

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.

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“Good Morning Peyton” Documentary Tells Incredible Story of Community Support

The documentary created by acclaimed filmmaker and director Alison Klayman captures the story of how on August 4, 2017, the town of El Dorado, Kansas, in collaboration with the National Organization of Rare Diseases (NORD) turned night into day for Peyton Madden.

On that evening, as far as Peyton knew, he was going for a bike ride with a couple of friends when they secretly took him to the local community pool. Much to Peyton’s surprise, when they showed up at the pool hundreds of family, friends and people from the community had shown up for a swim party that Peyton wouldn’t soon forget. A shocked but happy Peyton goes on to have the time of his life swimming, playing games with other kids and having yummy treats at the carnival-like atmosphere.



Aside from the fun he had, Peyton’s words to his mom Sarah were most telling on how much the event meant to him, “Mom, they are really interested in me and who I am.” Undoubtedly one of the most difficult aspect of living with a rare disease like XP is the isolating aspects of not being able to do all the things your friends do making that particular evening extra special.

Hopefully the documentary will inspire other communities to show their support for those living with XP and other rare diseases. To watch the documentary on YouTube, click here <https://www.youtube.com/watch?v=Xrksn7arvdw>.

IN MEMORIAM

2017 was a difficult year for many in the XP community whose loved ones passed on. In particular, Christian Phillip Wells, late son of XP Family Support Group Executive Director Michele Milota, passed away tragically in a motor vehicle accident in October of 2017. Christian was the brother of an XP child and was loved by all who knew him. Our thoughts and prayers continue to go out to the Milota family and we hope they find peace during this incredibly difficult time. Donations can be made on the XP Family Support Group website in Christian's honor.



Global XP Conference

For the first time ever, XP International Medical Conference and Camp will take place in February 2018 in London, England. The British XP Support Group will host families and support groups from the United States, Canada, France, Germany, Japan and more to learn about the medial advances and research on XP. Leading international clinicians and researchers, including the Nationally funded XP Clinic based at St. Thomas' Hospital London will share their latest work on XP. Complementing the medical discussion, the conference gives families a chance to share experiences, build kinship and learn from each other.



charitable giving

We know that you have many options when it comes to your giving. Why not choose XP Family Support Group? Your donation can make a difference in the life of an individual suffering from Xeroderma Pigmentosum.

Donations can be made at www.xpfamilysupport.org

Wichita, KS

2018

XPFSG Medical Conference
And Firefly
Kids Camp

November 8-11, 2018

Stay tuned for exciting information on the **2018 Medical Conference!**



Homecoming Queen Riley McCoy's Dream Come True

A shocked and happy Riley McCoy burst into a huge smile as the announcement came over the PA at Dana Hills High School in California, that she was named Homecoming Queen. Students chanted her name before and after the announcement to show their support for Riley as they had elected her as Homecoming Queen in a landslide decision.

Riley was proudly escorted onto the field by her father Mike, who along with mom Pam were overwhelmed by the support for their daughter. Sharing an experience faced by many parents after diagnosis, the McCoy's remembered wondering if Riley would ever be able to attend school. They were worried, not only about the sun, but that students would bully her. After a long search, they found Dana Hills, where many classrooms open to hallways, and the students turned out to be infinitely nicer than they expected.

To cap off the beautiful evening where every precaution was taken so that Riley could attend, Riley was crowned queen by last year's Homecoming King and good friend Jimmy Quick. He surprised Riley by flying in from Nashville to be the one to place the tiara on Riley's head. Riley's priceless expression of joy and her words of, "This is a dream come true," reminds us all how support from friends and family can lift people up despite the challenges they face.

Supporting the XPFSG



Board Members for the XPFSG have had a busy year staging events and raffles to raise money so the organization can continue to provide families with things like UV film and meters as well as host Medical Conferences and Camps for those living with XP. Highlights from this year include Krispy Kreme donut sales, El Dorado, Kansas golf tournament, Milton, Canada golf tournament, walks, gun raffles and more. While the board is working hard to raise as much as they can, they need your help too. If you would like to hold a fundraising event of your own or are interested in participating in an event in your area, just contact us and we'll be happy to assist you.

**Want to add someone to our electronic newsletter? Contact the office
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