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Bryan Caruso – Personal NF Story

My name is Bryan Caruso and I have a disease called Neurofibromatosis (type 1). When I was 3 years old, my mom noticed a tumor on my back and took me to a neurosurgeon to get it checked. That was when I was diagnosed with Nf type 1. We also have had genetics testing and no one in my family history has ever had Neurofibromatosis. I am the only one.

Neurofibromatosis has affected me physically, mentally and psychologically. I have spots, called café au lait, which look like birthmarks scattered all over my body. I also have had cyst called Neurofibromas grow all over my body, some deep in my skin tissue and some superficial. Thankfully, they have been very mildly. I had many surgeries to remove the Neurofibromas. I even had a neurofibroma removed from my brain when I was 12 years old. Just recently, I had a plexi neurofibroma removed from my right eyebrow.

Neurofibromatosis has caused me to struggle with learning disabilities. I have struggled my whole life throughout school. It has been very hard for me to remember, comprehend and perform well on test. I have had many tutors to help me all the way through out my school years. I even had many attempts to complete college courses in which I struggled to accomplish. As anyone can see, this is very emotionally hard and overwhelming for me and has left me with a great deal of depression and fearing for my future.

Neurofibromatosis is becoming more and more prevalent and needs to be stopped. We need a cure for Neurofibromatosis. It cost a lot of money to do research and with this economy, it's next to impossible to afford. Federal funding would be a major help in funding for the research that needs to be done. Curing Neurofibromatosis would save many lives as well as prevent future lives from suffering from this disease. Not just me alone, but being cured from Neurofibromatosis would save me from my life struggles. I would no longer have to worry about costly surgeries, which can sometimes be deadly. I would no longer fear for my future, as my learning disabilities would disappear. Most importantly, I would no longer fear that I will pass it down to my future children.

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