



FOR IMMEDIATE RELEASE

NEUROFIBROMATOSIS TUMOURS ARE NOT MONKEYPOX

The monkeypox (MPXV) outbreak has garnered widespread media attention around the world. Alarmingly there have been recent reports from people who live with the lifelong condition neurofibromatosis (NF), facing adverse reactions, harassment and confusion from the wider community, both online and in public, who have ignorantly mistaken their NF for the contagious MPXV.

NF is a set of complex genetic conditions (including Neurofibromatosis Type1 (NF1), which causes neurofibromas (tumours) to form on nerve cells, under the skin and deep in the body. In its most common form (NF1), it impacts more than 1 in 2,500 Australians, and while it is one of the most prevalent genetic neurological conditions, understanding and community awareness remains low.

The [Children's Tumour Foundation Australia](#) (CTF) is Australia's leading charitable authority existing to support all people impacted by NF and hopes to improve the understanding of the signs and symptoms of NF. This includes advocating to help mitigate any confusion between NF and MPXV. It is important to note, the CTF is not an authority on MPXV related news, but is an authority on NF. For specific information around MPXV speak to your GP or head to the [Australian Department of Health and Aged Care](#).

Associate Professor Mimi Berman is the Head of the Genetics Department at Royal North Shore Hospital and Chair of the Medical Advisory Panel to the CTF. She has a special interest in the care of adults and children diagnosed with NF and understands the challenges those living with NF already face.

"Monkeypox causes a rash that can look a lot like chicken pox, with early fluid filled blisters, then acne like pustules and scabbing. NF is quite different in that lumps are fleshy more like moles, and don't scab. NF is not infectious, but can be disfiguring, making daily living quite difficult and embarrassing for people. Being incorrectly accused of being infectious can be extremely upsetting and embarrassing for people living with NF, as it can be for anyone living with a chronic skin disorder," says A/Prof Mimi Berman.

Sydney-based Janu Dhayanathan lives with NF1 and recently shared her fears for the NF community, with one of her biggest concerns from the media reports around MPXV being that someone would assume she had the condition and accost her. In fact, before recently travelling overseas, she sought a letter from her doctor explaining what her NF is and stating it was not MPXV, in case she was questioned.

"Friends and family tried to reassure me that the likelihood of it happening [being ignorantly accused of having MPXV] was minimal. But the anxiety persisted. I dreaded going out in public...I also sought out counselling to keep those anxieties at bay," says Janu.

"Thankfully, I didn't have to use my doctor's letter. I did get a lot of stares which made me feel a little self-conscious, but I am used to people staring, so I let it slide...Unfortunately, the incidents in the U.S. and Spain confirmed my fears. I would be lying if I said I wasn't dreading the summer months when it would be harder to cover up."

The experience of a 33-year-old from Brooklyn in the U.S. is a [recent story](#) which Janu is referring to, where Lilly Simon was filmed without her consent while riding the subway and came under an onslaught of comments and abuse from a video that went viral on TikTok, claiming her neurofibromas were MPXV.

Similarly, Julia Szulerowski and her daughter Jess who are based on the South Coast of New South Wales, both have NF1 and are deeply concerned by the MPXV outbreak and what this means for people like them living with visible tumours.

“People were rude [pre MPXV], unkind, thoughtless, towards the NF community anyway, but now we have to contend with being considered contagious. Ignorant people now have even more reason to throw us off buses, aeroplanes out of swimming pools, or tell us we can't try on clothes. The list goes on and on. This happened before monkeypox, I feel that this virus is just going to make it worse,” says Julia Szulerowski.

The CTF are fiercely protective of the NF community; people living with NF and their families. No person should be shamed, accused or bothered by anyone as a result of their physical differences, not with NF, the unrelated MPXV or any other condition.

The CTF is a not-for-profit organisation dedicated to empowering families impacted by NF with the knowledge, connections and support needed at every stage of their journey. Providing telephone and online support, information days, camps and an abundance of educational resources, the CTF national support coordinators are available to work with anyone affected by NF in Australia.

While the impacts of living with NF can have many implications, it is important to remember there is help available. The CTF Support Team can be reached on 02 9713 6111 or support@ctf.org.au.

National 24/7 telephone counselling services are also available via Lifeline (13 11 14) and Kids helpline (1800 551 800).

**- MEDIA RELEASE ENDS -
BUT WITH YOUR ONGOING MEDIA SUPPORT
A NEW CHAPTER CAN BEGIN FOR THOSE LIVING WITH NF.**

About The Children's Tumour Foundation Australia:

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 three distinct disorders: NF1, NF2 and Schwannomatosis.

Clinical Associate Professor Mimi Berman | BMBS FRACP BSC HONS PHD

A/Prof Mimi Berman is the Head of the Genetics Department at Royal North Shore Hospital. Her special interest is in the care of adults and children with NF1, NF2, and Schwannomatosis. She has a PhD in Neurogenetics in the area of muscle performance and metabolism. A/Prof Berman is the Co-Chair of the ACI Clinical Genetics network, the current president of the Australian Association of Clinical Geneticists (AACG) and is the Medical Advisor to the Children's Tumour Foundation of Australia.

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