



**Newsletter
Number 15
March
2012**

Editorial

Dear friends,

OIFE is proud to present two interesting young women with OI in this edition; one of them will support her Boccia team at the Paralympics this year in London, the other has realized her dream of becoming an actress.

In the previous edition we reported about Toke, a Danish boy who tries to get the world record in collecting postcards – his mum told us that about 50 of our OIFE newsletter readers followed our call and sent a postcard. Thank you very much for supporting Toke!

Don't miss to pre-register if you are interested in psychosocial aspects in OI – you'll find more details here in the newsletter.

Hopefully you will enjoy reading this newsletter!

Stefanie Wagner

In this issue:

Editorial

**Announcement:
"Fragile Bones –
Unbreakable
Spirits?"**

**Interview: Boccia at
the Paralympics**

**Report: Latin
American OI
Congress**

**Interview: With OI
on stage!**

News in brief

Did you know that...

**"Fragile Bones – Unbreakable
Spirits?"**

A meeting about psychosocial aspects in OI moves to Portugal, September 21-23 ! Pre-registration open.

OIFE had to cancel the initial plan of holding this event in Denmark in April, so we are very happy that we can announce that we have found an alternative location in Lisbon, Portugal. This means our meeting will go on, which is very fortunate given the massive interest expressed in the topic of psychosocial aspects.

Especially from within the OI community but also from people working in the field. Psychosocial aspects of OI covers such topics as, fear of fractures, growing up differently, parenting (as an OI parent or as the parent of an OI child), work and relationships – topics that directly influence the lives of many of us.

The organisation is now a joint effort together with our local host APOI. The dates of the meeting have been set at September 21-23 this year. We already have several speakers and hope to present an initial program soon. "Fragile Bones – Unbreakable Spirits?" will be directly preceded by the regular OIFE AGM. The meeting 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 will be English. We hope it will be an inspiring event that will be a stimulus to further research in this field.

We ask everyone interested to please fill out a pre-registration

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!

**Ideas?
Feedback?
Questions?
News?
Interesting stories to tell?**
Please write an e-mail to editor@oife.org

form. Pre-registration is not binding, in case of overbooking we will give priority to pre-registrants. We will provide information to the pre-registrants about price, program and registration as soon as these become available. It might be necessary to book a hotel soon in that case. 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

You can also contact the chair of the organizing committee directly at Netherlands@oife.org

Boccia at the Paralympics

by Catherine Potterton

As the 2012 Olympic and Paralympic games approach, OIFE thought it would be interesting to get the "inside scoop" on Boccia, by interviewing Kat Watkins. Boccia (pronounced Bot-cha) is one of the few Paralympic sports which has no Olympic equivalent, and which is very well suited to people with OI. Closely related to ball games such as Bowls, Boules, Pétanque and Bocce, Boccia is a game in which two sides consisting of 1-3 players each, throw their 6 balls as close as possible to a small white ball called a jack. The side whose balls are closest to the jack when each side has thrown six balls wins the round. Kat Watkins is a Boccia player who has OI. She plays at National and International level, and is involved in encouraging young people to become involved in disabled sports.

OIFE: So, are you going to the Paralympics in 2012?

Kat: Yes, but as a volunteer, not a player. David, my boyfriend [who has cerebral palsy and is ranked third in the world] will be playing and his coaches don't want anyone who knows a player to be near in case we distract them! I will be a games maker and help with the general running of the event.

I am playing a major competition this weekend after only getting out of hospital a week ago, I was in there nearly 3 months and I've had 6 breaks this year so I feel this is quite an achievement!

OIFE: That is very impressive. Did you discover Boccia through David?

Kat: No, I actually started playing Boccia at my secondary school before David started, but he got me back into it after a long absence, after the sport officially invited people without Cerebral Palsy to play.

OIFE: Are there many people with OI playing?

Kat: People with OI do tend not to play, which is silly...as they are

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

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

the perfect people to play because it's not very physical or strenuous. Also the British team are looking for non-degenerative players - we fit that bill perfectly!

OIFE: The classification system of Boccia looks rather complicated. How do people with OI fit in?

