

## **Condensed report on AGM 14** June 9<sup>th</sup> + 10<sup>th</sup> 2006, Rome / Italy

### **Participants:**

There were participants from: Germany, France, Italy, the Netherlands, Sweden, Spain, Norway, Switzerland, Georgia, and The Padrinos-OI Project.

**with excuses from:** Belgium, Croatia, Denmark, Ecuador, Finland, USA) Australia, Mexico, and the HOI Foundation.

### **Opening and welcome**

Leonardo Panzeri, the president of the As. It. OI, welcomes the participants and Ute Wallentin, the OIFE president, opens the meeting.

The new participants Karina Svenheden (Sweden), Steffi Wagner (secretary) and Thomas Krüger (treasurer) introduce themselves.

### **Announcements**

- a. News from/changes in member associations
  - Spain: Miriam Escalante is the new Vice-president of AHUCE.
  - Netherlands: new board member, one deceased board member
  - UK: new board, possible new OIFE-delegate.
  
- b. News from other OI organisations/groups
  - Korea: 3<sup>rd</sup> anniversary in April – they sent pictures. Ute Wallentin gives some details.
  - Columbia: Maria Barbero informs that the Columbia group is struggling to get organized.
  - Russia: Kathuna Saganelidze reports that there are a lot of problems, due to the large country and to internal discussions. Three different groups (St. Petersburg, Moscow, Ural Region) try to act as an organisation, but they are not official yet. Kathuna has contact to 65 OI-people from one group, and to two other different groups as well. Georgia offers personal help to individuals.
  - Armenia: Kathuna says that 16 people from Armenia are in contact with Dr. Kolojial, they have an official registration, but work with Georgia as their umbrella association.
  - Kazakhstan: Kathuna has sent pamidronate for treatment.
  - Taco van Welzenis informs that through the Making-friends-project several individuals from other countries have been contacted.
  - Greece has a group of OI-people, but no association yet
  - Portugal set up an OI-organisation in May. Gilberta Couto E Silva and two other persons had it officially registered. They had to pay high fees that caused them a lot of problems.

### **Reports and questions**

- a. General EC-report + President's activities (Ute Wallentin))
  - Social committee: Hinke Panjer (HOI) collects money, pamidronate, walkers, wheelchairs, crutches etc. for Cuba and Ecuador. She also offered to support two families in Croatia.
  - Ute is in contact with two OI-families in Nepal. Possible transfer of a

young man to Kennedy-Krieger-Institute in the US or to a clinic in Germany.

- Contact in Zimbabwe through Ute and Steffi. OI-child Debbie might possibly have surgery in Germany
- Contact to Mary Peterson-Suri (USA) for building a support group in Bulgaria. First surgeries with FD-rods have been performed in Bulgaria already.
- Patrick Dupuy reports about contact to pharmaceutical industry concerning pamidronate production. We want to get a dosis-determination and an acceptation from the different governments. The French association last year initiated a letter (of OIFE and AOI) to pharmaceutical companies in order to ask different laboratories to produce pamidronate. Up to now only Novartis has answered and announced that they are working on zolendronate.
- Maria Barbero repeats that the pamidronate-production has been discontinued in Mexico. Patrick suggests to contact Novartis again and to talk about this issue for Mexico, Peru, Ecuador and other Latin American countries. He will prepare a letter for Ute to send.
- Ute reports about communication problems with the British Brittle Bones society. It is better now. The office is reacting to letters and e-mails again – Roz keeps no contact, but will perhaps be replaced soon.
- A German script-writer wrote a script for a movie about an OI family. She found a Northern-Ireland company who is going to produce the film about a young OI woman.
- Poland wanted to join the OIFE. Taco van Welzenis informs about his last meeting with Gabriel (Poland), who says that the Polish situation is delicate. They seem not to have anybody who could be their representative.

