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| THANK YOU!                                                                        | 38 |

OIFE Annual Report 2020
PRESIDENT’S STATEMENT

The year 2020 was a year like no other, both for OIFE and our worldwide surroundings.

At the start of the year we had a lot of meetings and conferences planned and organised by OIFE and our collaborating partners. We attended some important EURORDIS meetings at the beginning of the year before Covid-19 hit and country by country closed their borders.

Fortunately OIFE didn’t have any extra costs to speak of because of all the cancellations.

Covid-19 has of course affected our member organizations and their ability to host face to face AGMs, do fundraising, recruit members, board members and volunteers. Some of the problems were due to Covid-19 and some were just general challenges reinforced because of Covid-19. OIFE invited the organizations in a formal letter to get in touch with OIFE’s Vice president Bruno if they needed support and advice.

In 2020 we gained two new associate members and two organizations left us because they were no longer active in OI. During the year it became clear to us that we needed to clarify the role of the delegates. We started to develop an onboarding document for new delegates, that could also clarify the role for existing delegates.

The EC has continued working well together through monthly virtual meetings, but lack of time is still the big critical factor. We therefore continue our work to recruit more volunteers, more experienced patient representatives and preferably some kind of paid staff or hired services.
In accordance with OIFE's strategy plan these goals has been pursued:

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

Even if both OIFE and our member organizations were deeply affected by Covid-19 in 2020, we still feel we have reached important goals and milestones – especially within the domains of communication, networking and research. We published four well received magazines, we kept our web and social media up to date and we had two very successful campaigns on social media. This contributed to an increase in followers and more visibility for OIFE.

For the first time we were invited into research consortiums with potential of direct funding for the OIFE. However, being involved in R&D is immensely time consuming and a lesson learned is that research should be directly relevant and very important for the OI-community for the OIFE to get actively involved.

We would like to pay a tribute to the three important people who passed away in 2020: First Gemma Geisman, who founded the OI Foundation 50 years ago, then Peter Radtke who founded the German OI-organization and last but not least Margaret Grant, who founded the Brittle Bone Society as the first OI-organization in the world. May you all rest in peace. The OI-community will be forever grateful for what you all started.

On behalf of the Executive Committee
Ingunn Westerheim - OIFE president
The umbrella organization Osteogenesis Imperfecta Federation Europe (OIFE) consisted of 35 different organizations at the end of 2020.

This included 18 European member organizations, who are national organizations with full voting rights: Austria, Belgium (Flemish), Denmark, Finland, France, Germany, Italy, Latvia, The Netherlands, Norway, Poland, Portugal, Romania, Russia, Spain, Switzerland, UK & The Republic of Ireland (BBS) and Ukraine.

At the end of 2020 we had 13 associate members/partner organizations, who are national organizations outside Europe without voting rights: Australia, Chile, China, Ecuador, Georgia, Ghana, India, Mexico, Nigeria, Panama, Peru, South Africa and the USA (OI Foundation). In addition to the non-European associate members, we had four supporting member organizations consisting of research foundations (Care4BB, AHUCE Foundation and the Belgian AFBOI) as well as organizations providing aid & support for individuals (Padrinos).

We gained two new member organizations in 2020:

- The Indian Osteogenesis Imperfecta Foundation (IOIF)
- Fundación de Osteogénesis Imperfecta Chile – FOICH

The following organizations left the OIFE in 2020:

- The Swedish umbrella RBU, left OIFE in 2020 because they no longer worked with OI.
- Supporting member HOI was dissolved in 2020, because the chair person Hinke Panjer passed away and nobody was able to continue her work.
THE ADMINISTRATION

The Board

OIFE’s activities are overseen by the Board, which consists of one delegate from each organization. Only European members have a vote in the Board, but delegates from all organizations receive information. Approximately 30 internal email newsletters were sent to the delegates during 2020.

