

PRE-CONFERENCE SEMINAR OIOSLO2017 OI-COMMUNITY MEETING



Topic: Patient Participation in OI-Research

On behalf of the Norwegian Osteogenesis Imperfecta Association (NFOI), it is my great pleasure to invite you as an OI-delegate to a pre-conference seminar from Saturday 26th until Sunday 27th of August 2017.

Venue: Quality Hotel Expo
Participant fee: None
Target group: Delegates from OI-organisations worldwide

We are still working on the programme planning, but the subtopics will include both participation in research for individual patients and for OI-organisations. Many OI-organisations get requests from researchers and pharma companies regarding research projects. We feel there is a need to share experiences about this and perhaps agree on some common guidelines.

Potential subtopics:

- The patient's role in research – individuals and organisations
- Examples of patient participation in OI-studies
- Education of patient representatives
- Ways of collecting patient voices on priorities in OI-research
- Patient reported data & registries
- Patient reported outcome measures (PROM)
- Patient recruitment – challenges and opportunities
- In which phases of a project can and should patient participation take place?
And how?
- How should OI-organisations interact with researchers and the industry (pharma) - possibilities and pitfalls
- Patient participation in clinical settings - European Reference Networks & ePAGs

Time schedule

Saturday 26th of August

14.00 – 19.00 OI-Community Meeting
20.00 Seminar dinner at The Local Oven (included)
Address: Oksenøyveien 10, 1366 Lysaker - 7 minute walk from Quality Expo

Sunday 27th of August

09.00 – 11.00 OI-Community Meeting (continues)
11.30 – 12.00 Light lunch

How to register?

You can register for the pre-conference seminar by sending an e-mail to post@oioslo2017.org with your name and which organisation you represent. Please indicate if you plan on attending the meals and if you have any special needs regarding adaptations or meals.

Hotel booking

You must do your own reservations. The price is the same as during the conference, but we can only guarantee it until June 23rd:

<http://www.oioslo2017.org/info/accommodation>

Do you have ideas?

Since we are still in the phase of programme planning, we are happy to receive ideas on subtopics or speakers (who would like to contribute). Unfortunately we cannot offer to cover travel and accommodation for potential speakers.

Looking forward to constructive discussions in Oslo!

Kind regards from
Ms. Inger-Margrethe Stavdal Paulsen
Chairwoman NFOI

Oslo, 22th of June 2017