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PRESIDENT’S STATEMENT

The last months of 2019 was an emotional time after the sudden passing of OIFE’s 2nd vice president Ida Männistö in October. But 2019 was also a year with positive developments and many activities for the OIFE.

With the help of different volunteers, we managed to be represented on a record number of arenas. These events & activities were the ones generating most work for the OIFE Executive Committee (EC) during 2019:

- See, Hear, Smile! OIFE Topical Meeting & OIFE AGM in Riga, Latvia
- OIFE president’s work in the ad hoc management group of the European Rare Bone Forum (ERBF) incl. two network meetings in Salzburg and Amsterdam
- Activities connected to the setrusumab project (Mereo Biopharma)
- The MOI study (Conect4Children) - advice and recruitment of patient representatives from various countries & hosting an educational session in Amsterdam
- Assisting ERN BOND with their registry survey
- Activities connected to the Quality of Life 4 OI-conference in Amsterdam

It is obvious that our networking and communication work has had an effect, because during 2019 we got an increasing amount of requests. They came from all kinds of stakeholders who wanted our advice or who wanted to work with us some way or another.

Lack of time was still a critical factor for the EC, and some activities took an unproportionate amount of the time we had available. Especially the involvement in the European Rare Bone Forum (ERBF) and the MOI-study generated many emails for OIFE’s president in 2019.

To keep up with the current activity level and reach goals in our long term strategy, we need more volunteers, more experienced patient representatives and preferably some kind of paid staff. We do however feel that we are on the right track to reaching the goals in our long term strategy (2018-2022).

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 2019. This included 19 European member organizations, who are national organizations with full voting rights:

At the end of 2019 we had 11 associate members/partner organizations, who were national organizations outside Europe without voting rights:
In addition to the non-European associate members, we had five supporting member organizations consisting of research foundations (Care4BB, AHUCE Foundation and the Belgian AFBOI) as well as two organizations providing aid and support for individuals (Padrinos and Help OI - HOI).

We got one new member organization in 2019:
- Osteogenesis Imperfecta Foundation Ghana (associate member)
GOALS

In accordance with OIFE’s strategy plan 2018-2022 the following overarching goals have 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.
THE ADMINISTRATION

The board

OIFE is run by the Board, which consists of one delegate from each member organization. Only European members have voting rights, but all delegates receive the same information. Approximately 35 internal email newsletters and requests were sent from OIFE president to the delegates during 2019.

The Executive Committee (EC)

The Board elects members of the Executive Committee (EC) and in 2019 the EC consisted of the following people:

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

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

IDA MÄNNISTÖ  
Finland  
2nd Vice-President  
re-elected for 4 years in 2019

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

ANNA ROSSI  
Italy  
Communication Manager  
elected for 4 years in 2016
The EC have increased their contact and activity by having videocalls approximately once a month. In addition we had one weekend meeting in Oslo, Norway from Aug 30th - Sept 1st.

On October 19th 2019 we sadly had to announce the sudden and unexpected death of OIFE’s 2nd Vice President Ida Männistö (30). We will always remember her as a positive and creative member of our team.

The Volunteers

The Executive Committee is supported by the following formally appointed volunteers:

**Stefanie Wagner**
Germany
Secretary

**Oliver Semler**
Germany
Chair of OIFE
Medical Advisory Board

**Ivar Troost**
The Netherlands
Webmaster

**André Wittwer**
Switzerland/Norway
Assistant webmaster

**Ute Wallentin**
Germany
Social Network Coordinator

**Stephanie Claeys**
Belgium
Youth Coordinator

In addition to the formal volunteers, OIFE is supported by other people and ad hoc volunteers.
**POSITIVE DEVELOPMENTS**

- A successful topical meeting (See, Hear, Smile!) in Latvia – followed by an intense AGM, with contributions from members and external guests.
- OIFE is growing and we got one new member organization (OIF Ghana)
- An increased interaction with other rare bone stakeholders
- Being part of the biggest patient led conference on OI in history – the Quality of life 4 OI-conference in Amsterdam
- Being part of positive developments in international OI-research
- Positive feedback to OIFE Magazine – especially from professionals
- More active use of OIFE’s website for publishing news and updates
- A closer collaboration with ERN BOND
- More income from various sponsors and supporters

It’s our view that OIFE is seen as an attractive and trustworthy partner to collaborate with.

