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Did you know that...

Editorial

Dear friends,

at regular intervals of three years OIFE is organizing a topical meeting. In 2012 the topic will be about psychosocial aspects of OI. Below you find more details and the possibility to pre-register.

Toke, a Danish OI-boy is trying to get the world's largest postcard-collection – you can help fulfil his dream if you comply with his mum's request.

As announced in the previous newsletter you find a very interesting and also personal report from the perspective of OI-adults. Taco van Welzenis gave a speech about that topic at the Scientific Conference in Dubrovnik, Croatia this year.

Hopefully you will enjoy reading the newsletter!

Stefanie Wagner

Pre-registration now open for OIFE Topical Meeting "Fragile Bones - Unbreakable Spirits?"

OIFE is currently busy organizing a topical meeting about psychosocial aspects of OI. The title hints at the idea that people with OI sometimes have a remarkably strong spirit. Yet we placed a question mark behind this in order to study this "fact". On the one hand we believe that some experiences can make a person stronger while on the other hand we can think of a lot of psychosocial stress arising for people with OI and their families. It is all these aspects; from handling the fear of fractures, parenting in OI families, effects on healthy siblings and influences of childhood experiences on the OI adult later in life to the positive effects of living life with OI that we want to discuss.

Our meeting is to be held from 20-22 April 2012, near the town of Fredericia in Denmark. At the same venue will be held our next OIFE AGM, a national Danish OI meeting and an OI-Norden meeting all around the same time. "Fragile Bones - Unbreakable Spirits?" is open to all those interested, be it professionally as psychologists or social workers or as experts by living a life with OI. The language is English. We hope it will be a stimulating and inspiring event for all that could be a stimulus to further research in this field. Not all program details nor the exact participant fee are known at this stage. Therefore we

ask everyone who wants to be notified about further developments to fill out a pre-registration form. You can find the first announcement with a link to the pre-registration form at the top of the page here:

www.oife.org/projects/unbreakable_spirits/unbreakable-spirits.html.

Pre-registration is not binding, however in case of overbooking we will give priority to pre-registrants. You can also contact the chair of the organizing committee directly at Netherlands@oife.org.

You can help OI-boy realize his dream to get world's largest postcard collection!

Annika Wiinberg, an OI-Mom who has OI herself, asks for her son:

Dear non-Danish friends, I have a son soon 11 years. He is collector of postcards from around the world. Toke has OI like me. He has Denmark's largest collection of nearly 30,000 postcards and dreams of getting the world's largest collection. You can send him a postcard to the following address. Thank you very much!

**Toke Wiinberg
Hemmegårdsvej 15
5863 Ferritslev
Denmark**



Toke with some of his postcards

(editor's note: We will keep you informed if Toke succeeded!)

We mourn the death of Günter Averbeck who unexpectedly died on December 3rd. For many years he was a very dedicated chairman of the North-Rhine-Westphalian branch of the German OI-Association.

It doesn't stop at 18 – special concerns from the perspective of OI adults

By Taco van Welzenis

Student Exchange program:

Would you like to host an OI-student? Please write an e-mail to office@oife.org if you can help. Thank you!

Two months ago I attended the 11th scientific conference on OI in Dubrovnik, Croatia. I felt very honoured that Ute Wallentin and me were given the opportunity as representatives of the OIFE to speak at this meeting. After all we are not scientists and speaking time is a scarce commodity at such events, (in total 57 talks were squished in the overloaded program). I think it should really be seen as a very positive development that the organizers understood the importance of cooperation between OI people and scientists and that OIFE has gained respect among scientists as a serious partner in the OI field.

Ute, in her talk, had already presented about OIFE activities at the start of the conference, so I looked for a different topic. My over 40 years of OI experience are perhaps enough to fill a small OI-encyclopaedia, so I needed to focus on one specific thing. Being an OI adult myself and having organised activities for the OI adult group in the Netherlands I thought that was a topic close to my heart. Also relatively little research is carried out on adults with OI, as usual the conference program was divided into different sessions, there was for instance a session on mouse models of OI, while other sessions dealt with bone biochemistry, bisphosphonates and orthopaedics. All very important topics of course, but the adults were a bit underrepresented. Although I have to say that the organizers did try this time by adding a special session on adults in the program but from the 7 talks in this session at least 4 dealt with children, and only one was clearly about adults. So I thought a presentation about adults could be an addition to the program. Below I have tried to give a representation of my talk.

