

# OIFE AGM15 October 26th - 27th 2007, San Pedro del Pinatar / Spain



*Condensed report by: Vanja Zivkovic, Swiss OIFE-delegate*

The Annual General Meeting of the OIFE took place again in Spain.



## *San Pedro del Pinatar*

After landing in Alicante, where our hosts from the Spanish OI-association AHUCE were already waiting for us, other delegates and me went to a small coastal place called San Pedro del Pinatar.

During the ride I met Katerina, who as it turned out later was my roommate for the stay. Raised in Greece, she's now studying psychology in Sweden, from where she's trying to set up a Greek OI-association! This might seem as an impossible thing to do, after all Sweden and Greece are not really close, but she's actually doing very well. And so, thanks to Katerina, I got already during the arrival a foretaste of what was coming up to me during the next days. Not only were there a lot of impressive and dedicated people (as always :), but this time OIFE was also

younger than usual. As far as I know, there have never been so many young people from all over Europe at an AGM!

This time delegates from Germany, the Netherlands, Belgium, Italy, France, Finland, Sweden, Norway, Denmark, Georgia, Ecuador, Peru, Switzerland and of course Spain took part. Furthermore Padrinos-OI (godparents-project for OI children and adults in Latin America and other countries) and HOI (Dutch foundation supporting OI-individuals) were represented, and also guest from Spain, Italy, Greece and Sweden.



**Participants at OIFE AGM15 from left to right:**

*Leonardo Panzeri (pre. As.lt.OI, Italy); Maria Barbero (Padrinos + repl. del. Ecuador); Filip de Gruytere (2nd vice president, del. Belgium); Simona Paveri (del. Italy); Maria José Pico Fernandez (repl.del. Spain ); Carina Svenheden (del. Sweden); Susanne Qvist (guest Sweden); Khatuna Saganelidze (del. Georgia); Ute Wallentin (president, del. Germany); Vanja Živkovic (del. Switzerland) ; Thomas Krueger (treasurer) ; Katerina Kavalidou (guest Greece); Rob van Welzenis (honorary president); Jacky Goineau (del. France); Jaime Montalvo Dominguez de la Torre (guest Spain); Taco van Welzenis (vice president, del. the Netherlands); Hinke Panjer (HOI); Trond Gården (del. Norway); Eero Nevalainen (del. Finland)*

**Missing on the picture:**

*Michael Købke and Rune Mogensen (repl.del.Denmark ); Rosa Espino (del. Peru)*

On the day of arrival we had time to talk to each other and to get to know “newcomers”. And after we enjoyed our supper at about half past eight - which our Spanish hosts kindly arranged earlier than usual (!) for us - most of the people went to bed, in order to be fresh for the next day.

On Friday the conference began and in the next two days a lot of things were discussed, some caused fierce deliberations, many things were unanimously decided and many ideas and solution approaches were exchanged. The most important things are briefly listed below.

- Small changes of the statutes were made to make sure that OIFE, which is registered in the Netherlands, can acquire the formal status of a non-profit organization.
- OIFE’s homepage is visited regularly and is often the first contact address for people searching information on OI in general or specific answers and solutions. Through the “welcome-form”, which every visitor can fill out, OIFE secretary Steffi could for example connect people with OI living in the same country. This way of providing contacts is especially important in countries, where no OI-organizations exist yet.

OIFE welcomed Peru as newest and 21st member. Rosa, the Peruvian delegate, who some of us already met in Ecuador during the first Latin American OI-congress, presented her organization: AOI-Peru, was founded in 1994 which makes it the oldest organization in Latin America. Most members are children and most of them receive bisphosphonate therapy, which is partly provided by Padrinos-OI. They also have several adult members with OI.

- OIFE is in contact with a new OI-organization founded in Panama some months ago. Contacts to Israeli, Japanese and Korean OI-organizations exist as well and we cooperate with Doctors in Russia, Cuba and several other countries. And, mostly through the Georgian organization, OIFE is also in contact with more than fifty families in different Eastern-European countries.
- Novartis (pharmaceutical company) still hasn't made a statement on the general accessibility of bisphosphonate therapy. But at least, thanks to EURORDIS and OIFE the situation for OI-families in Romania has been improved.
- HOI ([www.hoistichting.nl](http://www.hoistichting.nl)), which celebrated its 10th anniversary in 2007, provided help, among other cases, for twins in Cuba and siblings in Turkey. The main problem remains the transportation of wheelchairs and other aids, but Hinke Panjer from HOI is very talented to solve these problems and to build up new support-networks.
- The AOI&OIFE international youth weekend in France was a great success. So there will be of course another one in 2008, this time a bit further north - in Denmark.
- Our "Making-friends project" is growing constantly and there are several mailing lists in Spanish or other languages and even new OI-chatrooms for OI-people to stay in contact with each other.
- In 2008 a „Scientific conference on OI“ will take place from 16 to 18 October in Gent, Belgium.



*The board of the OIFE at work*

After two days of hard work "the best part" came - a Spanish Fiesta! Thanks to the great Spanish mentality we celebrated, laughed and danced until late!

Collage of pictures on AGM15

