

He waka
eke noa

**brain
tumour
support**NZ

In it together

Annual Report 2022/2023



Chair's Report

Tena koutou katoa.

Perhaps the most important characteristic which people in the brain tumour community have needed this past year is 'resilience'.

The end of the pandemic and the re-opening of our borders was supposed to herald a return to life as normal in Aotearoa New Zealand. However, lingering Covid infections, severe weather events and the highest cost of living increases in over thirty years have collectively tested the nation's resolve. Add to that the challenges of navigating a brain tumour diagnosis in an over-stretched health system, and you begin to appreciate the remarkable resilience of the community which our charity so proudly serves.

In 2022 we made significant steps in the roll out of our paediatric brain tumour resources. Under the leadership of trustee Moira Coatsworth, we published our education guide: "Supporting Students With Brain Tumours – a Guide for New Zealand Teachers and Families". Our research shows that reintegrating into the school system is one of the greatest areas of concern for families dealing with a child with a brain tumour, so this publication was a logical first step in the roll out. Moira lead this project, in consultation with New Zealand health and education professionals, and I congratulate her on producing a publication that we can all be proud of.

This year we launched a new Facebook group – Brain Tumour Support NZ Parents Connect – bringing together parents of children with brain tumours. We also launched the "Brain Box for Kidz" – the paediatric version of our signature Brain Box programme – in partnership with Frankie to the Rescue.

Our Brain Box programme, under the direction of trustee Sarah Gibb, continues to go from strength to strength. In the year to March 2023 we despatched 226 Brain Boxes, an increase of 56% over the previous year. We achieved a significant milestone in April 2023 when we despatched the 500th Brain Box since the service commenced in July 2020. We are grateful to Sarah and her team of volunteers, and to those who managed the Brain Box programme before them, for getting us to this important milestone.

This new service allows us to provide age-specific care and information packages to children with brain tumours. I wish to thank Warrick and Michelle Wood of Frankie to the Rescue for their significant contribution in helping bring this project to fruition.





Support

Support is not only in our charity's name, it is woven into the fabric of our work.

This year we expanded our online support groups from two to five, splitting both the Caregiver and Patient groups into high and low grade brain tumours to better suit the needs of participants. We also launched a bereavement group so that support could continue to be offered to people following the death of their loved one.

Pleasingly, since moving to the new group format, average attendance across all groups has increased by 56% and feedback from participants continues to rate very highly in surveys. A large part of this success can be attributed to our wonderful volunteer facilitators: Vicky Gaunt, Sandra Parker, Tim Parker, Pauline Wood; and our Support Co-ordinator, Monique Gardiner. Our facilitators turn up every month to run these online groups, providing comfort and support to people in need, and I thank them for their important work.

In August we completed the first tranche of our Support Friend training, under the guidance of clinical psychologist Tania Anstiss. A total of twenty six Support Friend volunteers have completed the training and many are now actively supporting brain tumour patients and carers in the community. The Support Friends Training Handbook, produced by Tania Anstiss as part of the training programme, has become a useful ongoing resource for our Support Friend volunteers.



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Volunteers are a special part of our charity and we are fortunate to have a number of amazing people who are willing to give up their time, energy and expertise to help us in our Mission. To our Support Friends, support group facilitators, website and social media volunteers, the Brain Box team, our researchers, storywriters, minute-takers, and all of our other volunteers, we really can't thank you enough for your mahi.



Fundraising

The highlight of our fundraising year was undoubtedly the Brainy Beanies campaign, which not only raised significant funding towards our Brain Box programme but also raised the profile of brain tumours and Brain Tumour Support NZ in the wider community. As I write this report, we have just wrapped up the second Brainy Beanie Exhibition at The Meteor Theatre in Hamilton, and it is heartening to see this event attract such wonderful support for the second year running.

Brainy Beanies is tapping a new demographic for us, and is allowing us to reach out and connect with people beyond our established community of supporters. Many of our traditional fundraisers have been younger people running marathons, doing epic walks or shaving their heads, but Brainy Beanies is attracting support from people of all ages, young and old. I wish to acknowledge Sarah Gibb, who had the original idea for Brainy Beanies, and her team of helpers for their tireless efforts across both campaigns.