#### b. First Latin-American OI-Congress

Ute, Maria, Taco and Vanja report on the First Latin-American OI-Congress 2006 in Quito, Ecuador in februari 2006 at which they represented the OIFE.

#### c. OIFE youth activities

- Consequences of NL youth weekend in June 2005  
Ute says that following it two young men from Denmark got very interested in OIFE and are now replacement delegates for the new Danish delegate.
- Ute got several offers for next youth weekends from Denmark + UK, but nothing concrete yet.
- Vanja and Taco resigned from their positions as Youth Delegates.
- Italia had planned a youth-vacation in Southern Italy, but it is not going to work this year because the place is not completely adapted. Taco proposes to make it an OIFE activity, in order to get more funding. He asks Simona to provide him with more information about this.
- The French association plans to invite to a youth activity in fall 2006, if the money they applied for will be granted. They want to make it an exchange for youngsters from all over Europe. Vanja and Taco need information about dates and money.
- Miriam proposes to discuss on local-organisation level to know who would be interested in such an exchange.
- Ute proposes to put information together and send it as soon as

possible to the delegates. She proposes the OIFE could support the young people going to those meetings.

- We have no Youth Delegate at the moment. Everybody should be asking in their countries; Taco is going to ask Mads from Denmark first.
- d. Additions to National Reports (sent and read before!!) and activities in member countries:
- **Germany:** Ute reports about a new OI foundation in Baden-Wuerttemberg since March, in order to help people with OI all over the world. Representatives ask about the "OI-Knuffi" wheelchair and about the Risendronate treatment
  - **Georgia:** Khatuna presents her report and tells about her intention to organize a Georgian umbrella federation for rare diseases. Taco asks how she did achieve to increase the number of members. Answer: a lot of information has been printed. Additionally, the membership is free of charge. She has authority in her country and gets the OI patients transferred to other countries like Germany if they need a first surgery. After that, they are going to be treated in Georgia by the doctors who are actually trained in Stuttgart/Germany. Patrick suggests to collect information regarding which associations have contacts to pharmaceutical industries (personal contact or sponsoring contact). Taco suggests this information to be collected by the EC.
  - **Padrinos:** Maria presents her report and asks for help (volunteers and supporters). She invites other national groups to organize similar initiatives.
  - **Switzerland:** Vanja and Cornelia present their report and talk about the Foerder-Info-Freundeskreis, the new support group.
  - **Spain:** Miriam presents her report in detail.
  - **Norway:** Trond speaks about the online management center TRS for rare diseases in Norway and a new website-based project for OI-patients.
  - **France:** Patrick speaks specifically about cases of false accusations of child abuse in OI.
  - **Netherlands:** Taco introduces his report. He points out a general lack of interest and explains that they now organize meetings for small special interest-groups.
  - **Italy:** Simona didn't write her report. She will send it later. Their main activity has been to support the pamidronate treatment and the study of a new protocol with zolendronate and growth hormone. They have also been busy with the organisation of this triple event and the topical meeting.
  - **Sweden:** Carina explains her report and mentions the Summer camp as a special activity.
- e. Reports on activities in other OI societies or international coalitions
- TRS + OI Norden (see national reports)
- f. OIFE – Information material - OI-Pass, statistics etc. – (Ute, Steffi)

- OIFE leaflet – new, updated inlay
- OI pass – new edition is actually being prepared by Filip, please review last print-out!

#### g. EDF (Ute)

- Report on membership status – further “transitional period” until 2008
- Romanian off-label-use-situation. Ute explains that OIFE asked EDF and EURORDIS for support and that she is waiting for the reaction of both organisations regarding the Romanian situation. Depending on their answer we will decide if we remain a member of both organisations or if we should leave the EDF. She suggests to vote on the proposal to leave the final decision to the EC – this vote is unanimously accepted.
- Ute hands out copies of an EDF-resolution regarding the active termination of 22 severely disabled children (spina bifida) in the Netherlands.
- Ute attended the Annual Assembly of EDF in May in Rome.

