

XPFSG NIGHT TIMES NEWSLETTER

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.

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2022 XP International Medical Conference

In November 2022, the XPFSG hosted 24 families, or 100 participants, from all over the world at the XP Medical Conference at the Graduate Hotel in Minneapolis, MN. Families came as far as Australia and as close as Minneapolis. There were several speakers, which included medical doctors and research scientists from the University of Minnesota and the National Institute of Health, as well as presentations and discussions led by XP patients and their families. The kids partook in activities including jewelry-making, tie-dyeing, painting, a video game bus, a magic show, bowling, and the Minnesota Zoo! Families also had the opportunity to partake in an excursion to the Mall of America for some family fun and shopping. The weekend ended with a wonderful farewell dinner, which is always bittersweet for families as this conference is often the only time XP children are around others just like them. Overall, the conference was a great success! A special thank you to the University of Minnesota for funding this conference. Thank you to all the families, speakers, volunteers, and supporters for helping make this conference a memorable one for the XP Families.



XPFSG will be sending a survey soon to gather feedback on our most recent medical conference and our clinical study. Your opinion matters!
Please watch your email for the survey!

Please scan to visit our website, follow us on Facebook and Instagram, and see the photos from the XP Medical Conference.



Presentation slides from the conference are now available on our website.



In recent years, we have had to reduce the frequency of the XP Medical conference to biannually. It is never an easy decision but the cost of these conferences continue to rise and is now exceeding \$75,000 to host. We rely heavily on families like you to help raise the much needed funds to keep our services in existence. We continue to need more families to help join us in our fundraising efforts. We ask that you please consider assisting XPFSP in fundraising so we can continue to host these wonderful events. Bringing awareness to others about XP is essential and funding is needed so we can continue to help families in need. Visit the XP Family Support group website to donate and support those companies that continue to support us!