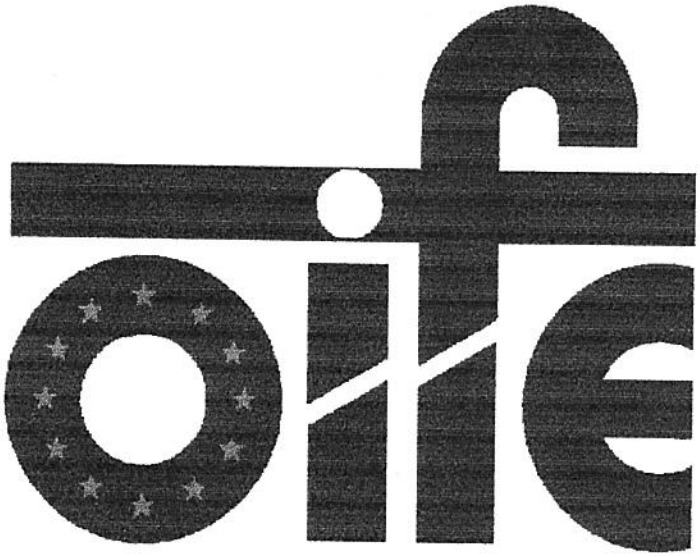

OSTEOGENESIS IMPERFECTA FEDERATION EUROPE

Report on the Ninth Annual General Meeting
24 – 25 August 2001, Birmingham UK

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Participating delegates:

• Rob van Welzenis	The Netherlands	(Honorary) President Dutch delegate till resignation
• Jean van den Boorn	The Netherlands	OIFE treasurer and new Dutch delegate
• Patrick Dupuy	France	Vice-President
• Ute Wallentin	Germany	(Vice-) President
• Simona Paveri	Italy	
• Roz Strudwick	United Kingdom	
• Kati Wink	Finland	
• Birthe Holm	Denmark	
• Filip de Gruytere	Belgium	
• Arthur Rønningen	Norway	
• Ueli Haenni	Switzerland	

Guests:

• Rebecca Johansson and Viola Larsson	Sweden
• Simona Rossi	Switzerland
• Joshua Paveri	Italy
• Stephen Brady, Rachel Purtell and Raymond Lawrie (only part of the time)	United Kingdom
• Taco van Welzenis	Netherlands

1. OPENING AND WELCOME

Rob van Weelzenis as President opened the meeting and welcomed the delegates and guests, in particular Mr Stephen Brady the Chairman of the UK Society, Rachel Purtell (UK) and Taco van Welzenis (NL) as replacement delegates, the newly appointed Norwegian delegate, Arthur Rønningen and the two representatives from the Sweden.

Apologies were accepted from Croatia, USA, Australia and Spain (a card would later be distributed to the OIFE delegates present to be signed and sent to the Spanish delegate Felipe and his family to congratulate them on the recent birth of their baby daughter).

Roz Strudwick had been asked to write the minutes of the meeting and agreed to do so – during a short absence that would be unavoidable Kati Wink offered to take over.

2. SETTLEMENT OF AGENDA

An addition to the agenda was introduced. Point 11 would now be "New Projects". Renumbering of remaining points.
A number of reports from delegates had been distributed immediately prior to the meeting, others were still missing completely. The President stressed the importance of pre-circulating delegate reports before attending an AGM. Discussions around individual reports were delayed until the afternoon session of the meeting, in order to allow delegates time to read those reports not previously circulated.
No other changes were made to the agenda.

3. ANNOUNCEMENTS

The Vice-President announced that the Australian OI-society has a new OIFE delegate, Lynne Foxall, who is also its president.
Then Ute gave an overview on the meeting's schedule and the foreseen breaks.

4. EXECUTIVE COMMITTEE

a. Resignation of President and confirmation-vote for new President

The current President confirmed Ute Wallentin's impending appointment as the new President of the OIFE and asked that delegates once again confirm their support of this proposal. All delegates present confirmed their support. Before handing over the Presidency to Ute, Rob delivered a speech to the delegates.

Following this speech, Rob then officially handed the task of Presidency over to Ute.

