



OSTEOGENESIS IMPERFECTA FEDERATION EUROPE

Minutes - AGM 22

18th- 21th September 2014 in Helsinki / Finland
Sokos Flamingo Hotel

Participants:

- Ute Wallentin (UW), Germany, President
- Taco van Welzenis (TvW), the Netherlands, 1st Vice-president
- Eero Nevalainen (EN), Finland, 2nd Vice-president
- Anna Rossi, Italy, Youth Co-ordinator OIFE
- Mads Dyrberg Haldrup (MD), Denmark
- André Wittwer (AW), Switzerland
- Rebecca T. Skarberg (RTS), Norway
- Laurette Paravano (LP), France
- Maria Barbero (MB), PadrinoS-OI + FEOI, Ecuador & AHUCE Spain
- Annelies Martens (AM), Belgium, ZOI
- Coreen Kelday, UK
- Leonardo Panzeri (LP II), Italy
- Ivar Troost, the Netherlands, Assistant Webmaster
- Stefanie Wagner, Germany, Secretary

As guests:

- Trond Gården (TG), Norway
- Knut Erik Tvedt Skarberg, Norway
- Ingunn Westerheim (IW), Norway
- Linda Ballegeer, Belgium, assistant + mother of Annelies
- Olga Witthauer, Finland
- Ikka (?), Finland

Thursday, 18th September

(The Meeting treasurer with financial sub-committee was canceled because of short-term cancellation of Céu our treasurer)

after dinner:

Open space – group discussions/Workshops

4 topics – discussed in small groups during one hour after dinner – start at about 20 h

Each group to take own notes, type them up and send to Ute

Friday, 19th September
Start 9:00 h in conference room

1. Opening and welcome (Ute)
+ announcements of the organizers (Eero)

Apologies and round of presentations

Ute welcomed all and gave apologies from Elisa (Mexico), Florin (Romania), Carina (Sweden), Helen (Australia), Elena (Russia, Moscow), Tracy Hart (USA), Åsa Hedberg (Sweden), Céu Barreiros (Portugal), greetings from Filip de Gruytere, Belgium....

No reply from PL, Peru, Ecuador, AFBOI, Georgia, Croatia recently

Who writes minutes and to-do-list?

Minutes Maria & Coreen, to-do-list Steffi & Taco (plus follow-up)

How many votes – 11 delegates of full members

All delegates and guests introduced themselves

2. Settlement of the Agenda and schedule

Agenda confirmed and all national reports mentioned. It was suggested delegates all read each others reports and talk out with meeting if any questions. If time allowed would discuss later during meeting.

3. EURORDIS

No written report, general remarks (Ute) about importance for the OIFE – immense valuable information and tools, connections, best-practice-examples OIFE could use, etc... – If OIFE had more human resources (active people with more time for such projects), as

- a. EURORDIS “Rare connect” – Ute regards it as a very helpful extra communication platform which should be used soon.

Ute explained Rare Connect works like a forum where people can ask questions in any language. There is no section for OI yet but there are volunteers who are willing to become moderators. One benefit is their translation services which they offer. Ute has not had time to send basic text, and examples of peoples stories of people living with OI. Coreen offers to help with this.

- b. EURORDIS “summer school” – participation May 2015?

Ute spoke about the importance of EURORDIS, and time to update all with information. She needs a volunteer to take responsibility to do this. A Danish rep is already on the EURORDIS board. The Spanish federation of rare diseases has a representative at EURORDIS and now discussing with Spanish parliament. EURORDIS helped with information on European travel laws for disability. Patricia from the BBS interested to attend the EURORDIS summer school in May and be OIFE’s representative.

4. Finance

a. Comments on Financial report 2013 (Céu) and remarks on finance

Amount of missing fees, fee payment
Fee-Solidarity fund - appeal
Fundraising activities + results (Ute, Céu)

Ute was too late with application to Novartis in 2013, OIFE failed to receive a subsidy from EURORDIS this time, reduced amount from German OI foundation

Main problem: lack of time to keep track of possible sponsors!!

