



Newsletter Number 8 February 2010

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Did you know that...

Editorial

Dear friends,

I hope you had a good start in 2010 and I wish the new year may make all come true that you wish for yourself!

Finally I could finish this newsletter, the first one this year that originally should have been published by the end of last year... As you might know, OIFE had its first conference in November 2009 (please see the report about "OI in Motion"), which took a lot of efforts, time and one or more sleepless nights. But, in the end, it was a big success we can be proud of.

At this point - on behalf of OIFE - I'd like to thank Anne-Miek Vroom from The Netherlands, who resigned as Youth Coordinator, and Catherine Potterton from the UK, who resigned as OIFE delegate, for their dedicated work! You will find some introducing words from Anna and Samantha, who will be the successors, in this edition.

Now I hope you will enjoy reading the newsletter!

Stefanie Wagner

OI in Motion

Report by **Taco van Welzenis**, chair of the organizing committee

OI in Motion – An inspiring conference

From 20-22nd November the "OI in Motion" conference on rehabilitation and physiotherapy in OI took place north of Berlin in the town of Rheinsberg in Germany. The event was initiated and fully organized by OIFE itself. OI in Motion was preceded by the OIFE AGM which enabled many OIFE delegates to take part in the conference too. Parallel at the same location was a family weekend of the Eastern branch of the German OI association "Deutsche Gesellschaft für Osteogenesis imperfecta Betroffene e.V." We stayed in a splendid accommodation that was very well adapted to the needs of disabled guests.

International character and well mixed participation

OI in Motion welcomed some 80 participants from 18 countries (Canada, China, Russia and various European nations): 49 rehabilitation experts like medical doctors, physiotherapists, occupational therapists and psychologists as well as 31 representatives of 16 national OI associations.



OIFE delegates and guests

We mourn the death of Colleen Stevens from New Zealand. She died in summer 2009. Some of the readers may remember her because she attended the first OI-Conference in Woudschouten, The Netherlands in 1992.

Varied program

During the three days various treatment concepts were presented by international specialists. Each bringing his or her own specific experience, covering a broad subject of physiotherapy and rehabilitation related topics. For instance several treatment concepts, spine surgery, special equipment, hydrotherapy, studies in adults, psychology and lever arm studies were presented. The presentations were accompanied by a poster exhibition; an abstract book of the presentations had been prepared in advance. Following each presentation ample time was scheduled for questions and discussion. Participants gave input from different angles which provided for an often lively discussion. Several workshops explained about exercise programs while manufacturers of rehabilitation equipment presented some of their materials suitable for people with OI. A festive evening together with the people taking part in the family weekend was scheduled on Saturday.

Results

The organizers were very pleased to see that their efforts paid off. For many of the specialists OI in Motion was the first time they had the opportunity to meet their colleagues in person. This resulted in international exchange of experience and discussion about the various treatment protocols. Also the interaction between the rehabilitation professionals and the representatives of OI patient organizations who often had personal experience was perceived as very positive. As hoped and asked for at the opening of the conference, several new and internationally composed workgroups for further research on some specific topics like "Rehabilitation in adults" and "OI-related heart complications" had been constituted by the end of the meeting. We hope this will lead to new results and insights. In this way OI in Motion gave a unique possibility for people to meet and to lay the foundation for future cooperation. In the

to meet and to lay the foundation for future cooperation. In the weeks following OI in Motion enthusiastic feedback from many participants was received, praising the friendly, open and constructive atmosphere of the event. Participants stated that they had benefited personally as well as professionally.

Projects:

[Making-friends Project](#)

[International OIFE youth weekend](#)

[Padrinos](#)

[HOI \(Help OI\) Foundation](#)

[Student Exchange Program](#)

[OIFE Pass](#)

For those who could not attend...

Many of the presentations can be seen and downloaded from the OIFE website.* The abstract book is also available in digital version through the [OIFE secretary](#). A picture gallery is shown on website as well.*

*In progress, if not available yet this will soon appear on the website

OIFE international Youth Week 2009

From July 17-23, 2009 12 young people spent their vacation together in Centro Ferie Salvatore in San Felice Circeo, Italy, which is completely accessible, inclusive beach! - A report by Anna Rossi from the organization team.

