# TABLE OF CONTENTS

<table>
<thead>
<tr>
<th>PRESIDENT’S STATEMENT</th>
<th>4</th>
</tr>
</thead>
<tbody>
<tr>
<td>THE ORGANIZATION</td>
<td>6</td>
</tr>
<tr>
<td>➢ Our vision, mission and goals.</td>
<td>6</td>
</tr>
<tr>
<td>➢ Our member organisations</td>
<td>7</td>
</tr>
<tr>
<td>THE ADMINISTRATION</td>
<td>9</td>
</tr>
<tr>
<td>➢ OIFE moved from the Netherlands to Belgium</td>
<td>9</td>
</tr>
<tr>
<td>➢ The General Assembly (Annual General Meeting)</td>
<td>10</td>
</tr>
<tr>
<td>➢ The Board</td>
<td>10</td>
</tr>
<tr>
<td>➢ The Volunteers</td>
<td>12</td>
</tr>
<tr>
<td>➢ Positive developments/happenings</td>
<td>13</td>
</tr>
<tr>
<td>➢ Challenges</td>
<td>14</td>
</tr>
<tr>
<td>OIFE EVENTS</td>
<td>15</td>
</tr>
<tr>
<td>➢ January - OIFE Leadership Meeting</td>
<td>15</td>
</tr>
<tr>
<td>➢ March - OIFE establishing meeting under Belgian Law</td>
<td>15</td>
</tr>
<tr>
<td>➢ June - OIFE Annual General Assembly</td>
<td>16</td>
</tr>
<tr>
<td>➢ October - 1st General Assembly under Belgian Law</td>
<td>16</td>
</tr>
<tr>
<td>➢ November - OIFE Investigator meeting</td>
<td>17</td>
</tr>
<tr>
<td>➢ OIFE Youth Events</td>
<td>18</td>
</tr>
<tr>
<td>OIFE PROJECTS</td>
<td>19</td>
</tr>
<tr>
<td>➢ Restructuring OIFE (OIFE 2.0)</td>
<td>19</td>
</tr>
<tr>
<td>➢ The IMPACT Survey</td>
<td>19</td>
</tr>
<tr>
<td>➢ The Pain &amp; OI Project</td>
<td>21</td>
</tr>
<tr>
<td>➢ OIFE Topical Meeting, Stockholm 2023</td>
<td>22</td>
</tr>
<tr>
<td>➢ A strong BOND between us (incl. ERBF)</td>
<td>23</td>
</tr>
<tr>
<td>➢ Flying OI Experts</td>
<td>24</td>
</tr>
<tr>
<td>➢ Help to Ukraine</td>
<td>24</td>
</tr>
<tr>
<td>REPRESENTATION, ADVOCACY &amp; NETWORKING</td>
<td>25</td>
</tr>
<tr>
<td>--------------------------------------</td>
<td>----</td>
</tr>
<tr>
<td>➢ Representation at events hosted by others</td>
<td>25</td>
</tr>
<tr>
<td>➢ OIFE attendance at online meetings hosted by others</td>
<td>28</td>
</tr>
<tr>
<td>➢ Online meeting initiated/hosted by OIFE</td>
<td>29</td>
</tr>
<tr>
<td>➢ EURORDIS events</td>
<td>30</td>
</tr>
<tr>
<td>➢ Advocacy, Representation, Networking</td>
<td>32</td>
</tr>
<tr>
<td>➢ Events hosted by OI organizations</td>
<td>34</td>
</tr>
<tr>
<td>➢ Networking</td>
<td>34</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>COMMUNICATION &amp; PR</th>
<th>35</th>
</tr>
</thead>
<tbody>
<tr>
<td>➢ Rare Disease Day Campaign</td>
<td>35</td>
</tr>
<tr>
<td>➢ Wishbone Day 2022 &amp; #1voice4OI campaign</td>
<td>37</td>
</tr>
<tr>
<td>➢ OIFE Magazine</td>
<td>39</td>
</tr>
<tr>
<td>➢ OIFE Website</td>
<td>39</td>
</tr>
<tr>
<td>➢ Internal communication</td>
<td>39</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>RESEARCH &amp; DEVELOPMENT</th>
<th>40</th>
</tr>
</thead>
<tbody>
<tr>
<td>➢ Patient involvement</td>
<td>40</td>
</tr>
<tr>
<td>➢ OIFE Medical Advisory Board (MAB)</td>
<td>41</td>
</tr>
<tr>
<td>➢ Access to new and innovative treatments</td>
<td>42</td>
</tr>
<tr>
<td>➢ Research projects where OIFE was part of consortiums</td>
<td>42</td>
</tr>
<tr>
<td>➢ SANOFI project</td>
<td>43</td>
</tr>
<tr>
<td>➢ Projects on care pathways in Europe</td>
<td>43</td>
</tr>
<tr>
<td>➢ The OI Variant Database</td>
<td>43</td>
</tr>
<tr>
<td>➢ Surveys that OIFE promoted in 2022</td>
<td>43</td>
</tr>
<tr>
<td>➢ Co-Authorship on and abstract and scientific articles</td>
<td>43</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>PEER WORK</th>
<th>44</th>
</tr>
</thead>
<tbody>
<tr>
<td>➢ Peer groups on Facebook</td>
<td>44</td>
</tr>
<tr>
<td>➢ Social Network</td>
<td>45</td>
</tr>
</tbody>
</table>

| THANK YOU! | 46 |
In April 2022 OIFE moved its formal registration from the Netherlands to Belgium. Between April and October 2022, assets & liabilities were transferred to the new legal entity in Belgium. OIFE in the Netherlands was officially dissolved October 1st 2022.

This Annual Report for 2022, therefore applies to both OIFE Netherlands and OIFE Belgium.

