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Due to the Coronavirus, we didn't attend a single face to face meeting in 2021. Through Zoom and other digital tools, we did however attend numerous meetings with familiar stakeholders like EuRR-Bone, ERN BOND, EURORDIS etc. With more visibility as the OI-umbrella, we were also contacted by many new stakeholders incl. researchers and companies working with OI.

In 2021 we welcomed two new ordinary members in Sweden and Georgia (new status) and a 2nd associate member organisation in China (Zero One), based in Shenzhen.

In 2021 OIFE started “preparing the ground” for potential new treatments and therapies through educational activities which included an OIFE leadership meeting and a seminar about research and development following the OIFE AGM. The work needs to continue in 2022 and further.

Another important activity we did to prepare for the future, was to gather big data. The IMPACT survey was our most time-consuming activity in 2021. With the help of the entire international OI-community we managed to gather more than 2200 responses from 65 countries. The project brought us closer to our member organisations and we learned a lot about how to implement projects throughout the organisation.
Although affected by Covid-19, we still feel we reached important goals in 2021. We finalised four magazines and we also did two successful campaigns on social media, which got extra attention because of the Black Pearl Award. Our voice was heard in many places, like the Rare Disease Week, Rare Bone Summit and the Rare2030 conference.

The OIFE EC has worked well together through monthly virtual meetings, but lack of time is still a challenge. In 2021 we intensified our effort to make OIFE more efficient (version 2.0). We decided to move OIFE’s registration from the Netherlands to Belgium, a process which took a lot of resources. With more diverse funding from industry, EU grants and Facebook donations, our goal is also to come closer to having staff or hired services in the not too distant future.

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 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 we did this to achieve our vision:

- 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 37 different organisations at the end of 2021. This included 20 European members, who are national organisations with full voting rights:
At the end of 2021 we had 13 associate members/partner organisations, who are national organisations outside Europe without voting rights:

- Australia
- China
- Chile
- Ecuador
- Ghana
- India
- Mexico
- Nigeria
- Panama
- Peru
- South Africa
- USA

We had four supporting members consisting of research foundations (Care4BB, AHUCE Foundation and the Belgian AFBOI) as well as one organisation providing aid & support for individuals (Padrinos).

We gained two new member organisations in 2021:
- Sweden: Sveriges Förening för Osteogenesis Imperfecta (SFOI)
- A second one in China (Zero One)

The Board also voted to change the status of “OI Georgia” from associate to full membership.
THE ADMINISTRATION

The Board

OIFE is governed by the Board, which consists of one delegate from each member organisation. Only European members have voting rights. Approximately 20-25 internal email newsletters were sent from OIFE president to the delegates during 2021. Some newsletters and invitations were only sent to our European members. Weekly reports from the IMPACT survey were distributed by email as well as invitations to AGM and other relevant events.

The Executive Committee (EC)

The Board elects members of the Executive Committee (EC) who run the day to day business of OIFE. In 2021 the EC consisted of the following people:

- **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 DIJCK**
  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

The EC continued having video calls approximately once a month in 2021 as planned. 13 EC video calls were held during 2021.
The Volunteers

The Executive Committee has been supported by our formally appointed volunteers:

SECRETARY: STEFANIE WAGNER
GERMANY

CHAIR OF OIFE’S MEDICAL ADVISORY BOARD: OLIVER SEMLER
GERMANY

WEBMASTERS: KEVIN VANANTWERPEN
BELGIUM
ANDRÉ WITTWER
NORWAY

SOCIAL NETWORK COORDINATOR:
UTE WALLENTIN,
GERMANY

YOUTH COORDINATORS:
STEPHANIE CLAEYS
BELGIUM
SIMEY TRUONG
GERMANY

ERN BOND EPAG: REBECCA TVEDT
SKARBERG,
NORWAY

In addition to these, OIFE is supported by other volunteers on project & ad hoc basis. In 2021 we said goodbye to some very important volunteers who had made a huge effort for OIFE through many years, including OIFE’s treasurer Céu Barreiros and the creator behind several versions of OIFE web pages, our webmaster Ivar Troost. We also thanked Marie Holm Laursen for serving as Youth Coordinator.
Positive developments/happenings:

