



PXE International
November 2022
eNewsletter
Volume 15 No. 9

A graphic with a light blue background. The words 'Season of Giving' are written in a red, cursive font. The word 'Season' is on the top line, 'of' is in the middle, and 'Giving' is on the bottom line. There are three red snowflake icons: one to the left of 'Season', one to the right of 'of', and one to the right of 'Giving'.

Season
of
Giving

Triple your donation this giving season: \$150,000 double match challenge!

Announcing an exciting challenge for PXE International in this giving season.

Two generous anonymous donors have offered to double your donation! Your contributions to PXE International fuel research and help make it possible for us to be finally testing potential treatments. Each dollar you donate this year will be double-matched by our generous donors and we plan to make every penny count triply!

Donate by credit card or PayPal with the button below:

[Donate Here](#)

or

Send us a check:
26400 Woodfield Road #189
Damascus, MD
20872-7509

Email Mary at mary@pxe.org for wire information.

Global PXE Meeting

The Global PXE Meeting will be held on Zoom on January 13th, 14th, and 15th. View the agenda by clicking the button below.

Some of you might have registered for the November dates (before we knew of speaker conflicts), and your registration will carry over. If you cannot make the new dates but already paid your registration fee, contact Mary at Mary@pxe.org for a refund or consider donating it. You will have access to the recordings in any case.

We hope to see everyone in January!

[Meeting Agenda](#)

[Meeting Registration](#)

Sometimes You Forget to Look

Shannon Spangler wrote a riveting article in *The Sepia Journal* chronicling experiences with PXE-related vision loss over the past nine years, titled "[Sometimes you Forget to Look](#)". In this creative piece, she expresses her fears, "curbs, heaved sidewalks...government forms," and the things she misses, driving and books. Isn't that relatable?

She also discusses life changes: practicing with a white cane, the changing relationship with her husband, and countless eye injections—experiences that many other PXEers face. Shannon personally shared this article with us, and we hope everyone finds solidarity in her words.

[Sometimes you Forget to Look](#)

Get your PXE Pin!

If you have participated in any of PXE International's clinical studies or trials, we want to send you a pin! You can wear it proudly at the annual meeting (on Zoom), or out and about, so people ask – "What is PXE?" or "What is a clinical study?"

Sign up for your pin [here](#). You will be asked if you have participated in the [studies](#) or trials. Just check all the boxes that apply, and we will mail you one or both of these pins.

[PXE Pin Sign up](#)

[Click here for the PXE Studies](#)

Local PXEers Wanted for Clinical Trial

The TNAP Inhibitor clinical trial is actively ongoing and we need more PXEers! We need PXEers interested in participating in this clinical trial and local to the study sites in Secaucus (NJ), New York City (NY), Philadelphia (PA), North Dartmouth (MA), and Bethesda (MD). Travel assistance can be arranged if needed. For more information, follow the link below to the online description of the trial or contact Mary (mary@pxe.org or 202.362.9599 x208) or Catt (catt@pxe.org or 202.362.9599 x 235).

[DS-1211b Clinical Trial](#)

Add PXE International to your Giving Tuesday List

The holiday season is upon us and there is no greater time than now to donate to PXE International. As a nonprofit organization, we run on grants and stakeholder donations. We work for all PXEers to further knowledge and raise global awareness of pseudoxanthoma elasticum. There are many ways to make a donation. We have a Paypal account for direct donations.

You can also donate while you do your holiday shopping through [Smile.Amazon.com](#). It is an Amazon browser extension that donates a portion of your order to an organization of your choice. You do not pay extra for the donation, you just shop normally.

[Smile.Amazon.com](#)

[PayPal or Credit Card](#)

Catch Up on Past Research

Get ready for this year's PXEer meeting by watching past videos. View them on our [YouTube Channel](#). You will find videos from past conferences, research presentations, and old webinars. Watch them all and get yourself up to speed with PXE research and care!

[2020 Conference Playlist](#)

[2021 Conference Playlist](#)

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.



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