



Osteogenesis Imperfecta  
Federation Europe

# Newsletter

## Issue 19 – Sept. 2013

### Editorial

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Dear friends,

With this edition we start another series. For those of you who could not attend OIFE's Topical Meeting on Psychosocial aspects in OI last year in Lisbon, we will publish summaries of some of the presentations.

As editor I am particularly happy about feedback – so I have been asked to publish a report about the dedicated work of CLAN for families with children affected by OI in Vietnam.

Please share your special "OI experiences" with us here and inform each other about "what is going on" – this newsletter is meanwhile read by more than 500 interested people!

Stefanie Wagner

### Euphoria and OI – Are People With OI Allowed to be Sad?

Rebecca Maskos, Germany

**A short summary of my contribution to „Fragile Bones – Unbreakable Spirit?“**

**1st International Meeting on Psychosocial Aspects of Osteogenesis Imperfecta, Lisbon, Portugal, October 26-28, 2012, OIFE and APOI**

„Those OI people are severely disabled – but still they are so happy“ - „I have never seen so much esprit, cleverness and humour at a support-group- meeting ever!“ – „Well, don't mention the body, but at least she is so bright!“

Comments like these every one of us has heard at some instances and to various extent, often followed by theories about a shared „OI personality“. While this supposedly also includes superior intelligence, articulateness and assertiveness, the stereotype of the „always happy“ OI person somehow sticks out. People find it particularly interesting because it implies a heavy contradiction to the physical challenges like the pain of fractures and surgeries that people with OI frequently face.

Some experts of the medical field therefore even speculate about a „happiness gene“ that should be common to all OI patients. I personally find the idea of a biological cause of „OI euphoria“ too simplistic – since not all OI patients are the same, there have to be at least social elements that are able to trigger this „genetic euphoria“, - and then we are already at the point to ask about the nature of those social elements.

One could easily dismiss the notion of the „all-time-happy“ OI person also as pure „positive prejudice“ or „positive discrimination“ by able bodied outsiders: Watching an OI person laugh or be outgoing violates their assumption that living with OI is only about pain and suffering. Therefore, there supposedly

must be some underlying „mystery“ to that „outstanding achievement“ of being happy when one should actually be in a state of constant depression. We find this astonishment in able bodied person's encounters with various people with disabilities, attributing them some kind of heroic „charisma“.

But while I think it is not rewarding to ponder about the existence of a special „gene“, for too long, I also think it is not sufficient to let it all boil down to pure „positive prejudice“. I have to admit that there seems to be some universality concerning the observation of „all-time happy and clever“ OI people. Me as a person with OI and psychologist, I can see that in most of my OI friends and acquaintances, - a lot of time I feel like being part of a family meeting when I am at a meeting of the German OI Society, not only because we all look so similar.

Medical anthropologist Joan Ablon, who directed interviews with 55 American adults with OI, confirms this observation, well knowing that it is a stereotype at the same time (Ablon, 2010). Almost every person she interviewed seemed to be emotionally „up“, at various occasions, over a long time (she directed mostly two or more interviews). Being able to compare her findings with research that she did on other self-help groups she confirms the outstanding coping mechanisms of people with OI – resilience as she prefers to call it.

So there seems to be some kind of benefit that relates to the special circumstances of living and growing up with OI when choosing humor and euphoria as a strategy to present themselves to the outside world, like a lot of people with OI do.

I would like to present some ideas on this topic that by no means should be fixed and are summarized only in a sketchy way here. I also cannot claim to be able to prove them scientifically, but I would very much appreciate more research in this field in the future.

First let me say that in general, humor helps against hardship. It seems to be the opponent of fear, helping to gain control and to comfort. Some therapists even use humor as a therapeutical technique.

Fear and anxiety are feelings that OI people have to deal with quite a lot – be it their own fears of fractures, surgeries and pains or be it other people's fears and insecurities about the unusual bodies and life circumstances of people with OI. Many psychologists and sociologists write about how people with visible disabilities become social symbols of dependency, pain and suffering. Most of them would reject this stigma, but still have to deal with it. Humor helps in two ways: First it serves as an active way of refusal of the „pain and suffering“ stereotype. And second it helps to put able bodied people at ease – there is nothing to worry of to feel guilty about when encountering a „happy“ person with the disability. A lot of people with OI seem to be exceptionally apt at this technique of controlling anxiety and insecurity of the outside (able bodied) world.

