



OSTEOGENESIS IMPERFECTA FEDERATION EUROPE

**Report on the eighth Annual General Meeting
3 – 5 November 2000, Deinze, Belgium**

Guests:

Jo Braet-Martens	president of the Belgium OI society
Martine Grandin	president of the French OI society
Marja Lehtinen	Finnish OI society
Simona Rossi	Swiss OI society
Marcella Zingales	president of the Italian OI society

Participating delegates:

Rob van Welzenis	The Netherlands	president
Ute Wallentin	Germany	1 st vice-president
Patrick Dupuy	France	2 nd vice-president
Filip de Gruytere	Belgium	
Marko Dzinic	Croatia	
Ueli Haenni	Switzerland	
Jose Felipe Mateos Diaz	Spain	
Simona Paveri	Italy	
Roz Strudwick	United Kingdom	
Kati Wink	Finland	

1. OPENING AND WELCOME

The president opened the meeting and welcomed the delegates and guests, especially Martine Grandin, the president of the French OI society, and Jo Braet-Martens, the president of the Belgium OI society. He excused two OIFE delegates: Rebecca Tvedt from Norway and Birthe Holm from Denmark. He also excused Jean van den Boorn, the treasurer, who had had a mild injury. The Board decided to send Jean a postcard to wish him a speedy recovery. Since not all delegates had arrived yet, the introduction of the new Board member Marko Dzinic from Croatia was postponed to later.

2. SETTLEMENT OF THE AGENDA

The agenda was accepted as suggested. The president informed that Ute Wallentin would chair the discussions late Friday night and also the meeting on Saturday morning.

3. ANNOUNCEMENTS

Ute told about the European Day of Disabled People 2000 Conference, which will be arranged on 6 December in Brussels. The EDF (European Disability Forum) has invited member NGOs to participate in the Conference. The EDF will cover the costs for one representative (+ a personal assistant if needed) from each NGO. The delegates had been informed about this in advance and asked to let Ute know if someone was interested in taking part in the Conference as a representative of OIFE. However, nobody had reacted to this and Ute repeated the offer. The Board agreed that the Day of Disabled People is still not very widely known in Europe.

4. IN MEMORIAM LOUS VAN EGMOND

On 14 September 1999 Rob had received the announcement of the decease of Lous van Egmond. She had been Rob's personal assistant in OIFE matters helping him with archives, letters, etc. The Board agreed on sending our condolences to her husband, expressing our gratitude for all she had done for the OIFE for which we will always remember her.

5. REPORTS AND QUESTIONS

First of all, Rob reminded the delegates about Article 11 of the OIFE-Statutes. According to this article, the EC and all delegates were requested to deliver a yearly written report. He added that in order to save precious meeting time, the national annual reports should be send in well in advance, so that the reading could be done before the meeting! This year many delegates had sent in their reports too late and reports had not been received at all from Denmark, Norway and the United Kingdom (the latter was distributed later during the meeting). Also USA and Australia had failed to send in a report, which would have been very interesting to the European members as there is little regular contact to these associate members. Most of the available reports had been distributed to the delegates in advance so that they could read them before the actual AGM.

a. General Executive Committee Report

There were no questions concerning this report.

b. President's visit to Portugal

Rob and his wife Lidy had paid a private visit to Portugal. They had stayed with Gilberta Couta E Silva, who had invited them. During their visit, Gilberta had organised a meeting for people interested in OI and about 20 participants had attended the meeting. Half of them had OI themselves, the other half were professionals. At the meeting, an introduction on OI was given by Dr. Pedro Magro. Rob had given a speech on OIFE and about various OI organisations. The Portuguese got excited about becoming more organised but so far nothing concrete has happened. Several delegates were surprised to hear that there actually already is a Portuguese OI society established but, unfortunately, it only

exists on paper. The Board hopes that Portugal will be able to establish an active OI society. Felipe said that Spain would be willing to help but it is difficult in practice. The French AOI has as well some contacts with Portugal.

c. Development in other countries

Ute told that she had contacts with some OI people in Russia, including Svetlana in Krasnoyarsk. Svetlana wanted to set up an OI society in Russia but it proved to be difficult. Rob had put Svetlana into contact with Hinke Panjer from The Netherlands (HOI Foundation), and several other people. She had offered to send in handicrafts, which she had made herself, to be sold to those interested. The HOI offered to import her goods, so anyone interested can order them from the HOI. Martine mentioned that the AOI also had contacts with Russian OI people.

