

At the age of 12 my world was flipped upside down. Severe pain, vertigo, tremors, and muscle loss led to many hospitalizations and countless different diagnostic tests and specialists, all leading to no answers. After two and a half years the doctors had given up on me and wrote me off as a psych case.

When I was 14 my dad got a job opportunity on the other side of the country in Arizona. Little did I know what God had in store for me how many questions would soon be answered. Shortly after getting settled I had to be pulled out of the 8th grade due to uncontrollable pain. Once again the doctor hunt continued.

After a few months of searching, a chiropractor suggested we go to see a rheumatologist because I had “super human stretchable ligaments.” Within minutes of walking into his office he had a diagnosis, he said it was painfully obvious I had Ehlers-Danlos Syndrome. As he explained the condition, not only the past few years made sense but so did the small things that had been going on my whole life, including random bruises, “growing pains”, and shoulder and ankle problems, what we learned later to be dislocations.

I am now 17 and much has gone on in my life between then and now, including secondary diagnoses, problems that are still awaiting diagnosis, long hospital stays, a new journey of homeschooling, and finding Starlight. I first heard of Starlight Children’s Foundation Arizona from one of the child life specialists at the hospital. Starlight has been invaluable to me and my family. Having the opportunity to get out of the house and meet other families going through similar situations at the Great Escapes has weakened isolation’s grip on us.

Last year after looking on Starlight’s website I saw a link for Starbright World, Starlight’s online community for chronically ill teens. Having the opportunity to meet and become friends with teens who could relate to what I’m going through has truly changed my life. Before Starbright World I knew of no one my age who could understand what I was going through, but now I know inspiring teens from all over world and we all rally behind each other. No one acts awkward when they find out you are in the hospital or when they learn of the procedures you’ve been through, everyone is so supportive. We also know how to have a good time on there! I can always count on my friends there to cheer me up. I would recommend Starbright World to any chronically ill teens.

My family and I can’t thank Starlight Children’s Foundation enough for what they have done for us.

With love,

Audrey Thoenen (Starlight Teen) and family