



OSTEOGENESIS IMPERFECTA FEDERATION EUROPE

Report on the seventh Annual General Meeting  
14 – 15 May 1999, Erba (CO), Italy

**Guests:**

**Maria José Pico Fernandez,  
Nevenka Kalac & Nevenka Grzetic,  
(president & translator)  
Chiara Gorla & Nadia Felisari,  
Marcella Zingales,**

**president of the Spanish OI-Society  
representatives of the Croatian OI-Society**

**translators of Italian OI-Society  
president of the Italian OI-Society  
(last part of the meeting)**

**Participating delegates:**

- **Rob van Welzenis, The Netherlands president**
- **Ute Wallentin, Germany 1<sup>st</sup> vice-president**
- **Simona Paveri, Italy**
- **Roz Strudwick, United Kingdom**
- **Jacky Goineau, France replacing Patrick Dupuy**
- **Filip de Gruytere, Belgium replacing Jo Braet-Martens**
- **Kati Wink, Finland**
- **Birthe Holm, Denmark**
- **Rebecca Tvedt, Norway**
- **Ueli Haenni, Switzerland**
- **José Felipe Mateos Diaz, Spain**

**participating EC member (non-voting):**

- **Jean van den Boorn, OIFE-treasurer**

## **Osteogenesis Imperfecta Federation Europe 7<sup>th</sup> Board Meeting**

### **1. OPENING AND WELCOME**

The president opened the meeting and welcomed the delegates and the guests. He briefly explained the division of the meeting into 3 parts and introduced some new Board members: Roz Strudwick as new delegate from the UK (BBS), Rebecca Tvedt as new Norwegian delegate and Jacky Goineau replacing Patrick Dupuy. Each of them presented him- or herself briefly to the Board.

Filip de Gruytere replaced Jo Braet-Martens as the Belgian delegate  
Rob read part of a letter from the Polish society who had not been able to send a representative because of the lack of funds.

### **2. SETTLEMENT OF THE AGENDA**

As the Italian EMAB-member would be available from Saturday on, the president suggested to postpone the EMAB-reports to the next day in case she would like to attend the meeting and present her report personally.  
There were no further changes.

### **3. ANNOUNCEMENTS**

Rob referred to some information he had distributed earlier, such as the updated list of delegates that he asked all delegates to control and correct if so needed, the latest OIFE-statistics and a statement of the EDF from its AGA in Brussels concerning the war in Jugoslavia.

Referring to the statistics he pointed out how important these were because discussions and decisions in Brussels were based on these numbers and they showed that the OIFE was the largest OI-organisation in the world. So he called upon every delegate to update these numbers regularly.

He invited the delegates to have a look into the lists of incoming and outgoing mail that he had brought along.

Then he distributed the new OIFE-folder and asked the delegates to take home as much copies as needed to show them to their boards or members and to use them for fundraising activities. He pointed out that he had found a possibility to print them with just minimal costs for the OIFE and apologized again to the delegate of the Society of Belgium for the mistake of mentioning the word „Flemish“ that could lead to the misinterpretation that Belgium was Flemish. Filip accepted the apology.

Simona once more welcomed all delegates and made some remarks about the organisation of the meeting and the programme. Rob asked the delegates to try to mix with the Italian members as much as possible during meals and breaks.

Ute referred to the „glass bones“ (brooches and pins) she had brought and a T-shirt with an OI-skeleton and asked the participants for their orders.

#### 4. REPORTS

Rob referred to the earlier mailed or distributed written reports of the EC, the treasurer and the delegates, suggested that they should be read later carefully and questions be answered either directly or during the next part of the meeting, when of common interest.

