



Newsletter Number 11 April 2011

In this issue:

Editorial

With OI high up in
the sky (Part II)

Welcome: new OIFE-
member Poland

Report: New OI-
Association in
Romania

Celebrate Wishbone
Day on May 6th

International Youth
Weekend 2011

Obituary: Rita
Amaral from Brazil

Did you know that...

Editorial

Dear friends,

Have you ever heard of "Wishbone Day"? In many (mostly English-speaking) countries it is the annual awareness day of OI. You find more information and a call for participation in this edition.

Since January 2011 OIFE has got a new member! Poland has had an active OI-association for many years. Why it took a long time to become member of OIFE, and many more interesting things you can read below.

And if you are aged between 15 and 35: Think about joining the International OI-youth weekend in the Netherlands, which is supported by OIFE. Sightseeing and fun guaranteed!

Hopefully you will enjoy reading the newsletter!

Stefanie Wagner

With OI high up in the sky Part II

In the last edition we reported about Anne from California who already got her pilot license with OI. Hans Christian from Germany, though, is still on his way to become a pilot. And this way is very long and steep, as you can read in his report...

My relation to aviation has been very intense and special all my life. My parents told me that "airplane" was my first word as a child. During my childhood I read all sorts of literature related to aviation. And whenever I was again confined to my bed because of a new fracture my aviation magazines were my constant companions.

After some time I had to acknowledge that it would be impossible to fulfill my dream of becoming a pilot, because of my OI. Nevertheless my passion for aviation has accompanied me all my life. In 2000 I left Mexico, the country where I was born, to start a new life in Germany with my wife Veronica and my daughter Frida.

In order to get some exercise I made a tour in the surroundings of our new home at the end of 2009. There I passed by an airfield and started a conversation with one of the members of the flight club. He told me he knew about some pilots in Germany who also use a wheelchair. He also said that he had heard about an organization of handicapped pilots in Germany.

I immediately started to search for this organization and finally was able to locate one of its members. He told me that the biggest obstacle for somebody with a disability was the so called "medical".

Projects:

[Making-friends
Project](#)

[International OIFE
youth weekend](#)

[Student Exchange
Program](#)

[OIFE Pass](#)

This is a confirmation that the person is physically and mentally able to fly an airplane. I was especially interested in flying a glider. First of all because I consider it a fascinating form of flying and then because it is easier to get into its cockpit from the wheelchair. The other guy in wheelchair recommended a flight doctor who he thought would be ideal for my case.

Sadly this doctor gave me a negative response when he found out that I had OI. He told me very clearly that he would not give me the medical certification. You can imagine how I felt after I got this news. I was confronted with the fact that all the other disabled pilots had some sort of paraplegia and that my case was very different. Still I decided to continue to pursue my dream, although I knew it would not be easy to find a flight doctor who would certify me.

My next step was to try to contact as many people as possible who could be helpful. With the help of Ute Wallentin (OIFE-president) I was able to contact another person with OI in the USA who had got the medical certification. This lady had not passed the pilot license for personal reasons, still it was a big motivational boost for my aspirations. Although the medical requirements are less strict in the USA then in Europe it helped me to continue on my quest.

After some time I got an Email in response to all those I had written in the past. It was a flight doctor who told me that I should contact Dr. Quast in Stuttgart. He is the head of the Aeromedical Center located there and a specialist for difficult cases.



The first appointment I had with Dr. Quast was very positive. Still he told me that he would need a certification that I was physically able to operate a glider. For this I did a test flight and different tests in gliders with a certified instructor. I was happy to get the certification as I was totally able to control and operate the glider. After I had got this I went back to the Aeromedical Center and underwent a long series of examinations. My nervous system, my reflexes and my organs were checked. At the end of this I was extremely happy when Dr. Quast told me that he would give me the medical certification to fly gliders. The only restriction was that the glider had to be adapted in a way that I could control the tail rudder and the speed brakes with my hands.

After all those years of dreams I had now surmounted the biggest obstacle in my quest to become a pilot. Now I am in the middle of the theoretical training and hopefully my practical training will start in the summer of 2011. It is still a long way to get the license, but I am confident that soon I might be telling you about my first solo flight and then my successful results in all the examinations that are awaiting me.

Most important: I want to enjoy the journey towards my goal.

Hans Christian Gaedke

News in Brief

Remember: The next **Latin-American OI-Congress** will be from Dec. 5th-11th 2011 in Quito, Ecuador. More info about: Preliminary program, Participants, Program for OI Assoc., Leisure program: Please contact secretary@oife.org

Two new OI-associations have officially been registered in Latvia and Romania.

