



OSTEOGENESIS IMPERFECTA FEDERATION EUROPE

Meeting report- AGM 26 Sunday August 19th– Monday August 20th 2018 Apex Hotel, Dundee, Scotland

List of participants

There were in total 38 participants to OIFE AGM 2018 excl. assistants and dinner guests.

Participants from ordinary members with voting rights:

1. Ingunn Westerheim (IW), OIFE president & delegate Norway
2. Taco van Welzenis (TvW), OIFE Vice-President & delegate the Netherlands
3. Céu M. Barreiros (CB), OIFE Treasurer & delegate Portugal
4. Ute Wallentin (UW), Social Network Coordinator & delegate Germany
5. André Wittwer (AW), OIFE Webmaster & delegate Switzerland
6. Dana Andrei (DA), delegate Romania
7. Patricia Osborne (PO), CEO Brittle Bone Society and delegate UK & Ireland
8. Ida Männistö (IM), delegate Finland
9. Markus Patzel (MP), delegate Austria
10. Filip de Gruytere (FdG), delegate Belgium
11. Maria Barbero (MB), delegate Spain (vote for AHUCE) & delegate Padrinos (no vote)
12. Michał Daszkowski (MD), delegate Poland
13. Dace Liepina (DL), delegate Latvia
14. Leonardo Panzeri (LP), delegate Italy

Other participants from ordinary members (no extra vote):

1. Oliver Semler (OS), Germany - Chair of OIFE's Medical Advisory Board
2. Anna Rossi (AR), Italy, OIFE Communication Manager
3. Coreen Kelday (CK), UK & Ireland
4. Rebecca Skarberg (RS), Norway, ePAG ERN-BOND
5. Florenta Plugariu (FP), Romania
6. Marta Rodrigues (MR), Portugal
7. Stephanie Claeys (SC), Belgium, OIFE Youth Coordinator
8. Bruno van Dijk (BvD), Belgium - *only before lunch Sunday*
9. Lieve Michiels (LM), Belgium - *only before lunch Sunday*
10. Marleen Hendrickx, Belgium - *only before lunch Sunday*

Participants from associate members (no vote):

1. Tracy Hart (TH), USA (CEO of OIF) - *only Sunday*
2. Dr. Francis Glorieux (FG), Canada (Medical advisor OIF)
3. Ken Gudek (KG), USA, (Chair of OIF) - *only OIFE's anniversary reception & dinner*
4. Karen Braitmayer (KB), USA
5. Rageema Livingstone (RL), South Africa - chair of Brittle Bones South Africa
6. Tarela Aghanti (TA), Nigeria - chair of OIF Nigeria (*voted in as members during AGM*)

Participants from supporting members (no vote):

1. Dagmar Mekking (DM), Netherlands, OIFE delegate (CEO Care4BrittleBones)
2. Graham Marshall (GM), Netherlands, Chair of Care4BrittleBones
3. Julia Piniella (JP), Spain, Director AHUCE Foundation

Invited guests for OIFE AGM (no vote):

1. Anthony Hall (AH), UK, Therapeutic Area Head, Mereo BioPharma
2. Claire Hill (CH), UK – Member OIFE's Medical Advisory Board - *only before lunch Sunday*
3. Eva Åström (EA) - Member OIFE's Medical Advisory Board *only Sunday*
4. Nick Bishop (NB)- ERN-BOND professional - *only the shared session with BBS*
5. Jacinta Whyte (JW), Canada, chair of COIS - *only before lunch Sunday*

Sunday, 19th August

OIFE Annual General Meeting (AGM) - business meeting part I

- Welcome and apologies
- Election of meeting volunteers
- Counting of votes & presentations
- Settlement of agenda
- Approval of minutes from 2017
- OIFE's Annual Report 2017 – including national reports
- Short status from Social Network Coordinator
- Short status on situation in 2018
- Practical information about the rest of the program

Opening session - welcome & apologies

IW has again prepared a PPT with many explanations and some graphics.

