



OSTEOGENESIS IMPERFECTA FEDERATION EUROPE

Minutes - AGM 24
Sun, 9th - Mon, 10th October 2016 in Lisbon / Portugal

Delegates from ordinary members with voting rights:

- Ingunn Westerheim (IW), Norway, President
- Taco van Welzenis (TvW), Netherlands (VOI), Vice-President
- Eero Nevalainen (EN), Finland, 2nd Vice-president
- Céu M. Barreiros (CB), Portugal, Treasurer
- Ute Wallentin (UW), Germany, Social Coordinator
- André Wittwer (AW), Switzerland
- Filip de Gruytere (FdG), Belgium (ZOI)
- Laurette Paravano (LP), France
- Patricia Osborne (PO), UK & Ireland
- Simona Paveri (SP), Italy

Delegates from Associate and Supporting members with no voting rights

- Dagmar Mekking (DM), Netherlands, Care4BrittleBones
- Julia Piniella (JP), Spain, AHUCE Foundation
- Elena Meshcheryakova (EM), Russia – *only attended Sunday*

Other participants from ordinary members (no vote):

- Coreen Kelday (UK & Ireland)
- Anna Rossi (AR), Italy, Youth-Coordinator
- Joshua Paveri, Italy – *parts of the meeting*
- Jean Moitry, France

OIFE Volunteers

- Ivar Troost (IT), Netherlands, webmaster – *only attended Sunday*

As guests:

- Gerald Brandt and Kimiko (assistant), HPP Germany
- Dace Liepina, Latvia
- Jeanette Chedda, Netherlands

1. Opening and welcome + announcements of the organisers

- a. Apologies and round of introductions from delegates
Apologies from: USA, Poland, Romania and Austria
- b. Volunteers - the minutes/meeting report
CK and UW to do minutes,
- c. Volunteers - to-do-list: DM and LP

2. Settlement of agenda and schedule

Agreed.

3. Executive Committee

a. Election EC – Election of 5th EC member

Anna Rossi was recommended by the current EC for the post of Communications Manager. AR gave an overview of how Communications could work better for OIFE. Vote: AR was voted on to the EC unanimously
Future years Elections: Members due for resignation (and possible re-election)
2017 CB, 2018 TW, 2019 IW and EN.

- b. Annual report from EC
No written report had been sent pre the AGM. Verbal update given which will be sent out in written form for voting at a later date.

SUMMARY:

Structure of OIFE currently consists of a paid secretary (Stephanie Wagner), EC (elected by the Board) and Volunteers appointed by the EC which consist of: Webmaster x 2, Youth coordinator, Medical Advisor, and Social coordinator. More volunteers and suggestions are welcome. From AGM 2016 we will have 2 new Youth Coordinators: Stephanie Claeys (Belgium – ZOI) and Marie Holm Laursen (Denmark - DFOI).

Main activities of EC during 2015/16: networking, updating mailing lists, website hacked so new website created, fundraising: donations received from Eurordis and pharma company Alexion.

PO suggested OIFE should have a pharma policy for accepting funds. EC confirmed they currently comply with Eurordis guidelines on this matter. PO offered to share BBS guidelines as an example to improve our own.

Attending meetings ie Eurordis, ECRD, BBS, SVOI. Working with Ukraine to accept bisphosphonates. Assisting the Mexican Association regarding advice on how to host medical conferences.

Youth Event held in the UK. Soft Issues Conference in Oslo 2016. Teleconference once a month (First Friday-calls) between BBS, C4BB, OIF and OIFE. ERNs x 3 members representing on BOND, 2 are from OI-organisations (OIFE and AOI).

Challenges: IW still learning and feeling new. Hard to find time for regular meetings in the EC. Not many volunteers closely connected. Awareness raising of OIFE is needed (1400 followers on Facebook compared to 300, 2 years ago). Some member organisations very silent. Too much energy on internal affairs: ie time needs to be spent on strategy planning. IW mentioned it is hard to recruit member organisations and wondered if membership fee is an obstacle and if organisations feel they get enough benefits from OIFE.

Positives: new member organisation: Austria, more updated documents and e-mail lists. Professional list on excel developed by OIFE secretary instead of numerous word documents, with limited possibilities of categorization. Italy asked for list of Italian professionals, to check for updates. Data Protection issues might arise. Policy required. AR mentioned that OIFE ask for permissions for distribution. More contact in Research. OIFE trying to learn more - currently involved with programmes such as: Stem Cell, steering committee on UK research project, and with Mereo Biopharma (anti sclerostin trial).

