

# OIFE Annual General Meeting (AGM17), 19th – 20th November 2009 in Rheinsberg, Germany



*Participants to AGM17*

OIFE's AGM 2009 took place in the beautiful little town of Rheinsberg, about 90 km north of Berlin, together with "OI in Motion", the first international conference on physiotherapy and rehabilitation in OI, and a family-weekend of the eastern branch of the German OI-association. All in all, there were about 130 people in the completely accessible hotel "Haus Rheinsberg", of which 29 attended the AGM.

Every room could be opened electrically, had much space for people using a wheelchair, as well as the bathrooms, which also had either an accessible shower or a bath tub combined with a shower stool. Furthermore, the hotel was able to arrange several aids like elevated toilet seats, shower stools, or a care bed etc.

Some of the rooms had an accessible balcony with view to the lake which was directly besides the hotel, so you could watch ducks and swans swim across the lake!



*View over the lake*

But as our time schedule was very tight, there was almost no time to enjoy the beautiful surroundings and the mild temperatures.

OIFE delegates from Germany, The Netherlands, Belgium, Finland, France, The United Kingdom, Switzerland, Georgia, Spain, Sweden, Norway, Portugal and Italy as well as guests from China and Russia arrived on Thursday and enjoyed dinner together. The AGM started right after dinner and was continued the next day.



*intermediate discussions*

Some major items from the AGM:

- It was agreed that the medical information on the OIFE website will be updated
- The OIFE photo contest will remain open and be given some topics (subject areas) like e.g. OI and sports, OI at the workplace etc.
- New OIFE member states are welcomed: Portugal and French speaking Belgium
- OIFE has established contact in the Czech Republic, Panama, Bolivia and Venezuela
- A Strategic Plan for the next four years is being prepared
- Padrinos OI: The need for more funding was discussed
- OIFE is receiving more and more requests from people and organisations requiring help, but has not enough people working on these requests
- New projects proposed: OI library on the webpage; study on the effects of OI and heart disease
- OIFE will keep an eye on “skull fractures and OI”
- Continuation of the Making Friends Project
- Continuation of the project concerning the subtitling of the Dutch DVD about handling children and teenagers with OI
- OIFE youth weekend 2010 will be organized by the Belgian OI-association
- The Dutch OI association will be asked about organizing the OIFE youth weekend 2011
- Exploration of the possibilities to organize an international meeting for OI adults
- Student Exchange Project: discussion about how to proceed; e.g. a database of willing host families will be established

**Zheng Zheng during her presentation  
in the background OIFE's secretary Steffi**

One further highlight was the presentation of our Chinese guest Zheng Zheng about the Chinese OI-association and the situation of people with OI in China. Some interesting and worrying facts:

- one goal of “China-Dolls Care & Support Association” is to build a society of understanding and equality for patients with OI and other rare diseases
- one of “China-Dolls” major activities is trying to find sponsors for basic medical care for OI-patients, for OI is excluded from the health insurance system in China and most patients are unable to afford necessary medication and care
- estimated OI Population in China: 130.000
- reality in China: In October 2009, a Shopping Mall declared that “People traveling with wheelchairs, the blind, smokers, and pets are not allowed in the shopping mall, for security reasons and to protect public facilities from unnecessary damages”
- “China Dolls” protested against this discrimination and achieved an official apology and the removal of the prohibitive signs
- The first national OI patients conference took place Nov. 7-9, 2009 in Beijing



Our next Annual Meeting will be held in Rome / Italy at the end of May 2010, parallel to a Medical Topical Meeting initiated by La Sapienza University and AsItOI about orthopedic aspects of OI.