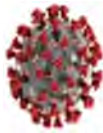


# Night Times

*A newsletter from the Xeroderma Pigmentosum Family Support Group, a registered non-profit organization dedicated to helping those touched by the rare genetic condition through education, research and kindness.*

## Newsletter

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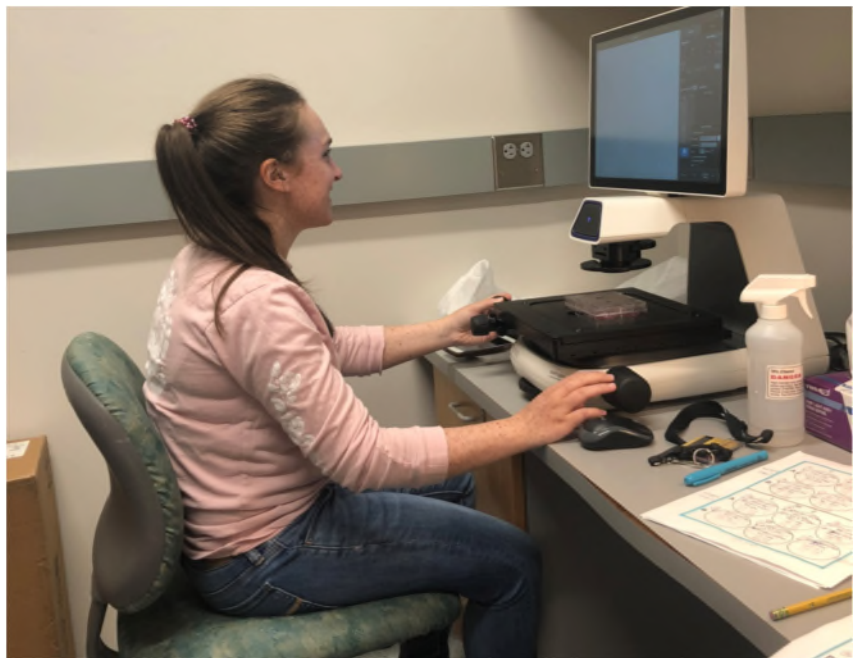
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### 2020 XP International Medical Conference **Rescheduled** due to COVID-19

Due to the ongoing impact of COVID-19 and the unprecedented disruption in the workforce, XPFSG in collaboration with our international partners have made the decision to reschedule the 2020 University of Minnesota international medical conference to November 11-15 2021 at the University of Minnesota. We have made this decision based on many families having an impact on their finances. The impact of COVID-19 has also made an huge impact on our fundraising and donation efforts. We are hoping that postponing will allow families to plan and save for 2021. The location will stay the same. You can register now for 2021 and can set up payment plans.



### My Summer in Minnesota, by Aimee Milota

At age sixteen, I became the youngest employee at the University of Minnesota. I had the privilege of working at the Niedernhofer Lab. My tasks included preparing tissue lysates, isolating RNA, quantifying protein concentration, preparing DNA, electrophoresis, preparing sample collection tubes for necropsies, and performing necropsies. I learned skills such as cell culture, western blots, blood work, PHA experimentation, and lab maintenance.

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My Summer in Minnesota continued...

Here is a typical day interning in Minnesota. I would wake up around eight o'clock every weekday morning. Then I drove five minutes to the lab (we drove my car from California to Minnesota). I would walk from the parking garage through underground tunnels to the elevators, which led to the third floor lab in the Niels Hasselmo building. I had a security clearance card that allowed me access into the research lab. Inside the lab, Matt, Mariah, Louise, Collin, Ryan, Rachel had their own lab stations. My fellow interns included Parker, Weston, Brian, and Brianna. We each had an experienced partner. Mine was Mariah. Mariah was an amazing mentor and fantastic teacher. She took the time to teach me everything I needed to know about cell culture and basic lab maintenance. She also made sure I fit in with everyone, especially since I was the youngest. Ryan taught me how to do IVIS with the mice. Collin taught me how to do grip tests, which tests the strength of the mice. He also taught me how to wean as well as number the mice. I would always mess with Collin by hiding chemistry cat memes around his station and in his backpack. Matt was the overall 'encyclopedia' of everything. He was extremely smart and oversaw all of our activities. One time Matt was laughing so hard, he passed out and knocked over the biohazard waste bin. Nothing was harmed, but it was hilarious. The lab also set up a mini birthday party for me on my 17th birthday, which I spent in the lab.

Going to Minnesota alone was nerve wracking. I was stressed and nervous about leaving home for the longest time I've ever been away. The drive took about three days from Sacramento to Minneapolis, a total of about 1,889 miles. When I arrived, my hosts Laura and Paul were incredibly generous and welcoming into their home. Laura also happened to be my boss. This was the experience of a lifetime. I learned more than genetic research and cell culture. I learned how to take care of myself and be resourceful; something that does not come easy. I will be forever grateful to my parents, Jeff and Michele Milota, as well as Paul and Laura Niedernhofer who gave me this opportunity.



