

# NEWSLETTER

Issue 2

#### Best wishes for 2023!

The ISSEC temporary Executive Board members wish you all a healthy and prosperous 2023!



#### **Our redactional team**

The ISSEC newsletter redactional team has doubled . Besides Olivier Vanakker, we welcome Virgil Tamatey to the team!





### We still need you!

We are urgently looking for enthusiastic and creative ISSEC members to form the redactional team of our bi-monthly newsletter. Interested to contribute and weigh in on the dissemination of ISSEC? Let us know via issec.sec@gmail.com

# **The PROPHECI trial**

Inorganic pyrophosphate (PPi) is not only known to inhibit ectopic calcification in soft connective tissues but is also a widely used food additive (a.k.a E450). Recent studies on Pseudoxanthoma Elasticum (PXE), a rare disease that deposits hydroxyapatite crystals on elastic fibers in the skin, eyes, arteries, and kidneys revealed the important role of plasma PPi levels). *ABCC6* gene mutations are known to cause PXE and PPi seems to be the best missing link to explain the calcification in PXE identified so far.

The development of an oral supplementation with PPi salts is one of several therapeutic strategies being considered to normalize physiological PPi levels in PXE patients. The PROPHECI trial (PyROphosPHate supplementation to fight ECtopIc calcification in PXE - NCTo4868578) is the first phase II randomized controlled clinical trial which will evaluate the efficacy and potential side effects (such as high intestinal enzymatic degradation of PPi) of oral PPi administration. Launched in September 2022, the study whose overall objective targets a better quality of life by reducing the development of arterial, renal, and retinal calcification - will include 99 PXE patients, 66 supplemented with 40mg/kg/day of PPi salts and 33 with placebo, for one year.

If successful, the PROPHECI trial could pave the way for future trials in other rare but also acquired diseases which can feature low PPi levels, such as chronic kidney disease. Contact: leftheriotis.g@chu-nice.fr

## **Upcoming events**

• January 10 2022: first INTEC/ISSEC webinar (virtual, itnintec.com)



# Novel webinar series

ISSEC is collaborating in a new series of webinars on various topics of ectopic mineralization which are organized by the International Network on Ectopic Calcification (INTEC).

Participation to these webinars is free, but registration is necessary to receive the link to join the webinar. Online registration can be done on the INTEC website, via: https://www.itnintec.com/ elementor-webinarseries/



## Nancy calcification meeting summary

The one-day meeting "Calcification Disorders: from mechanisms to therapeutic strategies" held in Nancy on December 13th was a success. The talks given by 15 internationally renowned experts overviewed some of the recent work on ectopic calcification both in chronic (atherosclerosis, chronic kidney disease, osteoarthritis, CAVD...) and rare (GACI, PXE, Keutel, ...) diseases. Gathering up to 70 attendees both on-site and on-line, this original meeting should be considered a benchmark for what ISSEC would be able to deliver in the near future with further exciting events on ectopic calcification.

Contact: herve.kempf@inserm.fr

## **INTEC Ghent meeting summary**

In the beginning of October, the two-day hybrid kick-off symposium of the International Network on Ectopic Calcification was held in Ghent, Belgium. A broad overview was given on ectopic calcification in rare and common disorders, focusing on comprehensive overviews as well as cutting edge novel research. Giving the floor to both renowned calcification experts as well as early career researchers and PhD students, it was the first official INTEC activity and has fully fulfilled the educational and dissemination goals of the network.

Programs and summaries of the talks: https://www.itnintec.com/education/ Contact: itnintec@ugent.be