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Editorial

By Anna Rossi
- OIFE Communication Manager

What or Who is the OIFE?

Doesn’t it look like a very simple and obvious question? Actually, you might think it is also idiotic to ask this on the editorial of the OIFE Newsletter. I can say my bad, sorry! But, on the other hand, I guess that if we all ask the very same question to the members of our National Associations it would be quite hard, and probably surprising, to find someone who really knows what OIFE is and does.

Want me to give you some more hints on this? Let’s check some data. As.It.OI (the Italian OI Association) has 1794 followers on Facebook, the Brittle Bone Society has 3031 likes while OIF from US has 8309!

Right now OIFE has 1488 likes on its Facebook page. Less than any other of the previously mentioned associations.

Can you imagine which can be the reasons? Well just briefly and randomly thinking - these are some reasons I can list up: English is or can be an obstacle. But nowadays browsers offer very good automatic translations tools. People prefer to have only one reference point preferably in their own country. Then why are international youth meetings or the thematic groups so popular? I really tried hard and I ended up with the answer I like less - people do not know and sometimes do not even feel the need to know what OIFE is and does.

Well let’s admit that it’s not exactly easy to explain who and what OIFE is and does; but this only makes the challenge more exciting! So here we are in 2017 with all the strong powerful online and offline media available to find a way to be able to create an OIFE communication strategy and strengthen the OIFE awareness.
The very first step was to create a clear, brief and understandable description that could work as a very strong basis for the whole strategy: "The Osteogenesis Imperfecta Federation Europe (OIFE) is an umbrella association. Its membership consists of national and sub-national organisations which, in one way or another, support people living with Osteogenesis Imperfecta (OI).” Well done!

After this a new phase has started. The phase that all housekeepers know as “Seasonal wardrobe change” - the choice of what to keep and what to put away to make order.

And here we are: we can now decide what to keep, what to change, what to transform or update as well as what to put aside or away. It is also time to try new things and new possible solutions. And as said web and social media are offering us a worldwide range of hints and inputs. How to be sure to take the right ones? Well easy, care about the core! "OIFE is an umbrella association, made by other associations which do have as their core topic the care of OI people, families and so on...”. So what we will need to do will be just pick the inputs that can help us develop the real mission of OIFE and boost the chances to reach the aims we do have. And again, something has been done already: a brand new website and on Facebook - a new management of the OIFE page, a new start for the OIFE Youth group and a brand new group for Adults with OI.

Why? Shouldn’t OIFE just communicate with the National OI-Associations? Well, good point! But in order to support our members organisations, OIFE need to listen to each and everyone of them and of their members. Even if OIFE is not taking action in supporting single individuals in their daily lives, it can still have a relevant impact on them. How? For instance by guiding the European research community and highlighting which are the real needs and the open questions OIers and their family have.

And from this it comes up quite clear. OIFE can think, build, develop or implement whatever possible communication strategy. But if we do want it to work, we will need the help and support of everyone and each of the National Associations and also of all their members. Sharing should be the keyword, not only for research but more generally for all the information and the communication regarding OI.

Let’s help OIFE to be well known among our members, let’s invite people to join the meetings for youth, let’s promote the OIFE projects and activities among the members and let’s invite everyone to click on the “like” button on OIFE Facebook page, or to download the OIFE Pass from www.oife.org. This is the one and only way to boost OIFE awareness, not only in the communication or social media figures and statistics, but for the good of the future of the research around OI and therefore for the good of everyone of us!

Anna Rossi
communication@oife.org
What is the OIFE doing?

By Ingunn Westerheim

News in brief from the OIFE

A new year has begun and we continue our work to improve the situation for people with OI. I myself am trying to juggle my two hats of being OIFE president and the Conference Coordinator of the 13th International Conference on OI (OIOslo2017) at the moment. A combination that can be both challenging and sometimes very useful. Through the two hats I get a lot of knowledge about what's going on in the OI-community - both the scientific world and in the organisations. And without our member organisations, the OIFE is nothing. One of my goals in 2017 is to share more good examples from our member organisations through the newsletter, our webpages and social media. Because a lot of good creative activities are happening. And with the help of our new Communication Manager Anna, I hope we will succeed.

Meetings and events

We have attended a number of meetings the last 3 months, but they have mostly been internal meetings about collaboration on different topics. An important future event is our first physical meeting in the Executive Committee, which will take place the last week-end of February in Milan, Italy.

