

Sasha's NF Journey

Sasha was born with several spots on her body we initially thought were birthmarks; but turned out to be cafe-au-lait spots. She did not show any signs of discomfort and seemed completely healthy otherwise. At the age of 2 years old, we became concerned and decided to consult with a doctor and met with two different physicians until one of them diagnosed Sasha with Neurofibromatosis (NF1).

It was frustrating because the doctors we were seeing did not know how to explain NF1 to us or what to expect for our daughter, they simply said "monitor the spots." At age 4, Sasha had freckling under her arms and developed tiny neurofibromas (benign tumors) throughout her body. This was puzzling and scary for us to see this happening to our little girl. We did notice her head was a little oversized and she was having some difficulty with her speech. We began yearly MRIs to monitor the progress of the plexiform on her brain and the neurofibromas. It was discovered that Sasha had an optic glioma in her eye that has appeared to remain stabilized after several years of monitoring by her ophthalmologist. We continue to have regular visits twice a year and are blessed that no significant changes have occurred with her eyesight.

When you see Sasha, you see a very happy, energetic and vibrant young 4th grader. She is full of life, loved by family, friends, teachers and everyone she meets. She has made great strides by working hard in speech therapy as well as her regular classroom activities where she is proud of making A's and B's.

Several years ago we started attending the Texas NF support groups at Cooks Children's Hospital. It has really helped our family understand this disorder and made us feel less isolated and alone. By meeting with other families and staff, we are able to share concerns with one another as well as our own experiences. The Cooks Children's staff has been nothing short of outstanding; they are very supportive and show genuine concern for our daughter as well as the many other families they serve.

God has blessed us with a beautiful daughter that has a bright future ahead of her. With the support of her family, friends, team of doctors and Cooks Children's hospital, Sasha will have a better understanding of NF and realize that the disorder cannot stop her from achieving her goals and dreams in life. With continuous prayer and positive strides in the medical field, we are confident her body will have minimal complications. Thank you for coming out and making a difference in the lives of NF families, your participation in this fundraiser is greatly appreciated! We send love and prayers to all the new friends we have met, and together we can help all children affected by this disorder feel confident and loved.

Sean, Dawnyelle, Sasha, Sean II, Sterling