

OSTEOGENESIS IMPERFECTA FEDERATION EUROPE

**Report on the sixth Annual General Meeting
25 – 27 September 1998, Vingsted Centret in Bredsten, Denmark**

Guests:

- Chiara Gorla, member of the Italian OI-Society
- Colin Wiggins and Julie Fernandez, boardmember of the UK OI-Foundation
- Moira Bisset, vice-chairperson of the British BBS-OI-Society
- Amparo Iborra Martin and José Felipe Mateos Diaz, representatives of the Spanish OI-Society
- Lidy van Welzenis, Dutch EMAB representative

Participating delegates:

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|-----------------------|--------------------------|----------------------------------|
| - Rob van Welzenis, | The Netherlands | president |
| - Ute Wallentin, | Germany | 1 st vice-president |
| - Patrick Dupuy, | France | 2 nd vice-president |
| - Simona Paveri, | Italy | |
| - Filip der Gruytere, | Belgium, Flemish Society | replacement for Jo Braet-Martens |
| - Kati Wink, | Finland | |
| - Birthe Holm, | Denmark | |
| - Per Tradnes, | Norway | |
| - Ueli Haenni, | Switzerland | (from point 5 of the agenda) |

**Osteogenesis Imperfecta Federation Europe
6th Board Meeting**

26-27 September 1998, Bredsten, Denmark

■ 1. OPENING AND WELCOME

The president opened the meeting and welcomed the delegates and all the guests. He excused Jean van den Boorn, the treasurer, who had had a fracture and still suffered from its consequences due to an infection. Rob then apologized the delegates from Croatia and Poland who had not been able to come because of the lack of funds. The Australian delegate Andrew Berry was still on his sabbatical leave in the US.

2. SETTLEMENT OF THE AGENDA

As the meeting had to be started late on Saturday evening, the president suggested some changes of the agenda, so that all items that needed more discussion or consideration could be treated on Sunday morning when everyone would be refreshed again. He then suggested to add a further topic to the agenda as point 10.: the question of a world wide OI-umbrella organisation that had come up recently. There were no further changes and everybody agreed to this idea.

3. ANNOUNCEMENTS

Rob referred to some informations he had laid out on a table., such as an invitation to an international symposium on genetics in India he had received during the year and kindly rejected because of the lack of financial resources.

4. REPORTS

Rob referred to the earlier mailed or distributed written reports of the EC, the treasurer and the delegates and gave some extra hints for the guests and delegates.

4.1 Report of the Executive Committee

The president read his report to the delegates and said that some of its issues would be taken up again later on the agenda (see report). Patrick specified that he had not really represented the OIFE at the EURORDIS meeting, but the French AOI, as only national but not european organisations can join EURORDIS.

4.2 Reports of the delegates

Rob suggested that all delegates who had not yet done so should now distribute their reports, those should be read until the next morning and questions could be asked then. Everybody agreed to this.

4.3 Reports of the EMAB

The president stated that only the Italian and the Dutch reports had been handed in yet and distributed earlier and asked the delegates to remind their national EMAB-representative of the report so that all of them could be sent to the OIFE delegates later. He then asked the present Dutch EMAB-representative Lidy van Welzenis if she wanted to add something to her report and Lidy declined but said that she just would answer any questions to it. There were none.

4.4 Report about the OIF conference in California

Several members of the Brittle Bone Society and the UK OI-Foundation had visited the OI-Conference in Long Beach, California in July and Rob asked Morna for a brief report. Morna referred to the written reports about the different courses and discussion groups she had handed out earlier and stated that they all had enjoyed the conference very much but had been surprised that the OIF was not further developed than most european OI-societies, as they had supposed earlier.

■ 5. OIFE-MEMBERSHIP

5.1 Membership Switzerland

Rob announced that the members of the Swiss Society ASOI/SVOI had finally decided to join the OIFE and that he particularly welcomed this decision. Ueli Haenni, the Swiss delegate, added that this decision was taken short after the visit of Rob at the Swiss AGM. His participation had given an more personnel aspect to the OIFE and that this had finally made the difference to the till then reluctant Swiss members.