Rob said that he had been approached by various people from all over the world asking for help for people with OI. As an example, he mentioned someone from Texas, USA, who had e-mailed him on behalf of his daughter working in Sarajevo. They asked if OIFE could send a doctor to a refugee camp in Sarajevo to cure a boy with OI. Naturally, OIFE has very limited resources to help in any concrete way. Felipe told that many Latin American countries approach the Spanish OI society asking for help and information on OI. If these requests are answered, often there is no response after the first contact. Rob and Ute have also contact with a lady in Yugoslavia. Before the war, there had been an OI society in Yugoslavia with 17 families as members. The society had been dissolved during the war and now four families were trying to re-establish it. OIFE has also has contacts with Philip Marais and family in South Africa. An OI society was set up there in 1999. They were hoping to join the OIFE in the near future.

The Board agreed that the member countries should exchange names and addresses of foreign contacts (outside the member countries) and inform OIFE about them. Ute promised to coordinate contacts according to language areas. The foreign contacts should first be asked permission to give their name to OIFE and to other OI-people in their country.

d. EDF – AGA in Brussels in June

Rob noted that at the moment only 10 of the 12 European OIFE members belong to the EU or the EEC. As the minimum should be 11, this could cause problems and the full membership could get lost. It was suggested that OIFE could argue that, for example, the German OI society has members also in Austria.

Ute, the president-elect, wrote the report on EDF's Annual General Assembly as she has taken over all the EDF tasks. She reminded once again of the European Day of Disabled People and also about the European Year of Disabled People (2003). The member countries of OIFE should start planning activities for the year 2003 now. They should ask their national umbrella organisations about it and, if necessary, contact their MEPs (e-mail list with names and addresses available from EDF). OIFE and its members have to help and support EDF in their efforts.

Patrick asked about the current situation with EDF. Rob answered that it was pretty well established by now but the NGOs need to be heard more. The most urgent problem is to get funding.

e. OIF Conference in Milwaukee in July

Rob and Ute had attended the OIF Conference as OIFE representatives. It was a large meeting with almost 400 participants with a very friendly atmosphere. Everything had been well organised. There had been several workshops, which had all been very good. Rob and Ute stated that we can learn a lot from the OIF but they should also be made more aware of us. We should try to establish good cooperation with them. OIFE members can translate material published by the OIF, but the OIF would like to check that translation first before it is published. The next OIF conference will be held in Orlando, Florida from 2 – 4 August 2002. OIFE members can participate the OIF member's rate.

f. EMAB

It was stated that the EMAB is expanding steadily. At the moment it has 7 European members and 1 overseas member. Rob reported about a letter that had been sent to the EMAB-members where the OIFE asked their opinions and visions on several points concerning OI research in Europe. France emphasized that one of the main tasks of EMAB is coordination of OI research (e.g. on bisphosphonates). Rob noted that this was not always easy as protocols were often different in different countries. The delegates were, however, asked to discuss this matter with their own EMAB representative and stress the importance of it. Italy pointed out that the problem is not always just the medical professionals but that, for example, also pharmaceutical companies may stand in the way of OI research. In addition, Italy suggested that we need a database for exchanging information about what kind of treatment etc. is available in each country. Rob stated that it should be emphasized to the medical professionals that it is also in their own interest to do this. It was concluded that OIFE should be informed about important contacts with medical advisors. Italy proposed a meeting for medical professionals organised by OIFE. It was noted that regretfully it is impossible for OIFE to arrange this kind of meeting, at least at the moment, without proper funding. We cannot force medical professionals to cooperate but we can invite them to do so. We should also try to support and build up the EMAB. France said that we as "patients" have a certain power, which we must use to strengthen the EMAB. Ute asked the delegates to inform their medical experts about the medical OI conference to be held in Annecy, France in 2001.

