



Number 6
November 2008

OIFE Photo Contest 2008 – Here are the winners: Moira (Philippines) and Serkan (Turkey) - Congratulations!

Contents:

- **Congratulations** to the OIFE Photo contest winners!
- **Report:** OIFE youth weekend 2008 in Denmark
- **Impressions** from the OI-conference in the US (OIF)
- **Announcement:** first OI-association in Portugal
- **News** in brief
- **Remember** our Making friends project!



The picture shows Moira lying on a log in Lake Balinsasayao, one of the major tourist attractions in the province. She writes: "Last year we went there twice. The first time, I was with my brother, sister and two friends. We enjoyed ourselves so much that we convinced our parents to go with us the second time around. ... This trip brought out the adventurous part in me. I also proved to myself that as long as I want to reach a specific place, I would surely get there, I realized this when I was able to climb my way up a number of steps from the foot of the lake to the top of the mountain ridge to view Lake Balinsasayao."

Editor:

editor@oife.org

Objectives of the OIFE

- Representation of its members on a European level
 - Presentation of problems and needs of people with OI to national and international organizations
 - Collection and publication of information about OI
 - Promotion of research on all aspects of OI
 - Support of member-societies by the exchange of information and experiences
- www.oife.org



(Serkan's brother Bülent took the picture)

Serkan is one of the biggest fans of Fenerbahce, the most famous soccer team of Turkey. He is also one of the news editors of the web site (www.antu.com) of the same team and broadcasts antu FM radio out of the same web site as well on a 7/24 basis. That picture was taken last year during the championship celebration parade of Fenerbahce at one of the most famous streets of Istanbul, namely "Baghdad Street", on the Asian Side of Istanbul where many Fenerbahce fans live as it's very close to a district sharing the same name as the soccer team "Fenerbahce".

Once again: OIFE International Youth Weekend a big success!

From 15.-17. August 15 young people with OI from five countries (Belgium, Denmark, Germany, Norway and the Netherlands) and 5 helpers and nurses (from Denmark) met in Jutland, Denmark. As in the years before, the weekend was very well organized. Mads Dyreberg from the organizing team gives us an impression of that weekend:

The OIFE Youth weekend was great. Everybody seemed to enjoy themselves and the general feedback of the weekend was very positive. On Friday we all just relaxed and had a good supper and talked about the OI organisations in Europe as well as getting to know each other.

Saturday morning a representative from a Danish scooter company - scooters for handicapped people - gave a nice presentation on their products. Everybody had a go on them and was really impressed by the way the scooters can handle sand, water and places where a wheelchair can't go. Also a Swedish wheelchair company had sent us 2 ordinary wheelchairs for general use for the entire weekend - great.

After the presentation of the scooters we travelled by car to "Kattegat Centeret" - a big aquarium where we saw all kinds of fish and sharks. In the evening we had a traditional Danish dinner and some wine provided by the Danish OI foundation. Later during the night some choose to take a dive in the heated pool while others concentrated on drinking beers. The atmosphere was terrific and it was quite late before everybody went to bed.



On Sunday we had brunch and discussed the weekend. Everybody agreed that the weekend was a success. Furthermore, that these kinds of get-togethers are a good way for young people with OI to meet and talk about things they have in common. From the outset, the goal was to limit the amount of formal talks and lectures regarding OI. We wanted to have a more informal weekend, where the social side of things had priority. The group is looking forward to the next OIFE youth function based on a similar model.

Impressions from the Bi-annual OIF-Conference in Arlington, USA August 1 - 4, 2008

By Ute Wallentin, using parts copied from a blog in an OI-NING-group

This was the biggest OI conference I ever attended so far and among the over 700 participants I was not even able to find all the people I have been looking for. The OI-Parents-yahoo group has over 500 members, and about 40 of them were at the conference with their family members.

Many of the sessions gave an introduction to and update about what the OI Foundation is doing and will be doing in the near future. The OIF is going to start a youth council, and one representative will serve on the OIF Board. In the past year the OIF provided over \$ 800,000 in research funds, and the OIF coordinates research efforts with other organizations.

I met some old friends again and talked to hundreds of new people.....

Some medical news:

In several sessions and talks doctors said that Vitamin D (which is actually a hormone) is critically important for everyone's bone strength but even more so for people with OI. Every OI person should be regularly checked for different health aspects to early detect possible changes in bone biomarkers,

Bisphosphonates have been shown to benefit OI-people, mainly children and young people up to age 16.

Another session stressed bone strength can be gained simply by vibrations. The vibrations are enough force on the bones to stimulate the development of stronger bones. Vibration therapy (as with the Galileo-program) would be useful for humans with OI or another brittle bones disorder.

Studies showed that standing up and walking strengthens the bone of the spine, whereas people sitting are more prone to bone loss in their spines.

In a discussion about rodding surgeries it was emphasized that rodding should only be pursued when needed to prevent fractures or enable a child to stand. If bones are only bowing but not fracturing, then surgery is probably not necessary. Rodding, when properly done, can not only lessen the number of fractures but also help minor fractures heal faster.

