



PXE International
May 2021
eNewsletter
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GLOBAL PX E MEETING

SAVE THE DATE: NOVEMBER 5TH-7TH

Multiple events, multiple languages, multiple time zones. Interact with all of the PXE researchers in the world, and PXEers from 17 countries. Hear the latest in treatment discovery, and understanding PXE.

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

Well, we cannot answer it 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 416 PXEers have shared their experiences. This means that only 12% 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**](#)

Meet a PXE Researcher

We are delighted to showcase our long time friend and advisor, Mark Lebwohl, MD. Dr. Lebwohl graduated summa cum laude from Columbia College in 1974 and graduated from Harvard Medical School in 1978. He then completed residencies in both internal medicine and dermatology at the Icahn School of Medicine at Mount Sinai, and has been practicing dermatology there since 1983.



Currently, Dr. Lebwohl is the Dean of Clinical Therapeutics at the Kimberly and Eric J. Waldman Department of Dermatology at Mount Sinai. He has served as president of the New York Dermatological Society, the Manhattan Dermatologic Society, and the New York State Society of Dermatology, and as chairman of the Dermatology Section of the New York Academy of Medicine. In 2015-16 he served as President of the American Academy of Dermatology.

Dr. Lebwohl has chaired numerous symposia and has written, edited, or co-edited several books, including the first atlas devoted entirely to cutaneous manifestations of systemic disease, and the leading book on dermatologic therapy, Treatment of Skin Disease. He has authored or co-authored more than 600 peer-reviewed publications, 21 books and numerous book chapters, invited articles, and other publications.

Dr. Lebwohl has worked with PXE International for 25 years and is actively involved in clinical trials of many new dermatologic treatments. He has spoken at almost all of our conferences. PXEers and their families tell us often how delighted they are to have Dr. Lebwohl as their clinician. We are grateful for all his years of service to the PXE community.

PXE and Skin Bulletin

We updated the Skin Bulletin, a resource with information about how PXE affects the skin. If you have any questions about anything related to skin, this is the first place to look. 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 Skin 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 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 retreat called Introduction to Gestalt Awareness Practice June 12-17. She is offering a 10% discount to any PXEer or their supporting friends and family. [Click here for more information](#).

[Listen to the Guided Meditations](#)

[PXE International](#)

