
The Race is Nearing the End!



We are in the midst of a very long race (the "lots of surveys" phase)!

All 5000 of us and our beloved friends and families are running a 30-year race course. We have 28 years behind us, and in the next two (or three) years, we will reach the finish line. All of us need to run these last few miles. We have you and 4,999 more people to run this race. This might sound like a lot, but the FDA is used to seeing tens of thousands of people in a study. Not so for rare diseases. Everyone's participation is critical.

LET'S GO!

The FDA needs information from you so that it can consider proposed treatments. The FDA considers the signs and symptoms of a disease, your experience with it.

It is up to us to collect this data for them to make decisions about what can be approved for use as a PXE treatment. Time for **EVERYONE** to report what they are experiencing.

Starting on August 1 and continuing for nine weeks, you will receive a notice of a new survey asking about a specific symptom or aspect of PXE. Answer every survey even if you do not have the specific symptom addressed in the

survey.

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



You COUNT! Each survey will only take a few minutes to complete. Log into your [PXE registry account](#) now to be sure you completed the [General PXE Study](#), is your entry to the following surveys!!

Here is the week-by-week line-up:

August 1st - Vascular Survey

September 5th - Diagnostic Journey Survey

August 8th - Gastrointestinal Survey

September 12th - Neurological Survey

August 15th - Burden of Disease Survey

September 19th - Cardiac Survey

August 22nd - Eye Symptom and Treatment Surveys

September 26th- Women's Health Survey

August 29th - Skin Symptom and Treatment Survey

October 3rd - Tobacco Use Survey

Don't worry if you miss a week – we will keep the surveys open until everyone responds. If you need help creating a registry account or have trouble logging in, contact Catt, who will help you (catt@pxe.org; 202.362.9599 x235).

Vascular Survey

PXE Global Meeting: November 10th-12th

Discover the latest in PXE research and meet fellow PXEers! Registration is open. We will have researchers present their latest findings, you will be able to speak with other PXEers in small groups, and you can ask all your questions. The cost is \$25 USD. If you need a scholarship, contact Mary mary@pxe.org. If you missed previous meetings, you can watch them anytime on the PXE International YouTube channel.

[PXE Global Meeting Registration](#)

[Past Global Meeting Playlists](#)

DS1211 Clinical Trial Recruitment Completed!!

Thank you to everyone who went through the pre-screening process for the DS1211 Clinical Trial. Recruitment is finished. This momentous occasion would not be possible without all of you.

If you missed your chance for this phase of the study, JOIN THE PXE REGISTRY so that you can participate in Phase 3.

[PXE Registry](#)

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 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.

[PXE International](#)



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

[Unsubscribe sterry@pxe.org](#)

[Update Profile](#) | [Constant Contact Data Notice](#)

Sent by sterry@pxe.org powered by



Try email marketing for free today!