

BRAIN TUMOUR SUPPORT TRUST  
NEW ZEALAND

# ANNUAL REPORT 2020

He waka  
eke noa

**brain  
tumour  
support****NZ**  
In it together

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# A MESSAGE FROM THE CHAIR



Last year, in June 2019 Brain Tumour Support NZ became a fully registered charity and we've endeavoured to position ourselves as New Zealand's leading brain tumour charity, with the emphasis on providing information and support for both the patients and their whānau. Three of our five trustees (Gavin Starling, Chris Tse and I) have personal experience about what it is like to live with a brain tumour, or to care for someone with a brain tumour. We came together knowing that brain tumour patients truly needed more New Zealand relevant information, support and access to best treatments so they could be confident that they were living as well as they could with the help they needed.

It's truly encouraging to reflect on how far we've come and how much we've achieved in a relatively short time. A real highlight of 2019/2020 has been to watch our community grow and use our services. I've personally received feedback, from brain tumour patients and their family, saying how much they've appreciated our delivery of quality information on our website, and our support - be that through having a Support Friend, ringing and talking to someone or through our social media platforms. We are working hard to further develop our educational resources and our Support Friend peer support programme. Our Brain Box initiative, whereby anybody who's been diagnosed with a brain tumour can receive our box of information and other essential items, free of charge, has just launched and I look forward to seeing this develop, ensuring people know how and where to access the support they need.

I've enjoyed working with, and am extremely grateful to our charity's incredibly hardworking, caring and effective Trustees and it has been my privilege to get to know them. They are remarkable people and it's been humbling to observe their passion for finding ways to support and advocate for those affected by this devastating disease.

Finally, as we continue to strive to reach our goals, I hope to see us improve collaboration with our brain tumour community as it is them that we are here for. As a board we know there is still much more to do and we will continue to work towards our vision that everyone who is living with a brain tumour should have the support, information and access to best treatments, so they can feel less afraid, less alone and more empowered.

He waka eke noa!

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 life threatening depending on its size and location in the brain and they have the potential to develop into a cancerous tumour.
- 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.

Knowing these facts doesn't help someone who has just heard the words "you have a brain tumour".

A brain tumour diagnosis may bring with it the double impact of a cancer diagnosis and a progressively debilitating neurological disease. The treatment is complex and debilitating, and diagnosis brings with it fear, isolation, disempowerment and a loss of control. This is where Brain Tumour Support NZ (BTSNZ) can help. Here at BTSNZ we believe that people need support from others, who not only understand the fear, confusion and isolation, but can also empower those with this diagnosis so they can feel more in control of their journey.



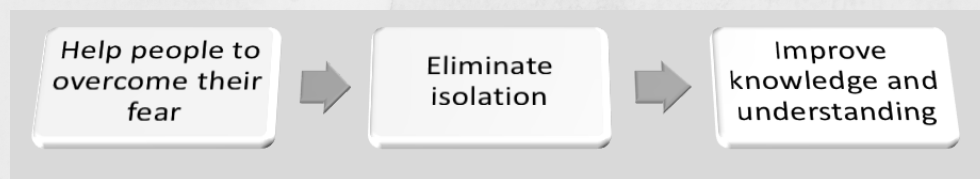


# THE VISION



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.

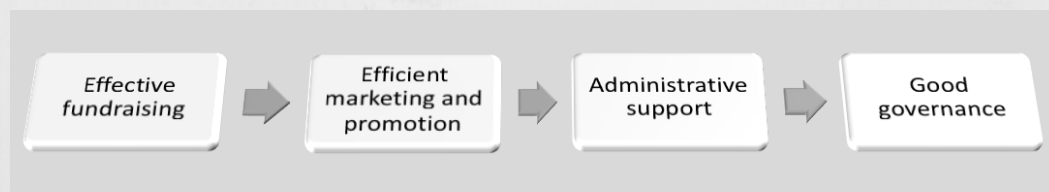
## TO MAKE THIS HAPPEN WE STRIVE TO...



## THROUGH OUR WORK IN THE FOLLOWING AREAS:



## WHICH IS ONLY POSSIBLE WITH:



# OUR VISION AND OUR WORK

When BTSNZ registered with the Charities Services in June 2019, we knew we had much work to do. We had five key strategic objectives for the first year.

- To be more visible to brain tumour patients and their family or whānau so they are able to easily access our support and information.
- To position BTSNZ as the reputable leader in its field, establishing trust with both the brain tumour community and those working in clinical areas.
- To provide quality education resources through both digital platforms and printed material.
- To provide quality support through our national Support Friend programme and social media platforms.
- To provide effective advocacy and lobbying with appropriate government and national governing organisations.



