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Did you know that...

Editorial

Dear friends,

first of all I wish you all a happy new year!

A couple of weeks ago OIFE got a request from an OI-person asking if we have any experience how to get a pilot license. I thought this might be an interesting topic for the newsletter, so we were using our "network" to find people who could help with information. We found Anne, who has a pilot license, and Hans Christian, who is learning to fly. In this edition you will find Anne's story, and the next newsletter will contain part two with the experiences of Hans Christian.

But there are two other interesting reports in this edition, so hopefully you will enjoy reading the newsletter!

Stefanie Wagner

With OI high up in the sky Part I

Anne from California got her pilot license - with OI. Here she tells her story and gives some helpful information for those who like to make their dream come true...

I have OI (probably type 3 and maybe some type 4 in my body somewhere). I am not flying airplanes now, but here is my story.

I am 61 years old, about 3 ft. 6 inches in height, and currently use a walker for walking short distances. I use a power scooter for navigating longer distances. Prior to a hip fracture 4 years ago, I walked with a cane for short distances.

In 1988 at age 39 I discovered IWA (International Wheelchair Aviators), and began the process of learning to fly. I sought a flight surgeon who had experience with disabled pilots, passed my medical clearance exam, and got my student pilot permit. I began the process of getting seat cushions designed to elevate me to the proper height for a Piper Warrior (my favorite aircraft), learned how to get into and out of the cockpit and how to check the fuel in the tanks (why I love low-wing aircraft) and began working with a flight school regarding extensions for the rudder pedals and toe brakes. Meanwhile I began studying the books for ground school and took a few lessons in the air.

I had never before in my life felt such exhilaration as I did on my first take-off at the pilot controls, with my instructor sitting beside me talking me through it. We took off from a commercial airport and

Projects:

[Making-friends
Project](#)

[International OIFE
youth weekend](#)

[Student Exchange
Program](#)

[OIFE Pass](#)

We mourn the death of Markus Triebswetter who unexpectedly died at the age of 36. He was an active member of the Bavarian branch of the German OI-Association.

talking me through it !!!! We took off from a commercial airport, and the control tower cleared us for take-off next in line behind a United Airlines jet. There is no way to describe in words the exhilaration of gently lifting your airplane off the earth and flying up toward the clouds !!!!!

Then life interrupted me.....both my husband and I got new jobs and we moved to a different state. My flying plans were put on hold for several years, because my new job was so demanding I had no time for anything else. Eventually I found a new flight school and resumed the process of working with that new flight school regarding extensions to operate the aircraft pedals.

In 1992 my husband and I moved to California, again for new jobs. Again, the demands of career meant my flying once again took lower priority.

Although I have since retired, I have not resumed flying lessons. Learning to fly requires both money and time commitment. In my life, I have not had both money and time simultaneously. I have no regrets because the "interruptions" were such wonderful experiences in my life. But whenever I get close to a small airplane, I get a strong urge to fly again...

If anyone wants to learn how to fly please contact the International Wheelchair Aviators (website: <http://www.wheelchairaviators.org/>)

The IWA is an international organization of pilots and flight students who have disabilities, and who want to help other aspiring pilots with disabilities get their pilot licenses. They can provide advice about types of adapted controls (such as hand controls for rudder pedals and toe brakes), advice on types of aircraft modifications for pilots with disabilities, and advice about getting your medical clearance and student permit prior to beginning flying lessons.

They might know whether any of their currently flying members have OI. They may not give you their names, because of U.S. privacy laws. However, you might get information this way: you can ask IWA to forward your request for info to all IWA members who have OI, and ask them to contact you at your email address. You can also ask IWA to forward your request for info to the entire IWA membership, and ask for experience with an OI person, and ask them to contact you. Some IWA members are flight instructors who have experience giving flying lessons to student pilots with various types of disabilities.

The best way to get information is to join IWA as a member. You don't have to be a pilot to join. IWA welcomes all who are interested in opportunities for people with disabilities to become pilots. There are quite a few IWA members who live in Europe.

If anyone wants to learn how to fly, I encourage you wholeheartedly! Start by talking with any wheelchair-using pilots you know, and getting all the advice you can from IWA members. You will benefit from joining IWA and being able to communicate with all the other members. A few of the European members of IWA moved to the U.S.

