



Night Times

Merry Christmas and Happy New Year!

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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Wichita Medical Conference and Kids' Firefly Camp Update

For three days in November XP families from across the United States gathered in Wichita, KS, to learn, play and come together as a community. The kids got to focus exclusively on having fun and hanging out with friends who were just like them (a big deal for most who can feel isolated and different). Parent's got to attend seminars and talks by doctors and other experts on the latest news on XP and how to manage it, all the while happy in the knowledge their kids were being spoiled and having a great time.

Some of the highlights included the Sedgwick County Zoo night tour, extreme race car driving, The Arcade, ComicCon, Wichita State University Tour, Get Air, and the final banquet at the Kansas Underground Salt Museum.



The semi-annual event is held at different locations throughout the United States and is among the most important functions for the XP Family Support Group. The sense of community fostered at the camp allows XP patients and their families to relax a little, have fun and be in the company of those just like them-things that can be elusive in their daily lives. To ensure the XPFSG can continue to fund this amazing camp, please consider donating to help send a kid to camp.



Land & Sea Tri-Tip & Crab Feed Fundraiser

If you're going to be in the Sacramento area on January 26, 2019, join us for our annual Land & Sea Tri-Tip and Crab Feed. Hurray and book your tickets as they sell out every year for this great event. Simply go to www.xpfamilysupport.org to book on-line or call Michele at 916-628-3814. Can't attend but still want to help? Silent auction and raffle items are welcomed just contact us to find out how you can help.

Skin Protection from the Pros

Many of us don't pay much attention to the sun and UV light in the winter but for those with XP winter can pose extra challenges. Learn from the XP skin protection pros to keep our skin healthy during the cold winter months. Here are some tips for dealing with winter skin care challenges:

- Be careful of reflective surfaces – Few things reflect UV better than snow so you should be extra careful to apply sunscreen to avoid UV damage. A scarf and a hat can also be an effective barrier to UV. Doesn't snow where you live? UV bounces off surfaces like concrete and glass too. Combine that with less foliage on the trees and you've got unexpected levels of UV.
- Make sure and moisturize – Dry winter air and wind can strip your skin of essential moisture so use a sunscreen with a moisturizer and use extra moisturizer at home.
- Stay hydrated – Drinking plenty of water in winter will help replenish your skin and counteract that extra dryness in winter.
- Eyes and lips need protection too – wear sunglasses that block UVA+UVB light and apply a lip balm with sun protection in it.



Give a Gift with Meaning

What better gift to give someone (or yourself) than a gift of hope, love and support? By donating to the XP Family Support Group on someone's behalf or in your own name you are helping to ensure that we will be able to continue supporting XP families in practical ways like UV protection and education as well as helping them with a sense of community with this isolating disease. During this time of giving and throughout the year, consider this gift that keeps giving long after the latest 'must have' gift has come and gone.

Donations can be made at www.xpfamilysupport.org

