

OSTEOGENESIS IMPERFECTA FEDERATION EUROPE



Minutes of AGM 15

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

Participants:

Ute Wallentin, president	Germany
Taco van Welzenis, vice president	the Netherlands
Filip de Gruytere, vice president	Belgium
Simona Paveri	Italy
Jacky Goineau	France (new delegate)
Eero Nevalainen,	Finland
Maria José Pico Fernandez	Spain (replacement)
Carina Svenheden	Sweden
Trond Gården,	Norway
Michael Købke + Rune Mogensen	Denmark (replacements)
Vanja Živković	Switzerland
Khatuna Saganelidze	Georgia
Maria Barbero	Padrinos-OI + Ecuador (replacement)
Hinke Panjer	HOI, the Netherlands (parts of the meeting)
Rosa Espino	Asociación Peruana de OI, AOI Peru (parts of the meeting)
Rob van Welzenis	OIFE honorary president

Guests:

Jaime Montalvo Dominguez de la Torre	Spain
Leonardo Panzeri + Joshua Paveri	Italy
Susanne Qvist	Sweden
Katerina Kavalidou	Greece

Excused:

Patrick Dupuy, France; Marko Džinić, Croatia; Niels Christian Nielsen + Morten Nørgaard, Denmark; Lucia Travez, Ecuador; Heller An Shapiro, USA; Lynne Foxall, Australia; Hugo Ruiz, Mexico

1. Opening and welcome

Welcome and apologies presented by Ute, information about schedule and breaks, presentation of participants.

2. Settlement of the Agenda

a. Further points to discuss?

Ute asks if further points should be discussed, some small items will be put under "any other competent business".

b. Time frame of AGM, schedule

The points of the agenda are slightly reshuffled, following Rob's proposal on Saturday the meeting will be continued late, so that the morning session of the Spanish Congress can be attended by those delegates who wish to do so.

3. Change of OIFE-statutes - vote

Ute points out that the OIFE has its legal seat and is registered in the Netherlands and that some national legal conditions are actually changing in the NL. She asks Rob to continue. So Rob explains that in order to receive the Dutch status of a non-

profit-organisation or a charity organisation before the end of this year, some small changes in the original Dutch “Statuten” will be necessary. The English version of the statutes that all delegates know is only a translation of that original Dutch document. OIFE should apply for the charity status now, later it will be more difficult or impossible. He suggests that the OIFE Board should empower the executive committee to change the Dutch “Statuten” according to the relevant conditions and to apply for the Dutch charity status soon.

Ute counts the present delegates of full members and states that the OIFE actually has 12 full members with a voting right, 11 delegates of full members are present and can vote. The UK delegate has received a voting form about this issue and sent back his vote before the meeting.

Ute repeats the proposal and as no further questions are asked she takes the vote:

Yes: 11 present votes, 1 written vote. No negative votes or abstentions

Rob brought a prepared letter from a Dutch notary that is then signed by the president and the two vice-presidents.

4. Adaptation of the Bylaws – number of member categories

Ute reports that Rob recently found an error – a discrepancy between the number of membership categories between OIFE’s statutes and our bylaws and asks Rob to explain. Rob prepared a short document showing the last version of the bylaws and the necessary changes which had been sent to all delegates before. After a short explanation he suggests to take a vote about the new, corrected proposed text version. Ute asks the delegates for their vote for the new, corrected text and receives again an unanimous approval by all 11 delegates present.

5. Report on website

a. Webmaster’s report

Ute points out how important the website is as an instrument of communication and information. Rob has nothing to add to his written report.

b. Delegates’ cooperation

Ute asks again for more contact and cooperation and would like to see the forum used – actually it is completely “dead”. Eero explains that often people don’t like to log in. Taco says that the log-in is necessary to protect it against abuse. 50 people have registered for it, but there is still no activity. Carina asks for details: would you get an e-mail if anyone posts a mail in the forum? At the moment you only get an e-mail if somebody answers to your question. Ute asks if this could be changed for some months, in order to give the forum more life. Taco supports this idea. Steffi/Olli should be asked.

Carina points out that it should then be possible to avoid such messages, if someone does not want them.

Rob reports about the small committee that worked on changes of the website. The committee has implemented some ideas, but the help of all delegates is necessary. As soon as the English texts will be finished, they need to be translated into each language. Most delegates make the translations or care for them to be made soon, but some delegates did not reply, so Rob asks the delegates again to either make the translations themselves or to care for a translation soon, when asked for it!