Due to the ongoing pandemic, we cancelled our face to face general assembly in Valencia, Spain for the 2nd time and held our AGM on Zoom in June. As the months went by, we realised that face to face events were back to stay. Fortunately, we were able to attend quite a few important face to face events in 2022. We also hosted a successful OIFE Youth Event in Belgium.

Events attended included an iCan course for children in Lyon, the ICCBH conference in Dublin and a GEMSTONE meeting in Rotterdam to talk about patient involvement. The whole Interim Board of OIFE Belgium attended OI2022 in Sheffield. This gave the board members important knowledge about ongoing research and contacts throughout the international OI community.

In addition to these face to face events, we hosted online events and attended events hosted by others. The most important OIFE events were the Leadership Meeting, the establishing meeting of OIFE Belgium in April, the AGM & educational webinar in June, the extraordinary GM (1st one under Belgian law) in October and the OIFE Investigator Meeting in November.
The meeting for OI researchers gathered almost 150 participants and gave us more than 80 new contacts.

The most important development in 2022, was the finalization of OIFE’s formal registration process in Belgium and the expansion of the Board with 2 more people. We started to use our new bank account with KBC in Belgium and managed to transfer all our assets from our German bank. In October the 1st OIFE was dissolved as a legal entity in the Netherlands. The planned task of developing a new long-term strategy was postponed until 2023. This was due to the lack of resources and time available. The Board needed to prioritise ensuring all legal, accountancy and governance measures were in place as per Belgium law.

More and more companies are moving into the OI universe, which gives us more work, more information, more possibilities of patient involvement and new and interesting projects to manage. It also opens up wider possibilities of applying for educational grants. We still have a focus on diversifying our funding, to avoid becoming too dependent on pharma. Our financial situation improved in 2022, which made it possible for us to buy in professional support for certain tasks such as the OIFE Investigator Meeting and the Topical Meeting in 2023.

OIFE is still growing and in 2022 we welcomed two new associate members in Canada and Kazakhstan.

During 2022 many different people helped us represent OIFE in various meetings and contributed to various tasks. This included elected volunteers, MAB members, appointed volunteers, ad hoc volunteers, patient advocates in policy work and patient representatives in research & development.

We send a big thank you to all the formal and informal volunteers of the OIFE! Thank you also to all collaborators, for wanting to work with us in such a constructive way.

On behalf of the Executive Committee

Ingunn Westerheim - OIFE president
THE ORGANIZATION:

Our vision, mission and goals:

Our mission is connecting and empowering organisations, professionals and individuals to improve the lives of people with OI.

International networking is still the most important activity for OIFE. We keep ourselves informed by attending events, talking to all kinds of stakeholders, and bringing the right people together, when needed.

Our vision remained unchanged:

“Children and adults with OI living active and independent lives - with access to competent healthcare and necessary social support.”

In accordance with our strategy plan 2018-2022 our goals were:

- **represent** our members on an international level, by being the voice of people with OI
- **grow an international network** between professionals, organisations, individuals and other stakeholders;
- **advocate** for access to competent healthcare and social support;
- encourage **scientific research** on OI;
- **empower** our members by sharing information, knowledge and best practices;
- **support development of OI organisations** and local support in more countries;
- **guide individuals** towards information, healthcare and support.
Our member organisations

OIFE had **39 member organizations** at the end of 2022.

This included **20 European groups**, who are national organizations with full voting rights:
We had 15 associate members, who are national organizations outside Europe without voting rights:

- **Australia**
- **Canada**
- **Chile**
- **China**
  (China Dolls and Zero One)
- **Ecuador**
- **Ghana**
- **India**
- **Kazakhstan**
- **Mexico**
- **Nigeria**
- **Panama**
- **Peru**
- **South Africa**
- **USA**

In addition to the non-European associate members, we had **four supporting member organizations** consisting of research foundations (AHUCE Foundation, Care4BrittleBones and the Belgian AFBOI) as well as one organization providing aid & support for individuals (Padrinos).

We welcomed **two new member organizations in 2022**:

- **Canada** - Canada Osteogenesis Imperfecta Society (COIS)
- **Kazakhstan** - Patients with Rare Bone Diseases
THE ADMINISTRATION

OIFE moved from the Netherlands to Belgium

In April 2022 OIFE moved our formal registration from the Netherlands to Belgium for logistical reasons.

Between April and October 2022, assets & liabilities were transferred to the new legal entity in Belgium. OIFE in the Netherlands was dissolved October 1st 2022 and the German bank Sparkasse Ansbach was closed. We could then start using our new bank account in KBC in Belgium.

The following terminology changed because of new Statutes:

- The former Executive Committee (EC) was from April – October known as the Interim Board.
- From October 2022 a permanent Board was elected, replacing the Interim Board.
- The OIFE General Assembly is no longer called the Board, but still has the same power and mandate as before, except from decisions regarding associate membership.
- The contact persons of our member organizations were from 2022 called representatives, except when voting at our GA where they are delegates.
The General Assembly (Annual General Meeting)

The highest authority of the OIFE is the General Assembly, which normally comes together once a year. It consists of one delegate from each member organization. Only European members have voting rights, but all official representatives receive invitations and the same information.

