

PXE International September 2021 eNewsletter Volume 14 No. 9



PXE Global Virtual Conference - encore!

When our conferences were in person, we held them every other year because they took so much time and money! Last year we went virtual of course, and the conference was fabulous. People attended from several dozen countries, it was easy for everyone, and a joy to be together - even virtually!

We have decided to hold the meeting again this year - and annually for the forseeable future! The conference will be held November 5 to 7, 2021 and you can view the schedule on the website here.

We will have timezone specific schedules, clinicians and researchers from around the world - so that all timezones will be able to participate.

To register for the conference, click the button below!

2021 PXE Conference Registration

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

Sharon Terry in a <u>podcas</u>t about PXE and beyond - listen to how PXE International has cut the edge in research. Make sure you join the effort.

Listen to the podcast on PXE's cutting edge model

Eating citrus might be good for people with PXE!

During a study on another condition, Koen van de Wetering, a PXE International funded researcher, discovered that citrate, present in citrus fruit and a common food additive, might help with decreasing calcification. Eat oranges, because they are good for you anyway, and maybe that will help decrease calcification. We plan to study this further and will keep you informed. Make sure you are registered in the registry above, so we can update you as we go.

Follow the link below to read about this recent discovery.

Research Summary

Clinical Trials Bulletin

What is a clinical trial? Why does PXE International keep talking about them? We have a clear description of clinical trials that we want to share with you.

You can find the Clinical Trials 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 <u>Gestalt Awareness</u> <u>Practice</u>, 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 <u>available here</u>. These are nonsectarian, and do not refer to any religious or spiritual tradition.

In addition, Sharon is offering a retreat called Introduction to Gestalt Awareness Practice, free to any PXEer or their supporting friends and family. Right now there are 2 offerings in October and November. They are scheduled to be convenient for either US or European time zones, but all are welcome. Click the dates below for more information:

Offering 1: October 16,19, and 21 (convenient for US time zones)

Offering 2: October 30, November 2 & 4 (convenient for European time zones)

Listen to the Guided Meditations

PXE International

