

YOUR NAME
YOUR ADDRESS
YOUR PHONE

January 10, 2015

REPRESENTATIVE'S NAME OR SENATOR'S NAME (in all there should be 3 separate letters)

Dear *Honorable* NAME OF CONGRESSMAN or *Senator* NAME:

I am writing to ask for your support for more federal funding for research to CURE Neurofibromatosis (NF). *What is NF?* NF is a set of genetic disorders that cause tumors to grow randomly on nerve endings throughout the body. These tumors commonly occur in the brain and spine and can cause bone deformities, disfigurement, deafness, severe balance problems, loss of mobility and blindness. NF is more prevalent than cystic fibrosis, Duchenne muscular dystrophy and Huntington's disease *combined*.

[Include your personal story] My five year old son, Austin, was diagnosed with NF at an early age. This disorder is said to have caused Austin's heart defect, which was repaired at four months of age. Though his heart is said to be repaired, the effects of NF are on-going. Currently, he receives physical and occupational therapy and is part of a special program offered through the public school system. Additionally, his geneticist confirmed numerous tumors on his sternum. We do not know how NF will affect Austin in the future, but we do know it is a progressive disorder. That said, though we are prepared to face new hurdles in the future, we continue to stay positive, raise funds, and ask for support from people such as yourself.

Austin is not alone, one out of every 2,500 children are born with NF. Research is needed to address the spectrum of potential complications, which can include tumors on the skin, spine, brain and internal organs and learning disabilities. It is life-long disorder with a variety of potential complications. *It is diverse and affects all races.* We need your help, Austin requires it now.

As someone closely touched by Neurofibromatosis, I am writing to ask for your support. *Funding is needed for further research.* Right now, NF research is moving out of the lab and into human clinical trials and at this critical juncture your support could move us closer to the promise of a cure. These successes include the discovery of nerve signaling pathways, new pain management models, and advanced brain and spinal imaging techniques. These findings are now being translated into drug development; to the great benefit of not only those afflicted with NF, but also others facing similar types of disorders.

In summary, we ask you, our representative to help. *Please allocate funding for research to find a cure for Neurofibromatosis.*

With hopes for our son's improved health and well-being,

YOUR NAME/SIGNATURE IF POSSIBLE BUT NOT NECESSARY