Overcoming Challenges

“Just another phone call,” I thought as my mom answered a call on her cell phone. Little did I know then that that same call could explain one of the most inexplicable events of my life; the improper formation and growth of the nerves in my eyes. I was born with a mutation of the ocular deformation known as OCA1b (a form of albinism). Because of my mother’s fair skin, no one thought to look into the causes of my lack of sight and depth perception along with, nystagmus, strabismus, irises that light pass through, sensitivity to light, and fair skin. A child with OCA1b can live a near normal life despite sight issues and unusually fair skin because unlike OCA1a (often known as true albinism) the strand allows some pigment, most notably in the hair. Children with OCA1a have pure white hair however, children with OCA1b can have blonde to a light brown. My mother and biological father were both unknown carriers of OCA1b, and they believed that I was just a child that looked a lot like her mother and happened to have many vision problems.

I can’t remember my first visit to the ophthalmologist; I just know that my biological father noticed that my eyes kept on twitching and that they had a mind of their own. After an appointment with my ophthalmologist, I was declared to have a wide variety of abnormal deformations and to be legally blind (vision under or at 20/200). This was very disappointing considering the average human has 20/20 vision, making my eyes 10x worse than normal. It was declared that I would have muscle eye surgery in an attempt to stop my left eye from wandering. The surgery involved fixing the muscles in place with a laser. I do not recall the surgery itself,
just a great pain and the wonder of why my right eye was patched and why my mom was crying. I would later find out that the eye patch was an attempt to work my left eye much like you work a muscle, to make it stronger. I would also find out that on top of my left eye undergoing surgery, in an attempt to align the eye muscles in my right eye, that eye was operated on as well.

Many years went by and there were many..."unique"...experiences. As a young child, I would often bluntly run full speed into a wall. I tripped on almost every curb my foot came in contact with. In fact, it wasn’t until I was nine years old that my mom quit saying “watch your step!” every time we went up or down a curb. I remember one trip to the ophthalmologist in particular, after my usual eye exam, my doctor said that I couldn’t see anything in front of me. My mom, refusing to believe this, said “Yes she can! Evangeline, draw me a person!” Obeying this simple command, I drew a stick figure and in sloppy handwriting, I drew out names above each of them in some feeble attempt to not only show who was who, but to show I could see. I don’t remember the rest of that conversation, but I do remember I walked out of that building with confidence... confidence that abided the fact that I COULD see... that there WAS still hope for me.

In 2008, I went through a series of genetic tests in an attempt to discover the cause of my sight issues. After throwing a fit when they drew my blood, they sent my blood to Boston where it would be tested. As luck would have it, the very last, most expensive test was positive. I had a mutation of OCA1b that they had never seen before. In fact, the only reason their computers detected it was because it was a “spin off” of the original strand. Apparently, it caused a great fascination in the scientists who examined it because they asked if they could keep the blood sample. Walking back to the car from a local supermarket, where my mom took that phone call, I remember sitting on that very curb I used to trip over every time I passed over it thinking no
longer will it trip me again... no longer... and faithful to that promise, I never again tripped over that curb.

Over the years, my vision has improved greatly. Now my vision is 20/60... well... according to the snellen chart that I have partly memorized. I am living with OCA1b quite well, adapting and growing in my methods all the time. To be honest, if I could go back and change my genetic code so that I wouldn’t have OCA1b, I wouldn’t. Coping with this disorder has taught me to be proud of what I have and to be very resourceful. I wouldn’t have it any other way.