



Osteogenesis Imperfecta
Federation Europe

Newsletter

Issue 22 – May 2014

In This Issue:

Editorial

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Page 1 Dear friends,

Interview:

Taco van Welzenis talks to Raúl Aguayo-Krauthausen Pages 2-4

Tori's Story Pages 4-5

News in Brief Pages 5-6

International OI-calendar Page 6

The OI world is changing drastically nowadays – we are now in the position that Scientists all around the world are more and more interested in OI and many are working on new strategies for its treatment. New OI mutations are found every year now, OI is no longer only a pure “collagene disorder” and not every form is a dominant type, but recessive inheritance is found in some very rare types and we begin to understand why we all are so different – but still so similar to some others.

Years ago we all saw NO real sense in finding out the exact genetic mutation of our disorder, but recent contacts to scientists and representatives of the pharmaceutical industry have made us aware HOW important and helpful it can be for us to know about our individual special mutation. New therapies have been found that seem promising for OI people with a very special, very rare “new type” – so it gets more and more important for many of us to look deeper into the exact “background” of our OI.

The OIFE is in close contact and cooperation with OI-specialists, treatment centres and national OI-associations all around the world and will be present at the coming International OI Conference in October for you.

Now let us all celebrate OI-awareness day on 6th May – Happy and successful “Wishbone Day” to all of you!



Ute Wallentin, OIFE President

Interview: Raúl Aguayo-Krauthausen, a young man with a vision on social change (who happens to have OI)

33-year old Raúl lives and works in Berlin. Although born in Peru, he moved to Germany with his parents at a very young age. There he studied communication sciences and worked in advertisement as well as for a popular radio station where he was occupied with its internet presence.

Raúl is a very socially engaged guy, and he was able to combine this social engagement with his technical and creative skills. The result has been several innovative projects carried out under the umbrella of "Sozialhelden" (Social Heroes), an association aiming at social change which he started together with a cousin. Current projects by Sozialhelden deal with the portrayal of disabled people in mainstream media and the mapping of accessibility for wheelchair users. Raúl has become quite well-known in his home country of Germany and received several prizes like the highly prestigious "Bundesverdienstkreuz" (Federal Cross of Merit on Ribbon) in 2013. In January of this year a book by his hand appeared. Today we ask him some questions for our newsletter.



Raúl, Picture © Esra Rotthoff 2013

How did Sozialhelden come about?

We started around 2007 in Berlin, at first with projects that did not focus on disability. Sozialhelden collected deposits from recycled bottles and donated the money to various social causes. By doing this on a large scale a sizeable amount of money could be brought together. Today we are 10 people. Our name Sozialhelden should be seen with a bit of humour, we do not literally claim to be heroes, often we prefer to use the names of our projects instead. With those projects we seek to actively make improvements in society instead of waiting for the government to take action. At the same time society still has to make big changes as well, but with our projects we have the possibility to increase awareness.



So can you tell a bit more about Wheelmap.org?

One day I was out with a friend, we discussed how accessibility is an issue for me as user of a powered wheelchair and we realized that there

should be a lot of knowledge about accessibility among wheelchair users. There just was no good platform to share this knowledge. That is how the idea came up for a website that maps accessibility for wheelchair users in an easy way. Anybody can enter data on accessibility of various places. The result is shown on a map, in red, green and orange the degree of accessibility of objects is indicated; red obviously means that a place is not wheelchair accessible, orange means partly accessible and green fully accessible. It also shows places in grey which have not yet been assessed. There is also a mobile phone application available now for Wheelmap.org. The project has been online for 4 years and meanwhile it is the largest of its kind with accessibility data for over 400.000 objects. Many are in Germany but the project is growing rapidly especially since the launch of the mobile app. Anywhere on earth people can enter the accessibility data. It can be an issue that not everybody needs the same degree of accessibility. To help with that we now offer the option that people can also upload pictures so that way you can judge by yourself if a place appears accessible enough for you.

How disabled people are shown in the media is also a thing you find very important, right?

