MEETING REPORT
OIFE General Assembly 2025

Date: June 6th 2025
Time: 10.00 – 13.00
Place: Idérommet (ground floor), Quality Hotel Expo, Oslo, Norway

WELCOME AND OPENING

Welcome & opening remarks given by Ingunn Westerheim, OIFE President.

Apologies noted from:

1. Julia Piniella – Spain
2. Cornelia Jungo – Switzerland
3. Maria Granlöf Skogman - Sweden

ATTENDEES & COUNTING OF THE VOTES

There were 35 people attending. All the Board members of OIFE were present, except Malene Sillas. Dedicated OIFE volunteers were also present (OIFE Youth Coordinators, Social Network Coordinator, ERN BOND ePag and OIFE honorary member). Lidiia Zhytnik attended on behalf of the OIFE advisory board.

Delegate members with a vote – in total 16 votes:

1. Andrea Kiel – Germany
2. Aneta Galazka - Poland
3. Eva Sacherer – Austria
4. Inger-Margrethe Stavdal Paulsen – Norway (and proxy for Switzerland)
5. Lieve Michiels – Belgium
6. Daniela Santos – Portugal
7. Rune Mogensen – Denmark
8. Elisabeth Hästbacka – Finland (and proxy for Sweden)
9. Patrick Dupuy – France
10. Taco van Welzenis – The Netherlands
11. Alessandra Tolaccia – Italy
12. Niveda Kiridan – UK and The Republic of Ireland
13. Dace Liepina – Latvia
14. Taco van Welzenis – proxy vote for Spain

AOI-Perú was present as associate member organization (without a vote).

APPROVAL OF AGENDA

Formalities and approval of agenda
Practical information & voting rules were explained.
Settlement of agenda – approved unanimously.

APPROVAL OF MEETING VOLUNTEERS

The following meeting volunteers were elected:
Chair of the AGM: Inger-Margrethe S. Paulsen
Meeting secretary: Andrea Kiel, and Lieve Michels
Counting of Votes: Roeline Labout and Dace Liepina

APPROVAL OF ANNUAL REPORT 2024

The full Annual report can be viewed on the OIFE Website.

Highlights covered during the AGM

- Presentation of OIFE vision and mission statements and goals (approved in AGM 2023).
- Presentation of OIFE members: 41 member organizations of which 20 European National organizations with full voting rights.
- Presentation of OIFE board members and OIFE volunteers

The Board had 12 online meetings in 2024. We also had two on site in Denmark and Belgium.

Board member Anna Rossi resigned in December 2024 due to work obligations. The Board co-opted Alessandra Tolaccia to take her place from the same time.

- Impact Survey updates: largest dataset on the experiences of people with OI and their families covering almost 3000 individuals with OI; 4 manuscripts published and 1 submitted; 4 manuscripts drafting or data analysis ongoing/planned in 2025. Resources available on the Impact survey hub.

- Stronger Together project – meeting held in Valencia, and new resources on OIFE website.

- Pain project – overview and update since Stockholm meeting.

- Online Events which OIFE have hosted such as leadership meeting, Investigator Meeting and clinical trial update.

- Events which OIFE have collaborated with – Youth meeting held in Norway and Remedi4All conference in Bologna: RemediAAll (Losartan repurposing trial for OI).

- Various events which OIFE have had representation at throughout year.

- Update on OIFE volunteer representation at EURORDIS, ERN BOND (ePags) and EuRREB (European Registries for rare endocrine bone conditions)
    - Main challenge with registries is getting doctors/hospitals provide data to the registry. The core registry is only used in 4 OI centers in Europe. E-REC reports only new reported cases, anonymously.
    - Hurdles are legal, GDPR, lack of knowledge and funding. Positive development is that Patient advisory board has funding for 2 students (NL) that travel across EU to support hospitals with adding data in the registries.

- Social Media engagement – including Rare Disease Day and Wishbone Day Campaigns.

- Website is continually being updated, and OIFE Magazine is circulated regularly.

- Patient Involvement in Research
    - From patient involvement/engagement at events, contributing to research trials, collaboration with researchers to informing member organisations of new and upcoming clinical trials, input to industry.
    - Patient expert: a person who has undergone extensive training to learn about, their diagnosis (for instance at scientific conferences), research & development or about the healthcare system and policy work (registries, ERNs etc). OIFE encourages individuals to access training and attend courses such as EUPATI, EURORDIS.

