



## Personal Story *and* 2014 NF Hero Lindsey Allee!

Hello, my name is Lindsey. I am 10 years old and in 5th grade. I really love to listen to music especially 80's music like Michael Jackson. I love to play on the computer. My favorite game is Minecraft but I also like Club Penguin. I love to ride my bike, and play outside as well as spend time with friends.

I have Neurofibromatosis type 1, or NF1. I was born with it, but didn't find out that I had it until I was in 2<sup>nd</sup> grade. My school nurse felt a curve in my back and sent us to the doctor. It was a roller coaster ride after that as we had to go to lots of doctor visits and have many tests.

My doctor at Children's Mercy in Kansas City diagnosed my case when he saw cafe-au-lait spots under my arms and on my legs or tummy. This was done when I was 7 years old. I had to have a few MRIs so they could see if I had any tumors. I have one behind my eyes, called an Optic Glioma, as well as several on my brain, and a few others in my back.

The ones in my back are the ones that have caused me the most trouble so far. They grew from my spine, and were so big they caused my spine to curve. I went from 0 degree curve to over 55 degrees in less than a year. My doctor said I have scoliosis. This is when your spine curves. My doctor said my curve was really big so I had to have surgery. The doctor put titanium rods on either side of my spine a few months later. It took 4 hours and I was really sore. After I came home I had to go back to the hospital because I had some nerve pain. My nerves are extra sensitive because of my NF1 and I had to wear a brace for a while until I felt better. Since they put the rods in I have to have surgery every 6 months as I grow to make my rods longer. We had surgery #7 in January 2014. I had to have one of my rods removed because it was causing so much nerve pain. I am feeling much better now, and I am back to school and playing with my friends. I still get really tired and my doctor says I need to eat more. This is very hard for me, and I do not gain weight easily.

I also have to visit lots of different doctors every year because of my NF. I have to have MRI's to see if my tumors are growing. I also see a special doctor to check my eyes and the tumor that is on my optic nerve.

School is very hard for me, as I have some learning disabilities and ADHD due to my NF1. The kids at school do not understand and have never heard of NF. When I have surgery they cannot see my bandages on my back, and often bump into me. I also struggle with anxiety and self confidence since I feel I am so different than everyone else. I have a counselor that is really great, but growing up is very hard with NF. My wish is for everyone to know about NF, just like everyone knows about cancer. Lots of people have it, so why don't people know about it?

My family loves to go to the annual NF Walk every year in Kansas City; our team name is "Lindsey's Lucky Stars!" We even had my Girl Scout troop come to walk with us last year. I like it because I get to see other kids with NF, and everyone there knows about NF.

On behalf of myself and many others with NF, thank you for helping to make a difference.

Lindsey Allee