The Executive Committee (EC)

The Board elects members of the Executive Committee (EC), who run the day to day business of OIFE. In 2020 the EC consisted of the following people:

- **INGUNN WESTERHEIM**
  - President
  - Norway
  - re-elected for 4 years in 2019

- **DACE LIEPINA**
  - Vice - President
  - Latvia
  - elected for 4 years in 2018

- **BRUNO VAN DIJCK**
  - 2nd Vice - President
  - Belgium
  - elected for 4 years in 2020

- **CÉU BARREIROS**
  - Treasurer
  - Portugal
  - re-elected for 4 years in 2017

- **ANNA ROSSI**
  - Communication Manager
  - Italy
  - re-elected for 4 years in 2020

The EC continued having videocalls approximately once a month in 2020 as planned. 13 EC videocalls were held during 2020. One of those were a longer week-end meeting on Zoom on April 3rd and 4th. Bruno Van Dijck participated as an observer and was later elected as 2nd Vice-President, to fill the vacant position after Ida Männistö.
The Executive Committee is supported by the following formally appointed volunteers:

- **STEFANIE WAGNER**
  Secretary
  Germany

- **OLIVER SEMLER**
  Chair of OIFE’s Medical Advisory Board
  Germany

- **IVAR TROOST**
  Webmaster
  The Netherlands

- **ANDRE’ WITTWER**
  Assistant Webmaster
  Norway

- **UTE WALLENTIN**
  Social Network Coordinator
  Germany

- **STEPHANIE CLAEYS**
  Youth Coordinator
  Belgium

- **MARIE HOLM LAURSEN**
  Assistant Youth Coordinator
  Denmark

- **REBECCA TVEDT SKARBERG**
  ePAG ERN BOND
  Norway

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

- A successful AGM on Zoom with a record number of participants from all continents.
- Two successful campaigns on social media – incl. Rare Disease Day and Wishbone Day
- Four editions of OIFE Magazine with positive feedback, especially from professionals
- An increasing number of members in our peer group “OI & Adult Health”
- A more solid and predictable financial situation, mostly due to grants from industry.
- A new financial policy for OIFE was finalized and adopted
- Invitations to be directly involved in several international project on research & development, with potential of direct funding for OIFE.

- Development of a database of potential patient representatives
- A constructive collaboration with Mereo Biopharma and OIF on the IMPACT survey
- Development of a valuable collaboration with similar federations like the XLH Alliance & European Huntington Association (EHA).
- Increased activity and visibility within EURORDIS, through attendance at many events

It's our view that OIFE is seen as an attractive and trustworthy partner to collaborate with. We are more frequently contacted by stakeholders instead of having to make the first initiative ourselves.
Challenges

Our challenges were as most other organizations affected by the Covid-19 virus.

- All face to face meetings (AGM, Youth Event) had to be cancelled due to Covid-19.
- Most events we were planning to attend in 2020 were cancelled in its original form or postponed, but most took place online.
- Work- and family situation of EC-members have been substantially affected by Covid-19.
- Many hours were used on R&D projects, without the payout we had hoped for.
- OIFE’s logistical challenges got even worse - especially with our German bank account.
- A substantial amount of our income in 2020 came from pharma.
- We struggled to come up with attractive youth activities
- Reaching target groups via email and recruiting new subscribers to OIFE Magazine became more difficult because of spam filters and GDPR restrictions.
- What we regard as competing initiatives developed in our surroundings during 2020.
- The amount of e-mails, requests and meetings increased also in 2020.
OIFE EVENTS

OIFE AGM 2020
We organized a two part meeting on Zoom on May 9th. Part one (66 participants) included approval of annual reports, budget and elections. We welcomed Bruno van Dijck as the new 2nd Vice President of OIFE.

In addition to European organizations (all but one) and three supporting members, we had representatives from organizations and invited guests from all different continents including Peru, USA, Chile, Ghana, Nigeria, India and Australia.

We had also invited people from Mereo Biopharma, our Medical Advisory Board as well as contributors from other rare bone communities, including XLH and HPP.
The 2nd part of OIFE AGM (62 participants) was dedicated to emerging treatments for OI and a presentation about plans for the IMPACT survey. Three representatives from Mereo Biopharma were present at OIFE AGM to answer questions. OIFE AGM part two included talks about:

- News on BOOSTB4 (Cecilia Götherström)
- News on setrusumab project (Mereo Biopharma)
- Access to treatments for rare bone diseases (Oliver Gardiner & Paul Connor)
- Registries & patient data (Lena Lande Wekre)

Between 70-75 people attended the event in total. 37 people answered the evaluation form with a overall rating of 46 % excellent and 49 % very good.

