



OSTEOGENESIS IMPERFECTA FEDERATION EUROPE

**Report on the third Annual General Meeting
28 - 31 april 1995, Tours, France**

Osteogenesis Imperfecta Federation Europe

3rd Board Meeting

28/31 april, Tours, France

1. OPENING AND WELCOME

The president opened the meeting and welcomed everyone, especially the guests, those who were present for the first time and Chantal Foloppe-Gatiné (présidente of the French OI Society). He asked the newcomers to introduce themselves and then read out apologies and greetings of some delegates and Marcella Zingales, Italy. He thanked the French society "AOI" and especially Chantal and Pierre for the invitation and organisation of the meeting.

Attention was drawn to the hand embroidered table cloth, with the logo of the OIFE and the signatures of those present at the founding meeting in Northampton. This cloth will cover the table at all subsequent OIFE meetings. The president asked Morna Wilson to convey the sincere thanks of the OIFE to Margaret Grant who has made the table cloth.

2. SETTLEMENT OF THE AGENDA

Rob suggested to continue the meeting on Sunday morning, so that there would be ample time for every topic. Everyone agreed. The president then proposed the following changes to the agenda:

- annual budget under point 4 -financial, so point 7 can be cancelled,
- relation to Non-Federation-societies after point 10, thus point 10a,
- Euro-pass under point 11, because of the financial problems with its realisation,
- Medical advisory board under point 3, so point 13 can be cancelled.
- Helios II-meeting, monday 2 may in Brussels, after point 14, thus point 14a.
- on the original agenda there were two points 15, but closing would be point 16.

The Board agreed.

3. ANNOUNCEMENTS

3.1 Rob handed out an updated version of OI-statistics and asked all participants for corrections and complements like those for the Walloon part of Belgium that he gave immediately. He offered to update the statistics for every AGM if he would be informed in time about changes in every society. Rob pointed out that according to these statistics the incidence of OI might probably be higher than assumed so far (at least 1:16000).

3.2 He also distributed an updated version of the medical advisory boards list (plus two new lists from Italy and Germany) and stressed again that these data were strictly confidential and had to be handled carefully. He asked every society to send one updated version to each medical advisor on the list in its own country.

3.3 Rob circulated a new list of delegates as well and asked again to name replacements for the delegates of Germany, Italy and Belgium.

Simona gave a correction to her address on the list.

4. REPORTS

The president referred to the written report of the EC, the treasurer and the delegates that had been distributed earlier and asked for questions or comments.

4.1 Report of Executive Committee

As there were no remarks, he reported about the anniversary meeting of the Flemish OI Society that Roeland and he had attended. He stated that his workload had increased tremendously due to the growing degree of popularity of the OIFE in the EEC and Europe and thanked Lous van Egmond for her help. Rob said he was not sure how long he would still be able to continue with this amount of work, he asked all delegates to start thinking about the next president of the EC, because he would

have to resign sometime.

Rob then asked the delegates for help in two important matters. First the EEC had asked for a case-description of some "typical OI-cases" that should be used to inform all Helios-members and the politicians about this disability (later on Karl Henn from the German society took charge of this task). Then Rob told that a detailed report about the seminar "Social Security" would have to be written for the EEC in view of the subsidy granted for this AGM. Ute Wallentin offered her help for this report.

4.2 Financial report and annual budget

Roeland Spoorenberg commented on the financial report and the budget for 1995 which the delegates had obtained earlier and he corrected one error in the balance-sheet. Then he asked for questions or remarks. As there were none, Rob asked for the Board's approval that was unanimously given by all members with one abstention. Referring to the annual budget, the president stated that there had been no difficulties the year before, so he suggested to continue in the same way. Only the administration costs would probably increase, he presumed. Again he asked for the Board's approval and got it from all members.

4.3 Reports of the delegates

The president asked for remarks or questions to the delegates about their reports:

Simona Paveri from Italy pointed out that they supported a research project about vitamin C and OI and asked all members to send her informations about similar studies or experiences in other countries. Taco promised to have a look into the OILIT literature database. Then she handed out a translation of the results of a questionnaire-research about psycho-social problems related to OI that had recently been done in Italy.

Rob asked Trond Gården for the names of the Norwegian medical professionals, to be added to the MAB lists.

As there were no further remarks, Rob asked Trond Gården and Christine Coppin to inform the meeting about their societies.

Christine Coppin from the recently-founded Walloon OI Society in Belgium said that this foundation had been necessary because of the language-problem in Belgium. Up to then the Walloon OI-population had not been represented in the (Flemish) OI-society of Belgium. Christine expressed her hope that her association would be able to prove its credibility and that there would be a union of both societies to some national association in future. Rob asked her to present the best wishes and encouragement of the OIFE to her friends in the Walloon board.