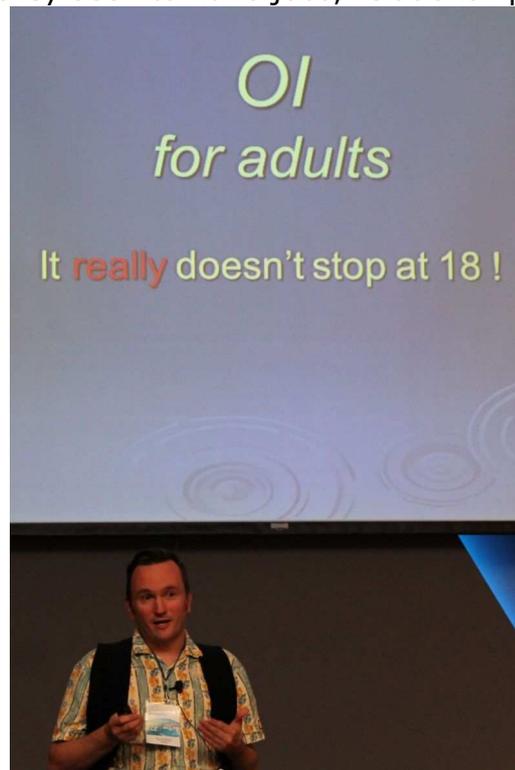
At first I analyzed the question why adults with OI get less attention. First of all every textbook on OI will tell you on page one that "it gets better after puberty". Now that might be true for the fractures, but fractures are not the whole story of OI. Hearing loss, chronic pain and fatigue are often problems which first arise or start to become problematic in adulthood. And of course each tooth that breaks does not grow back either.

Compared to fractures the problems of OI adults are of a more chronic and invisible nature, pain or hearing loss are not so visible to the outside world, and certainly they are less spectacular than the many fractures of childhood, but nonetheless they can be quite disabling to the individual. Also less fractures does not mean you have no fractures at all, actually when I look at my own case, I certainly became less fragile after puberty but the result was that I also became more active. So in total I have had almost as many fractures before as after puberty, and when you look into old age, people with OI do get more fragile once again and fractures take more time to heal than when you are young. I think many adults who

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can walk fear the day that this big fracture will happen that can put you in a wheelchair for good.

Another factor is that many children have – often concerned – parents who are willing to do everything in the world to help their OI child. For instance most OI associations in the world have started as parent organizations. Of course it is very good for an OI child to have caring parents, but the OI adult has to take care of his own life. And in the case of OI that includes dealing with doctors, insurance companies and often a lot of bureaucracy to get things done. At the same time OI adults have the same goals and expectations in life as everybody else. (We are somewhat normal after all!) In other words they seek to have jobs, relationships, families and a social life.



Taco van Welzenis giving his talk at the Scientific Conference

Psychology could be another factor, speaking for myself I can say that I have seen more than enough hospitals and doctors in my life. If possible I avoid them and often treat my own medical problems. At the same time I think I have somewhat accepted it as a part of my life that I have pain and health complaints on a daily basis as a result of my OI, so I will not run to the doctor that easily, an attitude which I have seen among many OI adults. Therefore often doctors will not be aware of what is going on with me either. When was in the emergency room in a far away city with a serious fracture 2 years ago the emergency doctor told me to go to

Please inform us if you change your e-mail address. Thank you!

“my own treating orthopaedist for advice” – not knowing that I do not have one since I have been able to treat most of my recent fractures myself! Other doctors have searched in vain for my X-rays – again often they have not been made because I was not in hospital. I am not saying that this avoiding behaviour is necessarily a good thing, but it is a fact.

However I do go to the doctor when something new appears, like my hearing trouble, or something where I know they can help me. For my presentation I had counted how many health care professionals I visited in the past 2 years. I was a bit surprised to see it where 26 different ones. In part this was due to things like doctors retiring or sending me to colleagues for second opinions etc. but still I went to 10 different hospitals and clinics in 5 cities. Each of these health care professionals would only treat one little part of my health. Almost none of them would cooperate or share information. So that means my healthcare is actually quite scattered all over the place. With one

OIFE's objectives:

- *Representing its members on a European level
- *Presenting the problems and needs of people with OI to national and international organizations
- *Collecting and publishing information about OI
- *Promoting research on all aspects of OI
- *Supporting member-societies by the exchange of information and experiences

notable exception I did go to an OI adult clinic. There I was seen by a number of doctors on one day – and together they came up with advice for me. Now I know that I am lucky to have an adult OI team available to me, and it only has been in existence for a few years now, but in many countries the care for OI is often aimed at children or it is provided in a children's hospital. That again is no help, many adults feel left to themselves once they have to say goodbye to the OI children's team when they get too old for that.

Solution wise I think that is one of the main things, the establishment of more OI teams for adults. That way expertise can be gathered and the care for adults becomes less scattered. Such a team should focus on adult OI issues, for instance it should have a gynaecologist on board to assist OI woman who (want to become) or are pregnant. It should know how to operate on OI ears, it should look carefully at posture and fitness in order to give advice about the optimal way to stay in shape and mobile, it should monitor things like bone density and heart valves in order to be in time before problems occur. And it should have some expertise on pain relief. Another crucial point in this is that they really listen to the the person with OI. How often didn't I encounter an arrogant attitude from doctors who thought they knew better, while in fact that was often not the case. Also it should be understood that an adult with OI has meanwhile learned to deal with the problems of OI in his or her own personal way. If an advice goes completely against this way then chances are small that the advice will be followed.

