



PXE International January 2020 eNewsletter Volume 13 No. 1

Thank You for Helping Us Raise Over \$1,000,000

Dear friends and supporters of PXE International,

We are so thrilled with the results of our matching campaign. First, we thank our anonymous \$500,000 donor. I cried when they first offered this challenge. My second emotion was fear – how could we possibly do this? We generally raise \$100,000 in a year! Well, YOU did it! I would love for each of you to look in the mirror, and as my 2-year-old granddaughter is want to say these days, feel your whole self from head to toe and proclaim: I DID IT!!!

We can now commit to another year of funding our PXE International Center of Excellence in Research and Clinical Care at Jefferson, the only research center dedicated to only pseudoxanthoma elasticum (PXE) in the world. The Center is doing excellent work. In this Center, we are testing a variety of potential treatments for PXE, both in mice and in humans. Most of the new announcements you have seen in PXE research are at least influenced, if not discovered and advanced, right there at our Center. We are immensely impressed with the team there: Jouni Uitto, Koen van de Wetering, Lili Li, and their colleagues. These amazing scientists published nine papers and submitted another four papers, detailing their discoveries in PXE, in 2019.

We are on the cusp of a lot of exciting trial and error this year. I say error, because we will have to endure failings to get to the right answers.

I am delighted to work for and with you. It is now 25 years since we founded PXE International (we will celebrate at the October meeting in Philly!). I often say: I started this for my two kids, and now we have 4,986 kids (the number of people affected by PXE we have discovered). Glad to call us "family!"

Let's hear from a few of the staff at this important time:

"I am so grateful to work at PXE International where I can help to make life a little better for those with PXE. I am honored to be able to support this community and create resources to help those in need.

I look forward to expanding and

"Dear Friends, I have worked at PXE International for more than 20 years and have talked or emailed with many of you over those years. It is so exciting to see how research on PXE is moving forward. Thank you all for your support of PXE International through all these years!" -- Christine Vocke

nurturing the avenues of support available to PXEers in 2020. Thank you so much to everyone who donated in 2019! We couldn't do what we do without you." -- Samantha Coley

"PXEers and Friends, It has been my pleasure to work with you for the past sixteen years. I am grateful for all the support given to the Match in 2019 and hope we can move forward with some treatments for PXEers real soon.

Let's keep up the good work and share a better horizon of hope and health for all PXEers and their families." -- Mary Peckiconis

"PXE International has been part of my life for most of my life, and I have been working here for nearly 8 years to give back to the community that supported me, and surrounded me with love as I grew from a child into an adult.

Thank you all so much for helping to make the dream of PXE International a reality. We couldn't do everything we do without you as a community, your participation as a group, your spirit, and your support for one another makes all of this possible, and worth every bit of effort!

The incredible accomplishment with the matching campaign this year has been incredible to be a part of. We are looking forward to all the amazing research and support initiatives we can now go forward with in 2020!" -- Ian Terry

Q&A with One of Our Anonymous Donors

As you know, we had an anonymous donor offer to match up to \$500,000 raised in 2019. When we were about \$123,000 away, another donor stepped forward and offered to match the match!

We caught up with our Anonymous Donor #2 who matched the last \$123,000 dollars of the PXE International Matching campaign. We asked her a few questions about what PXE International means to her and why she chose to participate in such a big way. (We will have a Q&A with the matching challenge donor in next month's newsletter.)

What does PXE International mean to you?

Well let me tell you the truth, when my daughter was diagnosed a year and a half ago here in London, she had the rash on her neck and it'd been there for a while, and I took her to a couple doctors and

dermatologists, and they would say it was Eczema or give us creams until I found this last doctor, who took a biopsy. And he said she's the first case he'd ever seen, the last time he'd read about PXE he was in medical school.

And he told me don't read about it until the biopsy result comes out. Of course

 **Hope.**
As a mother, hope.

when a doctor tells you don't read about PXE what's the first thing you do? Go read about it.

When I read about it it wasn't so scary because I didn't understand all of the medical words. And from there I started reading anything to do with PXE, and then I went to YouTube. And when I wrote in "PXE," Sharon came up, in her TED program. And then the results came after 48 hours: positive that she has PXE.

So I went back to Sharon's TEDMED talk where she was speaking about PXE International and I started sending her emails. What does PXE International mean for me? It means a lot because Sharon's a mother and her children were diagnosed so I know it's going to be 100%, because she's going to put all the effort, and she did already, to bring something, maybe not a cure from PXE but she will find something. I'm very positive.

What does it mean for me? Hope. As a mother, hope.

What motivated you to participate in this challenge in such a big way?

If I had more, I would've put more. I want to speed up whatever PXE International needs for them to do whatever they have to do. I know that with money and financial stability, when you have financial support, you can do lots of things. I wanted to match as much as I could so it's doubled, so they can speed up current PXE research.

How do you envision the funding provided by this challenge helping people who have PXE?

When people are paying attention and want to know what's going on and they know there's a big match, I hope they feel relaxed in a way. I want them to know there is progress and speed. And for all the PXE patients and families and loved ones, will want to know that the research process is moving forward.

What would you like to say to everyone who has participated in the matching challenge?

We're very thankful, we're very grateful. Every penny, I think, will make a big difference. If every person donates one dollar, it's going to make a big difference!

I don't think this will be my last donation, I'm just saving more money so I can donate again. Hopefully Sharon and her team and everyone at PXE International knows we are really really thankful. We know you're working hard to reach a point in the research for all PXEers to get well soon.

PXE International Biennial Member Conference

Our Biennial Member Conference will take place later this year in October from the 16th to the 18th at Thomas Jefferson University. Registration will open in February so stay tuned for more!



You can still purchase PXE T-Shirts from PXE International. All shirts are \$25 (+shipping for non-US residents). Order yours today!

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