- OIFE is growing – we got 2 new member organisations
- Collaboration on the IMPACT survey, brought OIFE’s members closer together, which resulted in more than 2200 unique responses from more than 65 countries
- A step closer to a restructured OIFE, through investing time on the OIFE 2.0. project
- Many new requests of collaboration indicated increased visibility as the OI umbrella
- Transparent relationships developed to several new companies involved in OI-projects.
- Extra visibility for OIFE through Black Pearl Volunteer Awards & Rare Disease Week
- Diversified income, through documenting in kind volunteer hours and implementing Facebook donations. The income from pharma was reduced to less than 50%.
- OIFE was deeply involved in the creation of the OI-module in EuRR-Bone
- With OIFE’s help we managed to find a new home for the OI Variant database
- An OIFE library for OI research was established.
- New projects started included Pain & OI and OIFE Investigator Meeting 2022


Challenges:

Challenges we faced in 2021 included:

- All OIFE face to face meetings cancelled due to Covid 19
- Hard to get feedback from delegates between meetings
- The Rare Bone Mobility Photo Voice project had poor results despite effort.
- Huge challenges with bank, especially when transferring access between treasurers
- New requirements regarding access, forced us to close both our PayPal accounts
- Communication challenges between OIFE and the founders of Wishbone Day
- Companies and clinical trials have different methods for involving the patient voice
- Too many surveys cause survey fatigue – we should prioritise fewer and better surveys
- Disagreement on strategic choices with some of our central collaborators
- Enough time to follow up all projects and activities
**OIFE EVENTS:**

**First OIFE Leadership meeting**

February 1st the European members of OIFE learned about pharmacological research and how the patient organisations in Europe can work nationally and on a European level to improve access to new and potential treatments for OI. In addition to the delegates, leaders from the European OI-organisations were invited. Introductions included talks from Simone Boselli (EURORDIS), OIFE MAB and Oliver Gardiner and Tenna Toft from the XLH Alliance.

**OIFE AGM**

Our Annual General Meeting (AGM) 2021 took place on Zoom on June 19th. It was divided in 2 parts - the formal business part, and part 2 “OIFE projects and collaborations”. There were in total 48 participants to OIFE AGM 2021 part 1 with 19 voting members. Part 1 included approval of annual reports, budget and elections. We welcomed Coreen Kelday as new OIFE treasurer.

Part 2 was an educational webinar and included:
- OIFE projects & future events Pre Launch of the IMPACT survey
- Information on conferences and events in 2021 and 2022
- News from research (BOOSTB4, TOPAZ, SETRUSUMAB, EURR-BONE etc)

In part 2, both delegates, OIFE MAB, clinicians, researchers and collaborators from industry attended. We had 75 participants from Europe, US, Latin America, Africa, Australia and Asia.

**OIFE Youth Event**

The OIFE Youth Event 2021 which was supposed to take place in Gdansk, Poland, was cancelled for the second time due to Covid 19.
PROJECTS:
The IMPACT Survey

IMPACT was by far our biggest and most time-consuming project in 2021. It took a lot of energy both for OIFE EC, but also for all our member organisations and the community as a whole.

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 the steering committee led by dr. Frank Rauch. The project idea came from Mereo, who pays for the project, but the organisations took ownership because we saw the need for data to fill the knowledge gaps. To succeed we needed to involve all our members throughout the entire project. Our hope is that data from IMPACT can be used to enable better diagnosis, treatment and care, and to support availability of potential future treatments for OI.

The company Wickenstones was hired, and after a literature search and review was performed, they developed a survey draft. During spring 2021 OIFE volunteers provided input to the draft and checked the quality of the translations in eight languages: English, Spanish (incl. separate Latin American version), French, German, Italian, Russian, Dutch and Portuguese. This was a challenging task, which we should have estimated more time for. A big thank you to the volunteers who pushed through, and made it a good and relevant survey!

The questionnaire had three main sections about patient journeys (care pathways), physical and mental impact of OI (quality of life) and the economic impact on people with OI, their families and the healthcare system. It was pre-launched at the OIFE AGM, launched the first week of July and relaunched at the OIF Membership meeting in July. In addition to a communication package made by Wickenstones, we also developed our own material. This included key messages, hashtags, banners, Facebook-frame and a resource webpage.
We realised it was not enough to merely inform our members to spark action. Between July and September we contacted all our organisations individually to explain the purpose of IMPACT and motivate for action. We distributed weekly reports which we used to target organisations who needed support and advice. We also talked about IMPACT in a number of membership meetings, before we closed the survey September 30th. We did not promote any other surveys from OIFE’s side during the time period the IMPACT survey was open.