g. Eurordis

Patrick, the 2nd vice-president, wrote an annual report of the Eurordis activities. Eurordis has now 170 members in 12 EU member states + 2 other countries. It has financial problems and the running expenses have been cut off considerably. According to Patrick, Eurordis has achieved its primary object: European regulation on orphan drugs and was now looking for a new goals. They now try to organise associations at national levels (national alliances). Still only national organisations can join it, at the moment, 3 OIFE-members have done so. Rob noted that the orphan drug issue had not been the sole accomplishment of Eurordis as other organisations, including the OIFE, had been active in the lobbying work.

h. Activities and developments in member countries

As already mentioned, not all members had succeeded in sending in their report in time. Some countries had failed to produce a report at all. Rob emphasized the importance of preparing the reports in time.

Patrick asked Felipe about FEDER mentioned in his report. Felipe explained that it is a federation that works to lobby regional governments on certain laws and other similar issues (e.g. on having a "reference" hospital). Patrick also asked Ueli about the anaesthetic problem mentioned in his report. Ueli explained that a member of the Swiss OI society had died as a result of a problem related to anaesthesia during operation. Ueli suggested that this could be an underestimated medical problem connected to OI. He was asked to write a brief, more detailed report on the matter for OIFE. Rob told that the Dutch VOI has had a very difficult year but the main problem seems to be solved by now. The VOI has a new Board, which will try to continue the work. Due to these problems, the VOI can no longer take responsibility for the renewal of the Europas, as it had promised previously. Ute stated that the German society had among other topics focused especially on people with OI type I and adults. A special meeting had been arranged for the mildly affected with special problems such as pain and fatigue.

6. EXECUTIVE COMMITTEE

a. Training of president-elect

Ute has started her training to become the next president of OIFE in autumn 1999. In the meantime she has taken over the EDF-related matters this last summer. She asked the delegates to support and help her and said that in future all the delegates should get more involved.

b. Resignation of vice-president

According to the statutes, it was Patrick's turn to resign this year as vice-president. He thanked Rob and Ute and everybody for the trust and cooperation during the past four years.

(Re-) Election of vice-president

Patrick announced that he would stand for re-election. Rob supported his candidature, especially as OIFE cooperates with AOI on organising the Annecy conference. A vote was taken and Patrick was re-elected as vice-president unanimously.

c. New EC member

As Rob will resign next year, a new EC member is needed. No delegate volunteered for the post at this point, although several were suggested and asked. Finally everybody was asked to consider this matter and to come forward with suggestions as soon as possible.

7. FINANCE

a. Financial report

As the treasurer could not be present at the AGM, Rob represented Jean van den Boorn's financial report. A vote was taken to approve the report. The Board approved it with 8 votes in favour and 1 abstention. The Board thanked the treasurer and discharged him.

At this point Rob returned to item 1 on the agenda (Introduction of new Board member) and welcomed Marko Dzinic, the Croatian delegate, who had just joined the meeting.

b. Solidarity fund

Rob informed the delegates that one country had already given a donation to the solidarity fund (250 EURO) and another had promised a donation (170 EURO). Further donations were more than welcome. There were no applications for support from the fund.

c. Budget 2000 and 2001

Patrick told the delegates that France might get the Europas printed for free (in next year's budget a sum of 2.250 EURO is reserved for the revision). Rob announced that OIFE had received in 1999 a donation of about 2 200 EURO from the organizers of the 1996 Medical Conference. This was money left over from that Conference. He also said that the adaptation of the OIFE brochure was already accomplished and that the renewed version would be available soon. The brochure was printed for free again. Therefore, instead of a deficit of 150 EURO there actually is a surplus of 50 EURO in next year's budget, which could even become somewhat larger when the free printing of then Europas could be realised.

