OSTEOGENESIS IMPERFECTA FEDERATION EUROPE

Meeting report- AGM 31
Tuesday 11th June 2023
CET: 7.30 pm to 9pm

Online meeting via ZOOM

35 participants:

1. Ingunn Westerheim, president@oife.org
2. Stefanie Wagner, secretary@oife.org
3. Bruno Van Dijck, bruno.vandijck@oife.org
4. Stephanie Claeys, stephanie.claeys@oife.org
5. Coreen Kelday, coreen.kelday@oife.org
6. Anna Rossi, anna.rossi@oife.org
7. Rebecca Skarberg, rebecca.tvedt.skarberg@oife.org
8. Ute Wallentin, ute.wallentin@oife.org
9. Jacob Wittorff, jacob.wittorff@oife.org
10. Inger-Margrethe Stavdal Paulsen, inger-margrethe@nfoi.no
11. Isis Atuncar, isiselena@gmail.com
12. Malene Sillas, msj@dfoi.dk
13. Karsten Jensen, kj@dfoi.dk
14. Roeline Labout, secretaris@oivereniging.nl
15. Agnes Suard, agnes.suard@yahoo.fr
16. Alessandra Tolaccia, a.tolaccia@gmail.com
17. Aneta Galazka, anetgalazka@gmail.com
18. Andrea Kiel, andrea.kiel@oi-gesellschaft.de
19. Eva Sacherer, eva.sacherer@gmail.com
20. Lieve Michiels, lieve.michiels@zoi.be
21. Cornelia Jungo, connie_jungo@gmx.net
22. patricia osborne, patricia.osborne@brittlebone.org
23. Simey Truong, simey.truong@oi-gesellschaft.de
24. Cynthia Jacobs, c.jacobsgrau@gmail.com (observer from Care4Bones)

25. Natalia Verduzco, nataliaverduzco@hotmail.com
26. Dagmar Mekking, dagmar.mekking@gmail.com
27. Taco van Welzenis, tacovanwelzenis@gmail.com
28. Julia Piniella, info.fundacion@ahuce.org
29. Teresia Harri, teresia.harri@gmail.com
30. Channel Asanov, channelasanov@hotmail.com (observer from Care4Bones)
31. Dobra Awobokun, dobsawobokun@gmail.com
32. Zahraa Maatouk, zahraamaatouk1@hotmail.com
33. Tarela Aghanti, info@oifn.org
34. Dana Andrei, fatadesticlalbastra@gmail.com
35. Simona Paveri, simona.paveri@asitoi.it

Delegate members with a vote:

1. Andrea Kiel – Germany
2. Eva Sacherer – Austria
3. Inger-Margrethe Stavdal Paulsen – Norway
4. Lieve Michiels – Belgium
5. Céu Barreiros – Portugal (voted from her car)
6. Malene Sillas – Denmark
7. Julia Piniella – Spain
8. Ella-Riikka Isometsä – Finland
9. Cornelia Jungo – Switzerland
10. Agnes Suard – France
11. Zahraa Maatouk – Sweden
12. Taco van Welzenis – The Netherlands
13. Simona Paveri – Italy: **Only attended parts of the meeting (last 64 minutes)**
14. Patricia Osborne – UK and The Republic of Ireland
15. Dace Liepina – Latvia: **Absent**
16. Karina Prokopiuk – Ukraine: **Absent**

Poland and Romania were present but did not have voting rights for AGM 2024 since they didn't pay a fee this year. Poland is under re-establishing.

In addition to 14 voting European members and 2 non-voting European members – we also had attendance from the following associate members (without a vote):

- OIF Nigeria (2)
- OI Peru
- Care4BrittleBones
- Care4Bones (2 with observer status)

Meeting volunteers

Chair of the AGM: Inger-Margrethe Stavdal Paulsen

Meeting secretary: Lieve Michiels and Andrea Kiel

Counting of Votes: Cornelia Jungo and Eva Sacherer

Annual General Meeting (AGM)

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

Agenda

- Welcome and opening remarks
- Housekeeping and formalities:
    - Settlement of agenda
    - Practical information & voting rules
    - Counting of votes
    - Election of meeting volunteers
- Approval of annual report 2023
- Approval of financial report 2023 & budget 2025
- Elections of Board members
    - Re-election of OIFE Vice-President Bruno van Dijck
    - Re-election of Board member Anna Rossi
- Status from the OIFE Board – what are we working on?
- Final comments & closure

Vote taken to approve the agenda – approved with 13 votes

Annual Report 2023

1) Highlights from OIFE's annual report 2023: presented by Stephanie Claeys
    - OIFE organized several face to face and online events: Topical meeting "Balancing Life with OI", OIFE general assembly, OIFE Youth Event (Italy), OIFE Leadership meeting, OIFE clinical trial update, OIFE investigator meeting, OIFE drop in sessions
    - New member organizations: Brazil and CLAN
    - Patient experience data projects: pain project, IMPACT survey, SATURN project, Care Pathways project
    - Patient input to many clinical trials: Mereo Biopharma & Ultragenyx, UCB & AMGEN, Sanofi, BOOST Pharma
    - New main goals for OIFE were approved in the OIFE general assembly June 2023:
        - Increase awareness on OI and its impact
        - Advocate for the OI community on European level
        - Empower, educate and inform the OI community
        - Grow of the International network of interested stakeholders
        - Encourage advancements in research
        - Promote patient involvement on different levels and areas.