## 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.



## OUR VALUES

Our values create a moral compass for our Trust and everyone who works with us. These values guide our decision making. We are... **inclusive, supportive, compassionate, honest and respectful.**



## SOCIAL MEDIA

The use of social media has enabled us to create relationships and to engage with our online community. On our general Facebook page and on Instagram we have focussed on a mixture of posts – INFORMATIVE – THANK YOU TO OUR VOLUNTEERS - EDUCATIONAL – THANK YOU TO OUR DONORS – FUNDRAISING NEWS – LATEST RESEARCH – BRAIN TUMOUR NEWS. Our Facebook page has increased its page likes from 228 in June 2019 to just under 500 to date. Our Instagram has increased 0 – 100 since June 2019. Through Facebook Messaging we have been able to help and provide advice to people that have contacted us directly. We are also able to direct people to our closed Facebook groups for patients and for caregivers. The patient group currently has 25 members and the caregiver group has 10 members. Although these are not regularly active at present, both groups do still have a small number of people engaging with each other and we envisage they will grow in usage as more people join.

This year, we planned a the #No Going Back and the 'Give A Little A Lot' social media campaigns to be run during May (International Brain Tumour Awareness month). These were postponed for later in the year due to the Covid 19 pandemic.

## THE POWER OF TALKING

**We are very grateful for your support and think your website is terrific. Such a variety of sensible advice and up-to-date information. Thank you for making a big difference to people's lives**

Comment on our Facebook page

**So wonderful to see this. My daughter passed away with a brain tumour 6 years ago. It happened so fast. More support is needed.**



Comment on our Facebook page



## OUR WEBSITE

This year we have focussed on building a quality website that is easy for brain tumour patients to use. With the help of HotHouse Creative and their generous pro bono work we have been able to design a website that has surpassed our expectations in terms of design and content.

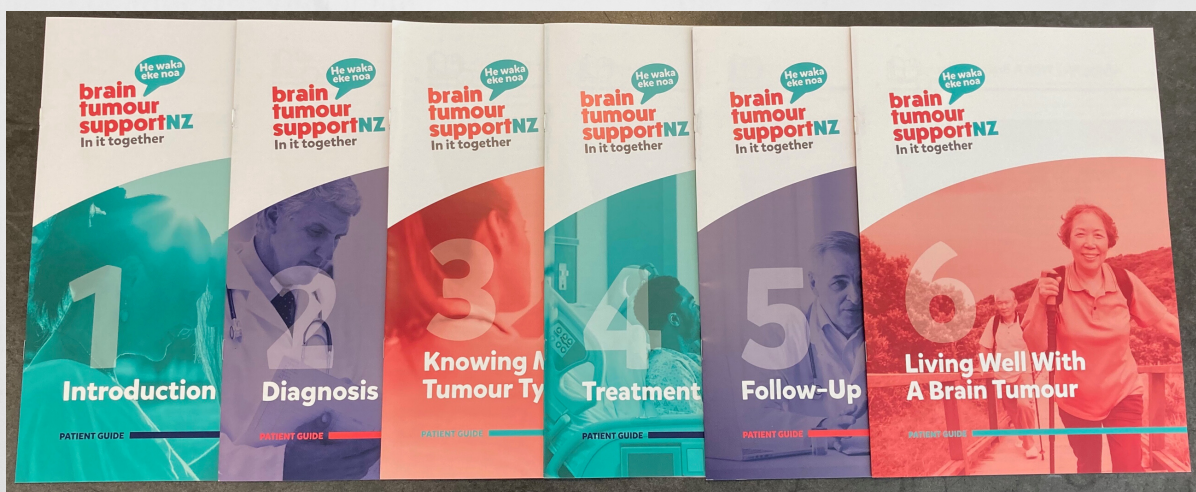
There is impressive imagery and graphics to create instant impact, informative menu options, making them easy to navigate for our community, and a clean and clear design.

Our intention, first and foremost, regarding the website is for brain tumour patients to easily find the support and information that they need, and to ensure that it is all New Zealand relevant.

In collaboration with New Zealand specialists, we have developed a set of six A4 Patient Guides to help patients and their whānau navigate their own pathway - 1. An introduction, 2. Diagnosis, 3. Knowing My Tumour Type, 4. Treatment, Follow-up and 6. Living Well with a Brain Tumour. We have also developed in-depth guides for Chemotherapy, Radiotherapy and Steroid Treatment. All our information regarding brain tumours has been developed with relevant clinicians who are currently working in New Zealand.

Our website users can access our Support Friends Programme online or over the phone and they can order one of our free Brain Boxes, a 'must have' support kit for newly diagnosed patients.

This year to day our website has had over 2000 visitors with over 4,500 page views in total. Our Patients Guides are the most popular page visited with over 360 views in the last six months.







