

Vice President of Basic Research and Therapy Development

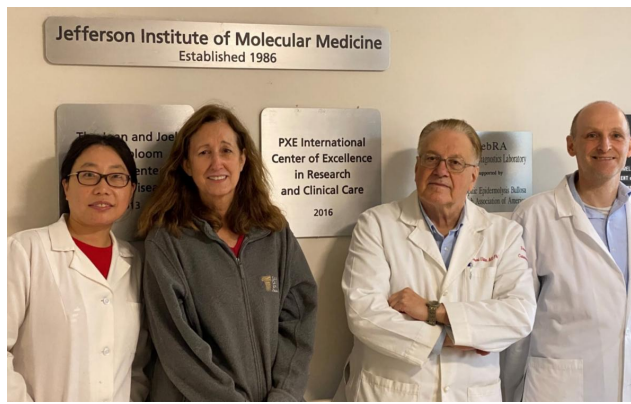
PXE International is excited to announce Jouni Uitto as the Vice President of Basic Research and Therapy Development. Dr. Uitto has conducted research on PXE since 1971, authoring hundreds of peer-reviewed papers, review articles, textbooks and over a thousand presentation abstracts for National and International meetings. His research focuses on the molecular aspects of PXE, and led to the discovery of ABCC6 being the most common gene mutated in PXE. Dr. Uitto has been able to create animal models for PXE which are vital for researching potential treatments. With PXE International, he established the PXE International Center of Excellence in Research and Clinical Care at Thomas Jefferson University. This center is supported by your donations.



He has received many awards like membership into the National Academy of Sciences and Letters of Finland, the Alfred Marchionini Medal in Gold, which is the highest honor in International Dermatology, and the “Giants of Dermatology” award from the American Academy of Dermatology. Dr. Uitto has also been bestowed with the honor of “The Knight of the White Rose, First Order, of the Republic of Finland”, and received the PXE International Award.

“We are so excited to announce this position. It signals that PXE has moved into the age of therapy development. Treatments will be coming, and we are actively engaged in managing all of the different aspects of such exciting endeavors,” said Sharon Terry, CEO. “I have been delighted to work with Jouni since our founding in 1995. His intelligence, drive, and sense of humor have made this an easy collaboration. The community is so fortunate to have this incredibly productive giant in research in our court!”

Please note, this is a volunteer position.



From left to right: Dr. Qiaoli Li, Mary Peckiconis, Dr. Jouni Uitto, Dr. Koen van der Wetering

End of 2021 Fundraising Raffle

We were able to raise a total of \$250,000 in 2021, and in gratitude for those donations, we held a raffle. Three lucky individuals received their prizes and were surprised and thrilled to win. Thank you to all who donated. Kate Williams, the winner of lovely Michael Kors accessories donated by board member Barbara Drewicz, was particularly excited. Kate remarked that they match her fashionista attitude.

Upcoming Webinars

How to join the registry and complete the questionnaires

March 31st, 7 PM ET/4 PM PT

What good news! We have a number of companies and many researchers interested in pseudoxanthoma elasticum (PXE). Now we need to be sure they have everything they need - especially data about you. Come to the webinar and we will show you how to register, find the PXE International surveys, and answer them in a few simple steps. Even if you are registered, you can still attend to connect with other PXEers or ask some questions.

[Click Here to Register](#)

Connecting your EHR to the PXE Registry

April 13th 7 PM ET/4 PM PT

We've got some really good scientists asking if they can see how PXE progresses and what symptoms they should target in trying to find a therapy. This is really terrific, after years of seeking scientists, they are starting to come to us. Let's make sure they find some wonderful data. At this webinar, we will teach everyone to connect their US based EHR - so if you have an electronic health record in the USA, come with your URL and your login. And, it will be a great time to catch up with one another!

[Click Here to Register](#)

Calling all PXEers!

Yes, we are literally calling every person with PXE! Imagine that! We have several volunteers who have stepped up to help call each of you to ask you to PLEAAAASSSSEEEE participate in the **PXE International registry**. Sharing your experience of PXE is the only way we will ever find a treatment for PXE.

It is important that everyone participates. Let us know if you want to volunteer to call your fellow PXEers - our volunteers report some very nice conversations and a feeling of community as a result. To participate as a volunteer contact Catt (catt@pxe.org).

What are the symptoms you experience related to PXE? How do you manage your PXE - treatments, ways of relieving your symptoms?

If you are affected by PXE, tell us your symptoms and treatments in this simple, two question, survey!

[Click for survey link](#)

