**RESOURCES TO REQUEST A PROCLAMATION FOR   
NF AWARENESS MONTH**

Thanks for helping spread awareness about NF in your community!

May is NF Awareness Month, a time to connect, understand, and educate about NF. World NF Awareness Day takes place every year on May 17. NF Awareness Month lasts throughout the entire month of May.

NF refers to a group of genetic **conditions that cause tumors to grow on nerves throughout the body. NF includes neurofibromatosis type 1 (NF1) and all types of schwannomatosis (SWN), including***NF2*-**related schwannomatosis (***NF2*-**SWN), formerly known as neurofibromatosis type 2.**

Obtaining a proclamation from your state is an excellent way to raise awareness about NF. While it is often a simple process, every state/city has different guidelines. This toolkit will provide you with the resources you may need to request that your Mayor, Governor or other government official issue an official proclamation in your city, county or state.

**What is a Proclamation?**

Proclamations are typically issued by a government official to recognize the importance of a community event, significant achievements by community members, or to signal a state or city role in significant national events.

Proclamations may be read at a City Council meeting or at a community event, depending entirely on the process set forth by the council. Original, signed proclamations are often provided to the requesting party (sometimes must be received in person at city offices).

**Why request a Proclamation in your city or state?**

* Opportunity to meet/greet/photo with your Governor, Mayor and/or other representation
* Help your city/state recognize neurofibromatosis in an official capacity
* Get your local government more involved in local causes
* Creates a newsworthy, local story for your local news outlets
* Tell local NF Hero stories to new audiences

**What day/month should I request the proclamation for?**

* Proclaim May as NF Awareness Month

OR

* Proclaim May 17 as World NF Awareness Day

**STEPS TO REQUEST A PROCLAMATION**

**Visit your local government’s website**.

Some city and state websites will have a section on “How to request a Proclamation.” Some will even have an online Proclamation Request section on their website. If they do not have an online request section, send an email request to your Mayor and/or Governor.

*You can use the sample outreach email in this toolkit.*

**Plan ahead.**

Proclamations requested at least **two months in advance** have the best chance of being completed and provided to the requestor by a specific date. Make sure to reach out well in advance of May.

**Provide a draft**.

You may be asked to provide a draft of a sample proclamation.

*We have available sample draft proclamation language for you to personalize to your city/state and send.*

**Celebrate your city.**

Your local government office may invite you to attend a meeting to accept the proclamation on behalf of the Children’s Tumor Foundation. This is a great press opportunity and way to bring your community together to recognize other NF families living in the community.

**Notify CTF of your accomplishment.**

[**Fill out this form**](https://docs.google.com/forms/d/e/1FAIpQLSem11kfTmsBiDwaJ6iztMiDI3LYe1aOjsoQ5V5ORs-d71acVA/viewform) to let the Communications Dept. at the Children’s Tumor Foundation know about your accomplishment. We will add your city and/or state to our [**webpage**](https://www.ctf.org/get-involved/proclamations).

**Share your proclamation.**

Share your announcement, photos, videos, and other moments from receiving your proclamation with the NF community by:

* Email [media@ctf.org](mailto:media@ctf.org) with a photo or a scan of your proclamation.
* Email [media@ctf.org](mailto:media@ctf.org) with an explanation of what took place in your community and any photos/videos
* Tag #EndNF on all your social media posts
* Tell the media! We will provide templates for a press release and a Letter to the Editor, plus best practices for conducting this outreach.

Email Rebecca Harris at [rharris@ctf.org](mailto:rharris@ctf.org) or media@ctf.org with any questions!

**SAMPLE OUTREACH EMAIL**

The following email offers ideas and language you can use as part of your outreach to your Mayor, Governor, and local officials for Awareness Month or World NF Awareness Day. Feel free to copy/paste or edit as you see fit as you communicate about your involvement with the Children’s Tumor Foundation and NF Awareness.

Dear \_\_\_\_\_\_\_\_\_\_,

This year, during the month of May / on May 17, we are part of a nationwide call to action to bring attention to a genetic condition that causes tumors to grow on nerves throughout the body, and affects more than 150,000 people living in the United States and more than 4 million people worldwide. On behalf of the Children’s Tumor Foundation, the world’s leading organization dedicated to NF research, we are seeking city / state resolutions recognizing the [month/day].

[Add 3-4 sentences about your family and your connection to the community.]

Last year, Governors around the country supported the cause, including those from Colorado, Iowa, Ohio, Massachusetts, and Wisconsin, among others. NF is classified as a rare condition and for the community to learn of such absolute support from their city/ state goes a long way to increasing knowledge of a cause that deserves attention – and a cure. Proclamations are one component of a larger campaign that extends across the country, on- and offline, and include our popular “Shine a Light on NF” campaign, which is a grassroots initiative bringing awareness into the community by lighting up buildings, bridges and monuments in blue and green.

We are asking for your help in this effort by declaring May as [NF Awareness Month or May 17 as World NF Awareness Day] in City/State.

For additional information, please visit [www.ctf.org](http://www.ctf.org). Thank you for considering our request.

[Your Name]

*Last updated January 2024*