



**OSTEOGENESIS IMPERFECTA
FEDERATION EUROPE**

**Meeting report - AGM 30
Saturday 4th June 2022
CET: 11am to 1pm**

Online meeting via ZOOM

List of Participants

There were a total of (please see participants list attached) at the OIFE AGM 2022 with 17 voting members. At start of meeting 16 present.

Russia was present, but did not have voting rights at the AGM 2022.

Apologies

Austria gave their apologies. Georgia did not provide feedback.

Delegate Ordinary members (with a vote)

	Name	Position	Country
1.	Flip De Gruytere	Delegate	Belgium
2.	Rune Bang Mogensen	Delegate	Denmark
3.	Kirsi Kant	Delegate	Finland
4.	Benedicte Alliot	Delegate	France
5.	Andrea Kiel	Delegate	Germany
6.	Simona Paveri	Delegate	Italy
7.	Dace Liepina	Delegate	Latvia
8.	Taco Van Welzenis	Delegate	Netherlands
9.	Inger-Margrethe S. Paulsen	Delegate	Norway
10.	Karol Puchalski	Delegate	Poland
11.	Céu Barreiros	Delegate	Portugal
12.	Dana Andrei	Delegate	Romania
13.	Julia Pinella Martín	Delegate	Spain
14.	Therese Rudolfsson	Delegate	Sweden
15.	Andre Wittwer	Delegate	Switzerland
16.	Patricia Osborne	Delegate	UK & Ireland
17.	Karina Propkopiuk	Delegate	Ukraine (dialled in later)

In addition to this between 15 and 20 people without voting rights attended. This included attendees from associate members and OIFE MAB.

Election of Meeting Volunteers

Patricia Osborne

Inger-Margrethe S. Paulsen and Andre Wittwer

Dace Liepina and Taco Van Welzenis

Andrea Kiel and Julia Piniella

Meeting Secretary

Chairs of AGM part 1

Counting of Votes

Financial Sub Committee (finances 2021)

Annual General Meeting (AGM) – business meeting

President Ingunn Westerheim (IW) welcomed all present and opened the AGM with an introduction of the proposed agenda.

AGENDA

- Welcome and apologies
- House keeping
- Counting of votes
- Election of meeting volunteers
- Settlement of agenda
- Approval of OIFE's Annual Report 2021
- Approval of financial report 2021 incl. statement from financial sub committee
- Approval of budget for 2023
- Resolution to dissolve OIFE in the Netherlands and give the OIFE EC the mandate to implement as soon as possible
- Elections & appointment of OIFE volunteers
- Internal news & updates from OIFE EC
- Final comments & closure of OIFE AGM part 1

Annual Overview from OIFE's Executive Committee

Dace Liepina DL (Latvia) introduced EC members present, and thanked volunteers and the MAB for support throughout the year. DL gave an update on main activities of the OIFE for the past 12 months:

Medical Advisory Board update:

- No changes to members of the OIFE MAB in 2021.
- Dr. Oliver Semler remains chair of the MAB.
- May 31st OIFE hosted a MAB-meeting in 2021.
- An update about activities and projects, ongoing initiatives on registries, databases and networks.
- OIFE EC asked the MAB for a steer re knowledge gaps to focus on.
- Discussions held how the OIFE can support collaboration and networking between OI-researchers in Europe.
- It was decided to host an investigator meeting similar to the one held by OIF.
- A date agreed for event in 2022 and established a programme committee:
 - Antonella Forlino (IT),
 - Lars Folkestad (DK),
 - Liidia Zhytnik (ET)

- *Claire Hill (UK).*
- *Ingunn (IW) took on the role as conference organiser.*
- The committee had two meetings in 2021.

DL gave an update about the positive development and challenges for 2021:

Positive Developments

- *Surveys:* IMPACT survey more than 2,200 responses from over 65 countries
- *Restructuring OIFE – OIFE 2.0.* project (move to Belgium)
- *Collaboration:* Increased requests to OIFE
 - New contacts with several companies (Corporate) involved in OI-projects.
 - OIFE contributed to the creation of the OI-module in EuRR-Bone
 - OIFE secured a new base for the OI Variant database
- *Profile:* Increased visibility for OIFE through Black Pearl Volunteer Awards & Rare Disease Week
- *Income:* Increased diversification of income (volunteer hours + Facebook donations).
- Income from pharma was reduced to less than 50%.
- *Resources:* An OIFE library for OI research was established.
- *New projects:*, including Pain & OI and OIFE Investigator Meeting 2022

Challenges

- *Covid:* OIFE face to face meetings canceled due to Covid
- *Feedback/consultations:* Hard to get feedback from delegates between meetings
 - Promoting too many surveys we risk survey fatigue. Should prioritize less and better surveys
- *Collaboration:* The Rare Bone Mobility Photo Voice project had poor results despite effort.
 - *Strategy* Disagreement on strategic choices with some of our central collaborators
- *Governance:* Huge challenges with bank and PayPal accounts needed to be closed
- *Communication:* Communication challenges between OIFE and the founders of Wishbone Day
- *Industry:* Companies and clinical trials have different methods for involving the patient voice
- *Resources:* Not enough resources to follow up all projects and activities

