



PXEnews
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Save the Date!

The 2023 Global PXEer Meeting will be held November 3rd-5th. Stay tuned for the agenda and the registration forms! This is your chance to hear the latest findings about PXE, your care, and new discoveries. You can meet others with PXE, and have your questions answered. Most of the meeting will be recorded and you will find it on our YouTube Channel.

Past Global PXEer Meeting Recordings

Recruiting Final Call for DS1211 Clinical Trial

The clinical trial is almost completely enrolled! We need 10 more people and some alternates on standby in case some individuals do not qualify for the trial. Don't miss out on your opportunity to participate now. For more information, follow the link below and reach out to Catt (catt@pxe.org) and Mary (mary@pxe.org). They can answer any of your questions and can get you prescreened for the trial. The individuals enrolled till now have been enthusiastic and say the travel has been easy. A day off work now and then for research is not a bad way to spend a day.

I'd like more info about the DS1211 Clinical Trial

New Drug for Dry Macular Degeneration

The U.S. Food and Drug Administration (FDA) recently approved the first medication to treat geographic atrophy. Pegcetacoplan (SYOFOVRE™) is a monthly, or every other month, intraocular injection that slows the progression of the disease. We do not know if this will work for people with PXE who have what is sometimes called "dry macular degeneration" or "geographic atrophy". If you

have been told the antiangiogenesis injections will not work because you do not have retinal bleeds, then ask if Syofovre would work for you.

PRO-PXE Study

Drs. Kristina and Maximilian Pfau are recruiting for a European study for PXEers. The study's purpose is to use new ophthalmologic technologies to determine if they are better suited for monitoring PXE than the traditional CT-imaging method. If you are older than 18, have a confirmed PXE diagnosis, and can travel to their lab in Basel, Switzerland, visit their study page for more information.

PRO-PXE Study

Critical Study for FDA and EMA Approvals!

We are on the brink of numerous potential therapies being considered by the regulators, but the FDA and EMA still need to see that people with PXE suffer. Tell us about how PXE affects you in our Burden of Disease Study. The study asks about physical functioning, bodily pain, mental health, and other areas of pain and suffering. Let your voice be heard!

Burden of Disease Study

All Forms of Donations!

Last month's article on "How we work for you" discussed all the things we spend your donations on and also shared that we rely on a few donors to keep PXE going. That article generated 6 donations via PayPal. I know that some checks may be on the way. Thank you all so much for answering the call.

This month we want to tell you how you can donate and the ways people give to PXE.

- Ten donors give each month through PayPal, their amounts range from \$5 to \$50 each month. We can set this up to repeat, so you do not even have to think about it!
- Another ten donors give through their company annually, and the company matches their donation. These amounts range from \$25 to \$500.
- One donor sells items on eBay and gives PXE a percentage of that income, which she has been doing for more than ten years.

- If you use iGive, you are one of 248 supporters of PXE International. Of those 248, only 7 are using the iGive button. And the amount raised since 2004 is \$4,530. I know that we can all do better. This is free money that iGive wants to donate to us from shopping and web searching. Shops that contribute to this are Walmart, Etsy, BeallsFlorida, Eddie Bauer, IGH Hotels, and Candlewood Suites; the list is endless. Please check it out again, here is our link: [PXE International iGive](#).
- We receive donations in honor of PXEers on their birthdays.
- Some family members list PXE in the obituary of their loved one, and we receive “in lieu of flowers” donations.
- Some people have sent us their coin jars – you would be surprised at how much is in those jars!
- A few people give through work to the United Way, with PXE as the benefactor.
- Two donors are giving through their workplace to PXE through a repeating collection. These donations come in quarterly.
- More PXEers give annually through their workplace with a one-time donation.
- And, our bike rider, Sam Harper, rides different routes around the country and raises money for PXE.

Tell us how you too can find an easy way to donate to PXE International. Make your donation today. Treatments are on the horizon!

[Donate \(even a little\)](#)

Connect your EHR

A great way to share your data is by connecting your electronic health record to the PXE registry. This allows us to discover more about PXE: how does it progress, what organs are affected, and how can we slow it down. Click the link below for detailed instructions. Reach out to Catt (catt@pxe.org) or Mary (Mary@pxe.org) if you need help.

[How do I connect my EHR?](#)

Website Update - Share Your Story

As part of our changes to the PXE International Website, we are creating a testimonial page for individuals who would like to share their stories. If you would

like to take part in this, please reach out to Catt (catt@pxe.org) for more details.

Contact Us

We love to hear from everyone and help you in any way we can! Email us at 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.

[PXE International](#)



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