



**OSTEOGENESIS IMPERFECTA FEDERATION EUROPE**

**Report on the second Annual General Meeting  
3 June - 5 June 1994, Merone, Italy**

# Osteogenesis Imperfecta Federation Europe

## 2nd Board Meeting

3 June 1994, Merone Italy

### 1. Opening and Welcome

The president, Rob van Welzenis, welcomed everyone especially the guests from Switzerland who had asked to be allowed as observers. He hoped they would report to their members in Switzerland, this they agreed to do.

He was also happy to have been able to invite Gilberta Couto e Silva from Portugal who has started the Portuguese Society. He explained that one of the aims of the Federation was to help to set up OI societies throughout Europe.

He also welcomed Birthe Holm as the official delegate from Denmark, who was present for the first time, and said he was happy to have Denmark join the Federation.

Rob thanked the Italian OI Society for all its efforts in organising our meeting and expressed thanks to TeleMonteCarlo for their generous donation of 4 free flights.

He reported that vice-president Ute Wallentin from Germany was unable to attend this meeting as it coincided with the German AGM, which is also their 10th Anniversary.

Finally he excused Belgium that could not send a delegate, because of financial problems.

### 2. Settlement of Agenda

Point 5 has to be removed from the agenda, because external EC members can never have voting rights according to the statutes.

Instead the Europass item of point 4 is now promoted to a new agenda point 5.

The president suggests to add a point 15a. EAGS, he points out that this item can only be added for discussion purposes. This matter will have to be discussed at individual board level so a postal ballot can be taken later in the year.

A telegram was sent to Germany to congratulate them on their 10th Anniversary.

### 3. Announcements

1) Last Tuesday 31/5/94 the OIFE was legally established in the Netherlands. Rob produced a copy of the original document in Dutch drawn up by a notary. Everyone got a copy of the unofficial English translation he had made.

A lot of research had been done and it turned out that Holland was the easiest country for the OIFE to be legally established.

There were no contradictions to the statutes agreed at Northampton. The Dutch text is the only legally valid one, but it refers to our Statutes and By-Laws in its article 16. A legal translation will cost 400 ECU's. It was agreed that there was no immediate need for such a translation. It was agreed that if a translation was ever needed, the OIFE will meet the costs. It was cheerfully noted that the legal fees were half of what had been anticipated. There are 2 copies of the official document and 4 copies that are not signed. The president will keep one copy and the vice-president the second.

It was noted that the OIFE was one of the first European federations to be legally established. The

EEC has requested a copy and arrangements have been made with notary to send copies of the statutes papers to all interested parties.

#### 4. Reports

The president asked the delegates to excuse himself and the treasurer for not being able to send their reports along with the agenda for this meeting.

##### 1) Report of Executive Committee

The president read the report of the Executive Committee as circulated among the 8 delegates present the evening before. There were no objections or remarks.

##### 2) Financial Report

It was noted that there were two decisions to be taken.

- Approval of the financial status
- Do we want a financial sub-committee to check the finances?

In answer to a question Roeland said that reporting is complicated because of all the different currencies. So he has chosen to present all numbers in ECU. He is using a program from Rob to convert currencies. An overview of all the details (bank account etc.) is available in Dutch guilders. Birthe Holm from Denmark states that in Denmark an audit of the accounts is required. Rob answers that an Accountant's report is not required by Dutch law, but that the statutes leave it to the Board how they want the finances checked. An accountant is expensive and must be paid by the Federation. The financial report was approved and it was decided that at this moment we do not need a financial sub-committee nor an accountant's report.

##### 3) countries

Rob asked Birthe Holm, Gilberta and Simonetta to introduce themselves first in their own language first then in English.

Birthe Holm said she is 45 years old and has a son called Michael (age 10) who has very severe brittle bones. Their daughter is married and unaffected. After Michael was born they heard of the Danish OI Society which was founded in 1982, and they joined. Birthe is now chairman and is getting more and more involved. Birthe said her background is in law education and that she is presently employed as a Regional Director for Customs and Tax.

Gilberta Couto e Silva is trying to set up the Portuguese Association helped by the French Association. Rob wished the Portuguese Association strength and success.

Simonetta is 37 and lives in Switzerland. She has been with her boyfriend for 4 years and they live in Bern. She works as a teacher in arts. Veli Haenni was born in 1955 in Bern. He went to medical school. He runs a clinic as a physician, the clinic started 2 years ago. He also drives a taxi for the disabled and that is how he got to know Simonetta.

