

June 2021 eNewsletter Volume 14 No. 6



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 502 PXEers have shared their experiences. This means that only 15% 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

Laser Treatment Webinar

Dr. Eric Bernstein

June 23 5pm EDT

Dr. Eric Bernstein is joining us to share information about laser treatment and PXE. Register in advance for this free webinar using the button below and email <u>Tamara Wurst</u> if you have any questions.

Register for this FREE webinar

About Dr. Eric Bernstein

Eric F. Bernstein, MD, MSE earned a Bachelor of Science degree from Duke University in 1981 graduating Phi Beta Kappa, *summa cum laude* with distinction in his major. He then earned his degree in medicine from Yale University School of Medicine in 1986 where he served as Banner Bearer at commencement exercises and class president. He



completed a fellowship at the NCI at NIH, investigating PDT and cytokines for wound healing. Dr. Bernstein served as Associate Professor in the Department of Dermatology and Cutaneous Biology at Jefferson Medical College where he directed a photobiology laboratory and founded the Laser Surgery Center. Dr. Bernstein's research focused on the molecular causes of skin photoaging and its repair. He also earned an M.S.E. in Management of Technology from the School of Engineering and Applied Science at the University of Pennsylvania, co-administered by the Wharton School.

Dr. Bernstein founded DakDak Photoaging Technologies receiving an SBIR grant from NIH to commercialize a molecular model of skin photoaging. This company was sold to Charles River Laboratories (CRL). Dr. Bernstein is also founder/director of the Main Line Center for Laser Surgery. Dr. Bernstein served as president of the ASLMS, and serves on numerous laser company scientific advisory boards, and was a Director for Candela Corporation. Dr. Bernstein has also served as a director for Once Again Me, Inc., Intellectual Light, Inc., Chairman of Freedom-2 Inc., and co-founded American Medical Media, Inc (AMM). which was sold to InterActive Corp. (IAC). Call Compass, LLC was spun out of AMM and Dr. Bernstein now serves as CEO. Dr. Bernstein founded and

recently sold Alethia, LLC, a skincare company with the associated IP to a privately held aesthetic company.

Dr. Bernstein currently serves as volunteer faculty at the University of Pennsylvania and Temple University in the Department of Dermatology as a Clinical Professor. He has authored over 100 peer-reviewed articles and over 15 U.S. and international patents in addition to giving more than 400 presentations at scientific meetings.

Disability Bulletin

We wrote a Disability Bulletin, a resource with information about how to get support if your PXE is affecting your work. If you can't find the information you are looking for in this bulletin, please send your question(s) to <u>Tamara Wurst</u>.

You can find the Disability 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>.

In addition, Sharon is offering a 3 day retreat called Introduction to Gestalt Awareness Practice June 19, 22, and 24. 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

