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Did you know that...

Editorial

Dear friends,

In the previous edition we informed about the "Wishbone Day", the annual awareness day of OI. As an example of how this day might be celebrated, we got a report from the Portuguese OI-association.

Some of you might have heard about or even taken part in OIFE's Topical Meeting "OI in Motion" in 2009, which was a great success. In April 2012 it is time for the next Topical Meeting which will be about psychosocial aspects of OI. Taco van Welzenis, chair of the organizing committee, tells you more about it in this edition.

This year OIFE will publish an updated version of the OIFE-Pass, a very helpful travel companion, which you may order at secretary@oife.org.

Hopefully you will enjoy reading the newsletter!

Stefanie Wagner

Report: Chinese OI-association

Philippe Rahmy, a French writer with OI Type I, living in Switzerland, was very happy and surprised when he got an invitation to read some of his texts on the EXPO 2010 in Shanghai, China. Together with his wife Tanja he accepted the challenge to travel to that country. During their travel preparations they got in contact with the Chinese OI-association. Tanja reports about an inspiring meeting and Philippe tells us something about his personal situation.

Philippe: «With my OI Type 1 I have chronic joints/back pain and muscle injuries, I have to focus my energy during short periods when I feel better to do all my work in a short period of time. My job as a writer allows me to work this way but when I have to do public appearances I often have to cancel because of health problems. It's difficult to do long time planning. For travelling, I use a wheelchair, with all the related problems (trains, buses, planes, boats) and, of course, changing routine is a source of extra tiredness and can provoke injuries.

I graduated in Philosophy and French at the University of Lausanne, Switzerland and I am a founding member of the French literary site called remue.net. I have published my books in France (poetry, novels, scripts, critical articles see website: <http://remue.net/spip.php?rubrique201>).»



Philippe Rahmy

Projects:

[Making-friends
Project](#)

[International OIFE
youth weekend](#)

[Student Exchange
Program](#)

[OIFE Pass](#)

Tanja: "Some time ago we got an unexpected invitation: My husband Philippe Rahmy, an author affected by OI, has been asked if he liked to hold a reading of his texts on the Day of Francophonie on Expo (World's fair) 2010 in Shanghai, China. Something like that doesn't happen every day so it was clear for us to say "yes". But at the same time we were wondering if it was possible to travel using a wheelchair in China and how life for people with OI would look like.

We contacted Handicap International, who have an office in Beijing. They told us that there is an association for care and support of people with OI* (<http://www.chinadolls.org.cn>), founded in May 2007 in the Chinese capital. The association's first national conference for OI patients had already been organised in November 2009. Thanks to Helen Gao, an English-speaking employee of Handicap International we contacted Chinadolls and made an appointment in the hotel in Beijing where Philippe and I would spend some days after our stay in Shanghai.

Finally we went to the hotel lobby, a bit anxious, but already after a few minutes possible language- or cultural barriers were gone and we talked like old friends, with Helen's help. Three members of "China Dolls" had come: the two founding members Yoyo Wang, a dynamic 28-year-old attorney at law with OI, and Kevin Huang, who was supporting children with AIDS after his studies of economy and marketing, before he met Yoyo. The third member was Zhenyi Bai, who is responsible for information issues of "China Dolls".

Yoyo was born in Jin Nan Shan (Dong Province). During her childhood she "only" had six fractures and her parents were fighting so she could go to school. As schools in China are liable in case of an accident and although a nine year education is mandatory, the schools often refuse to accept students with a handicap. With only 16 years she learns about her genetic disorder and with 18 she has a surgery to correct her leg. After her studies in law in Beijing she becomes an attorney in a law firm, but decides rather quickly to help

improve the quality of life for disabled people in China.



