



ANNUAL REPORT 2020/2021

**Legal Entity: Brain Tumour Support Trust
New Zealand**
Known as: Brain Tumour Support NZ
Registration number: CC56933
Registered Charity and Incorporated Trust



Brain Tumour Support Trust New Zealand

Performance Report for the year ended: March 2021

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MESSAGE FROM THE CHAIR

Kia ora katoa

I am pleased to present the 2020/2021 Performance Report for Brain Tumour Support Trust New Zealand (Brain Tumour Support NZ, BTSNZ). This is our second report since incorporation in September 2019 and registration as a Charitable Trust in June 2019.

As we approach our second anniversary I would like to thank our loyal supporters, volunteers and my fellow trustees for all the hard work that has helped us to reach this milestone on our journey. All our trustees and volunteers are driven to make a difference to the lives of people affected by a brain tumour and the introduction of our 'Brain Box' initiative last year is an example of how we reach out to newly diagnosed brain tumour patients so they can have the information they need, find out about the support we offer and how to access it.

One of the highlights last year was Kate Coatsworth's 'Beating The Track For Brain Cancer' campaign. Kate herself was diagnosed with glioblastoma multiforme in 2019 and her story is an inspiration to us all. In September 2020, Kate set off on an incredible journey traversing the length of Aotearoa New Zealand on the Te Araroa Trail in order to raise awareness about brain cancer and to raise funds for BTSNZ. The associated mini-walks that took place up and down the country brought together groups of people, who on a daily basis are dealing with the impact of living with a brain tumour. And they, more than anyone else, are the ones who inform us about what 'support' needs to look like.

Due to Covid 19, 2020 was a particularly difficult time for all charities, including ourselves.

However, due to the hard work of our Volunteer Support Group Facilitators and the team, BTSNZ has managed to develop and meet our Vision by starting monthly online support groups that continue to evolve and change according to the needs of our community.

This year we were excited to announce the establishment of our Medical Advisory Board (MAB) to provide our charity with professional oversight, expertise and advice. They continue to work closely with our Board of Trustees to ensure that the information provided to our community is up-to-date and accurate. They also play an important role in setting the future direction of our work so that New Zealand brain tumour patients continue to receive the best available care and treatments.

I trust that as you read this report and learn more about the work undertaken at Brain Tumour Support NZ, you will be moved by the stories and updates, amazed at what we achieved with our limited funds, and that you will see the passion which we all have for this charity.

When we began this mahi, I was acutely aware that the key to us being successful was to ensure that we place brain tumour sufferers and their families at the very heart of what we do. I believe that everything we have achieved has helped us to reach this goal. We have built a community of people who are dedicated to ensuring that if you hear the words 'you have a brain tumour', you won't have to face it alone.

MANDY BATHAN
Chair



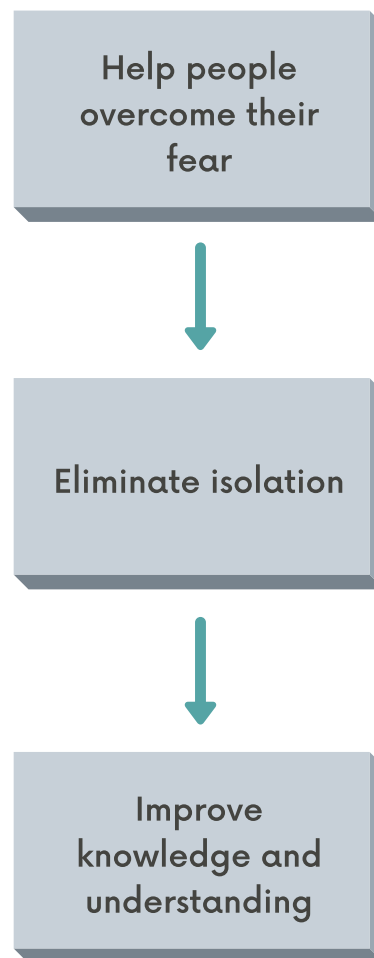
OUR CHALLENGE

Approximately 1500 people are diagnosed with a primary brain tumour every year in New Zealand. Primary brain tumours are tumours that start in the brain. They can be cancerous (malignant) or not cancerous (non-malignant or benign).

