



## OSTEOGENESIS IMPERFECTA FEDERATION EUROPE

### Minutes - AGM 25

Fri, 26<sup>th</sup> - Sun, 28<sup>th</sup> May 2017

Best Western Hotel Portos, Warsaw, Poland

### AGM 25

Participants from ordinary members with voting rights:

- Ingunn Westerheim (IW), Norway, President
- Taco van Welzenis (TvW), Netherlands (VOI), Vice-President
- Eero Nevalainen (EN), Finland, 2nd Vice-president
- Céu M. Barreiros (CB), Portugal, Treasurer
- Aneta Galazka (AG), Poland
- Ute Wallentin (UW), Germany, Social Network Coordinator
- André Wittwer (AW), Switzerland
- Jean Moitry (JM), France
- Hans Wiesmüller, (HW), Austria
- Alexandra Romanycheva (AR), Russia
- Maria Barbero (MB), AHUCE, Spain
- Leonardo Panzeri (LP), Italy – *participated Saturday + Sunday*
- Dace Liepina (DL), Latvia - *voting right after being accepted as an ordinary member*

Participants from observing members with no voting rights

- Dagmar Mekking (DM), Netherlands, Care4BrittleBones
- Julia Piniella (JP), Spain, AHUCE Foundation
- Maria Barbero (MB), PadrinoS-OI

Guests:

- Rob van Welzenis, (RvW) Honorary president, the Netherlands
- Lidy van Welzenis, the Netherlands
- Gabriel Zubowski, (GZ, member of Polish OI association)

*Saturday there was a shared session between the OIFE and the Polish OI-association, where a number of other members from Poland attended.*

### Friday, May 26<sup>th</sup>

#### 18.00 - 18.15

##### 1. Opening and welcome + announcements of the organizers

IW opens the meeting officially welcoming all and thanking Aneta Galazka and the Polish hosts for all the preparatory work. A special warm welcome goes to Rob and Lidy van Welzenis, who decided to use this first AGM in Poland to meet many old friends again and to make new ones.

a. Apologies were given from:

- Steffi Wagner (OIFE secretary),
- Ivar Troost (Webmaster),
- Anna Rossi (Communication Manager, OIFE EC),
- Filip de Gruytere (ZOI; Belgium),
- Patricia Osborne and Coreen Kelday (BBS),
- The Danish and the Romanian associations also sent their apologies,

- Rebecca Tvedt Skarberg (ePAG representative in BOND) could not attend the AGM, due to an accident, but has created a video message to be shown later.
- b. Counting of the votes  
IW states that the meeting will begin with 10 votes. At the most, there were 13 delegates with voting rights present during the week-end.
- c. Volunteers - the minutes/meeting report  
UW and MB had volunteered to do the minutes.
- d. Volunteers - to-do-list  
DM and TvW will keep the to-do-list.

## **2. Settlement of agenda and schedule**

IW suggested some small changes in the agenda concerning several financial matters and informed about the planned schedule for the rest of the day and the weekend.

## **3. OIFE membership**

- a. Status regarding current OIFE members: IW briefly explains some differences between these categories, showing parts of the statutes on a PPT.
- Ordinary members – currently 17 full members (the newest member being Russia in 2017). IW adds that the Swedish members RBU have made contact again and paid their annual fee in January 2017, but have not yet named a delegate.
  - Associate members (outside Europe) – 7 associations, IW is pleased that contacts to all of them was re-established recently via different EC members. All organisations are currently active, except Georgia, which have been inactive for ca 4 years.
  - Supporting members – 5 organisations.
- b. Applications from new organisations: IW announced that the Latvian OI association (LOIB) had applied for membership and that the EC recommended to accept them from this day.
- DL explained that LOIB was founded in 2011, but only recently started to organise regular activities. Recently the 12 families had their membership meeting in early May, in July 17 they will have a picnic. The new board has goals to contact and find more surgeons, to join the national Umbrella organisation for rare disorders and to reach out to more new members. Dace Liepina is elected as the chair of LOIB.
  - TvW asks about relations with the other Baltic States and DL mentions some contacts to Estonian OI people, but so far does not know anybody in Lithuania and would be happy for possible support to find more.
  - MB and JP arrive – now 12 votes in total.
  - Vote: LOIB is unanimously accepted as ordinary member with 12 votes.
- c. Potential new members
- IW shows a list of organisations in Ukraine, India, South Africa, Ghana, Nigeria, China, Hong Kong (Little people), Japan, Taiwan, Indonesia and South Korea. Vietnam and Pakistan are both lead by CLAN from Australia.
  - RvW asks about the Greek association, UW and IW reply that due to the absence of its founder (Katharina who now lives in Scotland) the group seems to be rather inactive, but UW is in regular contact with a few active individuals in Greece