    - Presentation of OIFE Board, OIFE Volunteers and OIFE Medical Advisory Board

    - OIFE Topical meeting (June 9th -10th 2023, Stockholm, Sweden):
        - 180 participants and 40 online participants from 20 different countries

    - Attendees included healthcare professionals, researchers, pain specialists, people from the OI-community and rare bone community and industry
    - Covered topics such the impact of pain on fatigue, sleep, mobility, family, relationships and more
    - Abstract book, reports and photo gallery published on OIFE website; Official report has been finalized and will be published soon; Most of the presentations/talks with English subtitles are on OIFE's YouTube channel

- OIFE youth event in Italy (Lido di Jesolo, September 7th -10th 2023): 30 participants from 12 countries

- Representation, Advocacy and Networking: presented by Jacob Wittorff
    - Work through EURORDIS: OIFE delegates were attending Rare Disease week in Brussels, General Assembly, Membership meeting, Summer school, Task force on THA, Council of Federations meeting (CEF) Brussels
    - Active participation from OIFE in European Reference Network for Rare Disease (ERN BOND) and the EuRR-Bone (registry)

2) Communication: presented by Anna Rossi
    - Rare Disease Day campaign
    - Wishbone Day
    - Social media (Facebook, Instagram, LinkedIn, YouTube): active sharing of information and to promote OIFE events, activities, campaigns, surveys
    - 4 editions of OIFE magazine published in 2023
    - 85 blogposts, 2 new videos

3) Research and Development: presented by Ingunn Westerheim
    - Increasing number of new and potential treatments being investigated for OI at the moment (preclinical and clinical phase)
    - OIFE provides advice from patient perspective to 9 commercial stakeholders
    - Ensure national organizations are knowledgeable on regulatory processes and health technology assessments
    - Projects where OIFE was involved: EJP RD call "Natural History Studies"– not funded / HR-pQCT Working Group OI / Remedi4All–the MOI-A trial (Losartan)
    - OIFE members contributed to a number of abstracts and scientific articles as co-authors
    - Research related support letters provided to three researchers and two other stakeholders
    - Patient Experience Data (PED) projects like IMPACT survey, Pain and OI survey and others. Data from these surveys can be used to document unmet needs, impact of the condition, patient priorities and value in future processes about approval and reimbursements.

      "The journey is not "just" about developing a therapy: it is about ensuring equitable access to that therapy."

        - Pain and OI survey: designed to gather information from community members to better understand the impact of pain on individuals with OI, developed by OIF with input from OIFE, for adults and young adults (18 years and older) and their

guardians, caregivers; 1088 responses recruited; Baylor's College of Medicine researchers volunteered to write a report.
    - IMPACT Survey: one article published in 2023; Talks and posters presented at conferences throughout 2023; OIFE participated in three Steering Committee meetings in 2023; More details on https://www.impactsurveyoi.com/.

- Peer work: Presented by Ingunn Westerheim
  Facebook group for adults with OI (1300 members); Topics people are concerned about are: Hearing impairment and surgeries, Pain, Bone density and fractures, Pregnancy related topics, Parathyroid problems and possible relation to OI, Medical treatment, Cardiopulmonary topics, Endocrinology, Mobility aids, Dental problems/solutions

4) Positive Developments 2023: presented by Anna Rossi
   - Very successful topical meeting on Pain and OI
   - Well received Pain and OI survey (1100 responses)
   - Large increase in income (grants from industry and EU)
   - Lots of interest in OI research
   - Increased awareness of aspects of OI
   - Two successful campaigns created attention about OI and OIFE
   - Large increase of followers on LinkedIn -with increased visibility among professionals.

5) Challenges 2023: presented by Anna Rossi
   - OIFE drop-in sessions – low interest from community
   - Lack of time to prepare a complete strategy document
   - Facebook increasingly complicated to use (a lot of noise)
   - Complex rules to adhere to as a Belgian nonprofit – costs a lot of time and money
   - Lack of enough diversity in funding
   - More interaction with pharmaceutical industry brings complexity and new legal questions
   - Time involved in sourcing patient experts
   - Distribution of 50 wheelchairs project failed

Thank you to all volunteers of the OIFE and to all collaborators!

