



**PXE International
January 2021
eNewsletter
Volume 14 No. 1**

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Happy New Year!

We hope you had a wonderful holiday season and a happy and safe new year. Our deep gratitude to all of you who shared your data through the secure PXE International Registry portal - you are what it takes to make a difference. Whether for PXE, COVID, or general health studies, your time and generosity is put to good use.

If you have not yet registered and would like to join the registry, there is still time to sign up. Or if you already registered and would like to check for new surveys, click one of the buttons below.

Anyone Can Join!

Please click a button of your choice below and share your health information. We have PXE studies (for those affected by PXE), general health studies (even if you do not have PXE), and a few COVID studies (whether you have COVID or not) for your participation. You can also share your electronic health record and any genomic/genetic information you have. This will greatly help PXE research and ALL scientists.

We've partnered with LunaDNA so that your information is safe and secure. It will take you about 15 minutes (or less) to register in the secure portal. Choose the button that interests you most, and give us 15 minutes of your time.

**PXE: I have
PXE**

**COVID: I have had or haven't had
COVID**

WOMEN'S HEALTH: We should set

GENERAL: Happy to help in general

If you are affected by PXE, we want you to know that we will use this platform for all of our research and clinical studies - we are enrolling some now. We need you to sign up today! Choose the PXE button.

We're here to support you!

We hosted a webinar to introduce the new system, including a walk through of the sign up process. You can watch that webinar on the [PXE International YouTube Channel](#).

Please [reach out](#) if you have any questions or need any help at all!

PXE and COVID-19

There are a lot of questions about the effects of coronavirus and COVID-19 on people with PXE and also the COVID-19 vaccines. As far as we know, the corona virus and COVID-19 don't affect people with PXE any differently than people without PXE. Therefore, you should be taking all of the precautions recommended by the CDC or your country's public health department. This is not a political issue, it is a health issue, so you need to protect yourself and your loved ones. At the time of this newsletter, there are several more seemingly virulent strains emerging. You should be wearing masks and staying 6 feet away from others. For more information see you country's health department website, such as [CDC](#) for the United States and [ECDC](#) for Europe.

As far as the vaccine, consult your state or country's health department for the stage or tier relative to your health condition and age. If you're in the US, you can find this information on the CDC website [here](#). It is critical, given the fact that we are a community concerned about health, that we set an example and get vaccinated as soon as a vaccine is available to you.

Thanks for doing your part.

PXE Bulletins

In response to all of your requests, we have revised all of the PXE Bulletins in the past month and have made it much easier for you to access them. Click the button bellow.

[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 about 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](#).

In addition, Sharon is offering a weekend retreat called Introduction to Gestalt Awareness Practice. She is offering a 10% discount to any PXEer or their supporting friends and family. For more information click [here](#).

[Listen to the Guided Meditations](#)

[PXE International](#)

