

## **SHINE A LIGHT ON NF**

### **Community Toolkit**

Thank you for helping raise awareness of neurofibromatosis (NF) in your community. May is NF Awareness Month, a time to increase understanding, foster connection, and shine a light on a condition that is often unseen. World NF Awareness Day is May 17, and communities across Canada and around the world mark the day by illuminating landmarks in blue and green, the official colours of NF awareness.

This toolkit provides guidance and sample language to help you request that a landmark, building, bridge, or monument in your community Shine a Light on NF during the month of May.

### **About Neurofibromatosis (NF)**

Neurofibromatosis (NF) refers to a group of genetic conditions that cause tumours to grow on nerves throughout the body.

NF includes:

- Neurofibromatosis Type 1 (NF1)
- All types of schwannomatosis (SWN), including NF2-related schwannomatosis (NF2-SWN)

NF affects approximately 1 in 2,500 births worldwide and can lead to a wide range of health challenges, including learning disabilities, vision and hearing loss, bone abnormalities, chronic pain, and cancer. While there is currently no cure, awareness plays a vital role in advancing research, improving care, reducing stigma, and supporting individuals and families living with NF.

### **What Is Shine a Light on NF?**

Shine a Light on NF is a community-driven awareness initiative that brings visibility to NF by lighting buildings, bridges, monuments, and landmarks in blue and green during NF Awareness Month.

In British Columbia and across Canada, this initiative helps:

- Increase public understanding of NF
- Honour the lived experiences of those affected
- Spark conversations in local communities
- Show solidarity with individuals and families living with NF

Shine a Light on NF is one meaningful way communities can participate in NF Awareness Month and demonstrate their commitment to inclusion, compassion, and public health awareness.

## Why Request a Landmark to Shine a Light on NF?

Requesting a landmark lighting is a simple but powerful act. It can:

- Invite your city or province to recognize NF in an official, visible way
- Create a compelling local story for media and community channels
- Offer a gathering point for individuals, families, and supporters affected by NF
- Amplify local voices and lived experiences within the NF community
- Help make an invisible condition visible

## Steps to Request a Landmark Lighting

### 1. Brainstorm Locations

Think about landmarks, bridges, and notable buildings in your community.

- Is there a site that stands out on the skyline?
- A building associated with civic pride?
- A location where people naturally gather or pass by?

Both public and privately owned buildings may participate.

### 2. Plan Ahead

Lighting requests often need to be submitted weeks or months in advance, especially for municipal landmarks. We recommend starting outreach early and following any formal request processes required by your city, province, or organization.

A sample outreach email is provided below to help you get started.

### 3. Be Flexible

The official NF awareness colours are blue and green. However, some landmarks may only be able to display one colour. If that is the case, we recommend requesting blue, the primary colour of NF awareness.

### 4. Choose a Date

First choice: May 17 - World NF Awareness Day

Alternate options: May 1 or any other date in May

Some locations may be willing to light up for multiple days or the entire month

Every opportunity to shine a light helps spread awareness.

## 5. Share With Your Community

Once your request is confirmed, help spread the word!

You can:

- Share the lighting on social media using hashtags such as #ShineALightOnNF #NFawareness | #TumourBC
- Invite friends, family, and members of the NF community to view the lighting together (in a safe and accessible way)
- Share photos with the Tumour Foundation of BC for use in awareness efforts
- Reach out to local media outlets to let them know about the lighting.

## Sample Outreach Email

You are welcome to copy, paste, and personalize the email below when contacting a landmark, building, bridge, or monument in your community.

### **Subject: Request to Light Up [Landmark Name] for NF Awareness Month**

Dear [Recipient's Name],

I am writing to request your support in lighting [Landmark Name] in blue and green during NF Awareness Month this May, ideally on May 17, World NF Awareness Day.

This lighting would help raise awareness of neurofibromatosis (NF)- a group of genetic conditions that cause tumours to grow on nerves throughout the body and affects thousands of individuals and families across British Columbia and Canada.

Each May, communities participate in Shine a Light on NF by illuminating landmarks to spark conversation, increase understanding, and show solidarity with those living with this often under-recognized condition. A lighting at [Landmark Name] would be a meaningful and visible way to support health awareness and community inclusion.

NF affects approximately 1 in 2,500 births worldwide and can lead to significant medical and social challenges, including learning disabilities, vision and hearing loss, chronic pain, and cancer. While there is currently no cure, increased awareness helps advance research, improve care, and reduce stigma.

If May 17 is not available, we would be grateful for consideration of another date in May, or for lighting the landmark in blue if multiple colours are not possible.



Please let me know if additional information or documentation is required. Thank you very much for your time and for considering this opportunity to support NF awareness in our community.

Warm regards,

[Your Name]

[Your Role or Connection to the NF Community]

[Your Contact Information]

### **Questions or Support**

If you have questions or would like support with your Shine a Light request, please contact:

Tumour Foundation of BC

[info@tumourfoundation.ca](mailto:info@tumourfoundation.ca)

Thank you for helping shine a light on NF and for being part of a more informed, compassionate community.