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## WHY AM I ORGANIZING A FUNDRAISER?

Neurofibromatosis is a word that most people have never heard. Have you? Neurofibromatosis, otherwise known as NF, is a genetic disorder where tumors form anywhere in or on the body. It affects 1 in 3,000 people and is more prevalent than cystic fibrosis, Duchenne muscular dystrophy, and Huntington's Disease combined, yet most people have never heard of it. I first heard this word in July of 2009 at a doctor's appointment when my son, Nicolas Cohoon, was 5 months old. Seven months later, on March 29, 2009, Nic was officially diagnosed with NF type 1. Our journey towards diagnosis began when we noticed his "birthmarks" multiplying. We later found out that these "birthmarks" are called café au lait Spots and are an indicator of NF. Over the past 2 years, Nicolas has endured more than 50 doctor visits, 3 sedated MRIs, and weekly physical and occupational therapy sessions. Nic's NF related issues include bilateral "thickening" on his optic nerves (which could develop into tumors), low muscle tone (hypotonia) and a slight curvature of his spine. Although most cases of NF1 are mild to moderate, as is currently the case with Nic, it is possible his disorder could cause disfigurement, blindness, skeletal abnormalities, dermal, brain, and spinal tumors, loss of limbs, cancer, and learning disabilities. Learning disabilities are five times more common in those with NF1 than in the general population. Nic's future will consist of annual doctor appointments with 5 different doctors and yearly MRI's to monitor any new or increased tumor growth.

## WHERE WILL THE MONEY GO?

As a mother who wants to help her child get well, I support the work of the Children's Tumor Foundation. The Children's Tumor Foundation is a 501(c)(3), non-profit organization dedicated to improving the health and well-being of individuals and families affected by Neurofibromatosis (NF). The Children's Tumor Foundation encourages and supports research that develops treatments for Neurofibromatosis type 1, type 2 and schwannomatosis. They also support people with NF and their families and caregivers by providing thorough, accurate, current and readily accessible information about the disorder. They have assisted in the development of clinical centers and best practices in order to create better access to quality healthcare for affected individuals. Lastly, the Children's Tumor Foundation expands public awareness of NF to promote earlier and accurate diagnoses by the medical community, increases the non-affected population's understanding of the challenges facing people with NF, and encourages financial and other forms of support from public and private sources.



## HOW CAN YOU HELP?

As Nic's mom I feel helpless because I cannot give him a pill that will rid him of NF. I cannot tell him that he will be OK tomorrow. All I can do is raise money for NF research, and make the most of EVERY DAY. I need your help. We are organizing a fundraiser in honor of my NF Hero, Nicolas Cohoon. I would greatly appreciate your company's commitment and support so that this fundraiser is a spectacular event for my NF Hero, and all the NF Heroes.