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THE ORGANIZATION

Member organizations:

The umbrella organization Osteogenesis Imperfecta Federation Europe (OIFE) consisted of 34 different organizations at the end of 2018. This included 19 European member organizations, who are national organizations with full voting rights:

Austria  Belgium  Denmark  Finland  France  Germany  Italy

Latvia  The Netherlands  Norway  Poland  Portugal  Romania  Russia

Spain  Switzerland  Sweden  UK & Ireland  Ukraine

Sweden has been represented by a subgroup of the Swedish umbrella RBU supported by SFOI (established in March 2018).

At the end of 2018 we also had 10 associate members/partner organizations, who are national organizations outside Europe without voting rights:

Australia  China  Ecuador  Georgia  Mexico

Nigeria  Panama  Perù  South Africa  USA
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 & support for individuals (Padrinos and HOI).

We got three new member organizations in 2018:

- Ukrainian Association of Crystal People - UOCP (ordinary member)
- Brittle Bones South Africa (associate member)
- Osteogenesis Imperfecta Foundation Nigeria
GOALS

One of our main goals in 2018 was to develop a new long-term strategy in order to help us prioritize in a world with many tasks and few resources.

During the AGM 2018 the following new overarching goals were proposed and approved in OIFE’s strategy plan 2018-2022:

- 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 25 internal email newsletters were sent from OIFE president to the delegates during 2018.

The Executive Committee (EC):

The Board elects members of the Executive Committee (EC) and in 2018 the EC consisted of the following people:

**INGUNN WESTERHEIM**
Norway
President
re-elected for 4 years in 2015

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

**IDA MÄNNISTÖ**
Finland
2nd Vice-President
elected for 1 year in 2018

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

**ANNA ROSSI**
Italy
Communication Manager
elected for 4 years in 2016
Ida Männistö was elected for one year only, because vice-president Eero Nevalainen resigned after 3 of 4 elected years.

The EC has increased their contact and activity by having videocalls once a month.

Eight EC videocalls were held during 2018. In addition we had two week-end meetings in Milan, Italy from March 9-10 and in Lisbon, Portugal from November 24-25.

**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
  - Assistant Youth Coordinator

- **Marie Holm Laursen**
  - Denmark
  - Assistant Youth Coordinator

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

During 2018 many different people helped us represent OIFE in various meetings and contributed on various tasks.

We send a big thank you to all the formal and informal volunteers of the OIFE!
POSITIVE DEVELOPMENTS / HAPPENINGS

- We had a successful celebration of OIFE’s 25th anniversary. Feedback from delegates to a new format of OIFE AGM was positive, and people seemed to be motivated by it.

- We have become more visible as the international OI umbrella organization.

- OIFE is growing and we got three new members in 2018.

- Increased contact between EC-members though monthly skype meetings and two face to face meetings. Communication between the meetings remains a challenge.

- More use of tools like Wunderlist, WhatsApp (chat) and Google Drive as an attempt to reduce the amount of emails.

- OIFE was successfully approved for „Google for Nonprofits“ in 2018.

- We developed a new and improved website with updated content, better security and possibilities of easier maintenance.

- We further developed and expanded our newsletter to become the OIFE magazine.

- The OIFE president had substantially more contact with delegates and OIFE volunteers through videocalls.

- We developed a privacy policy and made an effort to fill the requirements of GDPR.

- We developed more knowledge about and established new contacts in the pharmaceutical industry.

- A constructive collaboration with other organizations for rare bone diseases was further developed

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

- The EC have clearer goals & priorities, but enough time is the big critical factor. All members of the EC are busy people with jobs, families and other interests.

- Logistical challenges still steal time and energy - especially on the financial side. We are formally registered in the Netherlands, have our bank accounts in Germany and EC-members spread all over Europe.

- Our funding is still relatively hard to predict from year to year. We are still lacking a clear financial policy and a policy on how to interact with the industry and other commercial stakeholders.

- It’s a challenge to find patient representatives with enough knowledge and time to represent OIFE in research projects and meetings with stakeholders like the EMA, MOCA and others.

- Reaching our target groups through email seems to become more difficult each year. Ordinary email is a very fragile communication tool and especially hospitals have firewalls that causes emails from OIFE to end up in spam.

- With more visibility comes more requests. The amount of e-mails, requests and meetings with external stakeholders have increased substantially.