The new President thanked the delegates for their support and spoke of how important it was for them all to continue to give her their help and actual support over the years to come.

b. **Election new EC-member.**
The President discussed the need for a further EC member to join with the existing EC members in order to further divide the workload. Rob explained briefly what that EC member would have to do.
Ute stated that nevertheless no one was available at the moment and that the EC would have to cope with this shortage for the time being.

c. New Dutch Delegate (Rob)
Jean van den Boor was announced as the new delegate for the Dutch OI Society (replacing Rob) and Taco van Welzenis was announced as his first replacement. Jean van den Boorn will remain as Treasurer of OIFE, but now no longer as "external EC-member".

d. Distribution of tasks among board members
The President thanked those delegates who had taken on specific tasks and fulfilled them since the last AGM, in particular those from Spain and Belgium. Ute then explained the need to distribute more tasks amongst delegates in future.
The President asked for better co-operation with the EC in the future and she commented how in the past co-operation from delegates had been somewhat limited. She asked for more exchange of information between delegates to "improve our work and our relations".

e. Definition of position of Honorary President
Ute referred to her email entitled "Principle Ideas". The idea behind these came from Rob, who wished to have the position of Honorary President formerly recorded and explained, in order that the responsibilities of the said Honorary President are fully understood by all relevant parties.

The President discussed Point 1:-
In the event of the OIFE being forced to elect a new Honorary President, the Principle Ideas would need to be amended accordingly e.g.

Point 4, "unsolicited advice" – it was considered that this might not be appropriate for an Honorary President in general, "unsolicited" should be left out.

Point 6, "taking" – to be amended to "taken", "advisory vote" (two objections recorded against this phrasing) – to be amended to "will be asked for his opinion".

The delegates agreed to these "principle ideas" with the suggested amendments as detailed above being implemented, with one abstention.

f. Nomination of Honorary President
The President officially nominated Rob as the first Honorary President and presented him with a small ceramic sculpture of a "Wise Raven", a creature often featured in fairytales which symbolises wisdom and knowledge.

5. REPORTS AND QUESTIONS

(the new president took the chair from this point on)

a. General EC-Report (Rob and Ute)
The President asked if any delegates had any questions relating to this

written report.
No questions were put forward. Ute described both her and the Honorary President's disappointment at the application for funding not being successful despite a large amount of hard work being put into the application by herself, Rob and John Dart from DEBRA Europe.

Again the President asked that delegates should offer as much help and support as possible in these matters.

Rob explained how it had been indicated that the application put forward had not expressed the required "non-discrimination action", as detailed in the application criteria, strongly enough.

Kati Wink asked if there had been any response from Sophie Beaumont who had attended the 8th AGM and who had offered to look at the structure of the first proposal put forward, which had also proved unsuccessful, and give her comments, views etc on the format used. There had been no further response from Miss Beaumont, despite approaches being made by the OIFE.

The Honorary President discussed considerations to establish a "combined office" in Brussels, with at least one professional working there for the OIFE.

The President reminded the delegates that the OIFE office would now be situated in Bamberg/Germany, whereas its legal seat would remain in the Netherlands.

b. EDF (Ute)

- **AGA in Brussels**
- **Situation EDF and Sector**

A number of delegates had not received their copy of the AGA Report by e-mail yet. No comments were given to the Report prior to the AGM from the delegates.

The President indicated a number of important points discussed in Brussels:

- OIFE is seen as a respected full member like others which are much bigger, older and financially stronger
- Specific speeches about the situation of disabled people in the USA were very enlightening
- EDF information regarding bus and coach directives for accessible transportation. (The Honorary President gave a brief explanation of the European structure concerning directives – the EC puts out a directive on a certain issue, the directive must then be accepted by the EP, then it has to be signed by all the individual Governments in Europe and then "made a law" and put into action by each of these national Governments.)
- A speaker from Denmark reported on the changed situation of disabled people formerly living in institutions, which had been almost abolished.

At this point, the President pointed out the importance of the often neglected "annual reports" which every OIFE member was supposed to write and referred to the example of the Danish reports which had so far not described this special Danish situation – probably as it seemed too obvious and

uninteresting to mention, which it was not for most non-Danish OIFE-delegates. Birthe Holm then spoke about the issue of information exchange relating to OI adults and, how they live within their respective European countries.

