



OSTEOGENESIS IMPERFECTA FEDERATION EUROPE

**Meeting report- AGM 28
Saturday 9th May 2020
CET: 11am to 1pm**

Online meeting via ZOOM

List of participants

There were in total 61 participants to OIFE AGM 2020 (please see Registration List for full list of participants)

DELEGATES ORDINARY MEMBERS (WITH A VOTE)

- | | |
|------------------------------------|--|
| 1. André Wittwer | Delegate Switzerland |
| 2. Andrea Kiel | Delegate Germany |
| 3. Aneta Galazka | Delegate Poland |
| 4. Coreen Kelday | Delegate UK & Ireland |
| 5. Dace Liepina | EC-member + delegate Latvia |
| 6. Eero Nevalainen | Delegate Finland |
| 7. Elena
Meshcheryakova | Delegate Russia |
| 8. Fatima Maria
Vasques Godinho | Delegate Portugal |
| 9. Filip De Gruytere | Delegate Belgium |
| 10. Florin DĂNĂNĂU | Delegate Romania |
| 11. Hans Wiesmüller | Delegate Austria |
| 12. Ingunn Westerheim | EC-member + delegate Norway |
| 13. Jean Moitry | Delegate France |
| 14. Malena Sillas Jensen | Delegate Denmark |
| 15. Maria Barbero | Delegate Spain |
| 16. Simona Paveri | Delegate Italy |
| 17. Taco van Welzenis | Delegate the Netherlands & Honorary Member |

Apologies from : Julia Piniella: Delegate Fundacion AHUCE

DELEGATES ASSOCIATE MEMBERS

- | | |
|------------------------------|-----------------------|
| 1. Andrea Medina | Delegate Chile |
| 2. Isis Atuncar | Delegate Peru |
| 3. Justina Yiadom-
Boakye | Delegate Ghana |
| 4. Rageema
Livingstone | Delegate South Africa |
| 5. Tarela Aghanti | Delegate Nigeria |

DELEGATES SUPPORTING MEMBERS

1. **Dagmar Mekking** Delegate of Care4BrittleBones
2. **María Barbero** Delegate Padrinos

OIFE EC-MEMBERS (NON-DELEGATES)

1. **Anna Rossi** EC-member
2. **Céu Barreiros** EC-member

OIFE VOLUNTEERS

1. **Ivar Troost** OIFE webmaster
2. **Marie Holm Laursen** OIFE Youth Coordinator
3. **Stefanie Wagner** OIFE secretary
4. **Stephanie Claeys** OIFE Youth Coordinator
5. **Ute Wallentin** OIFE Social Coordinator & Honorary Member

GUESTS

1. **Wills Hughes Wilson** Mero BioPharma
2. **James Clancy** Mereo BioPharma
3. **Arun Mistry** Mereo BioPharma

OIFE Annual General Meeting (AGM) - business meeting

Ingunn Westerheim (IW) gave introduction and welcome and covered technical and admin duties for the AGM

- Apologies were given from Ukraine and Fundacion AHUCE, Spain
- Slide of the suggested Agenda was shown and approved by all.
- Inger-Margrethe Stavdal Paulsen to be the Chair of the AGM and Anna Rossi to be Co-chair
- Slide of suggested volunteers for meeting was shown. Coreen Kelday and Ute Wallentin to take minutes, Coreen to keep note of the to do list, André Wittwer and Hans Wiesmüller to be the Finance Sub-committee. Inger-Margrethe and Ceu Barreiros to count votes. All agreed and approved.
- Slide of voting members was shown and all delegates able to vote were asked to type their names in the chat so that numbers could be checked and counted. Voting rules were explained to all. NB: *Due to technical problems, Maria Barbero could not be present from the beginning, so the meeting started with 16 delegates, Maria Barbero joined before the Financial report.*

Dace Liepina (DL) gave an overview of the EC members and a short memoire of Ida Mannistö, the previous Vice Chair, was given.

Report from OIFE's Executive Committee – given by Dace Liepina and Ingunn Westerheim

Dace gave an update of main activities of the OIFE for the past 12 months which were:

- See, Hear, Smile-Conference in Latvia
- Involvement in the Setrusumab/Asteroid and MOI studies
- Ad hoc work and involvement in the European Rare Bone Network
- Assisting ERN Bond with the Registry Survey
- Youth Event in Bilbao
- Activities connected with Quality of Life 4 OI Conference in Amsterdam

Ingunn then gave further updates on work undertaken

- OIFE has a new Associate member from Ghana
- More involvement with other rare bone groups
- Had positive feedback in relation to OIFE Magazine and EC has been updating the website more frequently
- Closer collaboration with ERN BOND and continue to be the patient voice in international research
- Also received higher income than usual this year mainly from Industry.