OIFE needs more reliable volunteers to help with this!!

b. Report of financial control sub-committee regarding 2013 (Laurette, Carina)

As Carina and Céu are both absent, the financial report was not gone through. However, Taco did go round table and asked if anyone had questions for Céu in relation to the accounts which were sent out.

Time constraints for completing funding applications, Ute forgot last year to put in the Novartis application. OIFE needs a volunteer willing to assist in this area. Ingunn volunteered for this as she would like to learn. Everyone welcome to make suggestions re funding possibilities throughout the year.

c. National financial situation – sources of income and yearly budgets – exchange

As announced earlier by email, Ute suggests to go round the table and for each representative to tell the income of their country for the previous financial year.

- DOIG – Ute 2013 and 2012	151.505,29 (2013)	190.695,59 € (2012)
- UK BBS 5 staff	335,405 sterling	approx 370,000 euros
Spanish 4 staff	100,000 euro	
Denmark	90,000 euros	
Switzerland	62,000 swiss francs	approx 80,000 euros
France	70,000 euros	
Netherlands	42,000 euros	
Norway 0,2 paid staff	200,000 euros (80% state fund)	
Italy	100,000 euros	
Finland	? to be confirmed	

Denmark, Norway, Finland, Germany, UK all get lottery funding. Spain have to pay a % tax back to government. State funding in Norway and Denmark is activity based. Italy large part of income is payroll giving, and they are assisting research studies. Netherlands 35,000 is state funding but system due to change and monies to be given to umbrella body.

d. Financial policy and budget proposals 2014 (prepared by Céu) +

discussion.

- e. vote on report 2013 and budget proposals 2014 (Céu)
2014 Budget was unanimously passed.
Discussion was raised re OIFE Youth fees, more income received than paid out. Spain ended up being out of pocket due to late cancellations and delegates not turning up. Ute suggested delegates going to Delaware would discuss this there as Céu, Ute, Taco and Maria will be in attendance.
- f. new future control sub-committee - Laurette and Coreen willing

5. Change of Bylaws

See proposal EC, finished by Ingunn – draft sent by email on Tuesday only

Ingunn gave an overview of reasons to change the bylaws. Main reason was lack of payment of membership fees. Proposal to be made to allow organisations to apply for reduced fees. Members who don't pay will stay as an observing member. Discussion held on how long members should stay as Observing Members. EC to decide on a case to case basis, but in general 2 years as guideline. A few changes to be made by Ingunn on the bylaws. A written proposal to be sent to delegates at a later date.

- a. Membership categories -
- b. Fee structure – no immediate changes now, but possibly in future – action of delegates required

A minimum membership fee was discussed and bank charges with non euro paying countries. Minimum fee has to be higher than bank charge. Exceptions can be made down to 10 euros, but 100 euros to be paid preferably. Currently organisations can apply for reduced fee, but no system in place to make decision on how much this should be.

6. Executive committee

- a. Discharge of EC – vote – postponed as finances could not be checked
- b. Resignation of 1st Vice-President Taco van Welzenis
- c. (Re-)Election of 1st Vice-President
No second person came forward for post of Vice-President, Taco re-elected (1 abstention)
- d. Resignation Ute in September 2015, AGM 23, in Oslo
– nomination of president elect – who will then be regarded as an EC-member until her final election as president

Ingunn willing to take this role on, and become Ute's trainee this year in the run up to Ute retirement from the role of President of OIFE. All agreed with this and voted for Ingunn to be President –Elect (for a year) and a member on the EC Board.

7. EC Report and questions (Ute + EC)

- a. see written activities report – Ute hoped all had read this prior to meeting. Some of these topics to be discussed tomorrow. If anyone had any questions, comments please raise them.

- News from Abiogen:

Abiogen produces several bisphosphonates, one of them being Neridronate [Nerixia], approved for use in Italy.

Abiogen in the meantime is filing the registration application in China, Taiwan, Hong Kong and Macau. Abiogen had the product efficacy review with Professor Nick Bishop (UK), Professor Belova and Dr. Gevorkyan (Russia). In addition, Abiogen presented Nerixia to Fragile Children (Russia). Abiogen has been working to create a panel of experts in OI as an advocacy panel.