Trond Gården gave a short overview of the development of his society since 1979 and reported about the last 4 years of his presidency. Main effort had been to establish a special center for small groups of disabled, called the "TRS-project". Rob asked him to give a separate report about this project at the end of the meeting and pointed out that the Norwegian society was very efficient because almost 90% of Norwegian people with OI were members of their Society.

5. SOCIAL SECURITY FOR OI-PEOPLE IN EUROPE AND PSYCHO-SOCIAL QUESTIONNAIRE

Pierre Verhaeghe reported that Marcella Zingales had suggested an inquiry about psycho-social problems of OI-people for whole Europe (re.:4.3). He had then prepared a questionnaire and asked Rob for his opinion. Rob had considered it important to have clear objectives and a good reason to present to the European members for such an inquiry because there had been several questionnaires before and the people should not be bothered too much by them.

Moreover he had proposed to discuss the questionnaire and its realisation in the OIFE-Board first to come to a common point of view. Pierre, who didn't want to wait so long, had decided to spread his questionnaire among the French members this year.

After some discussion, most of the delegates showed their interest in such an European inquiry but

shared Rob's opinion that such a questionnaire had to be well prepared. Rob asked them to bear in mind that this would mean a lot of work, but Simona said that an Italian doctor had offered to collect the European data and to do the evaluation.

The Board finally agreed to wait for the results in France and take advantage of their experiences to improve the questionnaire and to plan such an European inquiry in 2 or 3 years.

6. DISCHARGE AND (RE-)ELECTION OF THE FIRST VICE-PRESIDENT

According to the schedule for discharge of the EC, Pierre should retire at this meeting. He answered to Rob's question that he was available for re-election, however. Of course he would have no objections if someone else should stand for this position, he added.

As there was no other member willing to become 1st vice-president, Pierre was unanimously re-elected with 5 votes and 1 abstention.

Looking forward to next year, when the president will stand for (re-)election, Rob reminded the Board that he would not be automatically available for ever. He suggested to introduce a system of "president-elect" to be able to pass on presidency fluently.

7. ANNUAL BUDGET, cancelled, see 4.

8. AGM 4

As the next AGM will take place in the Netherlands during the 3rd European Conference on OI, Rob asked Taco van Welzenis as vice-president of the organising committee to present its programme. Taco handed out a booklet with informations and the provisional programme of this conference "Life and OI" and said that there would be a preference to non-Dutch participants in case of too many inscriptions.

As the approximate costs would be quite high, they would try to establish a special fund for participants. The president asked for the delegates' approval to the provisional programme and got it unanimously as the delegates were impressed by the extensive, interesting programme.

Rob referred to the 6th International Scientific Conference that would take place there at the same time and said that its organising committee had asked for sponsoring by the national OI-societies. He reminded the delegates to think of the "Life and OI"-conference as well and reported that the Italian society would sponsor both conferences and the Dutch VOI was considering at least the "Life and OI"-conference or perhaps both. Every delegate should ask for a decision of his national board and report it to Rob as soon as possible.

As English will be conference-language, Pierre reminded of the language-problem for French participants and Taco pointed out that they were well aware of this problem and would do their utmost to provide some solution. Nevertheless basic knowledge of English would be helpful, he said.

9. AGM 5

The German society offered to organise the 5th AGM in 1997, but in combination with a smaller meeting in Germany and not with the national AGM because of organisational difficulties. The Board gratefully accepted this offer.

Ute asked for proposals for the date or at least the time of year of this AGM. Pierre repeated his suggestion that he would collect the data of all national meetings, AGMs or conferences and said that the possible date of the 5th AGM should be set up after he would have received the data for 1997 from all delegates.

Rob mentioned that it might become more difficult to get subsidies for AGM5 after the conference in 1996, because the Helios-II-programme would run out and nobody knew how Helios III would be, if there would be a Helios III at all. But he promised the ECs help for the preparation of AGM 5.

10. AGM 6

Rob suggested to ask Birthe Holm if the 6th AGM could take place in Denmark. Everyone agreed.

Pierre asked Trond to discuss the possibility to combine this AGM with the Scandinavian OI-Norden meeting with the other Scandinavian societies.

10a. NON-FEDERATION-SOCIETIES

The president put up the question of the limit of services to societies that do not (yet) belong to the OIFE such as those from Switzerland, Sweden, Norway, Greece, Walloon part of Belgium, Portugal or Spain.

The members of the Swiss society have not yet decided whether to join the OIFE or not, in Norway this question will be discussed again after Trond Gården's return.

