**RESOURCES TO SUBMIT A LETTER TO THE EDITOR DURING   
NF AWARENESS MONTH**

Thanks for helping spread awareness about neurofibromatosis in your community during NF Awareness Month!

Submitting a Letter to the Editor to your local newspaper is an excellent way to raise awareness about NF. While it is often a straightforward process, every newspaper and website has their own specific guidelines.

**Why Letters to the Editor matter**

Writing a letter to the editor is a great opportunity to share your opinion, educate the public, introduce a local NF Hero, volunteer or fundraiser, explain why a building is lit up blue, or express the need for money to fund critical research. One letter cannot do it all, but should pick specific things to focus on.

**Determining where to submit your letter**

After you’ve identified which paper you want to write to, visit their website and look for the Contact page or a link to “Submit your letter.” Remember to follow instructions and include all requested contact information.

**Technical Tips**

We have included two sample letters below, but encourage you to personalize them or write your own, keeping in mind the following tips:

* Research and then follow the policies and specifications of the publication to which you are submitting your letter. Except as noted, it is OK to send the same or similar letters to more than one publication.
* Generally, letters to the editor should be less than 250 words, but check the suggested word count on each specific paper’s website.
* E-mail your letter in the body of the email (never send unsolicited attachments). Always include your name, address, and daytime telephone number. Include exactly one e-mail address in the To field. Don't send to editors via Cc or Bcc.

* Editors prefer to run letters about issues of local importance and interest. Be clear and concise about your relationship to the cause; mention if you live with NF, are relative of someone living with NF or an active volunteer committed to supporting fundraising efforts.
* Avoid jargon or acronyms (spell out any name the first time you use it, followed by the acronym in parentheses).
* **"Humanize" your article. Use** anecdotes and personal stories to help explain and bring complicated issues to life.
* If your letter runs, obtain a hard copy of the issue for your own records, as well as a copy for the Children’s Tumor Foundation archive. Please send it to:
  + Digital copy by email: [media@ctf.org](mailto:media@ctf.org)
  + Hard copy by mail:

Children’s Tumor Foundation

ATTN: Rebecca Harris

370 Lexington Avenue, Ste 2100

New York, NY 10017

**Sample 1**

To the Editor:

Imagine being told that your child has a disorder for which there are few medical treatments and no cure. That’s what happened to me (number) years ago when my son/daughter was first diagnosed with neurofibromatosis (NF).

NF is a genetic disorder that causes tumors to grow on nerves throughout the body and can result in blindness, deafness, bone abnormalities, disfigurement, learning disabilities, disabling pain, and even cancer. With no cure and few treatment options, everything felt hopeless. Then I started to realize how courageous my son/ daughter is; he/she was fighting NF with strength, dignity and even a sense of humor!

Well, I stopped being hopeless and became a fighter, too. I joined forces with the Children’s Tumor Foundation (CTF), the largest a non-profit organization committed to ending NF through research. CTF believes that full-scale collaboration will lead to solutions for NF. That alliance includes not only clinicians, researchers and other experts in the field, but patients and their families, too. This Foundation has been leading the fight to end NF since 1978, and, in 2020, saw the FDA approve the first-ever treatment, Koselugo (selumetinib), for inoperable plexiform neurofibromas, a treatment that helps a segment of NF1 patients. This momentous step forward started with early research funded by a CTF grant.

May is NF Awareness Month and I invite other members of the (name of city/ town) community to fight with our family by learning more about NF at [www.ctf.org](http://www.ctf.org).

Sincerely,

Full Name

Phone number

**Sample 2**

To the Editor:

Imagine being told that you have a disorder for which there are few medical treatments and no cure. That’s what happened to me (number) years ago when I was first diagnosed with neurofibromatosis (NF).

NF is a genetic disorder that causes tumors to grow on nerves throughout the body and can result in blindness, deafness, bone abnormalities, disfigurement, learning disabilities, disabling pain, and even cancer. With no cure and few treatment options, everything felt hopeless. Until I found the Children’s Tumor Foundation, the largest a non-profit organization in the country committed to ending NF through research, and got involved in the NF community.

I met tons of other people just like me, people living their lives and fighting NF with strength, dignity and even a sense of humor. NF is a rare disease, and one of the most important things we can do is raise awareness and talk about what it means to live with the NF. This is why I’m recognizing NF Awareness Month in May, and why (identify a local landmark that is Shining a Light on NF, a proclamation in the area or an upcoming event). I invite other members of the (name of city/ town) community to fight with me by learning more about NF at [www.ctf.org](http://www.ctf.org).

Sincerely,

Full Name

Phone number