The board approved the budget proposal for 2001.

The treasurer had made two proposals:

First of all, according to Article 8.5 of the By-Laws, "the Board may install a financial control sub-committee to check the accounts and bookkeeping of the Federation". Jean van den Boorn had expressed the wish that 2-3 members of the Board formed this kind of sub-committee. A vote was taken on the matter. The vote resulted in 5 votes in favour and 5 abstentions. According to the By-Laws, since there were more than 30% abstentions, this required a new vote in which abstentions were not allowed. This time everyone voted in favour of the proposal. It was decided to set up a sub-

committee with two members. The accounts and bookkeeping will be checked just before the AGM and one member of the sub-committee will be replaced at each AGM. If necessary, the president will nominate the member(s). All agreed with this decision. Filip and Ueli were suggested as the first two sub-committee members. A vote was taken, and all were in favour of their election.

Secondly, as the financial report has to be made in the beginning of the year, the treasurer hoped that he could send the report to the delegates right away as soon as it was made. The report would still have to be formally approved at the AGM. This was agreed on. The delegates were reminded to bring the report with them to the AGM.

7d. Had to be postponed

11. INFORMAL DISCUSSIONS

After dinner, the meeting continued from item 11 on the agenda: informal discussions. Ute chaired this section. She divided the delegates and guests into small groups of 3-4 people. She asked each group to consider the following questions:

- 1) How is OIFE seen in your country?
- 2) What do you/does your society expect from OIFE?
- 3) What is necessary in order to achieve those goals?
- 4) What could you do?

After the discussions, each group presented their results.

7. d. Annual fee proposal

Ute reopened the meeting on Saturday morning. The EC proposed again not to change the annual fee. The Board agreed unanimously. Rob remarked that next time a fee raise might be unavoidable, as the fee had not been changed since OIFE's foundation. Patrick pointed out that Norway had some remarks about the matter as expressed in a letter from Rebecca Tvedt but this could not be discussed further as Rebecca was not present.

8. CONFERENCE GUIDELINES

The guidelines had been sent to the delegates in advance. Patrick was not happy with the wording of the proposal and offered to reformulate the text. As everyone agreed on the content it was agreed not to take a vote now, but to refine the text first without fundamental changes.

9. CHANGE OF BY-LAWS

The delegates discussed the wording of the change of Article 6.5 of the By-Laws. After a lengthy discussion, Patrick formulated the following: "In case of a written vote according to article 6.5 of the By-Laws, the quorum, defined as the number of votes received before the deadline, will be at least half the number of members eligible to vote."

A vote was taken immediately and the Board agreed on this wording unanimously. The deadline is defined in By-Laws as at least two weeks. Rob noted that if someone feels that the time was not long enough, he or she should react immediately.

10. ITEMS FOR DISCUSSION

Item 10 was skipped.

11. INFORMAL DISCUSSIONS

See above.

12. FUNDRAISING

See below.

13. GENERAL POLICY AND FUTURE PLANS

The Board felt that it needed to discuss OIFE's objectives once more. On the basis of the previous discussions, it had become clear that it has two alternatives on how to function in the future:

- 1) The first alternative is to function as a coordinating body creating links and promoting exchange. This is an achievable goal, which is already partly achieved. It does not require more money and "human resources".
- 2) The second alternative is a more ambitious one. The objective here is to make OIFE a more independent body, which promotes separate actions for the benefit of its members. This requires more money and resources.

Ute emphasized the fact that we need most of all more human resources. Rob pointed out that when OIFE was first founded, there was a need for a coordinating body. Now OIFE has developed and new ideas have been presented. OIFE has also become more important in the eyes of the "outside world". He stated that new Board members could not know what it was like in the beginning and Ute encouraged them to talk with their predecessors. Italy had last year presented an idea that OIFE could announce a special theme for each year (e.g. young people with OI). Many delegates stated that they would like to do more but they simply lack the time-resources.