#### h. Report on Eurordis (Patrick, Ute) and OIFE’s relation to it –

- EC-proposal to join Eurordis + vote. Patrick explains the relationship to Eurordis. Italy is no longer a member, but Spain, Denmark and Germany are members already. EURORDIS has about 300 members and almost 20 employees. Patrick explains the importance of developing reference centers.
- Participation in pediatric task force: Trond asks about the advantages of this: Patrick wishes a vote about that because an OIFE-representative should be sent regularly. In his opinion contact by e-mail is not going to be enough, but nobody is available for participation at around twelve meetings. Ute insists, that we do not have the means to send somebody there so actively, but we might look for sponsors for the participation in these meetings.
- Ute underlines the importance and convenience of being a member of Eurordis and explains the low extra expenses. She thinks the membership would be very useful.
- Ute asks the delegates for a vote: Unanimously it is decided to join EURORDIS.

### Finance

#### a. Financial report – update

- Ute reports about problems with the previous treasurer who could not fulfill his tasks sufficiently due to personal and health problems, Thomas Krüger has taken over completely in May 2006 – but he is still waiting for the OIFE books and the financial files from Sebastian.
- Ute apologizes for higher expenses in 2005 than planned and explains their reasons.
- The higher expenses are no real problem thanks to OIFE’s savings, but we have to be more cautious in future, in order not to spend all our resources.
- Budget for 2006: proposal is not complete, as the new OI passes will cost some extra money – if they will be printed in 2006
- Simona asks about an OIFE-participation in the costs for the topical meeting. The EC will decide this later, but Trond suggests to take a vote now about the maximum contribution. Ute proposes a limit of

2.000 Euros. If more is asked for, she proposes a written vote and decision on that issue. Vanja suggests to pay only a certain percentage, like 50 %, of the actual costs. Thomas proposes to fix a contribution for this kind of events in future.

Vote regarding payment of a maximum amount of 2.000 Euros or fifty per cent of the costs of our participation. All agree except one abstention (France).

- Ute wants to talk with the medical participants about their impression after the topical meeting in order to decide how useful is this kind of medical meetings and if they should be continued.
- Compensation for AGM 14: 300 € per Person (for delegates from full members); Support for Maria, Steffi and Khatuna is discussed, will be given according to their individual need.

**b. Payment of annual membership fee**

- 2005: only CRO and AUS did not yet pay
- 2006: invoices came very late, so far F, E and D have paid

**c. Discussion of annual fee and vote**

- EC proposal to leave fee as it is now
- vote: this is unanimously accepted

**d. Fee-Solidarity fund**

Actual balance: 1267,38 €. Ute informs that nobody has applied for help from the fee solidarity fund for the last two years.

The question arises if this money should be used for travel expenses of delegates who could not come to the AGM without support. Ute points out that this support should be and is given, but not from the fee solidarity fund!

Carina asks if Belgium has not applied for that. Ute explains she has offered Filip to pay because Belgium could not send him, but he never answered. Croatia did not ask for help from the solidarity fund again, although Marco had been asked to do so.

**e. Report of financial control sub-committee (Trond and Vanja)**

Trond informs that the paperwork was difficult to look at. Sebastian could not find the reason for the difference of 40 € too much on the account. The date of every movement in the books is not the real date of the transaction, but the day of the declaration, and there are some times three weeks delay in between and it takes time to find the transaction.

Vanja and Trond wrote and signed a statement and Ute reads it to the board. The statement is regarded as satisfactory.

**f. Discharge of treasurer Sebastian Schicht and EC**

Vote on the discharge of the old treasurer Sebastian and the EC until the end of the financial year which ends at the end of January. Sebastian will have to be discharged again for the following three months next year  
Result: all delegates vote for discharge, except one abstention (Ute)

**g. Report on fundraising activities**

Since October 2005 Ute received 2850 € (1200 + 1000 + 350 + 100 + 300) for the OI-children's surgery in Ecuador.