Georgia has not been asked yet to do the updates because contents have to be renewed and approval of the medical board is necessary for that renewal of

information. New information refers to genetical advances, typing and even definition of OI.

We need new experts who are willing to look into the English text and give approval. Simona Paveri proposes Dr. Corradi Venture as a Genetician who could improve the text and give his advice. Filip knows somebody in the Gent University who can be asked about this.

About typing/classification, Rob contacted David Sillence long ago. Dr. Sillence answered two months ago and the work on that issue can now be finished.

Carina asks if it is possible to get the support of the national social departments and if a link to the national organisation can be added.

Rob says, the concrete information should be always the same, but the information of national departments can also be included as a link in the website.

Rob wishes the delegates' comments on the general issues of the page, and also concrete comments on special points.

Trond repeats his former proposal to combine national websites over the OIFE website instead of translating all information into many different languages. He thinks that the information on the actual website will never be completely updated. It seems very difficult to translate everything and he does not think that translating everything is very effective, as long as everybody can get the English information on the OIFE-website.

Rob contradicts that this refers to national organisations (and those do not always have a website), but that it is necessary to have information in every language. Many people discover their own country organisation through the OIFE-page.

Jacky proposes to ask the scientific committee of the French association about their opinion.

Simona proposes to solve the updating problem through a disclaimer. Rob thinks the disclaimer and the dates on the page should be sufficient.

Simona asks if the searching engines are also covered. Yes, they are!

Khatuna speaks of a serious translation-mistake in the Russian version of the OIFE website.

c. Forum moderator report

This will be discussed together with the secretary report.

d. Welcome forms

Ute explains about the Welcome form: it was installed in order to give visitors of the OIFE-website a possibility to leave a trace and to possibly enable OIFE to bring different people from the same country together if they want that.

The welcome form gives a possibility to give an e-mail address and some little data and to ask questions. This is used very often and Steffi collects the information and works as in-between to help establish the contact between these people.

Trond points out that this collection of data might not be legal in some countries, but Ute says that there have been no problems up to now and that the data are treated very carefully and confidentially. Rob confirms that any abuse of the information can be punished. Trond warns again that already collecting might be illegal! Ute confirms that she is aware of that possibility.

e. Introduction of Delegates-discussion-table and Picture Gallery

The question is how to get the delegates to communicate more and to cooperate more closely, and if that could be reached by one of the following possibilities that Rob describes shortly:

- installation of new e-mail-addresses ec@oife.org - mail to the EC and delegates@oife.org - mail goes to all delegates, can be answered and we

have a public discussion table. Rob expresses his concerns, that this address could be misused by spammers.

- password-protected blog for delegates. This could as well be used for information exchanges by a selected group of people.
- closed part of the forum for delegates only - restricted area that has to be authorised by the forum moderator.

Carina asks if the forum gives the possibility to chat. The answer is: no.

Trond suggests a link from the e-mails to get immediately to the forum website. Rob does not know if the direct linking is possible here.

Trond suggests to first use the delegates@oife.org address, but to perhaps try one of the other two possibilities – general approval. So Ute proposes to open one of the means, forum or blog. Rob and Eero should be in charge of that because there are some technical issues that should be solved.

Simona wants to know what the substantial differences are between forum and immediate e-mail communication. She prefers e-mail, but Ute points out that Simona's mailbox is very often full and mails are then rejected. Taco explains that the advantage of a forum is that the messages don't get lost among all the private e-mails.

Picture gallery: according to Rob, we had a change in the conditions of our provider that now allows us to put up a picture gallery. We also have a photo archive that could be transferred to the website. Eero is willing to manage the entry to the picture gallery. The pictures of the AGM should be there. The permission of the persons on the picture must be given before putting the pictures there.

Vanja asks if a written permission is necessary? Eero confirms that comments and names can be added to the pictures.

6. Reports and questions

a. General EC- and president's report + activities since AGM 14

Ute is satisfied about OIFE's work during the last year because she sees that people outside are appreciative of OIFE's existence. Also many medical professionals contact OIFE, ask questions (for instance about contact to certain OI clinics or OI specialists or about the next Scientific Conference). The reputation of the OIFE is increasing. Ute has been asked for OIFE's main mission and she thinks that contact between OI-people and spreading knowledge about OI are most important.

After the last AGM OIFE and AOI sent letters to Novartis to get information about availability of pamidronate in several countries, but we got no replies at all.

