

*Brief report on AGM 10
(an abstract from the full report)*



The Board of the OIFE 2002

Apart from the UK and the US, all 15 OIFE-members were represented at the OIFE's Annual General Meeting (AGM).

New members of the executive committee

Sebastian Schicht from Germany was installed as OIFE's new treasurer, and Filip de Gruytere, from Belgium was elected 2nd vice-president during this 10th AGM.

New OIFE-publication: the "OI-Pass"

This helpful travel document for cases of emergency contains basic information concerning the handling and treatment of OI-patients (after a fracture, when taking x-rays, hints for operation and narcosis) in 13 European languages as well as contact addresses and phone numbers of different countries. This document can be obtained from the national OI societies or directly from the OIFE.

New tasks for OIFE

According to OIFE's President an increasing number of e-mails or letters with all kinds of questions from OI-people all around the world reach the OIFE office in Bamberg/Germany. Among those are requests for information, addresses of clinics or contact to other OI-individuals as well as urgent pleas for help, supply of medication like bisphosphonates or equipment like e.g. wheelchairs and necessary treatment or surgeries. All questions are answered individually or forwarded to the right people or institutions, where further information, advice or support can be obtained. More difficult are requests for necessary and often expensive operations, medication or equipment. The OIFE is still run by volunteers only and has little financial resources which can not be used for expensive individual help. So each case needs to be thoroughly examined and external resources have to be found. In this respect the cooperation with the Dutch OI-Foundation "Help OI" (HOI) and with the recently started "God-parents-project" will be intensified.

Foundation of new national OI societies:

the OIFE-EC actually supports the creation of a new OI association in Slovenia.

OIFE - future plans and projects

- OI-registry / directory:
first attempts that were undertaken to build up OI-registries or databases in some countries (UK, I and USA) lead to a proposal to discuss the possibilities to set up a common European OI-database, perhaps on initiative of the OIFE.
The idea was discussed by the OIFE Board, the basic points of view differed between rejection of such plans due to risks and problems of confidentiality or abuse of such data and strong support and hopes in the possible benefits. Finally no decision could yet be made, as the first proposal was not detailed and clear enough. A sub-committee was set up to work on a more detailed proposal, apart from that the Board-members voted to put further steps on ice for some time and to observe the start and progress of such a register in an North American clinic that could possibly be used as an example for Europe, too.
- Common "International Youth Camp for OI-youngsters":
following an earlier offer to organise such an event, young people from Belgium, the United Kingdom, the Netherlands and Germany have again stated their intention to plan a holiday youth camp - more possible participants and volunteers for the organisation are welcome!
- "Living-in-programme"
exchange of apartments or accessible houses between OI families from different countries:
would you like to spend a holiday in an OI-family's house in Norway or an apartment in Spain or somewhere else ? And welcome this family in your home? If you're interested in such a possibility, contact the OIFE and we will try to connect you!
- "Music for OI-children"
The OIFE President announced that in winter 2002/2003 several concerts will be organised in Germany for the benefit of the OIFE and its projects and goals.
- European Medical Advisory Board on OI (EMAB):
This institution shall be enlarged and restructured in order to raise its efficiency and impact. During the Scientific Conference a short informal but very inspiring meeting was held between the OIFE President and the seven EMAB members present.

- OIFE-Statement about the "Importance of adequate first information to parents of newly diagnosed children"
As the experience is still frequently made in many countries that new OI-parents often get incomplete, insensitive and sometimes wrong information about OI, the OIFE will try to emphasize the importance of adequate first information and publish recommendations on the possible content of such a first informative encounter between doctor and OI-family.
- "2003 - European Year of Disabled Citizens":
The OIFE-members will participate as much as possible in activities around this event on local and national level and thus try to raise awareness for the situation and needs of people with OI - see www.eypd.2003.org

Some news from OIFE members

- France: have been very busy with the organisation of the 2002 International OI Conference and are trying to start a research project on heart problems connected with OI.
- Italy. AsItOI is actively involved in a recently started study on the use of "Neridronate", a new bisphosphonate that can be intramuscularly administered!
Intensified cooperation between AsItOI and OI-clinic in France for some difficult types of surgery.
- United Kingdom: the BBS recently celebrated its 30th anniversary - congratulations!

News from other OI-associations or groups

- In Brazil a large OI-conference had been held in summer 2002.
- Several South American OI associations are interested in more contact and cooperation with the OIFE and its members. The OIFE would welcome such cooperation the whole board was enthusiastic.