The Board

The General Assembly elects members of the Board who runs the day to day business of OIFE. In 2022 the Executive Committee/Interim Board and Board consisted of the following people:

Time period January – October 2022:

- **PRESIDENT:**
  - **INGUNN WESTERHEIM, NORWAY**
  - RE-ELECTED FOR 4 YEARS IN 2019

- **VICE - PRESIDENT:**
  - **DACE LIEPINA, LATVIA**
  - ELECTED FOR 4 YEARS IN 2018

- **2ND VICE - PRESIDENT:**
  - **BRUNO VAN DIJK, BELGIUM**
  - ELECTED FOR 4 YEARS IN 2020

- **TREASURER:**
  - **COREEN KELDAY, UK**
  - ELECTED FOR 4 YEARS IN 2021

- **COMMUNICATION MANAGER:**
  - **ANNA ROSSI, ITALY**
  - RE-ELECTED FOR 4 YEARS IN 2020
Time period October – December 2022 – the following people were elected to the new Board

**PRESIDENT:**
INGUNN WESTERHEIM, NORWAY  
ELECTED UNTIL 2023

**VICE - PRESIDENT:**
BRUNO VAN DIJK, BELGIUM  
ELECTED UNTIL 2024

**TREASURER:**
COREEN KELDAY, UK  
ELECTED UNTIL 2025

**COMMUNICATION MANAGER:**
ANNA ROSSI, ITALY  
ELECTED UNTIL 2024

We sent a big thank you to our vice president Dace Liepina who resigned after 4 years of service. The following people were elected as new members of the Board for 1, 3 and 4 years:

**RENA T A H O E S**  
ELECTED FOR ONE YEAR IN OCTOBER 2022

**MALENE SILLAS**  
ELECTED FOR ONE THREE YEARS IN OCTOBER 2022

**STEPHANIE CLAEYS**  
ELECTED FOR FOUR YEARS IN OCTOBER 2022
The EC/Board had video calls approximately once a month as planned. The Board had 13 online meetings in 2022 and one face to face meeting in Mechelen, Belgium from November 26-27.

### The Volunteers

The EC/Board is supported by the following formally appointed volunteers:

- **Stefanie Wagner**
  - Secretary
  - Germany

- **Kevin Vanantwerpen**
  - Webmaster
  - Belgium

- **André’ Wittwer**
  - Webmaster
  - Norway

- **Stephanie Claeys**
  - Youth Coordinator
  - Belgium

- **Simey Truong**
  - Youth Coordinator
  - Germany

- **Oliver Semler**
  - Chair of OIFE’s Medical Advisory Board
  - Germany

- **Ute Wallentin**
  - Social Network Coordinator
  - Germany

- **Maria Barbero**
  - Social Network Coordinator
  - Spain

- **Rebecca Tvedt Skarberg**
  - ERN BOND ePAGs
  - Norway

- **Claudia Finis**
  - ERN BOND ePAGs
  - Germany

In addition to the formal volunteers, OIFE is supported by other volunteers on project & ad hoc basis.
Positive developments/happenings:

- Lots of **new requests for collaboration** indicated increased visibility as the OI umbrella organisation.
- More interest in **research on OI** – especially from industry
- **OIFE Investigator Meeting** was a success and brought us lots of **new contacts**.
- The **Pain and OI project** was kicked off with **4 constructive workshops** in 2022
- Our **knowledge about unmet needs of people with OI increased** (for instance through IMPACT). This will be documented and systematized in 2023/24.
- We opened **new bank and PayPal accounts** – registered in Belgium
- Received an **increase in grants and donations** from industry, which makes it possible to buy services
- **OIFE Magazine** received positive feedback, especially from professionals
- **Two successful campaigns** created awareness about the needs of people with OI
Challenges:

- It’s increasingly difficult to get feedback from OIFE representatives.
- OIFE has different target groups with very different needs (researchers, industry, PAOs)
- Reaching interested people through social media (especially Facebook) is increasingly difficult due to changing algorithms.
- The moving process to Belgium took a lot of time and resources.
- Tax rules, accounting and our need for legal advice (formal or pro bono) were not completely settled/clarified.
- We temporarily lost our opportunity to do Facebook fundraisers due to change from Netherlands to Belgium.
- Decrease in donations and grants from other sources – made us move closer to the 50% limit of pharma funding.
- Documenting in kind hours takes time and resources, but is a necessity.
- Companies all work in different ways when it comes to patient involvement and processing of funding applications.
- We did not have time to create a new long-term strategy.
OIFE EVENTS:

OIFE Leadership Meeting
OIFE’s 2nd Leadership Meeting took place on January 24th. More than 25 representatives from most of our European member organizations attended. Topics included future events, restructuring of OIFE, IMPACT survey, news from research and clinical trials, the Pain & OI project, EU advocacy, ERN BOND and our upcoming campaigns for Rare Disease Day and Wishbone Day.

OIFE Establishing Meeting under Belgian Law
March 8th we organized a simplified establishing meeting of the new OIFE with Board members from four of our member organizations as new founders. The founders approved new Statutes developed in collaboration with a lawyer, they formally established OIFE as a new legal entity under Belgian law and elected the new Interim Board. After this, a simplified membership application process was organized, where all the member organizations of OIFE had to re-confirm their membership and pledge that they wanted to be an active member of the OIFE.
OIFE Annual General Assembly

Originally our plan was to organize the general assembly 2022 in Valencia, Spain. Due to insecurity related to the pandemic, we decided in February to do the AGM online. Saturday June 4th we were ca 35 people representing 18 member organizations, who came together for OIFE’s Annual General Meeting (AGM) 2022 on Zoom. The agenda included internal news & updates approval of annual reports and dissolution of OIFE 1 in the Netherlands. The general assembly unanimously voted to approve the annual and financial reports for 2021. The Interim Board was given the mandate to finalize the process of moving OIFE to Belgium and dissolving OIFE in the Netherlands. The members also heard about future events.

1st General Assembly under Belgian law

On October 23rd our members came together online to elect a new and expanded Board, increasing from 5 to 7 people. In advance of the meeting, the new Statutes were sent to the members, and changes were possible to suggest within a deadline. There were 29 participants who attended with 16 voting members. The OIFE Board presented news and future activities of OIFE. Members were also informed that the process of re-establishing OIFE in Belgium had come to an end.
On November 18th OIFE hosted our very first OIFE Investigator Meeting online. The programme committee consisted of OIFE MAB members Antonella Forlino (IT), Lars Folkestad (DK), Liidia Zhytnik (ET) and Claire Hill (UK) and we had several meetings during 2022. Ingunn was the conference organizer and we hired the professional conference consultant Janet Crompton to help. OI-researcher Paul Coucke (BE) also helped out during the event in addition to the OIFE Board and volunteers.

