



## Newsletter Number 7 May 2009

### Editorial

Dear friends,

I am very happy to present the OIFE-newsletter with a new "face"! Besides some changes in the layout there will be a regular editorial part. Furthermore, in the *left column* you will not only find the topics of the newsletter but also information like for instance:

### In this issue:

#### Editorial

\*current projects linked to a description on the website or a contact person

#### OIFE photo contest 2009

\*news in brief

#### OIFE-EUROPASS- New edition

\*an invitation to contact the editor if you have something to tell that could be of interest for our over 200 worldwide OIFE-newsletter subscribers

\*a note if you like to support the work of OIFE with a donation

\*a brief description of OIFE's objectives

#### OI in motion 2009 – Meeting on Rehabilitation and Physiotherapy in OI

The new regular heading "Did you know that..." will close the newsletter.

#### Interview: Student with OI six months abroad

In this year's first edition I'd like to encourage you to take part in the OIFE photo contest 2009 – it is very easy and there are some nice prizes to be won – so just read the following article and go for it – good luck!

#### OIFE – International Youth-Week 2009 in Italy

It was a coincidence that Julia, a teenage student from Germany with OI type I, had the opportunity to go to school in the US for half a year and almost at the same time OIFE started a new project called "International Youth Exchange Program for OI people". So I am glad to present an interview with Julia.

#### Did you know that...

I hope you like the new "face" and enjoy reading the newsletter!

Stefanie Wagner

## OIFE photo contest 2009

For the second time OIFE is running a photo contest this year. The aim is to get a nice collection of pictures of people with OI from all over the world. Everyone with a digital camera, young or old, can take part (only members of the jury and their family members are excluded). The rules are simple and there are some nice prizes to be won! To take part a contest form must be filled out by both photographer and portrayed person. This form can be downloaded from the OIFE website. For inspiration you can check some of the entries we received this year on the OIFE website: [www.oife.org](http://www.oife.org) (click "Photo contest")

#### The prizes:

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

#### The rules:

- Pictures should depict a person(s) with OI
- Pictures must be submitted by the original photographer and become property of the OIFE
- Both the photographer and portrayed person(s) consent to free use and publication of pictures by the OIFE, (e.g. for promotional activities, the website or information materials)
- Each photographer can submit a maximum of 20 pictures
- The deadline to submit pictures is October 1st 2009
- Only digital entries will be accepted, these should be e-mailed to: [secretary@oife.org](mailto:secretary@oife.org) together with a filled out contestants form

Good luck!

## Projects:

[Making-friends Project](#)

[International OIFE youth weekend](#)

[Padrinos](#)

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

## EUROPASS: New edition with 17 languages!

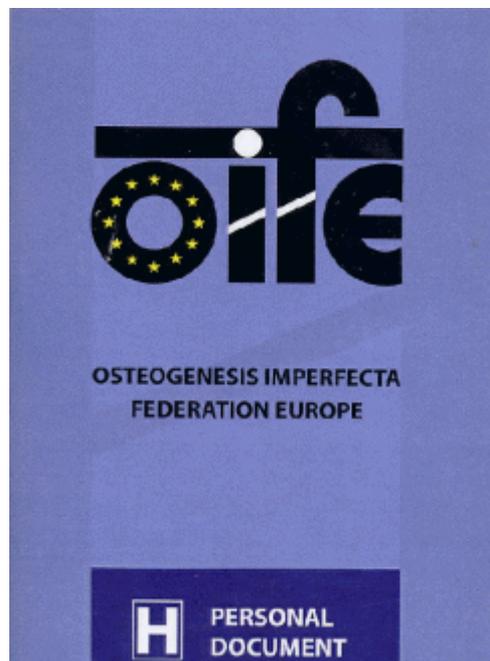
### OI + Travel insurance = problem!?

OIFE got an inquiry from an Irish woman with OI who has problems to find a travel insurance.

At that time OIFE cannot help with information but wants to start a new project on this subject.

Therefore we'd like to ask our readers: Do you have the same problem or can you give advice?

Please contact [OIFE office](#). Thank you very much in advance!



The OIFE EUROPASS 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 phonenumber for personal assistance/information in a number of countries.

Members of OIFE member societies can obtain a copy of the EUROPASS from their national OI society. Others should [contact the OIFE](#).

