

## PXE International August 2019 eNewsletter Volume 12 No. 8

# PXE International Breaks Ground on Exciting Clinical Study

On August 6<sup>th</sup> PXE International conducted a clinical study to see if people affected by PXE experienced increased levels of pyrophosphate (PPi) in their blood if they took capsules containing PPi.

PPi might be a treatment for PXE, so this is an important first step. We had a magnificent day with 11 volunteers who gave their time (and blood) to this study!

Researchers Drs. Jouni Uitto and Qiaoli Li also participated in the day (pictured right).





We look forward to sharing the results of this study as soon as we can! Thank you so much to everyone who participated. Stay tuned for more news on how you can be a part of upcoming clinical trials and PXE research! In the meantime, you can read the full summary of this study here.

Watch Dr. Jouni Uitto discuss how this study works and why we are doing intere.

#### Don't Forget to Complete Our Research Survey!

If you have not done so already, we'd like you to answer a couple of questions in our recent research survey! We need answers to questions about PXE symptoms and treatments for both you and our researchers.

So far 52% of PXEers are reporting that they feel pain in their calves when they begin walking. How does your experience compare?

If you haven't completed a survey in the last month for us, please take 10 minutes to answer now. Here's the link, please let us know if you have any questions!

Take the Survey

### **More Webinars Coming Soon**

We are planning three new webinars for the fall covering PXE and the vascular system, biomineralization, and women's health. You can watch all of the previous PXE webinars on our <a href="YouTube channel">YouTube channel</a>. Email us at <a href="info@pxe.org">info@pxe.org</a> and let us know what webinar topics you'd like to see covered in the future!

You can also listen to our interview with the Ditheridge family on how they approach PXE and why they feel driven to fundraise for PXE Research. That interview is available here.

PXE YouTube

#### **T-Shirts Available**

Get your PXE T-shirts while they are still available! Our shirts are made out of a moisture-wicking material to keep you cool in the summer heat. Fill out the order form below and you will receive an invoice from a PXE Team member.

Any shirts bought during 2019 also contribute to our matching challenge!





Order Here

### **Matching Challenge Update!**

Remember that a generous and anonymous donor will continue to match every donation given to PXE International for the rest of 2019, and up to \$500,000!

The year is almost over, so please donate what you can to help us meet the goal of receiving \$500,000 in member donations and the matching funds. To date, we have raised \$367,633 from more than 530 donors!

Thank you to everyone who has contributed so far. Share our donate link with your friends, family, and co-workers to help us reach our goal by the end of the year and double every donation!

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