New OIFE-member: Poland

OIFE is very happy and proud to have Poland as its 24th member since January 2011. Magdalena Lapinska, a very nice and ambitious young woman with OI and official OIFE-delegate, tells us more about the polish OI- association and about herself:

The first organization associating people with OI in Poland was founded in November 1985. For many years, the OI Society existed as a semi-independent branch of Towarzystwo Przyjaciol Dzieci (the Children's Friends Society). Since the beginning, the OI Society has organized about 50 OI camps, spread awareness of OI and helped its members in every possible way. However, the dependence on TPD put some limitations on the Society's activity preventing us from fully supporting our members. That is why, in August 2009, during a meeting of the OI Society's members, we decided that it was time to gain full independence and become a separate organization. In such instances, the Polish law requires for the organization to be disbanded and then registered again under a different name, but we were so determined to find new ways to support our members that there were no obstacles for us and on 1st February 2010 Stowarzyszenie Osob z Wrodzona Lamliwoscia Kosci (OI) – Polska (the Association of People with Brittle Bone Disease (OI) – Poland) came into existence. The Association continues the Society's work. Our members could not imagine summer holidays without the OI camp where people with OI from different parts of the country gather in one place to enjoy one another's company, share experience and have fun together.



During these two-week-camps we also have physical therapy

sessions, teaching sessions, meetings with doctors and therapists etc.

Student Exchange program:

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



The Association's main goal is to raise awareness of OI, especially among doctors, as it tends to be the biggest problem for people with OI. Many doctors have very vague idea about OI and some seem to have never heard of it. Happily, the situation is constantly improving. We have several excellent specialists who are very dedicated to their OI patients but unfortunately, there are too few of them and they are spread across the country. In Poland, OI can be treated effectively but in order to do that, OI patients have to travel to at least three different hospitals because of now, there is no clinic that would treat all the aspects of OI. But we believe that if we join our efforts and work really hard, we can make it happen.

As a new OIFE delegate, I feel like I should tell a little about myself too. I am the Association's Board Member and a webmaster of the Association's website. Me and my younger brother, who also has OI, have been members of the OI Society since 1994. Apart from that I am an English Philology graduate and a third-year student of Economics. My big passion are languages, I am learning Spanish and I would like to learn Arabic. I love Scotland, Ireland and Spain and all things Scottish, Irish and Spanish and I cannot really explain why. In my free time I read crime novels, watch medical drama series (ER is my favourite), cook and improve my photographic skills. I try to lead a life as normal as possible. I have never treated my disease as a curse but rather as an inseparable part of me. If it had not been for OI, I would not have met all those wonderful people I know today.

Magdalena Lapinska

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

New OI-Association in Romania

It is a great pleasure to announce to the worldwide OI community the very recent set up of a Romanian OI association. As a matter of fact, this new association came into being as a result of coordinated efforts of a few families whose children are suffering from this very rare genetic condition.

The complete name of our association is "Romanian Association for Osteogenesis Imperfecta "Fragile People"" (in Romanian:

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

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

Asociatia Romana de Osteogeneza Imperfecta "Oameni Fragili") and it was established in January this year. First and foremost, we are grateful to the wholeheartedly, continuous support we received from the National Alliance for Rare Diseases in Romania, especially from Ms. Dorica Dan, whose invaluable work and example in this field paved the way for this accomplishment. Ms. Dorica Dan is not only a person, who, as a mother, lived the thorny and sad experience of having a child affected by a rare disease, but also found inner resources and morale to cope with the almost impregnable Romanian health system, in order to "move things forward" for all persons with genetic rare diseases in our country.

As to the treatment of OI children, Romania has a few children hospitals in which the essential is bisphosphonate perfusions are periodically administered, with good results. Approximately (I do not have the exact data), this approach has been successfully used from 2000-2001 on, therefore for about ten years.

Another good news is that from 2008 on, (that year was the first one when the Rare Diseases Day was publicly marked in Romania), Osteogenesis Imperfecta is covered, from the view point of drug treatment, by the National Program for Rare Disease. That is, the cost of purchasing and administering the drug is entirely funded from the state health budget. Moreover, starting from the last year, two children hospitals in Bucharest are specifically nominated to carry out the OI treatment: the Emergency Clinical Children Hospital "Grigore Alexandrescu" and the Emergency Clinical Children Hospital "Marie Curie". A little, but not unimportant detail: the latter was built as a donation from the Polish nation to Romania, following the devastating earthquake on March 4, 1977.

If we take into consideration the vast matter of rodding surgery in OI, we must say that the most utilized rods are still the K-rods, and also there are some children who already "wear" the most appropriate titanium elastic rods (TEN nails). But we regretfully must mention that the telescopic rods, admittedly one of the best medical devices worldwide used in OI surgeries, are completely nonexistent from Romanian orthopaedy "landscape".

There is also a lot of work to be done in the field of genetic counselling and diagnosis for OI, dental care for those affected by secondary Dentinogenesis Imperfecta, specific kineto-therapy directed towards these people.