Yes, people with disabilities are often portrayed very stereotypically and often there is too much emphasis on the disability. We would like to see that disability is treated as just one aspect of a person not as the only one that matters. It are those all too commonly used phrases – often by non-disabled people - like “bound to his wheelchair” and “suffering from her disability” that we would like to see disappear. We provide examples of alternatives on the website of our project “Leidmedien”. We have good results with this project and get a lot response from journalists. We also give workshops and the project even makes a profit at the moment. The goal is that disability will become more visible in the mainstream media in future, and that it is portrayed in a normal way.

Do you think humour has a role to play in acceptance as well?

I would prefer to call it lightness of communication. So avoid making the topic heavy by asking for compassion, invoking a bad conscience, or lamenting about your fate as a disabled person but instead communicate actively and live in a self-determined way. That is at least what we try to do with Sozialhelden. If you need humour to get accepted you risk making a clown of yourself.

On your website I noticed another project called “2 Sames”, here you show examples of disabled and non-disabled people having relationships.

Yes that is meant to show the world it is possible, and to break the taboo on disability and relationships. The project now runs for 10 years already, it is carried out privately by me and a friend, I think it is still necessary. I am not old enough to say if things are a lot different, but I do believe the perception in society is slowly moving in the right direction.

You recently published a book, can you tell us what it is about?

Well it is mostly an autobiography. It is titled "Dachdecker wollte ich eh nicht werden – Das Leben aus der Rollstuhlperspektive" (I never really wanted to become a roofer – Life from a wheelchair perspective), in it I want to show my philosophy that we should treat each other as humans and not according to arbitrary labels like "sick or healthy", "disabled or non-disabled", or with misguided compassion. (Raúl's book is available via Amazon, it's in German).

Do you think inclusion can best be achieved at a national level or is there a task for Europe as well?

Europe must take care that all of its countries provide equal opportunities for disabled people under the law as well as protection from discrimination, it should look at the Scandinavian countries as an example of best practise. With some of these issues Europe has an important role in setting a decent standard otherwise countries – and I suspect this is certainly true for my country Germany – will only make the minimal changes that do not really help in reality.

For further info:

His website: Raul.de

The Wheelmap: www.wheelmap.org

Leidmedien: leidmedien.de

(see also many clips on Youtube)

Interview: Taco van Welzenis

Tori's Story

Osteogenesis Imperfecta, OI, is not something I'd put on my Christmas list if I didn't have it already. Medical literature says that people "suffer" from it and arguably that's not too far from the truth. Breaking bones repeatedly (be it 20 times or 200) is painful and, most of all, boring. I don't even know the half of it really, given that I've never had surgery or spent more than 5 days on the trot in hospital. I don't envy those who have and I know a lot of them!

Disregarding the above facts, which you could call the harsh realities of OI, the biggest challenge to continually face is other people and their attitudes. The misconceptions, usually borne out of ignorance and nothing more, often cause more emotional pain than the chronic physical pain that someone like me is used to. As a child you're generally kept sheltered from that sort of thing or, if you have fun parents, you make fun of it by sticking your tongue out at people who stare.

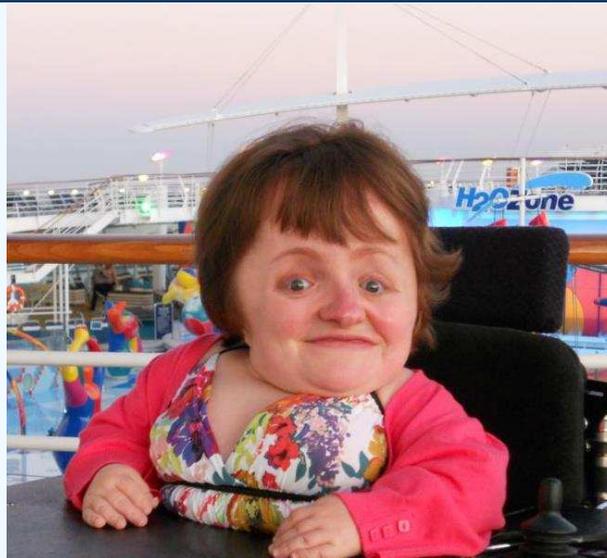
As a teenager or young adult sticking your tongue out doesn't hit the mark anymore. You're bored of being "different" and you don't feel "special". It's different when you're a kid because special is cute; or that's what you're led to believe!

