

Create a person letter to distribute to your mail and email list. Be sure to encourage friends to pass it on or to create a letter of their own. A sample is included here.

It helps in your letter to include your personal story about why you are raising funds for the NF cause and your goal such as, **“This year our goal is to raise \$2,000 and a lot of hope. Please help us reach and exceed this goal”**. Including the different ways to donate (i.e. online at nfmidwest.org; by mail; or on your firstgiving.com site) is also very helpful as is suggesting different amounts. For example, **“a \$20 donation is a great start; \$50 is just amazing; \$100 would put us over the moon; but any amount is appreciated”**. It’s just a thought; be creative.

Since our letter this year is NF2 specific, we have included here verbiage for NF Type 1:

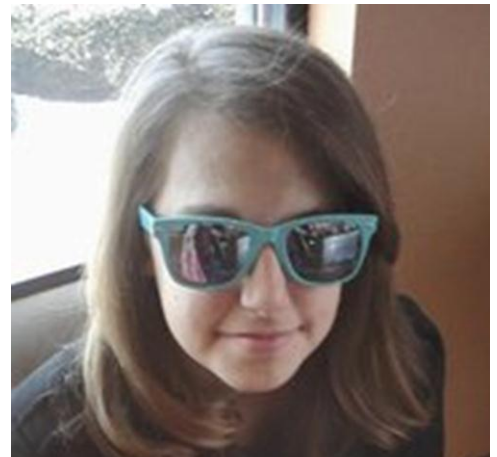
Neurofibromatosis is a condition that affects approximately 1 in 2,500 people. It is a complicated, highly variable genetic disorder of the nervous system that causes tumors to form on the nerves anywhere in the body at any time. NF can cause tumors, cancer, hearing loss, learning disabilities, seizures, bone deformities, vision impairment, chronic pain and more. There is no cure, and very little in the way of treatments. Tumors may be partially removed, but often grow back.

Sample Letter

Dear friends and family,

Take a BITE out of NF2!!

Ali’s Gaitors was created to help raise awareness about Neurofibromatosis Type II (NF2 for short) and to help fund and support NF research. Our daughter Ali (now 14 years old) was diagnosed with NF2 in June 2007 and has had two brain surgeries thus far. On Jan. 29, 2008, Ali underwent surgery to remove a tumor from her right ear. While the facial and auditory nerve were left intact, she still lost the hearing in that ear. Then, on July 23, 2009, she had a large tumor removed from behind the bridge of her nose, followed by extensive reconstruction of her orbital bone and the roof of her sinuses. Currently, she has a tumor in her left ear (threatening total deafness) and three other tumors in her brain as well as a multitude of spinal tumors. Every MRI brings the threat of tumor growth or new tumor development.



Where do all these tumors come from?? NF2 is a rare neurological disorder that causes tumors to grow due to the lack of a protein that suppresses tumor growth. Though they are benign, people with NF2 can develop these tumors in the brain, spinal cord and throughout the body. As the tumors grow and press on the nerves, it can lead to deafness, balance issues, vision impairment, seizures, paralysis and sometimes life-threatening conditions. Currently, the only treatment for children with NF2 is surgical removal which poses great risk, so ***we need to find a cure for NF2!***

Thankfully, Ali has no surgeries on the immediate horizon and our campaign to raise funds exclusively for NF2 research was very successful last year, as we were able to make a sizeable grant to a research lab doing promising work on

potential drug therapies for the nasty type of tumor that Ali had removed in 2009. But we cannot rest on our laurels!! While there is some research being done today specifically for NF2, there needs to be lots more so that we can wipe this disease out during Ali's lifetime! This year, raising funds for continual NF research is more critical than ever. Not just for Ali's sake but for all those NF families who are struggling with life-altering decisions on treatment, often when their loved one affected by NF is not yet in their teen years. Fundraising is also imperative during these slow economic times because research labs have less access to research dollars through grants and other avenues, so they have to rely on private funding, especially in the case of rare diseases and disorders such as neurofibromatosis.

Join Ali's Gaitors as we participate in *both* Great Steps for NF walks again this year: June 4, 2011 at Naperville's Riverwalk and June 18, 2011 at Effingham's Community Park. This year, we also will be sponsoring a new Candlelight Bowl/Bean Bag Tournery Fundraiser on May 14, 2011 at Oak Forest Bowl (15240 S. Cicero, Oak Forest; call Laura for more details). We dedicate our involvement in these fundraising efforts to Ali but we also walk as a tribute to our many friends in the NF2 community and in memory of those we have lost to the disease (including several last year). Please honor all of them by joining Ali's Gaitors at any of these events and contributing to NF research NOW to stop tumor growth from destroying more lives.

You can donate online at our personal page at <http://www.firstgiving.com/aligaitors-naperville-2011> or at nfmidwest.org. Donating online is simple, fast and totally secure. It is also the most efficient way to support our fundraising efforts. However, if you would rather donate offline, please go to this webpage and print out a donor form http://nfmidwest.org/files/Donor_Form.pdf. Fill it out and be sure to include "Didier Family/Ali's Gaitors" as the Participant/Family Name and "16" as the Participant Number. Then mail in your donation to the NF Midwest address on the form (new location).

Other ways you can support our efforts:

- Gather a group of friends and come out and join us for either walk. You won't regret it! Great Steps makes for a wonderful fun-filled day! (Details are here Greatsteps.org)
- Check out our new Bowling/Bean Bag Tournament event. Fun for the entire family! Check back here for a link to more information, coming soon.
- Forward this to anyone who you think might want to donate too!

Many thanks for your continued support. May God bless you for your generosity!

The Didier Family: Mark, Laura, Sam and Ali