4. Change of Bylaws

Proposal regarding category associate members
IW gave update based on last year's discussions.

Change 1 proposal – an organisation can't be an associate member if in Europe.

Current Text **3.2.II**

- **II Observing members**
 - **A. Associate members**
 - European and non-European OI-Societies, which comply with the following conditions:

Proposed change to:

- **II Observing members**
- **A. Non-European associate members**
- **Non-European OI-Societies**, which comply with the following conditions:

Votes: – changes 1 agreed unanimously

Change 2 proposal – an organisation which pays more than the unit fee, will not change status into sponsoring member.

3.2 III (new text)

- III Sponsoring members
- Every organisation that, to the judgement of the EC, supports the objectives of the Federation and that will pay a yearly fee, to be agreed with the EC, that is larger than the unit fee (see paragraph 8.1). **A member belonging to category I or II, does not change category even if they pay more than the fee agreed with the EC.**

Sponsoring members: Discussion held around what is a Sponsoring member? What is the difference between a sponsoring member and a corporate donor? There is no category for Corporate. IW to clarify the term “organisation” in 3.2. III for next AGM.

Vote: change 2 - to include additional sentence agreed unanimously.

Change 3 (new text)

§4.4 - top 4 continued

- **The delegate of a Non-European associate member (category IIA) has no vote on the Board and is not eligible to the EC.**
- **The delegate of a supporting member (Category IIB) has no vote on the board and is not eligible for the EC.**

Vote: change of § 4.4 agreed unanimously.

5. OIFE membership

- a. Status regarding current OIFE members + change of status of Russia to ordinary member. IW gave an update on possible new organisations. Currently there are 16 Ordinary members, 8 Associate and 5 Supporting members (research foundations and organisations for helping individuals). Some not currently responsive and/or active (Sweden, Panama, Georgia & Ecuador). Ordinary members belong to Europe, Associate members are not in Europe. Russia would like to be an ordinary member. Discussion held around their status as Russia lies within both Europe and Asia.
- b. EM gave an update on the Russian association. Lots of patients with OI in Russia (contact with 300 families), but no current structure for OI people regarding treatment - this needs to be built. The Russian organisation, which is seeking ordinary membership has existed for many years. However 2 years ago a charity was created in order to raise more funds. Plans on merging these 2 organisations within the next few years. EM gave personal update on her life with a child with OI and challenges within Russia. Currently trying to influence doctors to use bisphosphonates. Would like to be in contact with Europe to learn more.

Discussion was held around whether Russia should be recognized as a European country by OIFE, regarding to the OIFE bylaws. IW confirmed both Eurordis and other umbrella bodies (including WHO, European Council and ERNs) class Russia as European.

Votes regarding IWs suggestion to use Eurordis as guideline for future membership application: *It was decided no vote was required on IWs suggestion on using Eurordis as a guideline for future membership application on the definition of European. However clearer definition in bylaws regarding "European" was needed.*

c. Applications from new organisations

Russia wants to be an ordinary member: Vote: unanimously voted in as an ordinary member (bylaws § 2.3) and will change status from associate to ordinary member from 2017 (when membership fee is paid).

d. Status on possible new members in the future

Ukraine almost submitted an application, Latvia present at meeting. Serbia and Croatia are both working on setting up an organization (The former Croatian organisation no longer exists). South Africa currently trying to set up an organisation as is India. OIFE is also in touch with individuals in other countries where there are no organisations as such yet.

e. DL gave an update on the organisation in Latvia and confirmed they would like to be members in the future. Currently they have 5 families, but they are also in touch with and working jointly with Estonia.

f. Dismissal of Swedish member organization RBU (no contact for more than 2 years)

No current delegate in Sweden, the organisation is not a specific OI group it's a group for parents with disabled kids - with working administration.

Vote: proposed unanimously to dismiss RBU of Sweden unless contact is established before 31.12.16. We will follow the formal procedures.

6. Reports, networking & collaboration

a. Short report from "OI in 2016 - Lisbon" (for those who were not present)

DM gave update: Joint meeting from Portugal and Spain "UNbreakable alliance". An international congress with ca 170 participants from Europe, US, Canada, Honduras, India, Egypt and more. 25 presentations and also poster presentations. Mixture of professionals and OI community members.