##### 4.1 Report of the Executive Committee

The president explained his report to the delegates and said that some of its issues would be taken up again later on the agenda (see report). He referred to his visits to Croatia and Norway and the written reports about both, mentioned the EC-meeting in Maastricht and talked about the results of the AGA 2 of the EDF and the Sector meeting in Brussels in April:

- as Johan Weseman had resigned as EDF-president, Yannis Vardakostanis from Greece had been elected as successor, Rob pointed out that in the EDF disabled people were in the majority and made the decisions and that fortunately the OIFE had become a full member due to the fact that it is represented in 75% of the EU (thanks to the 11 EU-members and its contacts in CRO, GR and POR) whereas DEBRA Europe was just associate member.
- In reply to a question about the importance of a full membership Rob explained that the OIFE as a full member had been able not only to protest against the raising of the annual fee to 300 EURO, but had as well put in alternative suggestions and had been able to arrange an "escape" possibility.
- Important EDF matters are the bioethics question and the political situation (human rights and non-discrimination) for disabled people.
- Rob asked for the delegates' votes whether the OIFE should stay in the EDF even with a raised fee and got unanimous approval of all delegates.
- The "sector" to which the OIFE belongs is a group of 5 members that represent rare disorders. At the last meeting the importance of an office in Brussels was discussed, despite the financial problem. There appear to be two possibilities:
  - perhaps one of the 5 members will get a regular office in Brussels and the others could participate.
  - there are contacts with Autism Europe, the coordinator of the former sector, that had offered to help, if necessary – both possible ways will be followed.
- Rob reminded the Board of the rare-diseases-programme of the EU (started in January) that might as well be interesting for the EMAB-members.

##### 4.2 Reports of the delegates

Rob asked the delegates to present the highlights of their report.

- Ueli reported of political activities of his society to get a referendum against a 25% abolition of support for disabled people and talked about the language problem within the Swiss society,
- Felipe said that he had forgotten to mention the application for membership to the OIFE in his report and called this an important step for his society,
- Rebecca reported about the 20<sup>th</sup> anniversary of her society in March and pointed out that the visit of Rob had been very important for the Norwegian members because the OIFE had thus "got a face" for them and they had overcome their doubts about the sense of their membership in it.  
Then she informed everybody that the „TRS-centre“ for 7 rare disorders, in which NOI was involved, would belong to the government from 1<sup>st</sup> July and had proven to be efficient and useful – a big success, not only for OIers in Norway!
- Kati invited everybody to their 20<sup>th</sup> anniversary in September (on their own travel expenses, as she added)
- Simona expressed her society's interest in orphan drugs and bisphosphonate-studies and was promised that this would be discussed separately later
- Jacky informed that the AOI now participates in a centre for genetic research in Paris and that currently there were two studies on bisphosphonates running in Lyon and

Paris, he distributed a report from Patrick about orphan drugs.

## 5. FINANCE

### 5.1 Financial report

Rob referred to Jean van den Boorn's financial report and asked for questions. He reminded the delegates of the importance of these figures because some important decisions would have to be taken. When there were no questions or comments, Rob asked for the delegates' votes for the profit and loss statement and the budget and got approval of the Board with only two abstentions (DEN + GB) so that the treasurer was formally „discharged“ and thanked once more for his demanding task. Jean van den Boorn in return thanked the Board for their confidence and added that the figures would be in EURO only from next year on.

### 5.2 Annual budget

The president asked for questions about the budget plan. The treasurer answered two about the fee to the chamber of commerce and the disability intergroup. The president then asked for the votes on the annual budget. The delegates approved unanimously with two abstentions (DEN + GB).

### 5.3 Annual fee

Rob informed the delegates about the EC-proposal, not to change neither the fee nor the fee-system at the moment due to the results of some calculations Jean and Rob had made and sent to the delegates before the meeting. In reply to a corresponding question Rob again explained the possibility for new members to pay a reduced fee for 3 years.

Ueli said his society had really hoped for a different fee system with a reduced fee for smaller countries and/or societies like Switzerland, Belgium and others and asked if it would be possible for larger societies to pay more. Ute suggested not to change the fee, but to ask the larger societies for some kind of donation to the OIFE so that fee reductions for smaller societies could be arranged more easily.

Rob asked the delegates to discuss this question informally before the next part of the meeting and sojourned the meeting to the next day.