OIFE Youth Event
The OIFE Youth Event 2020 was planned to take place in Krynica Morska (Gdansk, Poland) in August 2020. Together with the local organizers, we decided to postpone the OIFE Youth Event in Poland to 2021. Since the decision was made early, no cancellation costs were inflicted.
Representation in meetings & events hosted by others

OIFE was planning to attend a number of European meetings hosted by others in the time period March to May 2020. Because of Covid-19 most things were postponed or cancelled in its original form and moved online, which made it possible for a wider audience to attend. We attended more or less all the meetings as planned only in another format.

Events hosted by OI-organizations

OIFE had several representatives attending both the OIF National conference and the Annual conference of the Brittle Bone Society (BBS).

We also attended most of the webinars connected to Covid-19 hosted by the OIF and the BBS.

During the year we were also represented at national events hosted by the OI-organizations in Germany, Norway, Austria and India as well as a workshop for the OI-organizations in Ibero-America, initiated and hosted by FOICH (Chile).
**ICCBH Virtual Forum**

Since the 14th conference on OI (OI2020) was postponed until 2021, the International Conference on Children’s Bone Health (ICCBH) decided to do a virtual conference in November 2020 as a replacement. After an initiative from OIFE, the ICCBH invited OIF and OIFE to host a workshop on patient involvement at the ICCBH Virtual Forum on November 18th.

Ingunn Westerheim, OIFE & Tracy Hart (OIF) hosted more than 50 participants from Europe, US, Canada and beyond.

The workshop included 3 talks about patient involvement from different perspectives as well as a constructive Q&A and discussion with active participation from OI-experts, clinicians, researchers and patient representatives. There were several people from OIFE attending the whole conference, which brought interesting talks and very constructive workshops with input from researchers, clinicians and patient representatives from the OI and rare bone community.

**ECTS conference**

The annual ECTS Congress brings together health and science professionals to exchange latest advances, challenges and controversies in bone and calcified tissues field. The 47th ECTS congress went virtual in 2020. Live Prime Time sessions were held from 22-24 of October. Lidiia Zhytnik represented OIFE. She had free admission thanks to OIFE’s membership in the European Rare Bone Forum (ERBF).
Representation in other meetings & events

In addition to meetings mentioned in other sections of this report, we attended the following:

- Webinar Care4BB about plans for 2020, March 10th (IW)
- OIF Covid19 webinar, March 19th
- OIF Mental Health & OI Webinar, March 26th
- VC Chan Zuckerberg Initiative, April 7th (IW)
- Webinar European Rare Bone Forum on patient engagement, May 11th (IW)
- Brittle Bone Society Webinar on Covid19, May 28th
- ERBF Webinar Genetics of Rare Bone Diseases Sep 17th (IW)
- Webinar on Strategies for Annual Fundraising Oct 27th (BvD)
- ERBF webinar QoL-research Oct 29th (4 patient representatives represented OIFE)
- Launch of Rare Impact report Nov 23rd (IW)
- EMA-meeting on orphan drugs (IW)
- Margaret Grant Memorial Dec 18th (IW and UW)

Videocalls & phone conferences hosted by OIFE

Videocalls (VCs) hosted by OIFE in 2020 included meetings with many different stakeholders. There were also a substantial number of VCs with OIFE members and volunteers in addition to:

- VCs European Huntington Association, March 10th and 20th and Dec 1st (IW)
- VC Kyowa Kirin International - about collaboration project OI & XLH, April 20th (IW)
- VC Walter Atzori (Alexion), June 5th (IW)
- VC Pega Medical July 8th (IW, DL and BvD)
- VC with three US OI-surgeons on case discussion project & Flying OI Experts Aug 5th (IW)
- VC with company Longenesis Sep 7th (IW and RTS)
- VC with dr. Joan Marini Oct 1st (IW and Tracy Hart)
- VCs with XLH Alliance (A stronger BOND between us) Nov 9th, Dec 14th (IW)
POLICY WORK & ADVOCACY

OIFE managed to attend three EURORDIS events face to face, represented by Dace Liepina and Rebecca T. Skarberg. In 2020 we had a record number of representatives attending different EURORDIS events – giving new people an opportunity to learn and get engaged in policy work.

EURORDIS events

EURORDIS ‘Reframe Rare’ Policy Event
On February 18th at the European Parliament, EURORDIS relaunched the Network of Parliamentary Advocates for Rare Diseases, made up members of parliament (MEPs).

Participants heard from MEPs who hosted conversations with patient representatives from across Europe including Rebecca T. Skarberg from OIFE. Topics included research and innovation, access to medicines, holistic care and cross-border health care and access to specialized care. OIFE Vice President Dace Liepina was also present.