Challenges

- Main challenge is time and personnel resources.
- Logistical challenges remain.
- There have also been issues with the Bank in Germany. *This to be discussed further.*
- Need a policy on how to deal with Commercial Stakeholders
- Need more patient representatives
- More contacts getting in touch from around the world. Thanks to Ute Wallentin for dealing with most of these enquiries.
- Lots of emails to deal with especially around MOI study.
- List of main events attended were shown – this has increased on previous years
- List of the Research projects which OIFE had been/are involved in was shown.
- A slide showing all of OIFE “official” volunteers were shown and they were all thanked along with other volunteers by Ingunn Westerheim as well as a special thank you to Rebecca Tvedt Skarberg for her input and time spent as an EPAG-representative in ERN BOND.

VOTE taken to approve the OIFE Report. This was approved unanimously by 16 delegates present.

The Full OIFE Report for 2019 can be viewed here: <https://oife.org/what-we-do/annual-reports>

Financial Report - given by Ceu Barreiros

- Good year for Income, but for the first time more than 50% of donations were received from industry. The four companies were shown in the slide. A policy is being looked at as to how this should be dealt with.
- Projects where funds had been spent were discussed, ie: Topical meeting, Stronger Bond Between Us, Flying Doctors. A project in Ecuador has been supported, but money currently lost as this had not gone ahead due to political unrest in Ecuador.
- Financial Sub Committee then endorsed accounts and confirmed they have reviewed them and were happy.

VOTE taken to approve Accounts – this was approved unanimously with 17 votes (Maria Barbero had been able to get connected).

Elections

Positions of 2nd Vice Chair and Communications Manager both up for election for period of 4 years.

Vote for Bruno Van Dijck to be 2nd Vice chair: no other candidates. Unanimously elected

Vote for Anna Rossi to be re-elected as Communications Manager: no other candidates. Unanimously re-elected.

Status from OIFE EC given by Ingunn Westerheim (IW)

- IW mentioned OIFE had been working on providing updates around COVID19
- Issues with replanning of events ie hosting this AGM online
- It is likely that the Youth Event will need to be re-scheduled
- Awaiting to hear updates in relation to OI2020 Conference to be held in Sheffield.
- EURORDIS has published a Rare Barometers Voice questionnaire in relation to consequences Covid-19 has had on people living with rare conditions. IW requested that Organisations promote this nationally.
- OIFE has agreed on a new Financial policy (this was forwarded to delegates prior to meeting). It was recommended that everyone reads in particular the section on travel expenses.
- Also working on a new Budget model – this is likely to include accounting for volunteer hours provided.
- Working closely with Mereo, and currently looking at developing a “Burden of Disease Survey” which will be

covered in more detail later.

- OIFE to be represented in the next week at EURORDIS webinar conference.
- Lots of activity in the last 2 weeks around Wishbone Day, including take over the Rare Revolution Magazine online resources. IW thanked Anna Rossi for all her hard work. Lots of these resources can be found on OIFE youtube channel, including the #Wish4OI Campaign comments.
- The OI Foundation (OIF) have their 50th Anniversary this year, this conference has now been moved online. Anyone can join. Registration to be open soon.
- Stronger Bond Between Us is an umbrella project where OIFE collaborates with other Rare Bone Conditions (eg XLH) – planning to have shared webinars with them.
- ERN BOND - potential rare bone disorder webinar
- OIFE has a new database for members who may be interested in being patient representatives in Research
- Rare Disease Research Challenge - OIFE has been asked to support a grant application for this project from Italy which will entail monitoring mobility for people with rare bone conditions.
- ERN Bond have received EU funds to develop a Rare Bone Disease Registry. OIFE has a resource group to assist with this.
- OIFE MAB held their first Meeting via Zoom in April 2020
- OIFE Bank account is currently being hacked. The German bank is not able to stop this from happening. Therefore the EC is currently looking at moving the bank account, but this is complicated due to Logistics (ie Treasurer in Portugal, President in Norway, OIFE registered in the Netherlands). Any suggestions from members are welcome. Discussion held around the Bank account being an online account. Maria Barbero suggested “Consorsbank” or “ING”
- Question raised around the relationship between OIFE and Kyowa Kirin, IW answered this by stating the relationship is in conjunction with XLH Project.