- We still don’t have a developed culture for sharing ideas & good practises between the delegates.
EVENTS

OIFE AGM & OIFE Youth Event are events hosted by the OIFE every year. In addition to this we attend events hosted by others, as well as numerous meetings with external collaborators and partners on Skype.

**OIFE 25th anniversary & AGM 26**

The 26th OIFE AGM & celebration of our 25th anniversary took place in Dundee, Scotland from August 19th - 20th. The OIFE events were held after/in parallel with the 50th anniversary of the Brittle Bone Society (BBS), which took place from August 17th - 19th.

The weekend started with a scientific seminar organized by the BBS on August 17th, followed by the opening of the History Bones exhibition. Saturday and Sunday many of the OIFE delegates attended the BBS’s family conference & anniversary celebrations together with participants from UK & the Republic of Ireland.

The OIFE AGM took place from Sunday morning (Aug 19th) and began with 10 votes present. Representatives from 14 full members with voting rights were present at most. In addition to usual AGM business, sharing of examples & ideas from the different organizations were in focus.

As part of the OIFE AGM, the delegates participated in a joint session with the Brittle Bone Society, where the main topic was patient priorities in research. A parallel workshop for the OIFE delegates on patient involvement in research and development was hosted by Dr. Nick Bishop and ERN BOND ePag Rebecca Tvedt Skarberg.

On Sunday night we celebrated the OIFE’s 25th anniversary with dinner, invited guests, speeches, anniversary cake and the launch of an anniversary video.

Taco van Welzenis & Ute Wallentin were officially awarded a diploma as Honorary Members of OIFE, securing free lifetime admission to OIFE AGMs. OIFE AGM continued on Monday where research was one of the main topics.

There were in total 38 participants excl. assistants and dinner guests.
OIFE Youth Event 2018

The OIFE Youth Event 2018 took place October 25-28 in Denmark.

It was hosted by a group of Danish girls with the support of the board in the Danish organization DFOI. 42 participants from 8 European countries took part.

The event received initial financial support from the OIFE, but the organizers managed to fully finance the event without support from OIFE.

A few people received travel support from OIFE (max 100 euros each) after applications.

Representation in meetings & events hosted by others

We strive to be represented in various events & conferences where OI or rare bone diseases are topics and we have therefore chosen to ask more people outside the EC to represent us during 2018. These are some of the events where we were represented in 2018:

- EURORDIS webinar about recruiting & managing volunteers Jan 17th (Ingunn)
- ECTS webinar about research opportunities in BOND Feb 8th (Ingunn)
- Inauguration of Swedish OI-organization in Stockholm, Sweden, March 18 (Ingunn & André Wittwer)
- European Parliamentary Meeting “European Reference Networks – Accelerating and Improving Diagnosis for Rare Diseases Patients”, February 28th (Filip De Gruytere)
- Conference on medical quality registries, Tromsø, Norway, March 20-21 (Ingunn)
- The 37th Annual Meeting of the European Pediatric Orthopedic Society (EPOS) in Oslo, Norway, April 11 and 13 (Ingunn)
- 18th Annual OIF Scientific Meeting, April 18-20, Chicago, US (Claire Hill - OIFE MAB)
- Rare Diseases International Membership Meeting, Vienna, May 10 (Ingunn)
- EURORDIS AGM, Vienna, May 10 (Ingunn, Dace & Rebecca T. Skarberg)
Meetings with Care4BB

On August 16th the EC had a meeting with the management of Care4BrittleBones (Care4BB), to discuss future projects and collaborations, including representation of individuals and/or organization in Care4BB committees.

During the AGM of the BBS, Care4BB organized a parallel meeting, which included representatives from OIFE, The OI Foundation (OIF), OIFE’s MAB, Care4BB, ERN BOND as well as central researchers & clinicians.

The topic was the project Key4OI and the upcoming conference Quality of Life 4 OI. It was agreed to create a steering committee consisting of representatives from OIF, OIFE, Care4BB and ERN BOND.

Ida Männistö was chosen as OIFE’s representative.
**MOCA-meeting**

OIFE’s honorary member Taco van Welzenis attended a meeting in MOCA (Mechanism of Coordinated Access to Orphan Medicinal Products) in Vienna, Austria.

MOCA aim at facilitating “early dialogue” between companies and national competent authorities (the payers) for pricing and reimbursement on specific orphan medicines.

The purpose is to speed up access to orphan drugs in developments for patients in EU Member States.

