



Osteogenesis Imperfecta  
Federation Europe

# Newsletter Issue 25

## In This Issue:

<b>Editorial</b>	<b>P. 1-2</b>
<b>Report: Int. OI Conference</b>	<b>P. 2-4</b>
<b>Report: Progress in Indonesia, Vietnam and Pakistan</b>	<b>P. 4-7</b>
<b>A talk to one's younger self: Back to the Future</b>	<b>P. 7-9</b>
<b>International OI-calendar</b>	<b>P. 10</b>

## Editorial

Dear Friends,

It looks like a dream come true!

When in 2009 I first met the OIFE team, I wouldn't imagine how it would be a part of my life, day-by-day. I was so new in the OI world, and just started an organization in Portugal...I would never have thought that only after one year I would be invited to be part of this amazing organization and would be surrounded by so many friends.

The OIFE is a non-profit organization, together

we have been growing into an organization recognized as leader in the O.I. world and partner of the O.I. scientific community... slowly, but with steady steps!

ONCE someone wrote, "volunteerism is a powerful means of engaging people in tackling development challenges worldwide. Everyone can contribute their time, skills and knowledge through volunteer action, and their combined efforts can be a significant force for achievement (...). Volunteering makes important economic and social contributions, contributing to a more cohesive society (...). It can be both challenging and rewarding and require you to use your skills in a new context. You can also transfer useful knowledge while gaining a greater understanding of the issues affecting other people."

Currently the OIFE works exclusively on its volunteers. These people spontaneously devote part of their time to the service of the O.I. community, without any compensation, just because they are focussed on developing new strategies and awareness that can lead people with O.I. to a better life.

Although not professional, these VOLUNTEERS have the strenght of a "fighting bull" because they are engaged to highlight O.I.

The different opportunities of access to diagnosis and treatment that are felt around the world, the stigma associated with being "different" and the lack of social support that is felt by most of the OI people, move us forward in this battle for our sons and daughters, for our beloved, for our friends and for OURSELVES.

This year we will have another excellent opportunity to make O.I. visible. The Topical Meeting 2015 is not only a scientific meeting, but also a major educational programme for OI people and families. Understanding your body and your disorder is one of the first steps to promote your health and avoid the negative effects of O.I. The Topical Meeting "Soft Tissues & Soft Issues" will also be an opportunity to bring the O.I. community

together and share a knowledge that can only be found when we bring together people from all over the world. If you want to be a part of this, please join us in September. We appreciate the collaboration of everybody to make this project grow. We are convinced that your interest will be invaluable to achieving our goal, because we believe that by joining forces in a true "unbreakable alliance" between professionals, patients, families and industry, we can play a fundamental role in the development of common medical and social interests, which may contribute to make the OI world a little better.

Céu Barreiros  
OIFE 's Treasurer  
Portuguese delegate



## Remember !

**OIFE youth weekend** Sept. 16-20, 2015 in Berlin, Germany  
Deadline for registration: June 15th

**OIFE Topical Meeting** «Soft Tissues & Soft Issues – OI is more than fractures»  
Sept. 17-18, 2015 in Oslo, Norway  
Early bird registration fee until July 1st

(for more information about both events see our website [www.oife.org](http://www.oife.org))

## International OI Conference and Global Communities Meeting

Report by Mary Beth Huber, Program Director, OI Foundation (USA) – October 2014

**The International OI Conference** provided the opportunity to meet and mingle with a large group of people (editor's note: about 200) who are all working to expand our knowledge about all aspects of OI. Participants included basic scientists, clinical researchers, representatives of University based research centers and OI family associations from around the world. While the centerpiece of the 4 day meeting was the formal presentations, there were many opportunities including the Poster Tour, breakfast and lunch meetings and social events to connect with each other. As a service to the non-scientist OI association members, the OI Foundation sponsored a Summary Session Monday and Tuesday afternoons. Dr. Frank Rauch provided an overview of the key themes from the day's presentations and answered questions.

Each day's presentations were grouped by themes. Monday's presentations focused on basic science and genetics. The first group of talks referred to work being done to understand mutations to COL1A1 or COL1A2. The second group looked at specific factors associated with recessive forms of OI. All of the talks referred to attempts to discover the exact mechanism responsible for how a mutation on a gene causes OI and to understand why there is such wide variability in OI symptoms. One set of talks on OI Type V and VI – types that do not have a type 1 collagen

mutation—opened up a discussion about why it is difficult to come up with one set of treatment guidelines for all people with OI and the probability that personalized medicine will likely be part of the treatment for OI in the future.

Probably the most important talk of the day was given by Dr. Brendan Lee about his work with TGF-Beta. This is based on findings from recessive OI and is leading to a drug trial. This would be the first drug for OI that is entirely based on OI research and not on osteoporosis work.