Since all people with visible disabilities (and also a lot who are invisibly disabled) encounter pityfull and negative stereotypical labelling, but not all of them use humor as a „counter-technique“, there could be some additional factors associated with growing up as a person with OI. What seems striking to me in this context is the multiplicity of trauma that people with OI undergo – be it by fractures, intense pain, hospitalization or surgery. One could speculate if humor serves as a specific coping technique to face living with past and ongoing traumatization and retraumatization.

Being born with a disability, children also have to face managing their parents possible feelings of deception and narcissic wound about having an „imperfect“ child. Humor and a „happy face“

can be useful to cheer parents up and comfort them about the child's fractures already at a very young age.

While a lot of coping strategies like these work out well for people with OI, there are also some dangers to them that should not be overlooked. The euphoria can only be maintained at the expense of splitting off the grief about trauma, about the narcissistic wound and about the (albeit socially attributed) identity of „being different“. Since the grief can never be completely suspended, the individual has to engage in extra efforts to sustain euphoria. Efforts that can be strenuous and might still be unsuccessful, because „even“ persons with OI can become depressive at times and then overwhelmed by feelings that they didn't have the chance to learn to deal with yet.

Being happy and euphoric is a great thing, a strength and in grown ups a very mature coping strategy. It makes life with OI much easier and more rewarding. We should value this ability – while not forgetting to give enough room for opposite emotions.

Further reading:

Joan Ablon (2010) „Brittle Bones, Stout Hearts and Minds: Adults with Osteogenesis Imperfecta“, Sudbury, MA: Jones and Bartlett Publishers

## OI in Vietnam

**CLAN is an Australian-based, non-profit, non-governmental organisation (NGO) dedicated to the dream that all children living with chronic health conditions in resource-poor countries of the world will enjoy a quality of life on par with that of their neighbours' children in wealthier countries.**

The OI 2013 Project started first with a visit to Children's Hospital 2 (CH2) in Ho Chi Minh City (HCMC), where Assoc Prof Munns working with Dr Quynh from CH2 discussed some of the more challenging aspects of Osteogenesis Imperfecta (OI) management, and in particular discussed a few patients in detail. Education days for the medical staff were then held at Children's Hospital 2 in HCMC on 3<sup>rd</sup> May and over 80 health professionals attended for training.

From HCMC the team travelled to Hanoi, and began with a training day for health professionals at the National Hospital Paediatrics (NHP) in Hanoi on the 8<sup>th</sup> May. Many health professionals attended, and were keen to interact with the visiting specialists to learn more about current multi-disciplinary management models of OI in Australia.

The second ever OI Club (Support Group) meeting in Vietnam was held on the 9<sup>th</sup> May at NHP and around 75 families attended. The OI Club meeting was scheduled for a date near 6 May deliberately, to help families connect with the international [Wishbone Day](#) movement, a day of awareness held on 6 May every year.



Families and their children attended from all over Vietnam to learn about the management of OI and how they can best help their children. The day commenced with the screening of a music video of a powerful song about OI recorded by Ms Nguyen Phuong Anh, a young woman who is living a full and active life with OI in Vietnam (music video below). The song was written by Mrs Jessamine Rhea, a close friend of the Filipino OI Support Group Network, and the words offer a lot of encouragement and optimism to those living with OI. Families in Vietnam knew Phuong Anh from her appearance on Vietnam's Got Talent, and were thrilled to see her performing a song just for them: <http://www.youtube.com/watch?v=XSbR2AiwWN8>

Another video screened for families was one developed from photos of the first OI Club meeting which was held in November 2011 and the many children in the audience delighted in seeing themselves on the screen: <http://www.youtube.com/watch?v=m8gxKz-p5yc> CLAN is very fortunate to have the support of media company [C3Vietnam](http://www.c3vietnam.com) who produced these videos and also filmed the recent meeting. Dr Craig Munns and Helena Young presented at the meeting and this was followed by a lively Q and A session.



Families at the OI Club meeting enjoyed socializing over lunch. Later in the day the OI Club executive members were elected and there was an opportunity for discussion of the issues faced by families. We are all hopeful that the life changing medications, bisphosphonates, will soon be available to children with OI in Vietnam. The media also attended the meeting giving much needed publicity to the lack of availability of medication for these children.