Rob pointed out again the language problems. He said each person should be proud of their language and that English is merely the working language of the Federation. Translations would always be needed, so our meetings will take more time, that is a fact that we will have to live with. All the different languages and cultures are also one of the charms of Europe.



Next the delegates from the United Kingdom, the Netherlands, Denmark, France, Italy, and Finland read their reports. Rob read the report from Germany that Ute had send him.

#### Belgium

Rob read and translated a letter from the Belgian Association. They were worried that the positions in the Executive Committee would not always be filled. Rob feared that this could in fact be correct. He also pointed out that the Belgium Association had no medical advisory boards and said this was a very difficult thing to do in Belgium.

The Belgium Association also raised a point regarding the AGMs. The question was asked "Is it necessary to have an AGM as it could lead to financial problems". The Belgium Association had stated that the OIFE is less important than our own organisations. Rob pointed out that an AGM is legally required and it is a very good opportunity to meet others and he continued to say that the OIFE will never replace any of the other societies.

The other points raised by the Belgium Association were:

- (1). They suggested to de-couple the meeting (AGM) from the OI society meeting. Rob explained that this was defeating the purpose of meeting other OI sufferers. Also by combining the AGM with a meeting of a national society costs could be kept at a minimum. The Board agreed with these statements.
- (2). They stated that meetings were difficult to attend on working days. Rob suggested we could possibly hold meetings on Saturdays and Sundays.
- (3). There is also the problem of funding a delegate. The president stated that we will have to try to find sponsoring for these meetings and that the fact that we are now legally established may help.
- (4). They did not understand what was meant with the manifest (point 16).

Rob would reply to this letter.

Rob reminded the delegates that it had been agreed that all delegates would receive a copy of the journals from the other countries. He did receive copies of the Finnish and French newsletters, but not regularly from the other members. Pierre reported likewise.

#### Data sheets

Rob referred to the data sheets he had previously circulated to the Board members and pointed out why these numbers were needed. He explained that the EEC had asked the Federation for the numbers of sufferers represented at EEC level. It was clarified that the figures for Great Britain also included those in Ireland and it was stated that the frequently stated ratio of incidence of O.I. of 1:25.000 may well be wrong. Rob and Pierre both stated that it was difficult to have an accurate number as people don't always wish to become members.

#### 5. Europass

Pierre, spoke about the first document and the corrections etc. He said we have to decide on the draft. Do we want the logo in colour? He pointed out it should be a common document for all in Europe. There was a full discussion Rob said every country must be responsible for their own text. The present draft was taken from the Dutch texts.

Roeland and Rob said their telephone numbers would change next year october, it was suggested that the solution would be to list them as - before ..... after .....

It was agreed that national numbers, which are sometimes slightly different from the international numbers, should be used in the Europass.

It was noted that the Dutch OI Society wants to order 300 copies, but the VOI will wait until they have seen the final draft. The Dutch text had not been corrected in the present draft.

Pierre said the approximate cost will be 6 French francs and that the number of copies should be decided by the OIFE. He is also trying to get subsidy, and said the idea is to help other countries such as the Portugal.

Rob said the OIFE will need some Europass copies for its own purposes, like representation or to apply for grants. He also suggested to charge one price for Federation members but a different amount to non-members.

The following prices were agreed - 6 francs to members and 10 francs to non-members. If any subsidy becomes available the costs to OIFE members will be reduced.

Pierre stated that the total costs for printing, distributing etc. amount to 50,000 FF. Thus the real price of the Europass should be 33 FF, supposing 1500 copies.

Pierre says he will try to convince the French Association to guarantee a price of 6 francs, even if we do not find a subsidy but he had to put this to the board of the AOI and their treasurer may say no. Rob said the OIFE cannot carry the costs nor take the responsibility for a deficit.

Rob asked for a vote to be taken:

Do we want to produce the euro-passport and do we leave the French Association to take care of it, only if the cost remains at 6 FF. This was agreed, as well as to have the logo in colours.

Pierre said that at first round of information the response was 1500 - 1600 copies but that so far only 1125 copies had been actually ordered. Rob noted that there were still an extra 300 of the VOI in stock.

Rob asked for a vote to be taken: If the price difference between ordering 1500 and 2000 is not too large, can Pierre be given freedom to decide? This was decided.

It was also agreed that the Federation should pay for 30 copies.

Pierre suggested we do not print a large amount.

Lidy Welzenis said we should be able to have the passports available at the conference in 1996.

#### 6. Schedule for discharge of the Executive Committee members (by-laws art.5.4)

The president referred to the letter of 13th March 1994 accompanying the agenda that contained the proposal by the EC. This proposal was accepted.