She welcomes all delegates and guests and after some organizational remarks she apologizes those who cannot be present:

- Steffi Wagner (OIFE secretary),
- IvarTrost (webmaster)
- Eero Nevalainen (vice-president)
- Simona& Joshua, who was registered but could not attend due to fracture
- Delegates from Sweden (RBU), Denmark, France, Russia & Ukraine

Election of meeting volunteers

The following people were elected as meeting volunteers:

- Minutes: Maria Barbero& Dana Andrei (Ute Wallentin volunteered to assist)
- To do-list: André Wittwer
- Counting of votes: Tracy Hart & Julia Piniella
- Financial sub committee 2018 (substitutes since those elected were not present): Filip de Gruytere& Dace Liepina

Counting of votes

IW states that the meeting will begin with 10 votes present. Some delegates will arrive later, but representatives of 14 full members should be present at a later stage.

Settlement of agenda

IW shows the agenda and briefly goes through its main parts.

Vote: the Agenda is accepted unanimously.

Approval of minutes from AGM 2017

The minutes from AGM 2017 were approved by email vote

OIFE's Annual Report 2017 & National reports

IW presented the annual report from the Executive Committee (EC) for 2017.
For detailed report see PPT.

“Good chemistry” in the EC. Presentation of the EC and volunteers. IW points out that OIFE is still mainly run by volunteers. Only paid force is secretary Steffi for just a few hours per week.

OIFE-Members:

- 19 ordinary members in Europe. Ukraine voted in few weeks ago as an ordinary member and will start acting as full members when they have paid the fee.
- 9 associate organisations all over the world, in Australia, Asia, South America, North America and Africa
- 5 supporting members

Networking is the most time consuming task. The number of Skype conferences has increased, with partners and volunteers. High workload on the EC.

Important events last year:

- AGM in Poland
- Youth Event in NL (youth events are getting increasingly popular)
- ERN meeting in Vilnius (establishing meeting of ERNs)
- Mereo investigator meeting in Copenhagen,
- EURORDIS
- ICCBH Conference
- OIOslo2017 - 13th international conference on OI

Communication activities:

3 newsletters, activation of social media, new format of OIFE Magazine developed (launched in 2018).

Policy work:

EU4Health campaign, Clan & WHO (bisphosphonate treatment in the countries where no bisphosphonates are available yet).

Peer Work/Support:

OIFE gets more individual requests& questions because we are more visible now.

Projects:

- Flying OI Experts (2 applications received and supported in 2017)
- Adult Health Project
- Reprint OIFE Passport

Finances:

No money received from EURORDIS in 2017. But OIFE received 10.000 € from Mereo.

Bigger topics:

Medical advisory board established from January 2018, but the recruitment took place in 2017 (mainly at OIOslo2017). Chair: Dr. Oliver Semler

Challenges 2017:

We need clearer goals and must gather more information on different topics.
IW asks the delegates to send input when requested.

Positive developments 2017:

Positive development in general, it was a good year for the OIFE. Thanks to the volunteers who helped to reach goals!

Vote:

EC Report 2017 is unanimously approved without objections.

Presentation of national reports were postponed until Monday morning.

Report from OIFE's social network coordinator

UW reports that Facebook has become a more important communication platform. In 2017 the OIFE received an increasing number of requests through the different channels (website, through member organizations, Facebook OI groups etc):

- Information for travel: OI Passport and contact persons in destination country
- Basic OI information: we try to direct them to a resource center (Some families ask the OIFE even if there is an OI organization in their own country)
- Many new families and adults ask where to get medical treatment or surgery
- Questions about pregnancy: we try to get their doctors in contact with other specialists
- We receive many individual requests every week.
- We are following protocols for data protection

Joint session with the Brittle Bone Society

The following topics were on the agenda:

- "What does the patient want?" Professor Nick Bishop & Penny Clapcott
- "Policy - the importance of public engagement" - Christine Collins MBE
- European Reference Network on rare bone disorders (ERN BOND) – Professor Nick Bishop and Rebecca T. Skarberg, BOND ePAG
- Breakout session "Looking forward with the BBS &OIFE
OIFE group about patient involvement in research & development chaired by dr. Nick Bishop & Rebecca T. Skarberg

OIFE Meeting continued after lunch

- OIFE strategy plan 2018 - 2022
- Financial report 2017 including report from financial sub committee
- Budget for 2019
- Launch of new webpage for OIFE
- Elections

Before the topics on the original agenda, an application of membership from OI Nigeria was processed.

Membership application from OIF Nigeria

IW explains that the EC received an application for membership from OIF Nigeria on August 18th. The EC recommends to accept this organization, which has been existing and functioning for 2 years and their statutes are consistent with OIFE's.