TW gave a very full update on content from meeting, including new research and findings. TW to send out this written report to members.

b. Report from social network coordinator Ute Wallentin

OIFE has set up a social network (consisting of OIFE's member organisations helping individuals + volunteers), with a social coordinator, which is Ute Wallentin. The social coordinator (Ute) replies to individuals seeking advice from OIFE on where to find treatment, doctors, help, support etc. Sometimes this contact leads to an initiative to start a group/organisation in the actual country and then OIFE can give support and advice on this. When the initiative to start an organisation gets more formal, OIFE's president is included in the communication together with OIFE's social coordinator. Sometimes the social coordinator will offer individual help (sending chairs, medication ect), but this is not done as an OIFE-representative, but as part of the social network of OIFE's member organisations (who offer help to individuals) or through individual volunteers.

- c. Status on European Reference Networks (ERN)
IW gave update on ERNs, which is an EU commission process to create networks of centres of expertise throughout Europe. BOND is the network for Rare Bone Diseases. Applications still being processed for ERNs – decision to be made in November 2016. To be started in 2017. Dr. Luca Sangiorgi is the professional lead and Rebecca Tvedt Skarberg is OIFE's representative in the ePAG (patient advocacy group). Jean Moitry is representing the French OI-organisation.
- d. Report from EURORDIS-meetings. IW gave an update on who they are. ERN information can be found on their website. They are a patient advocate umbrella with more than 700 member organisations for rare diseases. They hold webinars. OIFE is also part of Council of European Federations (CEF), with annual meetings in Paris on various topics. This year's topic is genome editing.
- e. Report from Skeletal Rare Diseases Coalition of Supporting Partners - International Osteoporosis Foundation (IOF)
OIFE initiated conversation with IOF 2 years ago to see if there was any collaborative work we could do. Meeting held with them on 6th Oct in Lisbon with a few members from OIFE organisations, HPP (Gerald Brandt), Skeletal dysplasias (Inez Alves), Alexion and 3 representatives from the IOF. OI-stakeholders need to agree to further approach.
- f. OIOslo2017 - Status from the organisers. International conference held every 3 years. Around 200 to 250 participants expected. Fee still to be decided, but could be around 500 euros for professionals, less for member organisations (most likely ca 300 euros in early bird fee). Much of the admin will go through an agency. In addition to participant fees around 40000 euros needs to be fundraised by local hosting country. Registration and call for abstract will open February 3rd. Early Registration will end May 2017. See www.oioslo2017.org . IW mentioned there is a half day slot still to be filled (Sunday before the conference starts) and asked for suggestion/ideas for this. Discussion held around what this time should be used for. LP suggested having some patient organisation input time. Perhaps topic about collaboration between researchers, professionals and patient organisations.

PO said she would take back concerns regarding lack of patient input in the conference programme to UK board.

IW will create a draft based on suggestions: good networking examples between professionals and patient organisations.

Other relevant reports – None given

7. Communication/Webpage/Social media

- a) Website
 - a. Report from webmaster Ivar Troost
IT gave a run down on the new website and email structure after hacking incident. New website now exists with a new provider. OI info still needs to be updated and expanded. Discussion held around where the Donate button should go. Emergency button not clear and obvious. Suggestion to call it SOS. GB suggested using google ads to promote the site's visibility on Google.
 - b. Language policy -
Currently we have most text in English, Dutch and Spanish.
IW: Suggested to have fewer languages than on the old website. JC

suggested google translate for webpage. CB suggested this might not work as a lot of OIFE documents are PDF's. AR suggested looking at other European organisations to see what they are using in way of languages. Discussion held around updating info. UW mentioned that each member organisation can share OIFE website link on their home website with short standard text about OIFE (translated into the local language).

A vote was taken regards how many languages the OIFE website should be translated into. The suggestion was to have 2 languages: English and Spanish (if the Spanish can provide necessary translations). The reason for this was that they are currently our 2 biggest languages. It was agreed two languages was enough

b) Facebook and social media (Twitter and YouTube)

- a. Status on social media
- b. Establishment of OIFE peer group for adults with OI (Facebook)
- c. Need for guidelines on use of social media for OI-organisations
- d. Photo contest – to get photos for web and printed material

OIFE currently on Facebook, Twitter and youtube. Not much news from OIFE to post, but try to post often (ie individual stories) to attract more followers. Many Facebook groups related to OI currently exist: all ages, some have moderators, some not, some have wrong info being spread etc.....