Ueli asked to what extent delegates were interested to hear about the lives of other non-OI disabled people, e.g. in Switzerland.

The Italian delegate, Simona Paveri, said that the Italian Association did not combine forces with other disability organisations.

The Honorary President said that OIFE's first interest and focus should remain on OI and people affected by it, but we should not exclude co-operation with other groups.

EDF Sector for Rare Diseases – This is comprised of seven partners. The President has recently met with two members, John Dart of DEBRA and Patricia Melsom of EAMDA and has had interesting discussions with both.

Ute discussed the issue of a French initiative which had adopted legislation which allows the legal sterilisation of disabled people (this time those with a mental disability). The EDF formulated and signed a resolution to protest against this.

The President at this point distributed pens provided by the EC in support of the European Day of Disabled People.

c. Updated statistics, lists and information (Filip, Ute.)
Filip discussed the updating being carried out by him of the delegate address list and, the creation of a new form, which will be used to collect precise data relating to each country's organisation. The delegates were asked to inform Filip of their respective organisations membership and, how many OI people are represented by their organisation, members or not. Delegates were encouraged to update Filip of relevant changes in information relating to their organisation, as and when they occur.

Filip will provide an updated address list for all delegates in due course. Filip also asked that delegates to send him updated lists of those professional people who are regarded specialists in some way for OI. Rob reminded again that this list had to be treated confidentially.

d. Conference guidelines – draft 2001 – vote
Ute presented the Conference guidelines which had been amended by the EC following Patrick's proposal and asked for a vote. They were unanimously accepted by the Board.

e. Activities in Member countries
This point was rescheduled to the afternoon session of the meeting.

f. Developments in other countries
The President has made limited contact with people in the former Soviet Union, a country that does not have an OI Society, and with the Yugoslavian and South African Societies. She described how the South African organisation continues to "grow slowly".

Ueli discussed his contact with people in Bosnia, Sarajevo and Herzegovina and asked if any other delegate had knowledge of others in any of these countries – no result.

Rob told how OIFE had been approached several years ago by an American girl who was helping out in a refugee camp in Sarajevo and, who had come across a Bosnian boy severely affected by OI. Despite intense contact between Rob & Lidy and the American girl, nothing further came of this enquiry.

As Rob said the Australian Society has shown renewed interest in OIFE and informed Rob about some interesting activities, such as an OI conference.

A doctor from India has also contacted OIFE regarding an idea he has had to establish a specialised OI Centre. He has been put in contact with David Sillence in Australia.

Three people in Romania have been put in contact with each other.

The two Swedish delegates attending the Conference updated the Board on the activities within their country. 100 families are currently actively involved in Sweden in working with and supporting people with OI and their families. They announced that they would soon apply for membership, which the President called a very welcome intention.

6. DISCUSSION OF SUGGESTION OF "COMMON TOPIC"

The President referred to a letter sent out by her in January, which repeated an Italian suggestion to introduce "special topics" to be discussed by all member organisations and then, reported back to OIFE by their respective delegates on an annual or two yearly basis. Results might then be combined and perhaps published in order to feed them back to the national organisations.

Ute asked the delegates for their opinion of this suggestion and after some statements had been discussed she asked for a vote: the basic idea of this proposal was accepted.

The President then asked the Board which topic might prove interesting enough for all the member organisations to research within their own organisation and report back on. The Honorary President made the suggestion that – as suggested - the experiences of adults with OI might be a worthwhile topic on which to share information.

Kati Wink explained that at this time this would be a difficult topic for the Finnish Association to become involved with as the organisation had received a number of complaints that it had in the past paid too much attention to adults with OI and, not enough attention to children.

Patrick Dupuy suggested a further topic could be based on scientific policies, as determined by each organisation.

The President asked that a vote be taken as to which of the two topics discussed would be the preferred choice of the Board. The result was as follows: Adults with OI 7 votes and Children with OI 3 votes

Ute promised to send a written proposal about this "Common topic" to all the delegates.

Rachel suggested that the BBS could possibly discuss and share information about scientific proposals with the French Association, Rob said that this would be a very productive venture and no objections to this suggestion were put forward.