Huge thanks to everyone who made this day possible - especially the many families who travelled such long distances to attend. CLAN and our partners in Vietnam are excited about plans in place to continue efforts for children living with OI in Vietnam in 2014, and we really welcome you to join us as partners in this endeavour. If you would like to make a donation to support the work of CLAN and the OI Community of Vietnam please donate here: <https://makingadifference.gofundraise.com.au/page/OIVietnam>

## Around Portugal with OI

Céu Barreiros, our Portuguese delegate

**The “Volta a Portugal” is a very important and well known international competition for bicycle riders. The participants have to get through several stages leading from city to city around the country. They all have one goal: the yellow T-shirt which means “victory!”. APOI, the Portuguese OI-association, thought it could be a good idea to somehow copy the “volta” in order to raise awareness for OI.**

It is very difficult to estimate the number of OI-affected people in Portugal because there is no official registry for the disorder. In consequence, a lot of patients are not (yet) diagnosed and have no or limited access to appropriate treatment.

All the difficulties felt by OI families regarding support, the lack of knowledge about OI (not only in the society in general but also among health professionals), the lack of legal protection for OI people, the lack of Reference Centers for OI in the country and of support structures that might support a better social integration of OI-people, lead APOI’s Board to develop a project that might be implemented on a national level and that might have impact at all levels (OI people and families, health professionals and general community).

“Volta a Portugal com a OI - Around Portugal with OI” is a project that aims to raise awareness for OI. It consists of temporary exhibitions (with posters and an explanation of OI that is easy to understand) in hospitals around the country. By involving the families in the project we also expect that OI people become active participants defending their own interests and help them to “have a word” in the development of strategies for better OI support.

The hospitals are invited to participate in the project allowing them not only to provide health services, but also being partners for social projects. By implementing this project, APOI also made OI known to the governmental institutions and so now gets the support of the “National Institute for Rehabilitation” and the personal support of the Director of the “General Health Board”.





A personal impression by Antónia Sequeira:

"Our "Volta" didn't begin on the road. It started in hospitals in Alcoitão, and many cities like Lisboa, Setúbal, Santarém, Coimbra, Porto, Faro and Beja. This time the families were in their hospitals not for reasons like accidents and fractures, but with smiles, friendship and solidarity to all people with OI. We shared happiness, information and experience and we talked to health professionals about living with OI. There was no competition in our spirit, but we also wore yellow!

Our "Volta" is not an annual competition and has not only one winner. Like climbing a mountain, we will continue our struggle for a change in mentalities and we will continue to raise awareness for OI so that the victory can be shared by all of us. Our dream does not stop with our "Volta". OI means a continuous fight, but also a lot of victories.

## Clinical Meeting on OI to be held in Baltimore, Maryland

Dr. Jay Shapiro of the Kennedy Krieger Institute in Baltimore, Maryland and the OI Foundation will host the 5<sup>th</sup> Annual Clinical Care Conference to be held November 6-8, 2013 in Maryland. The meeting titled, "Update on Managing Clinical Care Issues in OI" will examine standard and emerging treatments for pediatric and adult OI. The conference is open to physicians, nurses, physical and occupations therapists, genetic counselors and other professionals who care for OI patients.

There is no registration fee for this meeting, and is sponsored by the Charitable and Research Foundation and the OI Foundation. To view the conference agenda and to register visit [www.oif.org/ClinicalMeeting](http://www.oif.org/ClinicalMeeting) for more information.

## **Dates to remember**

2013, Nov 6<sup>th</sup> USA: Clinical Meeting on OI

2013, Nov 8<sup>th</sup> – 10<sup>th</sup> Spain: International youth weekend – contact: [youth-coordinator@oife.org](mailto:youth-coordinator@oife.org)

2013, Nov 8<sup>th</sup> – 10<sup>th</sup> Spain: AHUCE OI Congress near Tarragona – guests welcome!

2014, May 6<sup>th</sup> International WISHBONE DAY – OI-awareness all around the world

2014, June 19<sup>th</sup> – 22<sup>nd</sup> Germany: DOIG Meeting in Duderstadt – guests welcome!

2014, Aug 1<sup>st</sup> – 4<sup>th</sup> USA: National OIF Conference in Indianapolis

2014, Sept 18<sup>th</sup> – 21<sup>st</sup> Finland: OIFE Annual General Meeting + 35 years Finnish OI Society

2014, Oct 11<sup>th</sup> – 14<sup>th</sup> USA: International Scientific OI-Conference in Wilmington, Delaware

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