With regard to prospective new members that might not be able to pay the full yearly fee, Rob explained again the contents of article 3.2.I.a. of our By-Laws. New full members may pay a lower fee that increases during 3 years up to the normal fee, but have a full vote right from the beginning. According to article 3.2.II any OI Society (also from outside Europe) can also become an observing member, with a fee to be agreed with the EC, but an observing member has no vote on the Board.

After some consideration the Board agreed that we should of course keep in contact with non-Federation-societies and they should get informations about relevant items, but not on internal matters like e.g. the MAB-list. Rob's suggestion to leave the practical decisions about these matters to the discretion of the EC was accepted by all delegates.

11. FUND RAISING COMMITTEE

With the example of the Europass Rob explained why such a committee could be so very important: the Europass preparations were complete, but as there was a lack of money (about 5000 ECU, according to Pierre) this project couldn't be brought to an end at the moment. (Karl Henn will try to find a less expensive possibility in Germany to have the Europass printed and distributed.)

Rob stated that the problem of funds would have to be solved and that the OIFE needed a permanent sponsor, because one AGM costs between 5000 to 6000 ECU.

12. COMMITTEE OF RECOMMENDATION

At the moment this committee consists of just 2 members from Germany and the Netherlands and so Rob asked for further proposals.

He presented a written proposal from the Flemish OI-society: Jean-Marie Pfaff, the former national goalkeeper of Belgium, was available. He is a well-known person not only in Belgium. He asked for approval and explained again the character of this committee and the assumptions for its members. He got the approval of the whole Board.

The Italian delegation brought forward another suggestion: a famous Italian cyclist had accepted to stand for the COR. As this proposal did not meet the formal requirements the Board could not make a decision. Rob explained again the procedures for a proposal: it should be in written form, explaining why this candidate was proposed, including a brief c.v., so the members of the Board could get an idea who they were dealing with. It could be sent to the EC at any time. Depending on the date of the next AGM, the EC would decide whether to put it on the agenda or to take a written vote.

He asked Simona to send her proposal to him as soon as possible.

13. MEDICAL ADVISORY BOARDS, cancelled, see 3.

14. EAGS-MEETING IN BERLIN

Rob announced that the OIFE was now member of the EAGS (without paying the fee at the moment) and so an OIFE-representative could participate in the 5th Anniversary Meeting in Berlin from May 24-28 1995. The EAGS had sent a fax holding out the promise to pay for the participation of this delegate.

The programme of this meeting was discussed, especially the possible intentions behind the "World Alliance for the Prevention of Birth Defects". Rob made clear that the OIFE certainly didn't want to

cooperate with any organisation who intends to "prevent" birth defects or life in itself by means of abortion or other death-bringing methods. It would be very important to find out more about this organisation's intentions.

When the German delegation doubted that perhaps the EAGS might have similar objectives, Rob said that the OIFE should then give them a distinct signal that she didn't support this and that the OIFE could always easily leave the EAGS, if necessary.

From this the question arose, if the EAGS would really care for the OIFE'S opinion and participation. After some consideration this question was answered with "probably yes", because the EAGS has mostly British members and just 2 from the continent.

Finally it was decided that at least one representative of the OIFE should take part in the EAGS-meeting in Berlin, if the EAGS would really pay the major costs. Possibly a member of the German association, living in Berlin, could be present as well. Rob suggested to leave the final decision to the EC and to let the EC prepare a clear mandate for this OIFE-delegation stating:

- the OIFE will not take any official position in the EAGS or spend much money on it
- we reject all forms of participation in the "Prevention of birth defects".

He asked the delegates for a vote about this proposal and got unanimous approval.

Taco said he would be interested to be the OIFE delegate to the Berlin meeting if necessary and his offer was gratefully accepted.

14a. EEC-MEETING OF HELIOS II-SECTOR

Rob reported about this meeting that he would attend on behalf of the OIFE next tuesday and about its agenda that every delegate had got earlier.

Two points he regarded as very important:

- the case description from the different groups; Rob thanked the German Association for the offer to prepare the case descriptions about OI and
- the financing of the secretariat of the "All party disablement group"; he suggested to help a little in the financing, but to demand an actual list of names and addresses of parliamentarians who would stand up for the interests of disabled people.

All delegates agreed to this.

15. ANY OTHER COMPETENT BUSINESS

15.1 Rob presented several letters, one from South Africa to his wife, the others from Russia to the president of the OIFE, where people with OI asked for help and wanted to join the OIFE. He told that his wife had answered to the letter from South Africa by giving the address of the OI-society there, although it was not sure if it still existed. No delegate knew more about it.

He then asked what to do with letters from eastern Europe. Several delegates had got such letters to their boards and reported about their experiences that it was very difficult or impossible to help because of lack of money and because of the difficulties to send informations or even goods (e.g. wheelchairs) to Russia or its neighbours.