More than 140 participants from Europe and beyond took part in the online event which mainly included researchers (basic and clinical) and clinicians, but also some industry representatives, patient representatives and students. The programme included interesting talks about what is going on in European OI research (basic and clinical) as well as short workshops on how we can collaborate more closely within European OI research. The event had very positive feedback and a large majority wanted the event repeated as an annual online event.
The pandemic had prevented us from organizing youth events for several years, we therefore decided to organize two events in 2022. The first one in Belgium in spring and a second one in Poland in autumn.

The first event took place in Bruges (Brugge), Belgium from May 5 – 8.

The event was organized by the OIFE Youth Coordinators and the Belgian OI-organization ZOI. Stephanie Claeys was the event coordinator. There were 38 participants from nine countries. The programme included social activities like darts, park life, creative writing workshop, sightseeing, beer tasting, city game and a Wishbone Day dinner at a restaurant together with members from ZOI.

The second OIFE Youth Event of 2022 was supposed to take place in Gdansk, Poland, but had to be cancelled due to the tragic death of one of the organizers.
OIFE PROJECTS:

Restructuring OIFE (OIFE 2.0)

The process of re-establishing OIFE in Belgium came to an end in 2022. After a long and bureaucratic process with many phone calls, video calls and emails to Sparkasse Ansbach our money was moved from the German bank to our new functional bank KBC in Belgium.

Also in 2022 we used a lot of time and energy on activities like finalizing new Statutes, establishment meeting, registration in different national databases, dissolvement, meetings with Dutch and Belgian lawyers, transferring money to new bank, new PayPal, reconfirming memberships, finding out about VAT and accounting and rules for non profits in Belgium.

Other European federations (Hemophilia, Huntington and Cystic Fibrosis) were of great help in this process.

The IMPACT Survey

The IMPACT survey is an international research project exploring the impact OI has on people’s lives. The project was established in April 2020 and is a joint initiative between the OIFE, the OIF & the company Mereo BioPharma.

Five central OI-professionals from Europe and US/Canada are part of a steering committee led by Frank Rauch. Our goal is to use data from IMPACT to enable better treatment and care, and to support availability of potential future treatments for OI.
Five scientific articles were planned in 2022 and 2023:

➔ the scoping review that took place before the survey,
➔ methodology and demographics,
➔ clinical and humanistic impact
➔ access to healthcare
➔ economic impact on people with OI and the healthcare system.

However, due to the amount of data, and the fact it was in 8 different languages, it has taken much longer than expected to clean and systematize. The writing of the first articles was therefore delayed. No articles were published in 2022, but nr. 1 was submitted for publication.

There were many talks and poster presentations about IMPACT at conferences throughout 2022:

➔ Rare Disease Showcase (talk by Ingunn about how we recruited)
➔ ECRD (digital poster about how we recruited)
➔ ICCBH (OIFE poster about recruitment and a poster on findings from adolescents)
➔ OI2022 (poster about recruitment and a talk by Frank Rauch)
➔ ASMBR (poster about findings from adults)
➔ ISPOR (2 posters about impact of OI on adult quality of life and prevalence of signs, symptoms and events)
➔ SIOMMS congress in Italy (1 poster about participant demographics and perception of healthcare)

Taco and Ingunn attended one meeting in the Steering Committee where two OIFE MAB-members (Lena Lande Wekre and Oliver Semler) were also represented. This came in addition to meetings between OIFE, Mereo and Wickenstones about communication on the IMPACT survey. On February 18th we had the first official meeting in the data management committee of IMPACT, to plan how the data will be managed after the project is finalized. The data management committee consists of Frank Rauch (Shriners Montreal), Tracy Hart (OIF) and Ingunn Westerheim (OIFE).
The Pain and OI project

Recruitment was done in 2021 and on January 25th 2022 we organized a kick-off of the Pain & OI project, which is a collaboration between OIFE and OIF (USA) and a group of ca. 25 dedicated professionals who have experience on pain management, pain research and/or pain & OI.

We had 21 participants from 10 countries at workshop 1, where we agreed on common goals:

1. Recommendations on how to measure pain in OI
2. Educational activities – OI & pain (incl. different types)
3. Recommendations on management of chronic pain for children and adults with pain

We organized three more workshops in 2022

- April 26th about assessment and measuring of pain in clinical trials and the clinic
- May 31st about ongoing research and uncovering knowledge gaps
- October 12 about assessment (continued) and management of pain in the clinic

In the fourth workshop we started the creation of a pain survey organized by the OI Foundation with support from the OIFE and the resource group.
We started the planning of the topical meeting on pain and its impact in February 2022 and the Pain and OI resource group provided input for the planning.

We established an organizing committee and a programme committee, which were also the applicants behind a large application for a networking grant from EJP RD. We had 3 committee meetings in 2022 and we launched the opening of registration on December 19th.

In addition to the EJP RD application, we started applying for industry grants. We hired Janet Crompton to help with project support. Dr. Lena Lande Wekre agreed to be conference chair.
A stronger BOND between us (incl. ERBF)

The goal of "A stronger BOND between us" is to further develop an informal network between different stakeholders working on OI and other rare bone conditions (RBDs). The project has several subprojects and activities. We received a grant of 10,000 euros from Kyowa Kirin International, to continue with these activities during 2022.

European Rare Bone Forum (ERBF)
OIFE kept their position as an informal member of the European Rare Bone Forum in 2022. Through ERBF we got in touch with research & development projects on rare bone conditions. Activities included a project called “Rare Bone Diseases Mobility Systematic Literature Search (SLR)” where the objectives were to investigate mobility impairments that impact daily activities and QoL for patients with RBDs and identify disease-specific assessment tools. Ingunn also took part in a focus group discussion organised by ERBF September 13th.