Tarela Aghanti presents the Nigerian OI Foundation. They have been working for more than two years creating awareness about OI in Nigeria. They have found about 15 children with OI. Their work consists now in supplying wheelchairs and offer advice and support to the families, and also buying zoledronate for the hospitals. Tarela has been attending OI meetings and informing doctors about OI. She talks about the importance of making knowledge available to doctors.

Vote: OIF Nigeria is unanimously accepted as an associate member organization of OIFE.

OIFE Strategy Plan 2018-2022

IW presented the EC's proposal for OIFE's strategy plan 2018-2022, that had also been sent to all delegates more than 2 weeks in advance of the meeting:

Definition of OIFE:

OIFE has 33 member organizations in three categories:

- Ordinary members (national OI organizations)
- Associate members
 - National OI organizations outside Europe
 - Supporting members:
 - Aid organizations
 - Research foundations

The issue was discussed, if it would be interesting for OIFE to become an international organization.

Agreement: at least for the next four years OIFE will be kept as a European organization because of European laws and connections to EURORDIS and European Medicines Agency. We will keep associate members from other continents because it is important to share opinions & information. It is better to stay European because of travel distances, money transfers and, eventually, potential EU-grants.

Even if only European ordinary members have a vote, the others are still important and invited to share and participate.

New members are welcome to share contributions. The OIFE can also offer contributions and advice to organizations from outside Europe. The associate (non-European & supporting) members do not pay a fee. What is required from an associate member is to have a delegate and send national reports to keep OIFE informed.

New vision statement (approved):

Children and adults with OI living active and independent lives - with access to competent healthcare and necessary social support

New mission statement (approved):

We connect and empower organizations, professionals and individuals to improve lives of people with OI.

New proposed goals (approved) are to:

- represent our members on an international level and be the voice of people with OI and their families;
- grow an international network between professionals, organizations, 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 organizations and local support in more countries;
- guide individuals towards information, healthcare and support.

There were also a proposal regarding more detailed objectives included in the document. But IW proposes not to go into detail since the proposal has been spread to the delegates in advance. This unless someone wants everything to be presented.

Proposal I: "rare diseases" should be replaced by "rare conditions" or "rare disorders".
ProposallI: "Aid" organizations be "Support organizations"?

IW suggested that we vote on approval of the whole document including the change of the word "disease" to "condition". She proposes to leave the word "aid organization" unchanged.

New counting of votes:

Actually 13 people with voting rights present.

Vote: Unanimous agreement on EC's proposal with one amendment ("rare conditions" instead of "rare diseases")

Financial report 2017

Financial report was presented by OIFE's treasurer CB.

- Bank accounts are in Germany.
- Financial status of OIFE has been improving. We want to increase our income to a level that permits paid staff and a more professionalized organization.
- In 2017 we received missing membership fees from earlier years. We also had pharma grants.
- The expenses for the secretary were included in the project of developing the new website and publications.
- The costs for meetings of the EC have increased because of physical meetings.
- The expenses regarding the youth meeting appears blank because the money was transferred to the Netherlands in 2018 instead of 2017.

CB shows a graphic with the expenses in 2017. Communication development was very important. Income was larger than expected. We could therefore start new projects in 2018, as we had an increase of 19 % compared with the year before.

Financial subcommittee: DL and FG went through the financial files and they confirmed that the financial report is OK and recommended approval.

Vote: Financial report for 2017 approved unanimously

Budget 2019

Budget proposal for next year:

- Expected income of over 32.351 Euros (with donations from industry). Some money will go to a new project, "A stronger BOND between us" roughly presented by IW. With it, we will reach out to companies working with other rare bone diseases.
- Expected expenses for 2019: Higher expenses for EC meetings and also higher for projects: Flying OI experts, youth meeting, communication...
- Budget proposal is 32.351 income and 32.235 expenditure.

TW wants to further elaborate on the Stronger BOND-project before approving the budget. IW explains that the plans are not detailed yet, but the idea is to use the money primarily for informational and educational events and also to pay someone for administration of the Project.

TH is curious about the youth program and asks, if a higher registration fee would be a good idea to increase income. IW explains that the registration fee is low because we want the people from certain countries to come to this networking event and we don't wish to use it as an income event, but rather as an instrument to reach for future volunteers.

