



OSTEOGENESIS IMPERFECTA FEDERATION EUROPE

Report on the fifth Annual General Meeting
29 May 01 June 1997, Mauloff/Taunus, Germany

Guests:

- Filip de Gruytere, member of the Flemish OI-Society
- Chiara Gorla, member of the Italian OI-Society
- Simona Rossi and Ueli Haenni, representatives of the Swiss OI-Society
- Michal Daszkowski and Gabriel Zubowski, representatives of the Polish OI-Society
- Jonna Bang Mogensen, member of the Danish OI-Society
- several members of the German OI-Society

Participating delegates:

- | | | |
|---------------------|-----------------|--------------------------------|
| - Rob van Welzenis, | The Netherlands | president |
| - Patrick Dupuy, | France | 2 nd vice-president |
| - Ute Wallentin, | Germany | 1 st vice-president |
| - Simona Paveri, | Italy | |
| - Jo Braet-Martens, | Belgium, | Flemish OI Society |
| - Kati Wink, | Finland | |
| - Birthe Holm, | Denmark | |
| - Per Trapnes, | Norway | replacing Trond Gården |



Osteogenesis Imperfecta Federation Europe
5th Board Meeting
30 May 1997, Mauloff/Taunus, Germany

1. OPENING AND WELCOME

The president opened the meeting and welcomed the delegates and all the guests, especially the two delegates of the Polish OI-Society that he had just recently come across via the Internet. He excused the Australian delegate, transmitted Pierre Verhaeghes greetings and read a brief letter from Morna Wilson who apologized for her absence and explained that Jos Swart, the treasurer, had not been able to come, because he could find no personal assistant. Rob said that this was particularly regrettable because one of the OIFE's main objectives was that no one should ever be excluded because of his handicap.

2. SETTLEMENT OF THE AGENDA

When Rob had asked for changes of the agenda and nobody had such proposals, he stated that just the "provisional" could be crossed out on the agenda and one could continue.

3. ANNOUNCEMENTS

Rob handed out several informations, such as a new address list of the delegates. Kati Wink told that she had only mobile telephone and the other number should be deleted and her replacements telephone numbers were not correct, Birthe Holm said that the replacements of the Danish Society were no longer correct and Simona Paveri referred to a missing letter in the name of her town Introini. Patrick moved to 18 rue de Verdun in Toulouse, his new telephone number is +33.5.61.62.48.37.

The president asked to send him any corrections and to keep the OIFE informed about changes and events in the national societies.

As the reaction from the Scientific Conference after the meeting in the Netherlands had been so positive, Rob had tried to get in contact with the Canadian OI-Society to offer them advice in preparing the meeting in 1999 in Montreal, but it had been difficult to reach the president of this society. Just recently he had got in contact with her via e-mail. He suggested that it should be tried to send at least a European delegation to this next International Conference.

Rob then informed the delegates that the video of the Life and OI Conference was not yet ready, because there was so much material for it that had to be cut and put together, but that each delegate would receive a copy when it was finished.

Finally Rob referred to Christina from Greece who had been at the last meeting and informed the delegates of her recent return to Greece, although her treatment had not been finished. In the end there had been a lot of troubles with her.

Hinke Panjer, a member of the Dutch OI society, had established a special foundation Help for people with OI (HOI) in April 1997. This foundation intends to help individuals within Europe in cases where no other help is given. Rob suggested that the OIFE should become supporter of HOI, with a contribution for this year of ECU 50,=, and asked the delegates for their votes. All delegates agreed except one. Rob said that, as this issue had not been on the agenda, a written vote would follow during the next months so that all delegates could discuss this issue with their boards.

As a final announcement Rob suggested that in the afternoon the meeting should be interrupted for about two hours so that all delegates could attend a lecture about the treatment with biphosphonates. Everyone agreed.

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 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).

4.2 Financial report

Rob stated that as the financial report had not been distributed before the meeting, a written vote would have to be taken again if there was no unanimous consent about it. Then he thanked the absent

treasurer Jos Swart, who had done a tremendous job and would not be easy to replace from next year on. The president then read and explained the figures of the report and told the delegates that as Helios II had not been replaced by a new program, the OIFE would get no money from the EEC at all this year. The authorities in Brussels still wait for the evaluation of Helios II and Rob had had no chance to put in a request for a subsidy, because the guidelines for this subsidy had come very late and the deadline had been so very short after this date that it had been utterly impossible for him to react in time. He said that he would protest against this procedure as well as against some demands and conditions of the guidelines, but that at the same time he would suggest to fund a project for interconnection of all delegates via internet, because communication was one of the main objectives of the EEC in Brussels. Secondly, Hh would refer to the program and tell them that the NGOs could be the needed control mechanism by the delegates reports about the way new rules were put into reality in the various countries. Rob added that even the future of the disability intergroup in Brussels was insecure.

