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OIFE: Presentation

Member organizations
The umbrella organization Osteogenesis Imperfecta Federation Europe (OIFE) consisted of 32 different organizations in 2017.

This includes 18 European member organizations, who are National organizations with full voting rights: Austria, Belgium (Flemish), Denmark, Finland, France, Germany, Italy, The Netherlands, Norway, Poland, Portugal, Romania, Russia, Spain, Sweden, Switzerland and UK. Sweden is represented by a subgroup of the Swedish umbrella RBU. The Latvian OI-organisation LOIB was accepted as a new member from AGM 2017.

We also had 8 associate members, who are National organizations outside Europe without voting rights: Australia, Ecuador, Georgia, Mexico, Panama, Peru and the USA. China Dolls was included as an associate member from December 2017.

In addition to the National organizations, we had 5 supporting member organizations consisting of research foundations (Care4BB, AHUCE Foundation and the Belgian AFBOI) as well as 2 organizations providing aid & support for individuals (Padrinos and HOI).

OIFE Goals
OIFE has in the time period had the following long-term goals:

- Representing people living with OI and their families, and OIFE’s member organizations on both European and International levels.
- Advocating the needs of those living with OI to national and international organizations, focusing on inclusion within public health programs.
- Striving towards equal access to early diagnosis, appropriate therapeutic strategies and optimal medical treatment and care.
- Promoting and encouraging research into all aspects of OI, in coordination with medical professionals and advisors.
- Collecting, transmitting, exchanging and publicising information about OI.
- Developing and strengthening the structure of the OIFE; allowing it to carry out its routine tasks and to realise its current and future aims.
- Cooperating with other organizations representing people living with disabilities - such as rare genetic or connective tissue conditions – in order to achieve common goals.
- Helping to establish new OI associations, and supporting those already in existence.
- Increasing public awareness of OI
- Providing information and support to individuals and families living with OI.
The Structure

**The Board**
OIFE is run by the Board, which consists of one delegate from each member with voting rights. The Board was during 2017 advised by honorary president, Rob van Welzenis, The Netherlands, who sadly passed away in September 2017. Approximately 25 internal newsletters and e-mails were sent from OIFE president to the delegates during 2017.

**The Executive Committee**
The Board elects members of the Executive Committee (EC) and in 2017 the EC consisted of the following people:

- **Ingunn Westerheim**  
  *President*  
  Norway  
  re-elected for 4 years in 2015

- **Taco van Welzenis**  
  *Vice-President*  
  The Netherlands  
  re-elected for 4 years in 2014

- **Eero Nevalainen**  
  *2nd Vice-President*  
  Finland  
  re-elected for 4 years in 2016

- **Céu Barreiros**  
  *Treasurer*  
  Portugal  
  re-elected for 4 years in 2017

- **Anna Rossi**  
  *Communication Manager*  
  Italy  
  elected for 4 years in 2016

The EC has increased their activity by having Skype meetings once a month. Eight EC Skype meetings were held during 2017. In addition we had a week-end meeting in Milan, Italy from February 24-26.
Challenges:
- The EC have clearer goals, but enough time, money and volunteers are still missing.
- We have too few volunteers outside the ones appointed by the EC.
- We do not have a culture for sharing ideas between the delegates.
- Fees have been causing problems in communicating with associate members.
- Technical problems with webpage and spam causes problems.
- OIFE is still not visible enough among our members and people in general.
- Challenges regarding bank accounts (in Germany) - and volunteers spread around Europe
- Lack of experience on fundraising.

Positive developments:
- Regular monthly Skype meetings of the EC (and week-end meeting in Milan).
- Less emails between EC - more use of tools like Wunderlist and Google Drive
- More Skype contact with OIFE volunteers.
- More visible as the OI umbrella.
- More contact with member organizations
- OIFE is expanding with several new members in 2017
- More contact with OI groups outside OIFE (for example, professional communities in Africa).
- More knowledge about pharmaceutical industry.
- More secure webpage and less spam.
- Shared approach with OIF, BBS and the OIFE on Wishbone Day.
The Volunteers
The Executive Committee appoints a group of formal volunteers and in 2017 the following volunteers were appointed:

Stefany Wagner
Secretary
Germany

Oliver Semler
Medical Advisor
Germany

Ivar Troost
Webmaster
The Netherlands

André Wittwer
Assistant Webmaster
Switzerland

Ute Wallentin
Social Network Coordinator
Germany

Stephanie Clayes
Youth Coordinator
Belgium

Marie Holm Laursen
Assistant Youth Coordinator
Denmark

In addition to the formal volunteers, OIFE is supported by other people and ad hoc volunteers. We send a big thank you to all the people who have been helping us during 2017.
**Events**

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

**AGM 2017**

The 25th OIFE AGM took place in Warszawa, Poland from May 26-28. There were 13 delegates with voting rights present, and in total we were 19 participants excluding guests from the Polish OI- organization.