AR gave social media group update: Twitter useful during meetings, ie #, also think about streaming (ie youtube). Need to write a strategy. Content – need to have some guidelines regarding social media groups (ie not giving medical advice). Which tool is best to be used? A closed group on Facebook should have questions asked to be able to join (checklist), to secure the right target groups. Schedule content to be posted on pages. Check reactions. OIFE moderator group discussion to be opened. 2 x new youth coordinators to look at Facebook youth group. AR suggested EC should decide on what OIFE wants to achieve and gain from social media then create a sub committee. Step 1 - communication strategy, step 2 – find out what is happening in different countries regarding pages and groups. Step 3 - guidelines

c) Revision of OIFE brochure and other printed material.

AR mentioned the need for more photos to use in our brochure and printed material. Agreement to a) Ask delegates, b) Ask for photos at FB-page, c) Ask all organisations to include a "checkbox" in registration forms asking for permissions of sharing photos with OIFE.

d) Revision of OIFE passport

CK gave update on Passport group discussion. FvG will try to create an app so the OIFE Passport can be used on a smartphone. PO to find sponsorship. Indian Consultant (Atul Bhaskar) to do translations in Hindi? It was suggested Oliver Semler could look at medical content (if there is something that MUST be changed – remember that this affects all language versions). IT suggested we ensure with all design we keep brand style. Check print costs. AR to be project manager. The group recommended deleting the member logos on back page as members change each year. Instead insert all known organisations and contact information for each country (ie website details)

e) Status OIFE newsletter – not discussed

f) Future strategy of communication and PR – Still to be discussed and developed.

Monday October 10th

IW reopens the meeting and suggests some changes to the order of the Agenda, as several more delegates have to leave early, after lunch.

Short discussion about annual national reports: PO would like to see place in the agenda to exchange best-practice-examples; AR and TvW suggest to exchange special, outstanding examples from the national reports. LP and IW propose to highlight just one or two main important, innovative or challenging things of the last year. Shorter reports maybe.

9. Research, development and collaboration with professionals

- a) How can we collaborate to get more and better research in OI? (Proposal from DM)

DM gave an overview of C4BB and thoughts on international research. She encouraged OIFE's member organisations to go into full or partial alliance with Care4BB regarding fundraising for OI-research.

DM started discussion based on where we are now and where we want to go. Patient's voice through ERNs and European Medical Agency (EMA). PO mentioned EUPATI and said their toolkits in relation to patient reps in research are very good.

Summary of plenary group questions was given: Question: should OIFE raise more funds, should this be a role of the OIFE? Should we have research visible: examples such as Orphanet was suggested, and Researchgate. There is an overall desire to share info without deciding what is good or bad. PO – said need to get policies and a strategic plan in place, and a scientific committee in place.

- b) Should the OIFE establish a Medical Advisory Board (MAB)? The consensus was yes this would be essential with all the new research requests and pharma funding. Should be followed up by the EC before the next AGM.
- c) As fundraising was mentioned several times, many delegates expressed their interest to follow AR's suggestion and talk about fundraising strategies and best-practice-examples at our next AGM. CK and PO offer support that can be found on the BBS website.

8. Finance

- a) Financial report 2015
- a. Financial status: Céu informed about status.
 - b. Report from financial control sub-committee regarding 2015, CK confirmed she and LP had checked over accounts and were happy.
 - c. Céu gave an overview of our accounts, Accounts to be sent around delegates for final vote by email
- b) Proposal to change the fee for Associate members – Need to check first how easy is it for some of these countries to pay their fee. This currently concerns all our Associate members outside Europe. It was decided that instead of having a zero fee, the EC would solve the technical problems around payment and then create a table like the one for the Ordinary members (with 50% lower fees for Associate members).

- c) The voting to accept 2015 accounts and 2017 budget to be done via email and also to have fees for associate members as 50% of ordinary fee.