OIFE AGM 2017

The AGM 2017 will take place in Warszawa, Poland from May 26th – 28th. The venue will be Best Western Hotel Portos, ca 9km from the international airport. Mark the date! We will send invitations to delegates soon.

OIFE Youth Event 2017

The OIFE Youth Event 2017 will take place November 1st - 5th in the Netherlands. Stay tuned via our Youth Group on Facebook: www.facebook.com/groups/OIFEYouth

Rare Disease Day 2017 – topic: Research

Rare Disease Day - 28th of February 2017 is an opportunity to call upon researchers, universities, students, companies, policy makers and clinicians to do more research about OI: www.rarediseaseday.org Are you and/or your organisation going to be part of the event? Do you have creative ideas? Send them to office@oife.org

OIFE-passport

Thanks to the effort of the kind dr. Athul Bhaskar, we now have a Hindi translation of our important emergency document - the OIFE-passport on our webpage. The hindi translation will only we accessible online at http://www.oife.org
**OI-Community Meeting OIOSLO2017**

On Saturday the 26th of August there will most likely be a meeting for representatives from OI-organisations who are attending the OIOslo2017-conference. A potential topic is participation of people with OI/OI-organizations in research. But this is still being discussed. More information to come. Follow [www.oioslo2017.org](http://www.oioslo2017.org) for information.

**Support letter for CLAN**

CLAN is an Australian-based, not-for-profit, non-governmental organisation (NGO), who have been supporting OI-children in countries like Vietnam and Pakistan. They also work with other disabilities and diagnoses. CLAN contacted the OIFE to get our support for a letter to the WHO (World Health Organisation). CLAN’s goal was to include bisphosphonates for children with OI in the “essential medications” list of WHO. The OIFE supported the initiative and we hope this will make it easier for children with OI in countries where they don’t have access to this important treatment.

**Physiotherapy Consensus Project**

The OIFE has received a request from a newly established project in Germany. Their goal is to create a consensus paper on physiotherapy for children, and in this they need your help to find physiotherapists who are experienced in working with OI worldwide. Suggestions can be sent to Brigitte Müller: brigitte.mueller@unireha-koeln.de

**Adult initiatives**

The OIFE wants to gather more information about adult initiatives around the world. Please contact office@oife.org if you have information/tips on services that exist in your country for adults (only) with OI:

- Adult health initiatives/projects
- Clinics especially for adults with OI (existing or planned)
- OI-specialists focusing especially on adults
- Guidelines/checklists for treatment and/or follow-up of adults with OI
- Information material especially developed for adults with OI
- Research projects only involving adults with OI
- Other topics about adults & OI we should know about

**OI-guidelines in French**

Our French member organisation AOI has together with French professionals developed guidelines for treatment of patients with OI (in French language only). Are you interested? Then please contact the French delegate on France@oife.org

**Questions?**

Please contact president@oife.org
Au-pair with OI

By Marie Aubry-Brechaire

Dear OI community,

we all pursue our own dreams and what could be more empowering than seeing one coming true?

My name is Marie, I am now 24 and I was born in France. After having finished my master's degree in December 2015, I decided to put my new free time to good use by moving to an English-speaking country. My goal was to speak and write better English than I was taught at school because I really wish to work in a foreign country using English every day. This explained, I looked for a job opportunity and set a very challenging target. Which I don't recommend to us for I think we do it too often and put our health at risk. My true belief is that with a condition such as ours, we should, no, we must learn to take care of ourselves.

I left France in late March and stayed for five months in Ireland. But, beforehand, I had contacted people from the OIFE and other networks to make sure I had a few medical contacts there in case anything would happen. That was the least I could do. The family I found to welcome as an au pair, not a common one you had guessed it, was not at all familiar with our very special life but they made the effort to be interested in knowing a little more about it. Though, it was difficult to live there without anybody being aware of my physical capacities. First, because they didn't pay the same attention to my health and expected me to do more things than I was able to.

This is why I came back home exhausted but so happy to have lived this adventure. Second of all, because I felt I was in a dangerous position the whole time. Of course, this challenge allowed me to build up my confidence and helped me to strengthen my body in different ways. Nonetheless, an accident would have ended everything and made me go back to a place of fragility. Here is my advice, be wiser than me and you will enjoy your experience even more!