We were very warmly welcomed by the Polish OI-organization and had constructive discussions about **OIFE’s strategy - short and long term**, which was the main topic.

We also welcomed **Ol Latvia (LOIB) as a new ordinary member of OIFE**. The minutes from the meeting are available on our webpage.

Before the meeting, we distributed a Google Forms query, where we asked about status from the organizations and their priorities regarding OIFE strategy. We did not ask the organizations to send annual textual reports in addition to this.

It was decided to change the **fee for associate members to zero**, because the fee question was in the way of a constructive collaboration.

The only demand of associate members from now is to provide a delegate, active communication (in English) and an annual report about activities.
OIFE Youth Event 2017

The OIFE Youth Event 2017 took place November 1st - 5th in the Netherlands.

Ca 40 participants from ten European countries took part.
**OIFE representation in meetings & events hosted by others**

- **Training course on patient participation in research**, Oslo, Norway - March 9 (Ingunn)
- **Kickoff for the European Reference Networks** in Vilnius, Lithuania - March 9-10 (Rebecca T. Skarberg)
- **Kickoff Mereo Biopharma** - May 3-5 (Ingunn)
- **Eurordis AGM**, Budapest, Hungary - May 19-20 (Céu)
- **Kickoff for the European Reference Network for rare bone disorders (BOND)**, Rome, Italy - May 22-24 (Rebecca T. Skarberg via streaming - Dagmar Mekking from Care4BB was present)
- **ICCBH-conference** (Ingunn and Ute Wallentin represented OIFE)
- **OIOslo2017 - the 13th International Conference on OI** - Aug 26 - 30
  - Pre Conference Seminar on Patient Participation in Research (Ingunn, Taco & Ute)
  - Pre Conference Seminar on Physiotherapy (Ute)
  - The 13th International Conference on OI (Ingunn, Taco & Ute)
  - Meeting with Mereo Biopharma (Ingunn & Taco)

Ingunn gave a talk about OIFE & the OI-community - patient organizations and challenges/opportunities on patient recruitment at the Mereo Biopharma investigator meeting in Copenhagen, which gathered researchers from Denmark, UK and France.

The OI-community was also well represented at the International Conference on Children’s bone Health (ICCBH) in Würzburg, Germany with representatives from Norway, Germany, Estonia, UK and the Netherlands. Ingunn Westerheim and Ute Wallentin represented the OIFE and OIFE's medical advisor dr. Oliver Semler had an active role during the conference. Ingunn gave a talk in a workshop for allied health professionals about OIFE & the role of patient organizations. Care4BB presented their consensus project on rehabilitation for OI through a poster.

From 27-30 August the 13th International Conference on Osteogenesis Imperfecta (OIOslo2017) took place, which gathered 250 participants from 40 different countries worldwide. OIFE’s president Ingunn Westerheim was the conference coordinator (hired by NFOI) and had an active role during the whole conference. Taco van Welzenis (OIFE Vice-President) and Ute Wallentin (OIFE’s social network coordinator) represented OIFE during the conference. Delegates from many different organizations inside and outside Europe (USA, China and Australia) took part.

**Skype meetings & phone conferences hosted by OIFE**

- Phone conference with research project Rare Commons - February (Ingunn)
- Skype with Q & A session between OIFE president and people attending Russian youth camp - April 18 (IW)
- Phone conf. with Patient Primary - March 24th (Ingunn)
- Skype with dr. Luca Sangiorgi (BOND ERN) - June 16 (Ingunn)
Skype with UCB pharma company - Dec 8th (Ingunn)

In addition to these, there has been numerous Skype meetings with volunteers and our member organizations hosted by OIFE.

Policy work

During summer 2017, OIFE formally joined a number of European organizations in a campaign to tell president Juncker that Health Collaboration is crucial for Europe’s future. We also supported the initiative of CLAN’s (an Australia based NGO) with a letter to the World Health Organization. The goal of the letter was to have bisphosphonates for children with OI included in the list of "essential medications". Our hope was that this would make it easier for children with OI in countries where they don’t have access to this important treatment, which among OI-scientists is considered as the current gold standard treatment of children with OI. The initiative has so far been without results.