We are more frequently than before contacted by various stakeholders instead of having to make the first initiative ourselves.
CHALLENGES

• Time was the big critical factor for the EC. Our activity level is not sustainable considering that all the work is done by volunteers. In 2019 the EC was therefore looking for smarter ways to work together, to use the time more efficiently.

• Logistical challenges stole even more time and energy - especially connected to our PayPal and bank account in Germany.

• Our financial situation became more solid, but with increased activity and representation, we also had more expenses that were not covered by project funding.

• We are still lacking a policy on how to interact with commercial stakeholders.

• We have recruited and educated more patient representatives, but it’s still a challenge to meet the increasing demand.

• With OIFE more visible in social media, we get an increasing amount of requests from individuals seeking advice and peer support from our social network.

• The amount of project related e-mails increased substantially in 2019.
EVENTS

OIFE AGM & OIFE Youth Event are events hosted by the OIFE every year.
A Topical Meeting is organized by OIFE approximately every third year. In addition to this we attend events hosted by others, as well as numerous meetings with external collaborators and partners on Skype or similar.

OIFE Topical Meeting ”See, Hear, Smile!”

OIFE’s topical meeting „See, Hear, Smile“ took place from June 14 th to 15 th in Riga, Latvia.

This was the first time such a meeting on OI was held in any of the Baltic States, and it represented the first big-scale collaboration between OIFE and Latvian Osteogenesis Imperfecta association (LOIB).

The programme committee had three video meetings in 2019 and consisted of:

- Kristofer Andersson (Sweden)
- Jannie Dahl Hald (Denmark)
- Lars Folkestad (Denmark)
- Dace Liepina - OIFE - (Latvia)
- Kaija Kuurila-Svahn (Finland)
- Anna Rossi - OIFE (Italy)
- Christer Swan (Denmark)
- Taco van Welzenis - OIFE (The Netherlands)
- Ingunn Westerheim - OIFE (Norway)

It was four years since our last topical meeting in Oslo, and like all meetings before it took a lot of time and resources.
The event gathered more than 80 participants from 22 countries and we consider it as a success. See, Hear, Smile! brought excellent talks about eyes, ears, teeth and craniofacial issues in people with OI.
The event also included great discussions and good opportunities for networking in a relaxed atmosphere. The program included a video lecture on basilar invagination (BI) from Dr. Suken A. Shah, which was published on YouTube. Both the abstract book and PDFs with the lectures we had to consent to share, have been published on OIFE’s webpage.

More than 50% of the invited lecturers paid their own travel (or got compensated through work), which was a huge financial help. A big thank you to the local volunteers and the lecturers who came to Riga and contributed with their knowledge, with little or no compensation!
OIFE AGM 2019

At the Annual General Meeting in Riga the EC accounted for OIFE’s activities in the past year. 39 people participated, mostly OIFE-delegates, but also representatives from OIFE Medical Advisory Board/ERN BOND and Mereo Biopharma. Future plans and policies were discussed and members exchanged news and best practises.

Dr. Eva Åstrøm from Sweden gave an update on ERN BOND and the company Mereo Biopharma gave us a status on the Asteroid study and presented opportunities and challenges regarding generating real world evidence and the need for more and better registries.

OIFE Youth Meeting

The OIFE Youth Event 2019 took place October 23-27 in Bilbao, Spain. The event was hosted by the Spanish OI-organization AHUCE and saw 49 participants between 18 to 35 years from 10 different European countries come together for a variety of activities and socialising.

