



My name is Stephanie. I am 12 years old and in 6<sup>th</sup> grade. I am currently a member of student council, chorus, 4-H pet club, 4-H ambassador, NAAF Legislative Mentor and a dancer.

Three years ago, my life changed. My mom was brushing my hair, and she noticed a bald spot the size of a dime. Several months later, I lost all of my hair due to alopecia areata.

I didn't go to school for a few days because I was afraid of what people would think about me, now that I was bald, I felt alone, sad and anxious. Going to school was difficult during the hair loss, sometimes I was the last one picked for kickball at recess, some kids stared or asked if I was a boy.

We tried different treatments, topical creams, cortisone injections (20 needles) into the scalp but none of it helped, so we stopped those treatments. A year and half later, most of my hair grew back on its own. However, now I am having hair loss again.

This disease is so unpredictable. I went to see my dermatologist the other month and she recommended a new FDA drug, Litfulo, that is approved for kids 12 & older. I didn't have that option three years ago when I was first diagnosed so there has been some progress for alopecia patients and kids over 12 since my diagnosis.

Our insurance has denied the medication, Litfulo, twice so far and now we are on our third appeal. Sometimes getting treatment isn't an easy process but we are still hoping to get the medication. While some kids my age may be thinking about what color Stanley cup to get next, I am thinking and wishing for a cure for alopecia.

We need research. We need increased NIH (National Institutes of Health) funding to find more medications available for us. Investment in research will lead to more studies of the human body that can lead to a cure.