

My story begins with a bloody diaper. As I lay on the changing table of the pediatric clinic while my younger sister was having a routine check-up, my mother became horribly aware of my gross hematuria. I was three years old and, unfortunately, no diagnosis came from the observation of this symptom, nor from the risky biopsy procedure that followed. For thirteen years, my parents sought opinion after opinion and, after seeing nine specialists spanning six different states, experiencing an unexplainable profound hearing loss, and a second biopsy, I was finally diagnosed with Alport Syndrome. The news of having a chronic kidney disease that could result in kidney failure, deafness, and eyesight problems came as quite a shock to both my sixteen year-old self and my asymptomatic parents.

However, my doctor immediately prescribed simvastatin, spironolactone, and the ACE inhibitor Lisinopril at the minimum dosage and I began my routine visits to the nephrology clinic. With each visit, my doctor progressed to a higher dosage of the drug, and one night after taking my first pill of the highest dosage, I woke up to discover I was choking on my tongue from an allergic reaction. After an informative visit to the ER, my doctor changed my prescription to Atacand and I continued my life as normally as a high school girl with hearing aids and multiple daily prescriptions could. The long-term effects of Alport Syndrome seemed a distant, illusory ghost that would not catch up with me.

Reality swooped in when I was nearing my twentieth birthday and making the transition to an adult nephrology clinic, away from the pediatric nephrologists I had come to know and love for five years. During one of my final visits, I asked my attending fellow, who was (ironically) pregnant at the time, what my future looked like in regards to having a family. She then explained the effects of pregnancy on the kidneys, told me about antibodies, and cautioned that with a likely need for a transplant in my future, pregnancy was not a good idea. This information coupled with the looming possibility of my hearing becoming worse than it already was devastated me. For the first time in my life I actually felt sick- damaged because I had this terrible thing in me that could prevent me from something so blissfully normal as having a family. I felt hopeless and everything I was doing felt pointless. It didn't matter what I was studying in college or what kind of career I wanted to pursue, it

would all end the same way: with loneliness, kidney failure, and deafness .In my bitter resentment toward my disease, and the feeling of a ticking biological clock, I withdrew from college midway through the semester to pursue the exuberant life of a flight attendant.

World travel and life experience foremost on my mind, my employment with a regional airline suited me well. Perhaps the biggest benefit of that particular career was the constant interaction with a multitude of personalities, cultures, and insights provided by those I encountered in my travels. I quickly learned that I wasn't the only person in the world with problems and that there were others who had it far worse than I. Progressively, I found myself channeling the bitterness toward my own disease into empathy for those people who so inspired me. Eventually, I came to realize that I was not given a death sentence, and more importantly, I was meant to be more than a flight attendant. After a year and a half of self-discovery, I left my job as a flight attendant and pursued my new dream of becoming a psychologist.

My first semester back into college was a rough one, as I had spent so much time away that it was difficult to pick up where I left off. However, I later took this as a blessing since it was the reason I changed my foreign language requirement from Spanish to American Sign Language. With those classes, I discovered a new passion in the ability to express myself in ways I never thought possible. I learned that it is possible to listen without necessarily being able to hear, and it greatly fueled my determination to not let my hearing loss inhibit me from being who I ultimately wanted to be. This, combined with my incessant need to help people drove me to reach out in my community, where I participated in a youth mentorship club, volunteered with local theater, and sought out work where I could use my newly acquired sign language skills. In many ways, having Alport Syndrome strengthened me; inspiring my admiration for diversity, motivating my empathy for those in need, and arousing my gratefulness for life and a thirst for new experiences. Hippocrates once said, "It is more important to know what sort of person has a disease than to know what sort of disease a person has," and I am grateful to have experienced enough to know the distinction. I am not Alport Syndrome. I am Jessica, and I happen to have Alport Syndrome.

Now, as a third-year college student, the world is at my feet and there are unlimited

possibilities for me to experience, in spite of the fact that I have a chronic kidney disease . Heavily inspired by the youth I had the pleasure of meeting at the Alport Syndrome Family Conference this past July, I have been even more determined to make a career out of helping those struggling with chronic illness. I am currently studying at the University of Virginia, one of the best schools in the nation; to earn my Bachelor's in psychology with a specialty in American Sign Language. I am very privileged to be able to study at such a wonderful university that offers unique opportunities to its students, such as the ability (and encouragement) to study abroad. One such program at UVA is called Semester at Sea, in which students can spend a summer semester on a cruise ship traveling to nine different countries in Europe and North Africa while earning college credits for classes taught aboard the ship. I am incredibly excited to participate in the 2014 summer voyage to enrich both my college and personal life-experiences. The Paul Silver Tribute Award would significantly help me secure my finances for this \$16,000 voyage so that I might be able to take advantage of this once-in-a-lifetime opportunity.

Much like Mr. Silver's desire to document his journey through Italy, I would also use this award to benefit both myself and my university. I can hardly begin to fathom the enrichment I will gain from this first-handed cultural learning experience .The attainment of a global perspective will significantly benefit my continued understanding of cultural and social diversity as well as provide a new level self-discovery by my participation in service learning projects. I hope that my experiences on this voyage will further influence and encourage me in the pursuit of my goals to bring peace to the minds of those who struggle with chronic illness, inspire hope for those who have none, and make a difference in my life as well as the lives of others.