



PXE International
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eNewsletter
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Do you have a question about your life, symptoms, and PXE that you want answered?

We cannot answer your question without gathering the experience of thousands of PXEers. Your participation in the PXE International patient registry is the most effective way to help yourself and others with PXE.

So far only 620 PXEers have shared their experiences. This means that only 18% of potential PXEers have registered. When asked a question today, we can only base the answer on a narrow sliver of people's experiences and data.

Click the button below to register.

Already registered? Click the button to answer new questionnaires and connect your electronic health records.

[Click here to share your experience](#)

2021 ASHG Advocacy Award



We are excited to announce that our fearless leader, Sharon Terry, will be honored in October at the American Society of Human Genetics meeting for her work in Advocacy.

She is recognized for her major contributions as an exemplary advocate at the Genetic Alliance on behalf of people with genetic diseases. Her work has improved access to information and representation for individuals, families, and communities from around the world. She cofounded PXE International, a research advocacy organization for the genetic condition pseudoxanthoma elasticum (PXE), in response to the diagnosis of PXE in her two children in 1994.



In addition, she established the first ever lay managed biobank, registry, IRB, and research consortium, and as a result co-discovered the ABCC6 gene and has initiated clinical trials. For more than a decade, she led the coalition that was instrumental in getting the Genetic Information Nondiscrimination Act passed. Her [TED talk](#) has been viewed more than a million times.

The ASHG Advocacy Award recognizes individuals or groups who have exhibited excellence and achievement in applications of human genetics for the common good.

Click the button below to read more about Sharon and this prestigious award.

[2021 Advocacy Award](#)

Reconstructive Surgery Bulletin

We've received a lot of questions lately about reconstructive surgery. We have a resource with information about reconstructive surgery that covers everything from safety and efficacy to what to do if you need insurance coverage. If you can't find the information you are looking for in this bulletin, please send your question(s) to [Tamara Wurst](#).

You can find the Reconstructive Surgery Bulletin and all other bulletins on the website by clicking the button below.

[PXE Bulletins](#)

Mindfulness Through Gestalt Awareness Practice

In response to the stress many PXEers reported feeling because of the pandemic, Sharon offered three online experiences of [Gestalt Awareness Practice](#), something she has studied for five years. In these short practice experiences, Sharon helps open a space for you to feel support moment to moment. She offers tools to help ground you, even in a time of challenge. This practice can lead to self-support and openness to what is. Recordings of these guided practices for PXEers and others are [available here](#).

[Listen to the Guided Meditations](#)