Black Pearl Awards Ceremony
On February 18th Rebecca T. Skarberg, Knut Erik T. Skarberg and Dace Liepina attended the Black Pearl Awards as invited guests by EURORDIS.

29th EURORDIS Round Table of Companies
On February 19th Dace Liepina represented OIFE at the 29th EURORDIS Round Table of Companies (ERTC) “How to teach an old medicine new tricks – The importance of repurposing medicines for patients”. The workshop provided valuable information to its participants about repurposing of drugs including the STAMP initiative as well as networking opportunities.
EURORDIS AGM
On May 13th Ingunn represented OIFE at the Annual General Meeting of EURORDIS on Zoom. More than 240 people joined the first-ever virtual General Assembly of EURORDIS.

ECRD conference
On May 14th and 15th OIFE was well represented at the online European Conference on Rare Diseases (ECRD) with 5 representatives directly representing OIFE. In addition more than 5 people from the OIFE-community attended the event. 1,500 people from 57 countries took part in the conference. Rebecca T. Skarberg gave several talks about Rare 2030 at the ECRD.

The Rare 2030 Foresight study
Rare2030 was a two years project leading up to four possible future scenarios for rare diseases and a set of recommendations planned launched at the Rare2030 conference in February 2021. Rebecca T. Skarberg has been part of the expert panel of Rare2030, which has included a substantial number of volunteer hours.

Council of Federations Meeting
In November Ingunn and Bruno attended the online Council of Federations-meeting, where more than 90 people from all over Europe took part. Topics included Rare Disease Week 2021, ERNs, Access to therapies, EU policy work, newborn screening and a lot more.

Other EURORDIS activities where OIFE was represented included:
- EURORDIS webinar on Covid19, April 22nd (IW)
- EURORDIS webinar on data strategy for the ERNs, June 18th (IW)
- A number of webinars connected to EURORDIS Digital School (AR)
OIFE supported EU4HEALTH campaign

In 2020 OIFE joined EURORDIS and signed the campaign "Europe, Let’s Do More for Health", which calls for targeted and effective EU action to ensure that everyone is able to enjoy healthy lives in healthy environments. The organizations called for an EU leadership that respects EU treaty provisions on health, as well as its international commitments. The EU and its Member States should cooperate to effectively address the unprecedented health challenges they are facing.

ERN

Rebecca Tvedt Skarberg has represented OI-people as ePAG in the European Reference Network on Rare Bone Diseases (ERN BOND) and was during 2020 joined by Claudia Finis from DOIG (Germany). Rebecca and Claudia have attended numerous VCs in ERN BOND with the Midterm meeting November 10th-11th as the biggest. They have also been involved in development of webpage and SoMe and some initiatives around education in ERN BOND. OIFE has assisted ERN BOND in disseminating information about the Covid-19 Helpline, which was developed together with the Italian organization ASITOI.
EuRR-Bone

June 10th 2020 was the official launch & kickoff of the the European Registry for Rare Bone and Mineral Conditions (EuRR-Bone), which is funded by the European Union’s Health Programme.

OIFE was represented by Rebecca Tvedt Skarberg (ERN BOND ePAG), who also represented OIFE in the vertical theme 5 “Patient outcomes”. Ingunn Westerheim, Rebecca Tvedt Skarberg and Taco van Welzenis represented OIFE in the OI working group. Dagmar Mekking represented Care4BB and Claudia Finis (DOIG). The OI working group led by Dr Wolfgang Högler had as mandate to suggest clinician reported outcomes (CROMS) and patient reported outcomes (CROMS) for children and adults in the OI-specific module. We used input from OIFE’s Adult Health Facebook-group to have input from the larger community during the process.

EJP RD Summer School on Registries

Ingunn attended the EJP RD Summer School on Registries, which took place virtually from October 28th – 30th. Coreen Kelday (BBS) attended the last sessions of the training on behalf of Ingunn.

Other activities connected to registries

Other activities/meetings connected to registries and databases

* VC with dr. Lena Lande Wekre about registries & real world evidence, Jan 24th (IW)
* Findacure Webinar – How to build an international patient registry, Jan 15th (IW)
* VC Pulse Infoframe March 16th (IW)
* EuRR-Bone meeting for patient organizations Dec 4th (IW)
Increasing the visibility and recognition of the OIFE brand and our role as the European OI-umbrella were among the main goals of OIFE in 2020. In order to reach our goal, OIFE developed a communications strategy to boost our presence in different communication channels and social media.

