

## **Spotlight on Vision**

### **□ Vision Tech Spotlight: Smart Glasses for People with Central Vision Loss**

Wendy (PXEer, former board member, and current donor) says:

*"I lost most of my central vision years ago before there were shots, but with the Meta glasses I can finally read a menu and know what can is which on my shelf. It's like having part of my life back."*



For people living with vision loss due to PXE, everyday tasks like reading a menu or finding the right jar in the cupboard can become major challenges. New wearable technologies—including smart glasses—are offering powerful support.

Here's a quick guide to some of the most promising options:

□ **Meta Smart Glasses (Ray-Ban Meta)**

Popular but not designed for low vision—still, some users are calling them life-changing.

- Scene description and object recognition
  - Can help identify street signs, crosswalks, and landmarks
  - Works with apps like Voice Vista to announce your location
  - Limitations: Does not magnify or read printed text verbatim
- Affordable and stylish (~\$300), but limited in visual support.

**eSight Glasses**

High-tech vision enhancement for people with central vision loss

- Real-time magnification with contrast and brightness controls
  - Helps users read, watch TV, recognize faces
  - Built-in image stabilization
- Comprehensive support, especially for reading and close-up work. High cost (~\$6,000–\$10,000).

**OrCam MyEye**

Tiny camera that clips onto your glasses

- Reads printed and digital text aloud
  - Recognizes faces, products, and currency
  - Works offline with discreet audio feedback
- Great for on-the-go reading and identification. No visual magnification. (~\$4,000)

**Envision Glasses**

AI-powered smart glasses for blind and low vision users

- Reads text aloud, identifies surroundings
  - Real-time video call option for live sighted assistance
  - Lightweight and customizable
- Flexible and community-oriented. (~\$3,500)

Many of these are quite costly. Each PXEer experiences vision loss in their own way. Consult a low vision specialist to determine what is best for you.

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## **Topography of Slowed Dark Adaptation in Pseudoxanthoma Elasticum: PROPXE Study Report 1**

This study examined how individuals with PXE experience difficulties adjusting their vision after exposure to bright light.

As you know, PXE causes mineralization of the mid-lamellar layer of Bruch's membrane. Before this study, it was unclear whether individuals with PXE experienced difficulties adjusting to darkness; therefore, a number of scientists led by Kristina and Maximilian Pfau, investigated this in 26 individuals using a specialized vision test.

They found that for many people with PXE, it took longer than usual for their eyes to adjust to the dark after exposure to bright light, and their dark adaptation was slower than that of individuals without PXE. This delay occurred even in individuals who hadn't yet lost vision due to PXE, and it was more pronounced in areas of the eye closer to the center, where the calcium buildup typically begins. These results suggest that slow dark adaptation may be an early indicator of PXE-related eye problems, enabling doctors to detect changes more promptly and better monitor the disease's progression over time.

Why is this important? We are trying to find something we can measure that tells us that PXE is progressing, and that can also serve as a good measure of whether or not an intervention is working. This might be that measure.

#### Dr. Kristina Pfau, MD, PhD

Kristina Pfau connects clinical care and basic research in inherited and degenerative retinal disorders—especially those impacting Bruch's membrane, such as PXE and AMD. She leads a group at the University Eye Hospital Bonn (the Department of Ophthalmology at University Hospital Bonn) and serves as an attending consultant and researcher at the University of Basel's Department of Ophthalmology in Switzerland. She completed her residency in Bonn and subsequently held a postdoctoral fellowship at the National Eye Institute (NEI) before returning to her dual roles in Germany and Switzerland.

#### Dr. Maximilian Pfau, MD, PhD

Maximilian Pfau combines basic science, AI-driven image analysis, and visual function testing to improve precision in diagnosing and monitoring retinal diseases. He trained as an ophthalmology resident in Bonn and completed postdoctoral fellowships at Stanford University and NEI. He currently leads the Visual Neurophysiology Platform at the University Eye

Hospital Basel and serves as a senior researcher at the Institute of Molecular and Clinical Ophthalmology Basel, Switzerland.

Our CEO, Sharon Terry, was also an author on this paper.

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## **Collaboration with the PXE International Center of Excellence**

We continued to fund and collaborate with the PXE International Center of Excellence in Research and Clinical Care at Jefferson University. Under the leadership of Koen van de Wetering and Qiaoli Li, this center has made significant strides, publishing several important papers this year. Their research provides critical insights into PXE's underlying mechanisms and potential pathways for treatment, fostering hope for the future.