Kat: There are four classifications:

BC1 - severe cerebral palsy but able to throw.

BC2 - moderate/severe cerebral palsy but able to throw.

BC3 - All persons unable to throw whether they have cerebral palsy or not.

BC4 - All players with disabilities similar to the severity of BC1 and 2 and able to throw.

The length of a game depends on the number of players, and their classifications; those less severely affected have less time to complete an "end" [throw all their balls], and individual or pairs have fewer "ends" to complete.

I am a BC4.



Kat is very proud of the fact that she won her trophy with two broken arms!

OIFE: What are your favourite things about the sport, and what keeps you playing?

Kat: I think I enjoy most the fact I can play relatively pain-free and it is brilliant for fitness. It's very challenging and I love a challenge. I like trying to better myself and prove myself to people that even though I have OI I can play as well as the rest of them (plus I can play with 2 broken arms, not many people can say that!)

OIFE: I can't imagine another sport which you can play with two broken arms! Tell us a little about the teams you play for.

Kat: I play for Wales ultimately but I also have a club I'm the

Donations

If you want to support us with a donation please send us an e-mail to office@oife.org

Thank you!

treasurer of in Swansea, we have 2 of the Welsh top class players there (not trying to blow my own trumpet too much!) It is a highly international sport, though, so we get to compete against teams from all over the world.

OIFE: What advice would you give to someone with OI who wants to give it a go?

Kat: There are certain criteria which they would need to meet, and some people with more severe OI might want to play as BC3s and use a ramp if they can't propel a ball themselves, but they can definitely play. My advice would be to do what feels comfortable to them and develop that - they know themselves better than anyone. It's a great physical and mental challenge. There aren't any reasons anymore for people not to get into sport...

OIFE: Thank you very much for the interview!

(If you'd like to know more about Boccia, check out the videos on YouTube, or www.gb-boccia.org)

Latin American OI Congress in Quito, Ecuador, December 2011

OIFE Travel Reporters: Oliver Semler and Ute Wallentin
Translation: Stefanie Wagner and Catherine Potterton

The invitation arrived from Ecuador at the beginning of 2011. Lucia Trávez was organizing a second OI Congress in Latin America. Just as she did for the first conference in 2006, Lucia wanted the international conference to take place at the same time as the (biannual) Bisphosphonate treatment of Ecuadorian children. Attendees included a dozen international specialists in OI and representatives from the OIFE and other OI associations. They participated in examinations and surgeries, and went to presentations about OI. It was also an excellent opportunity for networking and meeting new contacts.

Ecuador is very far away in many ways; the journey is long, and our Spanish language skills developed very slowly. Yet other Europeans – representing Sweden, Switzerland, Spain and Germany – also made the journey. We were all rewarded with two weeks of unforgettable adventures and experiences!

Living with a disability or illness in a Latin American country – especially one which is rare and almost unheard of – is interesting to say the least! It is only those parents with money or who dedicate their lives to their children who are able to give their “special children” lives close to being “normal”.

Having OI in a country without a Social Security system can mean that a child with OI and their family live difficult and painful lives in isolation. These children rarely have a diagnosis, let alone any treatment for their OI, and therefore do not have the chance to get an education or live independently in adult life. Fortunately, there are increasing numbers of people like Lucia Trávez in Ecuador, who not only wish for a better life for their own child, but who also make the effort to enhance the quality of life of other people living with OI.



Lucia and daughter Maria Paula

When her daughter was born in 1996 with OI, Lucia Trávez was of the few Ecuadorian parents lucky enough to receive both an early diagnosis and treatment from excellent doctors. Initially, this treatment took place abroad, in Canada, but Lucia was not satisfied with that situation and began to search for other OI families and experts in her own country. By 1999, she had founded a support group: *Fundación Ecuatoriana de OI* (Ecuadorian OI-Foundation or FEOI - www.feoi.org).

Shortly after this, Lucia began to contact other OI families via the internet. It was there that she met María Barbero, who encouraged her private network of friends to support the treatment of poor children with OI in Ecuador, and later also in Peru. In 2006, following the first Latin American OI Congress in Ecuador, this private network grew to eventually become an association called PadrinoS-OI.

