



**PXE International  
March 2020  
eNewsletter  
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Dear PXE Community,

We have always felt like a global community, because we share mutations in the ABCC6 gene, and the special kindness and care that we all feel we share. Now we are clear that we are all a global community, unfortunately brought to us by the great COVID-19 crisis. Before we have time to absorb what is good and wonderful about that, we are suffering greatly, as all around us people are getting sick.

To state the obvious: we know your life is not “business as usual”, or family as usual or anything as usual. Please know we are here to support you in what will be the biggest event in all of our lives. We know that some of you are afraid, we know that you don’t have access to regular healthcare, that you cannot get your shots, that you are afraid for your loved one. We are with you, we feel fear too, and we also know we are strong when we stand together.

And so we do what we have always done, but we state it more explicitly, and with greater clarity: We love you. We are with you. We are here.

Sharon on behalf of PXE International Board and Staff

## **COVID-19 and PXE What You Need To Know**

As far as we know, there is nothing special about COVID-19 in people with PXE. In fact, we now share something with the general population – don’t take nonsteroidal anti-inflammatory medicines. And so, these guidelines for the general population are applicable to you. We will have a PXE COVID-19 survey to ask you about your experience in the coming months.

COVID-19 is a respiratory illness caused by a new strain of a coronavirus. In these strange and difficult times we hope that you and your loved ones are safe and healthy. There is nothing that makes people with PXE any more vulnerable to COVID-19. Nonetheless, we want to keep you informed and make sure that you feel prepared to protect yourselves and others. We’ve collected some information from the CDC below.

### **How It Spreads:**

The virus is thought to spread mainly from person-to-person.

- Between people who are in close contact with one another (within about 6 feet).
- Through respiratory droplets produced when an infected person coughs or sneezes. These droplets can land in the mouths or noses of people who are nearby or possibly be inhaled into the lungs.
- People are thought to be most contagious when they are most symptomatic (the sickest).
- Some spread might be possible before people show symptoms, but this is not thought to be the main way the virus spreads.

## How To Protect Yourself and Others:

- There is currently no vaccine to prevent coronavirus disease 2019 (COVID-19).
- The best way to prevent illness is to avoid being exposed to this virus.
- Wash your hands often with soap and water for at least 20 seconds especially after you have been in a public place, or after blowing your nose, coughing, or sneezing.
- If soap and water are not readily available, use a hand sanitizer that contains at least 60% alcohol. Cover all surfaces of your hands and rub them together until they feel dry.
- Avoid touching your eyes, nose, and mouth with unwashed hands.
- Avoid close contact with people who are sick
- Put distance between yourself and other people if COVID-19 is spreading in your community. This is especially important for [people who are at higher risk of getting very sick](#).
- Stay home if you are sick, except to get medical care.
- Cover your mouth and nose with a tissue when you cough or sneeze or use the inside of your elbow.
- Throw used tissues in the trash.
- Immediately wash your hands with soap and water for at least 20 seconds. If soap and water are not readily available, clean your hands with a hand sanitizer that contains at least 60% alcohol.
- Clean AND disinfect [frequently touched surfaces](#) daily. This includes tables, doorknobs, light switches, countertops, handles, desks, phones, keyboards, toilets, faucets, and sinks.
- If surfaces are dirty, clean them: Use detergent or soap and water prior to disinfection.
- Face masks are recommended for those who are sick or those caring for a sick person who cannot wear a face mask.

## Know The Symptoms:

Reported illnesses have ranged from mild symptoms to severe illness and death for confirmed coronavirus disease 2019 (COVID-19) cases.

The following symptoms may appear 2-14 days after exposure.

- Fever
- Cough
- Shortness of breath

## What To Do If You Think You Are Sick:

- Stay home: People who are mildly ill with COVID-19 are able to recover at home. Do not leave, except to get medical care. Do not visit public areas.
- Stay in touch with your doctor. Call before you get medical care. Be sure to get care if you feel worse or you think it is an emergency.
- Avoid public transportation: Avoid using public transportation, ride-sharing, or taxis.
- Stay away from others: As much as possible, you should stay in a specific “sick room” and away from other people in your home. Use a separate bathroom, if available.
- Limit contact with pets & animals: You should restrict contact with pets and other animals, just like you would around other people.
  - Although there have not been reports of pets or other animals becoming sick with COVID-19, it is still recommended that people with the virus limit contact with animals until more information is known. If no one else is able to care for your pets, wash your hands before and after interacting with them.
- Call ahead: If you have a medical appointment, call your doctor’s office or emergency department, and tell them you have or may have COVID-19. This will help the office protect themselves and other patients.

If you develop emergency warning signs for COVID-19 get medical attention immediately. Emergency warning signs include\*:

- Difficulty breathing or shortness of breath
- Persistent pain or pressure in the chest
- New confusion or inability to arouse
- Bluish lips or face

\*This list is not all inclusive. Please consult your medical provider for any other symptoms that are severe or concerning.

Please visit [the CDC Website](#) for more information.

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## PXE 2020 Member Meeting Registration Is Open

Registration for our Biennial Member Conference is now open. The meeting will be held at the PXE International Center of Excellence in Research and Clinical Care at Thomas Jefferson University in Philadelphia, PA. The meeting is set for October 16th to 18th, 2020.

We will share more information across all PXE International communication platforms as it becomes available. Please register at the link below, we can't wait to see you there.



[Register Here](#)

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# April 7th PXE Research Webinar

Join us for the second of two webinars on how PXE affects biomineralization in the body. Hosted by Stephanie Moore, this webinar will further the discussion of part one and better our understanding of this aspect of PXE. Register below to join us on April 7th at 7pm EST. Check out all of our previous webinars on [our YouTube channel](#).

[Register Here](#)

## Limited T-Shirts Available



We have a limited amount of PXE T-Shirts still available! To inquire about remaining sizes, please email me at [scoley@pxe.org](mailto:scoley@pxe.org). Order yours at the link below.

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