

Brain Tumour Trust

Founded by People with First-hand Experience



Northland DHB Sleep Physiologist Gavin Starling

A group committed to supporting people living with brain tumours and their families has launched Brain Tumour Support NZ. All the founders have either been diagnosed with a brain tumour themselves or have a partner or close friend diagnosed with a brain tumour.

Northland sleep physiologist Gavin Starling is one of the founders. His partner Natalie was diagnosed with Glioblastoma Multiforme in August 2017, and it wasn't long before Natalie began to feel isolated and alone. She often relied on overseas websites for support and information.

"Not having easy access to support and information was an additional burden while Natalie was going through treatment," Gavin said. Sadly, Natalie lost her battle in March 2018. "I felt compelled to help others and raise awareness about brain tumours, so other families don't have to go through what Natalie and I experienced."

Serendipitously, in October 2018, Gavin contacted Chris Tse, an International Brain Tumour Alliance (IBTA) senior advisor, around the same time that Mandy Bathan also approached Chris.

Gavin was seeking resources to prepare a display for Whangarei Hospital Outpatients Department to coincide with the annual IBTA awareness week. He was shocked at the scarcity of information and resources available in New Zealand. Chris's wife, Lynda, is a long-term survivor of Glioblastoma Multiforme. When Lynda was diagnosed in 2006, Chris too was appalled at the lack of treatment options for brain tumour patients in New Zealand.

Mandy reached out to Chris after her own experience of the disease. She was working as a primary school teacher when she found out she had an Oligodendroglioma in October 2017.

"I found myself disappearing down a rabbit hole of various overseas websites, blogs and social media posts for

information about brain tumours," Mandy said. "Some of the information I found was helpful, but much of it was irrelevant and didn't reflect the everyday experience of Kiwis living with a brain tumour."

Mandy contacted Chris with the idea of setting up a charity that would support brain tumour patients and their families. They began to recruit others – including Gavin – who could help. In 2019, they founded the Brain Tumour Support Trust. The Trust is committed to the vision that everyone living with a brain tumour has the support, information and access to best treatments, so they feel less afraid, less alone and more empowered.

Gavin considers himself fortunate to have been offered a role as a trustee. "Our mission is to inform, support and advocate for New Zealand brain tumour patients, their family/whānau, and friends," Gavin said. "Having lived alongside Natalie and supported her throughout her journey, I understand what it's like. Being a trustee means that Natalie's experience and mine can be harnessed to provide meaningful support for others."

Brain cancer is the leading cause of cancer death in people under 40. A brain tumour diagnosis may bring with it the double impact of a cancer diagnosis and a progressively debilitating neurological disease.

Brain Tumour Support NZ will help people live life with a brain tumour, and their support is available to everybody affected by any type of brain tumour and their whānau. Given its charitable status, the Trust relies heavily on donations to enable it to provide support, information and advocacy.

To donate, fundraise or for further information visit:

www.braintumoursupport.org.nz

or email hi@braintumoursupport.org.nz