News in Brief

Announcement: The next international OI youth weekend will be held in the Netherlands from **September 28th until October 2nd 2011**. The organizing team is already working on it. For further information please contact info@oijongeren.nl

The next **Latin-American OI-Congress** will be from Dec. 5th-11th 2011 in Ecuador.

There is a **new OI-support group on the Philippines** with currently 20 families. Please visit their website (in English!): Oisupportphilippines.wordpress.com

members. A few of the European members of IWA moved to the U.S. for a short time in order to take their flight training school and get their pilot's license. Ask a pilot in your area to take you up for a ride in the co-pilot's right-hand seat, so you can experience being in the cockpit and the feeling of flight in a small airplane. (It is polite to offer to pay for the pilot's fuel for your flight.) It is important to seek a physician who has experience with disabled pilots, in order to get your medical clearance. It is also most helpful to use a flight school and flight instructor who has experience with disabled pilots and adapted aircraft controls.

Fair winds and blue skies to you all, and best wishes!
Anne Barrett Swanson, California, USA

OI-Workshop in Albania

By Oliver Semler, M.D.

Some years ago a family living in Albania with OI-twins got in contact with Mr Schmid. He is a German, living in Durres – one of the major cities in Albania – helping different underprivileged people. He was touched by the history of the twins and tried to improve their situation. He was able to organize some money for the twins and send them and their parents to the German OI-center in Cologne. Here Dr. Semler and his team took care of the twins, started a therapy with bisphosphonates and taught the parents how important physical activity is for them. All this happened back in 2006.

During the following years 3 other families with OI children "appeared" at the local hospital in Durres. All families were in close contact with Mr. Schmid and so he was forced to take the initiative to improve their situation. He was able to motivate the local doctors to become interested in OI and together with them he was able to offer a bisphosphonate therapy to all children. After some time it became obvious that bisphosphonates alone are not enough and that there was a severe lack of knowledge about OI in Durres. Additionally there were no qualified doctors in the whole country. This was the point where Mr. Schmid again took the initiative. Together with the head of the orthopedic department, Dr. Neritan Myderizzi, he organized a workshop for the medical staff and for the parents. He invited Dr. Oliver Semler and the Tanja Petersen to Durres. Tanja Petersen is a physiotherapist, board member of the German OI-society and she is working together with Dr. Semler in Cologne.

Student Exchange program:

Would you like **to host** an OI-student? Please contact OIFE if you can help. Thank you!



The workshop took place at the hospital in Durrës, starting on a Thursday ending on Saturday. Dr. Semler and Mrs. Petersen gave lectures about all different aspects which have to be kept in mind when treating children with OI. Starting from first aid after fractures to bisphosphonates and to a daily physical exercise the patients need to do to strengthen their muscles and bones. The local doctors presented how they treat their patients and different strategies were discussed. The main focus of the discussion was how the ideal therapy could be adapted to the local circumstances and how therapy could be improved for the children. There were around 50 people participating in the workshop. They were medical doctors, nurses, physiotherapists and medical students.

During one afternoon the local doctors discussed the 5 different cases with Dr. Semler and Mrs. Petersen and then there were a few hours together with the kids. In this time Dr. Semler and Mrs. Petersen tried to explain to the parents how important it is for the children to use their muscles, move around as much as possible even if this increases the risk of fractures. Additionally there was a lot of explanations about OI in general and especially about the genetic background. Supervised by Tanja Petersen the children played together, tried to catch balloons and experienced fun while moving around on the floor.

Ideas?
Feedback?
Questions?
News?
Interesting stories
to tell?
Please contact the
editor

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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



At the beginning the parents were very anxious, but after some time they became more optimistic and were proud to see what their children actually could do on their own. It turned out to be very complicated to motivate the local physiotherapists to participate in this session. This might be due to the fact, that physiotherapy is not a profession in Albania. It is practiced by nurses who are doing it on a "learning by doing" basis. Keeping this in mind it seems obvious that they were very reluctant to train these OI kids without knowing much about the condition.