- d. Proposal to set the fee for associate members to zero EUR.
- IW explains the new proposal of the EC to abolish the fee for this category, as the fee payment developed into a problem for cooperation and communication with several of these members. Because a total removal of the fee would include changes in the bylaws, the EC suggests setting the fee for associate members to zero, similar to what the practise for supporting members has been for years.
  - IW asks for a vote to set the fee for associate members to zero, in combination with the condition that these members communicate (appoints a delegate) and send reports about their activities. If they should fail to do so, we could terminate their respective memberships.  
Vote: unanimous approval of EC's proposal

#### 4. National reports - successes and challenges

IW introduces a new way of doing national reports and reminds everybody to reply to the online-survey, even after the AGM. Each delegate gave a very short 3-minute-report about highlights and news from their organisations:

- CB (Portugal):  
- 2016 was a very busy and successful year with the "Unbreakable Alliance" congress, which brought much more awareness and very good feedback; the Project "dare to live" with horse-riding and swimming-with-dolphins.

- AR (Russia):  
- She explains with a PPT, that the organization has several huge projects: payment for surgeries and bisphosphonates; a new rehabilitation program (in cooperation with the Cologne University Clinic, Dr. Oliver Semler and Brigitte Müller, PT); a spring OI camp in Vladimir-district in April 2017; the first EURASIA Orth. Forum at the end of June 2017 and a planned new summer camp in August 17 in Sochi. In future such summer camps will aim to integrate OI children and non-disabled kids. They plan various educational projects, will raise more money for wheelchairs and will increase their initiative for OI adults (possibly in cooperation with the national Russian Osteoporosis foundation). AR asks all delegates for advice on all these plans and activities. IW suggests an article about the camps for one of the next OIFE Newsletters – to-do-list.

- JM, France:  
- He describes strategies developed by the AOI board to win back and activate members. Too many disappeared or act like "consumers", without much availability for cooperation and mutual support to others. AOI has a new format and design for its website and newsletter – with very good feedback so far. Also a new leaflet for recruiting members. Finally he mentions new French research projects on collagen and recommends the "OSCAR-project" with educational videos in French language. UW explains that she is in touch with several OI-groups in Vietnam and that at least one of them is very interested in information in French. She will establish direct contact soon.

- TvW, The Netherlands:  
VOI has a new board, new members, a new newsletter and recently had an adult OI meeting. One of the most urgent problems is the financial future, as 70% of VOI's income comes from the Dutch government, which is no reliable source.

- IW, Norway:  
- The transition phase from IW as former chair and Inger Margrethe as her successor is ongoing. NFOI had no youth meeting for several years; only two annual meetings – it is difficult to find volunteers and the big distances between members is an obstacle. Government funding is expected to decrease from 2018. NFOI carries the whole risk of the OIOslo2017 conference and for 6 months IW does 100% OI-work (leave from job).