Rob's proposal to treat these people just like the non-Federation-societies, i.e. to give advice, encouragement, and information was accepted unanimously. It will also be made clear that the OIFE regrettably is not in a position to give financial support.

15.2 Rob reported about the planned edition of an EEC-newsletter and suggested to try to have all delegates put on the circulation list, so that the OIFE could as well use this newsletter for its purposes.

15.3 He then spoke about the language problem that wasn't sufficiently solved, even in the EEC. He suggested to take up this point again in Brussels.

15.4 As if to show that language difficulties should never be a real obstacle, Rob asked the guests from

Spain to describe their situation, which they did in Spanish with translation by Pierre. Maria-José reported about their first assembly in January with 200 participants (who had been informed and invited by TV) and described the situation for people with OI in Spain as very difficult, due to the lack of information (even among doctors, doesn't this sound familiar?) and the still poor social security system. In Spain rehabilitation shortly after fractures is not available for most people, many can't afford to buy wheelchairs, so children often can't even attend school. Fortunately the active members of the new-founded Spanish OI Society (AHUCE=Asociation HUESOS de Cristal Espana) already found several sponsors. They asked for concrete objectives to spend these funds and for suggestions for their further work. All delegates offered to support the Spanish efforts and gave hints concerning their first steps, such as information to health institutions about OI, public relations, counselling and advice for affected people or families and medical staff. It was suggested that Spain also constitutes a medical advisory board. Rob pointed out that, as Spain belongs to the EEC, the people there had and should demand the same rights as everywhere else in the EEC and he offered our help and support in Brussels, if necessary.

15.5 Trond Gården was then asked to present the "TRS-project" in which the Norwegian society is involved. He gave out a leaflet and stressed that this center was mainly managed by patients, although the project was mainly paid for by the government and that the TRS-center didn't take responsibility away from the local authorities, but just added special help and offered extra courses and a special programme for all interested citizens. The TRS is one of 3 projects in Norway for "low frequency diagnostic groups" like the OI-Society.

At the end of the meeting each delegate was asked for final remarks and the round showed unanimous satisfaction with the meeting and its results. Pierre stressed the importance of the co-operation and asked for tolerance on behalf of different points of view. Trond said that he would again bring up the question of joining the OIFE in his board and Simona pointed out the major interest of her society in scientific projects.

16. CLOSING

Finally Rob closed the 3rd Board meeting, he thanked everyone for the co-operation and endurance, expressed his hope to continue in the same way and wished everyone a safe journey home.

The minutes for this report were taken by Ute Wallentin.

Ute Wallentin
Coburg, 1 June 1995

Rob van Welzenis
Eindhoven,

Guests:

- **Lous van Egmond, secretary OIFE-Board.**
- **Taco van Welzenis, vice-president organising committee "Life and OI" conference 1996.**
- **Trond Gården, president of the Norwegian OI Society.**
- **Karl Henn, president of the German OI Society.**
- **Christine Coppin, president of the Walloon OI Society, Belgium.**
- **Chantal Foloppe-Gatine, présidente of the French OI Society (part of the meeting).**
- **Maria Jose Pico Fernandez and José Maria Acosta Vera, representatives of the newly founded Spanish OI Society (part of meeting).**
- **Laura en Giovanni Giacometti, Italy**

Apologies:

- **Birthe Holm, delegate Danish OI Society.**
- **Jo Breat-Martens, delegate Flemish OI Society, Belgium.**

Participating delegates:

- | | | |
|------------------------------|------------------------|---------------------------------------|
| - Rob van Welzenis, | The Netherlands | president. |
| - Dierre Verhaeghe, | France | 1st vice-president. |
| - Ute Wallentin, | Germany | 2nd vice-president. |
| - Simona Paveri, | Italy. | |
| - Morna Wilson, | Great Britain | |
| - Kati Wink, | Finland | |
| - Roeland Spoorenberg | | treasurer |

The OIFE delegates and some friends, from left to right:

José Accosta Vera (Spain), Giovanni Giacometti (Italy), Roeland Spoorenberg, treasurer (the Netherlands), Simona Paveri (Italy), Trond Gården (Norway), Laura Giacometti (Italy), Taco van Welzenis (the Netherlands), Morna Wilson (UK), Maria Pico Fernandez (Spain), Kati Wink (Finland), Rob van Welzenis, president (the Netherlands), Karl Henn (Germany), Pierre Verhaeghe, 1st vice president (France), Ute Wallentin, 2nd vice president (Germany), Martine Verhaeghe (France), Lous van Egmond, (the Netherlands).