A new association in Panama has been founded and contacted OIFE immediately. Gilberta in Portugal is in contact with a national rare disorders organisation. She tried to set up a new second OI association together with several other adults (Ana + Mafalda), but after some internal problems between them, Ute did not get more information recently.

The other Portuguese association APOI does not cooperate with OIFE at the moment.

Israel: they always send New Years wishes. Someone from Russia asked information for a Russian family in Israel and was directed to the national association. OIFE is in loose contact with Japan and Korea.

We try to represent OI on an international level, mainly in EURORDIS at the moment. Jacky attended the EURORDIS meeting. He sent a short EURORDIS report. Jacky explains about a possible EURORDIS-support for research projects for

OIFE. This would be important for the future of the organisation.

Ute explains she contacted EURORDIS twice because of a difficult situation with prescriptions of bisphosphonates in Romania and in Belgium. In both cases they reacted immediately and the problem in Romania could be solved. They understand the problem of rare diseases and Ute is glad that OIFE is a member of EURORDIS. Ute asks Filip to clarify the Belgian situation.

Jacky is asked to send the report again to delegates@oife.org.

Ute informs about the increasing contacts between OIFE and the "medical world". She was contacted by MDs from Romania, Russia, South Africa, Sweden.

Ute was contacted by Natalia Belova, a Russian OI-doctor who wanted to visit an OI-clinic together with an orthopedist/surgeon. Ute contacted some clinics and after three months she has three invitations: UK, Paris and Italy. Now Natalia can choose where to go. This shows the growing importance of OIFE, even for the "professional OI-world".

But Ute reports as well about a problem with an Egyptian doctor in Mansura. He had asked for instructions to set up an organisation for his patients and seemed very eager to help them. OIFE sent recommendations, but he didn't reply again. She contacted him now because of two families who asked for help. A family wanted money to go to Germany for medical care and Ute advised them to go to this doctor in Mansura. They went to Mansura and the doctor wanted new x-rays and tried to charge a lot of money (probably because he suspected financial support from Europe for the family). The specialist recommended expensive braces for the child. He advertised with his international recognition as OI-specialist, which seems like an abuse of OIFE. This shows how careful we have to be with any recommendations! Carina confirms that only patient's recommendations should be made.

Vanja asks about how to handle recommendations in the own country. She speaks about the situation in Switzerland. Should the OI organisation give addresses of OI-doctors, even if the experiences of some patients with this doctor or clinic were not good? Simona suggests just to take into account the medical qualities/qualifications of the doctor. We discuss about the feeling that a recommendation from an OI-society could be seen as a "must". Jacky and Ute say the French, as well as the Germans, have a list of knowledgeable OI-doctors, but they are not recommended, they are just listed.

Ute thinks every country should have a list of doctors and clinics in their territory but Trond says in Norway that would never be done – OI people there do not choose doctors, the health system arranges the necessary assistance on the level that is needed and arranges referral to another clinic, if necessary. People in Norway are not interested in names, but in the general situation.

Filip says in Belgium you can choose your doctor and you can always look for a new opinion. Every country's situation seems to be different!

Internal news: as the contact with the Brittle Bone Society had been almost lost completely, Ute went to visit them in April. She renewed the contact and met Michael Young, the new British Delegate. He might come to Belgium next year. The relationship is re-established and the cooperation very effective again!

There is also an excellent relationship with the American OI-Foundation and its staff.

HUOI from Croatia was a full member until last year. For understandable reasons they cannot pay the full membership fee. So the EC proposed to Marko to become an associate member and to pay only 80 € - Marko, who is now HUOI's president as well, is not happy about this decision. The fee for 2006 and 2007 was taken from the fee solidarity fund. The contact to Marko is quite irregular at the moment.

Answering a question for his daughter Ana and her planned surgery, Ute explains that Marko told her, Ana was rather fine and they did not want to have her go through difficult surgeries now.

Ute asks if the Newsletter from Steffi got to everyone – yes! The External newsletter goes to 150 people.

Ute reminds that we decided to collect stories about how we started our national organisation. Only Taco sent the story in English, Ute meanwhile got more stories from Finland, UK and France (but only in French). Appeal to all to care for English texts!

b. Report of Social committee – cooperation with HOI and Padrinos-OI (Ute, Steffi, Maria, Khatuna, Hinke)

HOI – Hinke reports about HOI's 10th anniversary celebration in May and about a big Cuba-project for mainly one OI-family with twin girls, she cooperated with a German friend of this family and with a Dutch organisation called "Humacuba" and shipped new wheelchairs and other equipment, but as well bisphosphonates for Alina Garcia's patients to Cuba in summer 2007.