Consequently Ute Wallentin will retire at this meeting, Pierre Verhaeghe at AGM3 in 1995, Roeland Spoorenberg at AGM4 in 1996 and Rob van Welzenis at AGM5 in 1997.

#### 7. Discharge and re-election of the 2nd vice-president (Ute Wallentin)

Rob referred to a letter from Ute and read an extract from her letter which stated that she would stand for re-election, but that she found it difficult to make a contribution. Rob pointed out we must take notice of her remarks and said that we have to take into account that Executive Committee members have their limitations. As there was no other member willing to stand for the position of 2nd vice-president it was unanimously agreed to re-elect Ute. The Board members expressed their sincere appreciation for all the work she had undertaken and Rob agreed to convey that message to her.



## 8. Annual budget (statutes art. 10.5)

Roeland referred to the Financial Report and Budget he had prepared. With regard to the membership fees it was noted 6 countries should pay 400 ECU's each plus 2 countries paying a joint total of 180 ECU's. Rob noted the latter contributions would have to be raised next year because each country must achieve 400 ECU's within 3 years. If any country is unable to do this a decision will have to be taken as to whether the country's financial contribution or practical contribution to the Federation is important.

Each country should pay its membership fee only on request by the Federation's treasurer, so he can clear it with declarations in the same currency.

Roeland pointed out that the legal fees were much less than budgeted.

The French and Italian representatives remarked that there was no balance between the income and expenditures, a fact that would be impossible to defend in their countries.

Rob suggested that an item "communication equipment" should be added to the budget at a cost of 1110 ECU's to make the balance. This was agreed.

It was suggested that a budget should be typed on OIFE paper and signed by the treasurer and president in order that it may be used for fund-raising etc. Roeland promised to take care of this.

## 9. Travel fund

The data for the travel fund were needed for future use to get some idea of the costs involved and to be able to make a reasonable decision on how to spend the 4 free plane tickets.

It turned out that each AGM costs approximately 5,000 ECU's.

The Executive Committee made the following decisions:

- (1) The treasurer's costs for attending this meeting would be paid by the OIFE, 2 of the 4 free tickets were used.
- (2) The other 2 tickets were used for the people who had to travel the furthest distance which were Finland and Great Britain.
- (3) Finland could not pay for all of their ticket therefore a grant of 200 ECU's was made. The same grant was offered to Belgium but they did not use it.

The Federation was thus left with a 400 ECU's return on 2 tickets and used the money to invite Gilberta from Portugal to attend.

The president asked if the Board approved of these decision. Everyone agreed.

Finland thanked the OIFE for the grant on the ticket, without this they would not have been able to attend.

Pierre asked if the OIFE needed to contact TeleMonteCarlo. Marcella said that this was not necessary as she had already thanked them.

Rob reminded everyone to try to get free tickets or sponsorship to allow them to attend an AGM.

## 10. Fund-raising committee

It was noted that the Executive Committee was working on this matter. Rob had received 400 names and addresses from the German Association. Rob said he had contacted some people in the Netherlands and had received a book from the USA giving details on international companies.

### 11. Committee of Recommendation (COR)

The president explained once more the function of the COR. At most 2 persons from each country who are either prominent in their own country or within Europe should be on this Committee. The person has to believe in the views of the Federation and should not be someone with extreme views or a political person.

He said that initially this list would be used for fund-raising and that the members of the COR could be asked to help to promote this goal but further they are not required to do anything. At the moment there is only one member of the COR nominated by the German OI Society.

### 12. Medical Advisory Boards

Rob referred to the list of medical advisory boards which he had previously circulated and urged everyone to check the list and where applicable add telephone numbers etc. He suggested that the OIFE should send a copy of the list to the chairmen of medical committees with a letter suggesting that contact should be as broad as possible. He also suggested to give the list to the organising committee of the medical conference.

Denmark would like to check with their medical advisory board first, before this information was published.

Rob said that everyone on the list should agree to its dissemination. Switzerland agreed to send details of their medical advisory board.

It was decided to complete the list and to send a copy to everyone on it.

On Saturday afternoon the Italian medical advisory board will have a meeting and that in particular Lidy and Pierre were invited. Marcella added that anyone who was interested was welcome to attend.

The bringing together of all medical advisory boards might eventually achieve a European medical advisory board. Lidy said that this would probably be helpful and she would suggest for instance, the dentist from the Netherlands contact the Italian and French dentists.