After reading all the figures Rob asked for questions or comments. Patrick asked for the money for the HOI and was told that this had gone directly there. As, in his opinion, the finance was generally sound 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.

Ute Wallentin asked Rob to transfer the thanks of the Board to Jos for his excellent work.

4.3 Reports of the delegates

Rob asked the delegates if they wanted to read and discuss the distributed reports right now or later and it was decided to do it later during the next days of the meeting so that possible questions or remarks could be discussed. Those delegates who had not brought their reports were asked to send them the delegates themselves as soon as possible.

The president then invited the representatives of the (quite young) Polish society to present their society now. Gabriel did so, after having asked to replace the word company in their report by circle. Some delegates commented on the structure of the Polish association that has just people with OI as full members and no parents, but Michal and Gabriel pointed out that this was no problem in Poland, because their members just shifted on from the family-association 'National help circle for children with OI' that had existed for many years already. There was good contact and cooperation between both organisations.

5. EXECUTIVE COMMITTEE

Treasurer:

Rob referred to the letter Jos had written earlier in this year. It said that Jos would have to resign at the end of the year because of his professional situation that will demand much more time in future. Although this causes again a difficulty and he regretted Jos's decision, Rob pointed out that this showed again that someone with OI could be very successful in his job and that all should be proud of him. As again no one from inside the Board wanted to take over, someone from outside the Board would have to be found. He asked for possible candidates. Simona Paveri and Per Trapnes promised to ask their national treasurers and to inform Rob as soon as possible.

Profile for president:

Rob reported that Morna Wilson who had offered to write a profile and even contacted him some weeks before this AGM promising again to send it in time had not done so. This was particularly regrettable because this profile had been one of his conditions to stand for re-election at this meeting.

President-elect:

Rob reminded the delegates that it had been agreed last year that a president-elect should be found and that it had been his second condition for being available for re-election at this AGM.

President:

As his term ended now Rob van Welzenis had to resign. There were no candidates for the presidency, and as no president-elect had been found or even suggested, Rob did not stand for re-election. Consequently, Rob passed on the chair to Ute as vice-president and took seat again at the end of the table as the Dutch delegate.

Ute took over and reacted to the shocked silence by proposing a short break of 15 minutes. When the meeting was continued after this interruption, Ute first thanked Rob van Welzenis for all he had done for the OIFE during the past five years and even before and apologized for the whole Board for not having been more active in the search for a president-elect. She pointed out that on the other hand nobody had known of the missing profile in time and so it was not quite clear to the other delegates how many and what kind of tasks were connected with the presidency. Various delegates made similar comments and some considerations of possible delegates were all rejected at once. Per had meanwhile tried to call his national board to ask for advice. Simona asked for the quantity of work in Brussels and said that Rob's resignation had come too surprisingly and suddenly and begged him to continue at least with his work related to Brussels. Rob answered that it would not be possible to split this task off from the responsibility of the president. Patrick asked Rob if he was available to continue at least for a certain time until a successor was found, if this would really be tried hard by all the Board-members. Rob said he first would like to hear the other delegates' reactions, so Ute asked everyone for a short statement. All agreed that it would be absolutely necessary to convince Rob to continue at least for a some time and asked him to do so. Birthe suggested to write profiles for all EC-members and to delegate more work to the other members of the EC.

Finally Ute asked Rob for his answer and he declared that under the condition that this time he would be taken serious and real efforts to find a president elect were made, he would continue for another period, he added that this need not be for the full four years. Rob apologized for the shock he had given the Board but said that he had regarded this as unavoidable to show how important the question of the next president was.

Ute then asked all delegates to vote on the re-election of Rob as president and he was re-elected unanimously with one abstention (The Netherlands). Rob took over the chair again and Ute thanked him for his acceptance of the presidency. Simona then asked for the next steps to be taken and Rob answered that he would invite a candidate for a weekend to Eindhoven to explain him or her everything and that of course he would take the president-elect to Brussels, although there were not many meetings at this time. Morna will be asked again to make the profile.

6. FINANCE

6.1 Annual budget:

Rob stated that this point had already been discussed together with the financial report.

6.2 Fund raising committee:

As nothing had been done with respect to this matter since the last meeting, Birthe offered to

discuss the possibility of setting up a fund raising committee for the OIFE in Denmark with her board. She promised to inform Rob about that until 1st September and Rob said that he had meanwhile collected lots of information about fund-raising that he would then make available to the committee in Denmark.

6.3 Travel fund for OIFE-delegation to Montreal:

Patrick offered to take care of this matter and set up a travel fund for the International Conference in 1999 in Montreal.

