



PXEnews
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February 2024



PXE Extended Virtual Conference Series

This year the annual PXE Conference will take place virtually and still consist of many presentations. They will take place throughout the year, starting next week! You can attend a talk in person or listen later to the recording on our YouTube channel.

PXE Extended Virtual Conference

Presents: Dr. Kristina Pfau



Baseline Data of the ProPXE study - first lessons learned from a prospective natural history study (light dark adaptation)

[Register Now!](#)

Monday, February 12, 2024
1 PM EST (7 PM CET)



When: February 12, 2024 • 1 PM ET • Kristina Pfau, MD, PhD, University of Basel

Click here to register: [Baseline Data of the ProPXE study - First Lessons Learned from a Prospective Natural History Study](#)

Our first talk in this series will feature **Dr. Kristina Pfau** (pictured above) from the Department of Ophthalmology, University of Basel, Basel, Switzerland.

She has **generously donated her time** to share and discuss the results from her **ProPXE study**. In this research study, she looked at new tests for vision and eye imaging techniques to keep track of how PXE progresses.

Where: Zoom (register to receive the link)

All talks will be recorded and posted to the [PXE International YouTube Channel](#) for later viewing.

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

Extended Virtual Conference Series Continues...

February 28, 2024 • 6 PM ET • Yves Sabbagh, PhD, Inozyme Pharma

Click here to register: [Topic TBD](#)

March 3, 2024 • 3 PM ET • Olivier Le Saux, PhD, University of Hawaii

Click here to register: [PXE and Inflammation](#)

March 6, 2024 • 1 PM ET • Imre Lengyel, PhD, Queen's University Belfast and Sara Risseuw MD, PhD, University Medical Center Utrecht

Click here to register: [Clinical Knowledge and Fundamental Science of PXE and the Eye](#)

March 27, 2024 • 6 PM ET • Mark Lebwohl, MD, Mount Sinai

Click here to register: [What can you do to prevent complications of PXE](#)

April 2, 2024 • 2 PM ET • Richard Thompson, MD, University of Maryland

Click here to register: [Topic TBD](#)

April 10, 2024 • 1 PM ET • Qiaoli Li, PhD, Thomas Jefferson

University

Click here to register: [Topic TBD](#)

April 20, 2024 • 11 AM ET • Hubert Chou, MD, Daiichi Sankyo

Click here to register: [PXE Clinical Trials - It Takes a Village](#)

April 20, 2024 • 12 PM ET • Wayne Fuchs, MD, Mount Sinai

Click here to register: [PXE and the Eye](#)

September 14, 2024 • 11 AM ET • Koen Van de Wetering, DVM, PhD, Thomas Jefferson University

Click here to register: [Extracellular Pyrophosphate Regulation and PXE](#)

Register for Dr. Pfau's Talk

Pay Here

Empowering Triumph: How Cheryl's Exercise Program Reduced Her Vascular Symptoms



We recently received a message from Cheryl, a dedicated member of the PXE community, sharing that her vascular symptoms have significantly improved with the adoption of a new exercise regimen. Graciously agreeing to an interview, Cheryl's inspiring journey is one we're excited to share with you!

Q: How did you get started with your lifestyle change? Did you talk to your doctor? Join a gym? Hire a trainer?

My PXE experience started some 17 years ago in my mid-50s.

My first issues were with my eyesight problems identified with the Amsler Grid eye test. This was quickly followed by eye specialist appointments, laser treatments, and injections, eventually to a point that I was assessed as legally blind. The next issue was having a heart attack whilst on holidays. After the heart attack, the cardiac specialist referred me to a Cardiac rehab program which was based on gym exercises and lifestyle change.

Q: What sorts of exercises do you do now that you did not do before?

The gym work was initially supervised by medical staff and a trainer. The exercise program included a rowing machine, treadmills, and cross trainers (20 minutes on each) and sessions with weight and resistance exercises.

Q: When did you first start to see or feel an improvement in your vascular symptoms?

My vascular testing started to show good improvements. Over the last four years, my ankle-brachial index has increased from 0.6 to 0.9 bilaterally. The specialist is very happy with this improvement.

Q: Can you share specific challenges you encountered when initiating your lifestyle change, and how did you overcome them?

I had been experiencing difficulties with inclines, like walking up hills and stairs and particularly getting up from kneeling in the garden or floor exercises. Over time the exercise program has improved my strength, stamina, and body flexibility, and I am a lot more active overall.

Q: In terms of nutrition, have there been any significant changes that accompanied your exercise routine?

From the lifestyle changes in the rehab program, I have made

positive changes to my diet (and my husband's), predominantly focusing on white meats, fish, and vegetables.

Q: Were there any unexpected benefits or positive side effects from your lifestyle change that you didn't anticipate?

The lifestyle change, gym programs, and weight loss have combined to enable me to be a lot more active and enjoy outings with our social groups, including walks and tours.

Q: What message do you have for the PXE community?

At 72 years of age, my motto is “Move it or lose it,” and you are never too old to try!



Donation Matching!

It is that time of the year again!
Our **Winter Fundraising Campaign** is well underway, where every donation you make will be generously matched, **doubling the impact of your contribution.**

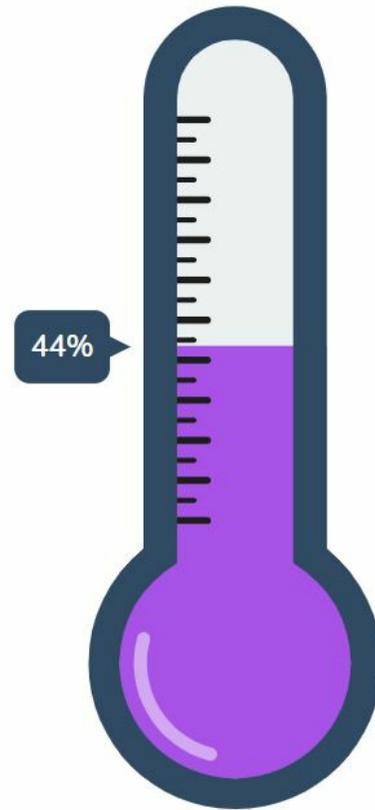
Thanks to a generous PXEer and her husband, we have the

opportunity to match donations
up to **\$200,000!**

GOAL: \$200,000

We are well on our way with
\$87,000 raised already! Thank you
to those who have contributed
and spread the word!

Your support will go a long way.
We are lean and innovative. Now
in the stage of testing potential
treatments, we have more work to
do than ever! Because we are a
nonprofit organization, **we
depend entirely upon donations
and grants** to fund research,
support, and the general functions
of our team.



In 2023, we funded \$225,000 for important research projects.
Your donation goes a long way.

Spread the word, share the love, and let's make this
Fundraising Campaign a tremendous success! Together, we can
create lasting positive change in our community. Thank you for
your generosity.

[Click here to DONATE using Credit Card or
PayPal](#)



[Point your phone camera at the QR code if you want to pay via your phone.](#)

Zelle: Send the donation to mary@pxe.org to PXE International - this is PXE's Bank of America account.

Check:

PXE International
26400 Woodfield Road #189
Damascus MD 20872-7509

Wire: contact sharon@pxe.org

Website Update - Share Your Story



As part of our changes to the PXE International Website, we are creating a testimonial page for individuals who would like to share their stories. Click the button below to share your story, or reach out to Catt (catt@pxe.org) for more details.

[Share Your Story](#)

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

Our Mission?

Support



A responsive lifeline to affected individuals, providing crucial information to those newly diagnosed.

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 or PayPal:** Secure and convenient.
- **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](#)

[PXE International](#)



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