



PXEnews
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Sneak Preview Webinar

Early results of the PXE surveys

November 11, 2023

9 AM PT/12 PM ET/6 PM CET

3 hours

Free Event

Join this webinar where we will discuss the initial results of surveys completed by hundreds of individuals with PXE. This will help to enhance your understanding of the disease and provide valuable insights on how to manage it. Furthermore, we will also be sharing our plans for future research.

[**Register Here**](#)

Natural History Study Ongoing

The Natural History Study is currently underway and we have received responses from many of you. However, there are still many who haven't participated yet. Our data shows that only 25% of you have completed any of the surveys launched so far. Don't be left out! We need participation from each one of you to get a complete understanding of PXE's diverse impact on individuals. We urge you to take part and not rely on your fellow PXEers. Your unique experiences matter and will give us a full picture of the condition. In case you need assistance, Mary (mary@pxe.org) will be happy to help you.

You are an important piece of the puzzle...
Answer the surveys today!



This is a puzzle -
you are an
important piece
of this puzzle!

Check to see if you have answered all of the surveys!

Neurological Survey
Survey complete

Tell us about your potential neurological symptoms of PXE, whether you have them or not.

Status: **Success**

Thank you for contributing your Survey data to this study.

Completed on 9/15/23

Diagnostic Journey Survey
Survey complete

Tell us about how you received your PXE diagnosis, all of the doctor visits, tests, etc.

Status: **Success**

Thank you for contributing your Survey data to this study.

Completed on 9/15/23

Skin Symptom and Treatment Survey
Survey complete

Tell us all about your skin symptoms and treatments related to PXE, even if you have none!

Status: **Success**

Thank you for contributing your Survey data to this study.

Completed on 9/15/23

Eye Symptom Survey
Survey complete

Tell us about your eye symptoms related to PXE, even if you have none!

Status: **Success**

Thank you for contributing your Survey data to this study.

Completed on 9/15/23

Eye Treatment Survey
Survey complete

Tell us about the eye treatments you had related to PXE!

Status: **Success**

Thank you for contributing your Survey data to this study.

Completed on 9/15/23

Gastrointestinal Survey
Survey complete

Tell us about your gastrointestinal signs and symptoms of PXE, including whether or not you have any?

Status: **Success**

Thank you for contributing your Survey data to this study.

Completed on 9/15/23

Peripheral Vascular Survey
Survey complete

A general health survey to inquire into additional risk factors for PXE.

Status: **Success**

Thank you for contributing your Survey data to this study.

Completed on 10/28/22

Click the button below for the direct URL for your registration and the various studies!

[Natural History Study](#)

If you have any problems at all please reach out to Mary,
mary@pxe.org

My PXE Story

A fellow individual with PXE has stepped forward to share their personal story with you. Their experience has been eloquently written in the hopes that no one out there feels isolated in their own journey with PXE. Click the button below to read this inspiring account

My PXE Story

The PXE Virtual Global Meeting is postponed until the new year

Stay tuned for updates on the new dates. In the meantime, you can view last year's sessions. If you have registered and paid, Mary will be in touch with you.

Past Meeting Recordings

Website Update - Share Your Story

As part of our changes to the PXE International Website, we are creating a testimonial page for individuals who would like to share their stories. Click the button below to share or story, or reach out to Catt (catt@pxe.org) for more details.

Share Your Story

Contact Us

*We love to hear from everyone and help you however 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 possible.*

[PXE International](#)



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