- EN, Finland:
  - The Finish delegate mentions rehabilitation courses, small local support group meetings in various parts of the country and a recent boat-rip to Stockholm/Sweden (through the generous donation of the employer of a deceased member of the association). They have a new president and secretary, but great difficulties to activate the OI-youth. Recently the new volunteers of the board successfully passed the audit for a government grant and this is regarded as a first, huge victory.
  
- HW, Austria:
  - The rather small Austrian association had two family meetings last year. In September 2017 the 10<sup>th</sup> anniversary will be celebrated. An image video is being planned for the near future. The organization gives financial support for necessary equipment, like special wheelchairs.
  
- JP, Spain, AHUCE foundation (with MB):
  - Ongoing research projects about genetics, thorax, stem-cells. Shared responsibility for "Unbreakable Alliance" Congress in Lisbon. Workshops for children and adults. Planned first OI adult meeting in special rehabilitation center.
  
- MB, Spain, AHUCE:
  - AHUCE recruited over 100 new members, mainly adults, now 430 members. In Madrid work 3 fulltime employees (physiotherapist, psychologist and a social worker) and a part-time fundraiser and administration officer. Main source of income are government grants for special projects. All research-related work has been switched to AHUCE Foundation. Replying to a question from IW, MB points out that both boards have the same members, so collaboration is very close.
  
- MB, PadrinoS-OI, Germany:
  - MB refers to her written report (attached) and summarizes a few important details. In 2016 about 20.000 € have been raised and spent for various treatment centers (Ecuador, Perú, El Salvador, Honduras and Nepal) for around 80 OI children and adults worldwide. In January 2018 the first Central American OI Congress with teaching surgeries will take place in Honduras – in cooperation and with the support of the OIFE, AHUCE foundation and others. IW adds that the OIF will pay for flights of 2-4 doctors. MB explains that the biggest problem is the high costs for rods.
  
- UW, Germany:
  - The DOIG and its 6 smaller regional organizations have many meetings, workshops, family-weekends and projects in different parts of the country. It is difficult to find volunteers and – like in France – the boards struggle with a paralyzing consumer-mentality of many members. This year the whole executive committee will retire, but fortunately a new team has been found and should be elected in June. One of the main goals for the near future is to reach new members and families – often through FB groups.
  
- DC, Latvia:
  - As the organization had earlier been presented, DL only adds that LOIB cooperates with another NGO to import wheelchairs and other equipment.
  
- AW, Switzerland:
  - SVOI had a cooperation with the national Bechterew organization for organizational and secretary services, but because of poor delivery, SVOI's volunteers try to do more again themselves - for instance new website. AW could not attend the last AGM, as he now lives in Oslo/N. He's still a member of the SVOI board as OIFE delegate and webmaster and participates via Skype/phone.

- LP, Italy:
- LP informs about the Italian association and its highlights since last AGM:
- Training course for PTs in Rome, with recognized credits by the Italian Health Ministry. The Italians want to cover PT treatment in the whole country.
  - Cooperation with Rotary Club explained.
  - Recruiting of volunteers is very much needed in Italy, as they have many activities planned, but volunteer work is missing.
  - The project "Take care of yourself", addressing scoliosis, respiratory problems, adequate nutrition, movement, fitness as well as autonomy.
  - Elections in the board. They need some community manager and somebody to organize events as well.
  - Campaign in collaboration with a chocolate company, slogan "Confetto imperfetto".

## **Saturday, May 27<sup>th</sup>**

Start 09:06. Welcome from IW. Vote counting (13 votes). She recalls briefly what was done yesterday.