A non-malignant tumour can be as life threatening as a malignant brain tumour, depending on its size and location in the brain and non-malignant brain tumours have the potential to develop into a cancerous tumour. The treatments for brain tumours are complex and debilitating. Diagnosis brings fear, isolation, disempowerment and a loss of control. This is where Brain Tumour Support NZ (BTSNZ) provides assistance.

TO MAKE THIS HAPPEN WE...

- Brain cancer kills more children than any other disease.
- Little is known about its cause or how to treat it.
- Brain Cancer survival rates are low and have hardly changed in 30 years.
- Only two out of 10 people will survive five years or more.
- Less than one out of 10 people with Glioblastoma Multiforme (a high grade Brain cancer) will be alive in five years.
- Brain cancer costs more financially, per patient than any other cancer as it is highly debilitating, sometimes affecting people in the prime of life, with other family members leaving work to become caregivers.



WORKING IN THESE AREAS



WHY DO WE EXIST?



VISION

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.



MISSION

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

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Purpose - He Waka Eke Noa

Here at Brain Tumour Support NZ, we are dedicated to addressing the issues faced by brain tumour sufferers and their families, by providing a 'one stop shop' for information, support and advocacy. All brain tumours are life-changing. A brain tumour diagnosis may bring with it the double impact of a cancer diagnosis and a progressively debilitating neurological disease. Brain tumours are unique because they can affect a person's personality, cognition, communication and behaviour. People living with a brain tumour often feel isolated, fearful and alone. This is where we help! Our aim is to build our community so that brain tumour sufferers and their whānau feel less isolated and more in control of their current situation, wherever they are on their brain tumour journey. All our services are provided free to our community.

Structure

Brain Tumour Support NZ is governed by its seven trustees. Early in 2020 we appointed two new trustees, Tim Franklin and Moira Coatsworth. The board includes a Treasurer, Secretary and Chairperson



Moira Coatsworth
Trustee



Mandy Bathan
Chair



Tim Franklin
Trustee



Chris Tse
Trustee



Marie Waterhouse
Secretary



Gavin Starling
Trustee

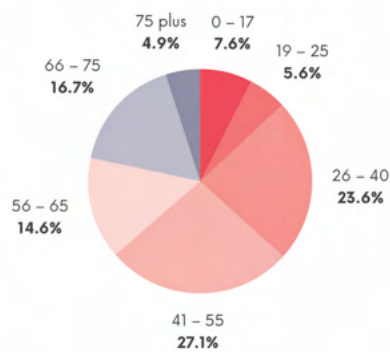
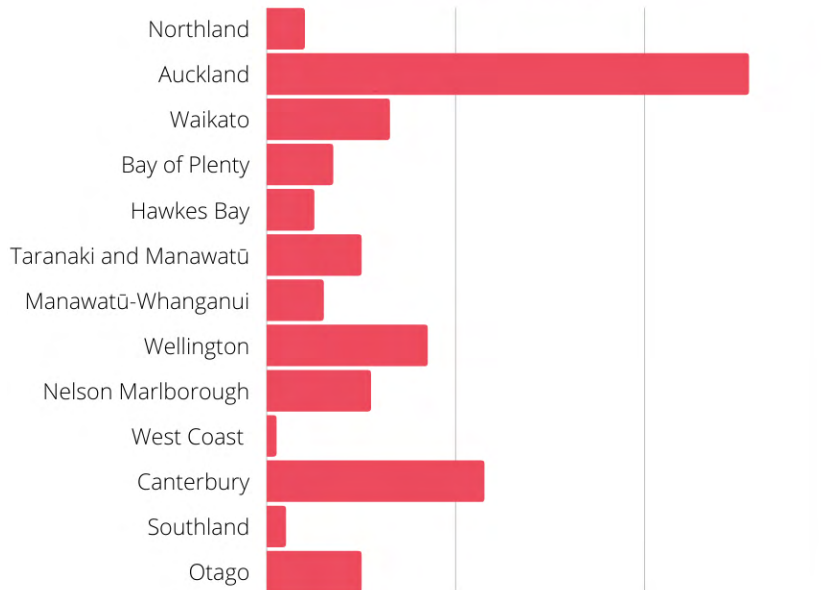


John Brydon
Treasurer

WHO USES OUR SERVICES?