Rob suggested that in 1996 a meeting could be arranged for all medical advisory boards and asked if the Board thought it would be a good idea if this would be part of the main programme. Pierre said that it might be difficult to get the scientists to stay. Lidy agreed but suggested that a short session might be preferable and pointed out that contact of this kind has to grow. Marcella said that the Italian medical advisory board was already very enthusiastic. It was therefore agreed that something should be organised on this basis.

Pierre said that if anyone was aware of any work or research being undertaken it would be wise to send the details to Lidy as she is on the organising committee and also on the sub-committee for the scientific programme. Marcella said that she hoped that at the next congress an atmosphere could be created for the paediatrician to work together.

### 13. AGM 3

Pierre stated that the next AGM would be in France probably in conjunction with the French Association's 10th Anniversary on 29-30 April, 1995. He said that a definite decision would be taken at their next board meeting on 17th June. The aim of the French Association was to allow the maximum number of French people to attend. The meeting would probably be held at a centre in Limoges however it was noted that Limoges is not in the centre of France and would involve a flight to Paris



then a flight to Limoges <sup>1)</sup>. However Pierre stated that help is available at the airport. It was noted that 29-30 April caused no problem except to the Danish Association.

It was agreed that the 3rd AGM would be held in Limoges in conjunction with the French Association and that Pierre would send the definite date to Rob. It was agreed that Rob and Pierre would be responsible for the programme.

The deadline for applying for EEC subsidies is November 1<sup>st</sup> 1994. It was agreed that the decision of how to apply to the EEC would be referred to the Executive Committee.

Rob stated that he would write to the EEC to ask for grant guidelines which he will send to all delegates. He reminded delegates to send their suggestions to him on the subject.

#### 14. AGM 4

The chairman of the organising committee of the scientific conference, Lidy and Rob had been given the job of finding a common venue for the conference and the OI people meeting. It turned out that Woudschoten was the best place. The centre has been booked provisionally from 19-21 September 1996 for both meetings.

Pierre referred to Point 4 of the notes on the 5th international conference and suggested the common events could be combined opening-and-closing sessions or vice-versa representations. Pierre felt that this point might be difficult to organise and it might be impractical to have combined closings. He felt that representation at both sessions could take place.

The chairman of the organising committee had suggested a common barbecue.

Lidy said that it was probably not practical to have the VOI meeting and the international meeting on at the same time. Pierre said that the Board meeting (AGM) was likely to last 1 day and that many people would be required to go home on the Sunday.

It was suggested having the Board meeting on the Saturday and the VOI meeting on the Sunday although there were practical problems because the VOI Board had not decided on their programme.

Rob suggested a common opening on Thursday and felt it was impolite to ask the scientific meeting for speakers. He suggested that the first day should be for the OIFE business meeting and he did agree that it was not a good idea to combine the closing ceremonies. He suggested obtaining 3 at the maximum top scientist to give an overview only at the end of the conference. This would also be of interest to the VOI members. He suggested having an excursion on Friday for OI participants but not the scientists. He felt it was not practical to mix the scientists and the members. He suggested that on Sunday there could be something run for the VOI members. Pierre said that this could not be decided without consultation with the scientific and VOI board.

Rob said he did need the opinion of the Board, so he could negotiate with the other parties.

The president asked the Board to vote: whether they thought an OI European meeting of OI sufferers was a good idea. Pierre suggested that a questionnaire should be sent out asking members who would attend a European conference.

New Zealand and Australia already expressed a keen interest.

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<sup>1)</sup>In the meantime it has been decided to hold AGM3 in Tours instead of in Limoges, the dates are unchanged.



Morna said that she did not think it was such a good idea as the response to the meeting at Northampton was not good and there was likely to be a lot of financial problems. Birthe Holm said that they would also have financial problems and that probably be 4 or 5 members might attend. Marcella said that she could probably organise a concert for this purpose.

Summarizing the Board was of the opinion that organising a real OI conference was a good idea provided that funding was available.

Rob said that the next meeting should be organised differently to Northampton. There should only be 2 to 3 doctors maximum giving talks for lay people and to discuss certain subjects. Rob suggested that it might be a good idea to persuade individual country members to combine this meeting with a holiday with the Dutch OI Society members. Kati thought this was a good idea for members and said it was important to get some members to pay some of their expenses themselves. Rob agreed to discuss these matters with the VOI members.

Pierre asked for the subjects to be discussed - could they be in the form of workshops. The Board members were asked to talk to their own members about subjects for the AGM's.