Vote taken to approve the OIFE EC Report for 2021 – was approved with 17 votes

Financial Report

By Treasurer Coreen Kelday

Income

- Financial income for 2021 is €51.514,97 (an increase of €12.410,84 from 2020)
- An additional €94.430 was gained through pro bono work provided by our many volunteers, including the Medical Advisory Board. Giving a total global income of €150.666,47.
- The financial income of €51.514,97 represents 34% of global income; support from pharma companies represents 23% of global income and volunteer hours (in kind) represents 63% of global income.
- Other sources of income were: Membership fees, gifts from individuals/member organizations (mainly NFOI), Facebook donations.

Expenses

- Expenses for the year were €11.752,90 with a large percentage of this covering secretarial/admin costs (39%) and the legal fees (31%) accrued in the move to Belgium.
- The Surplus for the year was €39.762,07. Due to not having any face to face meetings and no travel the expenses have been minimum for the last 2 year.

Vote taken to approve accounts – was approved with 17 votes

Budget proposal for 2023

CK presented a slide of the suggested Budget for 2023, comparisons were made to actual income and expenditure for 2021, and the budget for 2022 was also shown.

The Budget is a provisional budget and will be reviewed at the OIFE 2 AGM in Sep.

It is expected in 2023 to have a slight deficit due to the planned Topical meeting to be held in Sweden. However as we have had a surplus in the last 2 years this was not a concern.

Vote taken to approve the budget – was approved with 17 votes

Transitioning OIFE to Belgium

Aim to dissolve OIFE in the Netherlands and give the current OIFE EC the mandate to Implement as soon as possible.

Original plan A to transfer OIFE from the Netherlands to Belgium did not work out.

A new organisation had to be set up (which was plan B)

OIFE Leadership meeting in January agreed to follow plan B.

Same name and logo remains from OIFE Belgium and this history of first established in 1993 will still be applicable.

Everything such as statues remain the same as much as possible. Any changes made to the statutes have been to reflect Belgian law.

Main changes to the statutes are terminology:

- General Assembly (formerly The Board) is still the highest authority, with the same mandate except one thing – deciding about applications from associate members.
- The General Assembly will continue to come together in an AGM once a year and extraordinary GM if needed.
- The Board (former EC) will take care of the daily business – as in most other federations and associations.

- Also some minor changes made to membership categories. OIFE 1 had 4 membership categories. In Belgium you can only be a voting member or a non voting member, therefore subcategories have been made for non voting members.

OIFE 2.0. What has been done so far?

- **January 2022** a new bank account in Belgium was set up with KBC Bank,
 - OIFE have not started using this new bank.
- **February** we finalized the draft of the new set of Statutes after discussions with legal advisors SBB.
- **March 8th** we had an establishing meeting with organizations who agree to be the founders of OIFE2, which was the minimum requirement in the new Statutes.

The founding members are:

- NFOI (Norway)
- ZOI (Belgium)
- LOIB (Latvia)
- Ahuce (Spain)

- Being a founding organization gives no special rights or status in OIFE2.
- At the establishing meeting the chairs of the 4 organizations voted in favour of:
 - *Establishing a new organization called Osteogenesis Imperfecta Federation Europe (OIFE) under Belgian law*
 - *Approving a new set of Statutes in line with Belgian law*
 - *Electing an interim Board which is the same as OIFE 1 Board (Ingunn, Dace, Bruno, Coreen and Anna).*

OIFE 2.0. After the establishment

- **On March 4th** we sent an email to the delegates with the title “Formal invitation (convocation) to OIFE AGM 2022 on Zoom”, where we informed the delegates about the establishment of OIFE2 and that we were aiming to dissolve OIFE1 at the AGM on **June 4th**.

- **On April 7th** the Belgian company court approved us as a new non profit in Belgium and it was announced in the Belgian State Gazette.

- OIFE immediately started the paperwork to give the OIFE treasurer access to the new bank account in KBC.

- **April 11th** we asked all our members to complete a Google Form to agree to a transfer membership to the new OIFE under Belgian law. OIFE1 would still exist until the AGM of OIFE1 decide to dissolve the old federation.

- **May 4th** we sent all the delegates the documents which are up for approval at OIFE AGM (for OIFE1). This included the annual reports and the documents connected to dissolution of OIFE1.

- The Statutes (for OIFE2) were not included, because they are NOT up for approval at OIFE AGM (for OIFE1).

- **Sept 2022:** There will be a SEPARATE AGM for OIFE 2.

At the Leadership meeting it was noted this decision would be made at an extraordinary AGM, we wanted to maintain our commitment to the 3-month rule in the statutes of OIFE1. We decided to combine this with our normal Annual General Meeting, planned for June 4th.

Our goal was to have all organizations confirm membership before OIFE AGM on June 4th, so that the voting members could formally dissolve OIFE 1 at that meeting.