People approach our charity in many ways - via our website, the phone, email and our social media groups. However they find us, we believe it's important to know our community so we can tailor our support services to their needs.

Regions



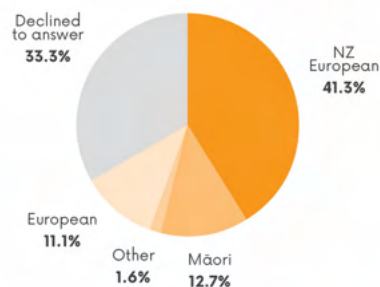
Age



Patient or carer



Gender



Ethnicity

SERVICE PERFORMANCE REPORT

OUR MAIN SOURCE OF INCOME AND RESOURCES

We are so grateful to everyone that has made a donation to Brain Tumour Support NZ. We have relied heavily on our army of fundraisers who have done all sorts of crazy things to raise money for us, from mammoth treks down the country to shaving their hair off and everything in between. We just couldn't do the things we do without them. We were also grateful to receive a grant from the Rātā Foundation to help us pilot our Brain Box programme. We receive individual donations through our website.

We also rely on non-cash resources from businesses in the form of:

- Dutch Rusk, a confectionery wholesaler has provided all our sweet treats for our Brain Boxes.
- HotHouse Creative has provided all our office furnishings.
- Access to discounted printed materials through Spectrum Print.
- Service Development, guidance and support through our Medical Advisory Board.

THE MAIN METHODS USED BY US TO RAISE FUNDS

The main methods we use to raise funds are by running social media campaigns to encourage donations, working to create corporate partnerships, applications for grants and appeals to philanthropic individuals.

OUR RELIANCE ON DONATED GOODS OR SERVICES

Our ability to achieve our Mission and Vision is greatly enhanced by our amazing relationships with individuals and with business. We receive donated services through HotHouse Creative for all our website design and management, creative design work for our information guides, social media campaigns and branding services. Through the generosity of Vertical Horizonz, we were donated temporary office space and services from December 2020 - April 2021 whilst we relocated to Hamilton from Nelson.

OUR RELIANCE ON VOLUNTEERS

The effectiveness of Brain Tumour Support NZ is driven by the commitment, hard work and the good will of its volunteers. We rely, almost entirely on volunteers to deliver the following. We currently have 61 volunteers working nationwide.

- Support Friends - A service where people who have experience of living with a brain tumour, or know someone who has a brain tumour provide one-to-one peer support to brain tumour sufferers and/or their whānau/family – either in person or via the phone or social media apps.
- Daily Website and social media management - This ensures that our brain tumour community can access the support and information they need.
- Medical Advisory Board - The Board is made up of nine clinicians, experts in treating brain tumour patients, who donate their time to ensure information provided on our website is accurate and up-to-date. They also play a vital role in setting the future direction of our work so that New Zealand brain tumour patients continue to receive the best available care and treatments.
- Our Cultural Advisor supports Brain Tumour Support NZ and ensures that our services are provided with due cultural consideration, honouring the Treaty of Waitangi.
- Online Support Groups - Our Support Group Facilitators donate their time to organise and facilitate these groups.
- Brain Box Initiative - Our volunteers manage packing and distribution of our Brain Boxes, a 'must have' support kit for people diagnosed with a primary brain tumour and their whānau.
- Grant writing - we have volunteers that help us to apply for grants.
- Phone contact - our volunteers take all our calls so that people can access our services.

ADDITIONAL INFORMATION

Our Chairperson currently volunteers 25 hours a week to manage the charity. We have increased our Board of Trustees from five to seven and envisage that we will transition from being a 'working' board to a more strictly governance board by employing key individuals on our operational side.

JUST A FEW OF OUR INCREDIBLE VOLUNTEERS WE COULDN'T DO THE THINGS WE DO WITHOUT YOU!



