

AGM 19 and Scientific conference: OIFE lived an important moment in Dubrovnik!

For that AGM 19, OIFE delegates met in Dubrovnik, in a nice place with a beautiful panorama on the Adriatic Sea. They worked hard in spite of the sunny weather and tempting swimming-pool! Delegates and friends from Germany, Portugal, Switzerland, Finland, France, Germany, Italy, Norway, Portugal, Sweden, Russia, Australia and the USA participated in the meeting, and some interested doctors joined us.



From left to right: Anna Rossi (Italy), Tracy Hart (USA), Anja Kladar (Croatia), Knut Erik + Rebecca Skarberg + Inger Margharthe Paulsen (Norway), Dr. David Sillence (Australia), Ute Wallentin (Germany), Carina Svenheden (Sweden), Vanja Zivkovic (Switzerland), Therese Stutz-Steiger (Switzerland), M. Céu Barreiros (Portugal), Jouko Karanka (Finland), Taco van Welzenis (The Netherlands), Helen Keogh (Australia), Simona Paveri (Italy), Trond Gården (Norway), Leonardo Panzeri (Italy), Laurette Paravano (France), Elena Meshcheryakova (Russia)

OIFE's AGM started on Saturday morning and ended on Sunday at 13.

Here are some major results:

Passport

The new OIFE pass has been edited. It contains four more languages (22 in total !) and some additional information. A good new for those who had already visited all the countries which were translated in the former passport!

Internet, our precious tool

Internet is a wonderful tool for OIFE so we will work to take all the advantages from it: we will create a Facebook page and our website is being renewed.

Steffi could redact more frequent newsletters. Subscribers are more and more numerous!

Successful youth week-ends... and an adult week-end coming soon?

The youth week-end was just taking place at the same time as the AGM in the Netherlands. The program was very interesting and attractive. We started thinking of the next youth week-end, we will see soon where it could be !

These youth week-ends are successful, so why not organizing a week-end for adults too? It seems that some of us are waiting for it! Let's us organize it, we hope to be able to do it in 2012.

Topical meeting 2012 : Psychosocial issues in OI

The next OIFE Topical Meeting on Psychosocial issues will take place in Denmark on the 18 to 22 april 2012.

Margarita, the Portuguese psychologist who initiated a psychological study on OI, told us about it and asked for cooperation from others countries to deepen the analysis. During the Scientific Conference, OIFE delegates made several promising new contacts and could further develop the draft program.

OIFE life and growing

- OIFE will soon have two new members: Russian OI association "Fragile children" from Moscow and the Romanian OI association. Welcome !
- We have a new second vice-president, Eero. Thank you Philip for having taken this charge for several years.
- Steffi, Taco and Ute tried to emphasize fundraising last year, with some good results.
- Several meetings and conferences all over the world gave opportunities to develop networking and cooperation between specialists and OI organizations.
- Networking and new contacts were established thanks to Eurordis.
- Ute and Steffi answered many requests from families from countries where they can't benefit any treatment and could help successfully in several cases.

Celebrate "wishbone day", the 6th of may!

OIFE will encourage people to celebrate wishbone day. This day is an opportunity to celebrate, to raise awareness and inform about OI.

Building some more projects...

- A committee has started working on an exchange program for OI students. This committee has been reinforced by new members and we guess that they will be able to set that program soon...
- Another "old" idea may become concrete soon: create a library of all our national publications.
- We lead a survey about relationships between medical doctors and scientists, and OI organizations. We are waiting for some more responses and will analyze it for a further meeting...

This was an intensive AGM, but we could have some breaks to relax, be filled with the wonderful view and go on with some private but useful conversations ! We had also a nice dinner together on Saturday night.

Our next AGM will take place in april 2012 in Denmark, stuck to the Topical meeting.

The Scientific conference (Ute)

- More than 10 representatives from the OIFE or national OI associations took part in the Scientific Conference and felt very welcome from the very beginning.
- We met doctors from Russia, Bulgaria, Hongkong, Korea, Albania and Poland who are very interested in a cooperation with OIFE to improve the national situation for OI people.
- During the SC OIFE was asked to nominate a representative who would be member of the advisory committee of a planned new international research project.

- At the SC we met many doctors and scientists again and could help introducing some “newcomers” to them.
- We could spread information on EURORDIS and its work and offers to Rare disorder groups.
- We got into contact with doctors who are interested in studies about respiratory function in OI patients.
- We could present a list of “open questions” to the participants and got several hints and promises for later replies.
- We could strongly and repeatedly request to develop better structures and treatment protocols for adult OI patients.
- We started to make new contacts that might lead to a European or even international Research-network for OI.
- We are hopeful that the Croatian Umbrella for Rare disorders will support the future development of OIFE’s Croatian member organization HUOI.