
In Memory of Joyce Kohn



Ian Terry brings Joyce her birthday cake while we all sing Happy 70th Birthday!

October 31, 1928 - October 22, 2022

We mourn the loss of Joyce in our PXE family. Sharon Terry describes Joyce: "When my kids were diagnosed, I felt lost and at sea, like so many of you when you or your loved one were diagnosed. I had the good fortune of meeting Joyce Kohn, who in 1994, was the Administrator for the National Association of Pseudoxanthoma Elasticum (NAPE). Joyce was a font of knowledge and reassured us and then assured us: together we could make a difference in this disease.

"Joyce graciously invited us to Denver, where she was headquartered. Over many visits, we helped her, and she helped us. She needed to update all of her operations to move into the digital age so we set up her databases and electronic communication systems. She shared her abundant knowledge. She was so wonderfully generous that we stayed in her home in Denver, enjoying the neighborhood, her stories, and the city with her.

"Joyce came to work for PXE International not long after we created it. Many of you met her at PXE International meetings. We honored her service at one of

those meetings. Ever a good friend, she always recognized PXE International staff with her lovely computer-made birthday cards each year. We visited each other often, and she was always ready to lend a hand. Joyce was a champion for all PXEers".

CJ Posk, former executive director of NAPE and active member of PXE International, says, "Joyce was a kindred spirit. She was always there when anyone was in need of services. We were lucky to have her work in our Worcester, Massachusetts, PXE office. She lived a full life."

Joyce Rothenberg Kohn died in St. Louis, MO, on Oct 22, 2022, at age 93, just shy of her 94th birthday. She was born in Fort Madison to parents Max and Cecelia Rothenberg, who operated The Parisian in downtown Fort Madison for 35 years. She graduated from public high school and continued to live in Fort Madison for a few years after her marriage to Stanley Kohn, who worked at The Parisian and preceded her in death.

Her brother, Harvey David Rothenberg, also preceded her in death.

Joyce returned to Fort Madison for many high school reunions to renew contacts with childhood friends.

She is survived by her two sons, Gordon and Russell (Gale) Kohn, and two grandchildren, Stanley (Shannon) and Crystal Kohn of St. Louis, along with two great-grandchildren, Aiden and Avery Kohn.

We are grateful for all Joyce did for the PXE community. Join us in remembering her life and mourning her death. Our condolences to her family.

Triple Matching Campaign



161 people have donated

\$33,624 raised of \$150,000

Our \$150,000 double-match challenge is well underway. We are currently at \$33,624 of \$150,000! Thank you to the 161 people who have donated.

Two very generous anonymous donors are tripling your donation, so let's reach \$150,000 to receive the most we can. When you give \$50, it becomes \$150 (or whatever amount!), then our research takes off - we are testing several treatments now.

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 for that information.

Check the campaign page often to see the amount of donations increase. Invite a friend to donate too!

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

Global PXEer Meeting

Register now for the Global PXEer Meeting! The meeting will be on January 13th, 14th, and 15th and will be held on Zoom. Check out the [agenda](#) here. Use the link below to [register](#) for the meeting.

If you registered for the November dates, you are registered for this meeting.

See you in January!

[Meeting Agenda](#)

[Meeting Registration](#)

Local PXEers Wanted for Clinical Trial

A few spots are still open for the Secaucus, NJ and Philadelphia sites for the TNAP Inhibitor Clinical Trial. Travel and lodging is covered. Learn more about the trial by clicking the link below. If you are interested (and willing to travel to Secaucus or Philadelphia), reach out to Mary (mary@pxe.org or 202.362.9599 x208) or Catt (catt@pxe.org or 202.362.9599 x 235).

[Clinical Trial](#)

2023 Survey Campaign

We are gearing up for an important part of the clinical research - we must have data from not only the handful of people participating in the clinical trials but from hundreds of people living with PXE. You can convince the FDA and other regulators that PXE is a serious disease with many ramifications. Could you

make sure you are registered and have done the surveys so far? We will launch several more in the coming weeks, and you will want to pace yourself!

2023 Survey Campaign Registration

Another Year Comes to a Close!

Profound thank you for your contributions and ongoing support. We hope you all have a great holiday season, and we will see you all in the New Year! 2023 will be a BIG year for taming pseudoxanthoma elasticum (PXE). See you on the other side!

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.

[PXE International](#)



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

[Unsubscribe sterry@pxe.org](#)

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

Sent by sterry@pxe.org powered by



Try email marketing for free today!