

He waka
eke noa

brain tumour supportNZ

In it together



Annual Report 2021/2022



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A message from our chair

Tēnā koutou katoa.

As I write this message New Zealand is experiencing a resurgence of COVID-19 with the latest Omicron variant spreading through the population. When reviewing the past year, it is impossible to look past the COVID-19 pandemic and its impact on brain tumour patients and their families.

The devastating effect the virus can have on people undergoing brain tumour treatment is well known, as a weakened immune system is less able to mount an effective response against infections. However the psychosocial impacts and other downstream effects arising from social isolation have been equally impactful.

Patients admitted for neurosurgery are facing recovery in their hospital beds without the support of their loved ones due to visitor restrictions. Many patients are waiting for MRI scans which are weeks, or even months, past their scheduled date. As one patient lamented to me recently: “what good is being on ‘watch and wait’ when there is no ‘watch’?”

This once-in-a-hundred year pandemic continues to strain our health system by testing its capacity to the limit, from emergency department overload to nursing shortages and everything in between. The increased levels of stress and anxiety due to cancelled appointments, delayed procedures and long wait times for scan results add to the hardships already faced by brain tumour patients and their whānau.

Put simply, a brain tumour journey is hard, and COVID-19 has made it even harder. Against this backdrop, I would like to acknowledge the courage and resilience of the community we serve – brain tumour patients, carers and their friends and whānau - over what has been a very challenging year.

To illustrate this, I need look no further than Mandy Bathan, from whom I took over as chair in September 2021. As our founding chair, Mandy set an example with the care and compassion she showed to every new person diagnosed with a brain tumour who contacted the charity. Now, as she deals with her own health issues, she is displaying the courage and fortitude which we witness from so many brain tumour patients and their carers every day.

Mandy continues to be an inspiration for our mahi here at Brain Tumour Support NZ. Despite the difficulties imposed by COVID-19 restrictions, we have strengthened our core support services to ensure that every newly diagnosed patient or carer who contacts us feels supported, less afraid and less alone.



This year membership of our Facebook Patients group grew by 64%, the Facebook Caregiver group grew by 93%, and we dispatched 15% more Brain Boxes than last year. Our monthly online support groups continued to expand their attendances and we initiated a complete overhaul of our Support Friends (peer support) programme which will ensure every volunteer Support Friend undergoes training from a registered clinical psychologist.

We could not provide this level of support to patients and carers without the significant contributions from our dedicated and loyal supporters - our fundraisers, donors and volunteers.

In the absence of large scale community events, again due to COVID-19, our fundraising has relied on the generosity of the many individuals and groups who have run, walked, climbed, ridden, cooked, shaved their heads, held events and donated money to raise vital funds for us. The creativity and commitment of the people who fundraise for us, some as young as 10 years old, never ceases to amaze me. My heartfelt thanks to everyone who gave up their valuable time, resources and effort to help us on our mission.

To our wonderful volunteers, thank you for always putting patients and their loved ones at the heart of everything that you do. This includes our volunteer Support Friends, the facilitators of our online support groups, our hardworking Brain Box team, and many others. It also includes the members of our Medical Advisory Board who take time out from their busy professional lives to lend their expertise across many aspects of our charity's work.

Finally I would like to thank my fellow trustees for their dedication and expertise in helping navigate our charity through these extraordinary times. It is an honour and a privilege to work alongside you in improving the lives of brain tumour patients and their families.

**Ngā mihi nui,
Chris Tse
Chair, Brain Tumour Support NZ**



Our 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.



Our Mission

To inform, support and advocate for New Zealand brain tumour patients, their family/whānau, and friends.



Our Values

The Trust is founded on values of inclusivity, support, compassion, honesty and respect.

Why Brain 'Tumour' Support NZ?

Around 70% of brain tumours are non-malignant (benign or non-cancerous). Although they are not classified as a cancer, these tumours can seriously impact the patient's quality of life and many can change into a malignant tumour in the future. Brain Tumour Support NZ offers support to all brain tumour patients, whether their tumour is initially deemed cancerous or not.