7. FINANCE

a. Financial Report (Jean)

Jean read his financial report and the members of the financial control sub-committee, Filip de Gruytere and Ueli Haenni, who had checked the accounts earlier, recommended to approve to the financial report and to discharge the treasurer.
All delegates approved unanimously to the report, with one abstention from the Italian delegate who was not present in the meeting at this time.
The Treasurer was discharged and the Board expressed their gratitude and warm thanks in respect of the reliable work done.

b. Solidarity Fund

Contributions received from Germany, Norway and the United Kingdom. No requests for financial assistance have so far come from any member country.

Patrick Dupuy spoke of the financial difficulties experienced within the French organisation and gave this as the reason why the French OI Society had so far been unable to contribute to the Solidarity Fund. These financial difficulties continue to improve.

Birthe Holm asked for the process involved in and the criteria for applying to the Solidarity Fund to be explained, which the Honorary President provided.

The President mentioned the situation of the Croatian OI Society with regard to their delegate not attending the Conference i.e. Marko being unable to attend the Conference due to the Society's limited finances. The Honorary President suggested that the Croatian Society be informed again about the existence of the Solidarity Fund for future reference.

c. Fundraising

The President began the discussion by pointing out how important it was to the continued success of OIFE and its members to fundraise in some way. In June, Ute visited Brussels and spoke with the Secretary of the EDF about the possibility of finding a fundraiser who would work for OIFE on a "no funds no pay basis". Ute was told that no one had any knowledge of anyone who would work on this basis.
It was suggested in Brussels that OIFE should look for fundraisers among its members, so the President asked that each delegate put forward this idea to his or her respective boards.

Ueli felt that the Brittle Bone Society would be able to find someone to do this fundraising post. Roz Strudwick said that she would take this suggestion to the UK Board at the next Committee meeting.

The French delegate asked that the issue of employing a fundraiser for the OIFE-members or OIFE itself, possibly via resources found from within a specific member country, be recorded as an official proposal.

Roz explained how this proposal would need to be implemented in such a way as to ensure that no individual country's laws were not adhered to. The BBS Chairman, Steve Brady, spoke at this point about how the Charities Act governs UK charities and Rachel Purtell spoke of the very tight restrictions in the UK with regard to individuals benefiting from monies raised by them for charitable causes.

The President said that whilst fundraising for the OIFE was very necessary, the actual amount needed to function was far less than that required for example by the BBS.

Ute suggested that something in writing, a formal recommendation, in respect of member countries assisting OIFE with fundraising efforts, as discussed above, be formulated and, that each delegate take this to their respective Boards.
The Honorary President added that each country should "implement it in such a way that it is not illegal in their country".

This proposal was formally voted on and the procedure accepted by the OIFE Board.

d. Budget 2002 – Vote
The Budget proposal for 2002 was formally voted on and the Budget accepted unanimously with one abstention due to Simona's absence.

8. EMAB – SITUATION AND FUTURE PLANS

The President asked Rob to give a brief explanation of the developments of the EMAB to date. The EMAB actually has seven (five European) members, the remaining seven member countries are still not represented.
Rob began by reminding the delegates of the letters he had sent to each EMAB-member with the following questions: current OI research being undertaken in each member country; those topics not covered under research projects in each member country; the role of the EMAB and OIFE as perceived by each member country.

Only three responses had been received from Australia, Norway and the Netherlands and the lack of response in general had been discussed at the EC meeting in April. The general feeling of the EC is that the original idea of the EMAB which had asked for one representative per country from its national Medical Advisory Board probably had to be modified due to the following circumstances which became obvious from the answers to Ute's question around the table:
many countries do not really have such an Advisory Board, only few of the existing boards do really function and co-operate successfully. In several countries there is no or not much co-operation between OI-specialists and

often little communication between the OI-society and the medical professionals (each delegate gave a brief report of the current situation with regard to their respective country's EMAB's)
Rob draw the conclusion that consequently the originally intended system could not work.
Nevertheless the EC had felt that the EMAB should remain as an integral part within OIFE's structure.

It was decided to reconsider the concept of the EMAB, to inform the EMAB members of the ongoing process and to arrange a meeting between the actual EMAB-members and the OIFE-EC in Annecy in 2002.

9. INFORMATION POLICY.

a. Status of new "Europass" (Filip)

Filip informed about the actual progress of the Europass and its new format and said that the texts from Portugal and Croatia were still missing.