Abiogen also spoke to Spain. Spain don't want to start a new bisphosphonate. In Ute's opinion it is too late. One consultant in Germany using this already. Ute just wanted to make everyone aware they could get approached by Abiogen.

- b. News from other OIFE member associations?

Are they still interested at all???

No reply from PL, Peru, Ecuador, AFBOI, Georgia, Croatia recently!!

This was discussed during membership-by-law discussion

- c. Reports from future "OIFE members"

Austria, Panama

- d. Website: assistant and possibly future webmaster Ivar Troost!?

- see under point 9 – website report

Ivar mentioned a few points which need to be discussed on development and implementation of data onto the website.

What does OIFE want to achieve from the website? Should it just be linked to other organisation website. However not all countries have good websites. Update medical information regularly – no one currently responsible. Taco offered to check current information and contacts Lidy and Oliver Semler. Anna volunteers to help with ideas considering the look of the site. Official language is English. Coreen mentioned BBS factsheets are reviewed maybe a link to BBS factsheets is all that is needed. Ivar will give an update on the website next AGM.

All voted they are happy for Ivar to take over work from Rob on website at time they consider right.

- e. Newsletters: 3 NL in 2013, 3 NL in 2014 (Steffi)

8. OIFE and HPP

update and reminder to look for more HPP patients!

Ute explains how she met an HPP-patient last year in Spain at AHUCE's conference and points out HOW important it is to get the correct diagnosis and access to treatment.

Discussion about the relevance of helping other conditions. OIFE should not try to be medical experts. Norway have experience of other rare conditions asking irrelevant questions at their meetings. Spain talking with and helping other rare conditions.

Saturday, 20th September

9. National Reports

- questions and comments of COMMON INTEREST to written national reports (D, N, I (first!), UK, CH, FIN, POR, Romania, Mexico, DK)
- Spain holding a medical day with the doctors in conjunction with Madrid University.
- Spain, Norway, UK and France have Medical Advisory Boards. Spain and Germany have designed a book for School based on the OIF book.
- Italy have a film for schools and creating some more movies in conjunction with the doctors.
- UK have a powerpoint for school, but working on creating films. Also medical talks on youtube.
- Norway working with Spina Bifida on a transition package. Talks about what a child goes through from starting primary school, to high school, to university and becoming independent.
- Netherlands have around 30 clips on youtube in relation to OI information.
- Italy holding a Rock Concert to raise awareness of OI. Next year will be the 10th year and all will be invited.

Taco suggested all societies send on interesting information to OIFE.

Other reports

- C4BB – importance – 2nd decision-making-process of C4BB has started
Ute explained who C4BB are. Dagmar has now some proposals which she has sent out. She sent out a large report.
- website-report: Rob had the intention to resign this year
- Boletin AHUCE - latest news from AHUCE and AHUCE foundation, Spain (Maria)
Received 30,000 donation to start a society. They now have a project to pay for genetic testing for everyone. Genetic institute in Spain have offered to do some testing for free. Cost if an individual wants to take test is 250 euros (usually over 3000 euros). This is to help individuals know what type they are. This will help to determine which type of treatment an individual needs. Maria is going to send information to everyone. DNA Bloods will need to be taken in your own country.

10. Other relevant reports

- a. International OI-network – Maria spoke about Padrinos. They do not offer individual help. If an individual asks them for help, they say go and set up a group and we will then assist. It works where the groups need to find a consultant to help them, consultant has to confirm patient has OI and Padrinos then help with providing bisphosphonates. In this way they are helping with setting up treatment units. Padrinos work mainly in South America, but also in countries such as Egypt, Syria, Mongolia.
- b. ERN – possibilities (Care4BB, BBS and OIFE) – Coreen, Taco and Ute
Coreen gave a brief over view of ERN Network. Explained that there is funding in Europe to hospitals for research if they collaborate with each other throughout Europe. As patient organisations we need to be aware of this and collaborate with each other to influence the medics to work with us.
- c. OIF national bi-annual conference in Indianapolis (August 2014) and “women-forum” - Rebecca will do a written report
- d. OIFE at BBS Conference 2014 in London – Taco will do a written report