Thanks to the impressive help of all our member organisations and the entire OI-community we managed to get more than 2200 unique responses to the survey from more than 65 countries worldwide! This includes even more individual people, since some people responded both for themselves and their children. Responses came from adults and adolescents with OI as well as parents/caregivers of children with OI.

OIFE also contributed to the poster “The patient clinical journey and socioeconomic impact of osteogenesis imperfecta: a systematic review” which was accepted to the ASMBR conference. It was based on the scoping review. OIFE also provided input to the manuscript of the scientific article “The patient clinical journey and socioeconomic impact of osteogenesis imperfecta: a systematic scoping review”, which is awaiting publication.

Taco and Ingunn attended several meetings in the Steering Committee of the IMPACT survey, where two OIFE MAB-members are also represented (Lena Lande Wekre and Oliver Semler). This came in addition to meetings between members in the OIFE EC, Mereo and Wickenstones about communication on the IMPACT survey.

66 countries
>2000 participants

People with OI
Children
Families
Caregivers
Restructuring OIFE (OIFE 2.0.)

For many years, our goal has been to strengthen OIFE as an umbrella, solve our logistical challenges and get administrative support – either by hiring staff or purchasing services.

In 2021 we took big steps in this direction. We did not have much choice, since our relationship with the German bank and both our PayPal accounts developed to the worse. New requirements made access from several countries more difficult, and we used a lot of energy in the process of changing our treasurer. It took 3 months and more than 50 emails and phone calls, before Coreen gained access to our German bank.

Based on advice from the European Huntington Association (EHA), the OIFE EC made a decision to move OIFE's formal registration from the Netherlands and continue under Belgian law. The plans were presented to the delegates at the OIFE AGM, who supported the plan. After advice from Dutch lawyers, we had to change our plans from a moving process to a complete dissolvement of OIFE (1.0.) in the Netherlands and starting up a new but similar umbrella association in Belgium, with the support from the company SBB. We developed a draft of new Statutes in Dutch and English language versions. We also opened a bank account in the bank KBC, but we need to finalise the establishment of OIFE 2.0. in Belgium, before we can use it.
The Pain & OI project:

In April 2021 we announced that the OIFE would like to get in touch with professionals (PTs, OTs, psychologists, medical doctors, researchers, pain specialists etc.) who had experience on pain & pain management in OI. Our goal was to develop recommendations on how to measure pain in clinical trials and the clinic and on how to manage chronic pain in children and adults with OI.

We managed to gather a group of ca 20 experts and invited them to a kick-off in January 2022.

“Flying OI-Experts”

The intention behind "Flying OI Experts" is to bring knowledge to less developed countries. Because of the Covid-19 situation, we had no activities in the Flying OI Expert project in its original form in 2021.

OIFE did however assist OIF Ghana with getting in touch with international experts, who could contribute as lecturers to the newly established MDT clinic, which was initiated by OIF Ghana.

There were no specific donations to Flying OI Experts in 2021 except a donation from the NFOI of ca 770 euros.
A stronger BOND between us (incl. ERBF)

The overarching 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. The project has several subprojects and activities:

**European Rare Bone Forum (ERBF)**

OIFE kept their position as an informal member of the European Rare Bone Forum in 2021. Through ERBF we got in touch with research & development projects on rare bone conditions as well as invitations for conferences like the Rare Bone Summit. Activities included a project called “Rare Bone Diseases Mobility Systematic Literature Search (SLR)” initiated by the company IPSEN and performed by the consultancy firm Costello. Ingunn contributed to the protocol, representing OIFE, and has also been invited to be a co-author.

**Rare Bone Summit**

On December 6th and 14th Oliver Semler, Ingunn Westerheim and Inger-Margrethe S. Paulsen represented the OIFE at the virtual Rare Bone Disease Summit. The Summit was a global multi-stakeholder group meeting for people active in the rare bone disease field to discuss challenges and opportunities. The Summit 2021 was led and funded by Ipsen Pharma, with Kyowa Kirin, Alexion, BioMarin, and Ultragenyx as the supporting strategic partners, in close collaboration with patient organisations, experts, and medical and scientific societies. It is planned to be an annual event. Oliver Semler represents OIFE in the Steering group.