This association - funded by sponsors and donors from Europe and the USA - provides medication, physiotherapy and mobility aids for more than 120 children and some adults in Ecuador (via partner organisations in Ecuador and Peru).

By the time of the second Latin American OI Congress in 2011, attendees included people from 15 countries, about 100 Ecuadorian doctors and physiotherapists, and over 60 families and children with OI. Many of the children who attended were very young, and their parents had only recently discovered the existence of FEOI and its Partners.

Many of these children were very young and their parents had only recently discovered FEOI and its partners. PadrinoS-OI is almost continuously looking for new "godparents" for children and youngsters with OI, who could finance regular medication with a monthly donation of just €25. More severely affected children need more help than this; they might need physiotherapy, a wheelchair or other mobility aids, or surgeries to help them walk and become independent. These have to be organized and financed. It is vital that disabled children get a good education - but this is almost impossible if they do not have a wheelchair or at least the ability to sit upright.

Besides the international participants, OI families also travelled from Ecuador and neighbouring countries - some via a 10 or 15 hour bus journey - in order to introduce their children to medical experts, receive their 6-monthly infusion, and learn more about living with OI.

On the day of the treatment, 6th December, more than 60 families with their OI children and young adults met in the large church hall in Quito, the capital of Ecuador. The children sat on chairs and mattresses on the floor, and waited patiently but nervously for their infusions. Each was first measured and weighed, and then two teams of nurses went down the line. The first team calculated the necessary dosage, and the second inserted the intravenous drip and monitored the infusions. Local volunteers from the parish and the international attendees and doctors tried to distract and calm the waiting children and their parents, as for many it was their first infusion. There was music, games and paints, for those whose infusions had finished or not yet begun, and lunch was served to everybody. The children who had finished played with their friends and waited excitedly for the Santa Claus celebration.

In order to finance all of this, Lucia Trávez, her parish and a large number of volunteers had been organising fundraising events for almost a year. Lucia had contacted medical and

therapeutic experts both in her home country and abroad, and brought them all to Quito, where they gave speeches, examined all the children, and carried out two large and complicated surgeries. All this was done on a voluntary basis, and the experts paid their own expenses and came during their annual vacations.

It has only been in the past year that orthopaedic surgeries for the straightening and stabilisation of children's legs have become possible in Ecuador, and even then the national health system only pays a small proportion of the costs. It is hard to believe the enormous difference made and achievements accomplished by the tireless dedication of an Ecuadorian woman, aided by her friends, family and other enthusiasts.



Infusion despite fever?



Young girl prepared for infusion

We international guests, some of whom were on their second or third visit to Quito, returned home filled with unforgettable memories of our experiences and the children and families who we had met. We were also moved and impressed by the hospitality and cordiality of the people we met, the gigantic size and diversity of Quito, and all of the beautiful sights which we were privileged to see in Ecuador.

The fact that the children of FEOI and their families can enjoy modern standards of treatment is thanks to that unique and determined young woman - Lucia Trávez - who refused to give up despite the obstacles which fate set in her way, and who sees "charity" not as a trite and sentimental word, but as a way of life!

If you have any questions, or would like to get involved in supporting our work in Ecuador or elsewhere, or would like to become a "godparent" to a child in Ecuador, please contact the OIFE at germany@oife.org.

Interview: OI on stage!

Interview by Stefanie Wagner
Edited by Catherine Potterton

Jana Zöll is a young woman living with OI. She is of short stature and uses a wheelchair, but this hasn't prevented her from realizing her dream of becoming an actress. All the more reason for the OIFE to find out a little bit more about Jana...

OIFE: When did you realize that acting was "your dream"?

Jana: Acting wasn't always my only dream, it just sort of happened. I just took every chance I could to act - even when I was in primary school, I took part in any show which let me act.

OIFE: So when did you decide to become an actress?

Jana: Well, for a long time, I didn't even think it would be possible, because of my disability. Not that my disability usually stops me for doing anything I really want to, but it just never crossed my mind that this could include acting. Then, during my A-Levels, I joined a theatre group at school. It was the first time that I felt like I really belonged in a group, that I felt part of an ensemble. That was what theatre meant to me. Then, while watching TV, I heard about an integrated and accessible acting school, and it was then that I knew: This was what I want to do. This, and nothing else.

