



Osteogenesis Imperfecta
Federation Europe

Newsletter

Issue 21 – Feb. 2014

Editorial

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200 FD-rods and free treatment for Panamanian OI-Patients: The Importance of Patient Associations like OIFE to Promote State-of-the-Art Knowledge of OI among Medical Professionals

by María Barbero, Spain

A collaboration on OI: Panamá, Spain, Germany and OIFE work together towards a better OI education for medical professionals in Central America. One of the most important results was the decision of the national health ministry to cover treatment costs and the purchase of 200 FD-rods for Panamanian OI-patients. The following report could be an incentive for OI- associations worldwide to develop or strengthen a network in order to improve the situation for OI-patients.

In October 2012, during the **International OI Scientific Congress** held in Spain by the Spanish OI Association **Ahuce**, Ms. Dayana Castillo, President of the Panama Foundation **Niños de Cristal de Panamá** seized the opportunity and approached Dr. François Fassier, from Montreal, and the Spanish specialists, asking them to come to Panama to instruct orthopedists about the management of OI patients. Doctors agreed and so started the plan for the I Central-American Congress on Osteogenesis Imperfecta, to be held in Panama City in October 2013.



Madrid, October 2012. Adult dinner table at the First Ahuce Internacional OI Scientific Congress: (from the right) X. Nogués, Spain; D. Castillo, Panama; C. Belzi, Peru; M. Soler and R. Benito, Spain; T. Van Welzenis, Netherlands; L. Franquesa and S. Jané, Spain.

Ahuce takes over some coordination work for the Panama congress. **Padrinos-OI** (Germany) sends a German volunteer to Panama to help with the organization in the country and to carry on translation- and administration tasks. In Spring 2013, **Fundación Ahuce** addresses the OIFE to ask for financial help to send two Spanish doctors to Panama as key speakers for the Panama congress, as well as to examine the Panama patients and perform some teaching surgeries.

OIFE kindly agreed to pay for the two plane tickets. Other expenses for the doctors were covered by the Panama group. The Spanish doctors Ana María Bueno and José Ignacio Parra, very well reputed and experienced specialists in OI surgery, took a week of leave from their jobs in Madrid and travelled to Panama to participate in the **First Central-American OI Congress**. Highlights of this event were:

1. Exhaustive medical exams of the Panama patients, both adults and children.
2. Performing some major corrective surgeries in children, using FD-rods. Surgeries would be transmitted by TV to the attending surgeons at the conference.
3. Acting as key speakers in the special seminar on OI for doctors and health professionals.

As the Panama Foundation has widely demonstrated its capability to organize effective and state-of-the-art treatment for OI patients, the national health administration in the country has decided from now on to cover treatment expenses for the Panama patients who are treated at the initiative

of the organization. It has been decided as well to buy 200 high-tech FD-rods to be used for OI patients.

The **First Central-American OI Congress** in Panama was a very successful event for the international OI community. It demonstrated that patient associations can be the very instrument to make possible specific OI-education for medical professionals and state-of-the-art-treatment for OI patients.



A job well done: the First Central-American OI Medical and Teaching Congress for Health Professionals, organized and performed by Dr José Ignacio Parra (Fundación Ahuce, Spain), Dayana Castillo (Fundación Niños de Cristal Panama), Dr François Fassier (Shriners Hospital Montreal, Canada) and Dr Ana María Bueno (Hospital Universitario de Getafe, Spain).

To work or not to work

by Ingunn Westerheim, Norway

A short summary of my contribution to „Fragile Bones – Unbreakable Spirit?“, the 1st International Meeting on Psychosocial Aspects of Osteogenesis Imperfecta, Lisbon, Portugal, October 26-28, 2012, OIFE and APOI

Besides being the president in the Norwegian OI association (NFOI), I work as a legal advisor in the Directorate of Welfare and Labour with unemployment and social benefits. This explains my interest in the topic work and OI.

At OIFE's topical meeting in Lisbon, October 2012, I gave a talk where I presented my non-scientific thoughts about employment and OI:

- How does OI affect employment?
- How does employment affect our health and life in general?

Employment is a topic we have discussed a lot in NFOI. At least once a year we have a peer gathering where getting a job/keeping a job is one of the topics. After Lena Lande Wekre (MD, PhD) published her article about demographic data, we discussed it even more. Work is a central part of people's life, including mine.

