



## **OSTEOGENESIS IMPERFECTA FEDERATION EUROPE**

**Meeting report- AGM 29  
Saturday 19<sup>th</sup> June 2021  
CET: 11am to 1pm**

**Online meeting via ZOOM**

### **List of participants**

There were in total 48 participants to OIFE AGM 2021 with 19 voting members.

#### **DELEGATES ORDINARY MEMBERS (WITH A VOTE)**

1. Therese Stutz Steiger Delegate Switzerland
2. Andrea Kiel Delegate Germany
3. Michal Daszkowski Delegate Poland
4. Patricia Osborne Delegate UK & Ireland
5. Dace Liepina EC-member + delegate Latvia
6. Teresia Harri Delegate Finland
7. Elena Meshcheryakova Delegate Russia
8. Marta Rodrigues Delegate Portugal
9. Filip De Gruytere Delegate Belgium
10. Florin Dananau Delegate Romania
11. Hans Wiesmüller Delegate Austria
12. Ingunn Westerheim EC-member + delegate Norway
13. Diane Maroger Delegate France
14. Malene Sillas Jensen Delegate Denmark
15. Julia Piniella Delegate Spain
16. Simona Paveri Delegate Italy
17. Taco van Welzenis Delegate the Netherlands & Honorary Member
18. Lana Bokuchava Delegate Georgia
19. Therese Rudolfsson Delegate Sweden

#### **DELEGATES ASSOCIATE MEMBERS**

1. Andrea Medina Delegate Chile
2. Isis Atuncar Delegate Peru
3. Justina Yiadom-Boakye Delegate Ghana
4. Jade Cross Delegate Australia
5. Archana Ravindra Delegate India
6. Tarela Aghanti Delegate Nigeria

## DELEGATES SUPPORTING MEMBERS

1. Dagmar Mekking Delegate of Care4BrittleBones
2. Julia Piniella Delegate of Fundacion Ahuce (also representing Spain)

## OIFE EC-MEMBERS (NON-DELEGATES)

1. Anna Rossi EC-member
2. Céu Barreiros EC-member
3. Bruno Van Dijck EC-member

## OIFE VOLUNTEERS

1. Ivar Troost OIFE webmaster
2. André Witter OIFE webmaster
3. Stefanie Wagner OIFE secretary
4. Ute Wallentin OIFE Social Coordinator & Honorary Member

## MEMBERS & STAFF OF OI-ORGANIZATIONS (INCL. SUBSTITUTES)

1. Andreas Matsangos Care4BrittleBones
2. Angie Stewart Brittle Bone Society (UK & Ireland)
3. Camila Herrera Ramírez FOICH (Chile)
4. Claudia Finis DOIG (Germany)
5. Inger-Margrethe Stavdal Paulsen Norsk Forening for Osteogenesis Imperfecta (Norway)
6. Trish McFerran Osteogenesis Imperfecta Society of Australia
7. Julliet Makhapila OIF Nigeria
8. Karsten Jensen The Danish Osteogenesis Imperfecta Society (DFOI)
9. Kevin Vanantwerpen ZOI (Belgium)
10. Leonardo Panzeri As.It.O.I.(Italy)
11. Coreen Kelday Brittle Bone Society (UK & Ireland)
12. Simey Desiree Truong DOIG (Germany)
13. Willemijn Döpp - van Berkum VOI (Netherlands)
14. Yvonne M Grant Brittle Bone Society (UK)

## OIFE Annual General Meeting (AGM) - business meeting

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

- No apologies were noted.
- 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. All 20 ordinary OIFE members except Ukraine were present. Voting rules were explained to all.
- Captioning was explained for those wishing to use this.
- 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 vice-chair.
- Slide of suggested volunteers for meeting was shown: Coreen Kelday to take minutes and note of any action points. André Wittwer and Andrea Kiel to be the Finance Sub-committee. Inger-Margrethe S. Paulsen and Dace Liepina to count votes. All agreed and approved.

