



Osteogenesis Imperfecta
Federation Europe

Newsletter Issue 23

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Dear Friends,

Since having taken up the 2nd vice-president role with the OIFE a few years ago I have had the pleasure of contributing to the organization's workings on a deeper level than before. This time has reinforced my view that the most important role the OIFE can play is in the field of international networking: In each of our individual countries, we represent a very small group of disabled individuals and our own countries themselves do not often alone have all the necessary knowledge or resources to provide for all the needs of such a small group, despite hopefully having an active OI patient organisation.

In addition, a lot of important actors that are relevant to us are international in nature: EU-level policy-makers and large pharmaceutical companies come to mind. In order to deal with them, we certainly need an entity of our own that can speak for us with one voice. Doing so as a multitude of smaller organisations is not only wasteful, but confusing for the receiver of our message. In countries where an OI organisation is not yet established, there is a need to do so and we can help in this process. We cannot collaborate with numerous individuals directly, as this tends to only mean financial support for specific, individual needs. The latter is not what the OIFE is meant to do.

I hope that our delegates keep these thoughts in mind while promoting the idea and need for the OIFE in their own organisations. We certainly need the visibility on the local level so that we get the needed support from our member organisations.

Personally I am already looking forward with excitement to the AGM 22 that is to be held in my native Finland and is hosted by our Association while we celebrate our 35th anniversary. In addition to the OIFE, we will also welcome Nordic guests and hold a seminar with speakers from Finland, Sweden and Norway. Let's get together in as great numbers as possible in September to advance our cause!

Eero Nevalainen, 2nd Vice-President



Hope for the Sahara

By Margot Taylor

Houda came to Spain with deformed bones, but she will leave with the ability to walk. Born in the Western Sahara with Osteogenesis Imperfecta, she has lived her entire life with little medical attention, and consequently one tibia was curved to almost 90 degrees. Her deformed bones do not hurt like a fracture does, but they greatly lessen her quality of life by taking away the ability to run and play with other children. Consequently, when the Dar al Karama Commission reviewed her case, they decided that due to her age and the severity of her situation, she would be one of the lucky ones to travel to Spain to receive treatment.

Nine months after arriving in Spain, Houda has received two surgeries, repairing all 4 major bones in her two legs. The surgeries inserted rods into her bones to straighten and support them, leaving her with two aligned legs. Just this week she will start aquatic physical therapy and has started standing with a walker. She cannot wait to walk, and also to swim, as her favorite places in Spain are the beach, the pool, and the Pink Mountain Festival.

At age 9, Houda is bright, intelligent, happy, and independent. She wheeled herself around the hospital, and although she is a little shy she joked around with Ferrán, who takes care of her, and the other adults she knows. Ferrán works for Dar al Karama, and noted that Houda is particularly strong for a child her age that is in a foreign place without her parents undergoing serious surgery. He said Houda "keeps moving forward."



At the hospital (from left): Sara (PT of the Spanish OI Association AHUCE), Margot (trainee at AHUCE), Houda and her social worker Ferrán.

The next steps for Houda? Physical therapy so she can walk, including aquatic physical therapy. There is also potentially another operation in her future to equalize the lengths of her legs, as one is currently longer than the other.

In reality, Houda is one of the lucky ones. Back in Western Sahara there are more children with Osteogenesis Imperfecta who are not receiving treatment, including Houda's own brother. Houda is from a refugee camp in Algeria, where many of the people from Western Sahara fled after the invasion of Morocco. Now occupied by Morocco, the people remain living in their refugee camps but avoid building permanent structures such as hospitals because building such structures would mean accepting they are not returning to their country. The situation in Western Sahara is one of our world's biggest fails to protect human rights.

Though fixing the political situation would be ideal, there is good that can be done for children and adults who, like Houda, need medical treatments that cannot be provided in the refugee camps. Dar al Karama is one organization that helps people from Western Sahara by bringing them to Spain to receive treatment. Ahuce is launching a new project, the Ahuce-Sahara Project, which will do just the opposite: it will send doctors to Western Sahara.



Houda standing for the first time in many years

The doctors will first go and review cases and offer consultations to the people there, and then after deciding which cases they will operate on and noting the necessary materials, they will return to Spain, collect the medical equipment, and go once again to Western Sahara to perform the operations. By sending doctors to the refugee camps, they will efficiently improve lives.

In the hospital Houda secretly steals a pamphlet from the bag of Ferrán then asks innocently "what are those?" pointing to the remaining pamphlets in his bag. He answers and then she asks "Didn't you use to have 6?" and reveals the pamphlet she had behind her back with a big smile on her face. She is a normal 9 year old, who before could not run with her friends. But now she can.

