



Rep. Tom Price  
100 Cannon House Office Building  
District of Columbia 20515-1006  
**Phone:** (202) 225-4501

### **Tosha Murphy – Personal NF Story**

To Whom It May Concern:

My name is Tosha Murphy. Both my husband and my 7 year old son have Neurofibromatosis form 1. This currently is a chronic disease. Money to help support research on NF could ultimately change this fact, which would have a profound effect on my family and our future generations.

My husband was diagnosed with neurofibromatosis in August of 2005 at the age of 26, a mere 2 months before our son was due to be born. His diagnosis was very late in life compared to most NF diagnoses. This was due to the lack of knowledge on this condition when he was growing up. When our son was born in October, we soon found out he also had NF1. Over the past 7 years, my husband has had to have a tumor surgically removed from his spine (Jan 2006). He currently has to get an MRI done every year to watch for additional tumors on his spine. My son had a tumor on his auditory nerve causing him to have hearing aids for 6 months (10-2009 to 4-2010), and most recently a tumor on his optic nerve which he received a year of chemotherapy (2012) to reduce its size. The tumor on his auditory nerve has set him back in school so much that he has to go to a special needs classroom. This is mainly because the hearing loss at such a crucial time in his development has caused him to have a significant speech delay. He now has to have sedated MRIs every 3 months to monitor for additional tumors in his brain and nervous system. Neurofibromatosis affects our lives every day. Many learning disorders are linked to NF as well as behavioral disorders. While there is only a 50% chance any other children we have will also have this disorder, it has even affected us to the point that my husband and I are very hesitant about having more children.

Please help us continue the research needed to find better ways to treat and diagnose NF and maybe even, someday, a cure. Your help is very much needed and appreciated by all of us who live every day in the shadow of this condition.

Thank you,

Tosha Murphy, RDH  
4748 Karls Gate Dr., Marietta, GA 30068 · (678) 276-6000