**XLH Alliance & OIFE**

OIFE continued their formal collaboration with the XLH Alliance in 2021. Some monthly meetings were cancelled due to sickness and workload. But we have continued to meet online throughout 2021 to share ideas, best practises, and potential collaboration projects. This has been especially useful when developing the IMPACT survey and working on access to treatments (HTA), since XLH had experiences from similar projects. We did not apply for funding from Kyowa Kirin International (KKI) in 2021.
REPRESENTATION, ADVOCACY & NETWORKING

We didn't attend a single face to face meeting in 2021. But we did attend numerous events online with a large number of stakeholders.

Events hosted by OI-organisations

During summer and autumn 2021 OIFE was represented at many national meetings to promote and explain about the IMPACT survey.

This included family meetings in Finland, Switzerland, Austria, Norway and Italy. We were also represented by Anna Rossi and Julia Piniella at several Spanish meetings both in Latin America and in Spain.

On September 14th the Brittle Bone Society (UK & Ireland) organised their annual conference online. OIFE was represented by Ingunn who gave a talk together with Dr Laura Tosi and Tracy Hart from the OI Foundation (USA) on how we can fill the many knowledge gaps we have in OI.
Online meetings and video calls hosted by OIFE

Networking is more important than ever for OIFE. Because of increased visibility as the OI umbrella, more stakeholders are reaching out to us to talk about shared interests and potential projects. Sometimes it is the OIFE who’s the initiator, sometimes it is the other way around.

In 2021 we established more relationships with federations and groups for other rare conditions, to learn and share best practices.

Meetings initiated by OIFE included videocalls with the following stakeholders:

- The European Huntington Association (EHA)
- The XLH Alliance (A stronger BOND between us)
- Shriners Montreal (Argerie Tsimikalis)
- Organisers of ICCBH and OI2020 (OI2022)
- Retina Pigmentosa International
- The Student Voice
- Dr. Richard Keen about adult clinics & OI in the UK
- SMA Europe
- Rare Diseases International (RDI)
- Cystic Fibrosis Europe
- The Belgian company SBB
Eurordis events

EURORDIS Membership Meeting & AGM
On May 13th and 14th we were several from OIFE who attended parts of the EURORDIS Membership Meeting, which included tips on how to do engaging online conferences and hybrid events. There were also discussions on research, registries and access to orphan drugs.

Ingunn represented OIFE at EURORDIS Annual General Meeting on June 10th, where long term strategy and policy work to achieve a new European action plan on rare diseases were the most important topics.

EURORDIS Council of Federations
Unfortunately no one from OIFE was able to attend the first Council of Federation (CEF) meeting in spring, but we were represented at the November meeting. Topics included:

- Revision of the general European pharmaceutical legislation (public consultation)
- A new EURORDIS programme for Community Advisory Boards (CABs)
- How patients can take part in Health Technology Assessments (HTA)
- How federations can prepare themselves for a new pilot at the EMA
- Status on access to orphan medicines
Informal workshops for EURORDIS Federations – an OIFE initiative

Ingunn Westerheim and Astri Arnesen from the European Huntington Association (EHA) hosted two informal workshops for the rare disease federations in May and October 2021. Topics were sharing of experiences on burden of disease projects like the IMPACT survey and challenges and opportunities of running a rare disease federation in Europe.

31st ERTC Workshop

The 31st European Round Table of Companies workshop convened patient representatives, policy makers, regulators, industry and payers to focus on key elements of the EU Regulation on orphan medicinal products. Ingunn was invited as a speaker, to represent the patient's perspective. She spoke about how the OI-community is preparing for future situations with discussions about approval and reimbursements of new potential medicines and advanced therapies for OI, where the IMPACT survey is an important tool. Ingunn's talk also sparked interest from EURORDIS, who were interested in using IMPACT as a template project for collecting big data for rare conditions.
Advocacy & Representation

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 2021 Rebecca and Claudia attended numerous VCs in ERN BOND which included meetings in the Steering Committee and the various Work Groups (WG).

EuRR-Bone
Rebecca Tvedt Skarberg represented OI in the vertical theme 5 “Patient outcomes” in the European Registry for Rare Bone and Mineral Conditions (EuRR-Bone).

