



PXE International
June 2022
eNewsletter
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GLOBAL PXE MEETING

SAVE THE DATE: NOVEMBER 11TH and 12th

Multiple events, multiple languages, multiple time zones. Interact with all of the PXE researchers in the world, and PXEers from 17 countries. Hear the latest in treatment discovery, and understanding PXE.

Join the Nutrition Study

Nutrition study launched! Don't miss this opportunity to simply eat better. Register today. Watch the [Nutrition Study Webinar](#) for more information. If you want to join the group of individuals offering each other daily/weekly support, email Catt at catt@pxe.org after you have registered. (We cannot see who registers because the system honors your privacy.)

[Join Nutrition Study](#)

[Nutrition Webinar](#)

**Board Member Sam
Harper takes on
Colorado Bicycle Race**



Pictured above: Quinn and Sam Harper

Sam Harper, board member and PXEer, traveled to Durango, Colorado to join his son and college pals for the 50th “Iron Horse Bicycle Classic”. This is a 50-mile trek from Durango to Silverton, Colorado. As he described it his “ancient legs and ailing eyes” got him through the 5,000 feet elevation rise to 10,900 feet so that he was able to reach the long, thrilling downhill ride into Silverton. Sam and his riding partner, Mike Romanow, will hit the road again this fall when they bike from New Jersey to Florida. Sam requests that you donate to [PXE International](#) in support of his efforts. His message to everyone: “Ride on, PXEers!”

[Donate to PXE International](#)

Ready? Set? Go! Tell us what matters to you!

If you are one of the 212 people who shared your experience of PXE symptoms and treatments, thank you. Now we prioritize. What should we focus on? What research needs to be done? What treatments work? Tell us today - it will only take a few minutes and you will set the course of activity for PXE International and the PXE Research Consortium.

[Symptom Survey](#)

PXEer Highlight

Tell us about your PXE experience. Support other PXEers: share your story. It is a great way to connect and strengthen the already tight-knit PXE community. To share your story in an upcoming newsletter, email Catt at catt@pxe.org or Mary at mary@pxe.org. We will set up a time to chat with you about your experiences.

Contact Us

We love to hear from everyone and help you in any way we can! Email us at info@pxe.org. Staff read emails daily. Or call us at **202.362.9599 x208**. If it is outside of office hours, leave a message and we will get back to you as soon as we can.

