

May is NF (Neurofibromatosis) Awareness Month

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Opportunities to Make NF Visible, get involved, and drive research for a genetic disorder that affects 2.5 million people worldwide and has no cure

NEW YORK – May 1, 2022 – The Children’s Tumor Foundation is pleased to announce that May is NF Awareness Month. NF, short for neurofibromatosis, is a group of genetic disorders that causes tumors to grow on nerves throughout the body. NF affects 2.5 million people around the world, but many have not heard of this rare genetic disorder that can lead to blindness, deafness, bone abnormalities, disfigurement, learning disabilities, disabling pain, and cancer.

NF affects all populations equally, but it manifests differently in each patient; patients with visible signs of NF struggle to be seen as more than just their NF, while patients whose NF is internal, or ‘invisible,’ struggle to make others understand. NF Awareness Month is an

opportunity to amplify the voice of all NF patients through the Children's Tumor Foundation 'Make NF Visible' initiative.

The Make NF Visible campaign focuses on the external things the NF community is doing to raise the profile of a disease that affects 1 in 3,000 births, while also bringing to light both the outward and internal struggles NF patients experience in their day-to-day lives. Through storytelling, photography, and intimate first-person videos, Make NF Visible covers the scope and scale of how NF's visibility impacts and influences public awareness, diagnosis, clinical care, and research investments in search of a cure.

Make NF Visible is a campaign for everyone. Chances are you know someone with NF and may not know it, because they've kept their diagnosis hidden," said Simon Vukelj, Chief Marketing Officer of the Children's Tumor Foundation. "This May and all year round, we're honored to bring these real-life NF stories to the forefront, both so that NF patients receive the care and treatments they deserve, while also inspiring those who are fighting for something or someone important in their lives."

A captivating part of the campaign is the 'Make NF Visible' video gallery, a collection of first-person stories from patients living with neurofibromatosis. Honest and raw, these videos capture what it's like to live with the rare disorder, the nuance of the visible and invisible aspects of NF, and how expanding awareness is changing perceptions and changing lives.

On May 17, 2022, the annual Make NF Visible: A World NF Day Live Event will broadcast live, for the first time, from LA's The Three Clubs on Vine. Hosted by actor/director Jonathan Sadowski with performances by actor/singer/activist Rumer Willis and 2019 'The Voice' runner up Jim Ranger, plus appearances by actors Ben Shenkman, Mark Feuerstein, Michael B. Silver, Chris Carmack and Paul Raci, professional golfer Mark Calcavecchia, professional wrestler Roman Reigns and inspiring stories from NF patients, all coming together for an evening to raise money, awareness, and make NF visible.

One of the most popular initiatives during NF Awareness Month, Shine a Light on NF, makes NF visible through the lighting in blue and green, the official colors of NF, of hundreds of buildings, bridges, monuments, water falls, and architectural icons across the globe. In 2021, the Shine a Light campaign grew to over 300 locations in 11 countries lighting up for the NF cause, including Niagara Falls, La Sagrada Familia in Barcelona, and London's National Theatre. This year, more than 350 landmarks in 12 countries have already agreed to Shine a Light on NF and Make NF Visible.

In addition to light-ups, the Children's Tumor Foundation leads the community in making NF visible through the pushes to Wear Blue & Green on May 17 and Wear Green & Blue on May 22 for NF2. These visual cues, utilizing the official colors of the cause and the campaign, are another way that makes the movement accessible, declaring NF deserves our attention and NF patients deserve a cure.

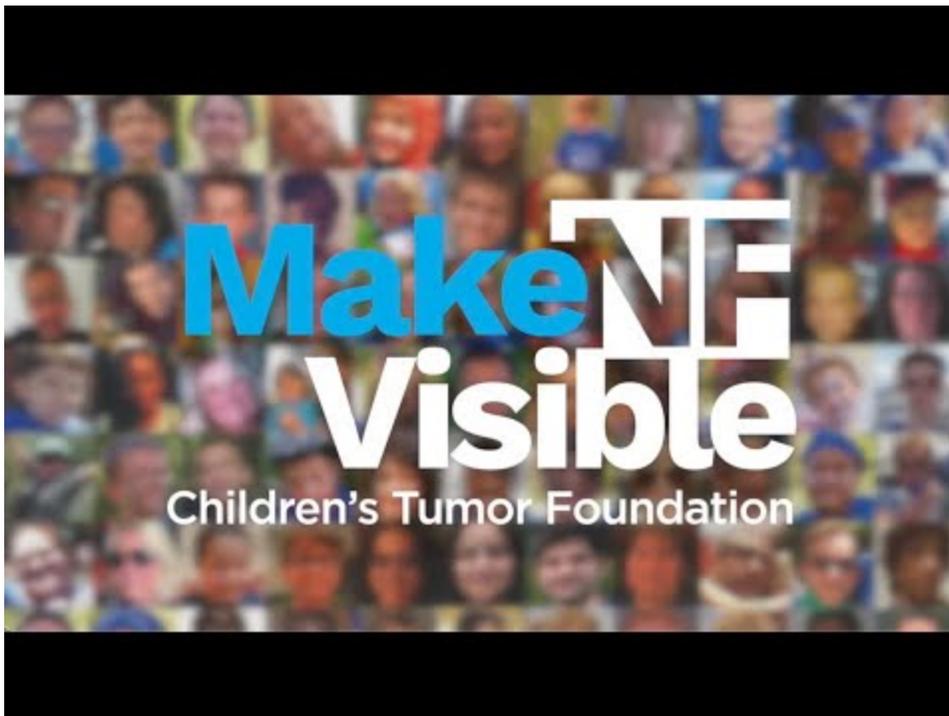
Additional year-round initiatives that peak during NF Awareness Month are #EndNF and I Know a Fighter, making NF visible through the use of a shared social rally cry and storytelling hook that reflects the bravery NF patients exhibit in their daily lives. Community events also take place across the country and around the world, on- and off-line.

For more information on the Children's Tumor Foundation, as well as all NF Awareness Month campaign initiatives, please visit makenfvisible.org.

Partners can join the growing Shine a Light on NF campaign by visiting ctf.org/shinealight or contacting the Children's Tumor Foundation at media@ctf.org.

Exclusive 'Make NF Visible' and other blue and green merchandise can be purchased at ctf.org/store.

The 'Make NF Visible' patient storytelling gallery can be viewed at youtube.com/makenfvisible.



Watch Video At: <https://youtu.be/87SnDxOK3Zk>

About the Children's Tumor Foundation

The Children's Tumor Foundation is the world's leading nonprofit dedicated to funding and driving innovative research that will result in effective treatments for the millions of people

worldwide living with NF, a group of genetic disorders that causes tumors to grow on nerves throughout the body. One in every 3,000 people is born with some type of neurofibromatosis or schwannomatosis, which may lead to blindness, deafness, bone abnormalities, disfigurement, learning disabilities, disabling pain, or cancer. NF affects all populations equally, and while there is no cure yet, the Children's Tumor Foundation mission of driving research, expanding knowledge, and advancing care for the NF community fosters our vision of one day ending NF. For more information, please visit ctf.org.