- Peer Support for individuals with OI and social network coordinators update provided
    - SATURN: registry project – try to align existing patient registries instead of having stand-alone registries.

Positives from the Year 2024

- Successful capacity building event in Valencia
- Increasing number of volunteers supporting OIFE
- Investigator meeting was successful in expanding OIFE's network of Healthcare professionals and Researchers
- Co-authors on 6 published articles
- Increasing number of patient experts around Europe
- Increasing awareness of OIFE which generates more interest our work
- Closer collaboration with relevant organisations such as ISCBH and ESE
- Lots of engagement on LinkedIn

Challenges from the Year 2024

- Lack of time and energy from existing volunteers
- Valencia event used a lot of resources
- Decline in activity/growth by some of the member organisations and knowing how best to support them
- Difficult to keep momentum after Valencia conference
- Lack of time to prepare a complete strategy draft
- Lack of diversity in income streams

VOTING: APPROVAL OF ANNUAL REPORT
Annual report from 2024 unanimously approved.

FINANCIAL REPORT 2024

Accounts were circulated prior to the meeting. The Treasurer confirmed:

The total financial income for the year was €106.999,90.
Expenditure for the year was €109.939,66
Leaving a deficit (minus) of €2939,76 for the year 2024.

The accounts have been audited by the company SBB to ensure all appropriate legislative requirements in Belgium are met.

The Board also acknowledge the time given free by volunteers as donated hours and account for this in their balance which equates to a further €113.820

APPROVAL OF ACCOUNTS
OIFE's financial report for 2024 unanimously approved.

BUDGET 2025

It was explained that the Budget for 2025 had already been approved by the OIFE AGM in 2024, however according to Belgium rules it has been noted that the Budget does not need to be approved a year in advance – therefore the revised Budget for 2025 was discussed and put up for final approval. The total Income and Expenditure of €112.300 remain the same as previously approved – there was some changes to the allocations.

APPROVAL OF BUDGET
OIFE's budget for 2025 unanimously approved (for the 2nd time).

ELECTION of BOARD MEMBERS

Election of Board members and appointment of volunteers

- Election of OIFE Vice-President (Alessandra Tolaccia, Italy) – 3 years until 2028
- Election of OIFE Treasurer (Bruno Van Dijck, Belgium) – 4 years until 2029
- Election of OIFE Board member & communication manager (Natalia Verduzco, France) – 3 years until 2028

- Thank you noted to both Anna Rossi (communication manager) to Dec 24 and Coreen Kelday Treasurer to June 6 for their time on the Board.

The other Board members were not up for election:
- Ingunn Westerheim, OIFE president, elected until 2027
- Malene Sillas, Board member, elected until 2026
- Stephanie Claeys, Board member, elected until 2026
- Jacob Wittorff, Board member, elected until 2027

Appointment of volunteers
- Thanks to Andre Wittwer for his 8 years as webmaster – this position is now vacant
- Also 2 new social network coordinators Stefanie Ritzrow and Dace Liepina

This concluded the formal business part of the AGM.

INFORMAL PART OF OIFE AGM 2025

WISHBONE DAY – DO WE NEED A MORE ALIGNED APPROACH?

- On 6th May, the OI community celebrates Wishbone Day – the international awareness-raising day for Osteogenesis Imperfecta.

- Wishbone Day was initiated by volunteers in Australia in 2010 and has grown to be the biggest international OI-event with contributions from more than 90 countries so far.

- It's recognized by the color yellow – which was chosen because it symbolizes optimism and a positive future and has his own graphics.

- OIFE has organized different annual campaigns connected to Wishbone Day (#Together4OI, #OneVoice4OI, #All4OI)

- Challenges experienced:
    - A small group of Australians set the rules (Jo Ragen and her supporters); not well connected to the Australian OI-organization.
    - The Wishbone brand and logo was designed by Jo Ragen, who holds the copyright.
    - No fundraising is allowed – which many regard as a missed opportunity. This has resulted in various constructions like the American OI Awareness Week (which is copied and adopted by others).
    - Websites: Main website is outdated and not secure: http://www.wishboneday.com/; Another domain is owned by Care4Bones: https://wishboneday.org/
    - Total chaos in communication and design.
    - The organizations are "not allowed" to take part (only individuals)?
    - Could have been bigger and better with some adjustments?