**XP Parent Shoutout...**

**Thanks Johanna for the amazing Facebook post!**



**Johanna Sweet**  
April 29

Imagine that the covid virus could be contracted just by breathing in fresh air. That it was everywhere in fresh air. That every time you did get some of the virus particles it damaged your body and too many would definitely eventually kill you. Every time you went outside you had to thoroughly wear your mask and make absolutely sure it was on perfect to save your life. Every mistake could add up and kill you. Imagine gearing up to open the door or window cause the particles will come in with fresh air. Imagine. What if this were permanent. You had to live the rest of your life this way. Imagine it was in every breath you took outside every. Single. day of your life you had to prepare and gear up! Would you overcome your fear and trust yourself and live life to he fullest?

This covid fear has me realizing how resilient, strong, brave and courageous Emma is, and all patients living with XP. They deal with this scare more deeply and every day of their lives. UV from the sun and lightbulbs are everywhere. Today, I celebrate the 80 brave XP children in the United States. Covid has me thinking we can never fully understand. I celebrate that we overcome fear and Emma does anything she wants to do. We just find ways to make it happen. How brave, how courageous she is!



**Want to add someone to our electronic newsletter? Contact the office at 916-628-3814 or email us at [mmilota@xpfamilysupport.org](mailto:mmilota@xpfamilysupport.org)**

## Recent Fundraisers

Every year the XPFSG board members work extremely hard on fundraising initiatives to be able to support XP families with education, medical conferences and kids' camps, support, UV protective film, UV meters and more. Check out some of our recent and upcoming fundraisers and help out if you can.

### **Sacramento Crab Feed**

One of the XPFSG's biggest and most successful fundraisers, the annual Sacramento Crab Feed raised \$13,000 this year. The Milota family has made this event a local must-attend with a sell-out crowd every year. Michele Milota and her family continue to inspire us with their drive and determination to make this event so successful.



### **Krispy Kreme Donut Sales**

The 2020 Krispy Kreme donut drive was another year of success. We set our delivery date for March 10th having no idea that the world would be shutting down just a week later. The Felnter family would like to extend a big Thank You to all those people in Southern Utah that bought donuts, gave donations, helped sell and deliver, or donated prizes. We sold 2000 dozen donuts this year. I would say there were a lot of sweet dreams in the neighborhood that night.

### **Toast for Hope**

On March 7th, Kyle and Sarah Madden hosted **Toast for Hope**, a wine-tasting event at Grace Hill Winery. 80 Attendees received 3 wine tastings with their ticket and enjoyed great food and prizes. Many said they are looking forward to next year. The Madden's raised \$5,000 to benefit the XP Family Support Group and said they hope to continue growing the event to become the "must-attend" event for Grace Hill Winery.



## Want to help support YOUR XP Family Support Group?

If you are purchasing products from amazon, go to <https://smile.amazon.com/> and choose Xeroderma Pigmentosum Family Support Group as your charity. Amazon will donate 0.5% of the purchase price of eligible products to XPFSG. Every purchase can help a family with XP. **Ask 10 of your friends to do the same!**



WE  
RE  
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WE'RE ALL IN THIS TOGETHER.

## Update from the National Institute of Health

COVID-19 is a new disease caused by the novel coronavirus infecting humans, and there is much that is still not known or understood about it. Currently, physical distancing, frequent hand washing, use of hand sanitizers and wearing face coverings such as tightly woven cloth face masks or even UV blocking face shields are the best way to prevent spreading the virus. With physical distancing, staying 6 feet apart, these measures help from contracting the infection.



We do know that people with neurological disease such as XP neurologic disease can experience a temporary worsening in their symptoms when they are suffering from any infections that cause flu-like symptoms or pneumonia. Therefore, we might expect if XP patients with neurological problems develop symptoms from the coronavirus infection, they may get worse while respiratory symptoms or pneumonia persist. The World Health Organization has also advised on the importance of treating Vitamin D insufficiency because of increased time indoors. We would recommend all our patients continue supplementation with oral Vitamin D.

We understand that social isolation, reduction in physical activity, unpredictability and changes in routine can all contribute to increasing stress. People living with DNA repair conditions often have some aspects of physical distancing. However, missing out on school activities, therapies or being required to attend school classes and work from home can feel isolating.

Several types of light bulbs including unshielded fluorescent and halogen bulbs emit higher levels of UVR (ultraviolet radiation) than is safe for people with XP. These are often found in areas like cafeterias and gyms. Recently, high UVR (UVC bulbs) emitting light sources have been proposed for use in public areas as a means to protect from the coronavirus. It is important for people with XP to be aware of all of these light sources in the environment. If necessary, re-check public areas with a UV meter to assess if it is safe.

If you have questions or concerns, please contact us at the mail and phone numbers listed below:

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Dr. John DiGiovanna 240-760-6138 jdigiovanna@nih.gov

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COVID-19 is an emerging, rapidly evolving situation.

- What people with cancer should know: <https://www.cancer.gov/coronavirus>
- Get the latest public health information from CDC: <https://www.coronavirus.gov>
- Get the latest research information from NIH: <https://www.nih.gov/coronavirus>

