



# OSTEOGENESIS IMPERFECTA FEDERATION EUROPE

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### International Youth-weekend in Paris for youngsters between 15 and 30 - register now!

The AOI (French OI association) organizes a youth weekend in Paris from April Friday 27th to Sunday April 29th. Everything will be completely adapted for people in wheelchairs. The weekend includes guided tours to Paris and the historical Palace of Versailles, a morning session about "Sports and OI" with guests specialized in the handisport field, and a lot more!

Voluntary members of the AOI will supply the translations in English and Spanish language night and day. Two medical students (known of the AOI and knowing the OI) will be present all the weekend for physical assistance.

Further information: <http://www.oife.org/home/index1-uk.html>

Total costs for the stay are 130 € per person - other costs will be covered by the AOI and the OIFE. Participants travelling to Paris from outside France can get a 50 Euro compensation for their travel costs to Paris from the OIFE.

### The deadline for registration is March 25<sup>th</sup>!

For further information or questions please contact the OIFE-youth coordinator, Anne-Miek Vroom at [youth-coordinator@oife.org](mailto:youth-coordinator@oife.org).

### 10 years HOI – so many things achieved and still a lot to do...

#### The OIFE

- \*Represents their members on a European level
  - \*Presents the problems and needs of people with OI to national and international organizations
  - \*Collects and publishes information about OI
  - \*Promotes research on all aspects of OI
  - \*Supports member-societies by the exchange of information and experiences
- [www.oife.org](http://www.oife.org)

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In the year 1996 I raised the "HOI" foundation ([www.hoistichting.nl](http://www.hoistichting.nl)) in the Netherlands. "HOI" means Help for people with OI (osteogenesis imperfecta), to support financially for medical treatment, for crutches, wheelchairs etc. We also support other OI projects like the Padrinos project in Spain. We gave them money, so that two little boys could have surgery in Ecuador. Last year we helped Kathuna in Georgia, with wheelchairs and infusomats.



wheelchair getting ready for the long trip to Tblisi, Georgia

My name is Hinke Panjer, I am also born with OI. I live with my life-partner Harm in an old farm in the North of the Netherlands. I have OI type III, but I can help myself at all the day needs. I also have a housekeeper, who cleans up the house and helps me with things which I cannot do by myself. As I am getting older I feel that my body is getting more painful and I become sooner tired. But this problem we all know, I guess...

### How everything began

Ten years ago in 1996, I met a Greek woman with OI during an OIFE congress in the Netherlands. She has had a lot of problems with her leg and had no money to get rid of the painful problems with her leg. We let her stay in our house for 8 months and collected money from our neighbours and friends so she could get medical treatment in the hospital.

After she had returned home, me and my partner decided to raise a foundation to help OI people. Because I have OI by myself, I can understand the pain and fear of fractures.



the home of HOI in Den Andel, The Netherlands

Anyway, in my country the government cares for disabled people with financial help and we have insurances for our problems. But I thought of all the OI children living in countries without any governmental subsidies – neither medication nor wheelchairs or crutches. And always in danger to fall and break something. Because of my empathy for them, I wanted to raise a foundation and started working on it immediately.

First we started to build a wooden guesthouse for OI people to stay while they get medical help. We have finished the guesthouse last year, but we still need to build a wheelchair shower on it. The costs are very high and we have to collect money first. (The small house is also adequate for a holiday for 2-3 persons. If people like to take a shower, they can use my special bathroom for wheelchairs in the farm house.)

During the last 10 years we gave financial support to the OIFE, so they could pay for bisphosphonates and other medication. We also sent wheelchairs and walkers to little OI children in Georgia, Ecuador, Philippines, Nepal, Siberia and Cuba.

For instance, in the Philippines, there was a young student with OI. 'HOI' supported her financially to get a wheelchair, and payed her study, in cooperation with the OIFE. In Siberia there is a young woman with OI, living in a small town. She needed help to set up a small business for knitting clothes and with that work she could make her own money. So 'HOI' sold jewellery made by that young woman. With that money she could fix her own house to her needs which made life easier for her. The story would be a long one if I told all the work of 'HOI'...

**In the year of HOI's 10<sup>th</sup> anniversary the focus will be on the following project in Cuba:**

Yainé and Yaineris Olivera, twin girls with OI type III, are living in a very old house with their mother, brother and sister in Cienfuegos. By the end of 2006 they had to move so they now live closer to the hospital. It is easier for their mother because now she does not have to carry the girls so far from home. She has a lot of pain in her back. Unfortunately the new house is very damp, so the children are very often ill.



Yainé and Yaineris Olivera, born in october 1995

Their Dad has left the family because he could not handle the problems with the two girls. He

is not paying for the kids, so the family has to live from a very small state pension. They cannot go to school; rehabilitation programs or surgery is not possible in their country. And, as you can see on the photo, the wheelchairs are too small for the girls. At least, in the hospital there is a doctor who helps them as good as she can.

You see, the family has to suffer very hard. Therefore 'HOI' is working out a plan how to help best - and fast.. This will take a lot of energy, ideas and money, and it would be great to have your support:

### **A call for help**

If you

- Have Spanish books and schoolbooks you don't need anymore (and pencils)
- Have toys and things to study for girls aged 12
- Like to be a donor for the kids
- Like to support the family mentally don't hesitate to write postcards or letters (in Spanish)
- Have any other idea how to help
- Are interested in helping 'HOI' in administrative matters like writing letters in English or writing documentary texts in English

**Please contact us:** [info@hoistichting.nl](mailto:info@hoistichting.nl)

We will regularly report about the situation of the twins here in the newsletter.

**Kind regards from the Dutch HOI team!**

### **OI Registry – a project from the North American OI-association (OIF) and the Kennedy Krieger Institute in Baltimore**

The OI Registry is a secure, confidential database of OI information managed by the OI Foundation and the Kennedy Krieger Institute. The easy to complete web based questionnaire collects information about OI symptoms and medical history. The questionnaire can be filled out on-line here: <http://www.oif.org/site/R?i=BNifjPvhXQ6lmwFCXBE8sQ..>

There is no charge to participate. The information you contribute will be studied and analyzed to improve understanding of OI. You will also be eligible for opportunities to participate in research studies approved by the Foundation's Registry Advisory Committee. Nine research studies are currently recruiting subjects through the OI Registry. The OI Registry is the first phase of the OI Foundation's Linked Clinical Research Centers. For more information about the Linked Clinical Research Centers, click here: [http://www.oif.org/site/R?i=jl52qQnC\\_bj3X01Q11NCXQ..](http://www.oif.org/site/R?i=jl52qQnC_bj3X01Q11NCXQ..)

### **News in brief:**

**Vietnam:** Following a documentary on German TV "Regen der Vernichtung" about Vietnam, Ute contacted James Pastouna, the maker of it, who had met 4-5 OI children there. A German-Vietnamese OI-family has been supporting 2 of these children for several years already, plans a next visit to Vietnam this coming summer.

**Georgia/Armenia:** Khatuna plans an OI-conference for Georgia's neighbour-countries for March 2007

**Spain:** We cordially welcome the new OIFE-delegate from Spain, Carlos Trabal and thank Miriam, who has resigned, for her dedicated work.