

{DATE}

Dear Honorable {*REPRESENTATIVE*} or Senator {*SENATOR*} [*note: there should be 3 letters – one for your Representative and one for each of your two Senators*],

I have a child with NF {*CHANGE AS NEEDED*} and as one of your constituents I desperately need you to support neurofibromatosis and schwannomatosis research.

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.

*A photo really helps! In fact the story and the photo are the most important thing to include!*

**{*INCLUDE OUR PERSONAL STORY – THE MOST IMPORTANT PART*}** My eight-year-old daughter, Lucy, has NF. She's lost her eye sight in one eye from an optic glioma and struggles with learning disabilities. She also has several tumors on her skin and a larger plexiform tumor in her hip. We know that she faces a lifetime of uncertainty as NF is variable but chronic.

Lucy is not alone, approximately one out of every 2,000 children are born with one of the NF disorders. 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 a life-long disorder with a variety of potential complications. It is diverse and affects all races. In fact, because the NF gene has such wide-ranging impact, it is believed that approximately 175 million Americans benefit from NF research.

As someone closely touched by NF, I am writing to ask for your support. More funding is needed for further research. NF research is finally moving out of the lab and into human clinical trials and at this critical juncture your support could move us closer to much needed treatments.

Lucy needs your help now!

Sincerely,

YOUR NAME/SIGNATURE IF POSSIBLE BUT NOT NECESSARY