

## **OIFE's 12<sup>th</sup> Annual General Meeting September 2004 in Espoo –near Helsinki / Finland**

This year 10 OIFE member associations were represented at the Annual Meeting (CH, DK, D, ECU, E, FIN, F, NL, N, S).

The OIFE actually has 17 members from 16 countries – 13 of those are European, another new „sponsoring member, the HOI („Help OI-Foundation, with seat in NL) was accepted as new member this September.

Together with OIFE's Annual Meeting, a meeting of representatives of „OI-Norden“ (a network of Scandinavian OI-societies) took place in Espoo in Southern Finland.

The Finish OI Society had invited everybody to the celebration of its 25th anniversary – with the usual festive dinner and a wonderful evening with dance and music and much fun for everybody! Congratulations again, Finland!

During the OIFE – AGM Doctor Kaija Kuurila, a renown ENT-doctor and OI specialist in Finland held an excellent and very interesting lecture on “Hearing loss in OI” (Balance problems and molecular defects).

News from some OIFE-members:

- US: recently an excellent and detailed statement about the treatment of people with OI with various bisphosphonates had been published by the OIF's Medical Advisory Board – the OIFE will soon have translations into different languages on its website
- ECU: the Ecuadorian OI-society FEOI has produced a new short instruction film together with Doctor Fassier from Montreal. It shows the new operation technique that should be used to implant the newly developed Fassier-Duval-rods and is meant for the use of surgeons world-wide. This “minimally-invasive“ technique is less stressful for the child and causes smaller incisions and scars and less pain. The film will probably be financed by the French Federation for Orphan diseases (FMO), this possibility was arranged by OIFE's president.

OIFE's latest news:

- further new member: probably from January the Polish OI-association (which exists since 1985) will join OIFE as 18th member
- OIFE got in contact with the Japanese „Network OI“ – this cooperation resulted in a translation of OIFE's website into Japanese!
- support of OIFE for future new OI-societies in:
  - Austria, where the first weekend of the new OI-group has been held in September and a very active committee and website are developing much interesting initiatives
  - Greece: group of OI-families, new website in development
  - Egypt, where a medical doctor is going to build up an organisation for his patients
- the foundation of several new OI-societies was reported from Argentina, Colombia, Venezuela and Spain (where actually four OI-societies exist)
- Reports from OIFE members – again surprising similarities got obvious:

- often offers for the „OI-youth“ are a special problem in many countries; in different OI associations special weekends and activities are offered for youth and young adults
- in several countries the needs of adult OI-people are not sufficiently met as mainly parents of young OI-children are active in those associations
- in some „older“ OI societies it sometimes seems to be difficult for new members to get into the group and special efforts have to be made to make them feel welcome and to give them all the basic information and the opportunity for exchange they need
- cooperation with other groups for „rare disorders“ on national and European level: in more and more countries coalitions to other small organisations for similar or other rare disorders (Marfan, Ehlers-Danlos-Syndrome and others) are sought
- thanks to internet and the OIFE-website many OI-families from all over the world find the OIFE, get advice and information and are (if possible and desired) brought into contact with other families, experienced doctors or even clinics in their country or abroad
- in some cases direct and individual support (equipment like used wheelchairs, medical support and even necessary operations) can be given or arranged - if sponsors can be found and if cooperation with other organisations or volunteers are successful

Next interesting goals and projects:

- „Making-friends-Project“ – the OIFE brings OI-individuals of every age and different countries in contact with each other – normally by phone, mail or e-mail
- support of international contacts between national OI-youth: in general national Youth weekends are open for visitors from other countries
- International Scientific OI-Conference 2005  
from 13th to 16th June 2005 medical doctors and researchers from different countries are going to meet in Annapolis / Maryland / US – at the same time a one-day so-called “leadership”-conference for active people from OI associations will be held
  - the OIFE is going to take part in both events with a small delegation
- Latin-American OI-Congress: in February 2006 a meeting of known international OI-specialists and interested representatives from OI-associations worldwide will be organized in Quito / Ecuador
- OIFE-budget 2005: the new budget comes up to 8.800 €, about one quarter of this amount needs to be covered by additional donations, as the regular annual income will not be sufficient to pay for all tasks and new projects
- the „Padrinos OI“ (OI-godparents-program“) which has been initiated by Maria Barbero (Spain) in cooperation with the OI-societies from Peru and Ecuador is growing and flourishing. Actually over 70 „Padrinos“ – godparents – from 13 countries support about 40 OI-children with the most necessary medication (mainly bisphosphonates), equipment, physiotherapy and sometimes surgery – more sponsors are needed, who can achieve to donate about 20 € per month for “their” OI-godchild

Do you have any further question?

Please contact the OIFE President under [info@oife.org](mailto:info@oife.org)