



## **OSTEOGENESIS IMPERFECTA FEDERATION EUROPE**

### **Minutes AGM 23**

**Fr, 18<sup>th</sup> - Sat, 19<sup>th</sup> September 2015 in Oslo / Norway**

#### Participants:

- Ingunn Westerheim (IW), Norway, President-elect
- Eero Nevalainen (EN), Finland, 2<sup>nd</sup> Vice-president, SOI
- M. Céu Barreiros (CB), Portugal, Treasurer, APOI
- Mads Dyreberg Haldrup (MD), Denmark (Friday 18th only), DFOI
- André Wittwer (AW), Switzerland, SWOI
- Rebecca T. Skarberg (RTS), Norway, NFOI
- Laurette Paravano (LP), France, AOI
- Maria Barbero (MB), Spain, Padrinos-OI
- Isabel Rufo (IR), Spain, AHUCE + AHUCE Foundation,
- Patricia Osborne (PO), UK (ARRIVED AT 6 pm), BBS
- Coreen Kelday (CK), UK (ARRIVED AT 6 pm), BBS
- Florin Dananau (FD), Romania (ARRIVED SAT 19th), AROI
- Leonardo Panzeri (LP II), Italy, ASITOI
- Simona Paveri (SP), Italy, ASITOI

#### As guests:

- Snjezana Jolic, Serbia
- Renata Alic, Croatia
- Dace Liepina, Latvia
- Olga Witthauer, Finland / Germany
- Fatima Godinho, Portugal
- Dr. Glorieux (was present only for the Sahara-documentary)
- Dr. Ana Bueno (was present only for the Sahara-documentary)
- Tamara Fernández (was present only for the Sahara-documentary)
- Pablo Ostarek, Padrinos (left after the Sahara-documentary was presented)
- Slavica Petrovic, Serbia

### **Friday, 18<sup>th</sup> September 17.00-19.00 (in Room Utsikten)**

#### **1. Opening and welcome + announcements of the organizers**

- 17:15: Apologies and presentation from Eero (Ute, Taco and Steffi not present). Round of presentations

- minutes: Coreen and Maria, to-do-list: Laurette and André (follow-up: Steffi)

#### **2. Settlement of the Agenda and schedule**

See Points 7 and 9.

### 3. National Reports

a. Sahara Report. Documentary was shown.

b. National reports (highlights):

Norway: Collaboration with many specialists, some patient meetings, hard work invested in the ST&SI Conference.

Denmark: Collaboration with the Muscle Dystrophy Association in order to get a branding strategy for the Danish OI Association.

Finland: Glad to see new families with children getting involved in the OI society.

France: New families, but the number of members is decreasing. There are many cases of confusion between child abuse and OI in France. Ingunn explains about their contact with the Society of Radiology, which offered the possibility to have some practical courses on x-ray reading and understanding child abuse injuries.

Italy: Organisation of the Italian National Congress for this year, focusing on Genetics.

Spain: Growing OI Society with many members and services.

Switzerland: They are collaborating with Bechterev regarding administration.

Great Britain: Starting a research project, celebrated their yearly meeting, they do a lot of charity work in order to fund research. They have a pool of money for conference and youth events, plus another pool for materials and research. They fundraise because they do not get government money. They help their members to get new wheelchairs through fundraising (£80,000 last year). Next year to work on an Adult service project.

Portugal: The organisation is going in the right direction, but a lot of problems, as the volunteers are too few. Education for families, stimulation for doctors and making awareness for the society are the main points. Second OI congress was celebrated last year (one congress every three years). Participation on the patient side is disappointingly low. Difficult financial situation. Partnerships with companies are welcome. Céu introduces some peculiarities of the Portuguese situation.

Croatia: The Croatian Association started in 1998, but not too much activity has been developed since, as the country is poor and there are not many funds. They have been offered the possibility to shoot a documentary on rare diseases, but the documentary didn't get to be published, in spite of the big effort put on that.

Romania: an update on rodding surgery in Romania.

