

PXE International October 2019 eNewsletter Volume 12 No. 10

PXE International Ireland Regional Meeting

On October 4th, PXE International hosted the Ireland Regional Meeting in Dublin. Several PXEers from around the area attended to discuss recent findings, personal health issues, and almost anything else that might have to do with all of our experience with pseudoxanthoma elasticum (PXE).

lan Terry hosted the meeting and was ecstatic to get a chance to interact face-to-face with individuals who we work so hard to serve. There were so many topics that we could address better if more PXEers would answer the Common Health Issues Survey. Ian and the folks attending really wished they had more information from that survey. So please answer the survey today--don't delay--we need your experience represented in the resulting data!

PXE is looking to serve as many regions as possible in as personal a manner as we can, so if you are interested in a regional meeting please reach out to Sam at scoley@pxe.org. We have no funding for these meetings, so we look for an intersection between places we travel for other meetings, and/or places that can raise enough money to bring us there.

Thank you everyone who attended the Ireland Regional Meeting and we hope to see you again soon!



Save the Date!

You asked us to tell you as early as possible - and so here we are!The PXE International Biennial Meeting will take place on October 16 -18, 2020 in Philadelphia, Pennsylvania, USA.

Join Our Next Webinar

Stay informed about the latest developments in PXE Research by watching our 2019 webinar series.

Our next webinar will be on December 12, 2019 at 7pm with Jonathan Schoenecker. Dr. Schoenecker will describe how the process of mineralizing tissue relates to and affects PXE. Please register below to join the discussion!

You can watch all PXE Webinars on our YouTube channel. Stay tuned for news on when to join us for our next PXE Webinar. Let us know what topics you want to see covered at info@pxe.org.

Visit our YouTube channel

Register for the Webinar

Here's How You Can Participate in PXE Research Right Now

If your vision is 20/200 or worse, or you are considered legally blind, PXE International needs your medical records! Download the forms below to take on your next visit with your doctor; your doctor will then have permission to send us your records.

You can also log into your electronic health records portal and download your records yourself and send them to us via email or Google Drive to get your records to PXE International faster. If you have any questions or require assistance please email Sharon Terry at sterry@pxe.org or give us a call at 202.362.9599 ext 222.

Adult Release Form

Child Release Form

Additionally, if you haven't taken our Common Health Issues survey you can participate here. Taking just ten minutes to share your experience with PXE can make a huge impact on our current research.

Order PXE T-Shirts

We still have T-Shirts available! Fill out the form below to order yours today. All T-Shirts ordered in 2019 also contribute to our matching challenge. Place your order now to double your impact!

Order Here





Matching Challenge Update

Think about whether you received anything of value from PXE International this year, If you did, let's make sure we get our entire \$500,000 match and raise \$1,000,000 for PXE.

We need \$126,535 to reach our goal. To cross the finish line we need you to chip in today!

DONATE