XLH Alliance & OIFE
We continued our collaboration with the XLH Alliance in 2022 with monthly meetings on Zoom throughout 2022 to share ideas, best practises, and potential collaboration projects.
The intention behind "Flying OI Experts" is to bring knowledge to less developed countries.

Together with the BBS and the OIF, OIFE decided to offer travel grants to researchers from low-income countries who could not afford to attend the Sheffield conference. We awarded 3 travel grants (3500 euros from OIFE) to professionals from Indonesia, Ghana and Pakistan. Sadly none of the grantees could get a visa. There was only one specific donation to Flying OI Experts in 2022, which came from the Norwegian organization NFOI.

Help to Ukraine

With the support from EURORDIS and OIFE volunteers, we established a task force and a list of resources to connect refugees from Ukraine to volunteers, patient organizations and healthcare professionals in new countries (Poland, Romania, Spain, Denmark, Germany and Italy).

Three volunteers in the task force could speak Ukrainian.

The resource list included information about what volunteers could contribute with (housing, translations, advice, guiding to medical care, information or coordination etc) and useful external resources for refugees with OI.
REPRESENTATION, ADVOCACY & NETWORKING

Representation in meetings & events hosted by others

ICCBH-CONFERENCE IN DUBLIN

Ingunn represented OIFE at the International Conference on Children’s Bone Health (ICCBH) in Dublin, Ireland from July 2 – 5. OIFE had a poster which was on display at the conference. Ingunn also paid a short visit to the ICCBH Rare Bone School on June 30th and attended the entire XLH-Symposium on July 1st, to learn more about the rare bone condition XLH.

The ICCBH conference included a lot of interesting talks and the event provided OIFE with excellent networking opportunities building relationships and making new contacts. Other OI-organizations represented included the OIF and NFOI.

THE iCAN SUMMIT IN LYON

The iCAN (International Children’s Advisory Network) Summit 2022 took place in Lyon, France from July 11-15.

It was an event for young people aged 12 to 19 from all around world to meet, exchange ideas and learn more about rare diseases and children’s rights, health and data protection. Emilija Liepina from Latvia represented children with OI, together with her mother Dace, who was the OIFE Vice Chair. They reported back via the OIFE Magazine.
OIFE Annual Report 2022

OIFE IN SHEFFIELD – THE 14TH INTERNATIONAL CONFERENCE ON OI

From August 30 – September 3 all members of the OIFE Interim Board were represented at the 14th International Conference on OI in Sheffield, UK.

In addition to the OIFE Board, a number of other representatives from the OI-community attended incl. NFOI (NO), FOICH (Chile), ZOI (BE), VOI (NL), UK (BBS) and Care4BB. We kicked off the event with an informal OIFE dinner on August 29th.

The conference was a big success and provided an opportunity for all those engaged in research and clinical practice in the field to come together and share experiences and their latest data.

A total of 290 delegates registered and 124 abstracts were accepted as posters with a further 31 oral communications. OIFE had a dedicated exhibit table, to present our flyers, OIFE passport and answer questions from interested professionals. We also made lots of new contacts.

OIFE also communicated actively before and during the event through social media.
OIFE AT GEMSTONE-MEETING IN ROTTERDAM

On September 21st OIFE was invited to the Netherlands to share our thoughts on patient involvement and research priorities of people with OI and other rare bone conditions.

The listeners were researchers belonging to the European GEMSTONE Cost Action network on musculoskeletal research.

The Cost Action is an open, interdisciplinary network welcoming academics, practitioners and relevant stakeholders to contribute to the activities of the GEMSTONE (Genomics of MusculoSkeletal traits Translational Network).

BRUSSELS INTERNATIONAL ASSOCIATION FORUM

From December 12-13 Renata Hoes (OIFE Board member) represented the OIFE at the Brussels International Association Forum, which was a large conference for international associations about trends, strategy, communication, hosting events and financial management for non-profits. Renata also got free admission to the MasterClass called Strategic Acceleration, and fed back this information and what she learnt to the rest of the Board.
OIFE attendance at online meetings hosted by others

International Rare Disease Showcase

The International Rare Disease Showcase was organized from February 1st – 3rd by Beacon, formerly known as Findacure. The online event gathered over 430 attendees and over 70 speakers from 25 different countries. Ingunn took part in the Pitch & Mix Challenge with a talk called “How the OI-community made an IMPACT”. OIFE also had an exhibit at the showcase, which provided us with new contacts for companies and professionals interested in OI.

The OIF Investigator Meeting & OIF Town Hall

The OIF Investigator Meeting in 2022 was a hybrid meeting which took place April 7. Ingunn Westerheim took part as observer via zoom and the day after she attended the OIF Town Hall Meeting for American OI clinicians and other interested parties (online). Other volunteers from OIFE also attended the event online.

Other online meetings organized by others

Meetings and conferences organised by others where OIFE attended included:

- Webinar Oslo Medicines Initiative – financing novel medicines, Jan 20th (IW)
- Webinar how to make videos with mobile phones Feb 9th (IW and AW)
- Quality of Life 4 OI-conference online, Feb 12th (several from OIFE)
- Webinar PEOF Patient Engagement on Market Value (IW)
- Webinar Aparito on video tools for measuring mobility, March 25th (IW)
- Steering Committee Norwegian registry for rare bone conditions, March 1st (IW)
- Ukraine Online OI-conference, Aug 17th (DL)
- European Haemophilia Consortium (EHC) Think Tank introduction, Sep 12th (IW)
- Webinar ICD-11 for rare diseases, Sep 27th (IW)
- Mereo Town Hall meeting (Dace and Emilija)
Online meetings and videocalls initiated/hosted by OIFE