Communication and PR

English is the official language of OIFE. In addition, we have a decision to use Spanish in our webpage. Our main goal for 2017 was to share more examples and ideas from our member organizations through our channels like the OIFE newsletter, web and social media.

OIFE newsletter

OIFE newsletter came out with 3 editions (English only) during 2017. During 2017 we expanded the format and included more fixed columns and interviews with different stakeholders. The responses to the change of format and size made before the last edition were mostly positive.

Web & social media

Developments regarding web & social media:

- OIFE’s new website now has a responsive design for smart phones and iPad. Information about our different member organizations has decreased, to avoid outdated information. We have plans to convert the whole page into Wordpress at some point. Bigger changes and developments have therefore not been prioritized.
- OIFE’s Facebook page has an increased amount of followers (ca 1700 per December 31st) and is steadily growing. We try to keep the page active and there is still potential to increase.
- OIFE deleted our general Facebook-group and has tried to develop two other Facebook groups with more narrow target groups in 2017 (youth and adults with OI)
- The Twitter account was revived during 2017 and connected to Facebook.
- OIFE’s YouTube Channels was revitalized and now contains 5-6 playlists with more than 100 videos from our members and people with OI.

**Development of guidelines on social media**

OIFE also had ambitions to develop guidelines for social media for our member organizations in 2017. This has unfortunately not been followed-up.

**Peer Work**

**Social network**

During 2017 we saw an increase in the amount of individual requests to OIFE coming via e-mail and social media, especially from countries without functioning OI-organizations. The requests could 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 can provide advice and peer support and help to find OI-groups or doctors where the actual person lives. In some cases we use our list of professionals to find local support and skilled OI professionals.

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.

**New Facebook Group - Adult Health & OI**

The OIFE established a new moderated Facebook-group in 2017 with the target group of adults with OI. The group is only open to people who have OI themselves and only topics related to OI & adult health issues are allowed. The group is moderated by 4 volunteers: Ute Wallentin, Ingunn Westerheim, Julia Piniella and Willy Hagelstein. The group had more than 450 members per 31.12.17 and has given us more knowledge about what kind of questions adults with OI are worried about. The group has had a lot of activity and is being actively used by people from both outside and inside Europe. We see active moderating as one of the success criteria.

**New Facebook Group - OIFE Youth Only**

Since the original OIFE Youth group on Facebook had tecnical problems, we decided to close the old group and create a new one for people with OI between the age of 16 and 35. OIFE’s Youth Coordinators Marie & Stephanie are moderators. There has been little activity in the group.
**Projects**

*“Flying OI-Experts”*

Many individuals ask for support to travel to another country with more competence in OI. Our strategy is however to rather support professionals in travelling to country without competence in order to establish better services and more competence in these countries. This can also lead to new initiatives in starting local OI-groups, that can provide support to more individuals and families.

OIFE has therefore continued our project “Flying OI Experts” by providing travel grants for professionals and volunteers to increase knowledge on OI in countries without a lot of experience. OIFE gave support to German physiotherapist Brigitte Müller to give a lecture at a Russian family camp in March. We also gave travel support to OIFE’s Medical Advisor Oliver Semler, who gave a talk about rehabilitation of OI-children June 29th at The First Eurasian Orthopedic Forum in Moscow, Russia.

The conference had more than 3000 participants and was a good opportunity to create awareness about OI among Russian professionals. The conference resulted in telescopic rods being approved as treatment for OI in Russia. After the conference, Oliver visited several clinics in Moscow - where he met children with OI and their doctors/physiotherapists.

**Adult Health & OI**

The OIFE has during 2017 been trying to gather information about adult initiatives around the world:

- Adult health initiatives/projects
- Clinics especially for adults with OI (existing or planned)
- OI-specialists focusing especially on adults
- Guidelines/checklists for treatment and/or follow-up of adults with OI
- Information material especially developed for adults with OI
- Research projects only involving adults with OI
- Other topics about adults & OI we should know about

The response from our member was not substantial in 2017. We will keep collecting information on the topic in 2018, but not organized as a particular project.

**OIFE passport**

A new template for the OIFE passport was developed in 2017.

With support from Mereo Biopharma we printed 2000 copies of the new passport in December 2017 and gave a special offer to our members to buy discounted passports before January 20, 2018.

The printed version now contains 22 different languages including gujarati (India) and mandarin (China).
Research and development

OIFE keeps a list of more than 900 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.