Yoyo and Kevin, the founding members of "China Dolls"

Dates to remember

International Youth Weekend 2011 in Schoonoord, Netherlands:

Long: Sept. 28th - Oct. 2nd
Short: Sept. 30th - Oct. 2nd

Latin-American OI-Congress in Quito, Ecuador: Dec. 5th-11th 2011

11th International Scientific Conference on OI in Dubrovnik, Croatia: Oct. 2-Oct. 5, 2011. [More info click here](#)

Thanks to the financial support of OIF (North American OI-Foundation) and the logistic support of Handicap International Yoyo and Kevin were founding an association that takes care of a better integration of people with OI (and other rare diseases) into the Chinese society by: information of affected persons and their relatives and medical doctors; public relations regarding OI and other rare diseases; their financial and juristic support; improvement of access to medical treatment (only 10% of the health costs are paid by the government, so many children cannot be operated); access to school education and working environment; creation of social networks; support of examinations and research about OI; co-design of legislation regarding rare diseases.

„China Dolls“ is publishing an annual magazine (1300 copies per print run). The first issue in December 2009 contained the first report about the situation of people with OI in China. There are approximately 83 million disabled people in China (who hardly ever leave the house), 130 thousand of which have OI. About 1000 of them are in contact with „China Dolls“.

We liked to know more about the name of the association „China-Dolls“ and its slogan „Love is still strong“. Yoyo explains to us that people with OI are often seen as „lovely“ because of their appearance, they „become“ dolls and are as fragile as those toys made of porcelain. At the same time they are a considerable part of the Chinese population, so: China-dolls. And as weak their bones might be, „Love is still strong“.

And this strength is needed if you seek contact with the government in order to avoid that new trains will be bought and new stations will be built without taking care of disabled people. We also learn that the Chinese people is not always as friendly towards persons with a handicap as we experienced it during our stay in Shanghai and Beijing. Many of the wheelchair accessible facilities only have been installed for touristic areas like the Olympic Games and for Expo. But

there is hope that with the help of China-Dolls further steps will be taken to raise awareness to the needs of people with OI and other rare diseases and to honour their rights."

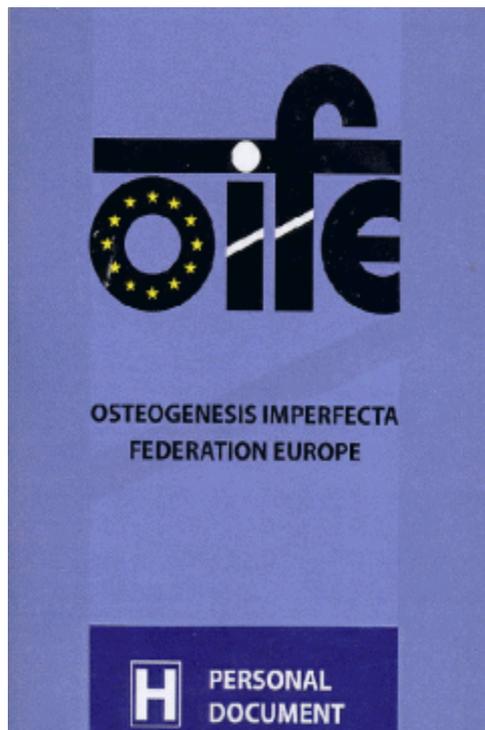
Text: Tanja Weber-Rahmy, Translation: Stefanie Wagner

**editors note: In 2009 a representative of the Chinese OI-Association „China-Dolls“ presented the association’s work and the situation of persons with OI and disabled people in China in general at OIFE’s annual general meeting*

OIFE-PASS: New edition with 21 languages in preparation

Student Exchange program:

Would you like to host an OI-student? Please [contact OIFE](#) if you can help. Thank you!



The OIFE-PASS is a personal document in the format of a passport. It is meant as a travelling companion and a guide to local OI assistance in foreign countries. It contains the statement that the bearer has OI, a brief explanation of what that means and how a person with OI should be treated.

Precautions to be taken with X-ray examinations are explained.

The contact list contains e-mail addresses and phone numbers for emergencies.