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

DL introduced EC members and a thank you was also given to all Volunteers and the MAB for their support throughout the year. DL then gave an update of main activities of the OIFE for the past 12 months these were:

- An overview of events attended
- Policy work including ERN Bond
- The various Research Projects OIFE have been involved in
- Impact Survey
- Increased communication.

DL also welcomed the 2 new OIFE Associate members India and Chile, and mentioned that 2 other members (RBU Sweden and HOI) had left OIFE, because they were no longer active in OI.

Ingunn gave further updates on work undertaken. The main points to note:

### Positives

- Successful AGM on Zoom with a record number of participants worldwide
- Development of Impact Survey
- 2 successful campaigns on social media and 4 editions of OIFE Magazine
- Peer Group on Facebook continues to grow – now has over 1000 members
- More predictable financial situation and new finance policy
- Invitations to be directly involved in international projects on R&D
- Development of database with potential patient representatives
- Increased activity and visibility within Eurordis.

### Challenges

- All OIFE face to face meetings were cancelled due to Covid19
- Work and family situations of EC members were affected by Covid-19
- Many hours were used on R&D projects, but without sufficient benefit for OI.
- Logistical challenges ongoing – especially with German bank account and spread of EC members throughout Europe
- Large percentage of income came from Pharma this was further explained in the Finance/accounts section with accompanying graphs/charts etc
- Struggled with attracting participation in Youth Events
- More difficulties to reach subscribers due to spam filters and GDPR
- Competing initiatives in the OI field

IW also encouraged delegates to contact Bruno Van Dijck as the official EC member who is dealing with any queries about organizations struggles from OIFE members. Bruno is happy to assist.

VOTE taken to approve the OIFE Report. This was approved by 18 delegates and 1 abstention.

**The Full OIFE Report for 2020 can be viewed here:** <https://oife.org/what-we-do/annual-reports>

## Financial Report - given by Céu Barreiros

- OIFE currently has 3 bank accounts in Germany and 2 PayPal accounts one of which is in Germany and 1 in Portugal. Reason for the Portugese PayPal account is due to the Treasurer being based in Portugal and could not access the German account.
- Increase in income from Pharma (leading to financial dependency). Therefore to diversify income stream, "in-kind" volunteers hours are now recorded as income. This is in-line with EC regulations and information provided by Eurordis.
- More members than expected asked for a reduction in membership fee.
- German bank account was hacked leading to ongoing issues, however all monies have been refunded and compensation awarded.

- Travel costs which had been paid out prior to Covid were lost.
- OIFE also had to purchase software licenses due to Covid (ie Zoom).

VOTE taken to approve Accounts – this was approved unanimously with 19 votes.

### **Approval of OIFE Budget for 2021 – Overview given by CB and IW**

Budget was sent to delegates prior to the meeting.

Main points highlighted and covered:

- Income expected to stay the same in 2022 to 2020/21
- Expenditure expected to be higher, mainly due to travel as the amount of face to face events will increase.
- IW gave a brief overview of planned projects and costs – ie due to lots of Scientific conferences OIFE expect to award more travel grants through the flying doctor budget. Also OIFE looking to develop projects with the XLH community around pain and possibly some joint communications.

Vote taken to approve Budget for 2021 – approved unanimously with 19 votes.

### **Elections for EC**

Position of Treasurer up for election for period of 4 years.

Vote for Coreen Kelday. Unanimously elected with 19 votes

**BvD** gave an official thankyou to Céu for her hard work as Treasurer over the last 11 years.

### **Volunteer Positions**

**BvD** thanked both the current webmaster, Ivar and Youth Coordinator Marie for their input and hard work. Both to step down from their volunteer positions. The new webmaster Kevin and Youth Coordinator Simey were then introduced and welcomed.

### **Registration of OIFE in Belgium instead of the Netherlands**

Q&A document circulated to members prior to the meeting

**BvD** gave an overview of the current situation, explained the OIFE had had meetings with European Huntington's Association who had put OIFE in touch with SBB - a company in Belgium who provide both legal and accountancy advice and services to non profits.