Tuesday's theme was therapeutic with speakers addressing multidisciplinary issues and surgical care. Sessions during the morning highlighted treatment with bisphosphonates and other drugs, long term evidence that physical therapy as an important factor in surgical and medical treatments, and a review of the data from the OI Foundation's Natural History Study. The afternoon sessions focused on surgical questions especially scoliosis.

Wednesday's theme was Non-Skeletal Issues. Presentations were made on heart issues, respiratory problems, updating growth charts for children with OI, quality of life studies, health questions of adults who have OI, and dentinogenesis imperfecta.



Many of the speakers were people who regularly donate their time to the OI Foundation including Drs. Frank Rauch, Cathy Raggio, Dan Green, and Paul Esposito, Francis Glorieux, Francois Fassier, Richard Kruse, Laura Tosi, Joan Marini and Jay Shapiro.

Presenters were very specific about what their work was showing.

By the end of the conference people were amazed at how much knowledge about OI has increased in the last 10-20 years and energized to continue looking for the next major breakthrough in basic science and clinical care.

**Global Communities Meeting:** The OIF hosted a half day meeting of representatives of OI Associations from around the world. Thirty-six people representing 15 countries attended. The agenda included a presentation by Tracy Hart on the NIH Grant and the opportunity for increasing international collaboration. Dr. Laura Tosi spoke on findings from the OI Adult Health Initiative Survey. Dr. Francis Glorieux answered questions about care for children and adults who have OI.

During the open discussion time, the question of awareness was explored. Awareness can be defined as awareness within the OI community; making people in the general community more appreciative of people who have OI; and as increasing knowledge among medical personnel and political bodies.

The group from Portugal reported that they do not use the words “wish bone” in their materials since they do not have any meaning in their culture.



(This idea was echoed by representatives from several other countries as well.) Instead, they refer to International OI Awareness Day, and use it as a kickoff for a month of activities aimed at making politicians, medical school professors and health care providers more aware of OI and the needs of people who have OI.

A second theme from the open discussion was the need to make health care providers and researchers more aware about OI. People spoke to the need to educate health care professionals about OI in general; to make them more aware of the variable nature of OI and more aware of OI as a life-long condition rather than only a concern for pediatricians. An additional concern was the need to make clinicians and researchers more aware of research going on outside their own country.

### **Physical Therapy/Rehabilitation Care for Individuals with Osteogenesis Imperfecta**

The OIF also hosted a half day program on the role of rehabilitation in treating and managing OI. Three physical therapists, Beth Jacks, Sheri Dawson, Reenee Donohoe and one occupational therapist, Kathleen Montpetit were the presenters. Thirty people were in attendance. The speakers covered many topics including a review of the medical literature about physical activity and OI, the role of aquatics for fun and therapy, the need to address obesity in the pre-teen, teen and middle age OI populations and the challenges of ensuring that adults with OI have access to necessary services. Important themes included:

- All drug treatments and surgical interventions are more effective when combined with a program of safe exercise
- Obesity is directly connected to loss of mobility
- Improved bone leads to improved opportunities to fully participate in more activities while still avoiding injury

Panelists stated that the goal for all of the work done by scientists and health care providers is to improve function for people with OI of all ages. In the medical literature, “function” means the ability to take care of self, and fully participate in activities at home and in the community. The meeting wrapped up with a strong sense that improving life for people who have OI is an important goal and one that is shared by the global OI community.

## Progress in Indonesia, Vietnam and Pakistan

Report by Kate Armstrong, CLAN

*Have you ever wondered about life for children living with OI in low- and middle-income countries around the world? Have you ever wondered what YOU can do to help? CLAN (Caring & Living As Neighbours) is an Australian NGO and our journey working with others to support OI Communities in Vietnam, Indonesia and Pakistan has been exciting so far. In this article we would like to share some stories about our work and invite anyone who may be interested in helping children who are living with OI in resource-poor countries of the world to contact CLAN directly and find out how you can get involved and help make a difference!*

Greetings from Sydney! CLAN (Caring & Living As Neighbours) is an Australian-based Not-For-Profit, formally associated with the United Nations Department of Information for Non-Government Organisations (UNDPI/NGO). CLAN is committed to helping children who are living with chronic health conditions in resource-poor communities enjoy the highest quality of life possible. Our work started back in 2004 in Vietnam helping children who are living with a range of chronic conditions, such as Congenital Adrenal Hyperplasia (CAH), and then Diabetes and Autism. CLAN first became involved in efforts to support children living with OI in 2011, and we would like to share a bit about our work with you here.

