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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

The OIFE Photo Contest 2008 – Living with OI - is now officially open

Send us your most beautiful, unusual, or artistic photo. It should show people with OI as portrait, or in everyday life (with friends, family, at work, in school...) or in medical environment.

Prizes: You can win a special subsidy for the international OIFE youth weekend in Denmark, or an MP3-Player or extra pocket money!

Give us your age and name and enclose one or more digital photo(s). The mail address is: editor@oife.org

The participation in this contest includes the permission for us to use the pictures you send us for publication in our print-editions (like the OIFE-leaflet) or on our website!

Situation in Greece regarding OI

By Katerina Kavalidou

Recently OIFE has been in touch with Katerina Kavalidou who is trying to set up an OI organization in Greece. We asked Katerina to tell us a bit more about the initiative and the situation of people with OI in Greece. Here is her report:

There are not many things that someone can say about the Hellenic society of Osteogenesis Imperfecta. Recently, meaning the last 2 - 3 years, we are trying to establish this society, since there is not enough medical and social information about OI.

Of course the medical approach the last twenty years has changed. In the 80's when the disease was diagnosed to me for example, doctors were reacting and diagnosing OI as a deadly disease, while now in Athens there is a hospital which is treating children with OI by using bisphosphonates like zoledronic acid. This medical development means a lot to our country since OI has always been viewed as something extremely rare and impossible to treat. A small number of Greek doctors are being informed about new treatment approaches for OI, while the new health system legislation about legal rights of OI families is giving a new way for the general approach that OI patients should have. After all the experimental or even inappropriate medical treatment to many OI patients and the legal problems that families had with their social security institutions regarding OI, we strongly hope and believe that the Hellenic society of OI will benefit to all of us who "suffered" from the medical and social ignorance of OI.

Let us hope that gathering all our OI experiences and with the support from other international OI members, we will change the quality of life of all Greek unique OI families.

(If you want more information or know people who could be interested with this initiative please contact Katerina through the hellenic website:
http://www.oif.gr/home_EN.html)



Katerina Kavalidou

Interview: Life and work of a woman with OI in Zimbabwe, Part II

Editor:
editor@oife.org

Ute Barschdorf emigrated from Germany to Africa. Together with her daughter and her partner she is living in Zimbabwe. Both mother and daughter are affected by Osteogenesis imperfecta Type I.

OIFE: Please tell us something about life in general in Zimbabwe

Ute: Life in Harare, the capital of Zimbabwe, is quite similar to life in other European cities: we have dinner at a Chinese restaurant, we go to the movies, to concerts and to theatre. Just with one "little" difference – you never know, if there is electricity or enough gasoline. So it may happen you go to the movies but cannot see the film cause there is no electricity.

There are many big supermarkets and fancy shopping centers, just the range of products often is not so big. The roads are very good all over Zimbabwe, and the main language is English so communication is quite easy. Sanitary conditions are quite good, too.

OIFE: What is a typical meal there?

Ute: The white natives usually eat the so-called English breakfast –sausage, egg, baked beans and tomato sauce. Black people prefer a mash made of cornmeal. They eat twice a day: in the morning together with curdled milk, and in the evening with vegetable and meat. This mash they call "saza" – it tastes delicious, and we eat it very often. Especially on Saturdays, when the children from our project are coming to our farm.

(Remark: more details about that project in the next newsletter)

OIFE: How do you spend your day?

Ute: A few months ago a friend has been killed by an elephant. She had this small farm and a lodge here and had begun to produce cheese. Richie and I decided to continue her work and since then we try to produce several kinds of cheese, are baking sourdoughbread, cultivating vegetable and herbs. Furthermore we are making sauces and different kinds of jam to sell it at a small delicatessen market. We are planning to buy sheep and chicken; and goats to have goat cheese. Today we were getting a field ready to plant peanuts on it to produce peanut butter later.



Ute Barschdorf on a market in Zimbabwe

News from HOI (Help OI Foundation Nederland)

By Hinke Panjer

Hello everybody!

HOI is an organisation that offers financial support for aid, medication and treatment to people with OI. Recently we helped a family in Sri Lanka who's

daughter Fathima has OI. Fathima needed a wheelchair and HOI was able to provide this. We want to thank Mr. Jan Kerkhofs who transported Fathima's wheelchair to Sri Lanka. He made a short clip of this which he placed on YouTube. If you follow this link you can see the success for this child:
<http://nl.youtube.com/watch?v=XU-7jUU1rr4>

Fathima now needs some other things as well such as schoolbooks and childrens' books in English for a 5-6 year old. Because of her fractures she cannot go to school as the transport with a tuktuk is too dangerous. We are looking for a buggy seat for her. Do you know anyone who has a safe buggy? Also toys would be welcome. If you have any of the above please contact me at hoi@oife.org .



Fathima in her wheelchair

Jan Kerkhofs also has his own project to help people in Sri Lanka, information about this can be found (in Dutch language) on his website www.ayubowan-yaluva.nl .More info about HOI at www.hoistichting.nl

Remember: OIFE International Youth Weekend in Denmark!

The weekend will be held between Friday 15th of August to Sunday 17th of August in the town of Pindstrup, situated in Jutland. There will be many different activities, among them a seminar on wheelchairs and other equipment used by people with OI. We will also be going on a trip to a nearby tourist sight (Kattegat Centret). There will be time for social activities at our location and Saturday night there will be a party. If you are interested in taking part or want more information, please mail to: oife_denmark@hotmail.com