I then concluded my presentation summing up some of the advantages of being an OI adult (in order not to finish on a negative or complaining note). Things like seeing the relativity of certain things, focussing on happiness, using the available modern technology to your advantage in a creative way and succeeding with things despite obvious problems.

International OI youth meeting 2011 in Schoonoord, The Netherlands

By Stefan from the organizing team

It had been announced in spring this year and now (sadly) it already is history: the International OI youth meeting 2011. This year the Dutch OI youth organization had the privilege of organizing this legendary event. Since it was such a huge success last year in Belgium, the Dutch had a lot to live up to.

The meeting started on Wednesday. On this first day, everything had to be prepared to welcome the participants from Holland and all other foreign countries. The organization started early so everything would be ready when people arrive. In total, 34 people from 7 different countries had registered for the meeting, a number to be happy with! The meeting took place in and around a beautiful, spacious accommodation that was fully adapted for people with a handicap.

And because there were so many of them, all the space that was provided was needed! At 3 o'clock in the afternoon, people started to arrive. They were welcomed with coffee, cake and a lot of enthusiasm. Because many of them had a long journey there was no further program for this day. After dinner there was an introductory game but the rest of the evening was all about relaxing, chatting with old friends and meeting new people.

On Thursday, a busy program was scheduled. In the morning, the group visited Orvelte (a small 'museum village' with several attractions and workshops) where they also participated in a glassblowing workshop. After everyone had lunch back at the accommodation (for the transport to all the different activities, taxi buses from the Red Cross were used), a visit to an organic farm was planned. The group was welcomed by farmer Albert and his wife with coffee and a presentation. In his best english and with a little help from others, he explained everyone what it means to work on a farm. This was followed by a tour where everyone got to see the farm and a lot of cows. For dinner that evening, there were pancakes on the program. But before dinner there was a djembé workshop planned. Several drums in different sizes were available for this. With the guidance of a professional djembé player everybody was able to go totally wild with a lot of rhythmic noise. Seeing the enthusiasm of a lot of fanatical djembé players was really great.

After this session the group became hungry, so it was time for those pancakes. When everyone had returned to the accommodation in the evening it was (again) time to chill. The karaoke set was very popular this evening (and during all the other evenings of the meeting).

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Thank you!



Friday morning was a tough one. At seven o'clock breakfast was served and for some people this meant getting up at a quarter past six. The reason for this was a visit of a flower auction in Eelde at a quarter to nine. Fortunately there was some time left to sleep during the trip. At the flower auction the group was welcomed and provided with a presentation about the ins and outs of the auction followed by

a tour of the auction halls. Afterwards it was time to return to the accommodation where people were able to enjoy a free afternoon and very beautiful weather, a perfect combination! Worthwhile mentioning that there also were a small sauna and hottub available! When everybody had rested a little bit, a gourmet meal was served (very nice!). The rest of the evening was filled with typical Dutch games. Some of these games weren't even known to the Dutch people. Conclusion: a big success!

And then it was Saturday already, the day before departure, and also the most hectic day of the entire meeting. The group was going to Amsterdam to visit the national museum and undertake a cruise through the canals of Amsterdam. The touringcar left a bit later than planned because it took some time to fix the wheelchairs. But that couldn't spoil the fun, it still looked like it was going to become a very nice day in the biggest city of the Netherlands. And so it was, the weather was great and the group enjoyed the sightseeing.

There were many enthusiastic stories afterwards! After the touringcar returned to the accommodation late in the evening (because we left later than planned in the morning, everyone wanted to stay in Amsterdam a bit longer) there was no further program. A (surprisingly small) number of people went straight to bed, others had a couple of drinks and enjoyed the company. And of course there were also some die-hards who turned on the karaoke set. And why not? It was the last evening before going home, incredible how fast time can fly when you're having fun...

On Sunday morning there were no wake up calls and some participants had a chance to sleep a bit longer. There were many who took advantage of this. But not everybody did, because those who came from far (for example Finland and Norway) still had a long journey ahead. So they left early in the morning. The rest started the day quietly. Around two o'clock in the afternoon, the first people started to leave. What a pity that these unforgettable days passed by so quickly! But everybody could take a lot of very precious memories home. We are all looking forward to the next International OI-youth weekend. We will just have to wait and see where and when that will be...

(editor's note: The next International OI-youth weekend 2012 will be in Norway)

Did you know that...

...OIFE's president Ute Wallentin has had her 10th presidency anniversary this year? Since 2001 she is doing this voluntary job in an excellent way. So this could be the right time to thank you, Ute, also in the name of many, many people worldwide you did already help on behalf of OIFE. You spend innumerable hours for travelling and representing OIFE at international events, giving speeches, establishing and keeping up contacts and networks, writing reports, answering mails, discussing and brainstorming, organizing the almost impossible in the last minute and much, much more...