The president stated that the Swiss Society had earlier handed in its statutes and their translation and thus proved that it fulfilled the OIFE's conditions. He suggested to let them begin the payment of their membership fee in 1999 and asked the delegates for their votes about the admission of the Swiss Society under this condition .As he got unanimous approval he welcomed Ueli Haenni as new delegate and invited him to take his seat at the table.

5.2 Membership Spain

The president then referred to a letter written by Maria José Pico Fernandez, the president of the Spanish Society, in which she applied for membership and named José Felipe Mateos Díaz as delegate. Rob said that due to the fact that he had just got the application and the Spanish Society had not yet handed in a translation of their statutes, they would principally have to wait until the next AGM, but that he would propose a „shortcut“ by the means of written votes as soon it was proved that their statutes met the requirements of the OIFE, what he took as granted. Everybody agreed wholeheartedly.

6. PRESIDENT ELECT

Rob passed on the chair to Ute as vice-president to discuss the question of the next possible president. Ute reminded the delegates that it had been agreed upon last year that a president-elect should be found within one year and that it had been only under this condition that Rob had been available for re-election until this AGM. She then asked the delegates for the result of their search but nobody replied.

Finally Morna spoke up and said that possibly the BBS would come up with a candidate for president-elect, but that Moira and she first had to talk again to the other board members at the end of October. Ute replied that although this sounded rather vague to her, it would be very welcome and she thanked Morna. She then reminded the delegates that this was a possibility but not yet a solution to the problem and that they should go on thinking hard about this question and remember that they all owed this to Rob after all he did for the OIFE.

7. EUROPEAN MEDICAL ADVISORY BOARD

The president took over the chair again and informed the Board that meanwhile 5 members (N, B, NL, I, and D) had officially named their representatives for the EMAB and that it had recently been established. Patrick stated that the French AOI had as well found a representative and would soon hand in his data and signature. Rob asked those who had no representative yet to name one as soon as possible. He repeated that the EMAB should care for the coordination throughout Europe and that the OIFE had a lot of questions to it, e.g. bioethics, the contents of the webpages and other things concerning the opinion about medical matters. But in case that there were other things to involve the EMAB in, every delegate should feel free to suggest them. Simona wanted to know why not every member society had named a representative.

Birthe answered that her board had decided not to name a Danish representative because they did not agree with the idea of the EMAB, as they feared that to them unknown physicians would thus interfere with the Danish Society's affairs. Rob pointed out again that this was absolutely not the idea of the EMAB that would never make decisions for individuals or national societies. It should be just a consultative body for the Board and mainly the EC of the OIFE in medical matters, but the OIFE itself and its members would stay independent from its advice.

The president then asked Birthe to talk again to her board and to explain those important facts to them once more.

Morna replied that the Medical Advisory Board of the BBS was just reconstructed and asked for some more time to name someone. Kati said that they had a lack of suitable candidates and Filip answered that the Flemish Society probably had found someone, but waited for the approval of the board in the next meeting in November.

Rob then asked the delagates to correct an error in the EMAB-list: in the e-mail address of Dr. Pontz from Germany (pontz@lrz.tu-muenchen.de) had to be a hyphen instead of a point before „muenchen“.

8. ORPHAN DRUGS

Patrick, who had attended a meeting of EURORDIS in Paris as representative of the French AOI, referred to his report about orphan drugs that had been mailed to the delgates earlier and gave a summary for the other participants and guests. He first explained that orphan drugs were such, in which the pharmaceutical industry was not interested and that the EU had just finalised the draft for a new law that shall encourage

pharmaceutical laboratories to develop drugs for rare disorders (see his report). He pointed out that these regulations had not yet been accepted but in case the European Commission agreed they could be working from the beginning of 1999. Most important to the OIFE was that as well Bisphosphonates could belong to the „orphan drugs“ when applied to patients with OI.

