

OSTEOGENESIS IMPERFECTA FEDERATION EUROPE

Report on the fourth Annual General Meeting
22 September 1996, Zeist, The Netherlands

Participating delegates:

- Rob van Welzenis, The Netherlands president
- Pierre Verhaeghe, France 1st vice-president
(until resignation)
- Patrick Dupuy, France 1st vice-president
(from election)
- Ute Wallentin, Germany 2nd vice-president
- Jos Swart The Netherlands treasurer
(from election)

- Simona Paveri, Italy
- Jo Breat-Martens, Belgium, Flemish OI Society
- Morna Wilson, Great-Britain
- Kati Wink, Finland
- Birthe Holm, Denmark
- Trond Garden, Norway (from acceptance as member of OIFE)
- David Sillence, Australia associate member

Guests:

- Lous van Egmont, secretary OIFE-Board, and her husband Eddy,
- Taco van Welzenis, vice-president organising committee "Life & OI",
- Maria-Jose Pico Fernandez, representative of the Spanish OI-Society,
- Gilberta da Silva, representative of the future Portuguese OI-Society,
- Simona Rossi and Ueli Haenni, representatives of the Swiss OI-Society,
- Philip and Sonja Marais, representatives of a future South-African OI-Society,
- Colleen Stevens, representative of the OI-Society of New Zealand,
- Birgitta Zakariasson and Rebecca Johansson, representatives Sweden,
- several members of the various European OI-Societies.



Some participants of the Life and OI conference that was held together with the AGM

1. OPENING AND WELCOME

The president opened the meeting and welcomed the delegates and all the guests, explaining them some particularities of the meeting. Then he gave a special welcome to David Sillence as replacement for the official Australian delegate, since Australia has meanwhile become associate member of the OIFE.

Rob then asked all participants to remember the former treasurer of the OIFE, Roeland Spoorenberg, who had died last year in a tragic accident. Rob had represented the OIFE at his burial and thus shared in the grief of family and friends.

2. SETTLEMENT OF THE AGENDA

Simona Paveri asked to shift point 9 on the Agenda from the afternoon to the morning, because the Italian delegation would have to leave after lunch. Everybody agreed, so point 9 was put after point 7 on the agenda. To save more time before the lunch-break, Rob suggested to shift point 4.3 (reports of the delegates) to the end of the meeting after point 16. Everybody agreed.

3. ANNOUNCEMENTS

3.1 Rob handed out updated versions of the statistics and the medical advisory board list. Pierre Verhaeghe asked to take Dr. Pierre Maroteaux, Paris, out of the French list, because he had retired recently. All the delegates were asked to send copies of the updated list to each medical advisor of their own country.

3.2 Then the president pointed out that the next meeting of the Helios sector in Brussels would be on the 31 October 1996 and that he intended to take part in it.

3.3 Kati Wink gave her new address (see list of delegates in the appendix).

4. REPORTS

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

4.1 Report of the Executive Committee

The president stated that the Board meeting was the least important activity of the EC and that there had been lots of important steps during the last year. The OIFE was now formally and legally established and new objectives should be found. But as the work-load had again increased immensely, more duties had to be delegated in future and the EC should at least have one extra meeting per year outside the Board meeting. Then he briefly mentioned the activities in detail (see report).

4.2 Financial report

Rob first stated that the final version of the financial report was still lacking. He explained that after the sudden death of the former treasurer he had to spend much time to find someone willing to take over and that during this time he had done all financial transactions through the bank.

When Jos Swart, the possible new treasurer, had been found, they both found out at a review of the books that Jos would have to set up a completely new bookkeeping. This task had not been accomplished yet and so the final version of the report would have to be distributed by mail and the delegates would then get enough time for their approval or

disapproval. The president then asked for the Board's approval to this procedure and got it unanimously.

5. MEMBERSHIP NORWAY

As announced to the delegates before, the Norwegian OI-society had applied for membership to the OIFE and named Trond Garden as delegate. So the president asked all the delegates, besides the Australian who has no voting right, for their approval, that was given immediately by everyone.

Rob welcomed Norway as new full member of the OIFE.

6. EXECUTIVE COMMITTEE

Treasurer:

The president first explained that for this position someone from outside the Board had to be asked because there had been no candidate inside the Board. Jos Swart, a member of the Dutch society VOI who had applied for the post of the treasurer, would therefore become a member of the Board without voting rights.

