PXEnews
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Do you feel burdened by PXE? We need to hear from you!

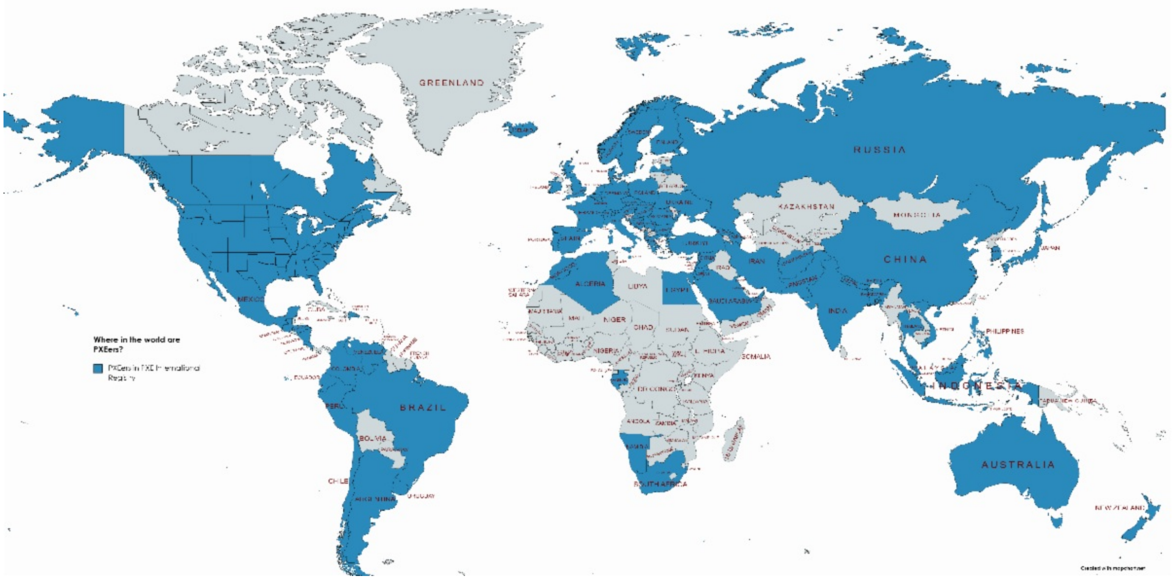
I am going to write something I have longed to write for 28 years: **We are on the verge of a treatment for PXE.** I am in tears at that thought.

BUT, the regulatory agencies that approve drugs - FDA and EMA - need to understand the burden PXE is to you! Without your voice, we will not be able to go forward. We need everyone to fill out the survey describing how PXE burdens you. How fast can you do this? Would you be able to do this before April 15? Mark this on your to-do list, put a post-it note on your mirror, and tell your family members to remind you!

We've come a long way - we have possible treatments!!! Now we need PXEers to step up - can you do it? Thank you!

Burden of Disease Study

Where in the World are you?



We often hear how isolated PXEers feel because they do not know another individual who has PXE near them. We want to show you how NOT alone you are. PXEers live in every country/state/province colored in blue. These are only people who registered with us. It is highly likely that there are PXEers in every country.

If you are interested in meeting other PXEers, register using the button below.

Where in the world are you?

New Look for PXE International Website

We are creating a new look for the PXE International Website! While this happens you may face some technical difficulties navigating the site. Let Mary know (Mary@pxe.org) if you have any issues or are looking for something in particular, and if you have anything you would like to see added or have any suggestions to make the website better.

2023 Epidemiological Survey

The 2023 Epidemiological Survey Campaign is expected to launch this month, and we need everyone to participate. They will be launched periodically so make sure to pace yourself to keep up. The clinical trials are important, but these surveys are vital to the development of even more potential treatment options.

Take the current surveys to make sure you complete them all.

2023 Survey Campaign Registration

My Journey of PXE

Cheryl Grandon, fellow PXEer, found solace in stories shared here and wanted to share her own story in the hopes that more individuals find company. She speaks of the diagnostic journey she and her family experienced. We hope her story speaks to you. Click the button below to read her story.

One new addition we would like to add to the website is PXEer testimonials. If you are interested in sharing your story, reach out to Catt (catt@pxe.org) to learn how.

My Journey with PXE

iGive Takeover

Unfortunately, the AmazonSmile program has been shutdown, but iGive is a great alternative! You can get a browser extension to make it that much easier to use. Here are instructions to access the browser extension. If you need help reach out to Catt (catt@pxe.org).

Step 1: Open Google Chrome and go to https://www.iGive.com/WaHyo5Q and sign up for an account with an email and password.

Step 2: Click the “Install Now” button found in the middle of the page. This will take you to the Chrome Web store.

Step 3: In the Chrome Web Store, click the blue “Add to Chrome” button found on the right side of the page.

Step 4: If a pop-up window appears, click “Add extension”.

Now every time you shop at a store affiliated with iGive, a percentage of your purchase will be donated to PXE International. This does not cost you any extra money. You can search for stores that donate through iGive here: https://www.igive.com/isearch/search.cfm

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