Vote taken to approve the 2023 Annual Report – approved with 13 votes

Financial Report

Financial report presented by Coreen Kelday

- The financial statement shows that OIFE reported a surplus of €16.357,29 for 2023.
- Total income for the year: € 196.588,13
- Expenditure for the year: € 180.230,84

- The accounts have been audited by SBB the accountancy firm in Belgium to ensure all appropriate legislative requirements according to Belgian law are met

Thank you to all the OIFE supporters in 2023!

Vote taken to approve the 2023 Financial Report – approved with 13 votes

Budget Proposal 2025

Estimated income and expenditures € 112.300, resulting in a zero net income; presented by Coreen Kelday

Vote taken to approve the 2025 Budget proposal – approved with 13 votes

Elections

OIFE has 2 places up for election at the AGM

- Bruno van Dijck (re-election for 4 years)
- Anna Rossi (re-election for 4 years)

Vote taken to approve the elections – approved with 12 votes

The Portuguese Association abstained, because they didn't know if there were other candidates.

2024 – What is OIFE doing

Presented by Ingunn Westerheim

1) Our voices have been heard in Brussels, Johannesburg, Barcelona and Vienna at different events, meetings, conferences
   - Learning about registries (data exchange in EU is challenging)
   - Conference on how to manage a large European association
   - Meeting about biobanks
   - Open academy school EURORDIS (4 attendees)

2) New collaborations: APOI Portuguese Association + OI Brazil (ANOI)

3) What is coming
   - Bologna conference June 13, 2024: REMEDi4ALL multi-stakeholder meeting: Ensuring patient centricity in Osteogenesis Imperfecta Research; how to recruit more patients or representatives – online registration still possible (link available on OIFE website)
   - OIFE Youth weekend: September 12-15 - Norway: fully booked
   - OIFE Clinical trial update: October 22 – anyone can join
     - Cosmic and the Orbit trials (setrusumab)
     - BoostB4 trial (stem cells)
     - Topaz trial (teriparatide and zolendronate)
     - MOI-A trial (Losartan)
     - More trials to be announced

Keep up to date on: https://oife.org/what-we-do/research-development/ongoing-clinical-trails/

- November 15: OIFE Investigator meeting – Primarily for researchers: Registration and Abstract submission is open – All to encourage researchers to send abstracts

- More events? All registration links of events on https://oife.org/calendar/ ; calendar is updated monthly

- Impact survey: Launch of new website; collaboration between OIFE/OIF/Mereo: https://www.impactsurveyoi.com/

- Stronger together project: Supporting the OIFE members; OIFE is planning:
    - More resources for OIFE members on our webpage
    - Library of resources for OIFE members on Google Drive
    - Library of research articles on Google Drive

- Capacity building conference in Valencia: September 6-8
    - For National OI organizations in- and outside Europe
    - Invitation only event; accommodations (hotel from Thursday – Sunday) and meals covered by OIFE; OIFE can NOT offer travel support
    - Registration 'prior' to July 1st will cover for 3 persons for National OIFE members in EU, for 1 person for associate OIFE members outside EU, and for necessary disability assistant (unless covered elsewhere)
    - After July 1st: availability not guaranteed, tickets cost € 250 and hotel accommodation € 465 minimum
    - Program
        - Organizational issues: Communication (website, strategy, social media etc.); Fundraising and grant writing; Recruitment of members, Board members and volunteers; Collaboration with OI professionals and industry; Motivation and smart ways of working
        - How to advocate for better treatment and services in your country? Whom to talk to? How to use data from the IMPACT survey?
        - Patient involvement in research and regulatory affairs: What is a clinical trial? What is Patient Experience Data (PED)? How are drugs approved on a European level and nationally? How do drugs come to the patient (HTA and reimbursement/payment) nationally?
        - Time to socialize on Saturday: Get to know each other better; See Valencia and have a nice dinner outside the hotel

    - Whom is the meeting for?
        - People who are invited!
        - Important that the national organizations send the right people!
            - People who are involved in managing the organizations
            - Dedicated volunteers (fundraisers, communication people, webmasters etc.)
            - People who are interested in becoming patient representatives/patient experts
        - People who want to volunteer for OIFE

        - In short…THE DOERS

- https://oife.org/: OIFE webpage
    - has a translate button (to select your language)
    - **Like/Share/Follow** OIFE on social media -helps people discovering and increases awareness for OI

Discussion

- Patient journey: share with Ingunn and Rebecca if countries have these available
    - map what patients need from birth to death (medical, dental, etc.)
    - written by patients on what effects patients at each area of life
    - a webinar is available on EURORDIS website

- International Scientific Conference: Hong Kong October 29-31, 2025

- Wheelchair project: A donation of used wheelchairs from a company in The Netherlands was supposed to go to OI-organizations in various countries; AstraZeneca took the logistical responsibility. However the project failed because of too many countries/stakeholders were involved; keep it simpler e.g. transport to one country.

Tuesday 11th of June, 2024

Ingunn Westerheim

OIFE president