

2nd European PXE Patient Information meeting

Saturday 08. May 2021

Organized by Tampere University Hospital, Tampere, Finland

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 Georges Leftheriotis (France): PROPHECI-trial to treat PXE

11.25-11.40 Wilko Spiering: Present care of vascular disease and TEMP-trials of etidronate (Utrecht, the Netherlands)

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

13.00-13.30 Update of PXE Associations - where are we now since 2019?
~5min/association

13.35-13.50 PXE patients networking - presentation by PXE Netherlands

13.55-14.10 Should PXE belong to four European Reference Centers? Helena Kääriäinen (Helsinki, Finland)?

14.15-14.30 Wrap up of the meeting