Serbia: Snjezana explains that she is trying to start an OI-group in Serbia, but there are few to none people who seem interested in that kind of organisation there. She will seek advice at umbrellas for rare disorders and similar.

### 4. Other relevant reports

a. Padrinos-OI Sahara project (Film was shown on Friday night)

b. Conference ICCBH (Int. Conf. on Children's Bone Health) Salzburg (Ingunn)

There were many lectures on OI. It is a conference worth visiting, easier to understand than some of the OI Conferences. Around 40% of the conference was about OI. Many of the doctors present in Delaware were also in Salzburg.

Ingunn attended in order to better understand how to organize an international conference. Not everything was a repetition from the Delaware conference, there were also new themes. This one was in general was about children's bone diseases. The American one was more specific on OI. The ICCBH-conference was organized by a medical committee, directed by Nick Bishop. Next one in two years will from what we have heard be in Scotland.

## 5. Executive committee

- a. Discharge of EC: EC was unanimously discharged.
- b. Resignation of 2<sup>nd</sup> Vice-President Eero Nevalainen – delegates were asked if anyone wished to stand for this position. There were no contenders.
- c. (Re-)Election of 2<sup>nd</sup> Vice-President: Eero's candidacy was voted and unanimously approved.
- d. Resignation of President – Ute's resignations statement was read by Eero in her absence. A new role for Ute was discussed, IW explained UW will be the contact person to coordinate new countries applying for the OIFE and individuals applying for help. She will be a social coordinator for the OIFE (her new title not being exactly defined yet). CB explained about the many calls for help that the OIFE has received during the years, and still receives. IW underlined that she was sceptical that the OIFE should help/advice individuals in the beginning, but UW convinced her that everything starts with a family or a person, and that is often the start of a new organisation. OIFE has a leaflet explaining how to start an organisation. IW explains that the OIFE already has member organisations who are in charge of such a mission (helping individuals), but the work of the OIFE is mainly to help organisations.
- e. Election of President  
Ingunn's candidacy was voted and she was unanimously elected as OIFE President.

## Saturday, 19<sup>th</sup> 10.30

**6. Bylaws discussion**, Ingunn read through slides from powerpoint updating all on the current bylaws and asked delegates to vote after lunch in relation to any suggested amendments in relation to membership interpretation. (See attached PPT document with edited changes).

In summary: Currently the EC can make an exception regarding fees. EC have suggested a table based on income (based on what Eurordis use); therefore if a society has a low income, their membership fee can be lower than the standard (unit) fee. The standard fee will still be €400, but societies will have to apply for a reduced fee providing documentation of their financial situation (last year's financial report). Level will be from €10 to €400. This allows newer organisation's to be included earlier. Currently if a society pays no or a lower fee – they are regarded as associate members and have no vote.

There are 5 categories of membership:

Ordinary members can only be European members and have a voting member on the committee.

Observing members. These are currently divided into 2 categories: Associate members and supporting members (both without voting right at AGM). Associate members can be European organization who pays a lower fee or non-European organisation. Supporting members have generally included the "aid organisations" like Care4BB and HOI.

Sponsoring members: ie if Osteoporosis wanted to support OIFE, they would not be allowed to vote, but would pay a larger fee than the unit fee. Currently there are no sponsoring members.

Advisory members are individuals ie Doctors again no vote.

Honorary Members are individuals with no voting rights.

A discussion was held around "what is meant by income". Different countries have different accounting procedures and it was felt the definition of the word "income" was needed to be made clearer. CB requested a fee structure also be set for Associate members.

Question was raised regarding the amount of membership categories and whether these categories could be reduced. IW confirmed it would mean changing the statutes which is a long expensive process which would need to be done in Netherlands. However the bylaws can be updated and amended. The thing we can do without changing the statutes is for instance to create subcategories and to reduce the number of subcategories within the category "observing members".

IW raised a question regarding how long should an organization remain a passive organization if they don't pay a fee? A discussion was held.