The OI working group (Vertical Theme 3) led by Dr. Wolfgang Höegler from Austria had a mandate to suggest clinician reported outcomes (CROMS) and patient reported outcomes (CROMS) for children and adults in the OI-specific module. The group consisted of European OI-professionals and patient representatives. Ingunn Westerheim, Rebecca Tvedt Skarberg and Taco van Welzenis represented OIFE in the OI working group. Dagmar Mekking represented Care4BB and Claudia Finis (DOIG).

We used input from OIFE’s Adult Health Facebook-group in the process and the workgroup presented their recommendations to EuRR-Bone in March 2021. In addition, we were represented at the following larger meetings:

- EuRR-Bone Annual Meeting online, March 25th (IW, TW and RTS)
- EuRR-Bone Patient Plattform (IW, TW, RTS and Claudia Finis), June 7th and Sep 20th
The OI Variant Database found a new home

After 6 months of coordinating and networking efforts from OIFE, it succeeded to find a new home for the OI Variant Database. The directors of the Amsterdam UMC Genome diagnostics laboratory have agreed to take responsibility for the long-term curation of the database after Dr. Dalgeish retirement from the university in Leicester, UK.

Save the European Health NGOs!

Large European health NGOs like EURORDIS and the EPF play a pivotal role in advocating for and communicating the needs of our members. OIFE supported the campaign to restore the operating grants for health NGOs in the EU budget. #SaveEUHealthNGOs

“We urge the European Commission to resume the support to civil society organisations in the field of health through operating grants. As similar mechanisms are still active in other fields, it is essential that the EU does not forget health.”
“Shining A Light On OI” - Webinar On The Topaz Trial

On June 8th Ingunn joined Patricia Osborne (BBS) as a speaker at the webinar “Shining a light on Osteogenesis Imperfecta” with an update on the TOPAZ trial. The event was hosted by the university of Edinburgh and included an update from Professor Stuart Ralston about the TOPAZ trial and a testimony from one of the patients who is taking part in the clinical trial.
Orphan Drug Policy Conference
On June 11th Ingunn attended a conference on European regulations on orphan drugs. The European Expert Group on Orphan Drug Incentives (OD Expert Group) presented their report with 14 policy proposals with different ideas on how to address the unmet needs of rare disease patients by evolving the European orphan drugs landscape from research to access.

OIF Investigator Meeting
The OIF Investigator Meeting in 2021 took place on Zoom instead of in Chicago and Tracy Hart was kind enough to invite both Dr. Lars Folkestad and Dr. Oliver Semler and Ingunn Westerheim (observer and patient representative).

EUnetHTA Stakeholder Meeting
On Friday 3rd of December, OIFE was represented at the EUnetHTA 21 Stakeholder Kick-Off meeting. The objectives of the meeting were the introduction of the ‘new’ EUnetHTA 21 Consortium. The EUnetHTA was established to create an effective and sustainable network for health technology assessment (HTA) across Europe.

Europa Bio Patient Forum
On October 19th Ingunn Westerheim represented rare disease patient organisations at a panel debate called the Patient Bio-Forum. This edition of the forum focused on the challenges and opportunities of the 24 European Reference Networks (ERNs). The forum agreed that a new European action plan on rare conditions is needed to address the overarching challenges.
OIFE attendance at other meetings hosted by others

Other meetings and conferences organised by others where OIFE attended included:

- Webinar Towards a European Health Union, March 11th
- Key4OI Update March 30th and Sep 28th
- Nordic Rare Disease Summit, April 12th – 13th
- Advisory Committee meetings in the Norwegian Skeletal Dysplasia registry
- ASMBR Webinar “Emerging therapies in OI”, May 25th
- Findacure webinars on HTA and measuring QoL July 8th and Sep 30th
- The Economist “Leaving the darkness, Tackling rare bone diseases”, Sep 22nd
- OIF webinar “Leveraging Virtual Communication to Advance PCOR Adoption”, Oct 21st
- OI Foundation’s Town Hall, Oct 28th
- Webinar on registries organised by George Reynolds, Nov 5th
- ECTS webinar on OI, Nov 10th
- A Nordic collaboration project on follow-up routines for OI

Networking

In addition to the list of subscribers to the Magazine, 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.

It's a huge challenge to keep the list up to date. And GDPR has made it more complex to recruit new people to the list.