**EURORDIS-meetings**

Ingunn, Dace & Rebecca attended the EURORDIS AGM & ECRD-conference on rare diseases in Vienna, which is a very good arena to be updated and to network with organizations and companies.

The 27th workshop of the EURORDIS Round Table of Companies took place October 16th in Barcelona and OIFE was represented by then elected Vice President Dace.

Discussions focused on the importance of patient engagement in the development of medicinal products and the development of community advisory boards (CABs).

Ingunn did not attend the Council of Federations (CEF)-meeting in Paris because of health issues.

Ida Männistö (Finland) and Edgars Liepins (Latvia) attended The Expert Patient and Researcher Summer School of EURORDIS that took place in Barcelona from 11th - 15th of June 2018.
Videocalls & teleconferences hosted by OIFE

The amount of Skype meetings & phone conferences was increasing steadily in 2018. More stakeholders were interested to speak with the OIFE and hear our opinion on various topics. Especially Mereo Biopharma and ERN BOND are important collaborators, which we have developed a closer dialogue to during 2018.

These are some of the stakeholders we had videocalls/teleconferences with during 2018:

- Various meetings with representatives from ERN BOND (Kassim Javaid, Nick Bishop Luca Sangiorgi & Rebecca Tvedt Skarberg)
- Shriners Hospital Montreal
- Various meetings with Mereo Biopharma
- Other pharma companies working with rare bone diseases: Alexion, Kyowa Kirin & Biomarin and UCB
- Janet Crompton - organizer of ICCBH & OI2020
- The European Calcified Tissue Society
- Cast Print (company in Latvia)
- Student’s Voice (essay competition)
- Other organizations representing rare bone diseases

In addition there were numerous videocalls with volunteers and members.

See, Hear, Smile 2019

During 2018 the EC decided to organize a topical meeting connected to the 2019 AGM in Riga, Latvia. The programme committee had one meeting in 2018 and consisted of:

- Kristofer Andersson - dental issues (Sweden)
- Jannie Dahl Hald - OI researcher (Denmark)
- Lars Folkestad - OIFE’s Medical Advisory Board (Denmark)
- Dace Liepina - OIFE - (Latvia)
- Kaija Kuurila-Svahn - Hearing issues (Finland)
- Anna Rossi - OIFE (Italy)
- Christer Swan - Hearing issues (Denmark)
- Taco van Welzenis - OIFE (The Netherlands)
- Ingunn Westerheim - OIFE (Norway)
POLICY WORK

Most of our policy work in 2018 was channeled through EURORDIS. For instance we supported the statement from EURORDIS calling on the European Commission to secure the continuous and sustained involvement of UK healthcare providers as members of European Reference Networks (ERNs) after Brexit.

COMMUNICATION & PR

Better communication was one of our main priorities in 2018.

Our main goals were to develop a new webpage and to become more visible as the umbrella organization for OI. OIFE’s new webpage in Wordpress was launched at the OIFE AGM.

It provides clearer information about who the OIFE is and what we do. It includes an updated events calendar. The page has better security which has reduced our spam problem and is easier to update for volunteers without technical skills.

The website was developed by a working group consisting of webmasters Ivar & André in addition to Ingunn & Anna from the EC.

During 2018 we developed our newsletter into a periodical magazine. We released 4 issues of OIFE Magazine including special editions on research and youth activities.
We increased our amount of followers in both Facebook and Twitter.

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

OIFE is now present in the following social media: Facebook, Twitter, Instagram, YouTube and LinkedIn - but Facebook is our main channel in addition to our webpage.

During Wishbone Day, we had a shared social media initiative with the OIF and the BBS.

Thanks to volunteers from Hungary and Latvia, we got our OIFE passport translated Hungarian and Latvian language during 2018.

These versions are only available online.
PROJECTS & ACTIVITIES

A more professional OIFE:
One of our goals in 2018 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 has not been reached, but we have had a positive development and are continuing to raise funds to make it possible.
- G Suite for Non Profits was implemented during 2018 and has improved our possibilities to work more efficiently together and secured access to shared files.
- Through our new webpage & templates for annual reports, we have created a more professional look.

A stronger BOND between us:
During 2018 we noticed an increased interest in rare bone diseases including OI from different stakeholders. This has created opportunities, but also some challenges.

OIFE tries to collaborate with relevant stakeholders when we see a long term benefit for OIFE and/or people with OI.

