is to recognise the work of female researchers and healthcare professionals towards the beginning of their careers who have already made a significant contribution to the field of paediatric bone health and who are based in low and middle income countries.

THE AWARD

The award winner will be offered all costs associated with joining the 10th International Conference on Children's Bone Health, 2-5 July 2022, in Dublin, Ireland, including registration, accommodation and travel.

ELIGIBILITY CRITERIA

1. A female researcher or healthcare professional working in a low or middle income country (World Bank criteria)
2. Under 40 years old

NOMINATION

The following nomination materials are required:

1. A covering letter on your letterhead outlining the reasons for your nomination. Maximum 2 pages.
   Please include the following:
   a. How long have you known the candidate and in what capacity?
   b. At what stage is the candidate in her career?
   c. Outline of her area of research or clinical care
   d. Her accomplishments to date
   e. How does the candidate represent the spirit of the award?
   f. How will the award assist the candidate in her career?
2. The CV of the person you wish to nominate, including publications, if any

Please send by email to iccbh@ectsoc.org by 10 January 2022.

DEADLINE FOR NOMINATIONS: 10 January 2022

Nominations will be judged by an independent panel and the results announced in February 2022.
Michael Geisman Fellowship Grant

The Michael Geisman Fellowship Grant program awards to post-doctoral trainees who are currently working on projects with clear relevance to OI or who have projects that will enable them to develop expertise in OI research. People from outside the USA can also apply for the grant!

Applicant Requirements:

- Applicant must hold an MD, DDS, DO, or PhD, and be appointed at the level of a post-doctoral trainee, or equivalent, within an academic institution.
- Applicant should have completed their Ph.D. or clinical training within the past five (5) years.

Fellowship Guidelines:

- Michael Geisman Fellowship awards provide up to $50,000 per year. It is the intention of the OI Foundation that grant monies be used to fund actual costs related to the research being performed including Fellow salary, fringe benefits, and supplies.
- Fellowship awards are for one year; a second year of funding may be approved based upon satisfactory performance during the first year of funding.
- Research must be done under the supervision of mentor with training and experience in osteogenesis imperfecta research or research in a related field.

How to Apply:

1. Download and complete the application.
2. Mentor of applicant must submit a copy of his/her NIH biosketch and a letter of recommendation on behalf of the trainee, which also confirms that the mentor will supervise the trainee’s research.
3. Applications require two additional letters of recommendation from scientists or clinicians who can comment upon the applicant’s training, ability, and potential to develop expertise in OI research.
4. Submit application, reference letters, and mentor biosketch as PDF documents to ecarter@oif.org NO LATER THAN November 30, 2021

If you have any questions, please contact Erika Carter at ecarter@oif.org.
Future events

**2. International Conference**
QUALITYOFLIFE4OI 2022
11-14 Feb 2022

**OIFE Calendar**

**Contact**

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YouTube: OifeOrg

OIFE is not part of the programme committee of QualityofLife4OI or OI2022, but we still hope to see as many of you as possible both in Amsterdam and in Sheffield! We will be there!

More info:
www.qualityoflife4oi.org
Registration opening soon