More stakeholders than before reached out to us to talk about shared interests and potential projects. We also continued our newly developed relationships with similar federations and groups for other rare conditions, to learn and share best practices. Meetings initiated by OIFE included videocalls with the following stakeholders:

- OI-organization in South Korea & Korean professionals Jan 11th (IW)
- European Society for Pediatric Endocrinology ESPE (Amanda Helm), Jan 18th (IW)
- Care4BB Board & OIFE EC on how we can collaborate, Jan 18th (OIFE EC)
- European Huntington Association Feb 10th (CK, BVD and IW)
- European Hemophilia Consortium April 21st (IW)
- Amsterdam VUMC about the OI Variant database, June 20th (IW and CK)
- Joan Marini & Tracy Hart, August 3rd (IW)
- Isala clinic (NL), Dec 13 (IW)
- EJP RD Webinar Natural History Study grant Dec 15 and Dec 21 (IW, RTS and CF)
EURORDIS events

EURORDIS WINTER SCHOOL
EURORDIS Winter School on Scientific Innovation and Translational Research took place online March 21-25. OIFE was represented by our volunteer and MAB-member Lida Zhytnik.

EURORDIS AGM
The 25th AGM of EURORDIS took place May 18th and Ingunn Westerheim and Rebecca Tvedt Skarberg represented the OIFE. Highlights & success stories from EURORDIS 25 years were discussed and plans for the future presented. Rebecca Tvedt Skarberg, was elected as one of the new Board members of EURORDIS, which now has more than 1000 member organizations.

EURORDIS Council of Federations (CEF) in Paris
From November 8-9, Ingunn, Inger-Margrethe and Renata attended the EURORDIS Council of Federations meeting (CEF) in Paris. Among the topics were information about access to treatments and the pharmaceutical legislation, information about Rare Disease Week, future funding opportunities in research, a discussion about access to genetic testing in Europe. There was also an update on the situation for people with rare diseases in Ukraine.
RARE DISEASE WEEK IN BRUSSELS

Rebecca Tvedt Skarberg attended the preparational activities for Rare Disease Week, scheduled to take place in Brussels in February 2023.

The Rare Disease Week is an advocacy training where the participants learn about policy work, EU advocacy and it includes meetings with Members of the EU Parliament (MEPs).

Other online EURORDIS events we attended included:

- ePAG education on guidelines Jan 31st (IW and RTS)
- Ukraine Emergency Meeting March 4th (IW and LZ)
- Videocall about Ukraine relief app, March 30th (IW)
- Round Table of Companies (ERTC), April 27-28, IW attended parts of the meeting
- ECRD-conference, June 27th – 29th, IW attended parts and we had a digital poster
- Open Academy Alumni about federations, Sep 19th (IW contributed as speaker)
- Meeting about Remedi4All Nov 23 (IW, CF and RTS)
Advocacy, Representation & Networking

ERN BOND

Rebecca Tvedt Skarberg (OIFE) and Claudia Finis (DOIG) have represented OI-people as ePAGs in the European Reference Network on Rare Bone Diseases (ERN BOND).

During 2022 Rebecca and Claudia attended numerous VCs in ERN BOND which included meetings with the Steering Committee and the various Work Groups (WG).

On February 8 and 9 OIFE had several representatives who attended the annual meeting and 5 year conference of ERN BOND.

On September 26th the following people attended the online network meeting of ERN BOND: Rebecca (ePag) and Lida and Ralph from OIFE’s Medical Advisory Board.

On June 23rd OIFE was represented at a webinar about strengthening the European Reference Networks (ERNs), which include ERN BOND.

The meeting brought a lot of different perspective on the opportunities and challenges of the ERNs and will be useful in our coming advocacy work.

We also organized several informal meetings between OIFE and representatives from ERN BOND to talk about shared projects – ongoing and potential.
EuRR-Bone

OIFE had 3 patient reps. and 2 MAB-members attending the annual meeting of the European registry for rare bone conditions (EuRR-Bone) on February 8th. It was a very informative meeting explaining the progress in the various parts of the project, including the development of a specific module for OI.

During the year, we also organized informal meetings between OIFE and representatives from EuRR-Bone and we were represented at the following meetings:

- EuRR-Bone patient organizations, June 27th (IW, CF and RTS)
- EuRR-Bone Nov 28 (IW, CF and RTS)

Several different people from OIFE have also been co-authors on abstracts about EuRR-Bone.

EUNetHTA & EURORDIS Task Force on HTA

EUnetHTA is a network between all the European health technology assessment (HTA) bodies, who makes decision about approval and reimbursement of new therapies.

OIFE signed up as part of the EUNetHTA Stakeholder Repository in 2022. Inger-Margrethe S. Paulsen has been our main contact for the EUNetHTA and together with Ingunn she created OIFE’s response to the EUnetHTA 21 public consultation on patient involvement, which was submitted in August.

Claudia Finis attended the EUnetHTA 21 Roundtable with Patients and Healthcare Professionals May 25. OIFE was also represented at several EUnetHTA 21 Stakeholder Forums in 2022. Inger-Margrethe has also been a member of the EURORDIS Task Force on HTA, where the first meeting took place in Paris December 9 2022. Inger-Margrethe also provided the General Assembly with an overview of this topic during our annual meeting.
Events hosted by OI-organisations

OIFE was not represented with talks at any national OI-meetings in 2022.

Networking

In addition to the list of subscribers and our industry list, OIFE keeps a list of more than 1000 professionals worldwide, that is mainly used to distribute the OIFE Magazine, invitations for scientific conferences and information about research grants. OIFE Investigator meeting added ca 80 new researchers to our list during 20220
When an OIFE representative attends a meeting, conference or when a new project is kicked off, we make an effort to post about it on OIFE social media and/or a blogpost on the website.

**Rare Disease Day Campaign**

The main objective of Rare Disease Day is to raise awareness amongst the general public and decision-makers about rare diseases and their impact on peoples’ lives. It is a globally-coordinated movement working towards equity in social opportunity, healthcare, and access to diagnosis and therapies for people living with a rare disease (PLWRD).