### Vietnam's OI Community comes of age

In 2011 CLAN was first asked to assist efforts in Vietnam to support children living with Osteogenesis Imperfecta, and this has been an incredibly rewarding experience so far... Whilst life with OI for those living in high-income countries can be fulfilling, inspirational and exciting, we soon learned that in low- and middle-income countries such as Vietnam, OI is more usually associated with pain, disability, despair and death. CLAN's experience with other chronic health conditions assured us that this did not have to be the case however, so CLAN was proud to collaborate with a range of stakeholders to bring Vietnam's OI Community together for the first time in November 2011.



*OI Club Hanoi 2014*

This first OI Club meeting in Vietnam was very emotional: children were not yet receiving bisphosphonates; fractures, severe disability, pain and premature mortality were a major issue; families did not have information on OI available to them in Vietnamese language; and families felt isolated and alone in their journey with OI. A video of that first meeting is online here:

<https://www.youtube.com/watch?v=27Jic12XUhE>.

Coming together as a national OI Community in 2011 was a pivotal turning point for families living with OI in Vietnam, and CLAN is proud to report that the community continues to go from strength to strength. Treatment for children with bisphosphonates has now been legalized and the majority of children are receiving therapy; ongoing education of health professionals and families alike is supporting a shift from a focus on palliative care to quality of life; children are encouraged to attend school and achieve to their full potential; and ongoing OI Club meetings and celebrations of Wishbone Day annually are connecting families and reducing isolation. An educational program for health professionals and families in 2014 that was sponsored by the Australian Embassy in Hanoi has been a critical ongoing investment in the lives of these children, and the future for the OI community in Vietnam is brighter than ever.

#### FOSTEO strides ahead in Indonesia!

In light of the rapid achievements for children living with OI in Vietnam, in 2013 CLAN was invited by health professionals in Indonesia to help them start FOSTEO, a national OI support group for families.

Indonesia's inaugural OI Club meeting was held in Jakarta in November 2013 and was a huge success. Explosive media interest in FOSTEO's first meeting helped launch this new community

with genuine flair, and things have never been the same again. Incredible efforts from paediatric endocrinologists across the country helped drive unprecedented change for the national OI Community.



*FOSTEO, a national OI support group for families.*

FOSTEO continues to take huge steps forward... Bisphosphonates are now prescribed legally for the first time; fundraising efforts by FOSTEO have been fun and exciting (including a fun run on Wishbone Day in 2014!); and extensive community engagement and communication through use of Watts App is transforming lives and empowering huge numbers of families every day to connect with one another and learn from one another so that the children can live happier lives with OI.

#### A New OI Community in Pakistan

Experience in Vietnam and Indonesia have given emerging OI communities globally new hope... When families are supported to come together as one, and connect with a range of partners, change is possible – and it can be profound and rapid! In 2014 CLAN was again asked to support the start of a new OI Community, this time in Pakistan. It was our enormous pleasure to travel to Karachi, and work with devoted doctors, allied health staff and families to launch Pakistan's first OI Club meeting at the National Institute of Child Health (NICH) in Karachi.

A more detailed report on this meeting is available online (here - <http://www.clanchildhealth.org/News/New-members-of-the-International-OI-Community-in-Pakistan>). CLAN is continuing to strategise with NICH around next steps to support this new OI Community. There are many challenges: understanding of OI is limited (new educational resources on OI were translated into Urdu for the Club meeting, but more are needed); mortality rates are

still high; surgical procedures are expensive; poverty overwhelms many families; mobility aids are largely unavailable; and the community will need support to ensure their 2015 Wishbone Day celebrations are enjoyed by all...

### Where to Next?

In the first instance, CLAN's commitment is to continue supporting our existing new OI Communities in any way that we can. Wishbone Day is a powerful way to connect families globally, and we sincerely thank the international OI Community for any efforts they can make to welcome the new communities in Vietnam, Indonesia and Pakistan into the fold. We have established a small fundraising page to support ongoing community development efforts for the OI communities we work with and would be grateful if you could promote this link: <http://makingadifference.gofundraise.com.au/page/LeaveNoChildBehindOI>

If you would like to ask any questions or get more involved in CLAN's work in any way please do feel free to contact us at [info@clanchildhealth.org](mailto:info@clanchildhealth.org).

## **Back to the future**

by Raul Krauthausen, translation: Olga Witthauer

**Once your wheelchair is fitted with all the gadgets, you'll miss nothing but a time machine for having a chat with your 14-year-old self. Blogger Raül Krauthausen would love a chance to talk to his younger self of 20 years ago and give him some piece of advice.**

I already upgraded my wheelchair with several gimmicks: among others, a USB adapter for charging my cell phone, and, just recently, a bracket for a portable tray table. As I'm looking out of the window over the roofs of Berlin and putting my cup of coffee down on the handy fold-away table, I'm dreaming of one more gadget for my wheelchair. How I'd love to equip it with a flux capacitor that would let me travel back into the past like Marty McFly, and give a few hints and tips to my 14-year-old self. That is because, in the course of my life, I have realized many things about my disability that I wish I had known already 20 years ago.