Asked for their votes, all the delegates agreed to Jos Swart as treasurer unanimously and Rob thanked him for his willingness to take over this position and installed Jos as treasurer.

Vice-President:

Pierre had announced in advance that he wanted to retire as French delegate and as 1st vice-president because of his many other duties in the French society and his demanding professional work. He said that he was very satisfied that many of his personal aims for the OIFE had been reached meanwhile and that he would not really leave the OIFE, but remain second delegate of his society. He thanked Patrick Dupuy for his acceptance to become new delegate of the AOI.

Rob pointed out that Pierre had served as vice-president from the very first meeting and had been active to set up the OIFE already long before this. He thanked him for all that he had done and for his many inspirations and said that most delegates might not be aware of the many tasks Pierre had taken over and accomplished.

The president then officially announced that the vice-president had retired and welcomed Patrick Dupuy as new French delegate. After the question, if a vice-president was needed had been answered positively, Rob asked for suggestions or candidates. When no suggestions were made, Patrick offered to candidate for this position and was immediately elected by all Board members with 1 abstention.

President and president-elect:

Rob said that it will be his turn to resign next year, but that he would possibly be available for re-election under the condition that a president-elect would be found within the next two years. This would make it easier to pass on presidency fluently. He stressed that after the next 4 years he would definitely retire. Then he asked all the Board members for their opinion to this suggestion. They agreed unanimously upon this procedure. David pointed out that the president's position was a very responsible and important one. Jos suggested to set up a profile for this position, which Morna offered to write in cooperation with the EC.

7. FINANCE

7.1 Annual budget:

Rob explained the balance sheets he had distributed. He said that mostly because of the late recompensation for travel and accomodation costs for meetings in Brussels it often occurred that the OIFE had to spend money that was only refunded months later, sometimes even in the following year, what makes bookkeeping quite complicated.

As to the financial plan, Rob pointed out once more that it was still provisional, but that the final paper would probably be not very different. He referred to the expenditures on representation that had been higher than expected and to the problem of the different currencies.

As it was very important for the EC to meet not just once a year at the AGM, Rob proposed to increase the amount for the "meeting costs", 200 ECU were not enough, because already travel costs were higher than that. Everybody agreed.

Rob explained again that it looked rather bad with subsidies on EEC-level because Helios II would end this year. Decisions on "social affairs" were blocked by the German government that pretended to be unable to decide upon this, because social affairs in Germany were under the responsibility of the "Lander" and not of the Federal government.

Answering David's question, Rob explained that the amount for AGM 1997 on the plan was just the estimated total for the travel costs.

7.2 Yearly fee:

Rob said that the EC proposed to leave the fee as it was at the moment (400 ECU). He referred to the rule that it is possible to pay a lower, but yearly increasing fee for three years for member-societies with smaller financial budget and that in two cases this time would run out next year. This could lead to the loss of full members, but on the other hand it would of course not be acceptable to have just some members pay for the others. Should the time of the 3 years be changed to 4 or more years or should the article in the by-laws be changed completely?

After a break the Italian delegate strictly demanded that we should keep to the rule that full members pay the whole fee. Rob suggested to keep the rules as they are, but to open the possibility for a member to apply for a subsidy from the OIFE for that part of the fee that they could not pay. Such a proposal would have to be done well in advance to the EC, which would than put it on the agenda of the next AGM for the Board to decide. He suggested to put this issue on the agenda for next year, so we could than take a vote upon it. This suggestion was accepted by all delegates except one.

7.3 Signing authority for treasurer:

Rob suggested to go up to the amount of 1000 Dutch Guilders (500 ECU). Everyone agreed. A second signature will be required for higher amounts.

7.4 Fund raising committee:

This question was a very important one, Rob said, as every Board meeting already costs about 5000 ECU and we really need a regular, independent source of money, but he had not had time for this unfortunately. He asked all delegates to put this question to their boards as well. Jos offerd to look into this matter as well and said he already had some ideas about it.

8. FUTURE OIFE-ACTIVITIES

The president first explained the "notes to the agenda" and the EC's proposals for future OIFE activities:

- Social questionnaire:

Rob recalled the history and said that we were stuck at the moment due to several facts. The Italian delegation proposed to stop this project because of the many difficulties, but Pierre remarked to keep in mind that similar ideas could occur later and that it could be important for discussions on European level to have common data for argumentation. It was decided to discontinue this project for the time being.