The 2022 theme chosen by EURORDIS was Equity. Therefore the OIFE campaign also focused on what Equity is and means, trying also to outline how people with OI might need adaptations or extra effort to have access to good quality healthcare, treatment and services.

The first week of the campaign was designed to create awareness about the meaning of the word Equity and the actions that some organizations of PLWRD have been taking and working on, such as the UN Resolution On Persons Living With A Rare Disease and the project Rare 2030.
Following that, the campaign moved on to show what was done to improve the understanding and more equal opportunities to access good quality healthcare, treatment and services through initiatives like the IMPACT survey.

The campaign also featured the stories, experiences and examples from member organizations and from individuals who represented the OI community in different arenas, events or conferences.

We encouraged member organisations to get involved by sharing information and posts by using the hashtags: #ShareYourColors and #LightUp4Rare and #RareDiseaseDay and others.
Wishbone Day and #1VOICE4OI campaign

Every year the OI community looks forward to the 6th of May to celebrate Wishbone Day. The aim of this day is to create awareness about the varied lives of people with OI and the challenges and solutions to living full and happy lives. It is quite common to refer to Wishbone day as the collective voice of people with OI, as in this day the community is invited to talk about OI and about the things that matter most to OI people, in their own way. The hashtag #1voice4OI offered a stage to the OI community to come together, raise their voices and share the messages or make a statement for improving awareness on OI and/or on all the OI related topics which might go unseen or not prioritized.

We are delighted that some of the most known OI activists as well as some VIP OI faces also agreed to be part of this campaign.
OIFE uses social media to actively share contents, and to promote our events, activities, campaigns, surveys etc. We also actively share examples, news and stories from other stakeholders, with content we believe can be of interest to the larger community.

On Facebook and Instagram our main target groups are people with OI and the general public. On Twitter and LinkedIn the main target groups are OI-professionals, researchers and industry.

During 2022, OIFE were more active on Facebook, Instagram and LinkedIn, our Twitter and YouTube accounts were used less. These were our social media statistics December 31, 2022:

- Facebook-page: 3800 followers (increase of 211 followers from 2021).
- The annual reach (number of unique accounts that saw OIFE contents) on Facebook increased by 17,5% in respect to the previous year.
- Instagram: 990 followers. The annual reach on Instagram almost doubled from 2021.
- LinkedIn: 609 followers
- Twitter: 1337 followers
- YouTube: 62 subscribers

OIFE Communication Manager also attended meetings to advice on communication activities connected to the IMAPCT survey and national initiatives such as the BBS #OICanCampaign.
We published three editions of OIFE Magazine in 2022. One edition in 2022 was a special edition on the topic “Pregnancy & Reproduction in OI“. Target group includes professionals, people with OI, collaborators and industry contacts – between 1500 and 1600 recipients.

The content range from news from OIFE, interviews with researchers, clinicians, OIFE volunteers, artists, activists and athletes with OI or just interesting people with a connection to OI. Many of the articles are also published as blogposts on our website and shared on social media, something which increases the reach of the magazine substantially. The main editor and distributor of the magazine is our secretary Steffi in close collaboration with Ingunn.

**OIFE Website**

OIFE’s website has been regularly updated with a focus on OIFE-related activities and projects. We published ca 65 blogposts in 2022 about events and projects as well as republishing articles from the OIFE Magazine. The event calendar was also regularly updated with both community events and also events relevant for clinicians and researchers working with OI.

**Internal communication**

Approximately 25 internal email newsletters were sent to the OIFE representatives/delegates during 2022. The email system of OIFE has been changed because there is more and more often a need to send emails to the European member organizations only. From 2022 we have 3 oife.org group emails to reach our member organizations: europe@, associate@ and supporting@
OIFE believes that all clinical trials and research projects affecting OI directly should have some kind of patient involvement. Patient involvement can happen in different ways and in different phases of a project.

**Patient involvement**

We provided advice from patient perspective to the following commercial stakeholders in 2022:

- Mereo Biopharma & Ultragenyx
- UCB & AMGEN
- Sanofi
- BOOST Pharma
- Angitia Bio
- Azafaros
- Sirana Pharma
- Quince Therapeutics

OIFE has signed confidentiality agreements (CDAs) with many of these companies.

In June 2022 OIFE was asked to help with recruitment to a patient advisory panel for adolescents. The purpose of the panel was to provide input to one of the clinical trials of UCB and took place in October. Begonya Nafria Escalera from Fundacio Sant Joan de Deu in Barcelona was the facilitator hired by the company. Dace Liepina and Inger-Margrethe Stavdal Paulsen recruited teenagers and parents from Norway and Latvia. Dace and Emilia also attended the panel.
We have also had contact with the following companies or industry related stakeholders who are not directly working with OI:

- Kyowa Kirin International
- PuREC
- KAL Research Initiatives
- Pega Medical R&D
- Alexion/Astra Zeneca
- Aparito
- Putnam Associates

Inger-Margrethe S. Paulsen represented OIFE in a joint scientific consultation (JSC) in EMA & EUNetHTA.

During 2022 OIFE started developing a contact list of people who can represent us in regulatory affairs, because these should not be the same people interacting with pharma.

We have also provided advice and helped with recruitment for the non-commercial TOPAZ trial which is a Clinical Trial run out of Edinburgh University, with sites in various European Countries.

**OIFE Medical Advisory Board (MAB)**

There were no changes of members in the OIFE Medical Advisory Board in 2022. Dr. Oliver Semler has chaired the MAB who had their first meeting on January 26th. Topics included information from OIFE, a proposal from dr. Anticevic on minimum criteria for OI health care providers and guidance from OIFE MAB on how OIFE should deal with the increasing number of requests for support from research projects and consortiums preparing grant applications.