Ute informs that she has given Lucia 3.000 Euros and she is going to give her more money for a special child in Ecuador.

Another donation has already been announced by a church in Coburg/Germany – probably for another child.

Ute tells about her intentions to find regular sponsors for OIFE activities.

#### h. Future financial policy and budget 2007

Ute asks if we need a new budget for 2006 and a new vote or if changes should be explained with the next financial report. It is decided to keep the same budget. The next budget proposal will be sent earlier.

#### i. Election of new financial control sub-committee

Trond and Carina volunteer for the new sub-committee and are elected unanimously.

### 2. Executive committee

#### a. Resignation of first vice president

Patrick Dupuy explains his reasons for the resignation as vice-president, but he will continue to be the French delegate. He might be here next time with Jackie, who is his substitute and who will be the next French delegate.

#### b. Election of new vice president

Taco van Welzenis presents himself as a candidate for the vice-presidency. He is unanimously accepted as new vice-president.

### 3. Report on (new) website and secretary

#### a. Status report (Ute)

#### b. new texts

Ute informs about the new texts on the website and asks the delegates to review the new texts that are going to be sent and to care for their translations.

#### c. OIFE-forum (Steffi)

The new OIFE-forum has been online since October 2005, but it has not been very much visited. Steffi asks for ideas to promote the existence of the forum. Some problems with orientation on the website are told and suggestions are made to improve the website and to make the forum more visible. Ute asks everyone to direct all questions or ideas to Rob directly!

Ute says that the website – mainly with the new “welcome form” was also meant to put people from different countries in touch. Steffi reports that this has already happened and some people have already been put into touch.

#### d. Secretary report

Steffi informs about her work in the last months. (see secretary report)

### 4. Report on OIFE – Projects-update

#### a. OI – Directory – report of AOI-experience and call for European cooperation (Patrick)

The original French idea was to collect information and addresses of OI-specialists and treatment centers in order to set up a European or international directory. After the first idea in Madrid, the committee didn't really get active, so AOI decided to continue alone. They have got good results that should be published at OIFE's next AGM. Patrick invites other countries to involve themselves in this idea and offers to send information to the interested persons.

Ute informs about the OIF registry of the Kennedy Krieger Institute which is open for non-American participants as well.

**b. Support for OI-individuals – cooperation with HOI and Padrinos-projects**

Ute is very pleased about the good cooperation between the "OIFE office" (Steffi + herself), Hinke and Maria on behalf of many OI individuals.

**c. "OIFE Project Fund"**

Since AGM 12 every year 500 € have been put into a special Project fund. Money will be used to put OI people in contact. So far only once about 600 € have been used for the Youth weekend in the Netherlands in 2005.

In April Ute had been asked by the Norwegian responsables for OI-Nordic meetings if they could be supported, but so far no formal application had been sent.

**d. OIFE – newsletter**

Ute apologizes for the lack of further newsletters after the two first editions. She has asked Filip if Steffi shall take over from him – the next newsletter will appear soon, they promised.

**e. OIFE – photo archive**

More pictures are needed, mainly those of adults. Please send them to Ute and Filip and make sure that the people in the picture agree to the publication by OIFE in its information material and on the website. For this purpose a special "consent form" will be prepared by Steffi and Ute and sent to all delegates.

**f. Making friends project (Taco)**

More people are welcome in the project that has been growing nicely. Taco asks for more publicity in the local organisations.

**g. Home exchange.** Trond and Maria inform about their first, private home-exchange project, inspired by OIFE initiatives like "Making friends". Trond and Unn will travel to Spain this summer.