During 2021 we also developed an expansive list of industry contacts.
COMMUNICATION AND PR

Communication in 2021 was focused on increasing the visibility and recognition of the OIFE brand and our role as the European OI-umbrella. The 2021 communication objective changed to creating more awareness about the activities OIFE promotes.

This translated into an increased focus on documenting OIFE activities throughout the different communication channels, which also required a learning process on the functioning of each channel to try to maximise reach also when using new solutions and approaches.

In 2021 OIFE experimented a lot, especially in channels like Instagram which confirmed to be a great way to engage people and get attention.

More or less every time an OIFE representative attended a meeting, conference or a new project was kicked off, it was posted on OIFE social media and/or a blogpost on the website.

During 2021, OIFE was mostly active on Facebook, Instagram and LinkedIn, while the accounts on Twitter and YouTube were used less.
In February 2021 OIFE got a lot of extra attention, mainly thanks to an active presence during the Rare Disease Day month and the extended Rare Disease Week - packed with meetings, events, politics and positive attention for the OI-community. It culminated by Rebecca Tvedt Skarberg and Ingunn Westerheim receiving the EURORDIS Black Pearl Volunteer Award.

Rare Disease Day Campaign & Rare Disease Day Week 2021

The EURORDIS Rare Disease Day Campaign 2021 went under the slogans “Share your Colours” and “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 peoples' lives.

Normally EURORDIS campaigns primarily target the general public and seeks to raise awareness amongst policy makers, public authorities, industry representatives, researchers, health professionals and anyone who has a genuine interest in rare diseases.
In 2021, the idea from EURORDIS was to use real life rare disease stories to create positive engagement across key audiences and beyond. This by using digital channels and our community to link rare disease stories, connecting partners and patients around the world and strengthening community and collaboration and demanding social opportunities for all.

OIFE participated in the campaign and encouraged member organisations to get involved by sharing information and posts EURORDIS suggested in their media pack for organisations. For the whole month of February, OIFE’s awareness campaign on living with OI, was building up to Rare Disease Day, which is a good opportunity to create attention about rare conditions.
To make it even more special, one of the faces of the EURORDIS campaign 2021 was Jon Kristian (12), a boy with OI from Norway.
In 2021 EURORDIS launched their first Rare Disease Week after inspiration from the USA. And it became a week filled with activities, highlights and lots of attention for the OI-community.

February 22nd kicked off Rare Disease Week, where OIFE had three young patient advocates participating, meeting Members of the EU-Parliament (MEPs) after months of advocacy training. On the 23rd the Rare2030 recommendations were launched at a huge online conference, where Rebecca Tvedt Skarberg (ERN BOND ePAG) gave one of the keynote speeches.

On the 24th it was time for Black Pearl Awards, where Rebecca and Ingunn won the Volunteer Award of 2021. And the photo of Khim Lamichhane Kazi from Nepal, won the 2nd prize in the photo contest.

This created a lot of buzz and attention, giving us access to talk about OI on live Television on the very popular Morning Show in Norway, and four interviews in local and national press. OIFE used the attention well and got a lot of buzz on our website and social media. We also hosted an informal award celebration on Zoom.
Wishbone Day 2021 & #OIStrong

Every year on May 6th 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 2021 called #OIStrong. The idea came from several brainstorming sessions to which delegates and communication managers of the national OI organisation were invited. The idea was inspired by the feeling of unity and strength that the OI community had, lived and showed, even in the most complicated period of the Covid-19 pandemic. The aim of the campaign was to collect testimonies from people about their successes, their stories and their ways of living happy lives with OI!

The campaign culminated with a WBD after-party on Zoom, where 50 people from many countries participated. The party featured quizzes, games and an award session during which some contents shared by the participants of #OIStrong campaign were awarded as winners for the following categories: Cutest, most educational, most powerful, yellowest and most creative.
OIFE Magazine

We published four editions of OIFE Magazine in 2021, which is distributed as a PDF through email to all our contacts. Target group includes 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 2021 had a main topic:

- Edition 1-2020 Special edition on Rare Disease Week
- Edition 2-2020 Special edition on registries, big data & knowledge gaps
- Edition 3-2020 Special edition on psychosocial aspects & ableism
- Edition 4-2020 Special edition on research