Ireland was a land of freedom because I lived there without any relatives, in a country I had barely known and in complete immersion. It is so good to be without any past, people only see what you show and it might feel like a rebirth. So go for it, invent a new self or just reveal the one that is waiting to become inside you.
Now, obviously I am planning all the necessary appointments but this period also gave me new ideas about my body. I came back with the firm intention to treat my scoliosis because I am 100% sure I can improve it, to get interested in physiotherapy for flat feet and to develop my muscles with the aim to protect my skeleton and to gain strength.

Irish people were exquisite, very friendly, also because I come from Brittany which is a region which shares the Celtic culture. The scenery there was breathtaking. Everything was new, from going to the supermarket, to driving and the food or the tax system. I felt very lucky to be born French when I heard of the Irish medical system. I would also say that alternative medicines and holistic solutions are more available than in France but with different guarantees. I started yoga in Ireland and I discovered something that was helpful for my mental health and my physical condition. Balance, core muscles, breathing are the keys of yoga and are the main challenges of our disease so, I was more than happy to practice.

You don't have to be as crazy as me to experience such feelings. Not every human being is made for travels. So look for your own source of happiness. Mine is for good living out of France in a country where English is spoken. It might change but today it is what feels the best for me. Thus, I am looking for a position in Ireland because the country and the friends I made appeal to me.

If I can't stop myself from giving advice, it may be related to my experience as an au pair, I sound like a mother, but also because I would like to hear more about stories of people going abroad with better support. Keep your mind open and formulate dreams, they could happen!

Best wishes, Marie marie.ab@zoho.com
Fundraising for OI Research ... by singing!

By Dagmar Mekking

For 5 years Care4BrittleBones has been working to improve the Quality of Life of people with OI by fundraising for OI Research. One of their key learnings is: Fundraising works best when people are having fun! And since many people get a lot of pleasure out of music, they have developed a 'formula' for companies, to have an amazing, engaging and fun evening whilst holding a charity concert for Care4BrittleBones.

A pilot project was recently held at Royal Dutch Shell. The opening act was performed by Mira Thompson, jazz singer and Care4BrittleBones ambassador. Thereafter 16 Shell colleagues sang with a professional band for an enthusiastic audience. They had been carefully selected through auditions and trained by a professional voice and performance coach, to ensure they are ready for the event. The winner of the evening won a "rock star package" at the Hilton Hotel in The Hague, in the tradition of John Lennon and Yoko Ono who once spend 7 legendary days making love in the Hilton in Amsterdam.

The evening raised 15.000 Euro for OI research! In addition the event won the first prize (10.000 Euro) amongst all charity projects Shell has gotten involved in during 2016. Shell already has plans for a repeat in 2017 and we are also in discussions with other corporations who have also started to become interested. It is clear that the event is one that has lots of potential for the future. Look here for a short video of the event: http://bit.ly/2jZNUph

Sing along

Are you also enthusiastic about music and do you know a group, company or organisation with 1,000 or more people who would enjoy "Singing for..."? Contact us on
info@care4brittlebones.org. With a professional band and vocal / performance coaching for singers, we are equipped to arrange a memorable evening ... and contribute to further research for OI.

Registration is open - OIOslo2017

The 13th International Conference on Osteogenesis Imperfecta will take place in Oslo, Norway from August 27 - 30, 2017.

Register at www.oioslo2017.org

Questions? post@oioslo2017.org
Hope for people with OI:
OI Foundation Nigeria

By Tarela Aghanti

In Nigeria, people with rare diseases such as OI are really suffering. No information and no awareness concerning OI and no care from the government. So after Steven’s birth I decided to move to the UK and got in touch with the BBS (Brittle Bone Society). This was eight years ago.

During an OI-conference organized by the BBS three years ago I met some Nigerian families and I realized how many children and families would be going through this pain and suffering alone in Nigeria. Not too long after that conference a doctor friend of mine called me from Nigeria to tell me he had an OI child born in his hospital and the father of the child was going to sue him, accusing the doctor for the easy breaking bone of the child without realizing the child has a medical condition and it wasn't the the doctor's fault.

Such kind of problems are always associated with witchcraft, evil spirit ect. People also believe the family or the child has been bewitched.