Italy also made a concrete proposal on medical cooperation. They asked the other delegates to send them the names and addresses of doctors they would like to recommend as experts on the field of "bisphosphonates and OI". Italy is trying to arrange a meeting for these medical experts and also arrange funding. They would like to invite this group of experts to meet in Italy on May 5th 2001. Naturally, they would welcome support from other countries. The delegates were urged to send Simona Paveri the names of the experts in their own country as soon as possible (during the following week).

As a conclusion, the Board agreed that OIFE should concentrate on certain smaller objectives but put aside larger projects for the moment. It should continue its work as usual as a coordinating body promoting exchange. Of course, new ideas and resources would always be welcome.

14. FUTURE STRUCTURE OF EC AND BOARD

As already mentioned earlier, the EC will need a new member next year. Some names were proposed but all the proposed potential candidates refused the honour. Roz asked what the EC membership actually entails. She was told that the EC runs the daily affairs of the OIFE and that there are only two EC meetings a year. Finally, Ute promised to talk with people in private and inform the Board if some progress was made.

The next point to discuss was Rob's position in the future after his resignation. (While Rob "by chance" left the room for some minutes...) it was proposed that he should be appointed as "honorary president". He would continue, as an advisor with may be some honorary functions. A vote was taken and all were in favour of this proposal.

Rob stated that some of the tasks of the EC members should be delegated to other members of the Board. They would primarily be responsible for the task in question, not necessarily having to do everything themselves. First, there was the keeping and updating of the statistics. Filip agreed to be responsible for this task. Secondly, there was the updating the list of national boards and the list of medical advisors. Filip promised to take both of these lists, as well. The third task was to keep the list of all information material from various countries. Ueli promised to investigate if this could be taken up by Switzerland.

15. INFORMATION POLICY

a. Europas

As Rob had stated earlier, the VOI is no longer able to renew the Europas. France might be able to get it printed for free but there still have to be made some changes and additions. The English text will be drawn up first and each country must then check and revise it. Filip agreed to take responsibility for the renewal of the Europas.

b. Web site and e-mail access for delegates

As sending material by e-mail is so much easier and cheaper, every delegate should have e-mail-access as soon as possible. Those delegates who still do not have e-mail access were asked to look into the possibility of somehow getting one. Rob suggested acquiring a web domain for OIFE (oife.org). This would cost less than 100 EURO a year. A vote taken on the matter resulted in 9 votes in favour and 1 abstention.

d. New OI publications – list update

The delegates were asked to update the list of OI publications. Simona Paveri and Simona Rossi will try to find someone to take up this task of updating the list.

e. "Glasfit"-programme in English version

Ute asked the delegates interested in an English version of the German "Glasfit"-programme to write down their names on a list. The price will be 10-15 EURO per copy (plus postage). A Spanish version will follow. Martine offered to have a French translation done.

16. ITEMS TO VOTE

Item 16 was skipped.

A matter outside the agenda was briefly discussed, when Roz reported about the current situation in the UK between the BBS and the OIF UK. She explained that the basic disagreement between the two societies was on a notion of "positive discrimination", which entails that parents of OI children would have less power in an organisation than adult people with OI. After extensive negotiations to merge these two societies, the OIF UK decided not to merge with the BBS. At the moment, there is no official communication between them.

Afterwards, a talk was given by Sophie Beaumont, the European policy officer of the EDF. She told about the structure, principles and objectives of the EDF. She urged NGOs like OIFE to give EDF feedback, to exchange information about special needs of disabled people. She also promised to investigate why OIFE's application for funding from the special Rare Disorders program had been turned down.