The Board agreed to include a Swedish section within the Euro pass.

Delegates were asked to check the pages relevant to their individual country in order to ensure that all translations were accurate.

b. Website and E-mail Access for Delegates

The website is currently doing well. Ute thanked Rob who had offered to stay webmaster. The Honorary President feels that he will now have more time to "improve" the site. Responsibility for the content of the site remains with the EC.

Rob announced that pretty soon an xxx@oife.org-e-mail address will be available for each OIFE delegate and this can be connected to existing personal e-mail addresses.

c. Information Exchange and Communication inside Board

Delegates were asked to inform the EC about any developments in order to keep the website as updated as possible.

d. New OI Publications – list update! (Ute)

New OIFE leaflets were distributed to the Board members.
Tables of information: Ute found someone in Germany who is willing to care for these tables, now an adequate system for their composition had to be developed.

10. INTERNATIONAL OI-CONFERENCE 2002 IN ANNECY/FRANCE

a. Status Report and Provisional Program (Patrick)

Patrick gave a report on the planned 2002 Conference.

b. Timetable for Actions

The foreseen date is Friday 30th August 2002-Monday 2nd September 2002. The French OI Society will meet on the 15th September 2001 to arrange the timetable for the Conference. The scientific section of the Conference will

begin on 1st September 2002-3rd September 2002. The OIFE AGM will be held on 30th August 2002.

Patrick was reminded that a written pre-programme with exact dates and prices would be necessary early in September for the national societies' applications.

c. Involvement of OIFE Delegates
Help will be needed for the announcement and spreading of information in advance, for translations (events and speeches will have to be translated). Volunteers are needed to speak on the issue of "social integration" within their own country.

The first announcement to delegates will be send in October-November 2001.

11. NEW PROJECTS

Patrick stated that the idea of Summer Camps had been rejected but that topics for projects should be chosen in order to facilitate bringing organisations together.

He suggested a new project which could be divided into two parts –
Part 1 – European registry of OI – to make available to clinicians and scientists a database of OI individuals from Europe.
Part 2 – European OI "dictionary" – compilation of information about OI, its treatment and scientific approaches.

After some comments had been made and a short controversial discussion showed the complexity of this issue, the President suggested a written summary of the above idea be compiled due to lack of time during the meeting to discuss this further.
It was hoped that discussions with Dr Zack (currently undertaking UK research project) would be possible during the weekend.

12. NEXT AGM'S

a. AGM 10 / 2002 in Annecy

b. AGM 11 2003 - Decision on Date and Venue
Spain was suggested as a possible venue for 2003. Due to Felipe's absence The decision had to be delayed – Ute will contact him and ask.

b. AGM 12 / 2004 – Suggestions
Possible venue is Finland in September-October.

Minute taker (Roz Strudwick) had to leave the Meeting at this point. Kati Wink agreed to continue as minute taker.

13. SUMMARY OF DECISIONS AND AGREEMENTS

The President reminded the delegates about the following:

a. They should in future please send a confirmation or some kind of reply (if only one sentence) to all e-mails, so no further information would be lost.
b. Exchange of information – send in updates to the lists, information about national meetings etc – don't forget the annual reports - there are still some national reports missing.
c. EC will send a proposal for –
   - fundraising
   - common topic
   - Patrick's registry project

14. **A.O.C.B.**

The Honorary President mentioned that as Sweden (RBU) seems willing to join the OIFE, this may require a minor change in by-laws (but it should be no problem).

There was no time to go (thoroughly) through the national reports but the delegates made some further remarks concerning their own country:

GERMANY – the President asked everybody to consider the sailing trip mentioned in her report.
ITALY – Simona informed about a new Italian mailing list.
FINLAND – Kati handed out the renewed version of the small leaflet of the Finnish OI Association.
DENMARK – Birthe showed a new booklet published by the centre for small handicapped groups about the life of disabled people in Denmark.

15. CLOSING

The President closed the meeting and thanked all participants for their contributions and the BBS for their hospitality. She asked everybody to mix as much as possible with the BBS members and wished them to enjoy the Conference.

Roz Strudwick
Monk Bretton, 20 November 2001

Ute Wallentin
President