

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

**Patient Study U of M
Genome Repair Page 1**



**A Higher Calling
Paxton Feltner Page 1**



**Jax's Wish Make-a-
Wish Minnesota Page 2**



**2022 Med Conf
Minneapolis Page 3**

2022 XP International Medical Conference

The University of Minnesota is excited to begin a new study for patients with genome repair disorders. The study is designed to establish a registry of XP patients and first-degree relatives (i.e. parents, siblings, or children). Participation in the study is voluntary and involves completing a questionnaire, providing a blood sample, and/or a skin biopsy. The questionnaire will be accessible online and covers medical history, sun exposure history, and lifestyle information. The blood and skin samples would be obtained at the University of Minnesota when we host the International Xeroderma Pigmentosum Family Support Meeting (XPFSG) in Minneapolis November 10-14, 2022. The samples will be used to measure senescence, inflammation, metabolites, and to measure the level of DNA repair.

-Cont. on Pg 3



A Higher Calling for Paxton Feltner

Ever since Paxton was a little boy he wanted to serve an LDS service mission for the Church of Jesus Christ of Latter Day Saints. Young Men are urged to serve for 2 years in a location all around the world that is chosen for them. Although he had all the determination and faith to serve, XP was an obstacle in his path. In order to serve a full time mission with little to no health restrictions he needed to write a letter to the First Presidency of the church explaining XP and the different accommodations he would need to be safe and be an effective missionary.

-Cont. on Pg 2

Make-A-Wish®



A wish come true for Jax

Jax is 8 years old and has XP-A. Jax loves playgrounds and cherishes the evenings when he is able to go to the park without his protective gear. Jax was granted his wish of an indoor playroom from Make-A-Wish Minnesota. His new playroom has a slide, swings, and lots and lots of balls! A muralist painted fun, cheerful walls in the room. Jax loves his new playroom and is smiling in it every day!! To refer a child for a Make-a-Wish visit <https://wish.org/refer-a-child#panel-2>



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



A Higher Calling continued...

After writing the letter he waited and waited and finally got an email that had his location and duration of his mission. He was called to serve in the Portland, Oregon mission serving the full 2 years. He packed his bags and left home to spread Gods light and love on August 2nd 2021. He is living out a lifelong dream and keeping safe from the sun. It may take extra effort but you can achieve your dreams.

2022 XP International Medical Conference

The patient survey and biological sample data will then be matched and used to advance the understanding of XP and to determine if new therapies available to target senescence and metabolic changes may be of value in XP. Once shared with other researchers in a deidentified (anonymous) manner, the registry information and samples will be a powerful tool to inform a series of multi-specialty clinical and basic science research initiatives aimed at discovering new therapies for XP and related genome repair disorders.



Register Now-2022 XPFSG International Medical Conference!

Registration includes hotel, food, activities, and classes at the conference.

General Schedule:

- Thursday, November 10th—Welcome Reception 6pm
- Friday and Saturday, November 11th—12th—Conference and Activities
- Sunday, November 13th—Farewell Banquet
- Monday, November 14th—Research participation appointments and travel home

Registration for the conference is \$199 per person. XP patients are \$99. Children 2 and under are free. Register at <https://xpfamilysupport.org/2021/08/08/xp-medical-conference-2022-minneapolis/>



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!*

Chat with us on Facebook

Have questions on the best way to talk to your school, need travel ideas, or looking for advice? Let us support you. Like and follow us on Facebook.