Quality of Life 4 OI in Amsterdam

Many people from the OIFE and the wider OI-community attended the Quality of Life 4 OI-conference from November 22nd – 25th in Amsterdam, which gathered more than 300 participants from all over the world. The conference was initiated by Care4BrittleBones, but was a collaboration between Care4BB, OIFE, OIFE and ERN BOND. Ida Männistö represented OIFE in the steering committee and attended many videocalls connected to the conference and Key4OI.
In addition to the plenary programme, there were 5 different parallel session with the topics: medical treatment, orthopaedic treatment, psychosocial issues, genetics and patient empowerment. The session on patient empowerment was hosted by OIFE in collaboration with OIF, BBS and the other OI-organizations. Included in the session was also a kick off meeting for the patient representatives in the MOI-study. Many people from OIFE contributed in various ways even if the biggest workload was definitely on Care4BrittleBones.

NETWORKING & REPRESENTATION

ICCBH-conference

Shortly after AGM in Riga, OIFE was represented by Ingunn at the International Conference for Children & Bone Health (ICCBH) in Salzburg, Austria. The purpose was mostly to network with central professionals and people from the rare bone community.

European Rare Bone Forum (ERBF)

Salzburg was also the venue for the establishment of the European Rare Bone Forum (ERBF) which included the following meetings in 2019:

- Meeting European Rare Bone Forum (ERBF), Salzburg, Austria, June 23rd
- Meeting ERBF Amsterdam, The Netherlands, Nov 22nd (Ingunn Westerheim)

Ingunn resigned from the ad hoc management committee at the ERBF meeting in Amsterdam, mostly because the workload was becoming too large.
From September 23rd - 27th Taco van Welzenis represented OIFE at the International Summer School on Rare Disease Registries and FAIRification of Data in Rome, Italy. It was a part of a series of training activities proposed by the European Joint Programme on Rare Diseases (EJP RD) and was made up of 5 intense days of residential training organized by Istituto Superiore di Sanità (ISS) in close collaboration with other stakeholders.

**Representation in other meetings & events**

These are other arenas where we were represented in 2019:

- Lecture about OI & OIFE for employees at Mereo Biopharma Jan 22nd (Taco van Welzenis)
- OIF Investigator meeting 10-12th April in Chicago, USA (Antonella Forlino repr. OIFE MAB)
- AGM of ASITOI (Italy) from June 28th - 30th (Anna Rossi)
- China Dolls 10th anniversary, Yantai, China, August 3rd - 6th (Oliver Semler - OIFE MAB)
- The 14th International Skeletal Dysplasia Society (ISDS) meeting, Oslo, Norway Sep 11th - 14th (Rebecca T. Skarberg represented OIFE & Antonella Forlino represented OIFE MAB)
- Preconference seminar ISDS for patient organizations, Sep 11th (Ingunn Westerheim & Rebecca T. Skarberg)
- Annual family conference of the Brittle Bone Society from Sep 13th - 15th (Ingunn Westerheim)
- Conference about Health Technology Assessment in Norway, Oslo, Norway Sep 26th (Ingunn Westerheim)
- Webinar “Successful industry strategies for implementing Federated European Registries”; Oct 8th (Ingunn Westerheim and Taco van Welzenis)
- Lecture at seminar quality registries & patient involvement, Oslo, Norway, Nov 11th (Ingunn Westerheim)
- Mereo Biopharma WS about real world evidence, Oslo, Norway, Dec 18th (Ingunn Westerheim and Taco van Welzenis)
Video calls & teleconferences hosted by OIFE

