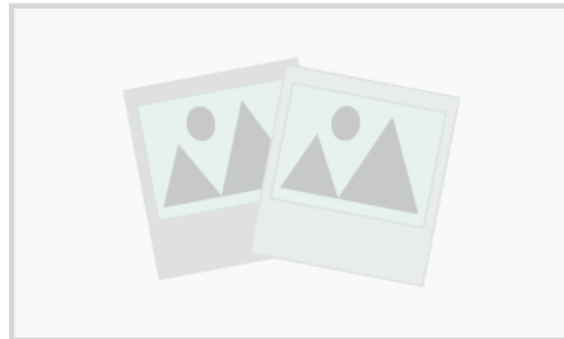




PXE International
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eNewsletter
Volume 13 No. 12



In this Season of Giving: Share your Health Information

It's been a tough year in so many ways. We are not asking you for money this year. We ask you to share your health data - it is the greatest gift you can give. Whether you have PXE or not, we are living in a time when health data is our most valuable offering.

Anyone Can Join!

In watching the development of the COVID vaccines, we know that volunteers are critical to this and every treatment ever made. Not everyone can join a clinical trial, but everyone can share their health data. You have seen the wide variation in who gets sick and who recovers from COVID, understanding why this happens is so important, and your health data can help.

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, 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 scientists 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. Give the most generous gift this season, and be part of the international quest for better health.

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
priorities**

**GENERAL: Happy to help in
general**

If you or a loved one is affected by PXE, we want you to know that we will use this platform for all of our research and clinical studies. We need you to sign up today! Choose the PXE button.

We're here to support you!

Last month we hosted a webinar to introduce the new system, including a walk through of the sign up process. If you could not attend, 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!

Congratulations to Jouni Uitto, MD, PhD

Bravo to Dr. Jouni Uitto, the Chair of the Department of Dermatology and Cutaneous Biology at Thomas Jefferson University. We have worked very closely with Jouni for 25 years, including establishing the PXE International Center of Excellence in Research and Clinical Care at Jefferson.

Jouni received well-deserved accolades for his work in dermatology and the impact he has had on families with rare skin diseases. Jouni was one of six people to receive the [Dermatology Times' 2020 Giants of Dermatology Award](#) this year! This award recognizes his many contributions to the field of Dermatology.



Jouni was also knighted this past weekend for his contributions to medicine and

science, receiving the honor of Knight of the White Rose, First Order, of the Republic of Finland.

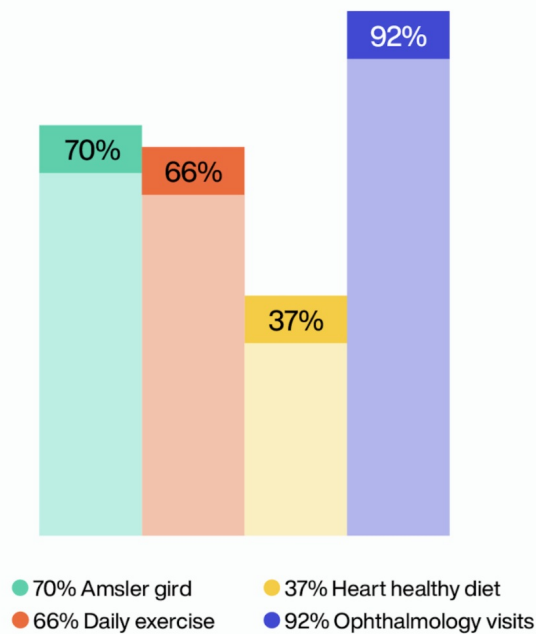
We are honored to have this white rose on our team. Jouni, we are grateful beyond words!

Data from a recent registry study

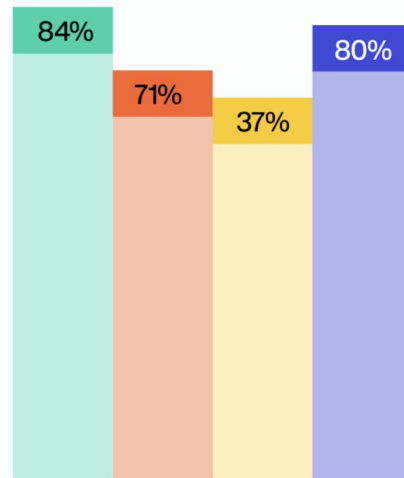
Thank you for participating in the most recent study on managing PXE! Here are some preliminary results from that study. If you feel these results don't reflect your needs and concerns, make sure you register and reply to the survey!

Go here: <http://www.pxe.org/registry>

Which methods do PXEs use to manage PXE?

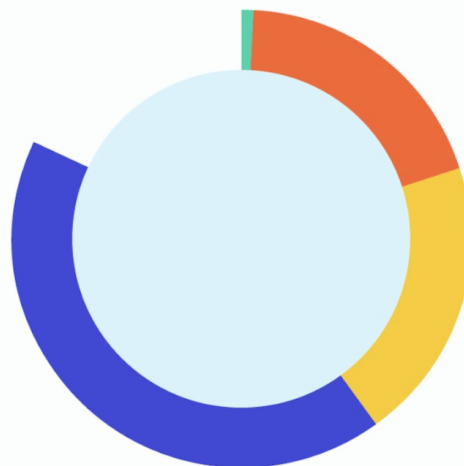


What % of PXEs, who have used these methods, deemed them effective?



- 84% Amsler grid
- 71% Daily exercise
- 66% Heart healthy diet
- 80% Ophthalmology visits

Which area of focus would PXEs most like to investigate further?



- 1% Amsler grid
- 19% Daily exercise
- 20% Heart healthy diet
- 42% Ophthalmology visits
- 18% Other

Staff Updates

Introducing you to Haviland Forrister and Lyle Wohlfarth

Haviland is a data analyst at Fannie Mae with a Master's degree in Atmospheric Chemistry and Climatology. Haviland brings phenomenal expertise in data analysis, and we appreciate her unadulterated analysis of the data.

Lyle, database developer by day and history buff by night, works with Ian to update content on the PXE website. He has a long and robust record of database

expertise, which helps to make sense out of the thousands of pages on the PXE website. Together with Ian, he will be making all of this more comfortable for you to access.

We are excited to have both of them join the team and enhance our ability to provide support and accelerate research.

Donations

As we stated above, we mostly would like you to share your health data. However, we do want to thank those of you who have already donated this year. We also don't want to make it hard if you wish to donate, so use this link to contribute. To mail us a check use the address below. If you would like to use a credit card, call Mary and she will take your number over the phone. Although we are not asking, if you are in a position and would like to donate, we want to make it easy.

Online paypal.me/pxeinternational

or

Call Mary: 202.362.9599

or

Mail check to our mailing address:

PXE International

26400 Woodfield Road #189

Damascus MD 20872

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.

[Listen to the Guided Meditations](#)