

Paul Silver Tribute Award Essay

Alport Syndrome has helped shape me into the person I am today. In some ways I think having Alports has made me a better person. I feel that I have grown up faster than others my age, having realized that life is short and you should surround yourself with people who truly care about you and make you happy. Over the years I have struggled with denying that I have Alports. I felt the need to be "normal". Now I am proud to say having Alports is just part of my daily life although it is something I am still learning to cope with on a daily basis.

It all started when I was an infant. My diapers were always colored with dark urine. I was sent to a urologist at Children's Hospital in Seattle Washington and diagnosed with benign gross hematuria. It wasn't until I was in 2nd grade and went to a well child checkup when they noticed that I had hearing loss. When my parents notified the school of my hearing loss the school realized that they had failed to notify my parents that I had failed their annual hearing test. After finding out about my hearing loss, I was sent to an ENT physician who did many tests which resulted in being referred to the nephrology department at Seattle Children's Hospital. My diagnosis was confirmed with a kidney biopsy in 3rd grade. I feel fortunate that I had doctors that were able to figure out that that my gross hematuria and hearing loss were connected. No one in my family history has had any type of hearing loss or kidney disease. My dad is the only one that has any symptoms at all and he just has hematuria. I currently wear hearing aids, take medication daily, and my kidney function is "nearly normal" (it has been slowly decreasing).

There is no denying that having Alports has made me different. I cannot understand people talking when I am in crowds, with a lot of background noise, when someone has their back turned to me, ect... School was difficult because even though I had a 504 plan that had accommodations, teachers and other students just didn't understand, did not remember, or simply didn't care that I could not hear.

In 10th grade I chose to finish High School online. This was one of the best decisions I ever made. I never missed lectures or homework assignments because of the kids being noisy or the teacher walking around the room while he/she lectured. My grade point average increased greatly. I was even able to receive a 3.8 GPA my first semester of my senior year.

My hearing loss has impacted my life the most. I have a tendency to avoid situations that I may have trouble hearing in or will not be able hear. Unfortunately this has created some anxiety along the way. I have been involved in 4-H for many years and have shown rabbits, cavy, goats, and horses. I had a lot of anxiety while showing horses because when I am sitting on a horse I cannot understand people that are standing on the ground. Even though my mom requested accommodations, people that can hear have a hard time understanding my needs. Many people called my mom overprotective because she would walk me up to the gate to tell me when I was called and what the people said. Emotionally it was very difficult because people assume things without wanting to find out the truth.

I think that another difficult thing for me dealing with Alports is the not knowing. Even though I am not ready to have kids now, I still don't know when I can have kids. My nephrologist recommends after I have a transplant, but when am I going to need a transplant? Will I be 25? 35? Will I have to wait until I am 40 to have kids? Many friends and family members have said that they would donate a kidney when I need one, but will they match? Will they actually follow through with it when the time comes? There are just so many unanswered questions that will not have answers until the time comes.

I have a passion for animal husbandry. I have wondered if it is because the animals don't care if I can hear or not. I have bred and raised chickens, ducks, rabbits, horses/mules, and guinea pigs. I am currently on a new project of incubated quail eggs. Out of all the animals, horses are my greatest passion. There is no need to see nor hear because I communicate with them through body language.

I just started my freshman year at college, majoring in Horse Production and Training. It is a 2-year associate's degree in applied science. The first week has gone very well. This may sound weird but my mom is going to school with me. I don't want to be the kid that has her mom go to school with her but in a lot of ways it is helpful. It is comforting to know that if I cannot hear what is going on my mom will fill me in. It is like having my very own interpreter. She never went to college when she was younger and stayed home to raise my brother and I so she is really enjoying the opportunity to go back to school. When we graduate we are planning on having a horse breeding and training business.

I would love to receive this award to help me finance my dream of becoming a rodeo queen and participate in barrel racing this spring. It is very expensive to try out to be a queen and to barrel race but receiving the Paul Silver Award would allow me to do it this year. I will need suitable attire that is needed for the different categories that I am scored on. Being a rodeo queen and barrel racing also requires a lot of traveling; even traveling to local rodeos can be very costly. The money would also help pay for entry fees at local rodeos. One of the biggest reasons why I want to do this is to help me continue overcoming my anxiety that I get in uncomfortable situations. I would also like to be able to bring awareness to Alport syndrome and the Alport Syndrome Foundation through being a rodeo queen and barrel racing. My heart knows I can do it, but sometimes my head still has doubts. Just because I am different doesn't mean I am any less.

Thank you for giving me the opportunity to apply for this award.