OIFE: Was it hard to convince your parents to let you become an actress?

Jana: No, not at all. My parents have always supported me, my sister and my brother. They want us to find our own paths and do whatever makes us happy. My mother helped me achieve my dream.



*Copyright: Uwe Klees,
thalmannverlag*

OIFE: Were there problems because of your disability? How did you manage?

Jana: Well, first of all, the acting school might have said they were integrated and accessible, but most of the lessons took place on the second floor, and there wasn't an elevator. My mum had to get me up and down the stairs four times a day.

Then there were problems if we had to do scenes in pairs, especially if it was for an examination. Maybe my acting method is different from those of others... anyway, my classmates found it hard to work with me. So they chose other partners and I had no one to work with. I always had to fight if I wanted to work with a partner. For example, I would find a scene I wanted to work on, and then I would find someone who had a partner and who didn't yet have a scene.... In the end it always worked out, but it was an uphill struggle. The teachers admitted that they didn't know how to work with someone who was disabled, and so I had to find my own way of handling the tasks.

OIFE: What did you learn during your studies? What makes you a good actress?

Jana: Despite the difficulties I described above, I am really happy to have chosen this path in life. I have learned a lot. First and foremost, my self-confidence has really increased. Plus, I've also learned a lot of acting techniques which enable me to use my body and voice to full effect. I have become more aware of my body, and lost a lot of weight.

I think that acting teaches you many skills. You learn to analyze your role, learn a lot about yourself, and learn what your method of acting is. For example, your acting method might involve emotions, intuition, how you use your body or it can be an intellectual exercise. I focus mainly on emotions and the intellectual aspect. I think I'm very good at using language. The most important aspects of acting are: talent, fun, and the need to be onstage.

OIFE: What was your first role? How did you get it?

Jana: My first role was in the theater in Ingolstadt, Germany. Peter Radtke (who also has OI)

was the director. You could say that it was a play about the history of the exclusion of disabled people within society. Radtke wrote it himself. It was called "Und raus bist du" ("And You're Out"). I got the job through personal connections, as both the director of my acting school and myself were already friends with Radtke.

OIFE: Have you ever been in a movie? (If not, would you like to and why?)

Jana: No, I haven't been in a movie yet, but I think I might be in one next year. The idea for it came about during a theatre project I was working on this year. It might even be released into cinemas!

Of course, I would like to be in more movies. It is always good to take up every opportunity, and I enjoy variety and working in different ways. You can't live just from acting in the theatre. Movies are seen by more people, so it would increase my visibility.

OIFE: Have you worked with any "famous" actors?

Jana: No, not so far. I worked with some pretty famous directors. The most famous being Niko von Glasow, with whom I worked on the theater/film-project.

OIFE: How often are you onstage?

Jana: Well, I finished acting-school three years ago. Since then, the longest time I spent away from the stage was four months.

OIFE: What are your plans and wishes for the future?

Jana: I would like to act more often, even continuously. And obviously I would like to earn more money from it! I would also like to move away from integrative projects towards more mainstream and normal plays and roles. Again, I would like to act in movies, and also perhaps do jobs as a speaker; the variety would be great.

OIFE: Thank you very much for the interview!

News in brief

The **international OIFE youth weekend** will be held from June 27th (Wednesday evening) to July 1st (Sunday) at Eidene (close to Tønsberg 1,5 hours Southwest of Oslo). Further information please see <http://www.heiasentrene.no/nor/Om-oss/Eidene>

OI Conference Dubrovnik 2011: Participants list and pictures taken by the official photographer have become available online at: <http://www.conventa.hr/osteogenesis.imperfecta2011/>

Did you know that...

...OIFE's Medical Website Editor, Dr Oliver Semler, has received the „Eva Luise Köhler Research Award for Rare Diseases 2012“. Affected by OI himself, the pediatrician and his team have discovered a new type of OI. They intend to treat OI with antibodies instead of drugs. Of course we will come up with more detailed information in one of the next editions.