A huge thank you also to everyone who raised funds or donated to us, over the past year. The fundraising ideas on our Give-a-little page continue to impress. Notable campaigns this year featured a head shave live on national television, a debut ironman, a triathlon, several running, walking and cycling challenges, and three rounds of amateur boxing. Thanks also to our corporate sponsor FRANKiE4 for their ongoing support.



Advocacy and Research

As both a rare cancer and rare disorder, brain tumours often struggle to make the headlines in our mainstream media. Brain Tumour Support NZ plays an important role in amplifying the patient voice. Our advocacy work is informed by our medical advisory board and our patient community, who are quick to identify any gaps in services or shortfalls in care. This year we shone the spotlight on a range of issues such as: the shortage of radiation oncologists, insufficient MRI capacity across the country, limited access to medicines, and the lack of clinical trials in New Zealand.



A major highlight on the research calendar was the inaugural New Zealand Neuro-Oncology Conference, held in Auckland in February 2023. Brain Tumour Support NZ was asked to run the patient session at this important event. My thanks to Tania Anstiss, Kate Coatsworth, and BTSNZ trustees Mandy Bathan and Moira Coatsworth for their excellent work on the patient and caregiver panel. As a result of this conference, a new neuro-oncology society has been formed –

the NZ Aotearoa Neuro-Oncology Society (NANOS) – and I am proud to represent Brain Tumour Support NZ as patient advisor to the executive committee.

It was great to see most of our medical advisory board (MAB) present at this meeting. Our MAB members are continuing to drive the field of neuro-oncology forward in New Zealand and I thank them for their dedicated work in improving outcomes for brain tumour patients.





Chris Tse

As for the Brain Tumour Support NZ board, it has been another busy year for our hard-working trustees. In January, we were delighted to welcome back our founding trustee and inaugural chair, Mandy Bathan, to active board duties. I'm sure my fellow trustees will agree that Mandy's return has reinvigorated the board and we are delighted to have her back.

In February, we farewelled one of our founding trustees, Gavin Starling, who was instrumental in the formation of the charity. We thank Gavin for his contribution over a number of years and wish him well for the future.

Most recently we are saying goodbye to Marie Waterhouse, another founding trustee. Marie has made a significant contribution to the running of Brain Tumour Support NZ from the very beginning. Her expertise, particularly in design, marketing and fundraising, has been hugely important in the growth of the charity and she has been an integral member of our board. We thank Marie for putting her heart and soul into her work as a trustee, and her departure is softened by knowing that she will continue to be available to assist us outside the boardroom.

Finally, a message to the many people who have participated in our various support platforms – the patients and carers logging on to our monthly support groups on Zoom, the members of our Patients and Caregivers Facebook groups, the parents who have shared their stories and supported each other on Parents Connect. Thank you for connecting, listening and sharing. It is your collective strength as a community which is helping provide support and hope to those who are newly diagnosed.

Ngā mihi nui,

Chris Tse, Chair

Brain Tumour Support NZ

Our Impact in 2022/2023



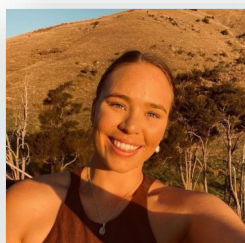
Launched education guide *"Supporting Students with Brain Tumours"*

Launched Parents Connect Facebook Group



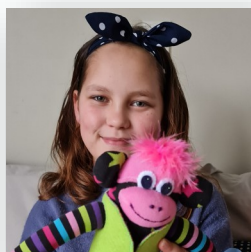
Launched the Brain Box for Kidz

Expanded monthly online support groups from two to five



Produced Support Friends Training Handbook and Course

Held the inaugural Brainy Beanies Campaign and Exhibition



Delivered 226 Brain Boxes across Aotearoa

Attended the inaugural meeting of the NZ Aotearoa Neuro-Oncology Group





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)
- Mandy Bathan
- Moira Coatsworth
- Tim Franklin
- Sarah Gibb

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



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