After reopening the meeting the President suggested to adopt Ute's proposal and to ask some countries for donations, but not to change fee or fee-system this year. He reminded the Board that at the next AGM the amount of the fee would have to be re-decided anyway. He asked the delegates for their votes and got common approval to his suggestion apart from one vote against it (CH).

Rob then announced that he had put in a grant proposal together with DEBRA Europe for a combined programme, but had got no answer so far, although the AGM in Italy lay already within the time of planned activities that should be supported by the programme. That's why the delegates should keep all travel tickets in case there was a chance of recompensation for travel costs. Other main items of the programme were: the OI-Europass, two „vocational training courses“ in Poland and Portugal, two EC-meetings, the OI-conference in Montreal and a meeting of both ECs of DEBRA and OIFE. Rob gave a short insight into the procedure of applications to Brussels, explaining e.g. how important it was to use the right key-words.

### 5.4 Fundraising activities

The president asked all delegates to report about their fundraising activities as promised at the last AGM:

- Ute had written to some large companies in Germany and got about 3.000 EURO from two sponsors, so she will continue fundraising. She already talked to the German board

about a donation of some percentage of this money to the OIFE, but still has to wait for a decision.

- Filip wrote some letters and as a result got about 2.500 EURO.
- Simona tried some insurance companies, but in vain.
- Jacky read a letter from Patrick who had been too late with his letters to some pharmaceutical companies last year, but will try again in July.
- Birthe's society and other smaller groups for disabled people negotiated with the state about the profits of a lottery and even succeeded to find rules how to divide this money between the participating groups. The OI-Society got about 1.000 EURO and is free how to spend this money.
- Ueli and Felipe did not yet try, Rebecca had too little time since she became delegate and Roz didn't know if or what Morna had done.
- Rob had written a request to 5 pharmaceutical companies (together with Patrick) to finance the travel costs to Montreal and together with the treasurer of the Dutch VOI he had written some proposals, all still without a reply. But he had found a possibility to have the OIFE-leaflet printed for free.

He concluded that fundraising seemed to be working quite well and all delegates should go on trying. Following a suggestion of one delegate he asked all of them to copy their fundraising letters and to translate them for the others and to send them around, so that all could learn from one another. He recommended that in future the new OIFE-folder should be added to those letters.

## 6. EXECUTIVE COMMITTEE

### 6.1 Resignation of vice-president

According to the statutes it was Ute's turn to resign this year as vice-president, but Rob was happy to announce that she would stand for re-election.

### 6.1 Election of new vice-president

Rob asked if someone else was available or wanted to suggest someone as vice-president. As no one reacted he took votes: Ute was re-elected as vice-president unanimously, with 1 abstention.

### 6.2 President elect

First Rob explained the idea of a president-elect once more, then he passed on the chair to Ute.

She informed the delegates that the EC still had got no proposal for a candidate, in spite of the fact that the president-elect should begin his or her "training" right now, to be able to take over the presidency in 2 years. As someone remembered that Morna had spoken of a possible candidate last year, Roz was asked, but she knew nothing about that offer.

Finally Felipe asked if one of the vice-presidents could become president in 2001, Rob said that the EC had discussed this possibility as well during its last meeting in Maastricht and read an e-mail he had received afterwards from Ute, stating that she would be available. Rob thanked her and said that he was very relieved that we had finally found a suitable candidate.

Ute added that the decision had not been easy for her, although she felt honoured by the confidence, but that she expected all delegates to really and actively support her in future and to share the many tasks as far as possible. And she asked everybody to keep on searching for a next president-elect, because she wouldn't want to stay president for many years. Rob stated that he would remain available to help and support Ute.

Rebecca suggested to write something like a „book of routines“ to give the Board more insight in the amount of work and responsibilities and to be better able to divide duties. Ute promised that this would be done as soon as possible.

Rob took over again and repeated the proposal to nominate Ute for president-elect for about 2 years and asked for the delegates' votes. He got unanimous approval, with one abstention.

### 6.3 Budget corrections

Rob asked the Board to mandate the EC to make some minor amendments or changes to the budget due to the new situation with a president-elect, e.g. for an extra meeting with Ute in Eindhoven to discuss matters with her and answer relevant questions for her future presidency. He got unanimous approval for those necessary changes.