Languages in alphabetical order: Arabic (new), Chinese

(new), Croatian, Danish, Dutch, English, Finnish, French, Georgian, German, Greek, Italian, Norwegian, Polish, Portuguese, Romanian (new), Russian, Slovenian (new), Spanish, Swedish, Turkish.

The updated version of the OIFE pass will be available in September 2011. Every language version can be found and printed separately from OIFE’s website and possible updates of contact addresses should be checked and compared before every voyage. If you are interested please contact office@oife.org .

Next OIFE Topical Meeting: "Psychosocial aspects of OI"

The aim of the OIFE Topical Meetings is to create a place where interested parties can meet and exchange about a specific OI-related topic. We choose topics that we find interesting and need some extra focus. We already had Topical Meetings on orthopaedic aspects and on physiotherapy in recent years.

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

This time we have chosen a topic that we think could lie close to the heart of many; the psychosocial aspects of OI. Our target group are psychologists, social workers, people and parents with OI and anyone else interested. Of course optimal medical care and rehabilitation are crucial for physical fitness, but managing the psychosocial aspects of life is crucial to wellbeing. The repeated trauma of fractures, hospitalizations and operations, coping with things like being different, looking different, dealing with emotions of fear, pain and guilt or even depression, can be a challenge too large for an orthopaedic surgeon to deal with.

At the same time people with OI seem to be managing quite well on average, despite all the obvious problems. People with OI have been described in the literature as being of above average intelligence, artistic and in the possession of a "euphoric mood". So what is going on? Is this all a myth and is all the positivity just a pose to the outside world, or is there some truth in it as well? Does OI have positive aspects as well? And what about our families and the stress OI can cause, to the relationship between the parents, and for the non affected siblings? What about people with OI and their relationships? How about finding a job and dealing with the challenges of adult life? How do people with OI succeed in fulfilling their life goals? And how important is the psychological support people with OI get from each other for instance through OI associations and the internet? Given all these questions it is almost a mystery how little research has been done in this field. Therefore we hope this meeting will provide a fruitful exchange of ideas that could give an impulse to future research.

Would you like to
receive the OIFE
newsletter regularly?
[Subscribe here!](#)

The meeting will take place in the period **18 to 22 April 2012** (exact dates are to be determined), in the Trinity Hotel & Konferencenter, Fredericia, Denmark. At the same time or directly following our meeting there will be 3 other OI meetings at the same location, organised by OIFE, OI-Norden and the Danish OI association respectively.

We are at the stage where we are determining the program. We ask anyone to come forward with ideas for topics and suggestions for possible speakers! If you want to stay updated, take part in some way, receive the program once finished or have other questions please contact the chair of the organizing committee: Taco van Welzenis – Netherlands@oife.org

Announcement: Study on respiratory insufficiency in OI

The As.It.O.I. (Italian Association Osteogenesis Imperfecta) is trying to build up a study to focus on respiratory insufficiency in OI thanks to the availability of Dr. Grandi of the Valduce Hospital - Villa Beretta / Como, who will also cooperate with Prof. Vianello of the University of Padua in the aforementioned matter.

The aim of the proposed study is not only to make specific evaluations on patients but also to try to establish a protocol. Under the above premises, we wish to know the following:

(A) whether any protocol on respiratory issue is already available in any foreign countries;

(B) if there is any further ongoing study on respiratory function (in order to contact any doctors involved therein and discuss the matter as to adopt the same or similar strategies).

Under the circumstances, please note that any comments/reply are welcome. You can contact either the Italian association at: Italy@oife.org or the OIFE secretary at: Secretary@oife.org

Thank you very much for your help!

"Wishbone Day" and 1st Portuguese Congress on Osteogenesis Imperfecta

By M. Céu Barreiros

In the previous edition we encouraged you to celebrate the 6th of May as "Wishbone Day", a day especially dedicated to Osteogenesis Imperfecta to be celebrated throughout the world ("get yellow"!). As an example of how this day can be celebrated we got a report from our Portuguese member.

