



## INVITATION TO OIFE AGM 2020 PART 1 & 2 ON ZOOM MAY 9<sup>th</sup>

Dear OIFE delegates & volunteers.

Each year all delegates are invited to the Annual General Meeting (AGM). Anyone from our member organizations can attend the AGM. In addition OIFE volunteers, volunteers from other organizations, professionals and other people with an interest in OIFE can be invited.

At the AGM the EC accounts for OIFE's activities in the past year, future plans and policies are discussed and members exchange news and ideas.

### AGM ON ZOOM

This year our AGM will be different. Our meeting that was planned to take place in Valencia, will take place on the video platform Zoom in two different parts:

#### OIFE AGM part 1 (business part)

Time: Saturday 9<sup>th</sup> of May from 10.00 – 12.00 CET

#### OIFE AGM part 2 – webinar “New treatments in OI”

Time: Saturday 9<sup>th</sup> of May from 15.00 – 17.00 CET

### REGISTRATION

Please register to attend **before April 30<sup>th</sup>** through this link:

<https://forms.gle/2HUPpeLHabWhmFRZ6>

**TO OIFE DELEGATES FROM ALL MEMBER ORGANIZATIONS:  
TO BETTER PREPARE FOR THE MEETING WE NEED YOUR INPUT!**

**TEXT SUMMARIES FROM OIFE MEMBER ORGANIZATIONS (“ANNUAL REPORTS”)**

OIFE is an arena for exchange of ideas, examples and information between our member organisations. Please help us by sending a text summary (max 2 pages) before April 30th to [office@oife.org](mailto:office@oife.org) explaining:

- What kind of activities & events you had in 2019?
- What kind of projects you did in 2019 (both finalized and ongoing)?
- What your biggest challenge was
- What your biggest success was
- Other information & ideas you might feel is relevant for the other delegates

We will make all the summaries available through a shared folder:

[https://www.dropbox.com/sh/4plqbc9bpvku9j4/AADoLzWcB1Sj6aXMXHv\\_PfpAa?dl=0](https://www.dropbox.com/sh/4plqbc9bpvku9j4/AADoLzWcB1Sj6aXMXHv_PfpAa?dl=0)

**NATIONAL REPORTS - ANNUAL SURVEY**

In addition to the text summary, we need your input through Google Forms

- to update our contact lists
- to learn more about how the organizations are working

Click here to go to survey: <https://forms.gle/4sSHZM7trQRzD255A>

Only one delegate from each country should answer – please agree between you who will do it.

**Deadline for answering is April 30th 2020.**

## DRAFT AGENDA OIFE AGM part 1 (business section)

09.45 – 10.00 Log in & registration

10.00 – 10.10 Welcome and apologies

10.10 – 10.20 House keeping

- Election of meeting volunteers
- Counting of votes
- Settlement of agenda
- Approval of minutes from AGM 2019

10.20 – 10.50 Annual reports

- Approval of OIFE's Annual Report 2019
- Approval of financial report 2019

10.50 – 11.00 Elections

11.00 – 11.20 What happens now?

- News from OIFE EC
- Highlights from national reports

11.20 – 11.30 OIFE budget for 2021

11.30 – 11.50 Planned survey on burden of disease in OI

11.50 – 12.00 Q&A

12.00 – 12.15 Final comments & closure





## **DRAFT AGENDA OIFE AGM part 2 “New treatments in OI”**

14.45 - 15.00 Log in & "registration"

15.00 - 15.10 Welcome & introduction (OIFE)

15.10 - 15.25 Status from BOOSTB4 - stem cells treatment in OI (Dr. Cecilia Götherström)

15.25 - 15.40 Status update - setrusumab as developmental potential therapy for in OI  
(Representatives from Mereo Biopharma)

15.40 - 15.50 Q&A

15.50 - 16.10 What is market access and why do you need to know about it? (Paul Connor, BBS)

16.10 - 16.20 Access to treatment - why the patient's voice matters (Oliver Gardiner, XHL Alliance)

16.20 - 16.25 Q&A

16.25 - 16.45 Registries & why patients might have to provide the data (Dr. Lena Lande Wekre)

16.45 - 16.55 Q&A

16.55 - 17.00 Closure of OIFE AGM 2020 (OIFE)

