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

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

Submitting a Letter to the Editor to your local media outlet is an excellent way to raise awareness about NF. While it is often a straightforward process, every newspaper, news outlet, or website have 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 funding critical research. One letter cannot do it all, but should focus on one or two specific messages.

**Determining where to submit your letter**

After you’ve identified which news outlet 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 publication’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 a relative of someone living with NF, or an active volunteer 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. Share a link or digital copy with CTF: [media@ctf.org](mailto:media@ctf.org)

**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 NF.

NF, which includes all forms of neurofibromatosis and schwannomatosis, is a group of genetic conditions 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), a global leader and catalyst committed to advancing treatments and ending NF through research. CTF believes in the power of collaboration—uniting patients, families, clinicians, and researchers to accelerate progress. This Foundation has been leading the fight to end NF since 1978, and, demonstrating the power of sustained investment in science, played a significant role in the two FDA-approved treatments for NF: **Koselugo (selumetinib) in 2020 and Gomekli (mirdatmetinib)** in 2025. These approvals are just the beginning – more treatments are urgently needed.

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 NF.

NF, which includes all forms of neurofibromatosis and schwannomatosis, is a group of genetic conditions 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. At first, I felt hopeless. But then I found the Children’s Tumor Foundation (CTF), the global leader advancing research and driving treatments for NF – and became part of a community that refuses to give up.

Through CTF, I met incredible people just like me – people who face NF every day with strength, resilience, and even a sense of humor. NF is a rare disease, and one of the most powerful things we can do is raise awareness and help others understand what it means to live with it. That’s why I’m recognizing NF Awareness Month this May and why (mention a local landmark lighting up for NF, a proclamation, or an upcoming event) is shining a light on this condition.

I invite the (name of city/town) community to join me in the fight against NF by learning more at [www.ctf.org](http://www.ctf.org/).

Sincerely,

Full Name

Phone number

*Last updated April 2025*