## 7. SITUATION CROATIA AND JUGOSLAVIA

As the guests from Croatia had arrived, they been delayed and thus missed the first part of the meeting, Rob officially welcomed them now and promised that they would get as much support as possible from all the delegates, they should just ask for it.

He then read parts of a statement of the EDF about the war in Jugoslavia and its consequences for the situation of disabled people.

Next, he asked the two Nevenka's to present their society.

Nevenka Grzetić reported that the Croatian society had been founded in March and had now 56 members (26 affected by OI), Croatia had about 5 Million inhabitants. They have a group of 7 medical advisors, but get no financial support and raise no annual fee from their members. The hospital in Zagreb had regular contacts and cooperation with a clinic in Trieste, Italy. She pointed out how much Rob's and Marcella's visit had helped them, because due to the international participation newspapers and two tv-stations and even their government had suddenly taken an interest in their situation and thanks to this fact 4 physicians would get travel expenses for the Montreal conference from the government. Nevenka thanked Rob again for his support and for the invitation to Italy and presented him with a honorary membership to their society and a video of their first OI symposium and AGM.

She added that their society was open to all OIers in Eastern Europe, regardless of nation, religion or politics.

## 8. GENERAL POLICY AND FUTURE PLANS

Rob reminded all delegates of his letter from 1<sup>st</sup> November 1998. He had received only one reaction and referred to last year's promises and plans and the tasks everyone should have fulfilled.

Birthe said that one could not have too high expectations from the delegates who had other private and professional tasks as well, she for example had not the capacity to do more for the OIFE. In her opinion one of the main problems of the OIFE was that it was almost „invisible“ to the members of the national societies who couldn't see the real sense and advantage of the OIFE for them.

Rob answered that the delegates where the „ambassadors“ of the OIFE in their country and should represent it and explain its function to their society's members.

It was generally felt however that the activities of the OIFE should be made more visible to the members of the OI societies.

The president stressed again that the OIFE should not take over activities of the national societies, but supplement them.

Rob compared the OIFE to the American OIF, the first a Federation with indirect members that represent patients/parents, a board of volunteers and still no official office, the second a national (fund-raising) organisation with direct members, paid staff and an official office through the cooperation with the American Osteoporosis Foundation.

During the following discussion about possible activities Rebecca suggested more international OI-conferences for OIers from all countries;

Felipe had the idea to ask every society to invite the delegate of a neighbour country to their national meeting and to ask him or her for a talk about his society and the OIFE (the travel costs to be paid by the invited society and the accommodation cared for by the host !);

Ueli said that he had been disappointed because they got no reaction to their invitation to the Swiss meeting – two weeks after the OIFE-AGM - but that he would continue to invite everybody;

Filip told the delegates that the next AGM in Belgium would be combined with a national meeting celebrating the 15<sup>th</sup> anniversary of the Belgian OI society and a small international conference about social issues related to OI and that they would invite all members of their direct neighbour countries (F, D and NL);

Ute asked to regularly exchange all dates of national events through the OIFE web-site

and to invite everybody to such events.

Rob finally asked every participant to write down (when back at home) what the OIFE should do and be – disregarding the realisation possibilities – before the summer and send it to either Ute or himself.

## 9. OI-CONFERENCE IN EUROPE

Rob referred to the planned conference for OI-patients in Montreal and said that the arrangements did not seem to be very satisfying because the patient-meeting was organised without cooperation of the Canadian OI-society and without contact to the medical conference. That is why the EC had come up with the idea to organise another conference like the "Life & OI"-conference in Woudschoten in 1996, in two or three years with mainly social issues and perhaps some medical specialists invited for special topics. He asked for a vote about the basic idea of such a meeting and got unanimous approval and suggested that he would announce this intention of the OIFE at the conferences in Montreal.

As several delegates (I, FR, N, CH and GB) were interested to have this conference in their country Rob suggested some kind of tender-system: the interested societies should write a short letter with some more details about the planned conference and the possible financing to the EC before the summer.

