

HOW TO: REACH OUT TO **MEDIA**

MAY IS
NEUROFIBROMATOSIS
AWARENESS
MONTH

Getting started

The Children's Tumour Foundation will coordinate national media outreach for May, but you can use this guide to engage with your local media to promote a message for Neurofibromatosis awareness month (NFAM).

Plan your approach

Think about your pitch to media.

Most often, local media will want to share your lived experience with Neurofibromatosis, and in this case, how navigating healthcare has been challenging for you or someone you care for. Think about your journey with NF ahead of time and develop key points about your story. You can also refer to the key messages, templates and information provided in this guide.

Identify local media outlets and journalists.

You know the local newspapers, radio and TV stations best. Take the time to develop a media list, which includes specific journalists, names and contact numbers by researching with an internet search. It is important to only concentrate on local media, as state and national media, publications, as well as social media influencers and accounts will be approached by the Children's Tumour Foundation.

Media outreach steps

1 Reach out

2+ weeks before May, send an email, either individually, or using BCC to approach multiple journalists. Ensure your message is clear, concise and includes your name and contact information. It is also best to include a link to www.ctf.org.au and overviews (examples provided in this guide).

2 Follow up

1 week later, reach out again, via email or phone to see if there is a media opportunity.

Key messages for NF awareness month

- Neurofibromatosis (NF) is a complex, lifelong condition that can affect the brain, nerves, bones, vision and more, it changes over time and can present differently from one patient to the next.
- People with NF often need care from many specialists, carefully coordinated to avoid serious complications. Yet access to specialist NF clinics, where a lead clinician and nurse specialist oversees and coordinates this care, is limited.
- Without these clinics, families are left to navigate this complexity alone: juggling multiple specialists, long waitlists, unfamiliar providers and travel, with no single team responsible for oversight. When care isn't coordinated, vital monitoring can be delayed or missed.
- This Neurofibromatosis Awareness Month, we're raising our voices for all Australians impacted by NF, because we believe that #careshouldn'tbecomplex.
- We're advocating to simplify the path to diagnosis, treatment, and multi-disciplinary care. Together, we can advocate for systems that are integrated, easier to access and centred around the people who need them most.

#NFawarenessmonth
#CareShouldn'tBeComplex
@ctfaustralia

www.nfawarenessmonth.com.au

CTF:
(02) 9713 6111
Fundraising@ctf.org.au

Message template: **NF awareness month**

Use the template messages below as a reference you can share with local media.

About NF awareness month

Neurofibromatosis awareness month, (pronounced neu-ro-fi-bro-ma-to-sis, and also known as NF), is held each year in May. It is a global, community-led initiative bringing awareness to the genetic condition, which is incurable, has limited treatment options and despite being more common than many better known conditions, remains relatively unknown, underfunded and undersupported.

More information: www.nfawarenessmonth.com.au

2026 theme:

Care shouldn't be complex

NF impacts multiple body systems, is highly variable, unpredictable and managed by frequent visits to multiple specialists. Despite being one of the most **common and complex** genetic conditions, up to 90% of kids and adults with NF cannot access coordinated, specialist care.

Complex conditions need simplified care. We're advocating to simplify the path to diagnosis, treatment, and multi-disciplinary care.

Message template: **NF + The CTF**

Use the template messages below as a reference you can share with local media.

About **NF**

Neurofibromatosis, pronounced neu-ro-fi-bro-ma-to-sis, and also known as NF, refers to a group of complex genetic conditions that can cause tumours to form on any nerve in the body.

More than 13,000 Australians and more than 4 million people worldwide have NF. A child is born with NF every 3 days. It impacts 1 in 2,000 births.

The impact of NF can range from minimal to disabling or life-threatening. It can lead to vision and hearing loss, mobility loss, learning difficulties, muscle weakness, bone abnormalities, ADHD, autism, chronic pain and itch, and more.

About **the Children's Tumour Foundation**

The Children's Tumour Foundation (CTF) is a not-for-profit providing hope for everyone impacted by Neurofibromatosis in Australia by advocating for change, advancing research and empowering this community with the knowledge, connections and support at every stage of their journey. NF is a term for multiple conditions, including those living with Neurofibromatosis Type 1 and all forms of Schwannomatosis, including NF2.

More information: www.ctf.org.au

Facts and stats

Use the template messages below as a reference you can share with local media.

Impacts of care gaps

90% of NF patients cannot access coordinated care.

Many need to see **12+** different specialists.

68hrs are spent caring for a child with NF by a caregiver each week.

77% of caregivers experienced a moderate to significant impact on their mental health.

90% of NF caregivers are women.

240 health care visits per year can be had by children with a rare, complex condition.

60% do not receive NDIS support

28% forgo care due to cost

1 in 4 wait more than 4 years for a diagnosis

Impacts of NF

1 in 5 will develop a brain tumour

80% experience neurocognitive challenges

3 in 4 experience chronic pain

60% risk of developing cancer in their lifetime

5x more likely for women to develop breast cancer

10% may develop scoliosis

4 x greater risk of suicide than the average population

Media terminology

As you engage with local media, you may encounter some new words. Use the guide below to understand their meaning.

Local media

Local media refers to news outlets and communication channels, including newspapers, radio, TV, and websites, that operate within a specific city, town, or region. They focus on community-specific issues, local government, events, and culture, serving as a primary information source.

Media release

A media release (also known as press release or media alert) is an official document, usually one-page in length with factual information. It is sent by organisations to journalists to announce newsworthy information, such as product launches, events, or milestones. If a journalist asks for a media release, please share the official media release located [here](#).

Media pitch

A media pitch is a short, personalized, and persuasive email (or message) sent to a journalist, editor, or influencer proposing a story idea to secure media coverage.

Boiler plate

A boilerplate is standardised text, usually an "about us" paragraph at the end of a press release providing organisation background, mission, and key information. You can use the message templates in this document, if you are asked for one.

More terminology explained at: www.pr.co