During 2020, OIFE was active on Facebook, Instagram and LinkedIn. Our accounts on Twitter and YouTube were used less.

In 2020 we tried to improve the engagement of the community through increased participation and user generated content for Wishbone Day.

The opportunity to have access to tools like Canva Pro also helped OIFE to create more quality content.
Rare Disease Day Campaign

The EURORDIS Rare Disease Day Campaign 2020 went under the slogan **Rare is many. Rare is strong. Rare is proud!** 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 patients’ lives.

The campaign primarily targets the general public and also seeks to raise awareness amongst policy makers, public authorities, industry representatives, researchers, health professionals and anyone who has a genuine interest in rare diseases.

OIFE participated in the campaign and encouraged member organisations to also get involved by sharing information and posts EURORDIS suggested in their media pack for organizations. We personalized the information campaign by adding insights and fast facts about OI. In parallel to this, OIFE created a series of posts about OI and about OIFE’s activities and initiatives to connect people and raise knowledge and awareness about OI and OIFE.
On May 5th 2020 OIFE took over the social media channels of Rare Revolution Magazine - a digital magazine giving a voice to those affected by RARE conditions and the charities and non profits that represent and support them.

With the #tuesdaytakeover on Rare Revolution Magazine OIFE’s goal was to create awareness about OI to a larger audience and create visibility about OIFE as the European OI-umbrella. OIFE took the opportunity to talk about, promote and build up to Wishbone Day and the special campaign #Wish4OI. Two 1 minute videos about OIFE and OI were also launched by OIFE thanks to the takeover and have been used on many occasions afterwards.
Wishbone Day 2020 and #Wish4OI

On May 6th every year the OI-community come together and celebrate the International Day of OI (Wishbone Day) with different social media activities.

OIFE created a user generated content campaign in 2020 called #Wish4OI where people with OI, parents and professionals shared their wishes and hopes for OI in the widest sense. 227 people used the Wishbone Day Frame on Facebook, and the hashtag initiative also resonated very well. According to the results and the engagement level reached we understood that people liked to be asked what they wanted, this initiative activated also people who are not very active in OIFE/their local organizations. All the wishes were gathered in a video that is still available on OIFE’s YouTube channel. Feedback on the campaign has been very positive, and led us to understand how important active engagement from community leaders is, in order for those kinds of call to actions to work.

Send your #Wish4Oi to communication@oife.org
Flyers at ICCBH

OIFE was invited to participate in the virtual ICCBH forum by having a branded partner page on the meeting platform. OIFE had the chance to set up a profile page with the option to post some downloadable PDF brochures. For the occasion 3 new flyers were created:
OIFE Magazine

We published four editions of OIFE Magazine in 2020, which is distributed as a PDF through email to all our contacts. Target group include professionals, people with OI, collaborators and industry contacts – between 1500 and 1600 recipients in total. Other volunteers are also asked to contribute. Each edition in 2020 had a main topic:

- **Edition 1-2020** QoL4OI conference and See, Hear, Smile
- **Edition 2-2020** Special edition on psychosocial issues & OI
- **Edition 3-2020** Sports & activities
- **Edition 4-2020** Special edition on research & development

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 and is also a way to drive traffic to our webpage.

The main editor and distributor of the magazine is our secretary Steffi in close collaboration with Ingunn. We have been positively surprised how easy it has been to have people contribute to the magazine.

Both clinicians, researchers, patient experts and other volunteers have actively contributed to the content after requests from our side.
**OIFE Website**

OIFE's webpage has been regularly updated with a focus on OIFE-related activities and projects and some information from our most important collaborators.

The event calendar has also been regularly updated.

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**EURORDIS Digital School**

OIFE’s Communication Manager Anna Rossi graduated from EURORDIS Digital School, which consisted of webinars and eLearning with an aim to empower rare disease patient advocates to use digital communication tools to improve the strategic outreach and community-building capacities of their organizations.