A special, uninterrupted effort have to be dedicated to raising awareness campaigns among those members of the public and private (this one *in statu nascendi*) healthcare system directly

private (this one, *in statu nascendi*) healthcare system directly linked to the various aspects of our disease: family doctors, neo-natologists, orthopaedists, geneticists and so on. After all, this is and will be the mandatory role of our organization for the years to come: to shape a better future for, and, hopefully, to straightforwardly contribute to the lives of OI individuals. "Due to the short interval from January, we do have a website, but it is possible to reach our "family" on a free discussion group at <http://health.groups.yahoo.com/group/oirom/>.

Understandably, the messages are posted in Romanian, but this is not quite a complicated language, at least for Italian, French, Spanish and, I dare to say, Portuguese-speaking people !

*Florin Dananau,
President*

Romanian Association for OI "Fragile People"

Donations

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

Thank you!

Celebrate "Wishbone Day" on May 6th!

Dear friends,

it got started in Australia: the idea to have a special "OI-day" all around the world - fortunately all the English-speaking people have a special symbol for this day, that all the others lack and cannot use to the same extent, because we do not have such a nice name for it: "wishbone" - which is a Y-shaped special bone that only flying birds have for stabilization during flights.

But even without the English name of this special bone we all can get together worldwide via the internet, on facebook and elsewhere and by organizing special OI-events to raise awareness on 6th May.

This could also be a good opportunity to raise funds for an OI-project! And if you have special activities you should please use yellow T-shirts and the wishbone-day logo for reasons of "corporate OI-identity".

Please connect with Jo Ragan, the founder and visit her website <http://www.wishboneday.com/2011/01/time-flies-when-we-blink.html> and have your organization and location linked to their map and website! And watch and spread an OI-film on youtube:

http://www.youtube.com/watch?v=xWqrU2MdNa8&feature=player_embedded#at=15
Enjoy many wonderful OI kids doing what they do best... just being kids. Thanks to Jo Ragan, founder of Wishbone Day. Celebrate OI Awareness by wearing YELLOW on May 6th.

If you cannot yet participate in an activity, please use your national website or any other means to participate in "our day"!!

Ute Wallentin, OIFE President

International OI-Youth Weekend 2011

Dates and Costs:

long weekend: September 28th until October 2nd: costs: € 150,-
short weekend: September 30th until October 2nd: costs: € 100,-

Location:

A small town called 'Schoonoord' in the province 'Drenthe', Netherlands. Accommodation and transportation during the weekend will be completely wheelchair accessible.

Preliminary Program:

A trip to Amsterdam, a visit of a flower auction, workshops

Age of participants:

People with OI (and their assistants) between 15 and 35

Assistance:

Can be provided, please contact the organizing team.

If you are interested and/or have questions please contact the organizing team: info@oijongeren.nl

Obituary: Rita Amaral from Brazil

It's a big sadness for us to inform you that Rita Amaral has died. Rita was one of the oldest members of the OI community and founder of the ABOI (Brazilian OI Association).



Loosing Rita means losing a good friend, means losing one of the first persons affected by OI who dedicated part of her live advertizing the problems related to the disease.

She was amazingly enthusiastic, had an enormous capacity for work and did not let herself go down by the difficulties related to OI.

Rita was an anthropologist and an authentic CELEBRITY in her field. She was a very intelligent person, and very active in organizing an infrastructure in her country to support OI. By her work, ABOI was able to create Reference Medical Centers for OI, recognized by the government.

Also she dedicated to creating /translating medical information that was spread around the world through the internet. Her webpage (<http://www.aguaforte.com/oi/>) was one of the first private pages on this topic and included a big amount of information in Portuguese.

We leave you with her obituary, and ask you for a thought, a feeling or a prayer in memory of a big woman and a friend who has now left us

May she rest in peace

Did you know that...

...OIFE has a new project called "flying OI-experts"?

OI, like most rare disorders, does occur all around the world. OI has a low prevalence and thus even countries with high standard of medical care do not have many centers of expertise and clinics with trained surgeons and other OI-experienced medical staff.

Every year many OI-families from less developed countries desperately search for help, treatment and surgery for their OI-child in other countries. Due to the high costs for (telescopic) rods, surgery, accommodation of patient and accompanying parents plus travel costs only very few fortunate families manage to reach their goal and receive expert OI-treatment abroad.

But even if they do: the situation in their home countries stays unchanged for the next necessary treatment of their child and for OI-patients in general.

Aim of project

One of OIFE's basic objectives is the global spread and increase of knowledge on OI and adequate treatment and care.

We regard it as more efficient to train medical staff like doctors, nurses or physiotherapists than to encourage individual patients or families to seek surgery and treatment in other countries.

We have thus begun to cooperate with clinics in countries like Albania, Russia, Egypt or Sri Lanka to help them organize internal or national training courses and workshops on best "OI-treatment and care". We try to support the costs of such seminars and to offer subsidies for travel costs of invited OI-experts from known centers of expertise for OI.

And we encourage those OI-clinics to invite colleagues from abroad for stages of several days in an OI-clinic, where they can observe and learn modern surgery-techniques and specialized OI-treatment protocols.

Please contact us for support to or questions about this important project:

president@oife.org