



PXE International September 2019 eNewsletter Volume 12 No. 9

Research Meeting in Budapest

PXE researchers from all over the world gathered together in Budapest Hungary on September 16 and 17. Most of these researchers meet annually, every other year in Budapest and the alternate years at the PXE International Center for Excellence in Research and Clinical Care in Philadelphia.

We have been meeting for 24 years. Each year gets more exciting!

At this meeting we reviewed the results of the various clinical trials and all of the animal studies. We decided to form the International PXE Research Consortium more formally than we have in the past. Our first goal will be to determine what we need to agree on, globally, to run a large natural history study. This study builds on and uses the PXE International registry. Additionally, this study will prepare us for the clinical trials for which we are gearing up.

More information coming soon!

How can we support you? Let us know!

Thank you to everyone who took our Member Needs survey in July. PXE International is continuing to work on learning how to best serve your needs.

In regard to how we can provide more support to you, please let us know the five most important tasks. If you have any questions or need any assistance please contact Ian Terry by phone at 301.633.4696 or by email at iferry@pxe.org and he will be happy to assist you.

**Rank Your
Needs**

Your Medical Records are a Treasure

If your vision is 20/200 or less or you are considered legally blind, PXE International needs your medical records for a current research project. First, try

logging into your Electronic Health Record portal and sending these records to us via email or Google Drive or mail.

If you cannot get them that quick way, then download the forms below and send them to your doctor. Your doctor will send us the records. If you have any questions, please contact Sharon Terry (sterry@pxe.org) or give us a call at 202.362.9599 ext. 222.

**Adult Release
Form**

**Child Release
Form**

Thank you, Erin!

At the end of September, we are saying goodbye to our Research Manager, Erin Oliphant. We are so grateful for the years of service she has given this organization, and the dedication she's shown to PXE Research.

Having recently graduated from George Washington University with a Masters in Forensic Science, Erin is exploring a new career and we wish her all the best in this new chapter.

Dublin, Ireland PXEers' Meeting

Temple Bar area (address will be given to those who register – private residence)
Sunday, October 6, 2019
4 PM to 6 PM

Come join Ian Terry, Digital Media Director (don't let the name scare you), for an informal gathering for PXEers. Ian will briefly describe what PXE International has recently learned about the signs and symptoms of PXE, and some exciting discoveries in the research arena. Most of the time will be dedicated to networking, questions, and answers.

This is a free event, though donations to PXE International can help defray costs.

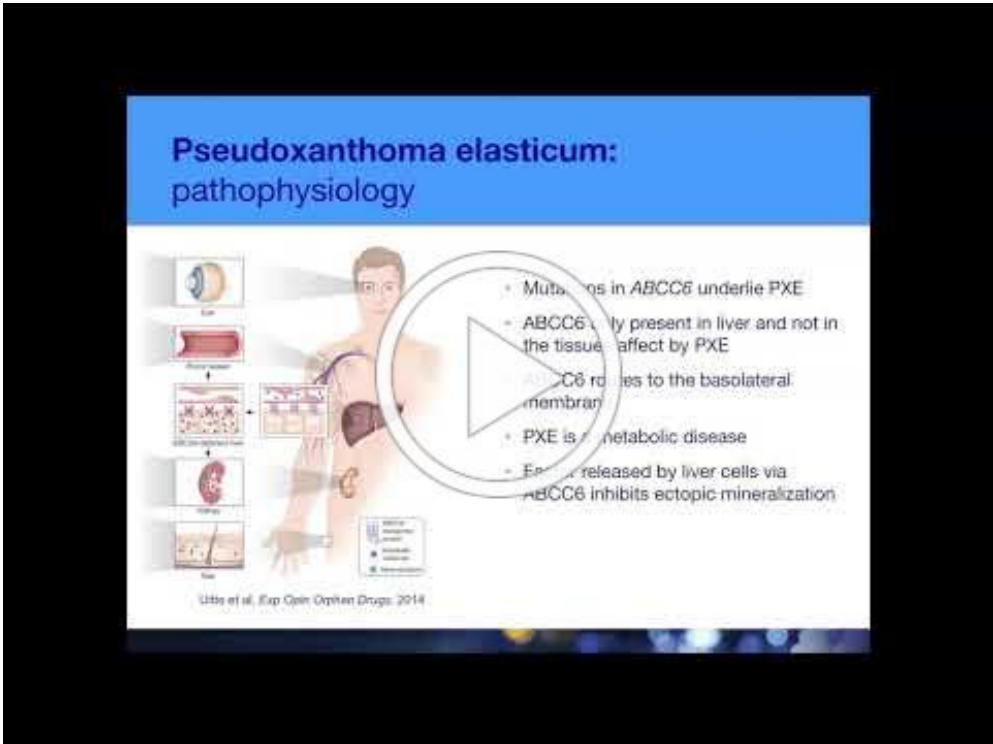
To register, send your name to Mary Peckiconis: mpeck@pxe.org

If we reach more than 10 registrants we may be looking for someone to host, since the AirBnB Ian has secured has only a small living room.

Targeting the Pyrophosphate Shortage in PXE

In our [August eNewsletter](#), we shared information about a clinical study on using PPI (pyrophosphate) to target the calcifications caused by PXE. We also ran a Webinar on this same subject earlier this year that you can watch below.

We will schedule three more webinars before the end of the year. Let us know what subjects you would like to see us cover at info@pxe.org.



T-Shirts Available

Get your PXE T-shirts while they are still available! Our shirts are made out of a moisture-wicking material to keep you cool in the summer heat. Fill out the order form below and you will receive an invoice from a PXE Team member.

Any shirts bought during 2019 also contribute to our matching challenge!



[Order Here](#)

Match Your Donation Today

There are only 3 months left in 2019, and we're \$131,550 away from matching our \$500,000 goal set by our generous, anonymous donor. Can you help us cross

the finish line? Every dollar donated to PXE International this year counts towards this challenge!

We are so grateful for everyone who has donated so far, you're all amazing. Share our donate page with your friends, family, and co-workers to help us with this final push. How incredible would it be to raise a million dollars for PXE research in just one year? You can make that possible!

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