The majority decides to vote now for the approval of the budget.

The budget is unanimously approved by 13 votes.

Launch of new OIFE webpage

AW and AR show us the new webpage, which has been a huge project, started in May 2018. Webpage is now based in WordPress. With the former system it was more complicated to add content. Now the system also looks nice on cell phones. Website has been on for a week now and details have to be fixed. AR explains the structure and the content of the website, which includes a calendar for OI events. The new events can be updated quickly. Webmasters now have a new and more technical role. All content & need for changes must therefore be sent to office@oife.org

AW explains that there will also be a change of email system (from Hostpoint to Google), but that this is mainly technical and that all delegates will receive mails through the same addresses as before.

The website will be translated into Spanish as the only extra language in addition to English. More pictures are also needed. AR speaks about the possibility of opening an Instagram account to generate more photos.

Executive Committee – elections

Elections: 2 positions must be filled. Eero Nevalainen was elected 2nd vice president for 4 years, but decided to resign one year earlier. Vice president Taco van Welzenis will retire now as well. He has been in the EC for 12 years.

We have two candidates:

- Dace Liepina is elected as Vice president for 4 years with 13 votes
- Ida Männistö is elected 2nd Vice president for 1 year with 13 votes

Business session of OIFE AGM II was finished by this.

A culture for sharing (plenary session)

- Projects of OIFE - IW & UW
- BBS Youth Events - CK
- Dare to live - CB
- Educational Activities – TH, MB & DM
- How do we do fundraising? TH, MB & DM
- Questions & exchange of ideas!

Projects of OIFE

IW and UW presented some of the most important planned projects & activities of OIFE for 2019-2020

- A more professional OIFE
- A stronger BOND between us - capacity building programme for rare bone organizations
- Flying OI Experts

A more professional OIFE

Presented by IW. OIFE needs to be developed as an organization in order for us to reach our goals. Activities & goals include:

- Professional staff
- New internal communication system: GSuite for non-profits
- External communication (webpage and magazine)
- Templates for reports and PPT

A stronger BOND between us

Presented by IW. OIFE sees the need to educate more patient representatives/experts and volunteers in the rare bone community to

- serve as volunteers
- run patient organizations
- contribute as patient representatives in research and development

We want to develop a capacity building program for rare bone disease organizations containing different activities: webinar, guidelines... We are interested in getting in touch with professionals, companies or contacts from rare bone groups who might be interested in taking part in the project.

We are not trying to compete with the EURORDIS Summer School, but we want to do something more basic for the people to get more people interested in research & development to serve as future patient representatives.

Flying OI experts

Presented by IW& UW. The intention was and is to bring knowledge and help to new countries, enable patient representatives and professionals there, instead of bringing few individuals to Europe, the US or Canada for surgeries or treatment. The idea is to offer travel support for different kinds of OI-experts (which does not only mean professionals). Guidelines should be created for this kind of program.

Projects & practises from OIFE members

BBS youth events (CK):

Some years ago BBS got funding for a Youth event that has been very popular since. They subsidize young people coming to this event.

"Dare to live" (MR):

The project aims for OI people and their families to challenge their limitations. Activities promote self-esteem and independence. CB and MR presented a video about it, showing people with OI doing different challenging activities.

Educational activities by Fundación Ahuce (MB):

- Workshops for adults
- Sex education
- Financial support for individuals
- Independent life
- Mutual support groups(through Skype etc), as well used by people outside Spain

Information material in Spanish language (for Latin American organizations as well) was presented. Leaflets and brochures can be downloaded from the website – contents and ideas were inspired from the OI Foundation.

Cooperates with other organizations (HPP, national umbrella for rare disorders, other bone conditions)

Has also hosted medical conferences on OI.

Fundraising of Fundación Ahuce

- Resources needed are financial resources, volunteers, service for patients and infrastructure
- Solidarity merchandising (sell mugs etc. to support OI research)
- Races, fundraising events, crowdfunding for certain projects
- Donations from companies
- "Imposible NADA" (nothing is impossible), 4 swimmers with OI swimming from Ireland to England
- Services provided by the foundation are
 - Possibility to borrow equipment like wheelchairs
 - Mutual support groups
 - Support people to prepare them for work employment

Educational activities in OIF (TH):

- PodCast series: Physical Rehabilitation, Mobility studies on OI etc
- National conferences every 2nd year. This year addressed pain and other topics (pulmonary issues)
- Starting to have more regional meetings because of the size of the country. The next one will be in Los Angeles.
- Organize lectures at the university for people that don't know about OI
- The "Brittle Bones Alliance" in the States joins organizations and companies working on rare bone diseases. OIF has the coordinating role. They are hosting a scientific conference in Montreal in September 2018. Over 100 posters and 350 attendants registered so far.