**- OI in motion -  
Meeting on Rehabilitation and**

# Physiotherapy in OI

## November 20-22, 2009

OIFE is organizing a meeting on rehabilitation and physiotherapy in OI. Specialists in the field from all over Europe and abroad are expected to attend. The meeting will take place in November 2009 in the town of Rheinsberg, north of Berlin, Germany. We want to cover such topics as; physiotherapy concepts for children, assessment of motor function, post surgery rehabilitation, mobility aids, hydrotherapy, rehabilitation in adults, population based concepts of rehabilitation and interdisciplinary approach of treatment.

## News in Brief

We welcome two new OIFE-members: **Belgium** (french speaking part) and **Portugal!**

The **russian OI-association** has got a new website: [www.osteogenez.ru](http://www.osteogenez.ru)

The **italian OI-association** AS.IT.O.I is celebrating its 25<sup>th</sup> anniversary this year. Congratulations! More info about the convention: [www.asitoi.it](http://www.asitoi.it)

OIFE knows of three newly founded OI-associations in **Andalusia** (Spain), **Colombia** and **Malawi**

**Bolivia** is planning to set up an OI-association

Please let us know if you want to be updated when further details become available about the program and registration procedure by sending a message to [secretary@oife.org](mailto:secretary@oife.org). For questions about the program please contact the chairman of the organizing committee [Taco van Welzenis](#)

## Interview: 6 months abroad with OI

**Julia Pfister, a 17 year old german student with OI type I, had the opportunity to go to the USA. She stayed there from September 08 until February 09 and lived the "normal" life of an american student.**

**OIFE: How did it come to your stay abroad and how did you organize it?**

**Julia:** Well, my parents and I thought it might be a good idea for me to go abroad for some time, and we chose the United States. So my dad asked a befriend couple in the U.S. if they can help us to look for an institution for student exchange which could find a host family for me. But then the couple invited me to stay at their house! So we could start planning my big adventure!

First we had to look for an institution for student exchange in Germany, because they organize everything that is necessary (visa, flight, insurances etc.). All in all it took about half a year until I could go.

**OIFE: How was your school day and did you understand everything easily?**

**Julia:** The english lessons I took in my german school were sufficient. Also, everybody was anxious to speak slowly and clearly and after about 2-3 weeks I didn't have problems any more. I even used their youth slang.

The school system in the US is completely different to ours in Germany: There is only one type of school and not three like in Germany. Students who find classes too difficult can change into a lower class. Each day before lessons started, the students had to stand up and promise they always do everything for their country!

The lessons are not 45 minutes like in Germany but 60 minutes and they were easy to understand. When there is a test, you never have to write the answer as a text – you just choose between answer A, B, C and D. I found it very easy. So my school report grade was very good!

You only have six subjects and you have them every day! This was quite

boring – every day the same schedule! History and english are obligatory but you can chose all the others. I decided to take mathematics, french, art and dancing.

**OIFE: Dancing? How exciting!**

**Julia:** Well, the steps and movements were very easy, this was no problem – anybody could have taken part!



Hip-Hop-dancing (Julia on the left)

**OIFE: Did you take any preventive measures because of your OI?**

**Julia:** Well, of course I told the german exchange organization about my OI, but that was no problem – probably because I have the “mild” type, I can walk and don’t have problems in everyday life. There was a regular insurance from the exchange institution, but my parents contracted an additional foreign insurance for me. And my doctor in Germany gave me an emergency address in case of a fracture. That would have been about 4 hours by car, but I was lucky, nothing happened to me. Additionally I had the contact data of the american OI-association.

**OIFE: Did you notice something about the accessibility where you lived?**

**Julia:** Yes. Every school bus is accessible for wheelchairs, and every public building, restaurant etc. is accessible and has restrooms for people in wheelchairs. The school I visited also was completely accessible. I met one boy in a wheelchair there.

**OIFE: Can you tell us something about where you lived?**

**Julia:** I lived outside of Boise, the capital of Idaho. My host family took me to the bus stop by car each day and the school bus picked me up. Imagine there isn’t really a public transport system! The reason for this is probably that everybody has his or her driver’s license at the age of 16.

Ideas?  
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Questions?  
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to tell?  
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landscape near Boise, Idaho

**OIFE: What did you do in your free time?**

**Julia:** I found two really good friends there. One was a girl from Spain and also an exchange student. We often went swimming, sometimes to the movies or shopping. Apart from that, there were not so many possibilities to do something together because I was located on the countryside. So I often met friends at my or their homes. And, I made my driver's license!