Ute added that now she would like to discuss the OIFE's attitude toward the EAGS in this connection because the EAGS would as well claim to represent patient groups on behalf of Orphan Drugs and had asked its members for a vote against or for a cooperation with EURORDIS. Ute said she was quite concerned about the policy of the EAGS that seemed to her somehow dishonest and hard to understand and Rob explained what he knew about some connections between EAGS and the new EDF-sector for rare disorders. He stated that the actual problems of the EAGS were quite obvious to many people and when Ute asked what she should answer the EAGS he suggested that the OIFE should send a clear statement to their board, telling them that the OIFE didn't want to be represented by the EAGS in this question and preferred EURORDIS instead.

9. PROPOSAL FOR EUROPEAN RESEARCH PROGRAM ON BISPHOSPHONATES

Rob explained that two years ago the Dutch medical community (the OI-group in Utrecht) had promised to set up a draft for the protocol of an European wide research program but that this draft was still not ready and that he had almost lost hope for it. Lidy remarked that she expected to get it before the end of 1999, but Rob was of the opinion that the EMAB should be asked for advice how to push this matter before it was too late. Almost every country had already set up a national study and there was no visible coordination in terms of methods, study population or used drugs. In such a rare disorder with a small group of patients it would be much more efficient to have at least an European cooperation. Lidy suggested to make at least an inventory about the yet existing or planned studies and to combine this list with the protocol.

Patrick asked the other delegates for their opinion and though some thought it was rather late for action the Board members agreed that Lidy should send e-mails to all the EMAB-members and ask for their advice and opinion.

The president added that although the OIFE was often asked for its opinion about bisphosphonates the position should be to collect as much unbiased information as possible but not to give any recommendations pro or against it. Asked for their opinion, all delegates agreed to this.

10. WORLD WIDE OI UMBRELLA ORGANISATION

Rob said that the OIFE had got signals that there were people who saw the need of such a world wide organisation and asked Colin Wiggins to explain this idea.

Colin replied that he had recently been approached by about 4 or 5 members from different national societies, one of them from Japan (the others he was not yet allowed to name), who had strongly supported this idea and that they intended to formulate a strategy for such an organisation. Asked for the causes for such a world wide organisation he mentioned e.g. financial support of OIers in poor countries, supply with equipment etc. He asked to be invited back later on to make a proper presentation of this idea.

The president asked all delegates for their reaction to this new idea and there was some discussion about cultural differences, human resources for this huge task, possibly lacking common issues that had to be found out and the possible aims of such an organisation, but the general consent was that it seemed to be an interesting idea and everybody was looking forward to Colin's next presentation of it though most had doubts in the possible realisation.

Before Rob closed the first part of the meeting, Patrick said he would like to give the Board something to think about until the pursuit of the meeting on the next morning.

His Society's board had a suggestion for a common action on behalf of all the national members: they would offer to take initiative to organise some sort of summer camp in France for European OI youngsters or exchange programmes for families. He asked all delegates for their feedback on this idea on Sunday morning and Rob closed this part of the meeting.

11. FINANCE

On Sunday morning Rob reopened the meeting and announced that Filip had fallen sick and could no longer attend the meeting because of his fever.

11.1 Financial report

Rob stated that due to the treasurer's accident he again had had to take over part of the financial report during the last months, but that Jean van den Boorn had started his new task successfully at the beginning of the year. The president then read and explained the figures of the report and concluded that the finance was sound in his opinion and asked for questions or comments. Finally Rob asked for the delegates' votes for the

profit and loss statement and the budget and got unanimous approval of the whole Board so that no written votes were needed.