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 Webpage

OIFE’s webpage has been regularly updated with a focus on OIFE-related activities and projects in addition to information from our most important collaborators. We published more than 100 blogposts in 2021 about events and projects as well as republishing articles from the OIFE Magazine. The event calendar was also regularly updated with both community events but also events relevant for clinicians and researchers working with OI.
RESEARCH & DEVELOPMENT

Patient involvement in clinical trials

OIFE believe 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. Sometimes advice from a new and inexperienced parent or a child is needed. Other times a person with OI, who can represent a larger group and speak on behalf of many, is needed. Sometimes a project needs the experience of a patient expert and sometimes advice from a patient organisation who knows the international OI-community is needed. Usually this is when OIFE comes into the picture, but we can also offer assistance to find people in all the roles described above.

We have provided advice from the patient perspective to the following commercial stakeholders in 2021:

- Mereo Biopharma
- AMGEN
- UCB
- Ultragenyx
- Sanofi
- BOOST Pharma

We have also had contact with the following companies who are not directly working with OI:

- Kyowa Kirin International
- Blueprint Genetics
- Alexion
- Castle Creek Biosciences
- IPSEN & Costello Medical
- Aparito – about the Patient Group Accelerator Programme
- Novadip (Stem Cell Technology)
OIFE is also invited to suggest patient representatives for meetings in the European Medicines Agency and the Mechanism of Coordinated Access to orphan medicinal products (MoCa). On October 15th Taco van Welzenis represented OIFE at a MoCa-meeting.

**OIFE Medical Advisory Board (MAB) & OIFE Investigator Meeting**

There were no changes of members in the OIFE MAB in 2021. Dr. Oliver Semler has chaired the MAB.

On May 31st we hosted our only MAB-meeting in 2021. It included a short update from OIFE about activities and projects, ongoing initiatives on registries, databases and networks. We asked the MAB for advice on what role OIFE should take and which knowledge gaps we should focus on.

There were also discussions on how the OIFE can support collaboration and networking between OI-researchers in Europe and it was decided to host an investigator meeting similar to the one they have in the US. We set a date for the event in 2022 and established a programme committee: Antonella Forlino (IT), Lars Folkestad (DK), Liidia Zhytnik (ET) and Claire Hill (UK). Ingunn took on the role as conference organiser. The committee had two meetings in 2021.

**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 need to make sure that knowledge on regulatory processes, health technology assessments and advocacy are present on a national level. We also need data/documentation about the current situation for people OI, preferably for each and every country. This kind of data is called real world evidence (RWE).

The IMPACT survey was our main activity to gather data for these purposes.

In 2021 we also worked with "preparing the ground" for potential new treatments and services, mostly by educating ourselves and our member organisations.

We attended several webinars organised by Findacure, which explored ways to measure quality of life in rare diseases for the purpose of health technology assessment (HTA), and the ways patient organisations can get involved in the process, depending on the country they live in.

Educational activities directed towards our members included an OIFE leadership meeting in January and a seminar about research and development following the OIFE AGM.
The CHRONOS/MONITOR project
The CHRONOS project was originally an initiative from Luca Sangiorgi and was established because of a grant application to the European Joint Programme on Rare Diseases (EJP RD) partially sponsored by the company IPSEN. 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. Unfortunately, the project did not get funding in 2020. A new initiative was established in 2021 called MONITOR, but OIFE decided to pull out of the project in July 2021, as we didn't see enough potential value for OI compared to workload.

The Photo Voice Project - #Rare Bone Mobility
This project was originally a part of CHRONOS, but because of lack of 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.

A kick-off was held on March 10th and from March to May the Austrian students worked together with ANDO and OIFE to recruit people to take part via social media and a webpage developed by OIFE's webmaster. Unfortunately the page to submit photos (hosted by the Austrian school) turned out to be a big obstacle, so few participants were recruited. A lot of lessons were learned, which we could later use when promoting the IMPACT survey.

Connected to these projects, OIFE also attended several meetings with the EJP RD to learn about potential funding for OIFE through the EJP RD grant.
Other R&D projects OIFE supported

OIFE is also asked to support research projects in more passive ways and these are some of the projects or researchers we have supported with support letters in 2021:

- The TOPAZ trial
- Ahuce Foundation – Clara I. Rodriguez López and Arantza Infante Martinez
- BOOSTB4 project
- Antonella Forlino

We also supported the project Key4OI, Key4OIPlus and Roadmap to Surgery with dissemination and PR.