Support



Supporting brain tumour sufferers and their whānau is at the heart of everything that Brain Tumour Support NZ (BTSNZ) does. From the information on our website to the full range of support services we provide, our aim is to lessen the feelings of fear, loneliness and loss of control that a brain tumour diagnosis causes.

This year we established the new role of Support Coordinator so that people newly diagnosed with a brain tumour and their care partners will receive immediate support from a qualified professional. The Support Coordinator also fills an important patient navigation role, assessing the person's needs and directing them to the appropriate support services both within BTSNZ and externally.



Hearing the words 'you have a brain tumour' may be the most scary thing a brain tumour patient will hear in their lifetime."



Brain Boxes

The Brain Box is a care and information package sent free to brain tumour patients or carers anywhere in New Zealand. Despite an enforced hiatus due to COVID-19 lockdown restrictions, we despatched 15% more Brain Boxes this year than the previous year. In October 2021 we reached an important milestone when we sent out our 200th Brain Box.

At the start of 2022 the Brain Box programme was overhauled by a new team of volunteers who have refreshed the contents and improved the delivery logistics. Feedback from recipients of the new Brain Box has been overwhelmingly positive.

“
A beautiful and thoughtful gesture in a time of need.”

“
It made us both feel special and cared about.”



Online Support

The New Zealand brain tumour community is spread the length and breadth of the country so delivering support over digital platforms has been a key strategy for BTSNZ since our inception.

In the year to 31 March 2022, our Facebook Patient group increased membership by 64% with the number of members fast approaching 200. Our Facebook Caregiver group grew even faster with membership increasing by 93%. Both groups have now accumulated a critical mass of knowledge and have developed into communities of caring, compassionate people willing to support each other.

Our monthly online support groups, through the dedicated work of our volunteer group facilitators, have also witnessed steady growth in the past year. These groups offer a safe, supervised forum where patients and carers can connect with each other.

This year we also initiated educational webinars where health professionals and researchers are invited to present on a wide range of topics. These webinars have proved very popular and attendances have been strong.

In March 2022 we launched our first creative writing course "Writing Your Story" in association with Northland writer, Jeremy Stratton. The inaugural cohort continue to meet and have now formed their own creative writing support group. Further initiatives exploring creativity in the form of art therapy are planned.

We continue to grow our community across all digital platforms. Our e-newsletter subscribers grew by over 100% in 2021, website traffic increased by 40% and social media engagement (mainly Facebook and Instagram) also grew by 40%.





Support Friends

Some people prefer to be supported in a one-on-one setting.

Our Support Friends peer support programme matches newly diagnosed brain tumour patients and carers with volunteers who have similar lived experience. This year we contracted a clinical psychologist, Tania Anstiss, to implement a major overhaul of the programme featuring a new handbook and training sessions for all Support Friend volunteers.

Supporting children with brain tumours

Childhood brain tumours are rare but can have a devastating impact on the patient and the wider family and whānau.

In response to an increasing number of requests, BTSNZ is developing a suite of resources for children with brain tumours and their families. Our paediatric brain tumour support services are on track for a launch in 2022.

Advocacy – providing a voice for our community

As a rare cancer and a rare disease, the needs of brain tumour patients and carers often go unnoticed. A key element of our charity's mission is to advocate and provide a voice for New Zealand brain tumour patients, their friends, family and whānau.

Raising Awareness

Without awareness of the problems and challenges faced by brain tumour sufferers and their family/whānau, it is difficult to convince policy makers to allocate more health resources, fund more pharmaceuticals or raise funds for research. Yet all of these factors are critical in improving outcomes for brain tumour patients.

Each year Brain Tumour Support NZ participates in two internationally recognised awareness raising campaigns: Brain Tumour Awareness Month in May (#BTAM, #GoGreyInMay) and the International Brain Tumour Awareness Week in October (#IBTAWeek). In 2021, both campaigns were well supported with a number of events and fundraisers held throughout the country.

