OSTEOGENESIS IMPERFECTA FEDERATION EUROPE

Report on the first Annual General Meeting
30 september - 1 october 1993, Northampton, UK

Participating delegates:

- **Marianne Marty, Switzerland**
- **Pierre Verhaeghe, France**
- **Ute Wallentin, Germany**
- **Rob van Welzenis, The Netherlands**
- **Morna Wilson, Great Britain**
- **Kati Wink, Finland**
- **Marcella Zingales, Italy**

Guests:

- Margaret, Yvonne and David Grant, Colin Paterson, Great Britain
- Christian Wiedmer, Switzerland
- David Sillence, Australia
- Annemiek de Groot, Netherlands
- Francesca Zingales, Italy
- Roman S. Lorenc, Poland
- Monika Käck and Viola Larsson, Sweden

Apologies:

- Jean Mandeville, US
- Lily Driesen, Belgium
- Birthe Holm, Denmark
- Remke Hermans, Netherlands

Participants to AGM 1 of the OIFE
from left to right:
back row: Colin Paterson, Marcella Zingales, Christian Wiedmer, Unknown, Monica Käck, Pierre Verhaeghe, Rob van Welzenis, Morna Wilson. David Grant
front row: Ute Wallentin, Marianne Marty, Kati Wink, Viola Larsson, Annemiek de Groot, Roman S. Lorenc, Margaret Grant, Yvonne Grant.

A. REPORT AND DISCHARGE OF THE PROVISIONAL COMMITTEE
Chair: Rob G. van Welzenis

thursday 31 september

1. Opening and welcome
Rob van Welzenis opened the meeting, welcomed the delegates and guests present and asked everyone to introduce themselves to each other by mentioning their names and functions in the national societies.
He read a FAX from Jean Mandeville (of the American society OIF) who apologized for not coming and he read out apologies from Remke Hermans (NL), Lily Driesen (B) and Birthe Holm (DK).

He thanked Morna Wilson and the Brittle Bone Society (BBS) for their invitation and organization of the meeting.

2. Settlement of the agenda
The chairman asked for necessary changes of the agenda. No alterations were proposed.

3. Report of the Provisional Executive Committee
As president of the Provisional Executive Committee (PEC), Rob van Welzenis referred to his written report that he had distributed earlier and asked for questions or remarks. Apart from one question about juridical matters which was delayed to a later part of the meeting, everyone agreed to the report.

4. Financial report
Remke Hermans, the PEC's treasurer, who couldn't attend the meeting because of personal reasons, had prepared a written report for the delegates that was explained by Rob van Welzenis.
There were no further questions, all the members agreed to the report and the Dutch delegation was asked to transmit their thanks and best regards to Mrs.Hermans.

5. Discharge of the Provisional Executive Committee
Rob van Welzenis reported about the legal difficulties concerning the OIFE:
At the moment it was still impossible to establish an organization on an European level because there was no European law. So the OIFE would have to be established in one of the European countries, according to the their existing legal conditions. This could possibly involve small changes to the statutes.
Rob van Welzenis therefore suggested to set up and sign a "declaration of intent" and to assign to the EC the task of legally establishing the OIFE as soon as possible.
He read a draft for the declaration of intent to the members.

Ute Wallentin stated that the PEC had efficiently fulfilled its tasks and asked all the delegates for its discharge. Everyone agreed.

Rob van Welzenis stressed again that the PEC did no longer exist.

6. Election of the interregnum chairperson
Pierre Verhaeghe was nominated as interregnum chairperson, and accepted.
He thanked the former PEC for its hard and successful work.

B. DISCUSSION OF STATUTES AND BY-LAWS
Chair: Pierre Verhaeghe

thursday 31 september

Christian Wiedmer (treasurer of the Swiss Board) announced that the members of the Swiss society SVOI at their last GM had decided not to join the Federation at the moment mainly because of financial reasons.

1. Rob van Welzenis stated that already all suggested changes were in the present draft, except one: article 4.3 of the statutes which the Dutch Board had proposed. Therefore Annemiek de Groot was asked to explain this proposal.
She said that, in the opinion of the Dutch Board, not only 1 person should become the delegate of its national society, but that it should be possible to choose several people for the delegation of one society. Her Board thought that it would be better to lay the work and the responsibility of the delegation on more than one person.
This question was discussed and finally it was suggested not to change the statutes or by-laws but to keep to one delegate only and to emphasize in the OIFE that visitors were always welcome and that every delegate could be assisted by others and should name two substitutes, if possible.
Everyone agreed to this solution and to the present version of the statutes.