In my talk I asked if people with OI are employed or not and why there might be differences between countries. In research studies from Norway and the US it seems like a large number of people with OI are employed. In the Norwegian study 64 % of people with OI were working (75% of the men and 50 % of the women) compared to 75% of the control group. For the group 'disabled people' the percentage was only 41 % (15-66 years) working in 2012.

My impression is that the high employment rate among people with OI does not apply for all countries. I guess this has to do with social benefits, discrimination and access for the disabled. It can also be related to the fact that more people with OI type I are registered in Norway, compared to the other OI-types.

Why do people with OI work? I think the main answer to this is education levels. The Norwegian populations study showed that people with OI tend to have significant higher levels of education than the average population. General social studies show that higher education often is the key to enter the labour market.



Ingunn Westerheim, president of the Norwegian OI Association

But why are there more people with OI working than people with other disabilities? OI does not affect cognitive functions in comparison to many other groups of disabilities. This can make it easier to get an education as long as access issues are solved. The OI-organizations can also play a part, providing peer groups, information about benefits and discrimination law, role models and networking (another important way of getting a job). I have also asked myself if it has to do with high levels of coping in the OI-group and verbal skills developed in challenging childhood situations. But this is purely speculations...

However it seems to me that women with OI seem to quit their jobs earlier than the average.

There are also reports about people with OI struggling to balance work and family life. People with OI type I, also tend to choose physically challenging jobs. Does this mean that they lose their jobs earlier? Should this affect career advice or should people follow their dreams?

Regarding the positive and negative side effects of working, I tried to focus on other issues than the obvious (salary and lack of energy). Having a job can also lead to self-esteem, a social

network, positive energy (that can even make you forget about pain) and not to forget - better health insurance (in the US).

Negative effects can be linked to fatigue and problems balancing work and everyday life. But having a part-time job can also cause financial problems in many countries, because there is no such thing as a 'partially disabled' person. If you are able to work some, you lose all your benefits.

Sometimes I even get the feeling that the OI-people I know are almost 'working themselves to death'. Many people strain themselves before they take the consequences. They spend entire week-ends sleeping, they neglect exercise and fixing 'disability stuff' and end up needing more help from family or friends.

Perhaps it is better to reduce the amount of work and still have a life, before you get so messed up that you have no health or energy left? Remember that a lot of the same benefits (except salary) can be found in an OI-organization: Friends, opportunities to grow, personal challenges and a network.

I don't have the answers. Just a lot of questions...

OIFE Youth Meeting in Tarragona, Spain

A personal impression by Jeanette Chedda from the Netherlands:

"I'm new to the 'OI-world' so this was my first OIFE meeting. It was also my first time travelling to another country by myself, so I was so excited about that, too.



I loved the location in Spain: Cambrils, a small town near Tarragona. A Beautiful boulevard and beach and everything was very well organized. The food was great. The room was comfortable and I liked the option to share a room with my roommate Anna. I loved the group who participated in Spain. The participants came from Germany, Italy, Spain, Denmark, Norway and the Netherlands.

I really enjoyed spending time with everyone. We did a lot together. I liked that, because I was there on my own. The people were very open-minded and enthusiastic. I really enjoyed every activity and the amount of free time we had between the activities.

At the information meeting on Saturday we also had the chance to meet Ute Wallentin, OIFE president who explained a bit more about OIFE and its aims and projects that are planned or have already been achieved. I really would like to be more involved. I cannot predict what this year will bring, but I will join the OIFE meeting next year, because I had one of the best weekends ever."



News in Brief

We mourn the death of Jean van de Boorn from the Netherlands, previous OIFE treasurer from January 1998 until May 2002. He died in October last year.

The British OI-association (BBS) will organize a youth meeting in April which will be open for international participants. For further information please contact Rebecca@brittlebone.org.

Dates to remember

2014, Febr. 28th International RARE DISEASE DAY

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

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

2014, Aug. 1st – 4th USA: National OIF Conference in Indianapolis

2014, Aug. 22nd UK: OI conference in London

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)

**Please send in YOUR dates as early as possible to
info@oife.org!**

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