### **5. Executive Committee**

Annual report from EC:

IW explains the activity of the EC:

1. Administration facts and volunteer coordination matters are explained.
2. Activities: networking, ERNs and ePAG (the representative suggested from OIFE) has had a large amount of work. Status on OIFE webpage, social media and newsletters presented.
3. Fundraising:
  - No funds awarded from EURORDIS for 2017
  - New Alexion representative in place and relationships to be developed.
  - 10,000 Euro from Mereo Biopharma for 2017.
4. Representation:
  - Eurordis AGM 2017 (Budapest) - CB attended
  - Council of Federations (CEF) meeting Paris - IW attended
  - Planned attendance at the ICCBH in June by EC members IW and UW. Also to attend are (Inger-Margrethe S. Paulsen from Norway, Coreen Kelday from BBS UK and Dagmar Mekking from Care4BB
5. Planning AGM this year has been difficult due to a lack of resources and the short time scale since last AGM.
6. Collaboration with C4BB in research & further development of Care4BB into a more professionalized foundation
7. Approval of bisphosphonates in some countries was discussed. Bisphosphonates are not approved for the use in children in several countries). This is due to the off label use + lack of placebo studies. DM suggests a consensus report be written on safe use of bisphosphonates in OI. IW proposes that this idea should be approached in the Oslo congress.
8. Email correspondence: takes up a large amount of time from all members on the EC

- b. Collaborations and networking:
1. First Friday of each month – skype group call held with UW, OIF, BBS and C4BB
  2. Contact/meetings with ERNs, Epags, EURORDIS, CLAN
  3. Contact/meetings with Mereo, AMGEN and PEGAMedical
  4. OIOslo2017 and ICCBH Conference are important networking events
  5. The collaboration with the IOF (osteoporosis) is not to be continued as they seem to have different interests to the OI community. DM and LP suggest remaining in contact and not to, close the door completely
- c. Projects: the main topic (and also social media) will be talked about tomorrow.
- d. Challenges:
1. The EC have clearer goals, but time, money and volunteers are missing.
  2. The EC is vulnerable.
  3. Secretary was on leave for longer periods of time.
  4. Too few volunteers outside the ones appointed by the EC.
  5. We do not have a corporative culture for sharing between the delegates.
  6. Fees are causing problems in the communication with associate members.
  7. Spam problem. Website update difficult.
  8. OIFE still too unknown.
  9. Bank accounts & treasurer/registration of OIFE (NL)/president spread throughout Europe.
  10. Lack of experience on fundraising.
- e. Positive developments:
1. Regular monthly skype meetings of the EC (also weekend Meeting in Milan).
  2. Less email between EC, Wunderlist and Google Drive are being more frequently used.
  3. More Skype contact with volunteers.
  4. More visible as the OI umbrella.
  5. More contact with member organisations including gaining new members. .
  6. Contact with OI groups outside OIFE (for example, professional communities in Africa).
  7. More knowledge about pharmaceutical industry.
  8. More secure webpage and less spam.
  9. Shared approach on Wishbone Day.
- f. Status on different matters:
1. OIFE Youth Conference 2017 is being planned by the Netherlands for Nov.
  2. Website:
    - New website has a responsive design for smart phones and iPad. Contact information is being updated. National organisations have to be in charge of updating their webpages, so that the OIFE can link to that instead of OIFE doing a lot of updating when changes occur. OIFE will keep a minimum set of data on the membership pages about the organizations (name of organization, URL + delegate name, photo and e-mail).
    - Spanish OIFE translations are being planned. Spain has a volunteer translator for the job. EC will follow up.
    - Discussion held about the kind of information that should be on the OIFE website and how easy is to find OIFE in a web search. Metadescrptions should be improved, as well as tags. We should improve keywords performance.

3. Social media:
  - OIFE FB page has some improvement potential. Statistics are shown.
  - There is a closed and moderated youth group. The youth group should be reorganised because it is hard to filter out potential members in the target group (and those who are not). Possible ways to reorganise the group are discussed.
  - The closed and moderated adult group will be talked about tomorrow.
  - Twitter hardly works. The EC should revive Twitter and connect it to Facebook.
  - The You Tube OIFE channel contains some favourite OIFE videos.
  - OIFE still need photos. Possible launch of Photo Contest in November 2017, together with the Youth Meeting.
  - New assistant webmaster: André Wittwer
4. OIFE passport: New template for the OIFE passport has been finished by Filip. Money from Mereo will be used for printing a new edition as well as creating an app. Hopefully we will have it ready before next AGM.
5. Other publications:
  - a. OIFE leaflet still in first draft revision.
  - b. UW suggests sending once or twice a year news about medical development in OI. DM suggests using other websites with information and investigate the potential in the European Reference Networks (ERNs), so that people do not only have the OIFE website as a resource.
  - c. OIFE newsletter has been distributed as planned. Now more than 1000 recipients (both professionals and other interested people).

