

# 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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## Register Now for the 2018 XP Medical Conference and Firefly Kids Camp in Wichita!

Registration is now open for the 2018 XP Medical Conference and Firefly Kids Camp in Wichita, KS. Visit the Sedgwick County Zoo, explore a salt mine, hangout in Old Towne. The XP Medical Conference and Firefly Kids camp is a life changing event for individuals of all ages in the Xeroderma Pigmentosum community. The conference increases self-esteem, self-image and allows people to discover they are not alone. Registration is open now. Space is limited. Register Today!

Register at <http://www.xpfamilysupport.org/2018/02/27/xpfsg-medical-conference-wichita/>

Registration is \$700 for a family of four and includes hotel, group meals, and conference sessions. Please call for pricing for families larger than four.





The last two months saw golfers swinging their clubs in support of the XPFSG in two tournaments on either side of the US-Canada border. The Madden family of El Dorado, Kansas, held their 8<sup>th</sup> annual tournament and the Jakovac family of Milton, Ontario held their 7<sup>th</sup> annual tournament. Although held on different days, ironically each tournament started off in the rain and dried up as the day went on. Despite the weather, spirits were high and everyone had a great time. In addition to raising an impressive combined total of over \$11,000, participants came away with a better understanding and greater awareness of XP. We hope the success of these two fundraisers inspires you to take on a fundraising event of your own. If you want some helpful hints or ideas for a different fundraiser, please contact us and we can help.



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!

**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!

## Get involved! Board members needed!



### We want you!

If you're looking to volunteer in a way that directly helps people with XP or maybe you want to give back for the help you've received from the XP Family Support Group, you should consider applying to be a member of our board. If your application is accepted, you'll do meaningful, rewarding work that directly supports our XP families. Below are some requirements and criteria to help you assess if this opportunity is for you. Anyone who is interested can contact us and send a brief note (a couple of paragraphs is fine) as to why you want to apply, any relevant experience and any other skills you can bring to the table that might help the board with various tasks. We welcome all applications and will assess each application based on its own merit.

#### ***Who can apply?***

Anyone. You don't have to have previous board experience, you simply have to be dedicated to improving the lives of people with XP.

#### ***What are the expectations of each board member?***

Board members are required to raise \$5,000 per year through their own fundraising efforts and assist in broader XPFSG fundraising. Board members are required to participate in a monthly teleconference where board business is discussed and voted on. Additionally, board members are required to attend an annual, in-person board meeting in Sacramento, CA, (travel, lodging and meals are covered by XPFSG).

#### ***Do board members do anything else besides raise funds?***

Yes. Board members are assigned tasks based on their skills and availability. For example, board members may help in organizing the medical conference and kids camp. Other board members may work with legislators to change window tinting laws or they may help produce the newsletter. There are many opportunities to put your skills and talents to good use.

#### ***Do you have to have XP in your family to be a board member?***

No. Anyone can apply to be on the board but knowledge about XP and the challenges faced by those affected is an asset.

#### ***How long are board member terms?***

Terms are three years in length. Existing board members can also be nominated and voted on to serve additional terms.

#### ***Do you have to live in the United States to be a board member?***

No. Most of our board are from the United States but the reach of the XPFSG is international. We currently have a board member from Canada.

**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)**

