



**PXE International**  
**Sept/Oct 2022**  
**eNewsletter**  
**Volume 15 No. 8**

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## **Register Now for the Global PXE Meeting**

Register now for the 2022 PXEer Meeting! Learn from each other, clinicians, and researchers knowledgeable about PXE. You are always saying, “I wish someone understood PXE...” Well, here you go. Agenda coming shortly.

### **Dates**

**November 11<sup>th</sup> (7 PM ET to 9 PM ET)**

**November 12<sup>th</sup> (10 AM ET to 5 PM ET)**

**November 13<sup>th</sup> (10 AM ET to 2:30 PM ET)**

[Sign up here](#)

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## **Important Clinical Studies: Everyone Wanted!**

The Daiichi Sankyo TNAP inhibitor DS-1211, or any other drug, cannot be approved without understanding the ins and outs of PXE. We don't understand it all yet. You always ask us good questions that we cannot answer about how PXE affects your body. And so, we have a suite of surveys for you – ALL OF YOU – to respond to now! We are particularly interested in you telling us about how your legs do or do not hurt because we have a researcher standing by to analyze the data. You can dive right in on the Vascular Study and then move on to other surveys on your dashboard.

[Join the Vascular Study!](#)

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## **Get your PXE Pin!**

If you have participated in any of PXE International's clinical studies or trials, we want to send you a pin! You can wear it proudly at the annual meeting (on Zoom), or out

and about, so people ask – “What is PXE?” or “What is a clinical study?”

Sign up for your pin [here](#). You will be asked if you have participated in the [studies](#) or trials. Just check all the boxes that apply, and we will mail you one or both of these pins.

PXE Pin Sign up

Click here for the PXE Studies

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## Investigator’s Meeting for the Daiichi Sankyo TNAP Inhibitor Clinical Trial

In September, PXE International participated in an “Investigator’s Meeting” in Philadelphia hosted by Daiichi Sankyo, Inc. An investigator’s meeting is held to prepare clinical sites to manage a clinical trial. That’s right, we are preparing for our upcoming clinical trial on an investigational drug that is being evaluated by Daiichi Sankyo, the sponsor. Sharon, Mary, Georgia, and Catt were planners and participants. This meeting helped to educate the clinical trial sites about PXE, people with PXE, and the process for the trial. Participants in the meeting included Daiichi Sankyo, the sponsor and organizer, representatives from the CRO (contract research organization) that manages various aspects of clinical trial operations, and the Principal Investigators and their staff (they are the individuals at the study site who implement the study protocol).

Sharon described pseudoxanthoma elasticum (PXE), and its effects and shared the power of PXE International as a partner in clinical studies and trials.

What is a Clinical Trial?

Mary interviewed several PXEers to get their reaction to the trial protocol over the last month. At this meeting, she shared important considerations on behalf of potential participants.

Several investigators (the people who will take care of you, administer the drug, and do the various tests) said they were so glad to meet you through us. They felt a strong connection to our need as a community to help to find a treatment and are ready to meet those of you who can participate.

Does this sound interesting? If you have questions, contact Mary ([mary@pxe.org](mailto:mary@pxe.org)) or Catt ([catt@pxe.org](mailto:catt@pxe.org)). You can also give Mary a call at 202.362.9599 x0.

TNAP Inhibitor Clinical Trial Lay Summary

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# Please Let Me Do More Laundry and Vacuuming!

Said no one, ever! Well, Sam Harper, a PXEer, said so. And he did it in a terrifically public way – in the New York Times Modern Love feature. Sam declares, “My computer font grew from 12 to 18 to 36 to 48” – sound familiar? Likewise, “In my shrinking life, PXE has shifted my perception of the domestic task, one micron at a time.” This reminds us of what many of you share. Sam’s Modern Love piece tells the tale of his, and likely your, experience of living with PXE.

Sam is a fabulous fund-raiser for PXE International, riding his bike across the country and soon the whole east coast to raise money for PXE. The toll PXE takes is terrible and not to be minimized (Sam doesn’t!). The studies and trials we have described above are critical. And Sam adds this too: “In humbling myself to that work, I find the moment, and in finding the moment, I see my place in the universe, and that brings me peace.”

Check out Sam’s piece and see if you can find some peace, perhaps in his company.

Please Let Me Do More Laundry and Vacuuming!

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## Sam’s Bike Ride

Sam Harper is not only a fantastic author, but he has a goal to bike through all 50 states. On October 12<sup>th</sup>, Sam and his biking partner, Mike, started their journey in St. Augustine, Florida and plan to bike all the way to Peapack, New Jersey by the first week of November.

Mike acts as Sam’s eyes on the road. Sam can follow his line and taillight while Mike calls out any obstacles that Sam might not be able to see. This cooperation has enabled them to bike through 16 states, and they are hoping to reach 25 states by the end of this trip.

Donate to support them on their journey by following the link below. Even the littlest bit helps!

[Donate here](#)



Left to right: Sam and Mike

*Update: As this newsletter was going to press, Sam let us know that he has suspended his ride because his brother Charlie, also a PXEer, and Sam's twin is very ill. Sam has gone to*

California to be with him and their family. We have you in our prayers, Charlie, Sam, Jessica and family.

Before Sam had to stop, he completed nearly 500 miles and has raised \$11,000 so far. He appreciates your support.

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## Nutrition Study Wrap-up

32 PXEers have been eating well, or at least trying, for 12 weeks now. We are so grateful to you for participating in the Nutrition Study. We have reached the end, and data analysis has begun! Ruby Price, the nutrition researcher for this study, and Catt Troutman, will analyze the results and look for a connection for how diet can help PXE symptoms. Look out for preliminary results on Facebook and in the upcoming newsletters!

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## Ways to Donate to PXE International

### Smile.Amazon.com

Thank you to all who signed up with [Smile.Amazon.com](https://www.smile.amazon.com). With the holidays coming, let's all sign up!

[Smile.Amazon.com](https://www.smile.amazon.com)

### PayPal

You can always donate by sending a check or using [PXE International's PayPal link](#) where you can use your PayPal account or your credit card. We will be gearing up for our annual campaign next month so please consider helping us advance all these studies and trials!

[PayPal or Credit Card](#)

### iGive.com

Thank you to those who signed up with [iGive.com](https://www.igive.com). This is the browser extension we introduced to everyone last month that donates to nonprofits with every web search you do. We should see an increase in our next quarterly check.

[iGive.com](https://www.igive.com)

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## Catch Up on Past Research

Get ready for this year's PXEer meeting by watching past videos. View them on our [YouTube Channel](#). You will find videos from past conferences, research presentations, and old webinars. Watch them all and get yourself up to speed with PXE research and care!

[2020 Conference Playlist](#)

[2021 Conference Playlist](#)

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## Contact Us

We love to hear from everyone and help you in any way we can! Email us at [info@pxe.org](mailto:info@pxe.org). Staff read emails daily. Or call us at **202.362.9599 x208**. If it is outside of office hours, leave a message and we will get back to you as soon as we can.

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