The second meeting of OIFE MAB took place October 12 and included news from OIFE, the Pain and OI Project and a discussion around which information we should develop for the OIFE webpage. We also discussed unmet needs in OI and how some of the knowledge gaps might be filled by the IMPACT survey.
Access to new and innovative treatments

There are many different treatments being investigated for OI at the moment. Some are in a preclinical phase (animal research) and some are in clinical trials (where people take part in the trial): Stem cells, gene therapy and different pharmaceutical products. Decisions about policy, politics and reimbursement are made in each and every country.

We have continued our effort to ensure that national organisations are knowledgeable on regulatory processes and health technology assessments. This was also a topic in our annual survey to the OIFE representatives. We have also tried to collect and systematise data about the current situation for people with OI in initiatives like the IMPACT survey and others. The data from these surveys can be used in future processes about approval and reimbursements.

Research projects where OIFE was part of consortiums

In January 2022 OIFE had several different requests to support grant applications for various research projects. After discussions with the OIFE MAB, we decided to support 3 applications by being part of a consortium. Sadly none of them received funding: We also supported two other projects by supplying a support letter.

SANOFI project on pain

In May 2022 OIFE and the OIF agreed to be part of a steering committee on Sanofi’s pain project which includes literature search and qualitative interviews in 4-5 different countries, incl. UK, US and Australia.

The goal is to investigate how and if pain can be used as potential outcome measure in clinical trials.
Project on care pathways in Europe

OIFE has also helped with recruitment to a project about care pathways for people with OI in Europe, run by the agency Putnam Associates (USA). We have attended 5 meetings connected to this project and provided input to question guides. The project was funded by Mereo Biopharma. Around 50 healthcare professionals and people with OI/parents from various European countries, were recruited to give a 1 hour qualitative interview on care pathways in their country. Topics included transition, GP vs. hospitals, collaboration between HCPs, access to expert centers, MDT clinics etc. Richard Keen, Valerie Cormiere Daire and Ingunn Westerheim provided advice to the company. The results are currently being analyzed and the goal is to share the outcomes with the community.

The OI Variant Database

In 2021 the directors of the Amsterdam UMC Genome diagnostics laboratory took over the curation of the database after Dr. Dalgeish retired from the university in Leicester, UK. In 2022 OIFE transferred the donation of 1600 euros, which originated from OI Australia to the Amsterdam UMC for the upkeep of the database. Several different representatives from OIFE have also been co-authors on abstracts about the OI Variant database.

Surveys that OIFE promoted in 2022

OIFE promoted the following surveys to our members in 2022:

- Survey about PROMS (Ultragenyx) – how to measure progress in clinical trials (besides counting fractures): Measuring pain, mobility, mental health, overall health etc.
- Survey about PROMS in EuRR-Bone
- Survey on pregnancy & family planning (ERN BOND)
- Survey on prenatal diagnosis and genetic counselling (Shannon Bonner, US)

Co-Authorship on and abstracts and scientific articles

In 2022 OIFE contributed to a number of abstracts and scientific articles as co-authors. This included the IMPACT survey, EuRR-Bone, The LOVD database, BBS Covid19 survey and more.
Peer groups on Facebook

We have two peer groups for different target groups on Facebook one for adults who have OI themselves and one for young people with OI between 16 and 35. We don’t have a dedicated group for parents, but we guide parents to the American Facebook group for parents if needed.

Facebook-group “OIFE – OI & adult health”

OIFE’s actively moderated Facebook-group “OIFE – OI & adult health” is used by individuals to have peer support from other OI adults with similar experiences. The group increased from 1190 members to 1259 members in 2022. The members come from more than 75 countries. The group was moderated by Ute Wallentin, Ingunn Westerheim, Julia Piniella, Rebecca Tvedt Skarberg and Taco van Welzenis. Through the group, we also receive feedback about what the health concerns of adults with OI are.

Topics that have been discussed in 2022 included:

- Pain management (by far the biggest topic)
- Medical treatment options incl. bisphosphonates, stem cells and hormones
- Arthritis and joints
- Surgery & non healing (rodding, spinal fusion, lengthening/shortening etc)
- Dental implants, TMJ and other dental issues
- Cardiopulmonary
- Neck problems
- Ear problems
- GI & diverticulitis
- Mental health
Facebook Group - OIFE Youth Only
The target group is for people with OI between 16 and 35. There was very little activity in the group in 2021, so we suggested to close it. However – some of the group members were very much against and we decided to keep it open for a while longer. The group had 174 members end of 2022. OIFE's Youth Coordinators were moderators.

Social Network
In the autumn of 2022 Maria Barbero agreed to support us with the incoming requests from individuals via e-mail, social media and WhatsApp.

Most requests in 2022 came from parents, fewer from OI adults. Often requests come from countries without an OI-organisation and can be anything from need for advice on how to find an OI-group, how to find competent care, the wish to emigrate to another country to requests for financial support and mobility equipment. Sometimes we get requests from a person in a country with a functioning organisation and in that case, we forward it to the local support OI-association or cooperate closely with them.

OIFE does not in any case provide financial support to individuals. But we give advice and peer support and help to find OI-groups or doctors with experience locally. We are still in need of more volunteers to help with replies to these requests.

In 2022 incoming requests came from all over the world, except from the bigger Asian countries. But we had requests from the US, the Philippines, various African countries and from inside Europe.

We cannot help when someone asks for money or help to get Visa for emigration into other countries, but often we can provide basic information on OI and addresses of organizations, clinics and connect families from a certain country with others we know.

Sometimes we receive a message with an update on a child from an email that dated many years back. Or a former OI-child gets back to us later and we can see what happened to the person during the last years. This is always very interesting and rewarding.
We send a big thank you to all the formal and informal volunteers of the OIFE! Thank you also to all collaborators, for wanting to work with us in such a constructive way.