11.2 Annual budget

After the president had asked for questions to the budget plan and there were no remarks, he stated that due to the falling phone costs in the Netherlands this part of the annual budget would probably go further down in future. He then reported that he had been invited by the Norwegian Society to the celebration of their 20th anniversary in March 1999, but that such travel costs were not on the budget. When asked for their votes to the profit and loss statement and the annual budget all the delegates approved unanimously, so that no written votes had to be taken.

11.3 Annual fee

Rob reminded the Board that this fee had to be reviewed this year but that the proposal of the EC was not to change the amount, but just to take EURO instead of ECU when necessary.

The Board again agreed unanimously.

After this Patrick said he would nevertheless suggest to raise the fee and when several delegates replied that a higher fee would be not tolerable for their boards (some societies take just minimal or no annual fee at all from their members) he suggested then to set up a different system so that each society would pay according to its capacity, some more, others less than at the moment.

This started some discussion until Rob proposed that the EC would talk to the treasurer and discuss this question again, then all delegates would get a detailed proposal in time before the next AGM and the subject would be put on the agenda again in 1999. So the EC would be able to look into technicalities and every delegate could discuss this issue with his or her board first.

11.4 Fund raising committee

As Birthe had offered at the last AGM to talk to her board and of possibly setting up a Danish fund raising committee, Rob now asked her for the outcome. She replied that they had found one Danish member who was willing to help, but who had no experience at all in fund raising outside Denmark and that he would need help by others.

Noone stepped forward to offer support and finally Ute stated that she was very disappointed with this common attitude inside the Board: quite often someone had a suggestion or an idea, an appointment was made to realise it until the next year or at least to further develop it and ... nothing really happened.

She added that the example of fund raising as it was common in the UK was certainly unaccustomed in Continental Europe, but that it seemed encouraging that such apply for funds was obviously possible.

The following discussion about the possibility and the emotional aspect of different fund raising methods through the appeal to pity or compassion for „suffering individuals“ in public showed again the big cultural differences between several European countries and there was consent about the difficulty to raise funds for an European association when it seemed almost impossible for the national ones.

Finally Rob suggested the following solution and all the delegates agreed to this appointment:

- before the end of the year every delegate will find out at least 5 possible addresses that could be applied to on behalf of funds for an OI organisation. He or she will either write to these addresses or at least send them to the EC
- the EC will write an example for a letter that could be used for fund raising and send it to all delegates in time
- fund raising shall be tried for the national societies, but every delegate should explain his or her attempts with the need to raise at least the amount for the annual fee to the OIFE and the travel costs to the AGMs to his or her board. In case someone would be very successful, at least a certain percentage of the thus achieved extra funds should be given to the OIFE.

Julie Fernandez of the UK OI Foundation gave some more hints for fund raising:

e.g. to ask companies in ones town for outdated computers and give them to OI-children, ask for support for OI group in local newspaper, enclose advertisements for shops, companies, ... in national newsletter etc.

11.5 TRAVEL FUND FOR MONTREAL 1999

When asked for his first results on behalf of a travel fund for an OIFE-delegation to Montreal, Patrick admitted that he had done no good job, because he had undertaken some efforts but without result. He intended to write some more letters to pharmaceutical companies.

Furthermore he had contacted Brussels for this matter, but their support would depend on a possible new law

that would not be accepted until the end of the year. Patrick promised to continue his efforts.

12. EUROPEAN DISABILITY FORUM

Rob first pointed out that the EDF still was in course of internal changes and that they had good proposals for redefining their structures:

12.1 Sector on Rare disorders

The president told the Board again that the OIFE had left the former sector and joined the one on Rare disorders that was coordinated by DEBRA EUROPE. The EC had put in a project together with Debra Europe because they had been told in advance that larger projects would be preferred, but in vain, the proposal was rejected because of the too large amount of money asked for. That's why no travel costs could be covered for this AGM. The EC would try to get informations about the true reasons for the denial of the project and start a new one as soon as possible.

