

Donate in Honor of Sam's Ride



From the Carolina Coast to Northern Jersey - A Bike Journey Conquered!

In late April, our esteemed advocate and PXE International Board Member, Sam Harper, embarked on a heartfelt bike journey from Wilmington, North Carolina, to Peapack, New Jersey. Joined by his friend Mike, they are showcasing their unwavering commitment to raising awareness for PXE, inspiring us with their

dedication and spirit. With nearly 750 miles under their belt, we can congratulate them on successfully completing this significant leg of their inspiring journey! Each mile pedaled represents a triumph of determination, strength, and resilience. Their dedication is truly admirable, and we eagerly await their next adventure!

We reached out to Sam along the way to ask some questions about his journey!



1. Sam (pictured right), what is your relationship with Mike (pictured left), and how did you meet?

Mike and I met 52 years ago, in high school, and were roommates and best friends. We've remained close friends over the years and spoke of doing rides together, but life intervened until we were close to retirement. At that point (2016), we were both looking after aging parents but committed to a cross-country ride whenever our parents (his father and my mother) passed. They died nine days apart, and a year later, we started riding with the goal of riding in all 50 states before we were too old to ride. (We just completed 27)

2. How many times have you and Mike set out to ride for PXE?

We've done four:

#1: Anacortes, Washington to Bourne, Massachusetts

#2: San Francisco, California to Moab, Utah.

#3: St. Augustine, Florida to Myrtle Beach, South Carolina

#4: Wilmington, North Carolina to Peapack, New Jersey.

3. How many miles have you traveled so far in this leg and how many do you have left?

As of today (May 8), we've completed just around 700 miles and have 42 to go!

4. What route are you taking, and are there any specific landmarks or places you're excited to visit along the way?

On this trip, the only national landmark we visited was Kitty Hawk, on the Outer Banks. ALL our rides tend toward the experience of being out in nature. An organization called Adventure Cycling provides mapping that puts us on THE MOST beautiful areas in each state.

5. How many flat tires have you experienced so far?

Mike and I have ridden roughly 6000 miles together. We've had four flats combined. The touring tires we ride on are reinforced with Kevlar. On the cross-country ride, we only had one flat! None on this trip.

6. Can you share any memorable experiences or encounters you've had so far on your ride?

This one for the PXE community: In a motel in Whitefish, Montana, I had met a blind motel housekeeper, a 30-year-old man who lost his vision at 26 when a car door slammed on his head. I explained that I was slowly losing my vision, and wondered how he managed his life and emotions around vision loss. He said, "You can do anything except drive." Then he leaned forward and poked the handle of his white cane in my chest for emphasis. "Anything." That has been a VERY sustaining message in my life and on my bike trips.

7. What are some of the biggest challenges you've faced, and how have you overcome them?

On these rides, the challenge is finding the meditative place that sustains you through the long hours, the long hills, and exhaustion. The first 5 days of any trip are devoted to physical and mental adjustments. Your body is saying, "Wait, what!? Again?" And your mind is asking over and over again, "Why is this fun??" After day five, those questions get answered by the simple, meditative rhythm of pedaling, moving forward, breathing deeply,

and taking in new places, new people, and beautiful views.



Starting in 2017, Sam and Mike have done numerous rides and **have raised over \$58,000 for PXE.**

Would you like to contribute to their cause? Click the button below to donate.

Sam and Mike are truly an inspiration to us, and we appreciate all of the support they have given us over the years.

[Donate in Honor of Sam's Ride](#)

PXE Virtual Conference

So far, so good - The PXE Extended Virtual Conference Series has been a huge success! With nine presentations already completed, covering topics you requested, and many more to come, June 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!

[Watch the Previous Talks Here](#)

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?](#)

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](#).

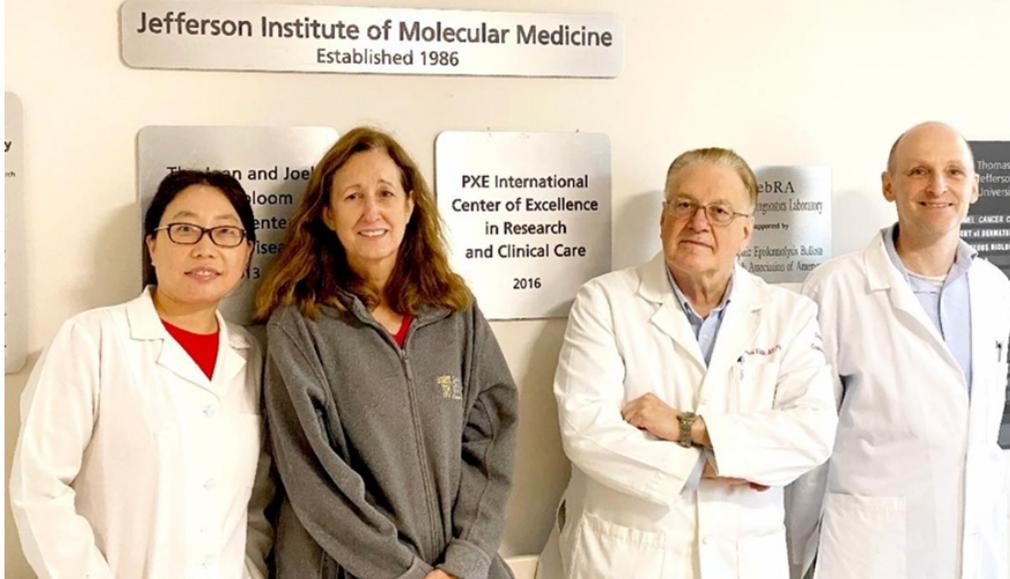
Check:

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!

Pay Here

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. If you missed her talk in our extended virtual conference series you can watch the recording on our YouTube channel:

<https://www.youtube.com/@PXEInter>

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

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!



The infographic is titled "PXE international" and "Help those suffering with Pseudoxanthoma Elasticum (PXE)". It is divided into several sections: "What is PXE?" (describing it as a rare genetic disorder causing severe legal blindness, skin issues, and vascular complications), "Who is PXE International?" (stating they have been the vanguard since 1995, pioneering research, and managing a tissue bank/registry), "Our Mission?" (divided into Support, Educate, and Research), and "How can YOU help?" (listing donation methods like Credit Card, PayPal, Zelle, and checks, along with a QR code and contact information).

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, 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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