**OIFE: You made your driver's license?**

**Julia:** Yes! For two months I took theoretical lessons twice a week at school and practical lessons once a week. I could use a "normal" car without any adaptations. It cost only about 150 Euros, and it is valid also in Germany!

**OIFE: What impressions did you get from the people?**

**Julia:** Well, the people are much more nicer and friendlier than in Germany – everybody is talking to you even if you don't know her or him! Another thing I found remarkable was that most of the people belonged to Mormons, a special religion. For example, they are not allowed to consume caffeine, and youngsters at my age had to be at home until 10 p.m. It is usual that parents have at least 10 children! And everybody was sad about the result of the president's election...

**OIFE: What about the food?**

**Julia:** Well, as you are in school until three thirty in the afternoon, the families have their hot meal in the evenings which I was not used to. So you just have a snack for lunch at school. Unfortunately in my family we almost every day had broccoli, which I don't like so much... But we also had a lot of delicious Mexican food because many Mexican immigrants are living there.

**OIFE: Did you have to pay a school fee?**

**Julia:** Yes, but only a small amount and it was not paid directly to the school but the organisation.

**OIFE: Can you tell a bit more about the exchange organization and give some recommendations?**

**Julia:** My parents chose a quite small organization near my home. And this organization had its partner organization in the US which had its special person who was supposed to contact me every two weeks to

make sure that everything is o.k. Actually, I must say, that person never

**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](http://www.oife.org)

contacted me. Imagine that once I called her up because I had a question and she didn't even know who I was!! For me this was not so important because the family I lived at were friends. So my recommendation would be to carefully check the organization in advance.

**OIFE: Did you miss something?**

**Julia:** I missed my family and friends, but I "skyped" with my family every day so I didn't feel very homesick.

**OIFE:** Julia, thank you very much for the interview!

*Editor's note: Are you interested in OIFE's newly started project "International Youth Exchange Program" as student, host family or sponsor do you already have experience you'd like to share with us? – Please [contact the OIFE](#).*

## Donations

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

**Thank you!**

## OIFE – International Youth-Week 2009 in Italy

The OIFE International Youth Week 2009 will take place during the usual summer holiday of and together with the Italian youth group which will be in Centro Ferie Salvatore (you can take a look at: [www.centroferiesalvatore.it](http://www.centroferiesalvatore.it))

This year you can participate a whole week from 17<sup>th</sup> July until 23<sup>rd</sup> July! We are not yet able to give you a detailed program because it also depends on the number of the participants and on how long they will stay (it is also possible to leave on 19<sup>th</sup> July). We hope many of you will stay with us for the entire week. We'll be able to plan more activities and to enjoy the beach and sun for more days!!!

There are two main themes we'd like to speak about during the week:

\*Sports for disabled people (we are trying to plan a number of different demonstrations of different sports such as wheelchair hockey, basketball, tennis, handbike ....)

\*Travelling with O.I.

You can get a detailed brochure with more information from [Anna Rossi](#) from the organizing team!

## Did you know that...

...**OIFE meanwhile has:**

**members in 20 countries:** Australia-Belgium-Croatia-Denmark-Ecuador-Finland-France-Georgia-Germany-Italy-Mexico-the Netherlands-Norway-Perú-Portugal-Spain-Switzerland-Sweden-the United Kingdom-The United States of America

**contacts to OI-associations and OI-groups in many other countries:** Argentina-Austria-Bolivia-Brazil-Canada-China-Colombia-Greece-Israel-Japan-Korea-Malaysia-New Zealand-Panama-Poland-

Romania-Serbia-Slovenia-South Africa-Taiwan-Venezuela

**and contact to OI-people and their families in:** Albania-Algeria-Armenia-Benin-Belarus-Belize-Bulgaria-Cameroon-Chile-China-Cyprus-Egypt-Estonia-Iceland-India-Indonesia-Ireland-Ivory Coast-Jemen-Kosovo-Latvia-Libya-Lithuania-Malawi-Maroc-Mongolia-Namibia-Nepal-Pakistan-The Philippines-Saudi Arabia-Sri Lanka-Sudan-Turkey-Uganda-Ukraina-Vietnam-Zimbabwe

**Where do you know more OI-people? Let them find us - and help us to find them! Please [contact the OIFE!](#)**