However the one story which featured prominently in the New Zealand media this past year was that of Wellington teenager, Jemima Gazley. Jemima sadly succumbed to an aggressive paediatric brain tumour called diffuse intrinsic pontine glioma (DIPG) in October 2021 but not before she had selflessly raised over \$725,000 for brain cancer research through a crowdfunding campaign. BTSNZ was in contact with Jemima's parents through various stages of her illness and provided commentary to the media as her story quickly grabbed the attention and hearts of the nation.

Not only did Jemima raise valuable funds for research but she helped shine a spotlight on brain tumours which too often remain hidden in the shadows.





Access to better treatments

A key part of our vision is that everyone living with a brain tumour has access to the best available treatments. Unfortunately this has not always happened in Aotearoa New Zealand, with access to some modern brain cancer drugs being restricted to those that can afford to pay for them.

In May 2021, supporters of BTSNZ joined other patient groups in the Lie Down For Life event on the steps of Parliament to lobby the government for an increase in the pharmaceutical budget. This advocacy campaign followed an earlier parliamentary petition to have the brain cancer drug bevacizumab funded by PHARMAC.

BTSNZ continues to advocate for better outcomes for brain tumour patients, not just in terms of access to medicines but also neuro-rehabilitation services, psychosocial support, timely MRI scans, radiotherapy treatment and better care coordination. Our written submissions in the past year include the Ministry of Health on the Pae Ora (Healthy Futures) Bill and PHARMAC on the decision to decline the funding application for bevacizumab (a brain cancer drug).