The reasons the EC would like to move:

- Documents currently getting lost in mail.
- Lack of digital access to some of the German bank accounts and only German speaking staff members – making it difficult to communicate.
- Problems linking PayPal to a bank account in a different country.
- Security concerns on the German bank account due to it being hacked.
- Lack of access to legal advice when needed.
- Expensive to change statutes in the Netherlands and due to new Not for Profit regulations coming into force in the Netherlands OIFE will need to change their statutes anyway.

IW continued by highlighting the benefits of moving:

- OIFE would be registered as a not for profit in a country with beneficial regulations for international associations.
- OIFE would be registered in a country where we currently have an EC member.
- Easier to update Statutes.
- Opportunity to open an international bank account with English menus, and digital access.
- Option to hire an accountancy and legal firm in the country OIFE are registered in.
- Postbox or post address in the same country.

Timeline for this:

- Inform members at this AGM
- Distribute new Statutes 3 months prior to an EGM
- EGM to be held 30<sup>th</sup> Oct 2021 to gain board approval
- Registration of new OIFE in Belgium
- Dissolve OIFE in the Netherlands

### **What is an OIFE delegate overview- given by Anna Rossi (AR)**

OIFE delegates are the most important people in the organisation, without their efforts the OIFE would not succeed in achieving their goals. They are official link between OIFE and the member organisation.

The Task for a delegate are detailed in the onboarding document which has been circulated and everyone was encouraged to read it.

In summary tasks include:

- Participation at AGM
- Inform OIFE about activities and news from their organisation
- Provide annual reports and complete surveys
- Keep up to date with OIFE news and circulate newsletters amongst their own boards and members
- Answer to requests from OIFE EC

### **National Report Updates given by Anna Rossi (AR)**

- Feedback was given from the Surveys which 17 Ordinary Members had completed, 4 Associate members and 2 supporting member organisations. AR thanked everyone for taking time to complete these.
- Biggest Challenge for most continues to be lack of personnel resources and lack of funding.
- Most Organisations are using a variety of social media avenues to engage with their members.
- Research and Development – most have a Medical Advisory Board and have some level of input into research.
- Covid Pandemic had impact on all organisations – lack of face to face meetings being the most negative and positive outcome from the pandemic was the increase in knowledge and use of technology.

Action POINT: IW to share PPT slide with all.

**IW gave a very quick overview of events happening in 2021 and 2022 and thanked everyone for their time and closed the meeting.**

Meeting was recorded on Zoom and Minutes taken by Coreen Kelday

## **AGENDA OIFE AGM part 2 (times are CET)**

13.30 - 13.35 **Welcome & introduction** (Ingunn Westerheim & Dr. Oliver Semler)

### **Projects, Events and Activities**

13.35 – 13.50 News from OIFE projects and activities (OIFE EC)

13.50 – 14.10 Pre launch of the IMPACT Survey (Ingunn Westerheim OIFE, Tracy Hart OIF, Dr Oliver Semler, and from industry - Arun Mistry & Wills Hughes-Wilson from Mereo Biopharma,

14.10 – 14.30 Conference & Events in 2021 and 2022 (OIFE EC)

Comfort Break

### **News from Research & Registries**

14.40 – 15.00 Introduction Ultragenyx & status on setrusumab trial (Ultragenyx Jessica Riviere & Mike Ominsky)

15.00 – 15.10 Status from BOOSTB4 - stem cells treatment in OI (Dr. Cecilia Götherström)

15.10 – 15.15 Status on Topaz study (Coreen Kelday)

15.15 – 15.25 EuRR-Bone (Dr Natasha Appelman-Dijkstra)

15.25 - 15.35 Status on other research projects (Dr Oliver Semler)

15.35 - 15.50 Q&A & discussion

There is no meeting report, but slides have been distributed.