Who doesn't dream of a holiday at the seaside? - lying at the waters edge, enjoying the sun, and when the sun is too hot simply move to a cooling swim in the sea.

All this was enjoyed by the participants of the O.I. international youth week in San Felice Circeo.

The holiday was a success, the participants, 12 people, had the possibility to enjoy the Italian sun and beaches, to know other people, and to discuss about sports for O.I. people, and in the case of wheelchair hockey they could also try to play! With us there were other 2 guys from Rome, who during summer time use to move to San Felice. Ciccio and Lele "the Twins", stayed with us for the whole week, since they are two of the most important players of the wheelchair hockey team of Rome, they had been very important for our discussion about sport for O.I. and in general for disabled people.



The accessible facility in Centro Ferie Salvatore offers enough space for sports !

News in Brief

The University La Sapienza will organize the Topical Meeting "tips & tricks" for surgeons. It will focus on surgery of the limbs, of the arms and of the back and will take place in May 2010 in Rome, Italy. For further information please contact the [secretary](#)

A new organization for OI people and those who care has been founded in **Czech Republic**. The website is in Czech language: www.lomivky.webnode.cz

The **OI-association Panama** has got a new website (in English and Spanish language): www.oipanama.org

Rare disease day February 28, 2010: please participate and/or support events in your country! More information see: www.rarediseaseday.org

Usually during the day, we went to the beach, and we enjoyed our "beach-life" playing cards, swimming, sun-bathing, playing ball and so on...

We also organized some trips in the surroundings: we went to the old San Felice Town that is on a hill from where it is possible to enjoy a fantastic view of the coast, then we went to Sperlonga, an ancient town located on a rocky spur at 55m above sea level: here lies the heart of the old city, with its narrow alleys and small shops, old churches and small bar.

Matthias and Brigitta from Germany, in addition, had the opportunity to visit The National Natural Park of Circeo, and also the city of Rome.

This are their impressions of the holiday:

*"Our impressions of the OI weekend were mostly great! Of course it was **incredible** to be able to go to Rome and we totally enjoyed it! But we appreciated your company a lot too!!! We thought it was really great to have a whole village wheelchair accessible and the beach and the sea were soooooo very nice! We miss you and maybe next year there will be something alike??"*

Valentina, from the north of Italy said: *"It was my first summer meeting and it was amazing!!! At the beginning it was a bit strange thinking about going on holiday with people I didn't know, of course I met some of them each year at the national meeting of As.It.O.I., but we meet only once a year....I have to say that I realized to have met real FRIENDS during that week!! Everyone gave something to the meeting with his own energy, sympathy, craziness (typical of O.I. people!!)...when I think back to the youth meeting an large smile appears on my face! I had recharged my battery a lot...I will slowly spend that energy in my life hoping it lasts until the next summer meeting!!"*

During the last evening the director of the village, Mr Salvatore, decided to dedicate a party to us! We all had the opportunity to sing during a fantastic karaoke session, to dance and enjoy our last evening together!

I think that pictures can describe our beautiful experience so much better than words! That's why I advise you to visit the web album about the Youth Week... <http://ciaodaanna.jalbum.net/>

No prize in the Photo Contest 2009 but new chances!

Because of the low number of entries the jury has decided not to nominate a winner yet for the 2009 Photo Contest. Instead the deadline for sending pictures has been extended till the end of 2010.

Student Exchange program:

We are desperately looking for people / families who are willing to host an OI-student – since the last edition we got several replies from youngsters with OI interested in going abroad for some time. So please [contact OIFE](#) if you can help. Thank you !

Ideas?
Feedback?
Questions?
News?
Interesting stories to tell?
Please contact the [editor](#)

With so few entries this of course means if you do send in a good picture you have a very real chance of winning!

What kind of pictures could be “winners”? We are looking for pictures that depict active people with OI from all over the world. Active could mean sportive, celebrating a party, busy with work or hobby; we think you “get the picture”. We are not especially looking for pictures of children. We know OI kids can be incredibly cute, but all ages are encouraged to take part.