On a personal note, I feel that my short stature doesn't exactly help me out when it comes to fighting stereotypes. I'm 2 foot 11 inches tall; there are 2 year olds who are as tall as me! This is why raising awareness is so crucial.

I will probably live with boring chronic pain all my life but by raising awareness I won't have to live with patronising comments or looks from people who, through no real fault of their own, just don't understand.

That's why I am fully behind the Brittle Bones Society's new Cool Bones project that has been set up to provide support and advice for young people going through that difficult stage in life. Only people with OI can understand how it feels and that's why it's important bringing the young people together; to show them that they're not alone.

In my opinion I don't "suffer" from OI. I fight the barriers it imposes, I live with and despite it and, if I'm honest, I wouldn't change myself at all!



Tori Siegler, member of the Brittle Bone Society, UK

News in Brief

Wishbone Day: Don't forget about Wishbone Day on May 6th. This is the official website: <http://www.wishboneday.com/>

Portugal: The Portuguese government wants to close down the only Children's Hospital in Lisbon. APOI (the Portuguese OI-association) is therefore organizing the "Mothers Day Walk", a 10 km run/ 3 km walk, on May 4th in partnership with the doctors from the Lisbon Childrens Hospital. This is aimed to advertize the need to keep the Children's Hospital and also to advertize Wishbone Day. Around 2500 people are expected.

Furthermore, during June and July 2014, APOI will have a series of workshops where people with OI can learn decorative arts so they can create things to be sold in handicraft markets. With this project APOI expects people with OI who are not able to work to earn some money and at the same time show their work to advertize OI and APOI.

Italy: As.It.OI will celebrate its 30th anniversary combined with the **30° National Congress** that will take place in Rome from 30th May to 1st June 2014. Please follow our website (www.asitoi.it), the official Facebook page (www.facebook.com/asitoionlus) and twitter profile (@asitoi) for pictures and also for info on possible live streaming of some session of the meeting. During those days we will also celebrate **Wishbone Day** even if with a delay.

Neridronate in Osteogenesis imperfecta. Neridronate is a bisphosphonate registered in Italy with Osteogenesis imperfecta as an approved indication for use in infants, children and adults. The

drug is in the Italian market since 2002 and regularly prescribed by specialists for this indication. Neridronate is now available from Clinigen (www.clinigengroup.com).

Maleah, a nice and funny 9 year old girl with OI explains OI and her life with it: watch the youtube clip in english <http://youtu.be/lAhs-piej1o> and here is the clip with Spanish subtitles: <http://vimeo.com/92339934>. French will follow soon!

International OI-calendar

- 2014, May 2-4 Denmark: DFOI Annual General Meeting in Copenhagen
- 2014, May 3rd Belgium: ZOI celebrates Wishbone Day
- 2014, May 6th International WISHBONE DAY – OI-awareness all around the world
- 2014, May 10th The Netherlands: VOI Meeting
- 2014, May 30th – June 1st Italy: 30th anniversary As.It.OI + 30th National Congress in Rome
- 2014, June 19th – 22nd Germany: DOIG Meeting in Duderstadt – guests welcome!
- 2014, July 20-27 Denmark: DFOI Summercamp in Hasle Feriepark, Bornholm
- 2014, Aug. 1st – 4th USA: National OIF Conference in Indianapolis
- 2014, Aug. 22nd UK: OI conference in London
- 2014, Aug. 30 Italy: "Fragile Rock" together with Italian youth meeting
- 2014, Sept. 5-7 Belgium: ZOI family weekend in Maasmechelen
- 2014, Sept. 18th – 21st Finland: OIFE Annual General Meeting + 35 years Finnish OI Society
- 2014, Oct. 11th – 14th USA: International OI-Conference in Wilmington, Delaware
(medical/scientific conference with pre-meeting for patient representatives)
- 2014, Nov. 23rd Belgium: ZOI autumn meeting in Malle
- 2015, July 3rd – 5th Australia: National OI Conference in Brisbane, Queensland

**Visitors are welcome to all events – please contact OIFE
beforehand under info@oife.org!**

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