## OUR SUPPORT FRIENDS

This year we started our National Support Friends Programme. A Support Friend is a volunteer who has experienced what it's like to live with a brain tumour, or to care for someone living with a brain tumour, they are unique and valuable conversation partners who are willing to share their experiences. Support Friends do not offer any medical advice but act as a 'listening ear' to provide hope and a way to cope during a difficult time. This service is offered to people diagnosed with a brain tumour, or to their family or whānau. The great thing about this programme is that it seems to help both the person who is using the service and the Support friend too!

Everyone here at BTSNZ are so grateful to our volunteer Support Friends. Their unique understanding means they have a distinctive insight. This year we have provided a Support Friend for 25 people nationwide and we currently have 18 Support Friend volunteers working for us. Our intention is to grow this programme further.

"Talking to someone on a similar journey to me has meant that I've ended up being supported too which is awesome!"

Brett - Brain tumour patient and Support Friend

"I jumped at the chance to volunteer as a support friend to others caring for a partner with a brain tumour diagnosis. No one else knows what it is like to live with this. It's great to be able to support each other and know that we are not alone. Through the website and Facebook we can connect to anyone in New Zealand going through the same situation."

Sarah - Caregiver and Support Friend

# OUR VOLUNTEERS

Some of our volunteers are personally connected to our brain tumour community and want to make a difference to the lives of people affected by a brain tumour, others want to develop new skills and some simply want to meet new people and have fun. We don't have a typical volunteer. Every person who volunteers for us does have one thing in common; they're absolutely vital to our work and we are so grateful!

This year, we went in search of volunteers to help us in all areas of our work. From Support Friends, to fundraisers to office workers, we thank you all! We have been fortunate to find a fabulous Volunteer Co-ordinator who is already working hard to support our volunteers. Being a volunteer herself, she has a good idea of how much our volunteers do for us. We've also managed to recruit people to help in our office which is amazing and, increasingly important, as we grow our charity from its small beginnings. By strategically increasing and supporting our volunteers effectively and professionally we believe this will be of benefit to our whole community.

So far this year we have 37 volunteers who are working hard behind the scenes and making a huge contribution to us achieving our aims and objectives.

"Volunteers don't get paid - not because they're worthless  
but because they're priceless!"

Sherry Anderson



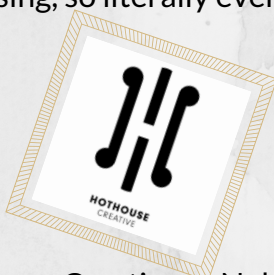


# FUNDRAISING AND AWARENESS HIGHLIGHTS



Every single person that fundraises for us, or who makes a donation, supports us through their business, or raises awareness of the disease and the work we do, plays a vital role in helping us to support New Zealanders who are diagnosed with a brain tumour.

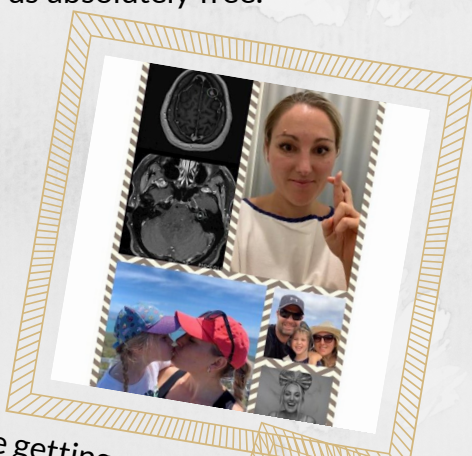
The charity receives no government funding and relies solely on voluntary donations and fundraising, so literally every bit of support counts!



HotHouse Creative, a Nelson business is supporting us every step of the way. by creating our impressive website and donating their time and expertise to us absolutely free.



Weekly yoga with Rosa



Nicole getting ready for the Goat Adventure Run



Gail and Sally's epic Lockdown fundraising run



In honour of Emma's mum 'hair today, gone tomorrow!'

# THANKYOU



# BRAIN BOXES - LAUNCHED IN JUNE THIS YEAR



The Brain Tumour Support NZ Brain Box is the 'must have' support kit for people with a new brain tumour diagnosis, and for their family.

We appreciate how difficult it is when someone is first diagnosed with a brain tumour - the countless questions that pop into their head, the confusion, the disbelief, the travelling to and from appointments, trying to remember the jobs of all the people that they'll meet on their journey, and knowing who to turn to and when. A juggling act that they don't need when they just want to focus their energy on feeling better.