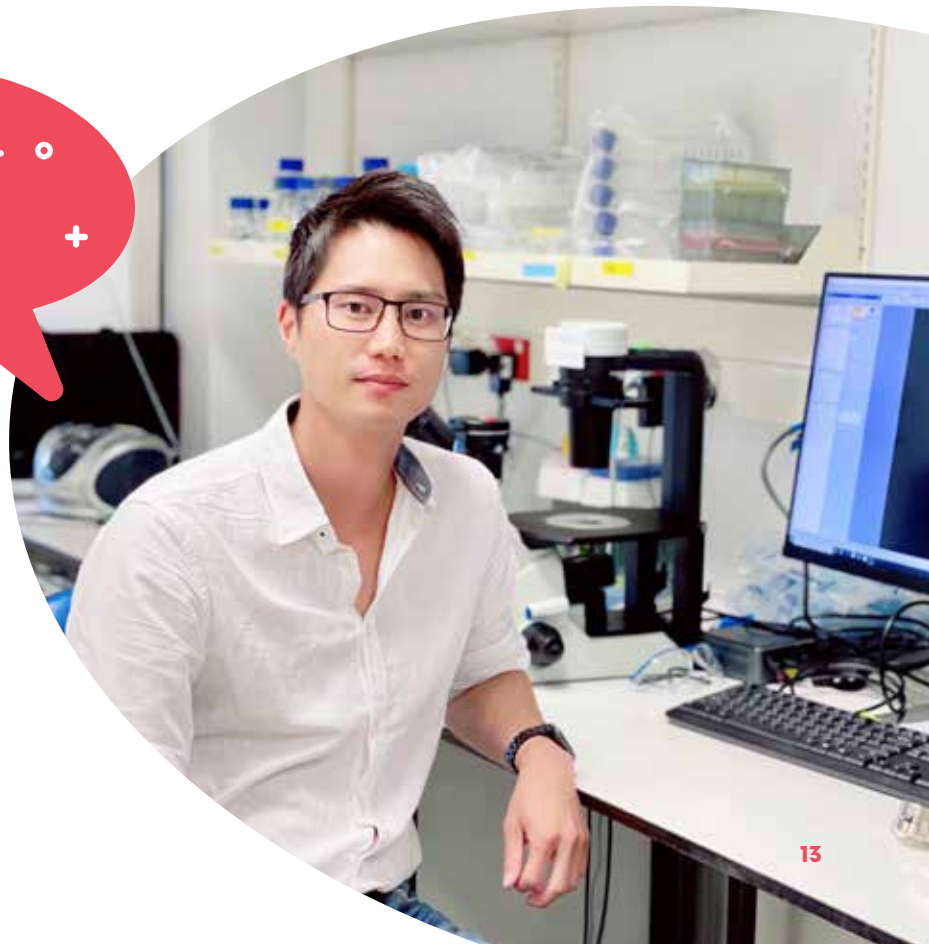
Research

Brain tumours have a poor prognosis compared with most other cancers. Glioblastoma, the most common primary malignant brain tumour in adults, has a 5-year survival rate of between 5-6%, a statistic that has barely changed in the last 30 years.

The only way to improve outcomes for brain tumour sufferers is through research. Brain Tumour Support NZ supports all brain tumour research initiatives from basic science to clinical trials.

National Brain Tumour Registry

There are currently no accurate statistics on the incidence of (how many people are diagnosed) or prevalence (how many people are living with) brain tumours in New Zealand. This lack of data has important implications for research funding, resource allocation, pharmaceutical funding and many other aspects of the health system. BTSNZ is collaborating with researchers and clinicians to establish a national brain tumour registry which will address this problem.



Clinical Trials

Clinical trials are the final research stage before a new treatment is approved for use in the clinic. Regrettably, there are currently no clinical trials available to adult brain tumour patients in New Zealand. BTSNZ supports the development of brain tumour clinical trials in New Zealand, both homegrown and international, so patients can participate in cutting edge research and gain early access to the best new treatments. We are grateful for the work of our medical advisory board in this area.

Research Collaboration

BTSNZ believes that collaboration is an important part of any research strategy. We support research projects from a number of institutions such as The Centre for Brain Research at the University of Auckland, the University of Otago, Victoria University of Wellington, the Gillies McIndoe Research Institute and Rare Disorders NZ. Internationally, BTSNZ maintains a connection with the Co-operative Trials Group for Neuro-Oncology (COGNO, Australia) where we participated in a study to determine research priorities for the Australian and New Zealand brain tumour communities.



People

Board

In August 2021 we welcomed Sarah Gibb as a trustee. Sarah has a wealth of experience and knowledge in the non-profit sector and has been a valuable addition to the Board. In September 2021, founding trustee Chris Tse took over as chair of BTSNZ from our founding chair, Mandy Bathan, who remains on the Board.

Medical Advisory Board (MAB)

In July 2021, Wellington radiation oncologist Dr Nichola Naidoo resigned from the MAB and was replaced by Christchurch neurosurgeon Mr Simon John.



Team

In September 2021 Monique Gardiner joined our team as Support Coordinator. Monique is a health professional with over 20 years' experience in the sector. The Support Coordinator is the first responder to enquiries from newly diagnosed patients and carers, and fills a key patient navigation role. Monique also provides telephone support, co-moderates both Facebook closed groups, co-facilitates the online support group meetings for caregivers and patients, and oversees the Support Friends programme.

Volunteers

Despite the challenges imposed by the COVID-19 pandemic, our volunteer base continued to grow in 2021-2022. From our Support Friends, group facilitators, digital and social media team, Brain Box team, fundraisers and donor support, to the medical advisory board members and our trustees, volunteers continue to contribute across all aspects of our charity's work.

We are incredibly grateful to all of the people who gave up their time and expertise to help us support brain tumour patients and families in Aotearoa, New Zealand.



In the Media

He waka eke noa! Brain Tumour Support NZ's call to the nation

Mandy Gortner
Chairperson Brain Tumour Support NZ

Brain tumours are a complex and often life-threatening condition. They can affect anyone, at any age, and can have a significant impact on the quality of life. Brain Tumour Support NZ is a national charity that provides support and information for people affected by brain tumours. We are calling on the nation to support our efforts to raise awareness and funds for research into this devastating disease.

