

2nd European PXE Patient e-meeting

Saturday 08, May 2021 from 9:00 a.m. to 2.30 p.m. (CET)

Organized by Tampere University Hospital, Tampere,

Chair: Pasi Nevalainen

Program

(timetable according to Central European Time (CET), please note timetable for time zones UTC -1 hour and EET +1 hour)

1st session: Clinical disease

- 9.00-9.10 **Pasi Nevalainen and Jutta Nurminen:** Welcome words
- 9.10-9.25 **Olivier Vanakker (Ghent, Belgium):** PXE as a genetic and metabolic disease
- 9.30-9.45 **Hannu Uusitalo (Tampere, Finland):** Eye care of PXE patients
- 9.50-10.05 **Ludovic Martin (Angers, France):** Dermatological care of PXE patients.
- 10.05-10.20 **Pasi Nevalainen (Tampere, Finland):** What is new in PXE?
- 10.25-10.45 *Virtual coffee break*

2nd session: Development of treatment

- 10.45-11.00 **Andras Varadi (Budapest, Hungary):** Preclinical evidence for supplementation of pyrophosphate deficiency
- 11.05-11.20 **Wilko Spiering (Utrecht, the Netherlands):** Present care of vascular disease and TEMP-trials of etidronate
- 11.25-11.40 **Georges Leftheriotis (Nice, France):** PROPHECI-trial to treat PXE
- 11.45-12.00 **Wilko Spiering (Utrecht, the Netherlands):** The search for PXE-related acceptable endpoints for clinical trials
- 12.05-12.20 **Piero Mendez (Pyrogenyx Inc, San Francisco, USA):** The path of drug development from experimental animals to an EMA/FDA-approved medicine
- 12.25-13.00 *Virtual lunch break*

3rd session: PXE patient associations

- 13.00-13.15 **Helena Kääriäinen (Helsinki, Finland):** Should PXE belong to four European Reference Networks?
- 13.20-13.50 Update of PXE Associations - where are we now since 2019?
- 13.55-14.10 PXE patients networking - presentation by PXE Netherlands
- 14.15-14.30 **Wrap-up of the meeting**

