



PXE International January 2019 eNewsletter Volume 12 No. 1

HAPPY NEW YEAR FROM PXE INTERNATIONAL!

Matching Challenge Update!

PXE-ers are killing it in our matching challenge in just a few short months! An anonymous donor challenged PXE International to raise \$500,000 this year and promised to match it. So far we have received \$309,160 from nearly 250 donors! Share this challenge with your friends and family, help us push PXE International to reach this goal by doubling your impact and having your donation matched!

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An Interview with Ashley Kidd

While we are still in the process of finding ways to treat the symptoms of PXE, we do know that living a healthy and active lifestyle can reduce the cardiovascular effects.

We have been so inspired by PXE-er Ashley Kidd as she has taken strides to improve her health over the past year, so we sat down with her this month to ask her questions about this process and what advice she can give to other PXE-ers looking to improve their health.



Ashley began her journey towards a healthier lifestyle in May of 2018 and she is committed staying healthy and living her best life. It all began when she started to notice that certain foods made her feel absolutely terrible.

"I made a doctor appointment and talked to him about my symptoms, he then thought I had diverticulitis and gave me medication; he told me to cut out the foods that are making me feel miserable."

Ashley says that the biggest obstacle she's faced so far is learning which foods to stay away from.

"I've completely cut out all the greasy/fatty foods from fast food. I quit drinking pop, energy drinks, and fake sugar drinks. I only drink water, hot tea, and milk now. I downloaded the [myfitnesspal app](#), and count my calories, I also measure my food portions."

One of Ashley's favorite things to eat now is all kinds of baked chicken. Check out some popular and [healthy chicken recipes here](#).

"I also started walking on my lunch breaks at work."

Ashley proves that you don't have to go on some crazy workout schedule or hire a personal trainer to get healthy. Preferring to keep it simple Ashley likes to go for walks for her cardio vascular health and she improves her core strength by doing sit ups.

"My biggest success during the nine months of doing this is actually sticking with it! I've dropped 43.4lbs, and I'm 2lbs shy of my goal weight. I haven't seen myself weigh that little in eight years. I feel so much healthier and I'm not sluggish or suffering with back and foot pain everyday!"

One of the most difficult parts of any journey towards a healthier lifestyle is the commitment it takes to stick with it beyond the first few months. We are so impressed with Ashley's dedication and determination that we asked her how

she stays motivated and committed to these new habits.

"What has helped me stay committed is that I have a great bunch of family and friends that support my decisions and people that tell me how I'm inspiring them to want to do better."

Having a solid support system is a key component of achieving any task, especially one that changes your whole life!

"Of course, I can also see the results in my whole body."

We asked Ashley what advice she would give to someone who has just made a choice to start improving their health.

"You have got to be proactive! Only you can do it for yourself, and if you continue to work at it things will happen. After nine months of doing this it is now second nature!"

We'd like to thank Ashley Kidd for sharing her story and we want to challenge PXE-ers to get active in 2019! Check out PXE International's [Health Challenge videos](#) for tips and inspiration for starting your own fitness journey!

PXE 2019 Webinar Schedule

Below are the remaining PXE Webinars scheduled for 2019. Please click the titles that appeal to you to register for those meetings! Let us know if you have any questions.

- **February 6 @ 12pm EST:** [Andras Varadi - Advancements and Obstacles to Oral Phosphate Therapy](#)
- **February 20 @ 7pm EST:** [Jouni Uitto - PXE Mutations and Current Research](#)
- **March 6 @ 7pm EST:** [Qiaoli Li - Mouse Models and Modifier Genes](#)
- **April 2 @ 12pm EST:** [Patrick Thibodeau - Insights into ABCC6](#)
- **April 16 @ 7pm EST:** [Koen van de Wetering - Targeting the Phosphate Shortage in PXE](#)
- **April 17 @ 3pm EST:** [Olivier La Saux - ABCC6 Pathways and Dietary Phosphate in Calcification](#)

Our webinar with Wayne Fuchs is now available on the PXE International Youtube page! You can view it below, or [click here to navigate to Youtube](#)

Ocular Manifestations of PXE

Peau d'orange
Angioid Streaks

Choroidal neovascularization
Leakage (distorted vision)
Bleeding (decreased vision)
Scarring (central scotoma)



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