- Internet and www:

Rob pointed out how important internet access was for the OIFE. Pierre explained that whereas an own home page for the OIFE would cost about 800 ECU, it would be possible to put an OIFE-page into the internet-informations of the AOI without payment. He will give all details to Rob.

The president asked all delegates to try to get internet access and to give him their address, because this would be very helpful and less expensive than fax. David put in a remark that one should nevertheless be very careful with internet with respect to privacy.

- Other suggestions

When Rob asked for other suggestions, Simona presented an Italian proposal to set up an European Scientific Committee. The delegates from Denmark and Australia supported this and Rob asked all delegates to ask their national advisors to help set up this OIFE Medical Board soon, because the OIFE will certainly be asked more often in Brussels to comment on projects with medical or scientific issues in future. As everybody agreed to this plan, but as well to the doubt that this wouldn't be possible in a short time, Pierre suggested to start with some names of our choice. After some consideration, Rob finally suggested to choose some advisors with the help of David Sillence and the chairman of the Dutch medical advisory board, his wife Lidy. Everybody agreed. Rob asked for further suggestions from the national medical advisors.

9. INAUGURATION EURO-PASS

The president once more officially presented the new document and thanked Pierre and his team for the final important steps. Every delegate should suggest changes and improvements for the next version that would have to be produced in some years. Pierre then presented a CD-Rom with all the informations of the EuroPass, all logos and the pictures of all the meetings and gave it to Rob.

10. HELIOS II

As Rob told there will be no HELIOS III in the future, but there are possibilities that money for those activities supported by HELIOS II will be available. At least the AGMs of all societies should be supported. The next sector meeting will be on the 31 October 1996 and Rob will participate. He read the agenda of this meeting to the delegates and asked their opinion about the annual fee of about 100 ECU that will be demanded for the European Disability Forum. He protested in Brussels against this fee, but probably it will come nevertheless. The Board unanimously agreed that it would be useful to stay connected with Autisme Europe in the sector, even if a fee might be demanded.

11. AGM 5 IN GERMANY

Rob asked Ute to inform the Board about the plans for next year. She told date (29 May - 1. June 1997) and place of the meeting that will be held together with the German AGM. Two difficulties would be the accomodation of the delegates and the language problem, because about 250 German members will attend this meeting. As she said, informations about the situation in other European countries would be very important to their members and following Rob's suggestion she asked to send her the reports of the different societies' activities in advance, so that they could be translated into German.

12. AGM 6 IN DENMARK

Birthe told the delegates about the plans for their meeting that should be held close to the airport in Billund. According to her question it was said that the meeting should be organised at the end of september on a weekend, preferably together with a Danish OI-meeting.

13. AGM 7 IN 1999

Rob asked for suggestions for the place and date and it was noted that the date shouldn't interfere with the meeting in Montreal/Canada in September 1999, where the next scientific conference will be held.

14. COMMITTEE OF RECOMMENDATION

Rob said that more suggestions for this committee were needed. By now it only has 3 members. Responding to a question he once more told that no obligations were connected with this position, it just should be someone well known in his or her country or better worldwide, to show that the OIFE was supported by these personalities.

15. MEDICAL ADVISORY BOARDS

Rob asked all the delegates to copy the updated lists and to distribute them among ones own advisors.

Pierre officially announced that Dr. Maroteaux should be taken from the list, because he had retired recently.

16. EAGS

Ute distributed informations about the EAGS and thanked Taco van Welzenis who had represented the OIFE in the last years' meeting. She said that the EAGS tried to establish an own secretariat in Brussels, but Rob was of the opinion not to join them. We will stay in contact, but not take more action.

17. (former 4.3) ACTIVITIES OF THE COUNTRIES

Rob pointed out that the delegates have a very important function for the OIFE, because the support of the national societies was very essential. Then all the delegates commented on their written reports they had distributed earlier.

18. AOCB

Kati thanked Rob and the organising committee for all they had done to arrange such an interesting and successful meeting. Everybody agreed that the connection between both meetings had been very good for all participants, the medical conference had as well enjoyed the contact to our meeting and all partners were in favour of a repetition of this double-meeting in 1999 in Canada.

Rob asked all delegates to send all their national informations to one another and not to forget the English translation of the index. All dates of national meetings and events should be sent to Rob as well who will publish them on Internet.

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
Coburg, 5 October 1996

Rob van Welzenis
Eindhoven, 4 November 1996