C. FIRST BUSINESS-MEETING OF THE BOARD OF THE OIFE
Chair: Pierre Verhaeghe / Rob van Welzenis

thursday 31 september

1. Installation of the Board
Pierre Verhaeghe named again the societies that intended to join the Federation as ordinary members and their delegates: Finland (Kati Wink), Germany (Ute Wallentin), Great Britain (Morna Wilson), Italy (Marcella Zingales), Netherlands (Rob van Welzenis), Denmark (Birthe Holm) and France (Pierre Verhaeghe).

Kati Wink stated that her society could not afford more than 80 ECUs as a unit fee and would therefore join the Federation as an observing member.

As the Danish delegate was not present, there were now just five delegates who were entitled to vote.

Rob van Welzenis reported that two societies, from Belgium and the US, had told him they intended to join the OIFE as observing members.

David Sillence, who represented the Australian society, said that they would probably join as an observing member, too.

2. Election of the Executive Committee (EC)
Pierre Verhaeghe asked for the nomination of the members of the EC. Pierre Verhaeghe asked if members would prefer a secret ballot or voting by show of hands. It was unanimously agreed a show of hands would be preferable. Pierre Verhaeghe nominated Rob van Welzenis for president and asked for further nominations.
There were no further nominations and Rob van Welzenis was elected with 4 votes and 1 abstention.
Rob van Welzenis agreed to accept the nomination.
Consequently Pierre Verhaeghe transferred the chairmanship of the Board meeting to Rob van Welzenis.

Now Rob van Welzenis nominated Pierre Verhaeghe as vice-president and asked him if he would accept the nomination. He agreed. There were no further nominations and Mr. Verhaeghe was elected unanimously.
The chairman stated that his question to the delegates for candidates for the Federation's treasurer had brought no result at all. He explained that the Federation would need someone for bookkeeping and for fund raising and stressed that the latter function didn't necessarily have to be the treasurer's task as well.
All the present delegates objected again to his request to become treasurer. The chairman stressed that the Federation must have a treasurer according to the Statutes that were just accepted. In order to find a solution Rob van Welzenis suggested to change the Statutes/By-Laws according to an earlier proposal of the BBS to discard the rule that the members of the EC had to be chosen from the Board. This would allow the EC to nominate another person if no candidate could be found within the Board. Pierre Verhaeghe added that of course the treasurer had to be in one of the member-societies. Marcella Zingales emphasized that this solution should be accepted because otherwise the formation of the OIFE would perhaps have to be delayed.
The chairman asked the Board to vote whether the statutes (7.1) and the by-laws (5.1)

should be changed accordingly. The delegates agreed again unanimously.

When still no candidate could be named, it was suggested to ask Remke Hermans if she would continue for a short time as interregnum treasurer, until another one had been found. Everybody agreed.
Rob van Welzenis stressed that Mrs. Hermans had earlier declared she would not accept this task for long and that she possibly would object now, but he agreed to ask her.
When asked if he would take charge of the treasury as well for the time being, Rob van Welzenis reluctantly agreed.

He asked all the delegates to discuss the question of the OIFE-treasurer and a fund raising committee with their national Boards as soon as possible. In particular the Dutch delegation was asked to look for one of their members willing to take on the task of a treasurer. The EC was mandated to appoint a suitable candidate.

The chairman suggested to elect a second vice-president instead of a secretary and nominated Ute Wallentin as candidate. As no one else was nominated, Miss Wallentin was elected with 4 votes and 1 abstention. She accepted on the proviso that she would probably resign after 1 or 2 years if she was unable to fulfill her tasks sufficiently, because of the lack of time.

Rob van Welzenis asked the Board if the EC should have further members than these, but no one thought this necessary.

3. Assignment for the EC
The chairman asked the members of the Board if they agreed for the EC to legally establish the OIFE. All agreed unanimously.

Rob van Welzenis suggested an alteration of the agenda, because firstly the question of the Federation's seat should be discussed:
The OIFE would have to be seated in one of the European Countries until a general European law would exist, he had enquired about the best possibility and got different answers by several lawyers.

As most favorable seats the countries Belgium, France, Netherlands and Great Britain had been proposed and Rob van Welzenis explained some details of the various conditions.
Finally he suggested to leave the final decision to the EC and asked the Board for its approval. This was immediately given by all delegates.

Rob van Welzenis added that his enquiries had brought the suggestion that the statutes should also contain the possibility to dissolve the Federation when the European law had been established. All delegates agreed to this suggestion.

