

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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California teen traveling to U of M to study her own rare skin disorder

Aimee Milota is making the most of a unique opportunity by working at the freshly-tinted University of Minnesota's Biology of Aging and Metabolism lab studying the rare disease Xeroderma Pigmentosum. The unique part of her story is that Aimee is studying the condition she herself has offering a perspective few other people could ever give. Check out the story reprinted courtesy of Kare 11.

GOLDEN VALLEY, Minn.—Aimee has always lived with the restriction of not being able to go outside.

She often wears special gloves and a hat that protects her from ultraviolet light because she lives with a disorder known as Xeroderma Pigmentosum, also known as XP.

Director Laura Niedernhofer, who works at the Institute on the Biology of Aging and Metabolism at the U of M Medical School, says, "Aimee usually has to go everywhere with a little UV meter to see if her environment is safe before she can walk into a room."

"Any ultraviolet exposure," she says, "leads to premature skin cancer or third degree burns."

And, early in Aimee's life, she frequently dealt with both. Aimee's mother, Michelle says, "Aimee was diagnosed at 16 months, with XP, and she did have her first skin cancer at that time. From the time of diagnosis to about the age of three she had 26 skin cancers removed."



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California teen continued...

But, in the 13 years since, Aimee has been cancer free, relying on a variety of UV blocking materials - developed by 3M - which helped her thrive and advocate for others with the disorder.

Michelle says, "She was very instrumental in getting window tint legislation passed in the state of California. Individuals with rare skin conditions can have their cars tinted, because without that she wouldn't even be able to drive a car."

The same UV blocking film is now being installed inside the University of Minnesota's lab where Aimee will intern this summer, thanks to a donation by 3M and Sun Control of Minnesota.

Aimee says, "It's really significant because I'll be able to do experiments without having to have my gloves on, without having a full hat on and I'm really excited and I'm really grateful."

Grateful because she'll be researching her own disease and, in the process, helping understand more about skin cancer in general.

Director Niedernhofer states, "We've learned everything that we know about skin cancer, which affects so many people in the United States, and we learned it all because of children with XP."

"It's not really normal for someone who has a condition to be researching their own condition," Aimee says. "I just hope it will get us closer and closer to finding something to help everyone who is affected."

Aimee and her mother will be driving from Sacramento to Minneapolis this weekend, so that she can have her UV blocking car when she begins her internship next week

Four Wheelin' Good Time

Paxton Feltner loves four wheeling near his home in St. George Utah and doesn't let XP hold him back. Paxton's story serves as an inspiration to those with XP or other chronic illnesses and teaches us that with a little planning and care we call all strive to do something we love in spite of our challenges.

By Paxton Feltner



Whenever I get the chance to ride on a four-wheeler or a side-by-side ATV, I get this feeling nothing else can give. This weekend I got to have a couple of my friends come over, and all we did all day was ride on our 2 four wheelers and RZR. To make it so everyone was comfortable we had my two friends Autumn and Emma in the side-by-side with me, and Elijah and Ethan on the two four wheelers. As we started the ride, I was feeling that adrenaline kick in and I could tell that all my friends could feel it too. We have a lot of dirt trails by my house and as we rode the trails farther and farther we eventually went into the hills. It's pretty sick climbing and I love going up into the hills when we ride.

As an XP patient, when I ride I have to put on a special helmet that my mom and I modified to fit my needs and make sure that I am safe from the sunlight. As I researched what I would be the safest alternative for me, I found a pair of goggles that have UV protective lenses (that is what I use now). As we started to climb a certain hill I knew what straight Bob Ross view that the top of this hill brings. Even with my limitations, I can still find ways to love what nature brings. Whenever you think that you can't enjoy what God created, I invite you to walk outside and take a long deep breath and take in everything around you.



Recent and Upcoming 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. You don't need to be a board member to have a fundraiser of your own; all you need is an idea and some spirit! Big event or small, every dollar raised helps support our families. If you'd like to plan a fundraiser but not sure what to do, contact us and our board members can offer great advice to get you going.

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

For 12 years, Jennifer Feltner and the rest of the Feltner clan have been doing a one-day donut selling blitz to raise money for the XPFSG. This year the Feltner's Krispy Kreme donut sales netted an impressive \$9,700 adding to their total of nearly \$65,000 since they have been doing this fundraiser. Way to go Feltners!



Canada Golf

The 8th annual Anton Jakovac Memorial Golf Tournament Benefitting the XP Family Support Group had another successful year raising more than \$6,000 for the XPFSG adding to the total of nearly \$50,000 since it started. The tournament is hosted by the Jakovac Family near their home in Milton, Ontario, and has become a staple event for friends and family.

Kansas Golf

The 9th annual Swing for XP Golf Tournament hosted by the Madden family of El Dorado, KS, was a great success this past July 27th. The Madden's raised \$5,000 to benefit the XP Family Support Group. This event has become a local favorite and has raised nearly \$50,000 over the years. Great job Maddens on another successful year!



Want to add someone to our electronic newsletter? Contact the office at 916-628-3814 or email us at mmilota@xpfamilysupport.org





TECHNOLOGY RAFFLE!

TICKETS \$5.00 EACH OR 5 FOR \$20.00



Apple
Air Pods



12.9 inch
iPad PRO!

Apple
iWatch!



iRobot
Roomba 690
Vacuuming
Robot & Braava
Jet 240 Mopping
Robot Bundle



Ring
Video
Doorbell
2

The Technology Raffle is happening right now and we need your help to sell tickets. Each board member and XP families have been given tickets to sell for the raffle and we want to sell all 7,500 before the draw at the Medical Conference and Kids Camp in Wichita this November. It's very important that we get help in selling the raffle tickets as raising money through events is the only way we can continue to host camps and help XP families through the support we offer. Please work hard at selling your tickets and ask for more if you can. Our board works hard at raising money but we can't do it alone, we need you!



Pick your prize!
**If your ticket gets pulled,
pick your prize!***

*First winning ticket chooses first, five winners in all, each winner chooses from the remaining prizes!

Need financial assistance to attend this year's conference? Each ticket you sell will earn you \$0.50 towards your conference fees. Example: Sell 100 tickets get \$50 off your fees!