Here's my memo for the conversation I'd have with young Raul, provided that the flux capacitor will work out:

**Don't let anyone else decide what you are not able to do! Find out what gives you pleasure**

Dear 14-year-old Raul, in the years to come, you will - more often than your non-disabled friends - have someone rub your nose in all the things you (supposedly) are unable to do, say, becoming a soccer star or a roofer. Granted, this may be realistic at times, but on the other hand, you will discover many things that you will find great fun, and no one should discourage you from doing them. Not your parents. Not your teachers. Not your friends. Have faith in your dream. If you would like to work for a broadcasting station, apply for positions and record your own podcasts in your room. For the feeling of gratification will motivate you to do it more often. And when you get

more practical experience, work on your hobby and ask for feedback, you will succeed. Regardless of disability.

### **Leave your comfort zone**

People will often cast a pitying glance on you; and your very physique, your voice, and the scary word "Brittle bone disease" will make them compliment you even on small "successes". However, what is well-meant will not necessarily get you anywhere, but will rather keep you stuck in your comfort zone. It's easy to meet the low-set expectations towards you, but can you really live up to your own ambitions that way? If you feel bored, raise the bar, without fearing the odd failure, accept criticism and use it to improve yourself. Leave your comfort zone, travel as much and as far away as possible, and try out new things!

### **It's okay to ask for support**

If you realize that there are certain matters you can't handle on your own, why not ask someone else for advice and support. No need for you to be a hero all the time and manage everything without help, just to prove yourself. Everyone seeks support, you don't have to be an exception in that respect.

### **Connect with other people having a/the same disability**

You will hopefully have non-disabled friends as well, which is crucial for your own development. That way, you will get to know a different perspective - and they will get to know yours. Of course, there are certain issues you will prefer to discuss with disabled friends. That is just because non-disabled friends cannot relate to certain issues to an equal degree, for example, how it feels for a disabled person to fall in love with someone non-disabled. A mixture of disabled and non-disabled friends will do the trick and expand your horizons.

### **Move out of your parents' place as soon as possible!**

In no way is this advice meant to criticise your parents, it is just an important tip for your independence. As for all young people, living in "hotel Mummy and Daddy" is simply a luxury, but, once again, you could easily slip into a comfort zone that may strongly affect your development and the life of your parents. A personal budget and assistance will allow you to move into a flat share or live on your own, even with a disability. In hindsight, moving out early has been one of the most important decisions of my life. Sorry, young Raul, about giving that away to you now, but you will love it!

### **Be yourself**

Yes, I know, this sentence sounds as if I had read it on a tea bag, but once you, 14-year-old me, will reach my present age, you will possibly agree with me. Your disability will stay with you all your life, so come to terms with it. It is part of you as much as your hair colour. And that's a good thing! There's no point in feigning, no point in acting as if you could cope with everything by

yourself and your disability never was an issue. This will only wear you out. Your disability is not the sole reason for everything you do (or don't) experience. Most often, we are restricted by society. Never forget: whether you will be a nice guy or a jerk, it's your call. A disability may also offer the chance to discover alternative ways, e. g. to find a job where your own wheelchair user perspective is appreciated as an enriching contribution.

Unfortunately, in our society you have to achieve and work even more than your non-disabled friends may have to, simply because we don't yet have an inclusive society. That's why it is so important for you to keep putting yourself to a test, to check whether you are still the person you want to be. Be charmingly disrespectful towards people who don't believe in you.

### **Never refuse to take sweets!**

If someone is offering you chocolate, take it! Because it's yummy. Oh well, Raider is Twix these days, but for the rest, same difference.

Alright, I have to rush. The church will be struck by lightning at midnight sharp, and I need the power to get back to the future! Ciao, young Raul!

One more thing: the coloured leggings look funny, in 2014, those will be in vogue again. Back to the present: what advice would you give to your younger self, if you could travel through time?

Raul Krauthausen: <https://www.aktion-mensch.de/blog/blogger.html>

## **International OI-calendar**

### **2015**

June 4–7 Germany: National OI meeting in Duderstadt/Göttingen

June 6-7 Switzerland: National OI spring meeting

July 3–5 Australia: National OI Conference in Brisbane, Queensland

July 18-25 Denmark: Family Summer Week

Sept 16-20 Germany: OIFE youth weekend Berlin

Sept 17-18 Norway: Topical Meeting "Soft tissues & soft issues – OI is more than fractures", Oslo

Sept 18-20 Norway: Peer meeting for adults, Oslo

**Visitors are welcome to all events – please contact OIFE**

**Visit OIFE at Facebook!**