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CH JUSTICE future treatment

Chris Tse, the chairperson of Brain Tumour Support Trust here Zealand, says government should invest more in brain cancer research over his lifetime.

The said, Jemima raised more money in 10 days than the government had allocated to brain cancer research over her lifetime.

"This is despite brain cancer being responsible for the most cancer deaths in children under the age of 14 (85 per cent of all cases) and the biggest cancer killer of young people and adults under the age of 40. This has got to change," Tse said.

"Although there was not a dry eye in the theatre as Jemima's tribute video was played on the big screen [at the awards night on May 10], I felt the overriding emotion was not one of sadness, but of inspiration and hope. Hope that if one remarkable young woman could move so many hearts and minds, then there is hope of a better future for people diagnosed with brain cancer," he said.



Brain Tumour Awareness Week: Wellington cancer teen Jemima Gazley praised for putting spotlight on issue

By George Campbell
Senior Multimedia Journalist

A young Wellington teenager's decision to go public with her treatable cancer diagnosis has broken through the stigma and helped raise awareness about brain tumours.


Jemima Gazley spent the last 10 days of her life fundraising for a cure for BDN, Plastic Hospital.



'A very brave and special person': Tributes pour in for Wellington teen who raised more than \$550,000 for cancer research

Bill Hickman - RNZ, Oct 13 2021

The father of the Wellington teenager who raised more than \$550,000 for cancer research has paid tribute to his daughter, Jemima, who died on October 10th.



TE AO MĀORI NEWS

NATIONAL REGIONAL POLITICS ENTERTAINMENT INDIGENOUS

10-year-old Rotorua girl's fundraiser in honour of her Nan

10:00pm, Sunday 24 October 2021, 8h 15m 10s

Major media team news of a special brain tumour support fundraiser in Rotorua today in honour of Addy, the grandmother of a young kiwi girl.

10-year-old Tia-Lisa, who can't be grandmother was her best friend, came up with the idea.



Wellington researchers believe cocktail of common medicines could extend lives of glioblastoma patients

Research scientists in Wellington believe a cocktail of common medicines could hold the key to prolonging the lives of Kiwis with an aggressive form of brain cancer.

Chris Tse
Brain Tumour Support NZ Chair



Partnerships and Collaborations

FRANKiE4[®]
footwear



Corporate

Brain Tumour Support NZ is fortunate to receive ongoing support from HotHouse Creative in many aspects of our marketing and communications, including our website, branding and publications.

This financial year we commenced a corporate partnership with Australian footwear and fashion company FRANKiE4 who have come on board to sponsor our paediatric brain tumour resources.

Our Brain Box programme is supported by goods donations from: Yoga and Oils, Barkers and Dilmah Tea.

We are grateful for the support of all the businesses which have chosen to assist us on our mission.

Non-profit

In New Zealand we work with other charities to support and advocate for brain tumour patients, including: The Cancer Society, the Brain Injury Association, Rare Disorders NZ and Patient Voice Aotearoa. Internationally, our collaborators include: brainstrust UK, the American Brain Tumor Association (ABTA), the Asia Pacific Brain Tumour Alliance (APBTA) and the International Brain Tumour Alliance (IBTA).

Medical

It is vital that newly diagnosed brain tumour patients and their care partners are made aware of our charity and the services we provide as soon as possible after diagnosis. BTSNZ continues to forge connections with key clinical staff, especially in the main neurosurgical and oncology centres of Auckland, Hamilton, Wellington, Christchurch and Dunedin. We are also increasing our exposure in the regional oncology centres, and in private clinics where brain tumour patients are being treated.

Our founding chair and trustee, Mandy Bathan, serves as the consumer representative on the South Island Neurosurgery Service (SINS). This is an alliance established by members of the Southern and Canterbury District Health Boards to resolve strategic and operational issues with neurosurgical services in the South Island.