- Numerous VCs connected to A stronger BOND between us - ECTS, ICCBH & ad hoc management group Salzburg event (Ingunn Westerheim)
- VC George Reynolds, RareUrn (consultant Mereo Biopharma), March 27th (Ingunn Westerheim)
- VC European Hearing Instruments Manufacturers Association (EHIMA), April 9th (Ingunn Westerheim)
- VC Nick Bishop & Janet Crompton about OI2020, April 23rd (Ingunn Westerheim)
- TCs Kyowa Kirin International, May 16th Sep 24th and Oct 18th (Ingunn Westerheim)
- VC Kara Ayers OIF about PCORI & patient engagement, September 4th (Ingunn Westerheim)
- VC Cecilia Götherström BOOSTB4, Sep 6th (Ingunn Westerheim)
- VC about repurposing of drugs in OI Anthony Hall, Oct 23 (Ingunn Westerheim)
- VC with delegates in Romania about acute access problems to pamidronate (Ingunn Westerheim and Dace Liepina)

In addition to a number of physical and virtual meetings mentioned, we have provided input to Mereo Biopharma (Asteroid study) on several occasions and we’ve been asked to find patient representatives to other research studies.

We have attended many videocalls (VCs) connected to ERN BOND and the C4C (MOI-study about Losartan in OI). OIFE president also had numerous videocalls (VCs) with OIFE members, volunteers and members of OIFE MAB.
POLICY WORK

Most of our policy work in 2019 was channeled through EURORDIS. We have attended a number of EURORDIS-events in 2019 - both educational and policy related events.

Black Pearl Events

The Black Pearl Events took place on the 12th of February and Rebecca Tvedt Skarberg and her husband Knut Erik attended. They had the pleasure of meeting the Princess of Romania and other royal guardians of the awards. The awards gather and pay tribute to people, organizations and companies who make outstanding efforts for people with rare diseases.

EURORDIS membership meeting

Over 200 representatives were present at the EURORDIS membership meeting in Bucharest on May 17th-18th. It included the AGM followed by workshops. The goal was to discuss next steps for implementation of the new position across Europe for the provision of holistic care for the 30 million Europeans living with a rare disease. Romanian delegates Dana Andrei and Florenta Plugariu represented OIFE with the support of Rebecca Tvedt Skarberg.

Round Table of Companies Workshop

On October 15th OIFE was represented by vice-president Dace Liepina at the 28th EURORDIS Round Table of Companies Workshop in Barcelona – “A New PARADIGM of Meaningful Patient Engagement in the Life Cycle of Medicines”. The event is an annual seminar for representatives from industry (pharma) and from EURORDIS and their member organizations.

Council of Federations-meeting

On November 8th Céu Barreiros represented OIFE at the Council of Federations-meeting in Brussels hosted by EURORDIS. Among the topics of the meeting of the 2019-meeting were status on ERNs, funding for research through Horizon Europe, news about the European Union and access to new therapies for people with rare diseases in Europe.
Other EURORDIS-activities

Other EURORDIS-activities included:
- VC Francois Houÿes, EURORDIS about Drug Repurposing project STAMP, May 23rd (Ingunn Westerheim)
- EURORDIS Summer School, Barcelona, Spain, June 10-14th (Claudia Finis)
- EURORDIS Webinar on registries June 25th (Ingunn Westerheim and Taco van Welzenis)
- VC Francois Houÿez EURORDIS about pamidronate in Romania, Sep 9th (Ingunn Westerheim)
- EURORDIS Leadership School - during the whole 2019 (Rebecca T. Skarberg)

ERN BOND

On February 13th – 14th the second technical meeting of the European Reference Network for Rare Bone Disorders (ERN BOND) was held in Brussels. 27 members of BOND participated and among these all 4 of the ePAGs (patient representatives), incl. Rebecca Tvedt Skarberg from OIFE.

In addition to the meeting in Brussels, Rebecca has attended numerous VCs in ERN BOND steering committee and working groups (up to several per week). There was also a face to face meeting in ERN BOND connected to the Amsterdam conference.

OIFE has assisted ERN BOND actively in developing and disseminating a large survey about people with rare bone disease's perspectives on registries/databases. The survey was first launched in English, but later translated to seven other languages. There were 596 responses from 447 adults, 24 children and 125 parents, guardians or carers (PGC) across 23 rare bone diseases. OI constituted 54% of responses.

