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Recruiting Final Call for DS1211 Clinical Trial

We are in the final round of recruiting for the DS1211 clinical trial. We have screened more than 100 individuals. That is amazing. But we still need about 30 more volunteers. Can you be one of them? You can find out more about the trial by clicking the link below and contacting Catt (catt@pxe.org) or Mary (mary@pxe.org). They handle all of the recruitment.

We have constant contact with the individuals already in the trial and receive feedback regularly - It is all positive.

"Everyone was friendly, professional, and helpful."

"It was a really good experience,
I am so glad to help the whole PXE community this way."

If you are on the fence about participating and would like to hear from someone who has participated in the study, please let us know, and we'll connect you.

I'd like more info about the DS1211 Clinical Trial

PRO-PXE Study

Drs. Kristina and Maximilian Pfau are recruiting for a European study for PXEers. The study's purpose is to use new ophthalmologic technologies to determine if they are better suited for monitoring PXE than the traditional CT-imaging method. If you are older than 18, have a confirmed PXE diagnosis, and are able to travel to their lab in Basel, Switzerland, visit their study page.

PRO-PXE Study

Critical Study for FDA and EMA Approvals!

We are on the brink of numerous potential therapies being considered by the regulators, but the FDA and EMA still need to be shown that people with PXE suffer. Tell us about how PXE affects you in our Burden of Disease Study. The study asks about physical functioning, bodily pain, mental health, and other areas of pain and suffering. Let your voice be heard!

Burden of Disease Study

How We Work for You

PXE International offers the community many benefits:

1. Support for thousands of individuals a year via phone, email, and Facebook
2. Monthly newsletter
3. Annual meeting with the latest info and research updates
4. Registry of more than 4000 individuals with PXE
5. Surveys about your symptoms
6. Repository of blood and tissue
7. PXE International Research Consortium – coordinating most of the PXE researchers in the world (everyone welcome)
8. Annual PXE research meeting
9. Support for the PXE International Center of Excellence in Research and Clinical Care at Jefferson
10. Support for the current clinical trials and more to come

We are grateful that donations from you, our members, keep us ready and able to provide all of the services above. We regularly ask you for donations through this newsletter, on Facebook, through direct email, and for those without email, through the mail.

There are about 4,500 PXEers registered with PXE International. In 2022, we received donations from 418 PXEers, their families, and friends. This means that fewer than one in ten people affected by PXE contribute to this worthy cause that directly benefits each of you.

Let's think together about this. Is PXE International's support worth \$1 a week to you? Could you contribute \$50 a year? Maybe it is only worth 50 cents a week to you? Perhaps \$25 a year? If even half of the people with PXE gave \$25/year, that would pay for #1, 2, 3, and 6 in our list above. **THAT WOULD BE AMAZING!!!**

We are not asking for you to give so much it hurts. We are here to support you, not burden you. We exist for you, and we exist because of you. Some of you know I am a former nun and chaplain. There is a story from my past life that I have always loved:

"Jesus sat down opposite the treasury and observed how the crowd put money into the treasury. Many rich people put in large sums. A poor widow also came and put in two small coins worth a few cents. Calling his disciples to himself, he said to them, 'Amen, I say to you, this poor widow put in more than all the other contributors to the treasury. For they have all contributed from their surplus wealth, but she, from her poverty, has contributed all she had, her whole livelihood.'"

Mark 12:41–44, Luke 21:1–4

I know there are similar parables for Jews, Muslims, Sikhs, Hindus, and more. In all of them, the simple point is that **giving reflects what you value according to your means**. No heroics are needed. Just a little in relatively large groups like ours means a lot.

I continue to work tirelessly for PXE International without taking a salary, so our/your money goes further! It's my small contribution. AND, I am so grateful to the 418 of you who make all this work possible. Look in the mirror today, smile, and say to yourself: I help to make a big difference in the lives of people living with PXE!

Donate (even a little)

Website Update - Share Your Story

As part of our changes to the PXE International Website, we are creating a testimonial page for individuals who would like to share their stories. If you would like to take part in this, please reach out to Catt at catt@pxe.org for more details.

Contact Us

We love to hear from everyone and help you in any way we can! Email us at info@pxe.org. Staff read emails daily. Or call us at **202.362.9599 x208**. If it is outside of office hours, leave a message and we will get back to you as soon as we can.

[PXE International](#)



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