Rules are simple. Full rules and contest forms can be found on the OIFE website www.oife.org, both the photographer and portrayed person consent to free use and publication of pictures by the OIFE. Pictures must be digital and mailed to secretary@oife.org before January 1st 2011. Members of the jury can't take part.

A first prize of 100 Euros or an MP3 player and a second prize of 50 Euros will be awarded for the best pictures. These prizes have to be shared between the photographer and the portrayed person(s). The jury is free to award extra prizes. Prizewinners will be contacted by us and announced here on the website, there will be no other correspondence about the prizes.

So grab your camera and take a shot – good luck!

OIFE-International Youth-Week in Belgium Nov. 4th-8th 2010

What? A weekend to meet other young people and enjoy the time together

Who? People with OI between the age of 15 and 35 and their companions (assistant, partner, sister, brother, ...preferably of the same age).

Where? Maasmechelen, Belgium. We will be staying in a youth centre for people with special needs: on the ground floor, there are 12 double rooms with an adapted bathroom, on the first floor (only accessible by stairs) there are 24 double-rooms.
→ www.kfh.be

Activities? Swimming in a tropical and adapted swimming pool, cycling with adapted bicycles, visiting a typical Belgian city, ...

How much will it cost?

if you stay from 05/11/2010 till 07/11/2010: ± € 100 per person

if you stay from 04/11/2010 till 08/11/2010: ± € 150 per person

If you have any questions and/or remarks concerning the programme, assistance, special needs, ... please contact Lien Roose (lien.roose@zoi.be) or Annelies Martens (annelies.martens@zoi.be).

(lien.roose@zoi.be) or Annelies Martens (annelies.martens@zoi.be,
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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
www.oife.org

New OIFE Youth Coordinator

Hello everybody!!!

I am Anna Rossi, the new OIFE Youth Coordinator. Maybe you would like to know something more about me...

I am 22 years old, and I come from Italy where I am involved in the board of As.It.O.I. (the Italian OI-association) as Youth Coordinator and Press Office assistant. I'm affected by O.I. I can't tell you which type just because doctors are not convinced if I am a type 1 or type 4...:-) I'm studying Communication in Milan and I hope I will graduate in March. My final project will be a thesis about the cinematographical representation of O.I.

I live alone in my small flat for students provided by university. And in my free time I love listening to music, going out with friends, support my boyfriend's wheelchair hockey team, playing guitar and many other things...



These are my contact data:

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New OIFE delegate United Kingdom



My name is Samantha Renke and I am 24 years of age. I have type 3 Osteogenesis Alongside teaching I am also a trustee for the Brittle Bone Society which enables me to work with a variety of people

organizing a youth conference along with other trustees which will take place in April. I have also had the privilege of becoming a delegate for the OIFE where I am able to utilize my language skills. I enjoy travelling and meeting new people from around the world; I am a very bubbly person and flourish in social situations. You can contact me under: uk@oife.org

Donations

If you want to support us with a donation please contact the [OIFE office](#) to get all the necessary information.

Thank you!

The Portuguese delegate likes to inform:

I'm writing to you all to inform you that APOI's (Portuguese OI-association) psychologist Prof. Margarida Santos is starting an investigation study trying to better understand the psychological aspects related to OI.

As the exchange of information and experience is very important, I ask all of you who have psychologists in your OI Society, or who know of any psychologist who has experience in OI to collaborate with us.

I truly hope that we can all benefit from this investigation. If you like to know a little more about the investigation, we'll send you a summary.

Please contact us:

a.p.osteogeneseimperfeita@gmail.com or portugal@oife.org

Thank you very much!
Céu Barreiros, OIFE delegate Portugal

Did you know that...

...OIFE has been existing for already 17 years? Established on September 31st in 1993, it has its legal seat in The Netherlands. The first AGM (Annual General Meeting) took place in Oxford, UK. Following seven countries were founding members: Denmark, Finland, France, Germany, Italy, United Kingdom and The Netherlands.