The idea of this workshop was to increase knowledge about OI in all medical professions treating children with OI. Another aspect was to increase the contact between these families and to highlight the importance of daily physical training. This is the basis for these children in order to reach future independency. This workshop was supposed to be a start-up for a closer cooperation between the hospital in Durres and the university in Cologne. Visits of doctors and physiotherapists are planned but have to be financed. Case conferences can be organized when local doctors have any difficult patients and when they are not sure how to handle them.

After the end of this workshop the parents, guided by Mr. Schmid formed some sort of OI-society in Durres and the hospital was announced to become national Center for OI in Albania by the national minister of health. Thanks again to Mr. Schmid who felt the urge 3 years ago to support the twins and who organized and financed this workshop. And to OIFE for helping to pay for the travel costs of the lecturers to the workshop.

Due to the limited financial resources in Albania the contact to OI professionals, parents and patients in other countries was very much appreciated by all people involved in Albania. Everybody participating in this workshop hopes that this was a first step to improve the treatment of OI-patients in Albania, where OI is neglected at the moment.

Report: OIFE Youth weekend 2010 in Belgium... Awesome!

By Stephanie, Annelies and Lien

A youth holiday in Belgium in November! That month is cold and rainy, and Belgium is not that special ... But it was the direct opposite!. 32 young people between 15 and 35 years, from 7 different nationalities met each other in Maasmechelen, Belgium.

Donations

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

Thank you!

During the first dinner it was quite silent, there was only little conversation in English. Most of us talked to their fellow countrymen. What a stark contrast to the days that followed! We all tried to speak English, and it worked excellent. Even a chat during the meals could be with someone from the UK or with someone of Denmark... we felt like one big family!

There were also a lot of activities planned. A subtropical swimming pool, fully adapted to the needs of people with handicaps ... you certainly cannot find a pool like that anywhere else. The enthusiasm was great, when Niels was using a lifter so he could use the slide, too! Simey who had never been on a water slide before, also gave it a try.



Cycling on a special bicycle with auxiliary motor, despite the cold weather was a hit.

On the international evening, everyone got a chance to present something about his / her country and we listened interested, tasted and enjoyed all the local gastronomic specialties. Some of them were a bit miscalculated ... Thus; the German girls brought bread for all of us and also wine and grape juice... ☺

But the absolute highlight for many was surely our day trip to Brussels. Although at first there was less enthusiasm because breakfast was already at 7.15, but everyone was on time on the bus! The rain made it a little difficult to get everybody in the bus with a lifter but we did it and left for Brussels. Upon arrival in Brussels, the sky cleared off! In Brussels we first took a guided bus tour. After a picnic we explored Brussels with a guide.

At the royal palace, we made this group picture:



A few weeks after our youth weekend I read in the newspaper that 'Brussels' Grand Place, has been voted as the most beautiful square in Europe. And this was the place where we were!

In the evening we enjoyed BELGIUM fries (no French fries) from a snack bar. Of course in obligatory paper bags!

You might think that, after such a long day, everyone would be tired and go to bed early, but the disco lights motivated people to start dancing.

The participants did certainly not get much sleep during the weekend, but that would have been a waste of time anyway, so... We have been laughing a lot, exchanging experiences, enjoying activities, and it was just fantastic! After 5 days, I (Stephanie) got the impression that most people have known each other much longer than just five days. The reactions on facebook were very enthusiastic and the posted photos speak for themselves, so we can end this report as we began: It was AWESOME!

This weekend will be in everyone's memories. Hopefully there will be many more of such weekends. We encourage the organizing team of the next youth weekend in the Netherlands to beat us!

Finally some nice words from participants:

'I really didn't know what to expect from the weekend with people from all different countries and it was amazing. If I can make next year, I will definitely be going! You worked so hard and arranged great activities. Made it very special so just wanted to say thank you. I can't wait to see you again'

'The weekend was so nice! :) All the week I have been memorizing the weekend and all the great moments we had, hopefully I get to

see everyone next year in the Netherlands!

'I almost forgot, but my (Lien's) English that weekend quite improved. I learned many new words and sentence structures. But one new word I like to hear ... and I heard it everywhere: AWESOME ... it means something like: wonderful, fantastic, excellent.'

Did you know that...

...OIFE is very happy to announce that since January 1st 2011 Poland joined OIFE as new member. So now OIFE has 24 member countries! The next newsletter edition will have more information about our new member. See: <http://www.osteogeneza.pl/>