Establishment of Medical Advisory Board for OIFE

During 2017 we established a Medical Advisory Board for OIFE, planned to launch in January 2018. Our wish is that the MAB-members will be speaking partners and advisors to the Executive Committee in more strategic questions - for instance:

- Policy planning where this has a medical component
- Discussions about new scientific developments
- When to support, promote or inform about research

Dr. Oliver Semler has served as OIFE's Medical Advisor for several years and will chair the Medical Advisory Board for the first period from January 2018 - December 2019. The following people have confirmed to volunteer as our advisors the coming two years:

- Oliver Semler, Pediatrician, MD PhD - Germany (chair of OIFE MAB)
- Darko Anticevic, Orthopedist, Professor - Croatia
- Eva Åström, Pediatrician, MD, PhD - Sweden
- Natalia Belova, Pediatrician, Professor - Russia
- Marijn Creton, Maxillofacial prosthethist, DDS, PhD - the Netherlands
- Lars Folkestad, Endocrinologist, MD, PhD - Denmark
- Antonella Fortino, Associate professor of biochemistry - Italy
- Fátima Godinho, Rheumatologist, MD - Portugal
- Aliaksei Pachkaila, Pediatrician, MD, PhD - Belarus
- Miguel Molina Rodriguez, Physiotherapist - Spain
- Lena Lande Wekre, Rehabilitation, MD, PhD - Norway
- Thomas Wirth, Orthopedist, Professor - Germany
- Liidia Zhytnik, PhD student in biomedicine & gene technology – Estonia.

BOND

Rebecca Tvedt Skarberg (suggested by OIFE) has been part of the steering committee and several working groups in The European Reference Network for rare bone disorders (BOND) during the entire 2017. OIFE as organization has been included in Working Group 9 and 10, but there has not been a lot of activity. OIFE has contributed with support letters for application for funding and have also recruited people to join the BOND-group in Facebook Workspace (hosted by EURORDIS). The OIFE has also volunteered to assist BOND in spreading information to patient representatives in countries who have health care providers (HCP) in BOND. This includes OIFE-members Belgium, France, Germany, Italy, The Netherlands, Portugal and United Kingdom. We have also reached out to our contact persons in Sweden, Estonia and Czech
Republic. OIFE has spread requests to provide BOND with existing guidelines for treatment of OI from different countries. In addition, we have spread a request to recruit individual patients/parents of children with OI who could answer a query about diagnostic challenges in OI.

**Care4BB & Fundacion AHUCE**

We have also collaborated with our research foundation Care4BB and Fundacion AHUCE on various projects and initiatives (mostly exchange of information).

**OIFE involvement in research projects**

During 2017 we were involved in the following research projects in various ways:

- **Asteroid Study Mereo** (attended investigator meeting, announcement in OIFE Magazine + Skype meetings/e-mail contact)
- **AMGEN Denusomab trial** (announcement in OIFE newsletter)
- **Rare Commons** (Spain) - phone conference & agreement of collaboration
- **Consensus Project Physio** - OIFE helped with recruitment of professionals
- **Boost4BB** (EMA-meeting as patient representative – Eero)
- **The TOPaZ Trial** - Treatment of Osteogenesis Imperfecta with Parathyroid hormone and Zoledronic acid (member of steering committee - Eero)
- **Pregnancy Study BBDC** (announcement Facebook)
- **Study about prenatal testing** (announcement on Facebook).

**Financial situation**

OIFE's financial situation has been stable the last years, but we are in need of more substantial as well as predictable funding to become a more professional and efficient umbrella organization.

It is also an issue that we have only had contact with one pharma company at the time. However less than 50 % of our income is from the industry.

The only pharma company we received support from in 2017 was Mereo Biopharma.

In 2017 we applied for funds with EURORDIS (for rare disease federations), but were not prioritized.

Other income was based on membership fee and gifts/donations from individuals/member organizations. We have started a process to develop a financial policy for OIFE and our member organizations as well as a new fundraising strategy.
General comments

Among the most important goals we reached in 2017 was to establish a Medical Advisory Board and do a revision of our signature document, the OIFE passport. Another goal was to share more examples, information and activities from our member organizations through our newsletter, webpage and social media. We feel that we succeeded in this, but there is room for further improvement. In general we feel 2017 was a good year for the OIFE, with positive development in several areas. We had more contact between EC-members and also between OIFE, our member organizations and our volunteers. We would like to thank everyone who contributed in making 2017 a good year for the OIFE.

On behalf of the Executive Committee

[Signature]

Ingunn Westerheim - OIFE president