17. INTERNATIONAL OI CONFERENCES

a. Conference in France in 2002 and OIF conference in Orlando

As the next scientific OI conference will be held in Annecy, France in 2002, a parallel conference for people with OI will be arranged at approximately the same time. The preliminary dates are 30 August – 2 September. The EC gives full support to France in organizing the conference. Patrick and Martine told the Board that there will be two separate conferences but they will partly overlap in time and there will hopefully be some programme exchange. The planned programme includes workshops and sessions on daily and social aspects of OI. The delegates were invited to send in suggestions for topics for the OI people's conference. France asked for everybody's support and input. The organizers are also planning a common boat trip for medical experts and people with OI. Patrick said that they are expecting maybe 100 French and 100 foreign participants. Rob suggested that it might be a good idea to extend the conference to Monday in order to have more overlapping time with the scientific conference. Italy suggested that OI people should make suggestions to the scientific conference for topics we think should be covered.

The Board was reminded of the next OIF conference to be held in Orlando, Florida, from 2 – 4 August 2002.

b. Norwegian withdrawal

At the previous AGM, Norway offered to organise an international OI conference in 2001 but has since withdrawn the offer.

c. South American plans

The Board was told that South American OI societies were planning their own conference but the plans are now postponed or rejected altogether. Felipe explained that most South American OI societies were relatively young and just starting to organise their activities. They are still struggling with many kind of problems.

18. NEXT AGM'S

a. AGM 9, 2001

AGM 9 will be held in UK, in Birmingham, from about 23 –26 August 2001

b. AGM 10, 2002, Annecy, France

AGM 10 will be arranged in connection with the OI conference.

c. AGM 11, 2003

Spain opted to arrange the AGM 11 in 2003.

12. FUNDRAISING

Everyone agreed on the fact that if we had more funds, we probably would not need so much human resources. The EC promised to look into the possibility of hiring a professional fundraiser. The Board supported the idea. Rob told the delegates that OIFE had applied for funds together with DEBRA Europe from the special EEC program on Rare Diseases but failed. Sophie Beaumont had promised to investigate the matter. Maybe it was possible to get funds if we combine our forces with organisations for other rare diseases.

19. SUMMARY OF DECISIONS AND APPOINTMENTS

As a summary, it was stated that the following decisions were made during the meeting:

- The delegates should inform Italy immediately about the names of specialists on bisphosphonates in their country

- Switzerland and Italy will investigate the possibility to take care of the information material list.
- OIFE needs a new EC member. Everyone should consider this personally.
- Exchange of information is utterly important. Therefore, every Board member should check that their newsletter is sent to all the other delegates. They should also remember to inform OIFE about important "news" and events in their country (e.g. meetings).
- The delegates should remember to update the lists of their MAB's, board members and information material, when necessary.

Only five countries had sent in their remarks on OIFE's future. Rob asked everyone to consider these letters. The discussion will continue.

20. A.O.C.B.

Italy said that Leonardo Panzeri had asked information about websites of the other countries. Felipe noted that a correction should be made to his fax number. He asked about the HOI. Rob explained that it is an organization founded to help and support those OI people who do not get any help otherwise. It was set up by a Dutch lady who has a farmhouse where OI people and families can go for a holiday, for example. Secondly, Felipe asked if anyone had more information about the Kennedy Centre in the USA. Rob told him that it is a private centre, which is specialised in OI. As to the previously presented suggestion to attend AGM's in other countries, Felipe stated that it is a good idea but, naturally, there are many practical problems related to the matter. The conclusion was that according to the individual possibilities, every society should invite all the delegates and try to offer at least a reduced conference fee.

Ute reminded once again about the European Day of Disabled People. She had distributed the delegate's information about The Bone and Joint Decade as well as Youth for Europe, a programme for youth exchange. She invited everyone to check the OIFE website and especially the EDF website. Finally, the Board members were reminded that each country should have 2 replacements named for their delegate.

21. CLOSING

The president thanked the Belgium OI society, especially Filip, for organising the AGM and closed the meeting.

Kati Wink took the minutes for this report.

Kati Wink
Espoo, 26 November 2000

Ute Wallentin, president-elect

Rob van Welzenis, president