



PXEnews
Special Notice

October2024

CEO Sharon Terry speaking in Japan (ZOOM) tonight

Sorry for the late notice - the talk will be recorded!

Sharon Terry will speak tonight, October 14, in Japan. The talk will be in English, translated into Japanese. She will describe her family's journey with PXE and her participation in research in general.

If you speak Japanese or are in a time zone near Japan - this is for you!

Register here: <https://peatix.com/event/4145620>

[Donate to our Matching Campaign Here](#)

PXE Virtual Conference

So far, so good—the PXE Extended Virtual Conference Series has been a huge success! Ten presentations have already been completed, covering topics you requested, and many more



are to come. The second half of the year has an exciting lineup!

Upcoming Talks:

October 17, 2024 • 11 AM ET • Viola Pomozi, PhD, Research Centre for Natural Sciences, Hungarian Academy of Sciences Centre of Excellence

Click here to register: [Animals in PXE Research and the Pyrophosphate Story](#)

November 6, 2024 • 12 PM ET • Flora Szeri, PhD, Research Centre for Natural Sciences, Hungarian Academy of Sciences Centre of Excellence

Click here to register: [Inorganic Pyrophosphate and PXE](#)

December 16, 2024 • 11 AM ET • Tamas Aranyi, PhD, Research Centre for Natural Sciences, Hungarian Academy of Sciences Centre of Excellence

Click here to register: [Are All ABCC6 mutations equal?](#)

Where: Zoom (register to receive the link)

All talks will be recorded and posted to the [PXE International YouTube Channel](#) for later viewing.

Cost: \$25; **inclusive of all talks** - payable through credit card, check, or [PayPal](#).

Check:

PXE International
26400 Woodfield Road #189
Damascus MD 20872-7509

If payment is a hardship, please contact Mary (mary@pxe.org). You are all set if you previously paid for the Conference in late 2023 or early 2024!

Pay Here

'SENIOR DISCOUNT' - A Bi-Monthly Column About the Ups and Downs of Managing PXE and Aging



Sam has also launched a bi-monthly column he is calling "SENIOR DISCOUNT." The column will feature short essays on the sustaining gifts and comic humiliations of metabolizing and managing PXE and age-related challenges. As you'll see, the introductory column doesn't mention PXE, but he assures us that many that follow will. We hope you'll subscribe (it's free!).

[Check Out His Latest Pieces Here](#)

Raising Awareness for PXE

Do you want to educate your community members, co-workers, friends, and family about PXE? In response to numerous requests, we've created an informative infographic to help you share what PXE is, who PXE International is, and how others can contribute!

Attached, you'll find a full-sized, printable flyer for your convenience. Let's join forces to raise awareness about PXE!



Help those suffering with Pseudoxanthoma Elasticum (PXE)

What is PXE?

A rare genetic disorder causing:

- severe legal blindness
- skin issues
- vascular complications

Who is PXE International?

Since 1995, we have been the vanguard against PXE by:

- pioneering research
- bringing together a global network of laboratories
- managing an extensive tissue bank/registry
- leading charge with clinical trials

Support



A responsive lifeline to affected individuals, providing crucial information to those newly diagnosed.

Our Mission?

Educate



Equip medical professionals with knowledge and resources to recognize and understand PXE.

Research



A collaborative research consortium that's the powerhouse for most of the world's research on PXE.

How can YOU help?

As a non-profit, we rely on donations and your contribution directly fuels research for treatment development and supports clinical trials.

- **Credit Card:** Secure and convenient - Scan the QR Code for more info
- **Zelle:** Quick transfer via mary@pxe.org, under PXE International.
- **Check:** Send to PXE International, 26400 Woodfield Road #189, Damascus MD 20872-7509



[Click Here to Download the PXE Infographic](#)



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