[Listen to them describe their research!](#)

[Dr. Li's Papers](#)

[Dr. van de Wetering's Papers](#)

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## **International Patient Engagement**

We connected with the PXE community through various platforms, including:

- A patient meeting in Ireland, fostering global solidarity and sharing vital updates.
- 11 webinars attended by more than 300 live participants and viewed over 1,000 times, offering updates on clinical care and research developments.
- Responding to 256 emails from PXEers, addressing specific concerns about symptoms, finding specialized care, and providing tailored advice.

[PXE International's YouTube Channel](#)

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## Engaging Industry and Regulatory Partners

This year, we held discussions with six companies actively exploring PXE treatments, demonstrating increasing interest in the field. Additionally, we met with the FDA to clarify the path forward for trial treatments, reinforcing our commitment to accelerating the approval process.

## Global Advocacy and Education

Our advocacy efforts spanned the globe, with 30 talks delivered worldwide in person and virtually. Highlights included presentations in Geneva, Tokyo, Kyoto, New York, and Nashville, sharing PXE International's work and inspiring broader engagement in the PXE community.

## Looking Ahead

The milestones achieved this year reflect the dedication of the PXE International team, researchers, clinicians, and our global community. As we look to 2025, we remain committed to advancing research, enhancing care, and empowering PXEers worldwide. Together, we will continue to drive meaningful progress toward treatments and, ultimately, a cure for PXE.

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**As we approach the middle of the year,  
we want to thank you for your support!  
All of our work is funded by your generous  
donations.**

**Double your donation! The Matching Campaign is  
in full swing.**

- [What do your donations pay for?](#)
- [Make a donation](#)

## Matching Campaign

\$225,875 of \$500,000 goal

45%



# Raising Awareness for PXE



Help those suffering with  
Pseudoxanthoma  
Elasticum (PXE)

Do you want to educate your community members, co-workers, friends, and family about PXE? In response to numerous requests, we've created an informative infographic to help you share what PXE is, who PXE International is, and how others can contribute!

Attached, you'll find a full-sized, printable flyer for your convenience. Let's join forces to raise awareness about PXE!

#### What is PXE?

A rare genetic disorder causing:

- severe legal blindness
- skin issues
- vascular complications

#### Who is PXE International?

Since 1995, we have been the vanguard against PXE by:

- pioneering research
- bringing together a global network of laboratories
- managing an extensive tissue bank/registry
- leading charge with clinical trials

#### Our Mission?

##### Support



A responsive lifeline to affected individuals, providing crucial information to those newly diagnosed.

##### Educate



Equip medical professionals with knowledge and resources to recognize and understand PXE.

##### Research



A collaborative research consortium that's the powerhouse for most of the world's research on PXE.

#### How can YOU help?

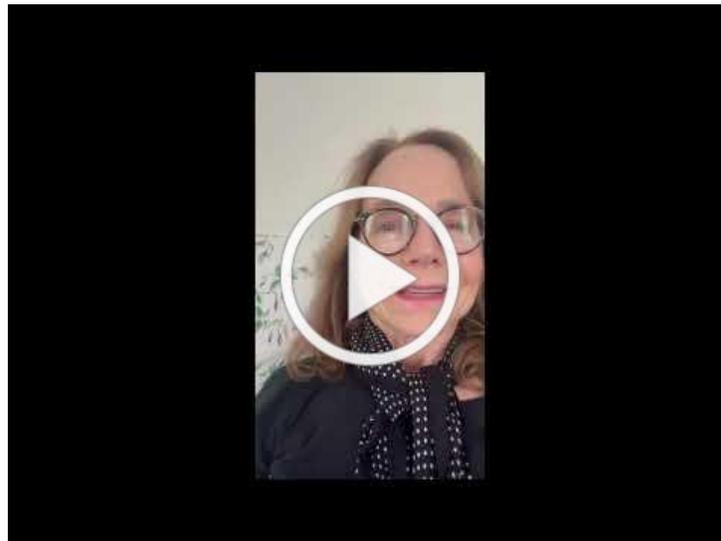
As a non-profit, we rely on donations and your contribution directly fuels research for treatment development and supports clinical trials.

- **Credit Card:** Secure and convenient - Scan the QR Code for more info
- **Zelle:** Quick transfer via mary@pxe.org, under PXE International.
- **Check:** Send to PXE International, 26400 Woodfield Road #189, Damascus MD 20872-7509



[Click Here to Download the PXE Infographic](#)

## Increasing Your Impact: a Message from our Dear and Famous Board Member



Our most well-known PXE supporter, Jessica Harper, is dedicated to advancing PXE research and will match donations. Please listen to her call for us to step up! We are very grateful to her and her

family!

Donate to our Matching Campaign Here

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