

## PXE Extended Virtual Conference Series

So far, so good - The PXE Extended Virtual Conference Series has been a huge success! With six presentations already completed, covering topics you requested, and many more to come, April promises an exciting lineup of talks. Whether you join us live or catch up later on our YouTube channel, get ready for more inspiring discussions!

**April 2, 2024** • 2 PM ET • Richard Thompson, PhD, University of Maryland: **New Imaging Technology for Calcification**

[Watch the Recording Here](#)

**April 10, 2024** • 1 PM ET • Qiaoli Li, PhD, Thomas Jefferson University  
**Therapeutics Development for PXE**

[Click Here to Register: Therapeutics Development for PXE](#)

**April 20, 2024** • 11 AM ET • Hubert Chou, MD, Daiichi Sankyo: **PXE Clinical Trials - It Takes a Village**

[Click Here to Register - PXE Clinical Trials - It Takes a Village](#)

**April 20, 2024** • 12 PM ET • Wayne Fuchs, MD, Mount Sinai: **PXE and the Eye**

[Click Here to Register - PXE and the Eye](#)

**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](mailto:mary@pxe.org)). You are all set if you previously paid for the Conference in late 2023 or early 2024!

*Other Upcoming Talks:*

**June 12, 2024** • 7 AM ET • Olivier Vanakker, MD, PhD, Center for Medical Genetics of the Ghent University in Belgium

Click here to register: [Let's Cut to the Chase: is There a Future for Gene Therapy in PXE?](#)

**June 17, 2024** • 11 AM ET • Georges Leftheriotis, MD, PhD, University Medical Center Utrecht-Dutch Expertise Centre for PXE

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

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

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

**October 17, 2024** • 11 AM ET • Viola Pomozi, PhD, Research Centre for Natural Sciences, Hungarian Academy of Sciences Centre of Excellence

Click here to register: [Animals in PXE Research and the Pyrophosphate Story](#)

**November 6, 2024** • 12 PM ET • Flora Szeri, PhD, Research Centre for Natural Sciences, Hungarian Academy of Sciences Centre of Excellence

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

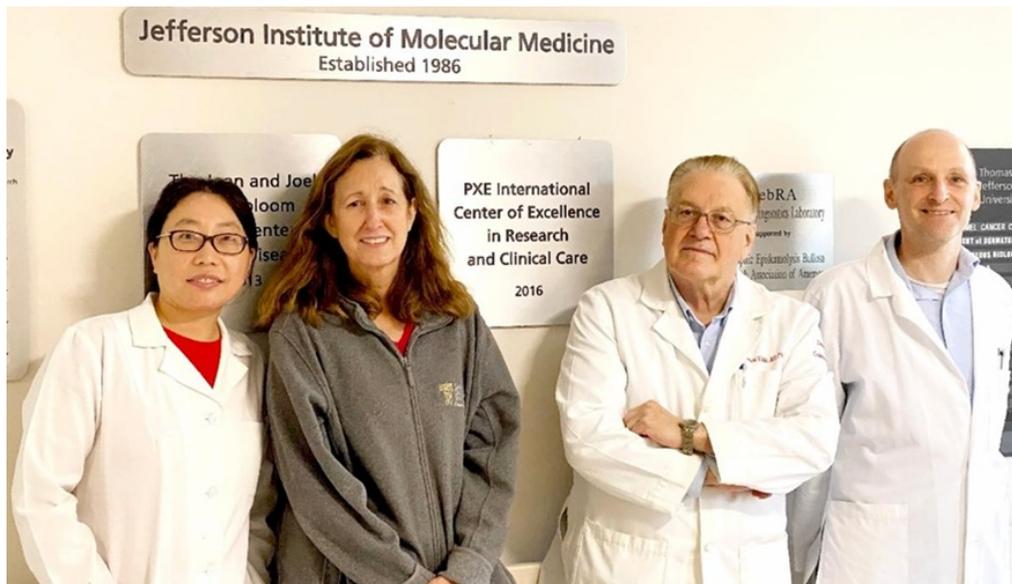
**December 16, 2024** • 11 AM ET • Tamas Aranyi, PhD, Research Centre for Natural Sciences, Hungarian Academy of Sciences Centre of Excellence

Click here to register: [Are All ABCC6 mutations equal?](#)

Pay Here

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## The PXE International Center of Excellence in Research



*Pictured above, starting from the left: Dr. Qiaoli Li, Mary Peckiconis (whom many of you know!), Dr. Jouni Uitto (passed December 2022), and Dr. Koen Van de Wetering*

The PXE International Center of Excellence in Research at Thomas Jefferson University was established in 2016 in collaboration between

Jefferson Dermatology and PXE International. The Center was established with the goal of finding effective therapies for PXE and developing personalized medicine based on specific mutations of the disease. Jefferson is the ideal environment for the Center as we have key players and core facilities necessary to make progress in PXE research.

PXE International Center of Excellence in Research at Thomas Jefferson University is funded by the generous donations we receive from you all! So thank you all who donate!

### **What Do We Focus On?**

Around 12 years ago, it was discovered that many individuals with PXE are missing or have low values of a protein called ABCC6. We know that this protein plays a role in releasing the energy molecule ATP from the liver into the bloodstream. Once the energy from the ATP is used up, it converts to two other molecules; AMP and pyrophosphate (PPi). Since PXEers have no or low levels of ABCC6, they also have no or low levels of PPi. This low PPi in your blood can lead to abnormal mineralization in the skin, eyes, and blood vessels - the common areas of concern for PXE. Our efforts have been dedicated to increasing PPi levels in individuals with PXE.

### **What Are We Up To These Days?**

The lab of Dr. van de Wetering, now part of the Department of Orthopaedic Surgery, possesses various state-of-the-art tools to study bone quality. They have begun studying the long-term effects of PPi treatment on bone quality in PXE mice. Initial findings suggest that while PPi administered as a pill can accumulate in bone tissue, it does not significantly alter bone quality. Additionally, Dr. Li's lab, now part of the Department of Biochemistry and Molecular Biology, is developing gene and enzyme-based therapies in a mouse model of PXE. She will be giving her talk for the extended virtual conference this **Wednesday, April 10, at 1 PM ET**. [Click to register](#)

This ongoing research aims to enhance our understanding of the effectiveness and safety of PPi administration as a treatment for PXE.

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## Donation Matching Campaign RESULTS

A big **THANK YOU** to all of you who donated this year to our fundraiser! We raised over **\$180,000** for PXE!



We want to express our heartfelt thanks to each of you for your generous contributions and participation in our fundraising efforts. Your support and dedication have truly made a difference, and we are grateful for your commitment to our cause! Together, we have achieved great things, and we look forward to continuing our work together in the future. Thank you once again for your kindness and generosity. The support you have given will go a long way.

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, so thank you once again!

If you missed our fundraiser, no worries! You can always donate using the link below!

[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](mailto:mary@pxe.org) to PXE International - this is PXE's Bank of America account.

**Check:**  
PXE International

**Wire:** contact [sharon@pxe.org](mailto: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](mailto: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!

**PXE international**

**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](mailto: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](#)

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