Other activities connected to ERN BOND:
- Several VCs and TCs with Luca Sangiorgi and/or Rebecca Tvedt Skarberg
- VC OIFE, Care4BB &; ERN BOND about Qol4OI, Sep 5th (Ingunn Westerheim, IM & Rebecca Tvedt Skarberg)
- Working dinner L. Sangiorgi & R. Tvedt Skarberg ERN BOND & OIFE, Dec 17th (Ingunn Westerheim & Taco van Welzenis)
COMMUNICATION AND PR

OIFE’s current webpage was launched at the OIFE AGM in 2018. In 2019 we have kept it up to date including the event calendar and news section.

Under News & Resources we also post many of the same articles that have been published in the magazine, something which drives traffic to the page.

The page is kept up to date by OIFE president, OIFE’s communication manager and our secretary. The webmasters contribute with technical support and bigger changes.

We released two issues of OIFE Magazine including special editions on research and youth activities.

We finalized the 3rd edition late December 2019, but decided to publish it as 1-2020 instead of 3-2019.

We increased our amount of followers in all our social media.

We also opened an Instagram account, which is mostly managed by our youth coordinators.

OIFE is now present in the following social media: Facebook (ca 2800 followers), Twitter (ca 1000 followers), Instagram (ca 450 followers), YouTube and LinkedIn.

Facebook is our main channel in addition to our webpage, and we try to post something almost every day to keep the Facebook-page active.

We did an awareness campaign about OIFE & OI connected to Rare Disease Day.

We also used social media actively to promote See, Hear, Smile, both before and during the event.

Thanks to volunteer Maria Barbero, we got the main content of our OIFE webpage translated to Spanish. Unfortunately we were not able to finalize the implementation of the text on the actual webpage, but the process has started.
PROJECTS & ACTIVITIES

A more professional OIFE

Our continued goal in 2019 was to become more professional - both in ways of running the OIFE and on how we are regarded externally.

- Our goal of having professional staff was not reached in 2019, but we had a positive development and are continuing to raise funds to make it possible.
- G Suite for Non Profits was implemented during 2019 and in February we changed our email provider from Hostpoint to Google. This has made it much easier to keep our lists up to date and reduced the amount of spam and phishing attacks substantially.
- During 2019 we almost finalized our work to establish a financial policy for OIFE.

A stronger BOND between us

One of the goals of the OIFE project called "A stronger BOND between us" has been to create an informal network between different stakeholders working on OI and other rare bone diseases. In December/January we established an ad hoc working group consisting of OIFE (Ingunn Westerheim), Inês Alves (ANDO Portugal) and Gerald Brandt (HPP Deutschland).

Our goal was to establish a multistakeholder network at the ICCBH-conference in Salzburg. We were supported by the European Calcified Tissue Society (ECTS), industry, ERN-BOND, the ICCBH and others. Even if the European Rare Bone Forum (ERBF) was established and led to an increased contact with rare bone stakeholders, it also involved an unproportionate amount of work for Ingunn, who was part of the ad hoc management group. She therefore decided to resign from the management committee at the 2nd network meeting in Amsterdam. OIFE remains a member of the (currently) informal ERBF, which is supported administratively by ECTS. At the end of 2019 the OIFE initiated a new collaboration project with the XLH Alliance, to which we received a project grant of 10.000 euros from Kyowa Kirin International.

“Flying OI-Experts”

The intention behind the project "Flying OI Experts" is to bring knowledge and help to new countries and enable patient representatives in less developed countries. This as a strategy to strengthen local communities and support instead of supporting a few individuals in going to Europe or US/Canada to have surgeries or treatment.

In 2019 we gave a larger amount in support to the planned 3rd Ibero-American conference on OI in Quito, Equador, which included a travel grant to MAB-member Miguel R. Molina. Sadly just before the conference, political riots broke out in Equador and the conference had to be cancelled. The organizers are trying to set up the conference at a later stage.