See HOI's new website: www.hoistichting.nl

Padrinos-OI: one year ago the organisation has officially been founded in Germany and found many new supporters. But at the moment the internal structure first needs to be set up and improved, before more godparents and children or adults to support can be accepted.

Ute reported of several cases: an used wheelchair from Germany for an OI-boy in Egypt, another one for a small girl in Latvia, the possibility for an operation for a girl from Zimbabwe.

Khatuna is in contact with over 50 OI people and their families in different Eastern European countries and mainly in Russia.

c. OIFE youth activities – report about Youth weekend in Paris (Anne-Miek)

As Anne-Miek could not come due to a fracture, Ute could only refer to her written report, but asked all delegates to bring young OI-people in contact with Anne-Miek.

A short report from the Danish representatives about the Youth weekend in Paris confirmed that it had again been a great success.

d. National Reports (sent and read before!!) and activities in member countries -questions and answers to these reports

Georgia: Taco asks about the Georgian guidelines. Khatuna reports about the national guideline for the treatment of OI that she published in Georgia: treatment with Aredia is available for free in Georgia and the guidelines describe the use of non-telescopic rods. These guidelines are for doctors and nurses.

Carina asks for the utility of the Glasfit program for the Georgians. According to Khatuna, the Georgian members regard the translated book as very useful.

Switzerland: Vanja explains that the Swiss "chocolate action" was a very good way to raise money and awareness about OI and the association.

e. Reports on activities in other OI societies or international coalitions

- the Austrian association was founded this June. They can join OIFE in 2009 after two years of function

- Portugal: Ute and Maria explain the activities undertaken by Gilberta and some others to set up another functional OI association there, as the first one seems to be inactive.

- OI-Nordic. Carina tells about their last meeting with doctors. The doctors asked for the dates of the Scientific Conference. (16 -18 October 2008 in Gent/B)

f. Report on EURORDIS

Ute could not attend the annual meeting, but representatives of other OI-associations were present and reported about a study about "Care" in which they took part.

g. OIFE – Information material – Newsletters, OI-Pass, etc. – (Filip)

- Newsletter (common and internal)

- Draft "fast facts about OIFE" (Taco) – Ute thanks Taco for this paper which should explain basic facts about OIFE for "newcomers" – Taco asks all delegates for comments, so he will be able to finish his first version

- OIFE leaflet – new, updated inlay (Filip)

- OI pass – next edition (Filip)

Filip is working on updates, will contact all delegates for their comments. Filip brought the last available copies of the OI-pass and all delegates are asked to take and to distribute them for free – a new, corrected and updated version will be printed next year. Maria asks for some OI-passes for the OI-Padrinos children.

h. OI – registry (Ute)

Ute presents the facts of this American registry (at Kennedy Krieger Institute in Baltimore) and the reasons why she is meanwhile in favour of it. She thinks that the OIFE should not recommend to join the registry, but that we should inform about it. Through the registry MDs and researchers of OI-aspects can be brought in contact for studies on OI. The registered OI people are informed about studies and can decide if they would like to take part or not. Jay Shapiro has asked OIFE through Ute to inform OI people from other countries as well as doctors or organisations who might also have registry data to share.

Carina tells that in Sweden some doctors are working on a similar directory. Ute asks Sweden for the contact data of these doctors.

Ute will send updated information on the registry to all delegates and asks them to inform their Boards and possibly the national OI people about this opportunity.

7. Membership AOI – Perú

a. Presentation AOI – Rosa de Chang presents her organisation and its work shortly. It was the first OI organisation in Latin America, founded in 1994 and it actually represents 78 families. Many OI children receive bisphosphonate treatment and other support with the help of godparents through PadrinoS-OI, but there are some adults as well in desperate need of regular treatment who should be supported.

b. Vote on application : Ute suggests to accept Perú's application to become associate member and receives unanimous approval from all delegates.

8. Finance

a. Financial report – update

Ute asks Thomas for a short update on his last report: Thomas reports that this year the situation is not as good as last year, because some membership fees have not yet been paid and so far we did not get any donations. So the credit balance of OIFE dropped from about 25.000 € in 2006 to 23.000 € in 2007.

b. Report on fundraising activities

The necessity of fundraising is obvious, but Ute so far has had no time to apply for external funding.