Membership – change of interpretation. IW explained that according to the bylaws the Board will decide if an organisation can become a member or not. Depending on the new system an organisation can switch between categories. The EC will decide if the unit fee has been paid. The fee must be paid before the AGM to keep a vote. If an organisation does not pay unit fee OR get an exception before the AGM – they lose the right to vote that year. It is the delegate's responsibility to check that their treasurer has actually paid.

Categories – IW suggest we keep categories unchanged. Consider putting categories in "observing members" together at next AGM. *Voted on and accepted unanimously*

Ordinary Members- IW suggest remove phrase "increasing from year to year....." And additions "if an ordinary member do not pay fee....." (*see appendix I for actual wording*). *Voted on and approved unanimously*

Table of Minimum fees – *vote and agreed on concept of fee structure.*

Observing Members – If ordinary fee is not paid (and you don't get an exception from the unit fee) you lose your vote until fee is paid again (or conditions are met), therefore this category stays same for present. Russia is currently the only European member in this category. *Voted on and approved unanimously for no changes to this category.*

Supporting member – pays a fee to be agreed by EC . EC can decide fee to be anything from zero fee to xxx euros: ie CBB4, HOI and are currently supporting members. *No change in bylaws, therefore no vote.*

Sponsoring member, Advisory member and Honorary member– *No change in bylaws, therefore no vote.*

Sub-committee – Discussion was held regarding thoughts on sub-committees. IW suggested a committee should be created to find new candidates for the EC board. CK asked if finding new candidates was something that should be planned a year in advance and requests should be sent out to delegates well in advance. Ie Steffi to send out newsletter/email. IW worried this would be a risk in that what if no one comes forward to offer their services. RS suggested anyone who stands down, looks for a replacement and works with new person. IW asked what happens if person does not want to stand down. PO asked if a term of office is in place. IW confirmed term is 4 years, but an individual can be re-elected. No vote for this.

The paragraph from the bylaws in relation to the OIFE language and Unit fee were shown. No vote for this.

## **7. Change of category of OIFE members:**

### a. AHUCE Foundation – report (Maria) and vote

MB explained the Spanish society is there to assist members. The association decided to set up AHUCE Foundation to raise funds for research. They have given small grants to students etc. AHUCE Foundation also talking to and collaborating with CBB4. AHUCE Foundation would like to be part of OIFE as a member independent from AHUCE, because they are two different organisations (they would be a supporting member with zero fee). AHUCE Foundation has the same board as the Spanish OI Society (AHUCE), but they are due to split and have separate offices to be closer to the university. RS asked why they have set up a new society. MB confirmed their statutes won't let them use money outwith Spain and they believe in international research, therefore easiest way around this is to create separate statutes/constitution and a new society. AHUCE Foundation *voted in unanimously as supporting member.*

### b. Panama – report (Ce u and vote) :

CB discussed membership request from Panama (non EU-member). There is a film about Dayana on OIFE Facebook page for those who are interested. They took Panama doctor to Spain to learn, they have continued working in Panama to create an OI society and would like to share experiences. Statutes have been checked and they fulfill criteria to be associate member. Panama *voted in unanimously as associate members.*

## **8. Change of category of OIFE members:**

- a. Romania
- b. Portugal
- c. Russia

Romania and Portugal were already associate members of the OIFE, however according to the new fee system both organisations requested for a reduced fee to be able to upgrade to Ordinary members and have the right to vote. Both sent their financial documents as documentation of their financial situation. The Board voted and unanimously approved this proposal and the Portuguese and the Romanian organisations were both upgraded as Ordinary members. Russia stay on as associate members (since they have not paid annual fee or presented any financial documents). CB requested Ivar to amend website accordingly.