Through Flying OI Experts we also supported the travels of Antonella Forlino to attend OIF Investigator-meeting in Chicago and Oliver Semler’s travel to the China Dolls-conference.
RESEARCH AND DEVELOPMENT

OIFE keeps a list of more than 1000 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.

**Medical Advisory Board (MAB) for OIFE**

From 2018 OIFE has had a formal advisory team of OI-knowledgeable professionals – a Medical Advisory Board (MAB). It involves both clinicians and researchers. Dr. Oliver Semler served as the chair of the advisory board in 2019.

- Oliver Semler - chair (Germany)
- Darko Anticevic (Croatia)
- Eva Åström (Sweden)
- Natalia Belova (Russia)
- Marijn Créton (The Netherlands)
- Lars Folkestad (Denmark)
- Fátima Godinho (Portugal)
- Claire Hill (UK)
- Lena Lande Wekre (Norway)
- Aliaksei Pachkaila (Belarus)
- Miguel Rodriguez Molina (Spain)
- Thomas Wirth (Germany)
- Lidiia Zhytnik (Estonia)

The EC has not asked the entire board for advice on many occasions.
The main input has been connected to our strategy documents and AGM. During 2019 several members of OIFE MAB represented/reported back to OIFE from various meetings including the OIF Investigator Meeting & the ISDS conference (Antonella Forlino).

**Activities connected to registries**

In addition to Taco van Welzenis attending Summer School on registries, OIFE has also done an effort to find out what kind of registries and databases that exist in Europe, without much success.

We have however attended several webinars to increase our knowledge on the topic and constructed a resource group consisting of 6 people, who are interested in the topic. Registries was also one of the main topics at the OIFE AGM, connected to the research project of Mereo Biopharma.
European Medicines Agency & MOCA

The European Medicines Agency (EMA) and EU healthcare payers continued their cooperation on June 17th at a meeting in Diemen, the Netherlands, to help improve timely and affordable access for patients to new medicines (MOCA - Mechanism of Coordinated Access to Orphan Medicinal Products).

Margriet Crezee from the Netherlands represented OIFE as a patient representative to talk about the patient perspective.

The meetings we have attended related to EMA or MOCA include:

- MOCA - Mechanism of Coordinated Access to Orphan Medicinal Products, Diemen, The Netherlands June 17th (Margriet Crezee)
- European Medicines Agency, Amsterdam, The Netherlands, July 9th (Taco van Welzenis)

OIFE involvement in research projects

During 2019 we were involved in the following research & developments projects:

- Key 4 OI (part of steering committee)
- ”Costs in OI - a Global Assessment of the Out-of-Pockets Expenses Incurred by Families of Children with Osteogenesis Imperfecta” (collaborator + co authors).
- The Asteroid Study (setrusumab), Mereo Biopharma (mutual exchange of information & advice from patient perspective)
- The TOPaZ Trial - Treatment of Osteogenesis Imperfecta with Parathyroid hormone and Zoledronic acid (Eero Nevalainen has been member of steering committee)
- MOI-study (c4c) - Losartan study - (OIFE agreed to help recruit patient representatives from a number of countries + hosted training session in Amsterdam)
- BOOSTB4 – study on stem cells in OI (OIFE has provided advice, recruited patient representatives and co-hosted session in Amsterdam)

In addition to these projects, we have also supported some grant applications that were not awarded with any money. The MOI-study was terminated in December 2019.
PEER WORK

Facebook Group - Adult Health & OI

Our moderated Facebook-groups adults are actively being used from people all over the world and is a popular way to have peer support from people with similar experiences.
We regard strict and active moderating as one of the success criteria.
We get many requests from parents and professionals who want to join the group, but these are all denied.
The adult group had more than 700 members per 31.12.19 and has been moderated by 4 volunteers: Ute Wallentin, Ingunn Westerheim, Julia Piniella and Taco van Welzenis.
Through the adult group, we also have the opportunity to have feedback about what the health concerns of adults with OI are.

