



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.

Share Structure Grant

Did you know that the American Association of Dermatology offers grants of up to \$8000 to public schools and non-profits to install permanent shade structures? The program began in 1999 and has awarded over 488 shade structures. The 2024 Shade Structure Grant application will be open October 1-December 15, 2023.

Emma Little and her Mom, Johanna Sweet, in Roanoke County Virginia worked with her Elementary School to submit a grant. The Principal of Oak Grove Elementary contacted the family to ask if they would partner with the school to obtain the grant. Of course the family said yes. While at a regularly scheduled visit with their dermatologist, Dr. Zlotoff at UVA, they asked for a letter of recommendation. Dr. Zlotoff was more than happy to write a letter. The school provided the details from the grant of what needed to be included in the letter. The sun-safety/skin cancer awareness program requirement was described as the annual training that occurs around educating teachers and students about XP and the importance of UV protection. The school currently uses the Little Ted Bear and books to educate younger grade levels. (If you have a child with XP you can receive a bear and book by visiting <https://www.actionforxp.org/little-ted.html>)



A ribbon cutting ceremony occurred in January for the new shade structures. The Principal highlighted XP in her dedication ceremony. Emma was not able to be present, but her brother cut the ribbon on her behalf. Johanna, Emma's mom, said "the process was so easy and not only does it provide more sunshade for all kids, it was a chance to educate others on XP". Emma wears all of her protective clothing including sunscreen, hat, jacket, and gloves. The shade structures offers another layer of UV protection and cooler temperatures. For more information on the Shade Structure Grant visit <https://www.aad.org/public/public-health/shade-structure-grants>. Contact your schools now and begin the process!

[Click here to visit our website, www.xpfamilysupport.org](http://www.xpfamilysupport.org)

Want to submit an idea for an upcoming newsletter?
Email sarah@xpfamilysupport.org