



PXE International
November 2021
eNewsletter
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GI ING TUESDAY

A year ago, we were all in such dire straits with the pandemic that we did not want to bother you with a donation request for PXE International. 2020 was also our 25th anniversary. It was hardly a year to celebrate. We are grateful for all of the families that have come to us over the years and make this big family what it is today. We are asking you to support our work, and hope that in a few years we will have achieved our mission. We are working hard to make it so. Walk, nay, run with us to the finish line!

If you donate before December 31st, you will be entered into a raffle to win one of these many items:

- A Michael Kors purse;
- Children's books by author, board member, and PXEer Jessica Harper;
- Biking jerseys;
- Greeting cards hand drawn by kids with PXE (20 years ago).

We will mail raffle items by January 31, 2022.

To donate:

Credit card or Paypal click the link below

Check:

PXE International
26400 Woodfield Rd #189
Damascus MD 20872

Thank you very much and have a wonderful holiday season. We cannot tell you how grateful we are for your support.

[Donate to PXE International](#)

PXE Global Virtual Conference Recordings

Thank you to all who attended the PXE International Conference. It was a pleasure to be with all of you for the weekend!

Whether you were not able to join us live, would like to rewatch, or want to share with others, we hope you find these recordings supportive and helpful. Click the button below to see all the recordings from the weekend.

[2021 PXE Conference Recordings](#)

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

Let's answer your questions!! To do that, we will capture the experience of thousands of PXEers. Your participation in the PXE International registry is the most effective way to help yourself and others with PXE.

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](#)

COVID-19 Vaccines Informational Webinar

We've received many questions about PXE and the COVID-19 vaccines and are grateful to Dr. Francis Collins for taking the time to talk to the rare disease community and address some of your questions.

In this webinar, Francis Collins, Director of the National Institutes of Health, shared with us why it is critical that individuals living with chronic diseases and conditions receive the coronavirus vaccine. He described the scientific evidence for the safety and efficacy of the vaccine and why it is important to get vaccinated when it is your turn. Click below to watch a recording of the webinar.

[COVID Vaccines Informational Webinar](#)