A session titled "Women's Health" mainly addresses gynecological exams. For women with short stature pediatric (thus smaller) instruments are needed and should be requested before the visit. Also, if scoliosis is severe, the pelvic region will be altered so that the gynecologist will need to change the angle of the internal examination. For women whose bodies cannot be conveniently subjected to a mammogram, a breast ultrasound is a valid option. Dr. Krakow also talked about birth control, the benefits and risks of various contraceptives, and pregnancy issues. Women with short stature are usually unable to "push" a baby through the birth canal; so a C-section would likely be scheduled. It was emphasized that women with OI may have differences in their bones, joints, and ligaments, but the rest of their body is "normal" -- including their reproductive system. Therefore they need "regular" gynecological care, although the procedures might need to be modified.

Another session was about neurological complications for persons with type 3 and 4 OI and mainly about BI (basilar invagination or basilar impression), which about 50 % of patients with these forms show. Normally there are no serious consequences of having BI. Very few people with OI (that Dr. Charnas was aware of) need surgery for BI. But he discouraged people with moderate-severe OI to get treatment from chiropractors

The Talent Show on Saturday night was a performance of twenty different "acts", ranging from singing to playing musical instruments to a "lyrical interpretation" of song lyrics to dancing to a "magic trick." Most of the participants were kids, but a couple of adults participated as well. Whereas some acts were high on enthusiasm but low on "talent," clearly there were several "talented" performances.

The Talent show was a welcome way to move attention away from the medical professionals who are presenting at most of the conference sessions and instead

focus on the people with OI themselves. It was meant to celebrate the abilities of OI-people even while seeking better understanding and treatment of our disability.

The next day several speakers said that there should be a lot more study of adults with OI.

The Closing Session was presented by the actress Suzanne Richard and had the title "Follow Your Dream." She talked about how her teenage and early adults years were "split into two lives." In one life she was a performer/artist. In the other life she was an advocate for people with disabilities. Over the years circumstances, which she did not foresee, allowed her to establish a theater group (Open Circle Theatre) in the District of Columbia. The group includes many actors and support personnel who have disabilities. So now she is simultaneously an artist and an advocate. <http://www.opencircletheatre.org/>

The 2008 conference closed with the dinner banquet and dance party. After eating a nice meal, a few awards were given out. Then the OIF formally announced the location of the 2010 OI Conference which is Portland, Oregon. The dates are 8 -10 July 2010.



Then the dancing began. People in various types of wheelchairs, walkers, crutches, or just standing on their own two feet got out onto the dance floor and had a good time. I especially enjoyed the children dancing like crazy, while their parents stood there smiling and happy because most had heard after birth that their kids would never walk (even less dance).....

Announcement: New OI-Association in Portugal!

OIFE got this official announcement from Maria Céu Barreiros, APOI president:

Dear friends and Colleagues

It's a great pleasure and joy for us to announce the creation of an Association for Osteogenesis Imperfecta in Portugal.

Our Association is called **Associação Portuguesa de Osteogenese Imperfeita – APOI (Portuguese Association for Osteogenesis Imperfecta)** and is an Organization that's meant to be National, volunteer and non-profit. We dedicate all our efforts to help people with OI deal with problems associated to their illness.

Our mission is to try to make the quality of life of these individuals better.

Our primary objectives are:

- a) Defend and support people with OI;
- b) Spread the Knowledge of the illness and prevent the complications;
- c) Help develop medical assistance and investigation on OI;
- d) Give Knowledge to the Health Authorities and to the Government about the measurements that are needed to make better diagnosis and treatments.

APOI is taking the first steps now. It's been created by a small group of people (OI patients and parents of OI children), supported by doctors.

Although we have very little resources, **APOI** develops all the efforts to stimulate the public and professional interests on OI, in order to support patients and families and promote research and investigation by health professionals.

At the moment we have several projects like gathering a room so we can meet and work, publish little books with information and advice to the patients and families, create a periodic journal with important information, gather orthopaedic materials that people with OI might use when needed, enlarge our website

www.freewebs.com/aposteogeneseimperfeita

To reach all this points we would like to get your collaboration, so that we can understand how you've been developing this activities in your country.

We keep ourselves at your disposal for further information that you might think of interest. We will wait for your answer, which we hope will be the first of many others to come.

We believe that sharing experience and information between patients, families and health professionals might be the best way to reach the development of medical and social strategies that might contribute to make the world of OI people a better world.

We send you a friendly hug

M. Céu Barreiros
(Installing Commission from APOI)

Associação Portuguesa de Osteogénese Imperfeita
Rua Abel Manta, 5 – 2º Dto
2780-174 Oeiras

Mobile phone : +351 918625460 (M Céu Ramalhete); +351 938260877 (M Céu Barreiros)

email: a.p.osteogeneseimperfeita@gmail.com

News in brief

Primarily it was planned to bring the third part of the interview with Ute Barschdorf, the woman who emigrated from Germany to Africa. But as the political situation in Zimbabwe threatened to escalate she decided to leave the country. Now she starts a new life in Malawi. OIFE keeps up the contact to her.

OIFE had its 16th annual general meeting (AGM) from 16th-19th October in Nazareth, Belgium. Soon there will be the next edition of the newsletter containing many interesting details about it (development of OIFE, new projects, new members, etc.).

Remember

OIFE-Making-friends-project

The aim of this project is to give people with OI the possibility to make OI friends. If you become a participant you can use the program in many ways; make friends through (e-)mail, chat or phone contact for instance. Or meet with visitors to your country and meet others when you are travelling to a foreign place. We now have participants "friends" from: Italy, Germany, The Netherlands, Russia, Switzerland, the USA, Australia, Scotland, Finland and Romania. Please contact Taco van Welzenis at makingfriends@oife.org for further information.