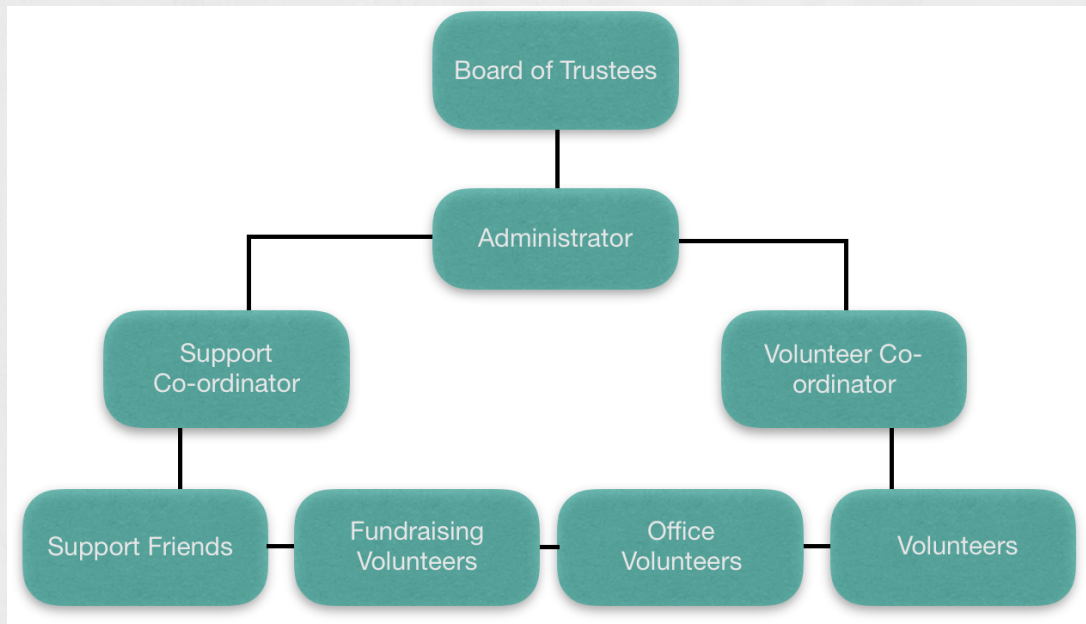
The Brain Box contains a number of essential items to support and provide information for brain tumour patients and their carers, including our six Patient Guides to help them navigate their journey, information about the support we offer and a whole bunch of good things to let them know that they are not on their own.

This new initiative is becoming more popular daily and we hope it will bring our brain tumour community together so we can support each other through this time.





## OUR STRUCTURE



## OUR TRUSTEES

Three of our five Board of Trustee members have direct experience of either living with a brain tumour, or with a family member who has a brain tumour.

The Board of Trustees meets formally at least on a quarterly basis, and often more frequently. All the trustees willingly give up their time and none of them receive any trustee remuneration. The trustees make up the governing body and oversee the governance of the charity, whilst the day to day management is lead by Mandy Bathan who is appointed Administrator of the charity.

The Board of Trustees are experienced people with a diverse range of skills who work hard to ensure the charity is governed effectively and efficiently. They take on a genuine responsibility of how the charity's income is used that will be of most benefit to all those people affected by the diagnosis of a brain tumour.

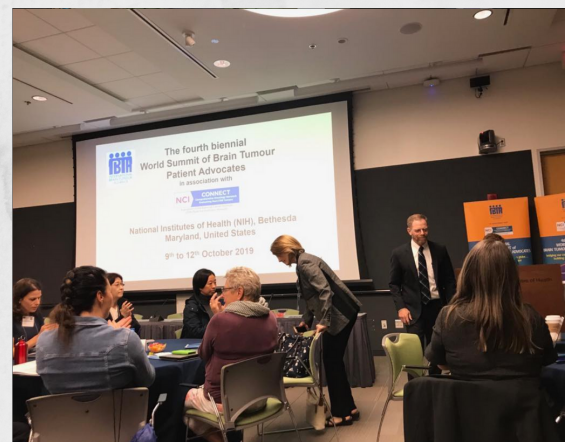


# OUR ENGAGEMENT WITH OTHER ORGANISATIONS

## International Brain Tumour Alliance

The IBTA's biennial Summit is all about building bridges across the international brain tumour community. Bringing key people together from 9th - 12nd October 2019 in Bethesda, Maryland, USA, the conference perfectly illustrated how important it is that we work together to bring about change. Whilst there isn't parity in treatment and care within New Zealand, there is even less in many parts of the world, and from those countries that are doing better than us, we have much we can learn.

Speakers and representatives from all around the globe offered presentations regarding brain tumours and their treatments, patient advocacy and looking at ways to improve the quality of life and care for brain tumour patients.



This was an amazing opportunity for our charity to learn from others and to be able to identify where changes can be adopted in New Zealand. The international community is growing and together making an impact around the world.

On the 21st of November, 2019, one of our trustees, Chris Tse presented a petition, on behalf of the Tahu Hikuroa Foundation, to Parliament via Tamati Coffey, the Labour MP for Waiariki. The petition urged the Government to publicly fund Avastin (bevacizumab) medication for New Zealanders with relapsed or refractory high-grade gliomas. We are so proud to be working with other charities to advocate on brain tumour patient's behalf.