## **9. Change of Bylaws**

*Suggested changes in bylaws were voted and approved unanimously. See section 7.*

## **10. EURORDIS**

a. Rare connect – IW gave a brief overview of Rare Connect. Lucas Lehning to work with Ute on this during the coming 3 months. Short OI texts are required.

b. Eurordis – Steffi has sent out newsletter explaining the summer school. There are links to their website in the newsletter. IW gave a brief overview of meetings attended. Felt they were very into orphan drugs, but not much use to OI. Short discussion was held around the benefits of Eurordis and what members would benefit. (Currently OIFE, Spain, Denmark and Norway are members. UK have applied and waiting for decision). Eurordis are also interested in politics, they hold internet meetings which can be dialled into. IW felt Eurordis was good if you have the resources to put into it. RS asked if OI should be represented? RA said maybe this is something for OIFE in the future to influence. Birthe Holm from Denmark (DFOI) is in the Board of Eurordis, so OI interests are already represented on a high level.

## **11. Finance**

a. Accounts Overview: CB Showed spreadsheet of membership payments. AGM costs 2014 were expensive, partly due to Steffi travel costs. OIFE could do more to raise money, however as most members are dedicated to their own organisations it is difficult to spend time on OIFE. Fee solidarity fund is open for any donations to be made. Financial Policy to be sent out via e-mail. OIFE give out money, but currently no rules around how this is done. CB would like to see a structure around applying for support.

b. Budget proposal for 2016 – CB thinks next year will not be a busy year with meetings, therefore budget prepared accordingly. Estimated income in 2016 to be €11200. Expenses estimated at €11125. *Budget voted and approved unanimously.*

c. Bank accounts currently in Germany. If anyone knows of banks with higher interest rates please bring to EC board. Currently OIFE received 18 euros in interest.

d. Financial report 2013 and 2014 approved by email last year. 2013 and *2014 Accounts voted and approved.* Laurette and Coreen confirmed they had checked the accounts.

e. Finance Sub-committee – CK and LP will check accounts in 2016 (related to book keeping 2015) as long as they are available for meeting.

## 12. EC Report and Projects (Part I)

a. General Report: IW has been working closely with Ute for last 6 months. Much of the time spent on organising Soft Tissues meetings. Also met with International Osteoporosis Society. OIFE has intentions of doing all kinds of things. IW asked delegates if they felt it necessary to revise a strategy, suggested a 4 year plan looking at concentrating on doing 5 things each year. EC to collect a document from delegates on what each member country wants from OIFE. General opinion was this document is necessary.

b. Indecisive/Future members : OIFE are in contact with China Dolls in China (however language barrier). Austria positive about becoming members. Kenya looking at starting an organisation. South Korea also have a group OIFE have been in touch with.

## 13. EC Report and Projects (Part II)

a. Website/Social Media: Ivar is now webmaster and wants to update website, Rob is still working with Ivar as the assistant webmaster. Ivar has sent a proposal for some design changes. Can discuss this later if time allowed. Facebook currently has 900 likes. Posting interesting articles gets lots of likes. OIFE has 5 moderators on Facebook: Ute, Taco, Ingunn, Ivar and Anna Rossi.

b. Denosumab – OIFE discovered study through facebook. OIFE contacted Amgen to find out more. Study now officially recruiting from some countries. Ute to contact relevant person in Germany. IW to contact Norwegian branch to see if any possibility re sponsorship.

c. ERN's - PO gave brief overview update on European Reference Networks (ERNs). All countries to put bids in to get some money by end of year. It will help with collaboration throughout Europe. Patient Groups will be involved. More info can be found on [www.eurordis.org](http://www.eurordis.org)

d. OIFE leaflets and OI Passport– they need to be reprinted. Not much needs to be changed, but do need updating. RS suggested an electronic version. IW confirmed it is already online. OIFE to keep paper print, possibly to look at sponsorship and create an app. CK and PO look at sponsors.

e. Delaware – CB gave update from the 12<sup>th</sup> international scientific conference on OI. Marvellous time for networking. Many countries represented. Interest from doctors in patient participation. Lots of research ongoing. Good to see so much interest. Countries should encourage their medical professionals to participate in these events that take place every third year.

f. Flying OI experts – MB explained about Padrinos project in Cuba. They have no up-to-date equipment. Padrinos help with this, and sending professional doctors. Cuba have invited 2 Spanish doctors to take part in a medical symposium and to train local doctors. Padrinos raising money for rods. Cuba to pay for accommodation. Padrinos still need money for flights. Norway have raised enough for this and will transfer the money to the projects via OIFE. CB explained the Flying Doctors project.

g. Secretary Fund- CB explained the OIFE needs to have the expenses regarding secretary (Steffi) covered. OIFE need €4500 euros each year to cover these costs. Donations for this proposal are welcome.

h. Youth Meeting 2015 currently going on in Berlin. Around 38 members in attendance. Awaiting report. 2016 UK happy to host Youth Meeting.