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**Other awareness raising activities**

We also contributed to other initiatives to create awareness about OI. Ingunn Westerheim was interviewed in Pharma Times about living with OI. And OIFE also contributed feedback to the international version of the animation video on OI, made by the Swiss OI-organization SVOI now available in 3 different languages (English, French and German).
RESEARCH & DEVELOPMENT

OIFE keeps a list of more than 800 professionals worldwide, that is mainly used to spread information such as OIFE Magazine, invitations for scientific conferences and information about research grants from other stakeholders than OIFE. It's a huge challenge to keep the list up to date. This is one of the main tasks of our secretary Stefanie Wagner.

Medical Advisory Board (MAB) for OIFE

In 2020 two of the members of OIFE MAB were replaced by new representatives: Dr. Heidi Arponen from Finland and dr. Ralph Sakkers from the Netherlands. To see an updated list of MAB-members, please visit our website.

April 6th 2020 we organized the first MAB-meeting since its establishment, mainly to give an introduction and status from OIFE.

On June 19th the MAB came together for their 2nd meeting. Topics included Key4OI and EuRR-Bone. We had also invited the OIFE EC, our resource group on registries and Tracy Hart from the OI Foundation. In total, 18 people took part.

During 2020 several members of OIFE MAB represented OIFE in various meetings, including the ECTS conference (Lida Zhytnik).

Two of the MAB-members have also been represented in the steering committee of the IMPACT survey.
Access to new and innovative treatments

Drug development, access to treatments & contact with industry
For many years, bisphosphonates have been the only therapy option for OI, but recently several different stakeholders have started researching new potential treatments specifically designed for OI. This include (not a full list):

- **Setrusumab** (Mereo Biopharma & Ultragenyx)
- **Fresolimumab** - antiTGF Beta (provided to the BBDC by Sanofi Genzyme)
- **Romosozumab** – AMGEN
- **Denosumab** – AMGEN & UCB
- **Stem cell therapy** – BOOSTB4 and others

OIFE had a strong focus on access to treatments in 2020. OIFE organized meetings with most of the companies/stakeholders doing projects on OI to provide input from the patient perspective.

OIFE has also had contact with companies working with other rare bone conditions including IPSEN (FOP and MO/MHE), Alexion (HPP) and Kyowa Kirin International (XLH). Our new financial policy include a section on how to interact with commercial stakeholders.

Medev-MOCA meeting
Taco van Welzenis represented OIFE at the VC in the Medicine Evaluation Committee (MEDEV), where the setrusumab project was the topic (Mereo Biopharma).

MEDEV represents an informal cooperation between 22 national authorities from 18 Member States and Switzerland responsible for the assessment, pricing and reimbursement of medicines in Europe. MEDEV members include national HTA agencies and social health insurers (payers).
The **Impact Survey**

Lack of data is a big challenge to access new treatments for rare conditions. As a measure, we launched the IMPACT survey project in April 2020.

The IMPACT Survey is a joint initiative between OIFE, OIF & Mereo BioPharma.

It is an international research project aimed at capturing and quantifying the true challenges of life with OI to enable better diagnosis, treatment and care, and to support availability of potential future treatments for OI.

Data can also be used in policy work by the patient organizations on a European and national level. The project is run by Wickenstones – a scientific agency. The overall process is governed by a Steering Committee with representatives from OIFE and OIF as well as expert OI physicians from Europe and the US treating children and adults.

The survey is planned to be launched in June 2021.

After the project the data will be managed by OIFE and OIF together with dr. Frank Rauch.

OIFE’s Communication manager has contributed with advice to and coordination of communication activities.
The European Joint Programme on Rare Diseases - (EJP RD)

The CHRONOS project
The European Joint Programme on Rare Diseases (EJP RD) brings together over 130 institutions from 35 countries. Following the networking event related to the RDR challenge nr. 3 “Characterize Rare Bone Disorders (RBD) Mobility Challenges in Real World Setting”, OIFE and ANDO Portugal were invited by dr. Sangiorgi to be part of the consortium for the CHRONOS project, who were applying for the EJP RD grant RDR Challenge, partially sponsored by the company IPSEN. OIFE’s role was to coordinate patient activities involving 5 bone conditions incl: OI, achondroplasia, MO/MHE, FOP and AKU.

The project included several parts, where analysing the patient needs through new and innovative methods (wearables, A.I., text analysis of social media and Photo Voice) were central. OIFE attended weekly meetings connected to the project to develop a protocol and a grant application that was submitted in June. Unfortunately the project did not get funding.

