

OIFE AGM 21

Paris, 11th -14th April 2013

This year the French OI-Association (AOI) hosted the 17 delegates and guests from all over Europe who came to the OIFE AGM. AOI held both its national meeting and a meeting for medical professionals on the topic "Women with OI". On Saturday we all had a more festive evening to celebrate OIFE's 20th and AOI's 25th anniversary. Below our report about about OIFE's Annual General Meeting.

A different start of the AGM

Usually our AGMs start on Friday morning. The participants arrive one day earlier, on Thursdays, and have dinner together. This year we tried to make better use of our precious time together by having open-forum discussions. The outcomes of the very lively discussions about OIFE's future will determine the policy of OIFE during the next year.

20th anniversary of OIFE: a reason for celebration but also for change

Founded in 1993 by 5 countries, the OIFE now has 27 member organizations, mainly from Europe. Since its foundation, the tasks and projects of OIFE have multiplied, but the number of volunteers has not. They have a very heavy workload, which means that unfortunately many important tasks and projects cannot be realised. In addition, OIFE does not receive any regular governmental or European funding, nor does it have regular donors. The realisation of very important projects such as the Topical Meetings (like the recent one in Lisbon 2012 on psychosocial aspects of OI) requires that OIFE puts a huge amount of time in fundraising FIRST. At some points OIFE was almost forced to cancel the TM because it would just have been too expensive for speakers and participants to attend! (unlike other organizations, OIFE is not in the position to pay for its speakers).

OIFE does not even have an office as such; the "headquarters" consist of a table and a private laptop, printer and telephone in a private apartment. The few active volunteers of OIFE's executive committee (most of whom work full-time in their "normal" lives) invest many extra hours per month (voluntarily!) for OIFE and it is very hard to find successors and replacements for them. Further hours are contributed by the secretary and few other volunteers.

So one of the main issues of this year's meeting was to find a solution for re-structuring OIFE.

Discussion points and outcomes of AGM in Paris

- presentation of preliminary results of the workshops (topics were all related to the current situation and the future of OIFE);

- agreement to find professional support for OIFE;
- presentation of Dutch OI foundation “Care4brittle bones” (see www.care4brittlebones.org) by Dagmar Mekking. Result: Care4brittlebones becomes new supporting OIFE member;
- discussion about inactive members / members that do not reply to emails;
- discussion about inactive delegates / replacement of long-term-delegates. general agreement that OIFE needs new, young, motivated delegates;
- presentation of RBU (Swedish member organization) by Asa Hedberg;
- due to the existence of new social media and the decrease of active participants: agreement to end the Making Friends Project;
- international youth weekends 2013 in Spain and 2014 in Germany;
- first International Adult meeting planned for 2015;
- planned: collection of national OI-literature (leaflets, brochures etc.) of OIFE members;
- planned: collection of data about national ongoing medical projects and treatment protocols



*From left to right: Åsa Hedberg, Sweden; Stefanie Wagner, Germany; Carina Svenheden, Sweden; Ute Wallentin, Germany; Taco van Welzenis, The Netherlands; Trond Gården, Norway; Rob van Welzenis, The Netherlands; Eero Nevalainen, Finland; Filip de Gruytere, Belgium; Lidy van Welzenis, The Netherlands; Vanja Živković, Switzerland; Céu Barreiros, Portugal
Missing on the photo: our delegates María Barbero, Spain and Laurette Paravano, France and our guests Meriem Benjelloun, Germany; Julia Pfister, Germany and Dagmar Mekking, The Netherlands*

What has been achieved since AGM in Lisbon 2012

Due to the short period between the two AGMs and vacation times as well as cases of illness, there has not been fulfilled very much, but still:

- thanks to Anna Rossi, our youth-coordinator, OIFE is now on Facebook;
- thanks to Taco van Welzenis for a document about OIFE to help members understand what OIFE does, what they can expect from it;

- another edition of the OIFE newsletter.