#### **14. Next AGMs**

a. AGM 2016: MB suggested next year Spain and Portugal to hold a scientific conference in Salamanca (2.5 hours from Madrid via train). They are happy to host AGM in April around 15<sup>th</sup> on a Wed/Thurs. To be confirmed shortly. Suggestion from group for it to be held Sun/Mon 17<sup>th</sup>. Poland have also offered but a few obstacles and issues around venue. IW will inform Poland that Spain/Portugal might be our preferred alternative because of practical issues.

b. AGM 2017: UK to consider possibility of hosting 2017 AGM. CK concerned about hosting along with UK conference as it is a lot of work. Italy also proposing to host 2017. Both countries to put in proposal to EC Board. Croatia also showed an interest in hosting an event.

#### **15. Any other competent business + Closing**

a. OI Conference to be held in Oslo 2017

The 13<sup>th</sup> international scientific conference on OI will be held in Oslo the last week of August 2017. See [www.oioslo2017.org](http://www.oioslo2017.org) for date and venue.

b. Collaboration with IOF and National Osteoporosis organizations (NOS): IW had meeting with International Osteoporosis assoc. This was in relation to a project in Italy about a registry regarding rare bone conditions. IOF want to spread awareness to medics about rare bone conditions. Want OIFE to be a partner and to collaborate together for Rare Disease day 2016. LP from Italy knows the doctor supporting this project. NOS in Norway and NFOI also collaborate. IW now has all direct contact with some pharma companies. UK also has good links with NOS in the UK.

c. FD asked to say a few words. We have task of giving back better world to our children. The goal of OIFE is to make life better. Little things can be done ie awareness campaigns, make OI visible (ie kings, presidents, politicians). 5% of global population have rare diseases. Second issue is funding – OIFE need donations. Thirdly direct funds into research. IW asks everyone send suggestions to EC in relation to ongoing strategy, and this get put on Agenda for next year. FD suggested a press release and PO volunteered to help create one. PO asked about Twitter. EC to make a twitter account.

d. CB raised the possibility that Ute be made an Honorary member. *This was voted on an agreed unanimously.*

*EN closed session and thanked CB for preparation and chairing the meeting.*

## APPENDIX I - BYLAWS AND FEES

# The Committee/EC



- ☞ **General change:**
  - ☞ The expression "The Committee" will be changed to the "EC" in the entire bylaws. This will make the bylaws more correct according to the Statutes.

# I Ordinary members



- ☞ European OI-Societies, which comply with the following conditions
  - ☞ a. they will pay the unit fee (see paragraph 8.1), **unless they prove to the Committee that they are unable to do so. In the latter case a lower fee may be agreed, increasing from year to year, for a maximum period of three years in total. After this three year starting period the unit fee must be paid, or one has to become an associate member (category IIA);**
  - ☞ b. they have been functioning for at least **two years** prior to the date of application for membership of the Federation;
  - ☞ c. **the statutes** of the Society in question must be compatible with those

If an ordinary member do not pay the annual fee within the AGM or do not document that they are unable to do so with financial report from the year before, they will have no vote at the AGM. If the organisation do not pay the agreed fee for 2 years or more, the Board will have the possibility to terminate the membership at the AGM.

# The minimum fees

<b>Income in Euros</b>	<b>Minimum fees in Euros</b>
Less than 1000	10
Between 1000 and 4999	50
Between 5000 and 9 999	100
Between 10 000 and 49 999	200
Between 50 000 and 99 999	300
More than 100 000	400