- Possibilities
    - Dialogue with the owners of the logo/trademark?
    - Will they ever allow that OI-organizations play a role in this?
    - Creating a more modernized communication kit (with permission) – timeless
    - Helping with making the website secure (and more modern)
    - Creating some guidelines for communication on WBD to the OI-organizations (do's and dont's)
    - Using WBD to create awareness on certain topics on WBD
    - Creating campaigns – with annual topics

- Encourage the national organisations to use the extra attention even more.

- Outcome of the Brainstorming:
  - Preference from the OIFE members is to keep the day and the yellow colour since well-known in the OI community (and took 15 years)
  - Setup of a working group to create a WBD concept to propose to the Australian organizers (Michael, Taco, Stephanie, Steffi and Natalia are volunteering for the working group).

WHAT IS OIFE DOING IN 2025/2026?

Ingunn Westerheim informed about what the OIFE have been doing so far in 2025 and the further plans for 2025 and 2026.

- Different conferences attended → our voices heard
  - Future events hosted by OIFE:
  - 2025 plans: Youth Event; Clinical Trial Update; Investigator Meeting
  - 2026 plans: AGM, Topical Meeting, Youth Event
  - Upcoming events from others, BBS Dundee 2025, OI 2025 conference Hong Kong, ISCBH, OIF National conference 2026
  - All events are on OIFE.org/calendar

- Clinical trials in OI can be found on this link
  - Cosmic and Orbit (setrusumab in children), Trial run globally by Ultragenyx, Recruitment phase 3 has been completed
  - Romosozumab (AMGEN & UCB), Is currently recruiting in 17 countries, Run by AMGEN, UCB are contacts in Europe
  - Other ongoing international trials: TOPaZ, MOI-A, BoostB4

- OI parents for OI panels
  - For parents of children or adolescents with OI who would like to help the OIFE with focus groups and panels hosted by researchers, companies or other stakeholders working to improve care and treatment for children with OI
  - People who want to join the group can send an email to office@oife.org and OIFE will contact you for further information.

- New tools for delegates: https://oife.org/news-resources/internal-resources/
  - Internal resources, Research Library, Organizational Resources

- New advisory board
  - 3 groups: medical / Researchers / Patient experts

- Youth Leadership Program of Rare Diseases International (Niveda informed).

Oslo, Norway, June 6th

Ingunn Westerheim
OIFE president

APPENDIX 1 AGENDA

Date: June 6th 2025
Time: 10.00 – 13.00
Place: Idérommet (ground floor), Quality Hotel Expo

10.00 – 10.10 **Welcome & opening remarks**
- Apologies from representatives who cannot attend

10.10 – 10.30 **Formalities and approval of agenda**
- Election of meeting volunteers
- Counting of votes
- Practical information & voting rules
- Settlement of agenda

10.30 – 11.00 **Approval of annual report 2024**

11.00 – 11.20 **Approval of financial report 2024 & budget 2025**
- Approval of financial report 2024 (incl. balance sheet and accounts)
- Approval of budget for 2025

11.20 – 11.40 **Coffee break**

11.40 – 12.00 **Election of Board members and appointment of volunteers**

- Election of OIFE Vice-President (Alessandra Tolaccia, Italy)
- Election of OIFE Treasurer (Bruno Van Dijck, Belgium)
- Election of OIFE Board member and communication manager (Natalia Verduzco, France)
- Appointment of volunteers

12.00 – 12.25 **Wishbone Day – do we need a more aligned approach?**

12.25 – 12.55 **Status from the OIFE Board – what are we working on in 2025 and 2026?**

12.55 – 13.00 **Final comments & closure** of general assembly business part

13.00 **Buffet lunch** in hotel restaurant

APPENDIX 2 BOARD MEMBERS

New Board Members
Alessandra Tolaccia, Via A. E L. Serena 5, 31100 Treviso TV, Italy
Social security number: TLCLSN75C65D530C

Natalia Verduzco, 936 Avenue de Villeneuve, 40000 Mont-de-Marsan, France
Social security number: 2941099405060 68

Re-elected Board Member
BRUNO VAN DIJCK
Postal address: Bruno Van Dijck, Schotelveldstraat 17, 2801 Heffen, Belgium
Social security number : 68.12.21-237.63

Board Members standing down are:
Anna Rossi
Coreen Kelday

Other Board members not up for election in 2025:

- Ingunn Westerheim, OIFE president, elected until 2027
- Malene Sillas, Board member, elected until 2026
- Stephanie Claeys, Board member, elected until 2026
- Jacob Wittorff, Board member, elected until 2027