



**PXEnews**  
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## **Global Meeting Recap**

Thanks to those who attended and made the PXE Global 2023 Conference a success! We hope you enjoyed spending the two days with fellow PXEers while you learned and networked. We've heard it was wonderful to meet other affected friends and swap stories. We have posted all of the talks from the meeting on the PXE International YouTube Channel. If you could not make it to the Conference or want to rewatch a presentation, you can do so whenever you want to by clicking the orange button below.

If you have any questions, feel free to reach out to us at [info@pxe.org](mailto:info@pxe.org).

[2023 PXE Global Conference Recordings](#)

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## **Donation Double-Match Challenge Update**

Thank you to all who responded to the double-match challenge. Your donation was tripled! We will have an update on the amount raised shortly. And, there is still time to support the research that will bring you a treatment for PXE. We are close!

**Donate by credit card or PayPal**

[Donate Here](#)

Or by check:  
**26400 Woodfield Road #189**  
**Damascus, MD**  
**20872-7509**

Or donate by wire, email [mary@pxe.org](mailto:mary@pxe.org) for that information.

**TO THOSE WHO HAVE DONATED -**  
**THANK YOU FROM THE BOTTOM OF OUR HEARTS!**

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## Study Opportunity for Central Europe PXEers

Dr. Kristina Pfau is offering a study for PXEers in Europe. 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. To participate, you must be over the age of 18 with a confirmed PXE diagnosis and able to travel to the lab in Basel, Switzerland. If you would like to hear more, follow the link below or contact the researchers directly: [kristina.pfau@usb.ch](mailto:kristina.pfau@usb.ch) and [maximilian.pfau@usb.ch](mailto:maximilian.pfau@usb.ch).

[Pfau Lab Study Information Website](#)

[Dr. Kristina Pfau's Conference Talk](#)

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## 2023 Epidemiological Survey

It is critical that we have data from not only the handful of people participating in the clinical trials but from thousands of people living with PXE. YOU can convince the FDA and other regulators that PXE is a serious disease that is a burden to you. Could you make sure you are registered and have answered all of the surveys? We will launch several more in the coming weeks, and you will want to pace yourself!

[2023 Survey Campaign Registration](#)

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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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