

PXE International March 2021 eNewsletter Volume 14 No. 3

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.

Watch the webinar

Meet a PXE Researcher

Dr. Wayne Fuchs, MD is a Clinical Professor of Ophthalmology at Mount Sinai Hospital. He limits his private practice in New York City to diseases of the retina, with a special interest in PXE. He graduated from New York University Magna Cum laude and was elected to Phi Beta Kappa in 1975. Dr. Fuchs earned his M.D. from the Mount Sinai School of Medicine in 1979, when he was elected vice-president of the honors medical society.



After completing a medical internship at The University of Florida Affiliated Hospitals, he studied ophthalmology at the Mount Sinai Medical Center. It was during his vitreo-retinal fellowship at The New York Hospital-Cornell Medical Center in 1983 that his interest in PXE was born.

Dr. Fuchs has been a long-time friend of PXE International and currently serves on its Medical Advisory Board. He continues to be enthusiastically involved in

teaching and clinical research, most recently taking time to log-on with us to give a presentation on PXE and the Eye, including what is known about treatments, at the PXE International Conference 2020 Virtual Event. <u>This presentation is now</u> <u>available online!</u>

Participate in the registry

Your participation in the PXE International patient registry is the most effective way to help yourself and others with PXE. Sign up with our registry to see all the opportunities to share your experiences with pseudoxanthoma elasticum.

Click here to participate in the registry

General Bulletin

We updated the general bulletin, a resource with general information about PXE. If you have any questions about PXE, this is the first place to look. You can find the general 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 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 <u>available here</u>.

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. Right now there are 2 weekend offerings in May. Click the dates below for more information:

May 15 & 16 - 8:00 to 15:00 EDT/14:00 to 21:00 CEST May 22 & 23 - 10:00 to 17:00 PDT/13:00 to 20:00 EDT

Listen to the Guided Meditations

