

OIFE AGM in Lisbon

By Laurette Paravano and Catherine Potterton

26 delegates and guests from all over Europe came to the 20th OIFE AGM. Here are some of the main themes and projects which were discussed.

An important topic: communication

Good news: the new OIFE website is now online! At the moment, it is only available in English and partially Dutch, but more languages will be added soon. Thank you to our webmaster, Rob van Welzenis, for all his hard work! Rob now plans to retire, so we should have a new webmaster in the near future.

Also coming soon is an OIFE Facebook page.

Our newsletter is still successful. Steffi is always looking for interesting stories to fill the newsletter.

We are also thinking about publishing a booklet about OIFE to help members understand what OIFE does what they can expect from it.

European Weekends

The last OIFE youth weekend in Norway was a great success; 38 young people participated, 11 from Norway with the rest coming from other countries. Such weekends are very important for OIFE; they are a perfect example of our Federation's aim to promote international exchanges among people with OI.

We have also been discussing organising an international weekend for adults. The event is still in the planning stages, but a committee has started to work on it and we hope to be able to hold the first event in the next few years.

Flying OI Experts

Every year, OI families from less developed countries carry out desperate searches for help, treatment and surgery for their OI child. Often, this involves having to go abroad, and only a few fortunate families can reach their goal of getting expert OI treatment abroad, as it is very expensive, and few can afford the necessary (telescopic) rods, surgery, travel to and from the country, and accommodation both for the patient and their accompanying family members. Going abroad also fails to change the situation in their home country, and those less fortunate are still unable to access the necessary OI treatments.

One of OIFE's fundamental objectives and values is global spread and increase of knowledge about OI and its adequate treatment and care. We see it as being more efficient and equal to train local medical staff –

doctors, nurses and physiotherapists – rather than to encourage individual families or patients to seek treatment in another country.

We have therefore begun to cooperate with clinics in countries as far afield as Albania, Russia, Egypt and Sri Lanka. We aim to help them organise internal or national training courses and workshops on the best OI treatment and care.

We try to contribute to the costs of such seminars and to offer subsidies for the travel costs of OI experts invited from known centres of expertise in OI. We also encourage existing OI clinics to invite colleagues from abroad to visit them, in order to spend several days in an OI clinic, during that time they can observe and learn modern surgical techniques and specialised OI treatment protocols.

Some Continuing Projects...

Topical meeting 2012: Psychosocial issues in OI

Some OIFE delegates have been very busy this year, acting as members of the organising committee of the topical meeting *Fragile Bones, Unbreakable Spirit?*

Student exchange program

As we recognise that each individual's situation is different, we prefer to not have a "standard protocol", but encourage our members to remember that the OIFE can – thanks to its wide network of friends and families who are part of national OI associations – help young students with OI to study abroad in another European country.

Fundraising

We are still fundraising. Only few OI associations (Norway, Germany), companies (Novartis, Alexion) and individuals supported OIFE this year, both with general donations and also with purpose-specific donations (for example, to fund Flying OI Experts).



Beyond Europe

The Latin-American OI conference in Quito, in December 2011, was a big success (see OIFE Newsletter 15th March 2012). It was an important opportunity to teach Ecuadorian (and South American) doctors about OI treatment and care.

The association Padrinos-OI is continuing to sponsor 90 OI children and young adults from less developed countries, with a particular focus on South-American countries.

Our AGM had to be very "efficient", as we had only a small time frame and many matters to discuss. We were, however, able to finish on time to start the topical meeting! Our next AGM will take place in April 2013 in Paris, and will coincide with the national French OI conference