12.2 STATEMENT ON BIOETHICS

Rob referred to the draft Ute had written as an answer to some questions of the EDF concerning a necessary bioethical convention to secure the human rights of disabled people and asked for the delegates' comments. After some misunderstandings about the intention of those questions had been explained, Patrick and some other delegates asked more to point out in the OIFE's reply that the OIFE wanted to promote genetic research for the benefit of all patients, but of course that the decision about the results had to be left to the patient.

Rob suggested to put a statement about this before the answers like a preambel and offered to send a copy of the final version to all delegates. The answer of the OIFE had to be in Brussels before the 30 September, so quick action was necessary.

13. INTERNET AND WWW, DEVELOPMENTS

The president stated the positiv aspects of the internet and e-mail-possibilities the OIFE meanwhile had and asked all delegates to send him their comments to the distributed draft for the basic webpage as soon as possible. As soon as he would have received further comments he would send the page to all delegates to be translated into the different languages (but the sense of the content should please not be changed). The detailed pages would be worked out later.

14. OI PUBLICATIONS

14.1 List of OI info per country

Rob announced that Ute was still gathering lists of available informations about OI in different languages and asked the delegates and the guests to keep her up to date on those lists and new publications. The cause of this collection were numerous questions to the OIFE about informations in different languages. Those questions would in future be transferred to Ute who would then answer them in cooperation with the national societies.

14.2 General information flyer

Ute presented the last draft of the OIFE-leaflet and asked for final comments. The main problem was the lack of a suitable picture for the front page (black and white, impression of obviously affected OI-adult with active, positive attitude). She asked for such a photo and Ueli promised to ask Monica Breuer and Carole Piquet in Switzerland while Patrick offered to contact Chantal Foloppe-Gatiné in France. The number of necessary copies was discussed and raised up to about 1000 copies.

15. AGM 7 IN ITALY

Simona invited the Board and the other participants to Milano/Italy on 7-9 May 1999 and promised to send out further informations and at least estimated costs before the end of the year.

16. AGM 8

Because of Filips absence Rob said that the Flemish board had invited the OIFE to Belgium in 2000 on the occasion of the Society's 15th anniversary and everyone agreed to this invitation.

17. AGM 9

The president suggested that by then perhaps Spain could organise the meeting and Felipe promised to talk to his board about that possibility.

18. A.O.C.B.

Felipe from Spain asked and was promised to be sent more informations about physiotherapy with OI patients and the written reports of the meeting (by Ute).

Patrick suggested to update the OI-Europass and asked who would be willing to do the work this time. The delegates will search for professionals among their members who could do that and in case noone is found, Colin Wiggins said he knew one of the British members, a designer, who could perhaps take over this task.

Morna will discuss this possibility with her Board and inform the EC about it.

Rob offered to try to find funding possibilities for the new reviewed OI-Pass.

Patrick then remarked that he was very disappointed, because noone had commented on his suggestion about a summercamp and asked for the delegates' opinions. Several delegates replied that they had thought and talked about this idea, but that they would suggest to invite whole families (thus the fear of the parents could be taken into consideration) and that OI-children should not be invited separately but together with not disabled children. Rob added that in summer 1999 a special campsite with facilities for handicapped people would be opened somewhere in France and that this could perhaps be used.

Ute said that to her repeated offers of similar projects to German members nobody had showed any interest so far and that she was quite sceptical about such projects now. Birthe pointed out that the Danish society organised summer camps for OI families now for several years and that she would ask her board if those camps could be opened to families from abroad in future.

Ueli finally asked to be given the possibility to ask some questions about their reports to the delegates and was offered the time after lunch for this reason.

Once more the committee of recommendation was mentioned and all the delegates asked to suggest possible candidates.

The president finally closed the meeting, thanked all participants for their co-operation and endurance and wished all a safe journey home.

The minutes for this report were taken by Ute Wallentin.

■. Ute Wallentin
Bamberg, 5 October 1998

Rob van Welzenis
Eindhoven, ... October 1998