We attached the incorporation deed which included the new (approved) Statutes for your information.

N.b. Statutes are not up for approval at OIFE AGM on June 4th.

OIFE 2.0. What happens next if proposal to dissolve OIFE is approved?

The first general assembly of OIFE2 will take place **September 17th 2022**

All members who have agreed to transfer their membership will in June receive the current set of statutes for OIFE2 and members will be able to suggest corrections/amendments before **July 15th** (in writing)

We then review the suggested corrections/amendments with our Belgian lawyers to see if they are in line with Belgian law

At the general assembly in September the following will be up for approval:

1. Election of a new Board (expanded to 7 persons). This will replace the interim Board, which was elected by the founding members.
2. Our organizations are free to suggest candidates.
3. Written proposals from the member organizations to modify the Statutes. If there are no written suggestions to modify the Statutes within the deadline, we will move forward with the current version.
4. A budget for OIFE2 for 2023.

Proposal to dissolve OIFE 1 in the Netherlands

Status is the following have confirmed they are happy to transfer membership to OIFE 2 (Belgium) :

- 20 European members
- 11 of 13 associates
- 3 of 4 supporting

The actual dissolution

Removing OIFE from the registry in the Netherlands (Kamer van Koophandel).

Moving OIFE assets (and liabilities) from the Netherlands to Belgium and transferring our savings from Sparkasse Ansbach (Germany) to KBC bank in Belgium.

Closing our bank accounts in the Netherlands.

Dissolution – Resolution - OIFE propose

I.1. to dissolve the federation as of the moment to be determined by the executive committee, which moment shall be as soon as possible after the settlement of all liabilities and the transfer of all assets of the federation to Osteogenesis Imperfecta Federation Europe, registered under number: 0784.600.930.

I.2. to discharge the members of the executive committee of the federation from liability in respect of the performance of their management duties during the current financial year up to the date of dissolution referred to under I.1.

I.3. to designate as the custodian of the books, records and other data carriers of the federation: Coreen Kelday, OIFE treasurer

Vote taken to approve dissolution proposal – was approved with 17 votes

Elections and Appointment of Volunteers

OIFE 2 has an interim Board, which is up for election at the AGM in September

- Ingunn Westerheim
- Dace Liepina
- Bruno Van Dijck
- Coreen Kelday
- Anna Rossi

Since OIFE 1 will be dissolved soon, we don't elect a new OIFE EC for OIFE 1.

OIFE Youth Coordinators – Welcome Matilde from February 2023

Thank you to Stephanie!

Social Network Coordinator to Team Social Network Support

Ute Wallentin remains as our Social Network Coordinator, but we have strengthened the team temporarily with Dace and Steffi (who helps with coordination right now).

Emails to socialnetwork@oife.org now goes to all 3 individuals.

AOB

General appeal from President of OIFE, IW to encourage members to note events in calendars:

EVENT	Date	Type of Meeting
OIFE AGM	17 Sept 2022	ZOOM
Youth Warsaw Poland	23-26 Sep 2022	In person
Investigators Meeting	18 th Nov 2022	ZOOM
Stockholm Topical meeting	8-11 June 2023	In person

IW also noted that EUPATI were running good courses for people to consider in terms of training.

Appendix/Notes

General Queries

Responses by OIFE

Q. **Library Database:** would there be access for everyone?

OIFE: Better access is being worked through by OIFE.

Q. **Financial report** – why volunteer hours allocated on balance sheet as they are?

OIFE: This was suggested by EURORDIS, that volunteer input should be recorded/represented. Also discussed volunteer income hours are all pro bono – and this way of presenting in accounts should be reviewed.

OIFE: **Wishbone Day** Collaboration: To note that it had been the hope of OIFE to collaborate more successfully. Unfortunately the initiators behind Wishbone Day decided to remove access to their account over a misunderstanding.

Auditor

Andrea Kiel: **Accounts:** AK / Auditor, Confirmed some errors found in accounts and these were now corrected satisfactorily.

Q. **Dissolution:** It was asked that assurance be given that historical links to ‘former OIFE’ be maintained. Others noted they too were upset how this process was communicated.

OIFE: **Membership/Powers** It was confirmed that the powers of the EC around membership remained intact and the same as previously. That the dissolution and new status was chiefly around the need to secure a new bank. There had been numerous issues with the German Bank. It was also further confirmed that the founding organisations – who were listed would have NO special status.

The dissolve being planned required 20 members.

Agreement of transfer was required as of today 4th June 2022

OIFE would like to enlist more elections to the board.

Q. **Governance/Statutes:** It was noted to be understood – that statutes are not the same issue: current OIFE is Board and some concerns there would be too much power allowed to that board.

Legal: It is a matter of terminology and wording.

Q. **OIFE Logo:** Some raised fears around goodwill and use of the same name and logo.

OIFE: The registration of the OIFE trademark was underway

OIFE: **Communications:** Overall there was genuine misunderstanding over ‘wording’ and language and the different meanings in different countries.