

**MEDIA RELEASE**

**BRAIN TUMOUR SUPPORT NZ**

Hamilton, New Zealand

[Friday 28 October 2022, 11.00am NZDT]

**International Brain Tumour Awareness Week  
29 October to 5 November 2022**

International Brain Tumour Awareness Week (29 October to 5 November 2022) is a global campaign where the international brain tumour community comes together to raise awareness about brain tumours.

This year, Brain Tumour Support NZ is showcasing the stories of five ordinary Kiwis who are adding their voices to the global chorus advocating for increased awareness, more research, and better treatments for brain tumour patients.

Chris Tse, chair of Brain Tumour Support NZ, says: “Despite brain tumours having one of the lowest survival rates of any cancer, and being responsible for around 270 cancer deaths each year in Aotearoa New Zealand, brain cancer tends to fly under the radar.”

“This lack of awareness often manifests itself in delayed or mis-diagnosis of many patients because doctors don’t think about the possibility of a brain tumour and tend to offer up a diagnosis of migraines, strokes or epilepsy instead,” Tse says.

“Even when a diagnosis has been confirmed, the lack of effective treatments, especially for the most malignant brain tumours such as glioblastoma, result in a poor prognosis. Pharmac has not funded any new medicines for glioblastoma in over sixteen years, so it is a wonder that survival rates have not changed during that time,” Tse adds.

Brain tumour patients in Aotearoa have suffered under the stresses and strains of the health system more than most these past few months. Christchurch baking entrepreneur, Renee Prescott, had to endure three cancelled surgeries before finally having her brain tumour removed last month. She starts a six-week course of radiation treatment next week, followed by a break over Christmas before starting chemotherapy in the new year.

The brain tumour diagnosis has come as a real shock to Renee, who previously had no serious health issues before suffering a grand mal seizure in May this year. A naturally positive person, she has found dealing with the treatment delays very hard.

“It's been a long, emotional and confusing road so far with many cancelled appointments, MRIs and surgeries along the way. The planning, getting organised and being mentally prepared prior to the surgery is pretty exhausting, that's the annoying thing about it,” she says.

Eight-year-old Elyse Johnson and her family are all too familiar with the world of brain surgeries, hospital visits and MRI scans. Elyse has been battling a DIPG (diffuse intrinsic pontine glioma) since the age of two. This is the same type of tumour which took the life of Wellington teen and research campaigner, Jemima Gazley, in 2021.

Mum, Casey Johnson, has ridden the rollercoaster of Elyse's brain tumour journey every step of the way. She rates the challenge of crowdfunding to raise money for the unfunded medicines which are keeping her daughter alive as “the biggest pain of all”.

Hamilton woman, Sandra Kivell, is also self-funding her treatment for a glioblastoma, the most common and aggressive form of primary brain tumour in adults. Sandra's brain tumour was discovered after she suffered a grand mal seizure on Father's Day in 2021. Her cancer failed to respond to standard treatments so her oncologist prescribed bevacizumab, a drug commonly used to treat glioblastoma in the United States, Australia and many other countries, but which is not funded by Pharmac.

The response was dramatic, with Sandra regaining her energy levels and feeling like her old self again almost immediately. She continues to self-fund her bevacizumab treatment, travelling to Auckland for infusions every two weeks. Her improved quality of life has allowed her to spend precious time with family and friends and she feels strongly that bevacizumab should be funded so that more brain tumour patients can access it.

Louise Curtis was a fit and healthy 42-year-old wife and mother, working two jobs in the health and fitness industry, as well as running her own business, when her brain cancer was diagnosed in 2013. Surgery, radiotherapy and chemotherapy have managed to keep the tumour at bay but life for Louise has not been without its challenges as she has had to deal with pain, fatigue, PTSD and depression since her diagnosis.

No longer able to work due to the tumour and its treatment effects, Louise has turned to cycling, as a mode of transport, for exercise and to fundraise for charity. For the 2022 International Brain Tumour Awareness Week she aims to ride 500km in one week, raising money for Brain Tumour Support NZ.

Also giving back, in more ways than one, is Dunedin nursing student, Nicole White. Nicole was diagnosed with a rare brain tumour in 2017 when she was just 17 years old, having experienced seizures for more than a year. She has since endured two brain surgeries and still takes an oral chemotherapy daily.

While this is a lot for any teenager to handle, Nicole has battled through the tough times and is looking forward to completing her nursing studies at Otago Polytechnic this year.

“Although the journey is hard, you will learn so many amazing life lessons that will shape who you are as a person and who you will be as a nurse,” she said.

Nicole hopes to inspire other young people who may be going through a similar experience as hers. She has signed up as a volunteer for Brain Tumour Support NZ and recently ran the Dunedin half-marathon, raising over \$4,400 for the charity.

“Nicole is exactly the type of nurse who brain tumour patients want to care for them during their treatment,” says Chris Tse. “This impressive young woman has overcome her own health issues to display the commitment, compassion and caring nature which will make her an excellent health professional.”

“Brain Tumour Support NZ deeply appreciates the courage and generosity of all the people who have shared their stories to raise awareness and help improve outcomes for brain tumour patients in Aotearoa New Zealand,” Tse said.



*From L to R: Renee Prescott, Elyse Johnson, Sandra Kivell, Louise Curtis, Nicole White*

#### ABOUT BRAIN TUMOURS

- In 2020, 373 New Zealanders were diagnosed with a malignant brain tumour.
- Each year around 270 people die from brain cancer in New Zealand, making it the 10<sup>th</sup> most fatal cancer.
- Brain cancer is the biggest cancer killer of children in New Zealand, being responsible for 38% of all childhood cancer deaths (the next largest is leukaemia with 25%)<sup>1</sup>
- Brain tumours can affect anyone, of any ethnicity, and at any age.
- Survival rates for brain cancer have not improved significantly in the last 30 years. The 5-year survival rate for glioblastoma, the most common form of brain cancer, is just 6% and the median survival is 15 months.
- The causes of most brain tumours are unknown which means there are no preventative measures and population screening is impractical.

#### ABOUT BRAIN TUMOUR SUPPORT NZ

Brain Tumour Support NZ is a registered charity formed in 2019 to provide much needed support, information and advocacy to brain tumour patients in New Zealand. Our Vision is 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.

Contact:

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Links:

Renee Prescott story: <https://www.braintumoursupport.org.nz/renee-prescott-story>

Elyse Johnson story: <https://www.braintumoursupport.org.nz/elyse-johnson-story>

Sandra Kivell story: <https://www.braintumoursupport.org.nz/sandra-kivell-story>

Louise Curtis story: <https://www.braintumoursupport.org.nz/louise-curtis-story>

Nicole White story: <https://www.braintumoursupport.org.nz/nicole-white-story>

Louise Curtis fundraiser: <https://givealittle.co.nz/fundraiser/why-i-ride>

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<sup>1</sup> Ballantine, K & the NZCCR Working Group (2017). *Child cancer survival in New Zealand 2005-2014: A report from the New Zealand Children's Cancer Registry*. Auckland: National Child Cancer Network  
<https://childcancernetwork.org.nz/wp-content/uploads/2017/12/Childhood-Cancer-Survival-in-New-Zealand-2005-2014.pdf>