Although Rebecca had a deadline to apply for subsidies in Norway on the 15<sup>th</sup> of July in every year, it was finally decided to wait with a decision for the announcement in Montreal where the next Medical conference (in 2002) would be held. After the Montreal-conference either the EC will decide about the year and venue of the conference or in case of possible conflicts send out a written vote to the delegates.

## 10. EMAB - OPERATION AND MEMBERSHIP

Rob informed the delegates that 3 members of the EMAB had sent in their reports in time, (the German report arrived just after the AGM and is appended). The Norwegian member had sent an excuse and explanation for not sending his report this year. He summarized that the EMAB was still not as active as he would like but that it operated at least.

When the president asked for the nomination of further EMAB-members, Jacky handed in a letter of the French OI society proposing a new member: Prof. Michel van den Rest.

Then Jacky asked the EC to attract the attention of the EMAB to the 5<sup>th</sup> Framework program of the EEC and its possibilities.

Rob then informed the participants that he had asked Prof. David Sillence if he would be interested to be an extraordinary member of the EMAB, as this would strengthen the cooperation with the Australian OI society and might also enhance the reputation of the EMAB. Prof. Sillence had assured Rob that he would be honoured. Everyone agreed that Rob should ask the spokeswoman of the EMAB to put this proposal to the EMAB, so Prof. Sillence could soon be formally invited.

In relation to this Rob again regretted that there still was no common European programme on bisphosphonates. Prof. Adami from Italy had just promised to contact some pharmaceutical companies in search of subsidies for a common study. In case he should succeed the EMAB-members would be asked for their advice.

## 11. SUMMER-HOLIDAY-CAMPS FOR YOUNG PEOPLE WITH OI

Ute informed the participants about the outcome of Patrick's recent search for funding possibilities: the PETRA-programme was no longer accessible for organisations like the OIFE and he had still not found another programme that really fitted our objectives.

Nevertheless the Board decided that it would be worthwhile to go on with these plans.

Following Rebecca's proposal it was decided that every delegate should inform the national members of the plans, ask for their interest in such a project and for their expectations.

Kati brought a report about the Finnish Summercamps that she will send to Patrick. Her experiences with these camps were that families from other Nordic countries rarely participated – perhaps because of the high costs.

## 12 EURO-PASS

Rob reminded that this project was part of his proposal to the EEC and as well in the actual budget of the OIFE and that the Dutch society would organise and coordinate the update, so he asked all delegates to send him corrections and updates of the text before the summer holidays and to include an estimate how many copies their societies would probably buy.

## 13. OIFE'S WEB PAGES + INTERNET-ACCESS

The president stated that the OIFE-website was very successful and often visited, most delegates had sent him their translations already and meanwhile the basic information on OI was available in 10 different languages. There had been requests for further translations from Russia, Croatia and Brazil.

Unfortunately he had not yet been able to care for free internet access for every delegate, due to a lack of time. Felipe offered to do this together with him because he had professional knowledge of such things and perhaps some relations. Rob gladly accepted the offer.

## 14 INFORMATION EXCHANGE

Ute informed the participants that the German society had been contacted by several families in Russia, Lithuania or other Eastern-European states and Rob had some more contacts to persons in such countries, so they would like to try and bring these families in contact with each other. So every contact in those countries should (with its permission) be forwarded to Ute who would try to coordinate possible support and bring them into connection with each other. Nevenka from Croatia again offered help from her society.

Ute then reminded the delegates that she was gathering lists of available information on OI in different languages and asked the delegates and the guests to keep her up to date on those lists and new publications. Meanwhile, these lists had already been very useful for people looking for information in their own language.

Finally the delegates were again asked to exchange newsletters, journals or other interesting information and to update the lists of OIFE-delegates in their own societies.

## 15 GENERAL QUESTIONS AND INFORMATION

Felipe informed the Board about the intention of some Spanish-speaking South-American societies to build a Federation like the OIFE, he offered to be the link between both groups as he was on the Spanish mailing list for OI

Rob reminded the delegates of the „twin-story“ from the American OI-mother Melissa D. and asked them to send her a copy of the newsletters in which her letter was published in translation

Then he reported of his contact with the European Osteoporosis Federation and the EC-conclusion not to cooperate intensely with them as they were no „real“ patient/parent organisation like the OIFE.