We kept the poll about which areas the patients wanted to see guidelines on pinned to the top and the results were:

- Pain treatment (83 votes)
- Orthopedic treatment incl. spine surgery (68 votes)
- Physiotherapy (47 votes)
- Medicinal treatment incl. bisphosphonates - adults & children (49 votes)
- Breathing issues (29 votes)

Examples of topics that have been discussed in 2019 include:

- Genetics & types of OI
- Pregnancy and breastfeeding
- Pain management (many) - both medication, injections and alternative therapies
- Spinal fusion
- Hormones & menopause
- Bisphosphonates in adults (many) & other bone building medications
- Kidney stones
- Migrating rods
- Cardiovascular issues
- Problems with healing
- Joint replacements in OI
- Soft tissue injuries (tendons, muscles etc)
- Gastrointestinal procedures
- Sleep apnea & respiratory issues
- Tinnitus, hearing and cochlear implants
- Laser surgery in OI
Facebook Group - OIFE Youth Only

The target group for the youth group is people with OI between 16 and 35.

We get requests from parents who want to join the group, but these are denied.

There has been some activity, but not as much as in the adult group. OIFE’s Youth Coordinators Marie & Stephanie are the moderators.

Social Network

During 2019 we saw a further increase in individual requests to OIFE coming both via e-mail, but in particular via social media and WhatsApp.

Requests are mostly coming from countries without functioning OI-organizations and can be everything from need for advice on how to find an OI-group, how to find competent care to request for financial support and mobility aids.

OIFE does not in any case provide financial support to individuals. We provide advice and peer support and help to find OI-groups or doctors with experience locally.

We have a dedicated person (Ute Wallentin), who serves as a coordinator and peer advisor. We see a need to create a bigger team around Ute in order to take care of the increasing amount of individual requests.
FINANCIAL STATUS

OIFE’s financial situation had a positive development in 2019, but we still need more substantial and predictable funding to reach our goal of establishing more secretarial support.

During 2019 we had increased logistical challenges connected to our PayPal account, which is connected to our very oldfashioned German bank account.

The decision to organize a topical meeting was done after the budget for 2019 was decided upon. In the budget for 2019 the Board had decided to prioritize the project “A Stronger BOND between us” with an equally large sum as the topical meeting turned out to cost us.

The AGM was somewhat more expensive than the budget. And since 2019 also included a record number of arenas we were represented on, our expenses to travel and accommodation were also higher than previewed.

We had support from 3 different companies connected to the topical meeting & AGM:
- Mereo Biopharma (unrestricted grant of 10,000 euros),
- Alexion (sponsorship of 7500 euros)
- CastPrint (sponsorship of 825 euros).

Looking back on previous years, OIFE had a minus each year we had a topical meeting. It looked like we would have a similar situation in 2019.

But thanks to a larger grant from Kyowa Kirin International (10,000 euros) connected to ”A stronger BOND between us”, received in December, we ended up with a surplus for 2019.

Regarding Flying OI Experts, the EC decided to use more than previewed, because we had unused funding earmarked for the purpose in our saving accounts.

OIFE does not have many different sources of income besides membership fees, smaller donations and industry support. For 2019 we therefore got more than 50% of our income from industry support, connected to grants/support from 4 different companies.

We applied for funding for rare disease federations from EURORDIS, but the application was rejected since they wanted to prioritize poorer federations. Other sources of income were membership fees and gifts from individuals/member organizations (mainly NFOI).

Our application to be approved for Facebook Donations did not succeed in 2019 either, but we continue to try. We also tried to apply for funding through a consortium application in the European Joint Programme for Rare Diseases, but it was not rewarded.

During 2019, we almost finished the task of developing a financial policy for OIFE.
We’d like to send a big thank you to all the volunteers who helped us in 2019. Without the effort of all of you it would not be possible to have the level of activity that we did.

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