The Photo Voice Project - #Rare Bone Mobility
This project was originally a part of CHRONOS, but because of lacking funding, OIFE and ANDO Portugal were approached by Austrian researchers who started a subproject (Photo Voice). This led to the project #RareBoneMobility, where OIFE and ANDO Portugal took on the responsibility of developing a webpage and recruiting patients for the project.

The project had several purposes:
1) Gather photos from people with rare bone conditions illustrating mobility challenges, and
2) Training for project management students from FH Joanneum in Austria.

EJP RD Joint Transnational Call
OIFE also supported other research initiatives through the EJP RD programme (The 2nd EJP RD Joint Transnational Call for Rare Diseases Research Project (JTC 2020), where Antonella Forlino was the main researcher. We also contributed with support letters to Spanish researchers.
Qol4OI, Key4OI & Key4OI Plus and Care4Bones

Qol4OI conference in Amsterdam
In January 2020 all stakeholders met online to evaluate the Qol4OI conference. We agreed on project to project collaboration and that a wider collaboration was not wanted for the time being.

Key4OI & Key4OI Plus
OIFE endorsed the report from the first Key4OI project, which was later published in Orphanet Journal. The report include domains and recommendations for outcome measures to be used in research and clinical work. We also endorsed the article called “Roadmap to surgery” and supported the establishment of Key4OI Plus (ear, teeth, cardiopulmonary) which was a combination of expert groups and focus groups of people with OI. OIFE helped to recruit the experts and gave some assistance regarding recruitment of people with OI.

Care4Bones Plattforms
The Care4Bones Plattform was introduced as an initiative from Care4BB and the initiative of a new foundation. Care4BrittleBones invited OIFE and the OI Foundation to collaborate on the platform project.

OIFE declined the offer in a meeting where the entire Board of Care4BB met with the OIFE EC. Later the OIF did the same. OIFE was particularly skeptical to the patient platform, which we regarded as competition to OIFE and the national organizations.
PATIENT ENGAGEMENT & EDUCATION

The OIFE database of patient representatives
In 2020 we developed a database where people with OI and other rare bone conditions interested in research & development on an international level could register, tell us about their experience and what kinds of research they want to be involved in.

The database is both a more systematic way of keeping track of those who already represent us in different projects/forums and an incentive for new people to get involved and/or educated. We had 16 people from 11 countries signed up in December 2020. We contacted them several times during 2020 to recruit people to various educational activities including the ECRD-conference, the patient Engagement Open Forum, EURORDIS Summer School and Winter School and many more opportunities.

Patient Engagement Open Forum
Representatives from OIFE attended several of the sessions of the Patient Engagement Open forum – a series of webinars from June 25th to November 2020. The topics ranged from tools and recommendations for effective patient engagement, methods for monitoring and evaluation of impact and outcomes in patient engagement activities, and fair market compensation for patient input to interactive sessions on assessing good practices in patient engagement and more.

EURORDIS Winter School
EURORDIS Winter School aim at deepening patient representatives’ understanding of how pre-clinical research translates into real benefits for rare disease patients. Claudia Finis from Germany represented the OIFE at the 2nd edition which took place online. The course covered topics including the history of genetics, diagnostics, new technologies in gene therapy and drug repurposing.
OIFE involvement in research projects

During 2020 we were involved in the following research projects (not already mentioned):

- The TOPaZ project (steering com- + information & announcements in the magazine)
- Published article on patient views on registries – ERN BOND (co-authors)
- Support letters to several researchers in Italy and Spain

We had a special edition on research in OIFE Magazine, where various projects were presented.

Meetings & events connected to research & development

In addition to a substantial number of meetings with several of the projects mentioned above, we have been involved in the following meetings:

- VC between OIFE EC & Mereo Biopharma April 21st
- EJPRD Research Challenges Workshop May 4th (IW)
- VC with European Joint Programme on Rare Diseases June 22nd (IW)
- Webinar on Innovative Medicines Initiative (IMI) Call (IW)
- VC - IMPACT survey steering committee Sep 21st and Nov 17th(IW and TvW)
A more professional OIFE (OIFE 2.0.)

Our continued goal for 2020 was to strengthen OIFE as an umbrella, solve our logistical challenges and get administrative support – either by hiring staff or purchasing services. We did not reach our goal, but took some important steps in the right direction in 2020. This is partially because of a collaboration with the European Huntington Association (EHA), that has provided us with a lot of important advice and support.