## 6. Finance

- a. Resignation and re-election of treasurer Céu Barreiros: 2017 CB is up for reelection for four more years. There are no other candidates. Céu elected with no votes against. No abstentions.
- b. Financial report 2016
  1. Financial status:
    - Big donation (16.400EUR) from Alexion in 2016
    - Membership fees still an important source of funding the OIFE.. We mostly stayed in the budget, except for the AGM, which was more expensive because of its connection to the Lisbon conference.
    - Expenditures are explained.
    - Secretary support funds and Steffi's situation are explained. She will be kept as the secretary. Refund will continue.
  2. Report from financial control sub-committee regarding 2016: AW and JM checked the accounts and gave a positive report.
  3. Vote on OIFE's financial report 2016: Approved - no votes against/abstentions.
- c. Budget proposal 2018, discussion and vote (this presentation was held on Sunday)
  1. Expenses:
    - Main differences are higher fees for both the Youth Meeting and Flying Experts.
    - A large grant has been received in 2017, and has to be spent this year, therefore cannot be allocated to the 2018 budget. It will be used to reprint OI passport in 2017.
    - **Budget 2018:** 15,210 Euro. Budget for 2018 approved.
  2. The EC will write to ordinary members regarding Financial and Control Policies in the next few months. CB gives us an overview on the coming policies and asks for future input on this issue. This information will specially refer to management

- of financial support of OIFE's activities: Flying OI Experts and Youth Meeting.
3. UW asks about the donations of pharmaceutical companies. IW explains that different kinds of funding are possible:
    - Sponsoring for events (like Alexion in Lisbon)
    - Educational grants (for educational events/conferences)
    - Grants for different projects (like developing an app and printing a brochure).
  4. Unrestricted grants (like the one from Mereo). IW also held a meeting with PegaMedical and contact has been established with AMGEN. EC will follow up on these contacts.
- d. Election of financial control sub-committee for 2018: Jean Moitry and Andre Wittwer-unanimously elected.

## 7. Reports, networking & collaboration

- a. Status on European Reference Networks (ERN)
  1. IW explains the basics about ERN and BOND, and mentions the excellent representation of the OI community and "rare bone diseases" in general.
  2. **BOND:**
    - Rebecca Tvedt Skarberg (OIFE), Jean Moitry (AOI) and Ines Alves (achondroplasia/ALPES Portugal) are patient representatives (elected until 2018) not only for OI but for rare bone diseases. The new role and mandate of patient representatives in BOND is a unique opportunity for OIFE. Rebecca as an ePAG has a place on the Steering Committee of BOND.
    - Video-message from Rebecca Tvedt Skarberg shown; explains the chances and possibilities for OI people and their medical professionals in this process. She encourage establishment of National contacts (between patients and health care providers), especially in the countries who have health care providers involved in BOND.
  3. IW asks DM to report on **ERN** conference in Rome:
    - DM was in Rome representing Care4BB, to tell BOND-members about Care4BB research funding opportunities. Rebecca had planned to attend as ePAG, but attended via streaming from hospital.
    - DM refers to a 4-page document about BOND that everybody already received and Rebecca's message. OI and Bone dysplasia are used as pathfinders to show what can be done in the ERNs. This can mean huge progress, if we cooperate and use the opportunity now.
    - DM: It would be important to go international and to not restrict this to Europe only, even if this is a European project. IW remarked that one has to separate between input internationally and the role of the ERN/BOND, which has to stay EU/EEA.
    - A challenge is that the ERN does not have a lot of money yet, but project funding is sought.
    - Work strings are: diagnostic challenge, research (care and research), good-practice guidelines, database and creating natural history studies, education of doctors and patients, Stakeholder work stream, etc...
    - DM concluded an opportunity not to be missed, if BOND can find enough funding to develop the projects they have planned.
  4. DM: The OI-community should together decide what we want, what guidelines does OI need? This in order to give the ePAG representatives the necessary input. The door is open, but we need to act. IW suggests everybody should go home and think, who could be the best person for supporting the ePAGs.
  5. DM: Health-tools are being developed to bring specialists together for difficult cases and information platform for rare bone diseases.
  6. DM: The ERN have different teams of health care providers (HCP), but they are

