



PXE News
Volume 29 No. 11
November 2024

It is time.
Support PXE Research

**Donate Today to
Speed us Toward Treatments**

Why Wait?

PXE International urgently needs your help this fall and end-of-year season. Your donation is essential to sustain the critical pace of research we've achieved, including supporting the PXE International Center of Excellence in Research and Clinical Care at Jefferson Medical University.

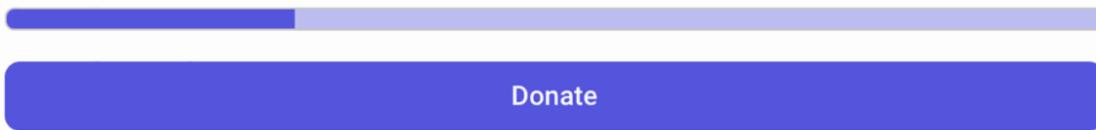
If you want to understand what's happening in PXE research and how we've come to be on the brink of several potential treatments, don't miss our new interview with Koen van de Wetering and Qiaoli Li. They offer insights into PXE research worldwide and the vital role PXE International plays in these advancements. The video ends with a heartfelt

message from board member Jessica Harper, acclaimed actor and writer with PXE, who has generously pledged to match your donation.

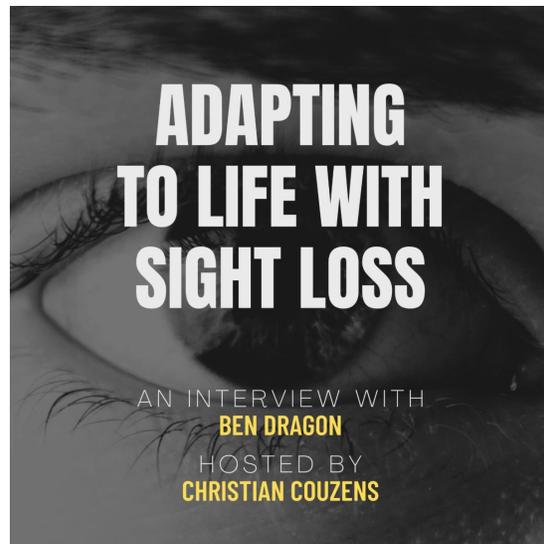
Listen to their powerful stories, hear Jessica's encouraging message, and make a difference by donating today!

- [PXE International Interview](#)
- [Make a donation: Donation Link](#)

\$92,064.05 of \$350,000.00



Christian Couzens & Ben Drago



Diary of an Average Joe

Podcast about PXEer

PXEer Ben Dragon from Farncombe UK is featured on *Diary of an Average Joe*. Christian Couzens is the creator and host. Ben shares his journey of adapting to life after losing his sight. I am sure many of you will resonate with his story. Give it a listen!

PXE Story on Diary of an Average Joe

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.



Upcoming Talks:

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: [Click here to register for Zoom](#)

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

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). If you previously paid for the Conference in late 2023 or early 2024, you are all set!

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

Pay Here

'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?

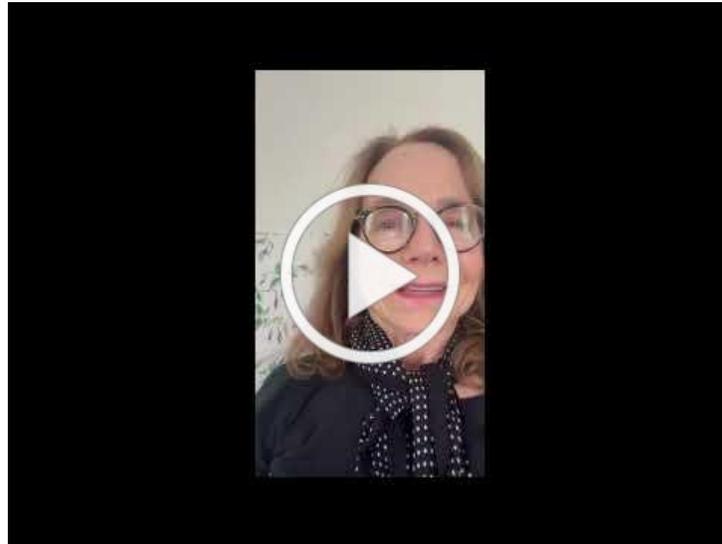
As a non-profit, we rely on donations and your contribution directly fuels research for treatment development and supports clinical trials.

- **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](#)



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