My heart desire concerning OIF Nigeria is to try and

• provide information and create awareness to the public and government
• support and encourage OI families
• link OI families in different states together so they don't feel alone and deserted
• Link OI specialist together
• Longterm aim: provide treatments
• Provide education for OI children
• And a lot more

During my visit in Nigeria in November/ December 2016, I have met some of the families and we have been able to link them up with each other to create a communication channel and to support each other. We have also been able to get a center for treatment and doctors who are willing to be trained to know more about the disease and to give treatment. We are a new charity that has just started, but we believe the charity all go a long way to help bring back smiles and hope for the future of people living with OI. For more information look here:
https://www.facebook.com/oifnigeria.org/
Get involved in ERNs

December 15th 2016 the European Commission announced the approval of the first 23 European Reference Networks for rare diseases (ERNs), among them the ERN for rare bone diseases (BOND).

Patient participation

ERNs are required to involve patients. In early 2016 EURORDIS developed a European Patient Advocacy Group (ePAG) for each of the ERN disease groupings. ePAGs will bring together elected patient representatives and affiliated organisations to ensure that the patient voice is heard. Through the ePAGs, patient representatives have been directly involved in the development of ERN applications, a great achievement and a milestone in increasing the role of patients in clinical care as it evolves in Europe.

Join a European Patient Advocacy Group (organisations)

If you represent an OI-organization who is interested in joining an ePAG you can register your interest using a patient organisation matchmaking tool: https://goo.gl/forms/BSX1YQSMs0Puoj4Q2

All patient organisations are encouraged to join, non-members and members of EURORDIS alike. As an ePAG-organisation, you will be consulted on specific ERN topics and the ePAG patient representative will relay your opinions back to your respective ERN Board. You will also receive information and updates on the activity of your ERN.

Join RareConnect online communities for your ePAG

As a patient representative (from EU or Norway) you can join the ePAG online community on RareConnect to stay informed about the activities of BOND (Rare Bone Diseases) and to connect with ePAG patient representatives and clinical leads to learn more about their work with the ERNs. First you need to register for Rare Connect: https://www.rareconnect.org/en/register

Once you have registered, please request access to BOND - Rare Bone Diseases choosing this link (you will be granted access within the 24 hours after your request): https://www.rareconnect.org/en/community/rare-bone-diseases-advocates

Become an ePAG patient representative (individuals)

86 ePAG patient representatives were in 2016 elected to represent the wider patient community in the development of ERNs. Rebecca Tvedt Skarberg representing OIFE and Jean Moitry from AOI are patient representatives in BOND in addition to Ines Alves who is representing achondroplasia (skeletal dysplasias).
ePAG patient representatives have an official permanent mandate to represent ePAG member organisations. The recruitment of these representatives is ongoing to ensure that patients are fully represented in the governance of each and every ERN. Members and non-members of EURORDIS are encouraged to apply. If you are interested in becoming an ePAG representative, please contact lenja.wiehe@eurordis.org or office@oife.org.

Artists with OI: Maija Karhunen - dancer

Who are you and what do you do?

My name is Maija Karhunen, I’m 29 years old and live in Helsinki, Finland. I mostly work as a dancer and performer in works of different choreographers and directors in Finland. I’ve lived in Berlin and Amsterdam, which still keeps me working around Europe as well. I also work as freelance journalist and art reviewer, I write mostly about the performing arts but also other forms of art and culture, as well as sometimes articles and interviews about politics, society and disability. In Finland I also work as editor-in-chief of a Finnish dance publication, trying to promote art critique and discussion about art in every level, among artists but also in a wider sense.

In what way has OI effected your art?

The art form that I work with concerns the body and often the theatre stage. So because of this I think OI and disability has a great effect but often in a subtle way. The works don’t many times deal with disability as a theme, but still they often provoke questions about what an ideal body is, what kind of bodies we can see on theatre stages, what the skills of a dancer are. For example, is it an important ability for a dancer or a performer to be able to walk? Many times audience, critics and colleagues might have misconceptions about people with disabilities but many times they also comment that after a while they start to get used to looking at a disabled body on stage and not focus on the disability so much.

I work both with and without the wheelchair, so many times the wheelchair is an object to work with. In one performance we built a function in the electric chair, so it could be remote-controlled, and it became a kind of an independent performer itself, a robot which seemed to have a personality of it’s own. Because the brand was Otto-Bock, his name became Otto.