open to the needs of the patients and do not exclusively concentrate in the teams they have in their 10 acting countries. DM wants to put OI advisors together to contribute in the ERN Working Groups (10 different groups based on topic), but the possibility of working separated is also there.

7. IW proposes the creation of an input group to the ePAGs/ERNs. Rebecca, Dagmar, Taco and Ute will be part of an input group for the ERNs.

- b. Report from EURORDIS-meetings - Ingunn and Céu  
IW and CB reported from EURORDIS-meetings in Budapest (2017) and Paris (november 2016).
- c. Report from social network coordinator UW  
See written report (attachment) – sent to delegates before AGM.
- d. OIOslo2017 - Status from the organisers  
Currently 165 participants and 130 abstracts. Budget of 2 million NOK.  
Pre-conference seminar on patient participation in OI-research.
- e. Other relevant reports  
None

12:00 – 13:00 Joint session with the Polish OI-Association for ca. 1,5 hours. Topics: introduction of both organisations and networking possibilities

## **8. OIFE's strategy**

- a. Ingunn introduces OIFE-strategy and hands over to DM to facilitate a brainstorming followed by a SWOT-analysis  
Short term strategy would be until next AGM; long term strategy should be from 2017 to 2021. Actual goals are:
  - Representation
  - Networking
  - Research
  - Awareness about OI
  - Information
  - Support
- b. Long term strategy/Short term strategy: Where are we? How can OIFE be attractive? What are our ambitions? Where will we be in 5 years? What should we do and when can we lean on our members? We want to put the conclusions in a strategy document. Our goal today is to find an agreement on what the OIFE goals should be. The EC will work on modelling those goals.
- c. Brainstorming:
  - Everybody tells what is the positive thing they find in OIFE. As everything can be improved, though, we should think of what could be improved here. After the brainstorming we compare with previously detailed objectives.  
Input from the roundtable:
    - How do we help people locally/where they are?
    - How do we secure access to treatment?
    - Is it clear for all members/potential members who the OIFE are?
    - Is the role of OIFE clear?

- How can OIFE support their members?
  - How can we be part of the ERNs (especially for the countries that are not in the EU)?
  - What is "support"?
  - What should be the role of OIFE regarding research?
  - How do we make the medical disciplines work together (multidisciplinary)?
  - How do we make professionals work together across borders?
  - How do we deal with language barriers (regarding access to info)?
  - Do we have the right balance between what we give and receive from our members?
  - What is the success criteria of the vibrant organisations (that is developing in a positive way)?
  - How should we best use our limited resources (what should our priorities be)?
  - How can we increase our resources?
  - How to justify OIFE's existence/priority to the National Boards?
  - How to communicate about OIFE to the National organisations?
  - How can we represent on a European level?
  - How can we become more professional?
  - How can we hire people?
  - How can we coordinate research internationally?
  - How can we coordinate the 1000 doctors we have (don't invent the wheel every time)?
  - How should OIFE collaborate with other stakeholders?
  - How to develop a shared "language" terminology when we talk about research?
  - Should we concentrate on Europe or international approach?
  - How do we make OIFE sustainable?
  - How do we develop good adult care?
  - How do we get guidelines to treat OI (ERNs)?
- SWOT-analysis discussed in groups: (Strength, Weaknesses, Opportunities and Threats). See appendix 1.