Roz told the delegates that the negotiations between the BBS and the UK OIF were

still continuing and that they all were quite optimistic about a future reunion of both societies.

Rob here added that he had never got further information from Colin Wiggins about his plans for a world-wide OI-association and had had no reaction at all from the UK OIF.

Ute asked every delegate to tell her as soon as possible how many copies of an English „Glasfit“-version the national societies would order, because it should be printed as soon as possible (as well some time later a Spanish translation!).

Ueli and Jacky informed the Board about a large demonstration to be held in Paris the following weekend against downcuts in payments for equipment for disabled and asked for the support of the OIFE through a letter to the organisers. The board agreed as this national action could certainly have recuperations to Europe and a letter was written immediately after the meeting.

Felipe asked everybody to use internet and e-mail as much as possible because it was so convenient and cheap.

#### 16 AGM's

AGM 8: Filip invited the Board to a conference-centre close to Gent/Belgium from 3-5 November 2000

AGM 9: possibly in F, I, N or CH eventually in combination with international OI-conference?

#### 17 SUMMARY AND CLOSING OF THE MEETING

After decisions and agreements had been summarized and deadlines for duties to be fulfilled had been found, Rob stated how satisfied he was with this meeting's results, the found president-elect and the participation with a lot of input from many delegates.

All of the delegates shared in his opinion and were quite content with this meeting.

Rob concluded that there had been some important results of this AGM like the planned OI-conference. Then he finally closed the meeting, thanked Marcella and Simona for their organisation, all participants for their cooperation and endurance and wished all a safe journey home.

The minutes for this report were taken by Ute Wallentin.

Ute Wallentin  
Bamberg, 2 June 1999

Rob van Welzenis  
Eindhoven, 5 July 1999

## SUMMARY OF DECISIONS and APPOINTMENTS

1.  
The Board voted unanimously that the OIFE should stay in the EDF in spite of the raised fee.
2.  
The profit and loss statement and the budget and got approval of the Board with only two abstentions (DEN + GB).
3.  
The annual budget was approved unanimously with two abstentions (DEN + GB).
4.  
The Board decided (with one vote against) not to change the fee or the fee system.  
The larger societies will be asked for a donation to enable the EC to relieve the burden of some of the smaller societies.
5.  
The delegates were asked to copy their fundraising letters and to translate them for the others and to send them around.  
In future the new OIFE-folder should be added to those letters.
6.  
Ute was re-elected as vice-president unanimously, with 1 abstention.
7.  
The Board nominated Ute for president-elect for about 2 years with unanimous approval and one abstention.
8.  
The Board mandated the EC to make some minor amendments or changes to the budget due to the new situation with a president-elect.
9.  
All delegates will write down (when back at home) what the OIFE should do and be – disregarding the realisation possibilities – before the summer and send it to either Ute or Rob.
10.  
The Board unanimously approval of the idea to organise another international OI conference for OI people. The president is to announce this intention of the OIFE at the conferences in Montreal.
11.  
The final decision about the year and venue of the conference will be made shortly after the Montreal-conference.
12.  
It was agreed that the president should ask the spokeswoman of the EMAB to propose to the EMAB to invite Prof. Sillence to become extraordinary member of the EMAB.
13.  
The Board decided that it would be worthwhile to go on with the plans for a summer holiday camp. Every delegate should inform the national members of the plans and ask for their interest in such a project and for their expectations.
14.  
Rob reminded that this project was part of his proposal to the EEC and as well in the actual budget of the OIFE and that the Dutch society would organise and coordinate the update, so he asked all delegates to send him corrections and Updates of the text for the EUROPAS are to be send before the summer holidays to Rob, including an estimate of how many copies the societies will probably buy.
15.  
Ute asked every delegate to tell her as soon as possible how many copies of an English „Glasfit“-version the national societies would order.