Vicky - Support Group Facilitator



Andrew - MAB member



Caroline - MAB member



Tim and Sandra
Support Group Facilitators



Graeme - Website Support



Ruby - Phone Support

JUST A SOME OF OUR AMAZING FUNDRAISERS HELPING US TO SUPPORT BRAIN TUMOUR SUFFERERS



Kirsty



Kate and her team



Rotorua High Tea



Laura



Emma



Ben and his supporters

SERVICE PERFORMANCE REPORT

What did we do?

Brain Tumour Support NZ's Outcomes:

Our Charity

- Ensures that we provide the necessary support to improve people's quality of life, so they become part of a supportive community whilst dealing with an extremely difficult time.
- Provides New Zealand relevant, robust and current information to help people navigate their pathway. Through this we will help people to feel less afraid and more in control of their journey.

Description and quantification of Brain Tumour support NZ's outputs:

Description and quantification of Brain Tumour support NZ's outputs:	Actual	Budget	Actual
	This year	This year	Last year
Support Friends (peer support programme for brain tumour sufferers and their caregivers)	35		24
Brain Boxes – a care and information package sent to newly diagnosed individuals and their families	127	\$11,982	0
Website with information and advice on how to access support Number of visits:	11,000		1,800
Online support groups (started October 2020), held monthly via Zoom Number of attendees:	126		n/a
Facebook – General Brain Tumour Support NZ page with information about how to connect to others. Followers:	845		405
Instagram – General Brain Tumour Support NZ page with information about how to connect to others. Followers:	400		0
Facebook – Patient Support Closed Group Members:	101		21
Facebook – Caregiver Support Closed Group Members:	83		8

SERVICE PERFORMANCE REPORT

Additional Output Measures

"I received my brain box today and I am so grateful. Great info and goodies made my scary waiting time a lot nicer today. Thank you so much team."

June 2020 we began sending our Brain Boxes, an information and care package, to newly diagnosed brain tumour sufferers and their caregivers. We have sent out a survey to all recipients and have received replies from 78% of those we sent, 96% of people had the highest possible scores for satisfaction. This initiative means that people know about our support services and how they can access them.

"The information helped me to know what I'm likely to face and also to feel a bit more in control, thank you."

In October 2020 we began our online support groups via Zoom. These meetings began as general friendship and support groups but have developed, with our community feedback, over the five months to include informative talks followed by question and answer sessions. Our speakers have included a neurosurgeon, a specialist nurse to talk about seizures and brain tumours, someone from Carers NZ and a representative from The Aratika Trust speaking on self-care and meditation. We are now in the process of developing targeted groups for low grade tumours, high grade tumours and caregivers so we can address their needs more fully. Research has shown that brain cancer places the biggest burden of all cancers on caregivers, both financially and emotionally.

"I feel so much better knowing that there are others I can talk to who really understand what we are going through, we can't thank you enough."

"The online support group tonight with the neurosurgeon was brilliant. It was so good to be able to ask questions and it all to be so relaxed. Thank you."

"I deeply appreciate the level of information and transparency provided by BTSNZ on the website. It is a million times clearer than anything else I have accessed."

SERVICE PERFORMANCE REPORT

Additional Information

We have produced an additional Patients Guide - No. 7, Palliative Care. Alongside our Medical Advisory Board, we are currently developing our Patient Guide No. 8, End of Life which will be available soon. These guides are invaluable to those who are terminally ill on diagnosis, or who are further down their pathway.

In 2020 we ran a campaign, "Beating the Track for Brain Cancer", where a young woman, Kate Coatsworth who was diagnosed with brain cancer, walked the entire length of the North Island. We were able to get fantastic media coverage through the press and TV and this helped us to reach more people, directing them to our services and the support we offer.

We have been working with Rare Disorders NZ to urge the Government to acknowledge the universal challenges faced by people living with a rare disease, and the inequity within the current system. We will also be supporting them in their efforts to improve funding for Pharmac to ensure all brain tumour sufferers have access to the medications they need irrespective of their income.

We are currently working on developing and improving our services for paediatric brain tumour sufferers.

This performance report has been approved by the Chairperson for and on behalf of Brain Tumour Support Trust New Zealand.

Date: 10 July 2021

Signature: 

Name: Mandy Bathan

Position: Chairperson

Date: 10 July 2021

Signature: 

Name: Chris Tse

Position: Trustee

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