d. Content of strategy:

- **OIFE's vision:** Definition of "vision", and explanation of why is that important for OIFE. What should it be? Debate on „worldwide“. IW explains that a worldwide improved situation is our vision, but not our mission.
- Agreement on OIFE's vision: *"Children, youth and adults with OI living active independent lives worldwide - with access to competent healthcare, follow-up and social support."*
- **OIFE's mission:** It describes what the group is going to do and why. Proposal:
  - EC-proposal: To improve quality of life for those living with OI through networking, collaboration and empowerment
  - DM's proposal: To improve quality of life for those living with OI through awareness, education, improved healthcare, research and mutual support.
  - Agreement on the mission statement not reached. EC will make a new proposal and send it to delegates.

- **OIFE's long term goals - take home message to EC:**
  - Access to accurate information about OI
  - Representation on an international level
  - Establishing priorities
  - Development of common guidelines/standards for OI regarding diagnosis, treatment, follow-up etc.
  - Better research through larger numbers/big data/registries
  - Better education/training of professionals and volunteers
  - More secure funds for OIFE
  - Binding the OI community supporting organisations
  - Supporting individuals through action points

20.00 Shared dinner OIFE & Poland OI

## **Sunday, May 28<sup>th</sup>**

Start: 09.00

### **Starting information**

- Presentation of the data from the National Reports sent through Google Docs.
- Presentation of "Rare Barometer Voices", from EURORDIS. If one country wishes to promote Rare Barometer Voices in their country, the possibility would be to get statistics on OI for that country (if numbers are big enough). IW states it would be good to at least inform the board and people in each country. But as long as the numbers are small (both per country and diagnose), the results are not very useful.
- Short information on the Oslo Pre-Conference seminar about patient participation in OI-research (hosted by NFOI).

## **9. OIFE Projects**

### a. Flying OI Experts

- It has to be more developed to address:
  - Travel grants for OI-professionals
    - To learn (conferences and staff exchange)
    - To teach
  - Travel support for volunteers to network, teach, competence building or training sessions.
  - Project support for professionals to go somewhere and offer seminars or perform surgeries (as Cuba & Honduras projects)
- Ways to fund it: Topic for project applications, crowdfunding landing page (with photos/examples), Christmas-gifts or similar. The OIF is interested to be a formal collaborator on Flying OI-Experts. We can set a group for development of the project. IW will organize meeting with MB, TracyH and CB.
- Adult Health Initiative: UW presents the project. The OIFE should try to coordinate and gather information on the Adult-initiatives (guidelines, clinics, check lists etc) in the different countries. Goal: Growing old with OI must be better understood and supported. So far there are many different initiatives, but they don't seem to be very well coordinated.

### b. Social Media

- Moderated Facebook group for adults is developing well with more than 300 members and growing.

- Developing of social media guidelines. A working group has been established, but little progress because of lacking follow-up from EC. There should be a new meeting with IW and AR to try to coordinate & development guidelines for the use of social media. Can be adopted by members, when finished.

10.00: Hon. President Rob van Welzenis bids farewell to all delegates.

