

PXE Virtual Conference

So far, so good—the PXE Extended Virtual Conference Series has been a huge success! Nine presentations have already been completed, covering topics you requested, and many more are to come. The second half of the year has an exciting lineup!



Don't miss our next talk on Monday!

June 17, 2024 • 11 AM ET • Georges Leftheriotis, MD, PhD, Côte d'Azur University - University Hospital Nice
Click here to register: [Pyrophosphate and PXE](#)

[Sign Up Here](#)

Upcoming Talks:

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](#)

[Click Here to Watch Previous Talks](#)

**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?

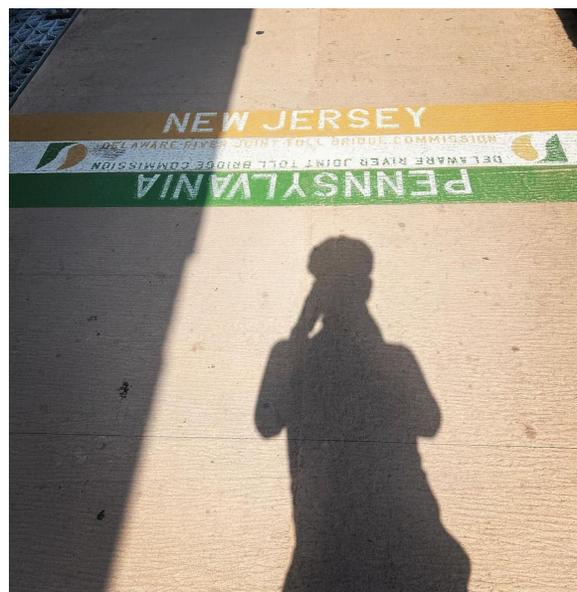
Mike and I have ridden roughly 6000 miles together. We've had four flats combined. The touring tires we ride on are reinforced with Kevlar. On the cross-country ride, we only had one flat! None on this trip.

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

'SENIOR DISCOUNT' - A Bi-Monthly Column About the Ups and Downs of Managing PXE and Aging



Sam has also launched a bi-monthly column he is calling "SENIOR DISCOUNT." The column will feature short essays on the sustaining gifts and comic humiliations of metabolizing and managing PXE and age-related challenges. As you'll see, the introductory column doesn't mention PXE, but he assures us that many that follow will. We hope you'll subscribe (it's free!).

Check Out His Latest Piece Here

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.
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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

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