



**PXEnews**  
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**PXE Global Meeting: November 10th-12th**

Discover the latest in PXE research and meet fellow PXEers! Registration is now open. Cost is \$25 USD (contact us for scholarship help if you need it).

Past participants have been very satisfied with the meeting content. They have left the following messages with us:

*"I am always happy to hear of research projects that give us hope."  
"It is always nice to meet people going through the same thing as me."  
'Always a great meeting!'"*

Register below! We hope to see everyone there and stay tuned for the agenda.

[PXE Global Meeting Registration](#)

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**DS1211 Clinical Trial Recruitment Closing**

Thank you to everyone who went through the pre-screening process for the DS1211 Clinical Trial. We finished the recruitment process. This momentous occasion would not be possible without all of you. If you missed your chance for this phase of the study, you can apply to participate in Phase 3 by joining the PXE registry. But meanwhile, stay tuned for the BIGGEST STUDY EVER!!! Register now to be ready to participate.

[PXE Registry](#)

[Study Registration](#)

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# New Drug for Dry Macular Degeneration

The U.S. Food and Drug Administration (FDA) recently approved the first medication to treat geographic atrophy. Pegcetacoplan (SYOFOVRE™) is a monthly, or every other month, intraocular injection that slows the progression of the disease. We do not know if this will work for people with PXE who have what is sometimes called "dry macular degeneration" or "geographic atrophy". If you have been told the antiangiogenesis injections will not work because you do not have retinal bleeds, then ask if Syfovre would work for you.

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## Connect your EHR

A great way to share your data is by connecting your electronic health record to the PXE registry. This allows us to discover more about PXE: how does it progress, what organs are affected, and how can we slow it down. Click the link below for detailed instructions. Reach out to Catt ([catt@pxe.org](mailto:catt@pxe.org)) or Mary ([Mary@pxe.org](mailto:Mary@pxe.org)) if you need help.

How do I connect my EHR?

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## 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. If you would like to take part in this, please reach out to Catt ([catt@pxe.org](mailto:catt@pxe.org)) for more details.

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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.

[PXE International](#)



PXE International | 26400 Woodfield Road #189, Damascus, MD 20872

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