Surveys that OIFE has promoted

OIFE is more and more often asked to promote different surveys created by organisations or researchers. This is sometimes a challenge, because we don't want to bother our followers with too many surveys and create more survey fatigue. Unfortunately, surveys are often the best and easiest way to get knowledge on different topics, so we cannot get rid of them.

Examples of surveys we have been asked to promote in 2021 beside the IMPACT survey:

- Covid-19 survey of BBS – March – April
- Rare Bone Mobility (survey and photos) – March – May
- Survey about Physical Activity & Exercise in OI - June
- Survey young adults 18-25 with OI on reproductive knowledge – Sept. – November
- Parents of children who received a diagnosis of OI prior to birth – Nov 21 – Jan 22
- Ultragenyx survey of adults & parents (planning of clinical trial) – Dec
We tried not to promote any other surveys in parallel with the IMPACT survey. This is why we declined some requests to promote surveys. We also limited the number of surveys that were not exclusively relevant for OI, like the Rare Barometer Surveys from EURORDIS.

**Co-Authorship on scientific articles**

The OIFE contributed to at least two publications based on surveys:

- **Rebecca Tvedt Skarberg** (ERN BOND ePag) and **Ingunn Westerheim** were co-authors on a published article in Orphanet Journal called "Patients’ priorities and expectations on an EU registry for rare bone and mineral conditions".

- **Representatives from the OIFE and BBS** were also listed as co-authors on the article "Patient Reported Experience Of Clinical Care Of Osteogenesis Imperfecta (OI) During The COVID-19 Pandemic", which is submitted awaiting publication.
PEER WORK

Peer groups on Facebook

We have two peer groups for different target groups on Facebook – adults and young people with OI. OIFE believes that peer work can only happen between peers, which is why we don't allow staff members, caregivers or other people who do not have OI themselves into the groups. OIFE never provides advice as an organisation in the groups. We only provide an arena where people with OI can advise and support each other, based on their experience and personal knowledge on OI.

Facebook-group “OIFE – OI & adult health”

OIFE’s actively moderated Facebook-group “OIFE – OI & adult health” is actively used by individuals to have peer support from other OI adults with similar experiences. The group increased from 970 to 1190 members in 2021. The members come from more than 60 countries.

The group was 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.

We also used the group for 3 informal polls in 2021:

- Covid & vaccination (flu, influenza and covid)
- Which fractures make sense to count?
- Patient reported data – rate the 5 most important topics to cover in a registry (see chart).
Results from the two last polls were used to provide input to the OI-module in EuRR-Bone.

Other examples of topics that have been frequently discussed in 2021 included:

- Pain and pain treatment (incl. pharmacological and alternative therapies)
- Medical treatment options incl. bisphosphonates and newer osteoporosis drugs
- Fractures incl. non unions
- Covid-19 vaccines
- Ageing & anxiety around it
- Pregnancy & women's health (ex: hormone replacement and contraception)
- Exercise & physical activity
- Where and how to find a good OI-doctor?
- Soft tissue: hypermobility, muscle spasms and soft tissue injury
- Neurological problems incl. basilar invagination
- Cardiopulmonary issues
- Dental & jaw issues
- OI and EDS and OI and POTS

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 2021. OIFE's Youth Coordinators were moderators.
Social Network

In 2021 we saw a reduction in requests coming from individuals via e-mail, social media and WhatsApp. Requests from individuals mostly come from countries where there is no 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 groups.

A large proportion of individual requests in 2021 came from countries in the Middle East, where there are currently no active OI-organisations. When it comes to development of local support and knowledge, there are currently several positive developments in African countries. But it is still a long way to go before access to treatment and services is at an acceptable level. The OIFE EC has also provided advice to individuals who want to start new national initiatives, both in Europe and Asia.

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 have dedicated volunteers who serve as coordinators and peer advisors, but we are in need of more volunteers to help with these activities.
THANK YOU!

During 2021 many different people helped us represent OIFE in various meetings and contributed to 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! Especially everyone who contributed to making the IMPACT survey such a big success. The data from Impact will give both us and researchers important knowledge and give us value for many years to come. Thank you also to all collaborators, for wanting to work with us in such a constructive way.