Budget proposal 2017 + discussion and vote – to be done via email
Vote to continue with the role of secretary post was passed unanimously

- d) Election of financial control sub-committee 2017
IW asked if CK and LP could do another year. CK unsure if will attend AGM in May 2017, but will check dates. To be confirmed by email.
- e) OIFE's financial policy in general
CB asked that OIFE plan better procedures for distributing expenses in order to get better documentation for financial reports. Requested BBS send documents. CK to forward

10. OIFE projects (starts)

- a) OI&SRDs – share the rare (SRDs = rare skeletal disorders like HPP and MO/MHE (Multiple Hereditary Exostoses). Alexion willing to give money as long as OIFE has projects, and have encouraged us to link to other rare bone diseases in web & written material. This year money received for website, written material and AGM. UW suggested money for Youth Event, Other suggestions for project funding were 2017 Oslo seminar; for EC staff to travel to meetings to network (ie ICCBH); to set up MAB and related expenses

International Osteoporosis Foundation (IOF):

CK gave update on SWOT (separate report prepared).

Summary OIF wants to train/educate their bone doctors on rare bone conditions.

IW commented that their meeting was not representative of previous meetings held.

DM/PO/TW all said we need more information/clarity from them before we discuss further. Firstly wait for minutes from IOF. Needs clarity from us to say there is no current coalition on SRDs (skeletal rare disorders).

- b) Rare connect
- UW gave an update on our try to include a site for OI on the web community RareConnect. There are benefits compared to Facebook: Automatic and free translations.
 - Translations are done by professionals. Quality check by volunteers with OI.
 - Open for everyone – without connections to OI-group. Open for people/countries who don't have FB.

However we lack enough volunteers and moderators, for implementing this. A decision was made to stop the project RareConnect and go forward with more moderated FB-groups instead and develop guidelines for use of social media in OIFE & our member organisations.

- c) Flying OI experts
OIFE helps experts from anywhere in the world to learn. There is a budget set aside to allow experts to travel. PO asked if this project was on the website. IW confirmed it wasn't on the new website yet. IW said it was an easy project to sell in relation to fundraising.

We agreed to support Maria Barbero's project for El Salvador/Honduras for 2017 but that we should establish some kind of grant, where different projects can apply for support. We should also consider to include travel grants for researchers to come to different conferences. OIF has agreed to support Maria's project for Honduras for 2017. For other we will establish guidelines.

11. OIFE's long term strategy – further meetings to be held (not discussed)

12. Hosts for AGMs, Youth meetings and Topical Meetings

- a. AGM 2017 - May 26-28 in Warsaw, Poland
- b. AGM 2018 – reminded that OIFE still need volunteers for future meetings. PO reminded everyone that it is the UK 50th in 2018. The BBS to look into possibility of hosting 2018 AGM
- c. Youth meetings 2017 and 2018 – 2017 to be possibly hosted in Netherlands. TW stated that the Netherlands would need a financial proposal to be submitted before final decision. Discussion held around age limit. Recommendation was 16 to 30 (16 to 18 yr olds need an accompanying person). Flexible with age up to 35.
- d. Topical Meeting 2018– should we have it? Topic? Host?
IW commented that there have been quite a few big meetings over the last period, and proposed should not to host one in 2018. DM suggested we keep this open.

13. Any other competent business + Closing

- a) Establishment of nomination committee for OIFE/EC – UW takes over responsibility for this task
- b) AHUCE Foundation want to give free genetic testing to OIFE members. IW said to give EC 3 weeks to make decision and get back to them. Need to confer with OIFE's medical advisor first.
- c) Letter read from Romanian delegate: IW would like to use his appeal as introduction into discussion on OIFE future strategy. As not enough time is left, she suggests that EC will initiate opinion poll about OIFE's most important tasks and priorities among all members by email to the delegates. With the results a new strategy document shall be prepared for the next AGM and final decision on OIFE's strategy can be taken at the 2017 AGM in Poland.
- d) CK reminds everyone that the EC should receive all reports from the workshops.
- e) IW – Mereo Biopharma have sent an email with potential research sites they need an answer to which will be distributed to delegates to check and add clinics and research facilities. IW states that OIFE did not promise to promote it, only help establish contacts. CB suggests to first install a Medical Advisory Board before we continue to cooperate with further research projects.
- f) UW suggested a change to the e-mail structure, emails to delegates should be separate to email lists for appointed volunteers by EC (ie webmaster, medical advisor etc) and potentially other volunteers. Agreement to do this. AR suggested to put more information about shared responsibilities on the website and to better explain functions and responsibilities.
- g) Ingunn closes the meeting at 16:30, thanking everybody for the constructive meeting and wishes a safe return home.

IW gave a thank you to Ute for all her work with OIFE, UW was not present at 2015 AGM for resignation.

Minutes taken by Coreen Kelday and Ute Wallentin - revised by Ingunn Westerheim