Marcella asked Lidy how the subjects of the scientific congress were arranged this time. Lidy said that the subjects were changed. It was not only genetics and biochemistry, but also dentistry, orthopaedics, physical therapy and psycho-social problems. Marcella suggested that neurological problems should also be addressed and basilar impression and the problem of fatigue.

#### 15. AGM 5 in 1997

Germany has offered to host AGM5 and Ute had send a letter about it from which Rob read the following extract:

*"I asked Karl about the OIFE's AGM in 1997 and suggested to invite all the delegates to Germany. He agreed (and the rest of our Board will as well, I think) but for us it would be absolutely impossible to organise the OIFE meeting at the same time and place as the German AGM and meeting. We would have to choose an extra date, otherwise it wouldn't be possible. There is not enough space in Mauloff for our members and about 10-20 OIFE delegates and we wouldn't be able to organise and attend two meetings at the same time. .... We always have our German AGM either at Ascension day (till following Sunday) or a little later at "Corpus Christi". As far as I know our AGM 95 will be from 15 to 28 June 1995".*

Rob said it was not necessary to have a meeting in the same place but he did not want the OIFE to miss out on a meeting of the local society. It was agreed that Rob would talk to the German Association to find the best possible way for the Federation to meet the German members.

#### 15a. European Alliance of Genetic Support Groups

Rob referred Board members to the Press Release about the European Alliance of Genetic Support Groups (EAGS) and said that no decision could be taken on this as it had been added to the agenda. So we can only discuss the matter. Moreover Germany was not present and they have some problems with genetics in general and Ute had asked not to take a decision. He said that the EEC is making rules on genetics for example, rules on patenting genes. This may influence us having disadvantages or advantages on genetics. Rob said that the OIFE is too small to have any impact. The VSOP in the Netherlands (an national umbrella organisation for Parent/Patient organisations in the genetics field)

is leading the EAGS and that they have written a genetic code of conduct.

The EAGS will accept national umbrella- or European-wide organisations who deal with specific disorders and are very keen to have the OIFE. The membership fee would be 150 ECU. Pierre said that the Federation should pay the membership. Rob said that 2 decisions should be made:

- (1) the OIFE had to decide whether to join or not and
- (2) whether to pay membership or not as membership could be waived.

It was suggested that the Board members take the information home and discuss it with their individual boards. Rob said that he would confer with the German Association and he hoped that they would allow the President some discretion. A written vote would be asked in September.

#### 16. Manifest (Press release/Announcement)

Referring to the previously circulated press release/announcement Rob said that this was needed to publicise that the OIFE exist. Rob said that it should be written in English and translated into other languages. It was agreed that Ute and Rob should prepare a document to be send to the delegates and any suggestions for the concept should be sent to Rob.

Marcella distributed a video from TeleMonteCarlo and explained that the intro may be adapted for use in other countries.

Pierre said the Federation should contact Art Cable TV and also TV 5 which was a French/German channel. It was agreed that Pierre would send the address to Rob.

#### 17. Any Other Competent Business

Birthe Holm congratulated the As.It.OI on their 10th Anniversary and presented a gift to Marcella. Kati, on behalf of the Finnish Society also expressed congratulations to Marcella and the As.It.OI. The Swiss members, Veli and Simonetta, thanked the Federation for allowing them to attend the AGM.

#### 18. Closing

Rob closed the meeting and thanked Marcella and her committee for all the arrangements they had made in order to make this meeting so successful.

The notes for these proceedings were taken by Morna Wilson.

Eindhoven, 17 September 1994

R.G.van Welzenis, president



### Guests:

- Ueli Haenni & Simona Rossi, Switzerland
- Gilberta Couto e Silva, Portugal
- Lidy van Welzenis (part of the meeting)

### Apologies:

- Ute Wallentin, Germany vice-president
- representative, Belgium

### Participating delegates:

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|-----------------------|-----------------|----------------|
| - Pierre Verhaeghe,   | France          | vice-president |
| - Birthe Holm,        | Denmark         |                |
| - Rob van Welzenis,   | The Netherlands | president      |
| - Morna Wilson,       | Great Britain   |                |
| - Kati Wink,          | Finland         |                |
| - Marcella Zingales,  | Italy           |                |
| - Roeland Spoorenberg |                 | treasurer      |



From left to right:  
Roeland Spoorenberg (treasurer), Gilberta Couto e Silva (Portugal), Pierre Verhaeghe (France, vice-president), Morna Wilson (UK), Kati Wink (Finland), Birthe Holm (Denmark), Marcella Zingales (Italy), Rob van Welzenis (Netherlands, president).