Of course because of OI I need to solve a lot of practical issues and also think about risks when working physically. I never fractured anything when I was dancing, I think it could be because it’s often a sensitive state, listening to one’s own body and surroundings. When I work with other people in physical contact, it takes some time to find out what we can do together in a safe way, but this was never an issue. I think working with movement and body awareness has helped me a lot to know my body physically, cross some of my boundaries but also to know and respect them, and think about my body in a more accepting and appreciating way as well, as more multifaceted than just medicalized.
What projects are you currently working on?

At the moment I work with choreographers who are working with themes such as failing and hysteria. Both very interesting, so let’s see what comes up! Hysteria was a theme I was also interested myself for a long time as a woman with a risk of being overly medicalized.

I tour at the moment in Europe with some works that both are dealing with disability. In Dries Verhoeven’s installation work *Ceci n’est pas* I sit in a glassbox in busy public places in a fancy outfit drinking cocktails, smoking cigarettes and flirting with passers-by. The question is whether we can see a disabled person as an object of sexual desire. Marc Philipp Gabriel’s work AJIMA is a solo where we question projections that people cast on each other in social interactions.

It concerns all people but for a disabled person whose appearance stands out it can more extreme.

What kind of work do you most enjoy?

The moment of premiere and the performances is the most enjoyably and rewarding moment for me after rehearsing for a long time. I love being on stage, because many times I’m quite insecure as a person. But on the stage I feel like I’m in kind of control of things. There I can do things on my own terms and to some extent have an influence on how people see me. As a disabled person this can be quite an empowering experience and a powerful position to take. I like also work where I can really sweat.
News in brief

“Wheelchairs of hope” is an initiative to develop, design, manufacture and provide a wheelchair to children in need of mobility. The wheelchair is specifically designed for children as they wish to empower education through mobility. It will provide an integral solution of a good quality wheelchair together with the necessary training capabilities to local teams. For more information check the website: www.wheelchairsofhope.org

Once more a photo of a child with OI won a EURORDIS photo-contest: The Instagram Prize went to a photo called ‘The path to the dream’ featuring 5 year old Lomeiko. The photo shows her participating in the Toners Children’s Fashion Day in Belarus – although she had fractured three weeks before!

Denosumab trial looking for participants

The OIFE would like to bring your attention to a clinical research study currently studying the safety and efficacy of Denosumab in children with Osteogenesis Imperfecta (OI).

Amgen is sponsoring a multicenter clinical trial to study the safety and efficacy of the investigational drug Denosumab on bone mineral and fracture occurrence in children who have OI. Currently, 34 sites are participating in this clinical research study in the following countries: Australia, Belgium, Bulgaria, Canada, Czech Republic, France, Germany, Hungary, Italy, Poland, Spain, United Kingdom, United States.
Children ages 2-17 who have a diagnosis of OI Type I through IV are eligible for this 3 year clinical research study.

Visit their Clinical Trials website http://bit.ly/2kLfg3l to learn more and view a complete list of study locations. If you have any additional questions, please contact the Amgen Call Center at 001 (866) 572-6436. Their Customer Service Representative will be able to find a site near you and provide you with the Site Study Contacts; who will tell you more about the clinical research Study.

Disclaimer: The OIFE is not involved in the design or management of this research, and as such, is neither endorsing nor supporting this study. One of the goals 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.

Calendar

2017
February 24th: The 1st BBS Scientific Symposium, London, UK
February 28th: 10th Rare Disease Day (international event)
March 11th-12th: AOI Annual Meeting in Paris, France
March 31st – April 2nd: 12th OI Congress AHUCE in Oropesa del Mar, Spain
April 28th – 30th: AGM & family meeting NFOI, Oslo, Norway
April 30th – May 7th: OI Awareness Week (OIF in the US)
May 6th: Wishbone Day (international event)
May 19th – 20th: EURORDIS Membership Meeting, Budapest, Hungary
May 20th – 21st: SVOI Annual Meeting, Nottwil, Switzerland
May 26th – 28th: OIFE AGM in Warszawa, Poland
June 15th – 18th: DOIG Annual Meeting, Duderstadt, Germany
August 26th – 27th: OI-Community Meeting in Oslo, Norway
August 27th – 30th: 13th International Conference on OI in Oslo, Norway:
- www.oioslo2017.org
September 1st – 3rd: OI Austria 10 year anniversary, Wien, Austria
November 1st - 5th: OIFE Youth Event in the Netherlands

2018

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