



Thirty years ago, on this day, December 23, my kids were diagnosed with PXE. They were 7 and 5 years old. My whole world was upended. They didn't quite comprehend that pseudoxanthoma elasticum (PXE) was taking a front stage in their lives. I was terrified.

Most of you know that story (my TED talk is a succinct description – https://www.ted.com/talks/sharon_terry_science_didn_t_understand_my_kids_rare_disease_until_i_decided_to_study_it?utm_campaign=tedsread&utm_medium=referral&utm_source=tedcomshare)

Thirty years—the vast majority of my kids' lives—and a little under half of my life. The challenges and opportunities have been immense. I remember the kick in the gut, the fire in my belly, the spark that ignited so much in my life and theirs. All of it—considering where it led me and where it has led them—is astounding.

We are on the brink of a treatment that will allow Elizabeth and Ian and 5000 other PXEers to go into their future with their sight. That is [expletive] astounding. But I am begging you - we don't have the funds we need to aggressively peruse this. So, can you give \$1? \$5? \$10? Really, the equivalent of a coffee makes a huge difference.

Jessica Harper is matching you! How about that! You can watch her video and make your donation (NO FEES!!) here: https://www.zeffy.com/en-US/fundraising/8f20a01e-399e-4fa4-b147-e6302b292f19?fbclid=IwZXh0bgNhZW0CMTAAAR1jkVZizYxHazgu1z9jTpUD6nos3Z7SuSwSdFgVKQCrfmgAWWVxZ18974M_aem_SKxRv54zevDUPhAxW8vZaQ

[Hear about what funds support: PXE International Interview](#)

[Make a donation: Donation Link](#)

PXE Virtual Conference

So far, so so good—the PXE Extended Virtual Conference Series has been a huge success! 11 presentations have already been completed, covering the topics you requested. We still have at least one more talk this year! See below.



All 11 prior talks were recorded and posted to the [PXE International YouTube Channel](#).

[View the 2024 PXE International Virtual Conference](#)

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



Sam Harper, PXEer and board member, has a bi-monthly column called “SENIOR DISCOUNT.” The column features short essays on the sustaining gifts and comic

humiliations of metabolizing and managing PXE and age-related challenges. We hope you'll subscribe (it's free!).

[Check Out SENIOR DISCOUNT 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](#)

Increasing Your Impact: a Message from our Dear and Famous Board Member



Our most famous PXEer (at least that we know about) is concerned about keeping the momentum for PXE research going. She will match donations - give a listen to Jessica Harper talk about us all stepping up! We are so grateful to her and her family!

[Donate to our Matching Campaign Here](#)

[PXE International](#)



PXE International | 26400 Woodfield Road #189 | Damascus, MD 20872 US

[Unsubscribe](#) | [Update Profile](#) | [Constant Contact Data Notice](#)



Try email marketing for free today!