## **5. Next projects - Proposals for discussion**

**a. OI-peoples Conference parallel to Next Scientific Conference 2008 in Belgium?**

According to Filip, ZOI in Belgium doesn't want/can't help to organize the Scientific Conference. This is a serious obstacle for an international OI-

people's-conference in Gent 2008, without local support and experience Ute sees no way how to organise such a big event. But she will probably meet Ann de Paepe in autumn to discuss possibilities with her.

#### b. Next Topical meeting?

We do have to decide if we need such topical meetings, where and when. As the doctors were very interested, it seems necessary to do so. Different considerations on the issue:

- Trond: Should it be an OIFE thing, or a country thing? How often?
- Carina: Topical meetings should be held whenever is a need, not on an absolutely regular basis.
- Simona: She thinks in the future the doctors will be interested in organizing their own topical meetings. Some Italian doctors are already planning this kind of activities.
- Taco: The topical meeting should be initiated by us, concerning issues that we consider important.
- Vanja: Agrees with Taco. Meetings should respond to our interest, not Only to the doctors interests. We should try to keep our influence on these meetings and to decide which doctors our organisations want to invite or "send" to them.
- Ute: It is not necessary to organize such topical meetings together with a big national conference. She proposes to have the OIFE meeting together with a topical meeting, maybe in a less expensive location.
- Taco proposes to form a committee to organize coming events in this line. Ute proposes that he should lead this committee. Simona, Maria and Carina will be part of it and until September they will work out a topic that should be presented. Financial possibilities should also be studied.
- Simona will send a new participation list of the topical meeting.

#### c. Guidelines for OI-treatment – AOI-call for collaboration

Patrick makes a call on collecting medical information and research on medical topics regarding OI-treatment. He will send an e-mail asking for collaboration on this issue.

### 6. EMAB – new Mini-EMAB

Ute will dissolve the old EMAB as soon as she can find the time, because it is too big and has little activity. But she reports that whenever she had a question to its members so far, the cooperation was very good.

### 7. Next AGM's

#### a. AGM 15, suggestions

Khatuna from Georgia invites us and will try to raise money for our stay. Travel expenses should not be that expensive if booked in advance. Boarding expenses are not high.

Norway wants to host the AGM as well in Bergen, but it would be necessary to agree on a date to present possible costs. This meeting wouldn't be at the same time than the Nordic meeting. Patrick asks the AGM to take place at the same time than a national meeting. Taco asks for a meeting in a less

expensive country.

Ute also proposes the possibility of meeting in Germany. Decision will be taken in September.

#### b. AGM 16 in Belgium?

We don't know about this yet. We would like the meeting to take place at the same time as the Scientific Conference in Gent. Ute will inform us about this in September.

### 13. A.O.C.B

- Rob van Welzenis (not present) has sent a note concerning: New developments in the field of nano-biology, he suggests to contact OIF on behalf of this.

It turns out that they are now able to re-construct the intercellular matrix in such a way that they can control the chemical signals to the cells. Concretely this means that it is possible to instruct a cell to grow bone or secrete a certain enzyme (e.g. to control the formation of collagen). This opens up a whole new field of medicine with bright prospects also for OI, it could be a lot better than bisphosphonates. Of course it will take years before this can take effect, e.g. for OI it would be necessary to find which signals to the cells are required (could even be different per patient).

As the OIFE has no means to support this kind of (expensive ) research and as this development is taking place in the USA anyway Rob proposes that the OIFE contacts the OIF on this matter and asks them to see if they can get the OI research community interested in this development. Maria is willing to assist. Decision: We are going to contact the OIF to ask for this development.

- Vanja asks everybody to send her the newsletters of their organisations.

- Taco would like somebody taking care of the youth activities,

- Spain asks if the national organisations would investigate possible funding from the European Community. Their social worker would be willing to help with this kind of projects.

Problem is (Ute says) that the organisations do not have enough time nor people to apply for this kind of financing. Carina will be learning how to do this and would then offer support.

### 14. Closing

Ute thanks for the good participation and collaboration of the delegates and closes the meeting.