ACTION POINT - EC to contact the suggested Banks.

National Report Updates - given by Anna Rossi (AR)

- Feedback was given from the Surveys which Ordinary Members had completed (15 out of 18). AR thanked everyone for taking time to complete these.
- Feedback was also provided by 2 Associate and 1 Supporting members – these results are available on request.
- AR looked at if there was a direct connection between Annual income of an organisation and their level of activity but didn't find any. Neither was there any link between activity level and numbers of paid staff in an organisation.
- 80% of organisations reported still keeping the same level or having increased activity in the last 12 months.
- Only 2 of the 15 organisations reported having more than 1 paid staff. Most operate on a volunteer basis only.
- Meetings and events is what most spend time on.
- Policy work is becoming more important.
- Fundraising is still not something that most spend time on.
- Most Organisations are using a variety of social media avenues to engage with their members.
- Biggest Challenge for most is lack of personnel resources and lack of funding.
- Research and Development – most have a Medical Advisory Board and have some level of input into research.

Approval of OIFE Budget for 2021 – Overview given by Céu Barreiros (CB)

Budget was sent to delegates prior to the meeting.

Main points highlighted and covered:

- Membership income expected to stay the same.
- Not expecting to hold a Topical Conference, so no expenditure will be incurred
- Pharma income expected to be increased. Policy to be looked at in relation to industry income so this is kept transparent.
- Also looking at having a policy to account for volunteers hours provided, which otherwise would have to be paid for.
- Expecting to have high travel expenses due to attending conferences and meetings.

- Developing more projects as previously discussed (ie Stronger Bond Between Us)

Comments & Questions from members:

Dagmar Mekking confirmed it to be a good idea to have Industry income transparent. CB confirmed this can't be transparent in the budget (as this is forecasted) but yes it is reported in the financial report.

Taco van Welzenis asked if there were earmarked funds for specific projects. IW confirmed that some of the industry donations are given to be used for specific projects.

Patricia Osborne – reminded IW that there had been a legal talk planned for OI2020 which would cover this area of transparency.

Vote taken to approve Budget for 2021 – approved unanimously

Burden of Disease Survey on OI - Ingunn Westerheim gave an overview of this Project

- An initiative from Mereo Biopharma with support from Organisations and clinicians working in OI from around Europe and the US.
- The plan is to implement a steering group.
- Collaboration will be needed from various countries to take part in development of this Survey and in promoting it. IW explained the need and the importance of needing such a survey and what it will include.
- Also how the results will be beneficial and how the results will be used.

Ingunn introduced the 3 Mereo representatives, who all introduced themselves thanked OIFE for their buy in and confirmed the importance and need for the Survey and how it would ultimately be used to improve the lives of people with OI.

There was some discussion around the word "Burden". People with OI don't think of the condition being a burden and feel the name should be changed to encourage people to complete the survey whilst it is online. Some suggestions were to change the word Burden to "challenges" or "impact". It was explained the word Burden is used by Policy makers in relation to the "financial burden" of the disease.

Rebecca Tvedt Skarberg asked if the goal was to produce a new therapy, were there plans to make it equally accessible to all countries? Wills Hughes-Wilson confirmed that the ultimate goal would be to have the treatment available as widely as possible, but explained how each country has their own rules and regulations to overcome.

Dagmar Mekking recommended using the structure of Key4OI for the parts relating to measuring quality of life. It would be a shame to start from zero again. IW confirmed they would look at all current projects.

IW gave thanks and closed the meeting.

Minutes taken by Coreen Kelday/Ute Wallentin

AGENDA OIFE AGM part 2 “New treatments in OI”

15.00 - 15.10 **Welcome & introduction** (Ingunn Westerheim & Dr. Oliver Semler)

15.10 - 15.25 **Status from BOOSTB4 - stem cells treatment in OI** (Dr. Cecilia Götherström)

15.25 - 15.40 **Status update - setrusumab as developmental potential therapy for in OI**

(Representatives from Mereo Biopharma)

15.40 - 15.50 **Q&A**

15.50 - 16.10 **What is market access and why do you need to know about it?** (Paul Connor, BBS)

16.10 - 16.20 **Access to treatment - why the patient's voice matters**

(Oliver Gardiner, XHL Alliance)

16.20 - 16.25 **Q&A**

16.25 - 16.45 **Registries & why patients might have to provide the data** (Dr. Lena Lande Wekre)