Simona proposes that somebody should be in charge of fundraising or asks if somebody could be hired as professional fundraiser. Carina proposes to hire somebody temporarily for that purpose. As nobody can suggest a possible fundraiser and Vanja asks for a decision on this proposal, Carina finally suggests that possible names of fundraisers or such organizations should be given to the EC.

Ute suggests that the country helping to fundraise for the OIFE would get the travel expenses for next year. This idea is rejected. Rob suggests to use one of those offices "no pay, no fee" in order to hunt for European foundation, but Ute says she has no time to prepare and perhaps later organize such a big project.

Jaime proposes to prepare a strategy paper suggesting projects that would be interesting for OIFE, with detailed information about the organisation that has to be addressed. His considerations are that we have to think big if we are aiming a big European project.

Taco proposes to set up a committee to look into fundraising, but following Rob's proposal agrees projects should be defined first.

Jaime asks if there are any concrete projects to offer to potential fundraisers and some (youth weekend, printing of OI pass- and leaflet-update, invitation to guests at next AGM) are listed. Ute proposes to contact Lions or Rotary Club and other service clubs. This would normally not interfere with the national interests of OIFE's members and she asks for everybody's support to contact such clubs.

Vanja would like to come to a conclusion about the fundraising. After some discussion the general consent is that we do not have volunteers now to do fundraising and that we need more projects and a strategy paper first.

The EC should decide, in case ideas come.

Vanja suggests a vote on the general idea of paying 5% for somebody to fundraise for the OIFE and this is proposed for a vote:

2 abstentions, 8 positive votes – (1 delegate absent)

c. Fee-Solidarity fund + Project Fund

We have a fee solidarity fund that was used 2005 to support Croatia with the membership fee. We also have the project fund (1.000 Euros a year to support projects in order to bring together people from different countries, for instance: youth weekends). The EC suggests to spend more money on such projects.

This year an income of about 9.700 € is expected. Up to now we only got up to over 4.000 €.

d. Report of financial control sub-committee (Trond and Carina)

The control sub-committee reports that obviously no money has "disappeared" and that the bookkeeping in general is okay. But they saw that from the books the use of the money spent was difficult to understand and wish for a better and clearer overview in future. Thomas explains that for this purpose the number of bank accounts has now been reduced to three accounts.

As many expenses are discussed and decided by the EC, it is suggested to keep a special record of all EC-decisions concerning financial matters. This will be done from now on. Rob reminds Thomas that the costs of the website should be separately mentioned in the next financial report.

The overview about the expenses should be clearer and contain the figures of the

budget draft.

The Financial control sub-committee affirms that the financial situation is good enough and that the books have been carefully kept and are satisfying with some explanations. The treasurer can be discharged – this is unanimously done with a vote.

e. Vote on financial report

Ute asks for a general vote about this new financial report and gets 2 abstentions and 9 positive votes.

f. Amount of future annual fee – EC proposal

According to an earlier EC-decision Ute proposes to keep the actual fee of 400 € for full members and the possibility of smaller fees for associate members.

Vote: 11 positive votes.

g. Project Fund – EC-proposal and vote about future

The EC proposes to continue with the project fund and an unanimous vote confirms that in future the strategy to put 1000 € into the virtual “project fund” will be continued.

h. Future financial policy and budget 2008 – vote

The recompensation (to those full members who sent a delegate) is discussed. Thomas suggests to at least reduce the recompensation to safe money. He thinks the recompensation should be paid only if an application is submitted. After some discussion Vanja proposes to pay only 100 € as general recompensation, and if a member needs more, they should ask for it. Ute proposes to vote on this and gets unanimous approval, 11 votes.

i. The budget proposal for 2008 is presented and voted on: 11 positive votes.

j. Election of new financial control sub-committee

Trond and Carina are asked to stay for another year, agree and are unanimously re-elected - 11 votes.

9.Executive committee

Ute had planned a formal discharge of the EC, but Trond explains that this has already been done when the delegates accepted the presented EC-report earlier.

Resignation and re-election of first vice president Filip:

according to the Bylaws Filip is due for resignation this year. As he is available for re-election and there are no other candidates he gets re-elected with 10 positive votes and one abstention.