The European Calcified Tissue Society (ECTS) has been trying to set up an (informal) network of stakeholders (conferences, researchers, companies and patient organizations) involved in rare bone diseases. Miguel R. Molina (OIFE MAB) represented us at a network meeting in Valencia, followed by a conferencecall in October, where Ingunn attended. No formal network was established in 2018, but the dialogue has continued.

OIFE gets more and more requests for patient representatives who can fill different roles in research projects, meetings at the European Medicines Agency and other regulatory bodies at a European level.

Our challenge is that we don’t have enough people with the right experience, expertise or background to fill these roles. Because of this we want to develop a capacity building programme to support rare bone organizations in recruiting and teaching patient representatives.

During 2018 we have been trying to get in touch with professionals, companies or rare bone groups who might be interested in being part of the project.
In 2018 our activities to reach this goal included:

- meetings with ERN BOND
- meetings with other rare bone organizations
- meetings with industry representatives - both for companies working on OI (Mereo) and others.
- established contact with European Calcified Tissue Society
- contact with ICCBH-conference
- contact with EURORDIS incl. attendance at various events
- recruitment of several new patient representatives who represented OIFE in research projects, EMA, MOCA and meetings with the industry

We are far from reaching our goal of a capacity programme, but 2018 has put us in touch with many important stakeholders and we continue the work.

“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 2018 there were no bigger projects or initiatives that received support.

But we gave support to several volunteers from different countries to attend the OIFE AGM 2018 and learn from peers. We also provided smaller travel grants to professionals to attend relevant conferences.
RESEARCH AND 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.

New Medical Advisory Board (MAB) for OIFE

From 2018 OIFE established a formal advisory team of OI-knowledgeable professionals – a Medical Advisory Board (MAB).

The OIFE MAB includes people from different professions – both clinicians and researchers. Dr. Oliver Semler serves as the chair of the advisory board.

- 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.

But during 2018 several members of OIFE MAB represented OIFE in various meetings including the OIF Investigator Meeting (Claire Hill) and ECTS Rare Bone Network-meeting in Valencia (Miguel R. Molina).
**ERN BOND**

Rebecca Tvedt Skarberg was part of the steering committee and several working groups in The European Reference Network for rare bone disorders (ERN BOND) in 2018.

OIFE has had meetings with several of the working groups in ERN BOND in 2018.

On the occasion of Rare Disease Day (February 28th) ERN BOND organized a European Parliamentary Meeting called: “European Reference Networks – Accelerating and Improving Diagnosis for Rare Diseases Patients”.

The aim of the event was to present the ERN-BOND White Paper on Diagnosis and discuss solutions on how to best reduce the average time to accurate diagnosis for rare bone diseases.

The OIFE was represented by Belgian OIFE-delegate Filip De Gruyter. Dagmar Mekking from supporting member Care 4 Brittle Bones also attended.

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**Community Advisory Boards**

EURORDIS reached out to OIFE and other organizations to get us involved in their initiative called “Community Advisory Boards (CABs)”. OIFE has chosen not take part in the initiative so far.

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**Care4BB & Fundacion AHUCE**

We have collaborated with our supporting members Care4BB and Fundacion AHUCE on various projects and initiatives.

The conference Quality of Life 4 OI will take place in Amsterdam November 22-25 2019.

The conference is initiated and led by Care4BrittleBones and a collaboration between Care4BB, OIFE, OIF and ERN-BOND and different professionals.

OIFE has been represented in the steering committee by Vice President Ida Männistö.
OIFE involvement in research projects

During 2018 we were involved in the following research projects in various ways:

- Key 4 OI (part of steering committee)
- The Asteroid Study, Mereo Biopharma (mutual exchange of information & advice from the perspective of a patient organization)
- The TOPaZ Trial - Treatment of Osteogenesis Imperfecta with Parathyroid hormone and Zoledronic acid (Eero Nevalainen has been member of steering committee)
- Survey on respiratory function in OI, USA (OIFE has spread information)
- AMGEN Denusomab trial (OIFE has spread information)
- Chronic pain in OI, Spain: Prevalence and variables of interest (OIFE has spread information)
- Consensus Project Physio - (OIFE assisted with recruitment of professionals)
- A Global Assessment of the Out-of-Pockets Expenses Incurred by Families of Children with Osteogenesis Imperfecta ("Costs in OI") - (OIFE was formal collaborator and has assisted with spreading information to potential contributors).
- Rare Commons (advice from patient organization perspective)
- c4c - Losartan study - (OIFE agreed to help find patient representatives)
- COST Action Proposal OC-2018-1-23069 " GEnomics of MusculoSkeletal traits TranslatIOnal Network " (support letter from OIFE after initiative from ERN BOND)
- Cardiopulmonary Outcomes Study, USA (OIFE has spread information)
- ”Incorporating Patient Perspectives in the Study of Rare Disease: Insights from the 2017 International Conference on Osteogenesis Imperfecta” (co-authors)
PEER WORK

Facebook Group - Adult Health & OI

Our two moderated Facebook-groups (for youth and adults) are actively being used and are popular ways to have peer support from people with similar experiences from around the world. We regard strict and active moderating as one of the success criteria.