OIFE bought an annual pro subscription of Zoom in January 2020, which made it possible for us to quickly adapt to the new world of larger online events. We were also able to help some of our member organizations with hosting events the first months after the pandemic started. OIFE is registered with TechSoup in the Netherlands, which makes it possible for us to have many digital tools for free or to a discounted price.

A stronger BOND between us

The goal of the OIFE project "A stronger BOND between us" is to create an informal network between different stakeholders working on OI and other rare bone diseases.

European Rare Bone Forum (ERBF)

Ingunn Westerheim left the steering group of the ERBF in November 2019. OIFE kept their position as an informal member of the network. OIFE was represented at several virtual events and we also got free access to scientific conferences like the ECTS and ICCBH.
People with OI and X-linked hypophosphatemia (XLH) struggle with many of the same challenges. With the kind support from Kyowa Kirin International (KKI) OIFE has developed a formal collaboration with the XLH Alliance for mutual learning. We had several meetings in 2020 and from November we established monthly meetings to share ideas, best practises and potential projects we could work together on. This has been especially useful when developing the IMPACT survey, since XLH had experiences from a similar project.

"Flying OI-Experts"

The intention behind "Flying OI Experts" is to bring knowledge and help to new countries and enable patient representatives in less developed countries. Because of the Covid-19 situation, we had no activities in the Flying OI Expert project in its original form in 2020. We did however provide a travel grant for Dr Lars Folkestad, to attend the OIF Investigator Meeting in April 2020, which was later cancelled.

OIFE also helped the Russian OI-organization by recruiting a lecturer on OI & orthopedic surgery for a large orthopedic conference in Russia.

There were no specific donations to Flying OI Experts in 2020 except a donation from the NFOI of ca 2000 euros.
Our peer group “OIFE – OI & Adult Health”

OIFE’s moderated Facebook-group “OIFE – OI & adult health” is actively used by individuals to have peer support from other OI adults with similar experiences. We regard active moderating as a success criteria.

The group had more than 970 members from more than 60 countries per 31.12.20, which is an increase of about 250 during that year.

The group is moderated by Ute Wallentin, Ingunn Westerheim, Julia Piniella, Rebecca Tvedt Skarberg and Taco van Welzenis.

Through the group, we also get feedback about what the health concerns of adults with OI are. Examples of topics that have been discussed in 2020 include:

- Pain and pain treatment;
- COVID-19, consequences on OI people and their families, important facts and experiences with this infection, vaccination and treatment of its symptoms;
- Orthopedic treatment incl. joint replacement or spine surgery;
- Physiotherapy, exercising
- Medical treatment options incl. bisphosphonates and newer osteoporosis drugs;
- Breathing issues; influence on quality of life, energy, importance of regular check-ups; sleep apnea & respiratory issues
- Cardiovascular issues; heart surgery with OI
- Soft tissue injuries (tendons, muscles)
- Gastrointestinal procedures;
- Hearing and cochlear implants;
- Genetics & types of OI

For new members, the posts from previous years also has a value.
Facebook Group - OIFE Youth Only

The target group for the youth group is for people with OI between 16 and 35. There was very little activity in the group in 2020. OIFE’s Youth Coordinators Marie & Stephanie are moderators.

Social Network

In 2020 we had a huge number of requests coming from individuals. They arrive via the website, e-mail, but in particular via social media and WhatsApp.

Requests mostly come from countries where there is no OI-organization 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.

OIFE does not in any case provide financial support to individuals. Nor can we help with migration. But we give advice and peer support and help to find OI-groups or doctors with experience locally. We have dedicated volunteers like Ute Wallentin or Maria Barbero (mainly for Spanish requests) who serve as coordinators and peer advisors. Our aim is to create a bigger team around Ute in order to take care of the increasing amount of individual requests.

One of the many tasks of the OIFE is to support new national initiatives by parents, adults and/or doctors to start an OI group and to support establishment of good quality OI treatment in new countries. For that we have been in touch with individuals in countries like Algeria, Morocco and Serbia for instance for years with little progress, unfortunately. We do however see some improvements and promising activities in Kenya, Burundi and some parts of Asia and Latin America and are happy to share knowledge, texts and information and support with advice by our more experienced volunteers.
THANK YOU!

During 2020 many different people helped us represent OIFE in various meetings and contributed on various tasks. This included elected volunteers, 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!

And thank you to all collaborators, for wanting to work with us in such a constructive way.