



You should. Tell us what matters to you.

What Matters to YOU?

Clinical Trial Updates

The Daiichi Sankyo clinical study "An Evaluation of Pseudoxanthoma Elasticum (PXE) Natural History Biomarkers in PXE Individuals and Their Biological Non-PXE Siblings" is fully enrolled and is nearing its completion. Those who participated have contributed to a fuller understanding of what biomarkers (measures) might work to tell if a drug is doing its job in slowing down or stopping PXE. Stay tuned for results in several months.

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The pharmaceutical company Inozyme has a clinical trial for individuals who have a condition called generalized arterial calcification of infancy (GACI), which affects children due to mutations in a gene called *ENPP1*. The trial is also open to individuals who have two disease-causing mutations in *ABCC6* (PXE). One person has received the drug, INZ-701, which is designed to help restore PPI levels in the body. The purpose of this early trial is to assess the safety of different dosages of the trial drug which will help determine possible dosages to investigate in subsequent clinical trials for effectiveness. [Contact us](#) if you are interested in participating.

Webinar Input Needed

PXE International hosts webinars for PXEers every month on a range of varying topics. To meet your needs, we want to hear what topics YOU would be interested in. Click the Webinar Poll button.

[Webinar Poll](#)

Look out for a Nutrition Study Launching Soon!

PXE International is currently developing a survey to investigate how a “heart-healthy diet” may be beneficial for PXEers to adopt. We are delighted that Ruby Price, a student in the nutrition sciences program at the University of Washington, is developing this study for us. Now in the early developmental stages, it will launch in early May. Stay tuned to this newsletter, Facebook, and the PXE Google CHAT Group for more information.

What are the symptoms you experience related to PXE? How do you manage your PXE?

If you are affected by PXE, tell us your symptoms and treatments in this simple, two-question, survey!

[Click for survey link](#)

[PXE International](#)