## 10. Research, development and collaboration with professionals

- a. Research initiatives OIFE are/have been involved in from last AGM: Ingunn gives a short account on the projects OIFE has been involved in: Mereo (US + DK, UK and FR), Rare Commons (Spain), Consensus Project Physio (Cologne, Germany - international consensus), Boost4BB (Europe - lead from Sweden), Steering Committee Stuart Ralston-trial from Edi Uni (Parathyroid hormone and zoledronic acid) - UK.
- b. DM, gives a detailed account on **C4BB** and the future development of the foundation:
  - i. Five years history that demonstrates that we can work together to enable more and better OI research. OI researchers need to be productive, but the kind of research that OI patients need is complex. Patients need better research with a large cohort to really make an impact and become useful research. DM suggests we need more collaboration among countries to get more funding. It is necessary to have a very close follow up of the projects. The projects have to be contractly agreed. DM makes a presentation on Care4BBs structure.
  - ii. Care4BB have ambassadors in various countries and 2 Advisory Boards (one with professionals and one with adults with OI).
  - iii. Care4BB don't only do fundraising, but also decide which research projects should be funded. They have raised approx. 500,000 Euro in 5 years. DM presents the different grants that they have already awarded.
  - iv. DM stated that Care4BB has a database of around 800 medical professionals and scientists around the world, mostly in Europe. In her opinion more and better collaboration is critical for the quality of health in OI. DM presents statistics on OI people around the world and suggests that the fragmentation on research should stop and there should be more work being done together.
  - v. Advisory Board: The Netherlands, Germany, Finland, Norway, Switzerland, Italy, Denmark. Patients Advisory Board: Ute, Therese, Eero, Karsten, Leonardo, Margriet (Holland) and Rebecca (Norway). These people work on confidential data all together in a very positive way.
  - vi. How does C4BB work: Research focused on worldwide research. They see their role in relation to OIFE/OIF/others as follows:
    - Share workload
    - Generate funding for OI research
    - Collect input that OI-community needs (input for ERN/BrittleBones, Disease Consortium etc.)
    - Actively cooperate with researchers on international research projects/ coordination /influence and bring OI data or information into 1 place worldwide
    - Create more value for OI working together across OIF, BBS, Ahuce Foundation, pharmaceutical companies...

IW asks if the goal of C4BB now is to influence the content, the kind of research that has to take place in OI. In that case, there should be a network agreement (for instance between OIFE, OIF and Care4BB) in order to establish the terms of collaboration among the stakeholders. OIFE is positive to developing a formal collaboration on research. DM says they will suggest the terms of a possible agreement. Goal should be to have something agreed before end 2017.

- b. James Lind Alliance (JLA) is Priority Settings Partnerships (PSPs) to agree what research matters in given disease areas. A survey has been launched to get information on fibrous Dysplasia, McCune Albright, OI or x-linked Hypophosphataemia. The survey is for the UK, Spain, Italy, France, Netherlands, Germany, Denmark or Norway (in English). Discussion about the fact that so many different surveys (on priority in research) are being done in OI. DM has a fear, that too many surveys would discourage people to participate later in more relevant surveys. UW will send JLA the list of OIFE priorities, but OIFE will not promote the study in our channels, more than we have already done.
- c. Research policy for OIFE: A proposal will be sent regarding this information where delegates are invited to give input to EC.
- d. Establishment of a medical advisory board (MAB) for OIFE. This was decided in Lisbon. It still has to be discussed further by the EC but mandate for MAB is proposed as the following: 1. Advice on questions regarding policy & strategy, 2. Advice on development & revision of medical content in webpages and written material 3. Advice in urgent medical matters that involves MANY people with OI. 4. Advice on how and when to support & promote research projects. More info on MAB will be sent by email to delegates.

#### **11. Hosts for AGMs, Youth meetings and Topical Meetings**

- a. AGM 2018 – UK (BBS 50<sup>th</sup> anniversary celebrations): Scotland. Date to be confirmed but probably mid to late August.  
AGM 2019: Riga, Latvia - possibly combined with topical meeting
- b. Youth meetings 2018 and 2019: Denmark or Spain
- c. Topical Meeting 2019 – should we have it? Topic? Host? Taco says it would be good to have one - because it creates awareness and can also create project funding. If we have the means, we should do it.

#### **12. Any other competent business + Closing**

Establishment of nomination committee for OIFE/EC - Not discussed.

AGM finished 1 hour before scheduled time, since 50% of the delegates needed to go early to airport.

## Appendix 1 SWOT-analysis

