**RESOURCES TO REQUEST A LANDMARK TO**

**SHINE A LIGHT ON NF**

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.**

This toolkit will provide you with the resources you may need to request that a landmark in your community light up blue and green as a way to draw awareness to NF on May 17, some other day in May or for the entire month.

**What is Shine a Light on NF?**

Shine a Light on NF is a grassroots initiative that brings NF awareness into the community by lighting up buildings, bridges, monuments and other landmarks in blue and green, the official colors of NF. It is one part of the Children’s Tumor Foundation’s month-long awareness campaign that includes online and offline events designed to educate the community about this under-recognized genetic disorder.

**Why request a landmark in your community light up?**

* Help your city/state recognize neurofibromatosis in an official capacity
* Creates a newsworthy, local story for your local news outlets
* Establishes a place to meet others in your local NF community on the day of the lighting
* Tell local NF Hero stories to new audiences

**STEPS TO REQUEST A LANDMARK SHINE A LIGHT ON NF**

**Brainstorm locations**

Think about landmarks, bridges and notable buildings in your community. Is there a site that stands out in the skyline? A place where people gather for large events?

**Plan ahead.**

Requests to light up blue and/or green typically need to be submitted 1-3 months in advance.

*You can use the sample outreach email provided below.*

**Be flexible.**

The official colors of NF are blue and green, however, many locations may only have the capacity to change one color. In these instances, ask for blue, the primary color of NF awareness.

When asked for a date, the first choice should always be May 17, World NF Awareness Day. If that date is not available, we recommend asking for May 1 or some other date in May. The entire month is NF Awareness Month, so there are plenty of opportunities for a location to be involved and help spread NF awareness!

**Tell your community!**

Once you’ve received a confirmation that a location in your area will Shine a Light on NF, it’s time to tell everyone!

* Email [media@ctf.org](mailto:media@ctf.org) so that your landmark can be added to the NF Awareness Month webpage
* Tag #EndNF on all your social media posts
* Plan a gathering for your friends, family and extended NF community at the location. Or, gather at a nearby spot where you have a view of the site (of course, be mindful about safety). It’s very powerful to meet like-minded families and view together!
* 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 your photos to [media@ctf.org](mailto:media@ctf.org) for use in future promotional materials and opportunity to be shared with the entire NF community.

Email Rebecca Harris, PR Director, 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 local buildings, bridges, monuments and landmarks to Shine a Light on NF. Feel free to copy, paste or adjust as you see fit as you communicate your involvement with the Children’s Tumor Foundation and NF awareness.

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

I’m reaching out to inquire about your selection process for changing the colors of the <write out the name of the site>. I am part of a global call to action to “Shine a Light on NF” and bring attention to a genetic condition that affects more than 150,000 people living in the United States and 4 million people worldwide. The disorder is NF, which is a genetic condition that causes tumors to grow on nerves throughout the body, and may cause blindness, deafness, bone abnormalities, disfigurement, learning disabilities, disabling pain and cancer.

<2-3 sentences about your connection to the community and your family.>

May 17 is World NF Awareness Day and we're raising awareness for this genetic disorder that currently has no cure. Over the years, hundreds of landmarks around the world have helped us Shine a Light on NF, including <mention a local site that lit up or mention the Empire State Building in New York>. NF is classified as a rare disease, and to see such visible support on such a well-known landmark will lead to tremendous excitement and pride among the entire NF community, here in the U.S. and abroad.

Many thanks for consideration in advance,

Your name