Funding

Fundraisers



Fundraising campaigns not only earn us valuable funds, they raise awareness about brain tumours amongst the general public and mobilise a community of like-minded people who want to help and support others. In a year where many community events were unable to be held due to the COVID-19 pandemic, we are indebted to the many individuals and groups who fundraised for us.

We are particularly inspired by the young people who support us. Like ten-year old Lucy Woon, who ran a 10km race, one kilometre for every year of her life, and another ten-year old, TJ Inia-McGarvey, who held a sports day in honour of her late grandmother "Addy". Thirteen-year old friends Tessa Couper and Annabelle Judd shaved their heads, Tessa in memory of her mum who died of a brain tumour when she was just four years old.

Other notable head shaves were the staff and pupils of Grey House at Whanganui Collegiate in honour of one of their teachers, Ruby Bathan in support of her mum Mandy (our founding chair) and friends Brad and Cam. Brad is an aspiring cancer biologist and Cam wants to pursue a career studying diseases of the brain.

Many more fundraisers walked, ran, cycled, climbed, baked and held raffles or events for us this year, some in support of family or friends with a brain tumour, or going through a brain tumour journey themselves, and others in memory of a loved one lost.

We are extremely thankful to everyone who donated their time and efforts to fundraise for us.



Grant Funding

In the 2022 financial year Brain Tumour Support NZ received grants from the Lottery Grants Board and Foundation North. These grants have been vital to developing training for our Support Friends and online support group facilitators, funding our Brain Box programme, funding the new Support Coordinator role and other aspects of our work.

Brainy Beanies

At the end of 2021 we launched a new awareness and fundraising project - Brainy Beanies. BTSNZ trustee Sarah Gibb came up with the idea for Brainy Beanies in memory of her brother Andrew who sadly died from a brain tumour in 2018. A call was put out to the New Zealand arts and crafts community to make and donate beanies for an exhibition to be held in May 2022 as part of Brain Tumour Awareness Month.

The response to this call for action has been overwhelmingly positive. All donated beanies will be catalogued and tagged with a Brainy Beanies logo for display at the inaugural Brainy Beanies exhibition in Kirikiriroa Hamilton on 3 May 2022.

The Brainy Beanies will be for sale at the exhibition, on the BTSNZ website and at selected craft markets and events around the country. Supporters will also have the opportunity to donate a Brainy Beanie to a Brain Box, ensuring every newly diagnosed brain tumour patient can enjoy the warmth and comfort of a beanie.

Brainy Beanies has allowed BTSNZ to connect with a whole new supporter demographic while tapping into the iconic Kiwi pastimes of knitting and crocheting. Typically our fundraisers have been people running, cycling or walking long distances which has tended to favour a younger demographic. Brainy Beanies has mobilised creative people of all ages and walks of life to get behind a common cause and support the New Zealand brain tumour community.



Brainy Beanies are created with love by someone who cares."





Legal Entity: Brain Tumour Support Trust New Zealand
Trading as: Brain Tumour Support NZ
Charities Services Number: CC56933
Incorporated Charitable Trust Number: 50011480
NZBN: 9429047714182

Board of Trustees

- Chris Tse (Chair)
- John Brydon (Treasurer)
- Marie Waterhouse (Secretary)
- Mandy Bathan
- Moira Coatsworth
- Tim Franklin
- Sarah Gibb
- Gavin Starling

Medical Advisory Board

- Dr Steve Delany
- Dr Catherine Han
- Dr Salina Iupati
- Dr Melissa James
- Mr Simon John
- Mr Andrew Parker
- Dr Frank Saran
- Dr Clinton Turner
- Caroline Woon

Contact Details

Brain Tumour Support NZ, 15 McInnes Place, Queenwood, Hamilton 3210, New Zealand





A special thank you

Brain Tumour Support NZ would like to thank Hothouse Creative for their generous support in the preparation of this Annual Report.

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Get in touch for more information

- 📞 027 292 3337
- @ hi@braintumoursupport.org.nz
- f braintumoursupportNZ
- 🐦 @btsupportnz
- 📷 braintumoursupportNZ
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