4. Unit fee
Referring to the amount of the unit fee, Rob van Welzenis explained that the PEC had come to the conclusion that the OIFE would need a yearly total of at least 2.100 ECU. After some short considerations about this estimate and the actual number of ordinary members, the amount of 400 ECU was suggested as unit fee and unanimously accepted by the Board.

5. Proposal to pool the travel costs
The chairman explained his proposal to pool the delegates' travel costs in the next year. This would mean that an extra travel-fund would have to be established and that every delegate should first discuss this question with its national Board.
Pierre Verhaeghe suggested alternatively just to support delegates from a great distance countries with a lack of resources, but not to delay the discussion because it seemed to be very difficult. Everyone agreed.

6. Financial operations
Rob van Welzenis informed the Board members about the best way to minimize the costs for bank transfers: transfers to the OIFE should be made by sending Eurocheques to someone (e.g. the treasurer) personally and not to the Federation as payee because as an institution it would have to pay bank changes.
Pierre Verhaeghe added that cheques should never be made out in ECU, but in any currency, because for ECU-transactions fees would have to be paid twice. Rob van Welzenis asked then for proposals for the maximum amount that the treasurer would be allowed to sign for (referring to article 8.4 of the by-laws).
The delegates agreed upon an amount of 500 ECU, or its equivalent in other currencies.

7. Fund raising
The president suggested that fund-raising should be done by a sub-committee and asked everyone to look out for capable persons for this important task.
Rob van Welzenis then spoke of the Federation's next projects and stressed that the planning of such projects, such as conferences about certain subjects, would be one of the tasks of the EC and that suggestions were always very welcome.

8. Approval to the first member of the "committee of recommendation" (COR)
Rob van Welzenis asked permission to add one more point to the agenda. He then announced that at the present time only the German society had suggested one person, Dr. Alfred Biolek, for the COR and asked the German delegate to give a brief description of him.
Ute Wallentin told the members that Dr. Biolek was not a doctor but a popular German showmaster who regularly had talk shows on TV. She said he was interested in the matters of disabled people and that he had been the patron of the German O.I. society for several years. In this function he was really interested in helping people with O.I. and had immediately agreed to become member of the COR and to use his connections for the OIFE as much as possible.
Rob van Welzenis added that he had met Dr. A. Biolek at the German AGM. Everybody agreed to his nomination for the COR.

Pierre Verhaeghe advised to be careful with the nomination of COR-members and to always ask for sufficient information about suggested candidates.

9. Participation in the European Alliance of Hereditary Connective Tissue disorders (HCTD)
Rob van Welzenis informed the members about the character and the aims of this organization and asked for the experiences in the national societies concerning other HCTD-associations like e.g. the "Marfan"-societies. He also mentioned that cooperation with related organisations for other diseases on an European level could in general be beneficial to the OIFE.

Several delegates spoke about their contact with such groups, some societies had had similar experiences and had come to the same conclusion that the contact was interesting but that it was not beneficial to "mix" different diseases, such as O.I. and Marfan. David Sillence agreed and added that it would perhaps be more advisable to cooperate with Osteoporosis-societies.
The Board decided that at the present time the Federation should first try to get more detailed information on this Alliance before deciding whether to become a participant.

10. Place, date and venue of the next AGMs
Rob van Welzenis suggested that it would certainly be interesting and economic to have the next Annual General Meetings of the Board in connection with the AGMs of the different European O.I. societies or with similar occasions.

Referring to this suggestion, the following invitations were announced:
- AGM 1994: in Italy (northern part) in May or June, at the occasion of the 10th anniversary of the As.It.OI.(Marcella Zingales)
- AGM 1995: in France, where at the same time the 10th anniversary of the AOI will be celebrated and in Paris a big conference about "skeleton dysplesia" will be held (Pierre Verhaeghe)
- AGM 1996: in the Netherlands, where the 6th International Conference on O.I. will be held in that year (Rob van Welzenis).

Relating to this last announcement, Rob van Welzenis asked the Board, if the OIFE would support this conference in 1996 and obtained immediate approval from all members.

11. Questions before closing
Ute Wallentin asked all delegates to send all newsletters to the delegates personally, not to the address of their society.

Rob van Welzenis announced that a new O.I. society would soon be set up in Greece and that the OIFE would assist where necessary. Then he asked all societies to send informations of all kind to the lady in Greece who was setting up a society.
There are also contacts with Croatia, Poland and Portugal. Ute Wallentin added that a new society had been founded in Peru.