Announcement

OIFE's AGM 22 is held this year in Vantaa, Finland together with the Finnish Osteogenesis Imperfecta Association's 35th anniversary meeting. Beside the celebrations, we are also arranging a seminar on the afternoon of Saturday the 20th. The speakers for the event are:

Patrick Willamo: Physiotherapy of OI children (Finnish)

Heidi Arponen: OI's impact on teeth and the development of the skull and upper neck (Finnish)

Östen Ljunggren (Sweden): Genetic research and treatments of the future (English)

Lena Lande Wekre (Norway): Adults with Osteogenesis Imperfecta -- what happens? (English)

The seminar is open for all willing to participate.

Claudette's Story

Dipping my toes into the world of work has always been a frightening prospect due to my condition of Osteogenesis Imperfecta. Although I have suffered almost 100 breaks and fractures, I look perfectly healthy, one of the many complicated factors of my condition. As skewed as it sounds, I find whilst I'm in plaster my situation can be visually recognised.

In the past each new experience, for example, starting school, or after school clubs, has always begun with me having to explain my condition. However, due to lack of understanding, it was often met with a negative response. This consequently contributed to a dip in confidence and ambition to delve into the outside world.

I was at a low ebb and felt extremely isolated but had decided, on impulse, to push my fears and anxiety aside, in the search of the limited opportunities that I believed were available to me.

This led me to approach the Brittle Bone Society and embark on a placement with them, which opened the doors of career choices and brought to light future opportunities. Being in an environment of people with an understanding and open mind towards physical impairment allowed me to carry out my role more confidently and safely.

I gained a vast array of skills through the enthusiasm of my co-workers and their general understanding and patience. This helped me to increase my options whilst still making a difference.

Attending Brittle Bone Society events up and down the country from small events to large scale conferences; has broadened my horizons and my C.V. It was daunting at first to go from an office environment to a venue with hundreds of people. But meeting a diverse range of people from all backgrounds and walks of life has always been something I've had a strong desire to experience.

The experience I have gained has allowed me to feel that, no matter what our circumstance, we all share the same core and we must not withhold any doubts on our capabilities to succeed. Sadly there is an overall shortage of similar opportunities. That I was fortunate enough to obtain this one – is thanks to the work of Brittle Bone Society and its magnificent team.



Claudette Day, member of the Brittle Bone Society, UK

For more information on the Brittle Bone Society go to www.brittlebone.org

Achievement in Romania

By Florin Dananau, OIFE delegate Romania

For the first time in Romania, FD rods have become eligible to be financed from the health state budget! The national insurance health authority issued an order at the end of this April, stating that children with OI may benefit from FD surgeries up to an amount of 40.000 lei (the approximate costs of 2 rods). Until now, only drug treatment (pamidronate infusions) was financed from the state budget.

This extraordinary achievement has been accomplished following intense lobby among authorities. Our associations, working in close association with dedicated medical staff, started the lobby activities two years ago. One more point: the Romanian children from Bessarabia (now Republic of Moldova) could also benefit, provided their parents are Romanian citizens.

The Rare Diseases National Program Osteogenesis Imperfecta (which now comprises telescopic rods treatment and pamidronate infusions) is implemented through two children hospitals, both located in Bucharest: The "Marie Curie" Emergency Clinical Hospital for Children (this one a donation from Polish people after 1977 earthquake!) and "Grigore Alexandrescu" Emergency Clinical Hospital for Children (the oldest of this kind in Romania). In addition, pamidronate infusions are made occasionally in other children hospitals in Romania.

News in Brief

Padrinos-OI: There are already 10 children getting bisphosphonate treatment in El Salvador.

There are two new OI-associations:

Costa Rica: *Fundacion Cristal Costa Rica* on Facebook:

<https://www.facebook.com/pages/Fundaci%C3%B3n-Cristal-Costa-Rica/105035886315830>

Dominican Republic: *Fundación Angeles de Cristal* on Facebook:

<https://www.facebook.com/pages/Fundacion-Angeles-de-Cristal/275056922607757>

International OI-calendar

2014

July 20-27 Denmark: DFOI Summercamp in Hasle Feriepark, Bornholm

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

Aug. 22nd UK: OI conference in London

Aug. 30 Italy: "Fragile Rock" together with Italian youth meeting

Sept. 5-7 Belgium: ZOI family weekend in Maasmechelen

Sept. 11th-12th Mexico: 2nd OI Congress

Sept. 18th – 21st Finland: OIFE Annual General Meeting + 35 years Finnish OI Society + OI Seminar

Oct. 11th – 14th USA: International OI-Conference in Wilmington, Delaware (medical/scientific conference with pre-meeting for patient representatives)

Nov. 23rd Belgium: ZOI autumn meeting in Malle

2015

June 4th – 7th Germany: National OI Conference in Duderstadt/Göttingen

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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