10. Update on OIFE – Projects – future plans

a.Next International Youth weekend in Denmark 2008

We already spoke about it. Michael asks if the money calculation of 50 € per Person for the weekend is realistic. Ute thinks 60 € would be more realistic if one further day is added.

b.OI – Directory – report AOI-experience and call for European cooperation

Ute reminds that Patrick called for a participation of other OIFE members and suggested to set up a similar system. As that is not known to all delegates, Jacky is asked to send information about the French system to delegates@oife.org. Jacky wants addresses of OI-specialised doctors of all the countries. Vanja says we can

give addresses, but we should not be guaranteeing for the doctor's quality. Carina speaks of a registry in Kopenhagen/Denmark, the TRS-center in Denmark collects data and Simona mentions Dr. Antoniazzi in Verona/Italy. Jacky asks for more information about this!

c. Topical meetings – future concept?

Two different forms of such meetings are discussed:

- First Simona speaks about new plans for another follow-up-meeting in Rome in 2009 on "Technical surgery approach on OI". She asks the delegates to give addresses of interested doctors or to provide doctors with this information. Taco proposes Simona puts that on paper and sends the information, so that the boards can be better informed. Every delegate should then forward the information. AsItOI wants to know if they can count on the OIFE members' help, not financially but providing with the scientific support of doctors or at any other level (paying for the doctor's trip). It would only be a doctor's meeting.

- Then the general idea of further OIFE-initiated topical meetings is discussed and everybody agrees that such meetings should be organized. Ute points out that basic general conditions have to be linked to OIFE's future financial support, such as a report before the payment of any OIFE-money and Rob adds that OIFE should be mentioned on all the documents.

Sub-committee for planning of next meeting: Khatuna, Simona, Taco, Carina. Simona adds that it is not easy and perhaps not necessary to organize the topical meeting at the same time as the OIFE-meeting. The committee should come to a conclusions on that.

d. Report on Making friends Project (Taco)

Taco informs that he decided to go for quality instead of for quantity. A better place on the OIFE-website will be looked for. A new printed brochure is being prepared. Spain is starting a similar program in Spanish. María José will inform us about an exchange program of houses.

f. Dutch DVDs

Taco presents the new Dutch film and asks if it could be interesting in other languages. He will send copies to all delegates later.

g. Patient-intended descriptions of OI (Ute)

Ute asks if the countries have a nationally accepted description of OI and its therapy. She would like to collect, combine and compare this information and come to an agreement for a description that would be useful for all. Rob proposes that everybody should improve the Wikipedia-definition of OI in their language. Simona has a report from Antoniazzi and Ute wants to get it.

h. Report of Social committee – cooperation with HOI and Padrinos-OI (Ute, Maria, Khatuna, Hinke)

Hinke explains about her Cuba-project and the support for two OI-brothers in Turkey. The biggest problem is to send the help to the countries. Hinke contacted a television team and got the help and some funding for the projects. HOI prefer small projects because they are easier to fulfill.

Ute informs about the positive effect of some support for Moira from the Philippines.

Maria explains the Padrinos-project and suggests a new OIFE-scholarship proposal. Katerina also has information on a similar program for disabled students and will

share it

11. OIFE 2013 – general objectives and plans until 20th anniversary

Discussion of EC- paper – questionnaire

Ute reads the general objectives-list which will be helpful to determinate OIFE's next goals and asks for comments and additions.

EMAB:

Ute speaks about the European Medical Advisory Board, which has been neglected because of the lack of time, but is still very helpful. Lidy suggests to write a letter to the doctors soon to "keep them warm" for OIFE's matters and to invite them for a special drink at the next Scientific Conference. Carina will help with this.

12. Scientific Conference 2008 in Belgium 16 – 18th October 2008

Filip is just starting with the organisation. On Saturday is the medical meeting. He proposes the OIFE-people to arrive on Wednesday already and to finish the AGM until Saturday, so that we have more time with the doctors. He will send a plan by e-mail, so that everybody can decide if they want to come one day sooner.

Ute asks the delegates to inform their doctors about the dates for the OI-Scientific Conference.

13. Next AGMs

- a. AGM 16 in Belgium
- b. AGM 17 (probably) in Berlin/Germany

14. Any other competent business + Closing

Rob informs about his exchanges with David Sillence. Rob contacted him because the American OIF is going to publish a book on "Mild OI". Rob affirms this to be a misconception, and Sillence agreed with him.

Up to date there are 8 recognized clinical types, as well as a scientific classification and a affectation calification.

Most of OI type I persons are mildly affected, but this does not mean that OI type I is mild.

Trond suggests by our next meeting we have to prepare ourselves better and bring some notes to read. This makes everything easier and quicker.

Taco has found on the web the lifestory of a woman with OI and he will send the information to everybody.

Minutes taken by

and finished by

Maria Barbero

Ute Wallentin