About OIF Fundraising (TH):

- They have big dinners (>100.000 Dollar) and small (10.000) branding their events: same materials, same napkins. Their members throw wine parties, lunches, breakfasts etc. The idea is to keep the same brand. They have a lot of committee work, recruiting volunteers and building regional councils.
- The special events (3 million dollar budget) generate a lot of money.
- They still ask for money by oldfashioned letters and it works.
- By Facebook you can celebrate birthdays and fundraise, donating the money to the organization. Facebook Fundraisers can be applied for by all registered NGOs. Portugal, USA and Norway have done it already.
- They also have Amazon Smile money (around 10 to 15 thousand).
- They did a "Walk & Wheel" fundraiser before their last conference.

Educational activities Care4BrittleBones (DM):

- Research study on Fatigue (to be found in their website)
- Mosaicism study
- Webinars and tutorials, connected to fundraising is planned
- PT and Occupational therapy consensus project - has recently sent newsletter for all the physical therapists they have on their contact lists.

Fundraising:

- Gala, concerts, running,
- Has developed a fundraising page of their own, which all OI-organizations can use to fundraise for OI-research: www.research4OI.org
- 1 mill. Euros raised for research 2012-2018.

Parallel workshops

Four parallel workshops were held on the following topics:

- A stronger BOND between us - capacity building program
- Flying OI Experts - for whom and how?
- Fundraising & finances - challenges & opportunities
- Communication - with whom& how?

A short summary was given from each workshop, because closing & information about next day of meeting.

Monday, 20th August

Presentation of national reports was originally on the agenda for Sunday, but was moved until Monday due to lack of time. National reports have 3 purposes:

- To have contact details for delegates & organizations updated
- To get input on certain topics in different countries (registries, MABs, centres of expertise, collaboration with doctors etc)
- To get the organization's views on certain questions & priorities

AR had made a PPT where she presented the most interesting data collected in the national reports for 2017.

Research & development

The following presentations were given:

- What is going on in Europe? (IW & OS)
- News from the Brittle Bone Disorders Consortium (FG)
- The BBS adult health project (PO)
- The scientific symposiums in the Brittle Bone Society (PO)
- What are the needs & questions of adults with OI? (UW)
- Key4OI –(DM)
- Cardio, genetics & the 'Research Support Unit' in Portugal (CB)
- The Pain Project –(MB)
- The sleep apnea study in Finland –(IM)

Future events

IW informed about the following events that will be hosted by OIFE in 2019:

- AGM 27 Riga, Latvia 14-16 June
- 23 – 27 October youth meeting in Bilbao, Spain
- 22-25th November Key4OI

She encouraged delegates to send information about National events & scientific conferences, to be included in the OIFE calendar: <https://oife.org/news-resources/calendar/>

Maria Barbero mentions the intention of Lucia in Equador to start an OI Federation for North and Latin America. They are also planning a Medical Conference in Quito, Equador - probably in October 2019.

Other competent business

- Rageema is asked to shortly present her organization "Brittle Bones South Africa". She said they have about 300 members, one third have OI – bisphosphonate treatment is available (Zoledronate)
- Professor Glorieux mentions a well-functioning OI group of doctors in Johannesburg as well as Algeria
- Anna informs the delegates that in September 2018 Italy will be the hosts of the world championship for powerchair-hockey. She encourages the delegates to follow the event on streaming and inform their members about the sport, which is accessible for people no matter what kind of ability you have.
- Discussion about possibility to develop an OIFE app. Agreement that content and use cases needs to be defined. In addition to costs of development and maintenance (both time and money).

Ingunn Westerheim closes the meeting at 13:30 h, thanking everybody for an efficient and lively meeting and wishing a safe journey home or continuation of holidays in Scotland.

Time: August 20th 2018

Place: Dundee, Scotland

Minutes taken by
Maria Barbero

Ute Wallentin