"For us, Wishbone Day's main goal is not only the dissemination of information about the disease and raising awareness in the community, but also the awareness of patients themselves for the strength to fight the adversities of life and disease, to live LIFE fully.

The challenge is to celebrate life and the International Day for Osteogenesis Imperfecta, all together, creating a network and spreading the word. To achieve this goal, APOI (Associação Portuguesa de Osteogénese Imperfeita) organized various activities, with intervention on several fronts simultaneously:

On 6th May, OI was present in our four national television channels and several reports were published on the subject in magazines and

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

newspapers of national character. We organized the First Portuguese Congress on OI (see report below), as well as several fun and social activities that promote independence. Furthermore, we created a facebook event dedicated to OI, motivating people to wear yellow T-shirts and scarves or a yellow flower in their hair."

1st Portuguese Congress on Osteogenesis Imperfecta

It took place on May 13th and 14th, in the Auditorium of Alcoitão's Rehabilitation Center, under the organization of APOI, the Portuguese Osteogenesis Imperfecta Association.

In a true "Unbreakable Alliance", the Congress had the collaboration of scientific, institutional and cultural partners, and represented a milestone in this important task that is bringing up the difficulties faced by OI people.



Donations

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

Thank you!

APOI also got the involvement of personalities of national and international reputation as the Portuguese General-Director of Health (on behalf of the Honourable Minister of Health), the Mayor of Cascais, the Director of Alcoitão's Rehabilitation Center, the Director of the "Paediatric Study Section on Orthopaedics", the Vice-President for FEDRA (National Federation for Rare Diseases), the OIFE, the "Teatro de Areia Group" from the Cultural Association "o Mundo do Espectáculo" and Novartis Oncology, that contributed to dignify this event and express solidarity with APOI in the development of common medical and social interests, which may contribute to make the world of OI people a little better.

The multidisciplinary approach

Being the first, this Congress was organized in a multidisciplinary approach, involving doctors of various specialties related to OI, nurses, physiotherapists, occupational therapists, psychologists, social workers and other health professionals. The importance of Reference Centers and the creation of multidisciplinary intervention strategies became clear.

A significant number of round tables and conferences with experts in different areas were presented, namely: "Clinical, genetics and imaging," "Pregnancy and OI", "Child abuse or OI", "importance of

Internal Medicine as a link, between specialities", "Medical-Dental Care", "Ventilation in OI", "Conference on Psychological aspects on OI", "Pharmacological Therapy", "Surgical Treatment in orthopaedics", "The OI column", "Pain in OI", "The approach of physiotherapy in OI and benefits the aquatic environment in the rehabilitation and prevention", "Maximizing independence, promoting participation", "Technical Aids", "Conference on Otorhinolaryngology", "What to do in emergency situations", "Project 5 from the Department of Orthopaedic Surgery of Hospital D. Estefania", "Rehabilitation of children with OI", "Integration of families in the community".



Socio-cultural Activities

In a meeting that was intended to be for ALL, several socio-cultural activities were developed parallel to scientific activities. For instance, there was an exhibition of artwork made by OI people and families that revealed many surprises and artistic qualities of some of our friends.

The closing party of the Congress was undoubtedly one of the highlights of the celebrations. The "Teatro de Areia Group" and our "Crystal children" presented a musical surprise, allowing the participation of all, and even those in wheelchairs were invited to dance. Finally, the Congress was closed by a brilliant performance of the "Choir Club Millennium BCP" who offered to perform voluntarily.

Did you know that...

...OIFE got a message from Mrs. Ute Barschdorf in Malawi (she has OI type I and lives in Africa; OIFE reported about her already) that she is building a lodge in Malawi that will have accessible rooms? It will be right at the beach of beautiful Lake Malawi, in a small village. Some touristic attractions like gameparks are not too far away. The lodge will also have a restaurant, fireplace and a nice veranda. We will keep you informed about the building progress.