The adult group had more than 550 members per 31.12.18 and has been moderated by 4 volunteers: Ute Wallentin, Ingunn Westerheim, Julia Piniella and Willy Hagelstein (later replaced by 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. Based on a request from ERN BOND, we gave feedback on which areas the patients wanted to see clinical guidelines on. We did a poll in the group and the top five topics were:

- Pain treatment (68 votes)
- Orthopedic treatment incl. spine surgery (53 votes)
- Physiotherapy (47 votes)
- Medicinal treatment incl. bisphosphonates - adults & children (30 votes)
- Breathing issues (28 votes)

We also provided input to dr. Richard Kruse from Wilmington, US on which issues were important to adults with OI regarding orthopedic surgery (before, during and after).

Facebook Group - OIFE Youth Only

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

We get many requests from parents who want to join the group, but these are all 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 2018 we saw a further increase in the amount of individual requests to OIFE coming both via e-mail, but in particular via social media.

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 medical 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 where the person in question lives.

We have a dedicated person (Social Network Coordinator Ute Wallentin), who serves as a coordinator and peer advisor in these cases. She works closely together with OIFE’s supporting members Padrinos and HOI to respond to the different requests.

We see the need to create a bigger team around Ute in order to take care of the increasing amount of individual requests.
FINANCIAL SITUATION

OIFE’s financial situation had a slightly positive development in 2018, but we still need more substantial and predictable funding to reach our goal of becoming a professional and efficient umbrella organization.

The only company we received support from in 2018 was MereoBiopharma (8000 euros for Flying OI Experts). We thank them for their wonderful support and our continuous constructive collaboration.

OIFE does not have many different sources of income besides membership fees, smaller donations and industry support. We’re therefore getting closer and closer to a situation where more than 50% of our income comes from industry support.

This, in addition to all of the support in 2018 coming from one company, is a challenge we’re working to solve.

We received a testamentary gift from Rob van Welzenis in 2018, which have been placed in a separate savings account. The gift was intended as a financial buffer for OIFE, but the OIFE Board can decide to use the gift for a project deemed suitable.

We applied for funding for rare disease federations from EURORDIS and received 2000€ in round two after first being rejected. Other sources of income were membership fees and gifts/donations from individuals/member organizations (mainly NFOI).

We made several attempts at being approved for Facebook Donations in 2018, but because we are spread in several countries (registration, bank accounts, board) this turned out to be difficult.

We have started a process to develop a financial policy for OIFE, but there is still substantial work that needs to be done.
GENERAL COMMENTS

2018 was a good year for OIFE and important goals were reached. A long term strategy was developed and we got a new Medical Advisory Board. We developed a new webpage, a magazine and improved our external communication in general. We became more visible as the international umbrella for OI and we got three new member organizations.

The AGM and anniversary celebrations left people inspired and during the AGM we welcomed two new EC-members - Dace Liepina from Latvia and Ida Männistö from Finland. We also thanked our vice presidents Taco van Welzenis and Eero Nevalainen for their long lasting contributions to the OIFE.

The EC developed new ways of working together through monthly meetings, Google for Non Profits, and tools like Wunderlist and WhatsApp. But even if we work more efficiently, lack of time is the big critical factor. Much of the follow-up between the monthly videocalls falls on the OIFE’s president, and the situation is vulnerable.

Considering that we don’t have paid staff, our activity level was high in 2018. Perhaps too high? We managed to keep track with the increasing amount of e-mails and requests from individuals and stakeholders who wants to work with us.

But it’s getting increasingly harder to keep up and one can raise the question if this level of activity is sustainable over time. 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.

In the meantime, we would like to take the opportunity to thank everyone who contributed to making 2018 a good and constructive year for the OIFE.

On behalf of the Executive Committee

Ingunn Westerheim - OIFE president