



**PXE International**  
**July 2022**  
**eNewsletter**  
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# **GLOBAL PXE MEETING**

*SAVE THE DATE: NOVEMBER 11TH and 12th*

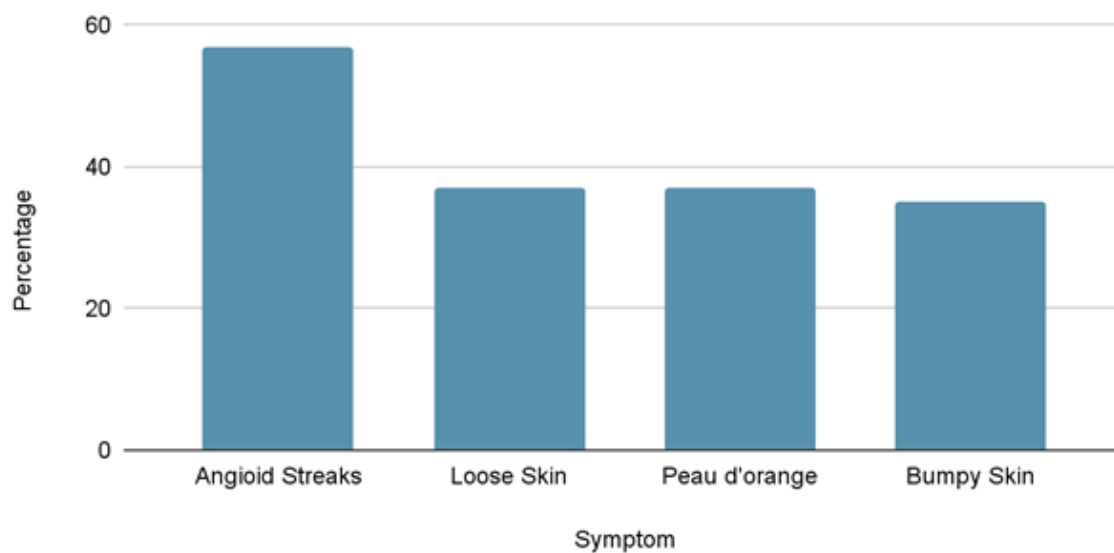
Multiple events, multiple languages, multiple time zones. Interact with all of the PXE researchers in the world, and PXEers from 17 countries. Hear the latest in treatment discovery, and understanding PXE.

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## **Your Symptoms: it is time to prioritize**

Thank you!!! 155 of you answered the Symptom and Treatment Survey. This resulted in a long list of the top symptoms PXEers experience.

## Most Experienced Symptoms of Symptom and Treatment Survey Takers



Now we need to prioritize. We have a list of 80 symptoms, now tell us which ones are most important to you. It will take you five minutes and you will change the course of PXE research and services.

[Tell us Your Priorities](#)

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## Your Treatments: it is time to prioritize

The top three treatments reported by you are (drum roll): regular ophthalmologist visits, walking/regular exercise, and Amsler Grid usage. Is that true for you? Tell us your top five here:

[Treatment Prioritization](#)

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## Kidney Stones and PXE

For years, some of you told us that you thought kidney stones were related to pseudoxanthoma elasticum (PXE). So we surveyed you last year. As usual, we had to wait until enough of you volunteered, but once you did, we forged ahead.

Last year, we teamed up with researchers from Thomas Jefferson University to analyze the data you gave us. The answer: Yes, kidney stones are more common in people affected by PXE than in the general population. They also seem to affect people earlier (younger) than the general population. To read a summary of the study and how you can prevent kidney stones, read the study summary by clicking the button below. And, thanks to all who participated in the study.

[Kidney Stone Study Results](#)

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## Donate While You Shop!

Are you an Amazon shopper? If so, we found an easy way for you to donate to PXE International. By using [Smile.Amazon.com](https://www.smile.amazon.com), you can shop all of the products that are available on Amazon and they donate a percentage of your purchase to PXE International.

It can be done in four easy steps:

1. Go to [Smile.Amazon.com](https://www.smile.amazon.com).
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Remember, each time you shop you must use [Smile.Amazon.com](https://www.smile.amazon.com) in order for your purchase to generate the donation to PXE International.

[Smile.Amazon.com](https://www.smile.amazon.com)

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## Catch Up on Past Research

Get ready for this year's PXEer meeting by watching all the past videos. You can view them on our [YouTube Channel](#). You will find videos from past conferences, research presentations, and old webinars. Watch them all and get yourself up to speed with PXE research!

[2020 Conference Playlist](#)

[2021 Conference Playlist](#)

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## Contact Us

We love to hear from everyone and help you in any way we can! Email us at [info@pxe.org](mailto: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.

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