7. EUROPEAN MEDICAL ADVISORY BOARD (EMAB):

Rob informed the Board about the complexities in setting up such an advisory board and said that the draft for the EMAB and the Italian comment should be discussed during the meeting, but that no decision would be made so that every delegate could discuss it first with his or her national board within 3 months. Until the end of August comments and clear statements should be sent in as well as the nomination of the national delegate to the EMAB. In Autumn the EC would then finish the draft and send it to all delegates who should then vote by mail. As soon as there would be sufficient, that is four, positive votes, the EMAB could get started. The Board fully agreed with this procedure.

During the discussion of the draft it became clear that some phrases would have to be formulated anew to avoid misunderstandings and that the position towards such a board was very different in the various countries. In some no difficulties were to be expected like in N, DEN, I and the NL, in D it seemed difficult to find a candidate who would be willing to enter the EMAB and in countries like B or FIN the national MAB either didn't exist or was still quite inactive. When all points had been discussed Rob asked again if all was well understood and if all delegates would please send in the comments and necessary alterations within 3 months and all agreed to this appointment.

Rob finally reminded the delegates that it might be necessary to compromise on some details so that the EMAB could get started as soon as possible, otherwise this project would be delayed with endless discussions.

Then Rob reported that the American OIF had asked to get the list of the European medical advisors and that he had answered them that this first had to be discussed with the national MABs to secure the privacy of those physicians. So he asked the delegates to do this and write him if he could send the lists to the OIF, otherwise he would not do that.

8. INTERNET AND WWW:

Rob said that the OIFE now was on internet for some months and that he would soon set up an extra text that should be translated to the different languages by the delegates. He then asked the delegates for their national boards authorization to publish the addresses of the societies as well as those of the delegates on internet and to send him this authorization in writing. He asked as well to be informed of internet access of societies or delegates and to get dates of national events if they should be published. He promised to inform the Board as soon as possible about the reaction in Brussels to his proposal about internet communication for all delegates.

9. EUROPEAN DISABILITY FORUM (EDF):

The OIFE is one of the founding members as well of the new EDF as of its controlling board and pays a fee of 100 ECU for it.

10. OI-PUBLICATIONS:

- Medical Manual:

this was published by the American OIF and Rob showed his copy to the delegates.

- Manual how to handle an OI treator:

Rob suggested that someone, perhaps from a national society should write such a humorous manual.

- General information flyer:

the OIFE urgently needs an information leaflet, to inform interested people about itself. Ute offered to make a draft and to send it to Rob in the next months.

- Glasfit programm:

Ute showed the new program for physiotherapy published by the GOIB and told that translations in different languages were possible, if there were enough interested people.

11. ORPHAN DRUGS & EUROPEAN COALITION OF RARE DISORDERS:

Rob first explained that orphan drugs were those in which the pharmaceutical industry was not interested and that the OIFE had been asked to join a group that wants to promote making such drugs. Patrick offered to care for this question and to inform the Board about it, because he regarded it as important in case that some day a drug would be found to help OI-patients.

12. AGM 6 IN DENMARK:

Rob asked Birthe to inform the Board about the plans for next year. She told the date (25 - 27 September 1998) and place (Jutland, in the Vingstedcentret, not far from Billund airport) of the meeting that will most likely be combined with a meeting of OI Norden.

13. AGM 7 in 1999:

Rob asked for suggestions where this meeting could be held. Simona offered to have it in Italy and was asked to come up with date and place as soon as her board had decided upon it.

14. AGM 8 in 2000:

Rob asked the delegates for proposals at the next AGM.

15. COMMITTEE OF RECOMMENDATION

Rob said that more suggestions for this committee were needed. By now it only has 3 members. Answering a question he reiterated 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 personalities of this caliber. It was suggested to Patrick to contact the French Jazz-Pianist Petrucciani in this respect.

16. AOCB:

Rob asked all delegates to keep him informed about numbers of their societies to enable him to update the statistics, especially to inform him about the number of professional people involved in OI.

Ute informed the Board about the contact to the EAGS that had just been observatory during the last year, apart from one action in which the OIFE did not participate.

Simona asked what would happen to a member that did not pay the full fee with regard to the discussion on this issue at AGM4. She was told that luckily this situation did not exist at the moment, but if it occurred this member would lose its voting rights.

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

After the official closure the guests were given an opportunity to make comments. Ueli Haenni reported about the difficulties to convince the Swiss members of joining the OIFE and asked for advice. He was given some hints how to change their mind perhaps.

Michal and Gabriel thanked for the invitation to the meeting and said that the contact to the other societies was very precious for them and that they would keep in touch.

The minutes for this report were taken by Ute Wallentin.

Ute Wallentin
Bamberg, 10 June 1997

Rob van Welzenis
Eindhoven, 17 June 1997