Finally, Rob van Welzenis read the final statement of the "Eurable conference" in Maastricht, the Netherlands to the members.

David Sillence asked if he could add an announcement and reported that his society would like to organise an International Meeting in Australia between 16 September and 4 October 2000. (This would be the time of the Olympics in Sidney.) Everyone was very excited about this possibility and Rob van Welzenis thanked the Australian OI-society for the invitation which would certainly be accepted if the problem of the high travel costs could be solved.

As there were no further issues to discuss, the chairman thanked all the participants and closed this part of the meeting.

Pierre Verhaeghe invited everyone to celebrate the inauguration of the OIFE with some French champagne.

D. PLANNING FOR THE FUTURE

Chair: Rob van Welzenis

friday 1 october

1. The chairman opened the last, open part of the meeting.

2. Announcements

For those participants who had not attended the Board's first business meeting yesterday, Rob van Welzenis announced that the OIFE had been founded, i.e. that a declaration of intent had been signed by six delegates and that the EC had been assigned the task of juridically establishing the Federation.

The chairman reported the dates of the next AGMs and the International Conference in the Netherlands.

He also reported about the international day of the disabled on 3 December and offered more written details about its aims.

Rob van Welzenis suggested some minor alterations to the agenda.

3. CBO-report

Rob van Welzenis presented a multidisciplinary report on O.I. in Dutch, called "CBO-report" and asked all the delegates to inform the Dutch society whether they were interested in an English version.

Several delegates spoke about similar reports their national societies had published in their own language (e.g. in Italy, France, Germany etc.).
It was emphasised again that all delegates should receive all published information of the other societies and be responsible themselves for necessary translations.

4. Travel in Europe

Following the chairman's request, Pierre Verhaeghe explained again his project "Travel in Europe", on which he had worked before. He suggested to publish an O.I.-pass in several languages for travelling O.I.-people.
He stressed that it would be important, not to translate basic information about O.I. into different languages, but to use original information under consideration of national aspects.
He asked the members for their opinion on this OIFE-project, everyone was very keen on this idea and it was agreed that one pass with about 10 languages would be better.
It was noted that several societies already had such a pass for their members, therefore it was decided to work on the international version in several languages. The pass would be published by the OIFE, printed in one of the countries (depending on the best price-offer) and ordered and paid for by the national societies.
Finally, Pierre asked the delegates to establish what quantity their society would order and to inform him as soon as possible.

5. Presentation of several national societies

Rob van Welzenis had beforehand asked every delegate to prepare a brief presentation of his or her society. These were given next (see appendix).

6. Developments in Europe
Rob van Welzenis reported on several initiatives of disabled people in Europe. First he spoke about efforts to stop violence against disabled people in Europe that had increased alarmingly.

He then explained that the "Helios I programme" had been a waste of money and the new "Helios II" seemed to be more efficient.
He emphasized that it would be important for the OIFE and its member-societies to be represented somehow in the Helios-Program, at least through one of the umbrella-organisations.
He explained that the Helios administration is advised by a forum consisting of 12 delegates from so-called NGOs (Non Governmental Organisation) and that it would be wise to try to get involved.

7. Scientific conferences on O.I.
The president emphasized the importance of such conferences, even when biochemical research and genetics were dominant and the clinical aspect was often neglected a little. He said that it was hoped that, as the next conference would be held in the Netherlands, it would perhaps be possible to influence the setting of focal points and the selection of subjects and that one could at least try to come to a multi-disciplinary approach. All the delegates showed a great interest in such an interdisciplinary conference with different aspects of O.I., including all methods of its treatment.

Rob van Welzenis therefore asked the delegates for written proposals from their national Boards to be sent to him as soon as possible.

8. Last questions and closing
As there were no further questions, the chairman thanked everyone for their concentrated and efficient cooperation and expressed his hopes that all participants would return home safely.

The chairman then closed the meeting.

Rob van Welzenis
President

Ute Wallentin
Second vice-president

When the meeting had been closed Margaret Grant read the following poem that she had made, p.t.o.

The Federation is Now Born
So none of us should feel forlorn
We should go ahead with FAITH
Knowing that we are getting stronger
Working for the things we need
If OIFE takes the head
To highlight all our Hopes and Plans
Through out this and other hands
So that the OI Patient
Can live and work and be equal
with his fellow man

Margaret T J Grant MBE
1 st october 1993

".and man to man the world over.
shall brothers be for all that."
Burns