11. New and old OIFE – Projects – we set priorities

- a. Topical Meeting 2015 – “Soft tissue or soft issue?” – Oslo – Sept. 17-18, 2015 (Ingunn)
Talks to be held on muscle, tissues, heart, lungs – check up for adults. Norwegian consultants keen to discuss this as it’s an area they get asked many questions on. Seminar to be held in English. There is a call for good speakers on these topics. They are suggesting 2 committees. One for programme and one practical committee. Connective tissue doctors. ie chronic pain, fatigue, gastric issues.
Details on the Topical Meeting website: <http://www.nfoi.no/issues2015.aspx>
- b. International Youth weekends 2015 and 2016
Berlin, Germany for 2015. Hotel still to be checked out. The date being looked at as it overlaps with the Oslo weekend. If not be held in Germany, the Netherlands will be happy to hold. A decision will be made in November 2014. UK happy to hold Youth Event in 2016. Ute requested information early

Rebecca suggested we think about holding a European Woman’s Conference. Topics such as gynaecology, pathways to parenthood, pregnancy, adoption, self image, hormones. Rebecca volunteers to be a contact person for questions about woman’s issues.
- c. Week(end) for adults 2015
Spain going to hold their first adult conference in Valencia. They are willing to invite other countries. It is decided that we will try to combine this with an OIFE adult meeting. Maria will pass on the details of the person responsible to Laurette and Taco.

- d. Student exchange program
This was set up to assist young OI people who are going to foreign countries to study, and needing information on living in that country. This project has been stopped.
- e. "OIFE research inventory" – initiated in Paris 2013 (report and em, Dagmar)
Dagmar started a list of different studies but this has been stopped. We will follow European Network instead.
- f. "Wishbone day" on May 6th – 2014 + 2015 (plans – all delegates)
Ute reminded everyone to encourage their board to get involved. ie go to newspaper etc.
- g. OIFE-fb-page – links from and to all active groups
Moderators can be added to this, if anyone is willing to help update posts please feel free to request moderator status. A link to the Facebook page (not to the group) should be created with the website, Ivar will do so. Ingunn volunteers to be additional moderator.
- h. OIFE-cloud – use of google drive (Eero) – final deadline for END?!
This is useful, for example: If a few people are using/updating the same document. Needs some structure as to how best to use this. Eero and Ingunn to discuss this in more detail.
- i. collection of national OI-literature (leaflets, brochures etc.) of OIFE-members (Maria Barbero). This project has been dead for three years. No need for this to have been on agenda
- j. Flying OI experts + possible tutorships + OI workshops (Ute)
This project is there to assist OI experts (not just doctors) to fly to various countries, to assist and learn about OI information.
- k. European Study about psychological aspects (Céu...?) – not discussed
- l. reprint of leaflet 2015 and new version of OIFE passes in 2015 – new leaflets to be re-drafted and printed.
- m. EFORT – "too much effort?" (in coop. with Dr. Manuel Cassiano, Lisbon) – not discussed.
- n. OIFE representation at OI Conference in Delaware/USA – Oct 2014 – 5 people from OIFE, Ute, Taco also on behalf of VOI, Céu also on behalf of APOI, Elena President of Moscow to travel, Dagmar, 3 from Norway, 2 from Spain, André from Switzerland. Tracy Hart wants one member per country at a National Organisation (OI Global meeting) meeting on Sunday. Not sure what this meeting is about.

Very important: question from Tracy Hart and Richard Kruse:

"what do we want and expect from the "OI global community meeting" on Sunday before the opening of the OI-Conference?" – Improve contact with OIF

and meet with people from Latin American countries.

12. Next AGMs

- AGM 2015 – mid September 2015 in Oslo
- AGM 2016 - possible host countries - Ute asked for host countries for 2016.

13. Any other competent business + Closing

No AOCB