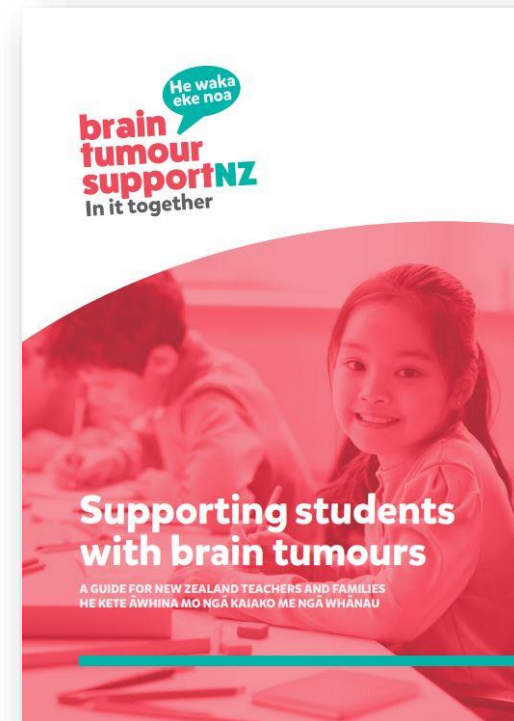


Back to school with a brain tumour

The Brain Tumour Support New Zealand experience

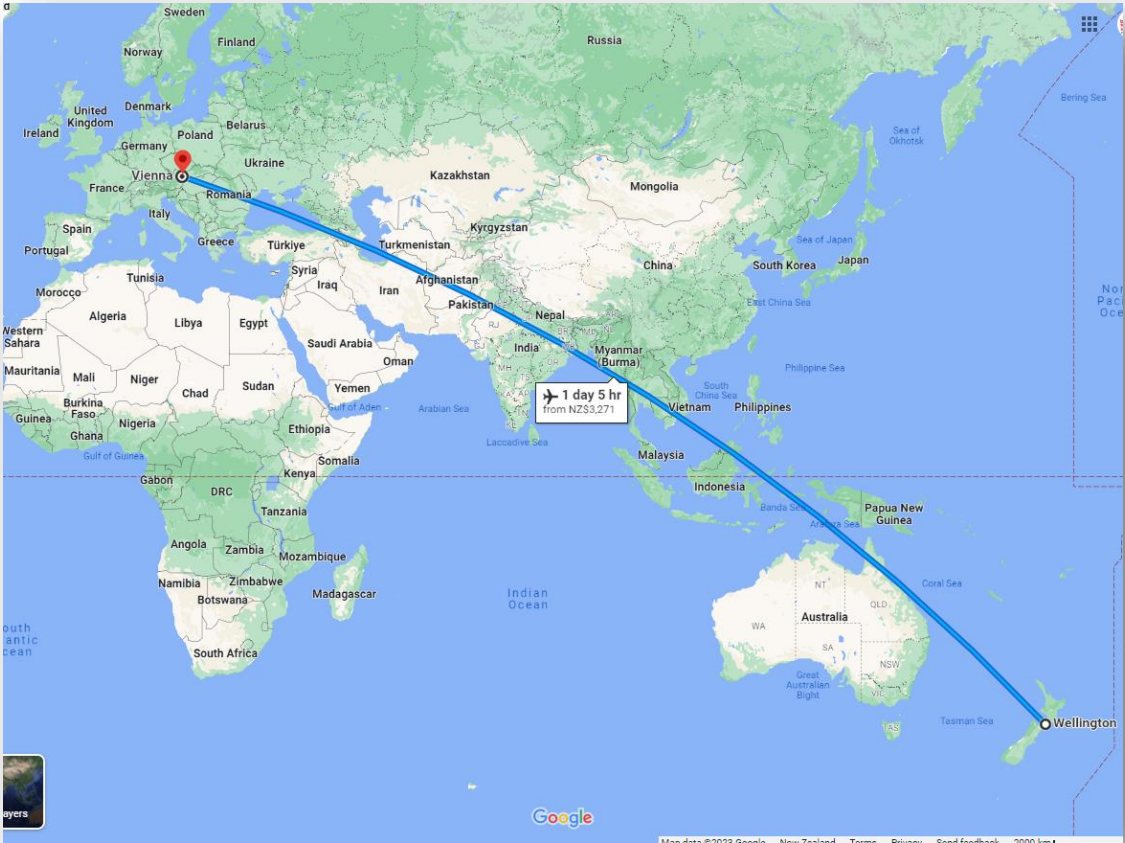


5th Biennial World Summit of Brain Tumour Patient Advocates
The Intercontinental Hotel, Vienna, Austria, 26th June 2023

Chris Tse, Chair, Brain Tumour Support NZ
Senior Advisor, International Brain Tumour Alliance



New Zealand – Where is it?





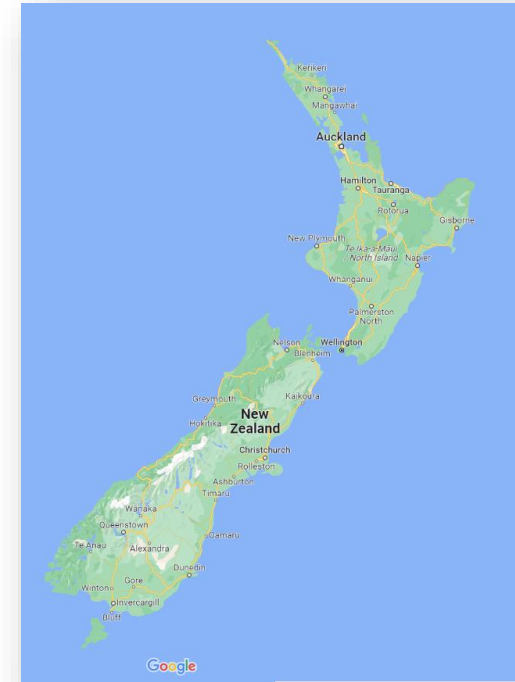
THE
LORD OF THE RINGS



He waka
eke noa
**brain
tumour
support
NZ**
In it together

New Zealand – Some Facts

- Population 5.1 million
[ranked 126th - similar to Ireland]
- Area 270,500 square kilometres
[76th - larger than United Kingdom 242,900]
- Nominal GDP per capita \$43,400
[20th - on par with Canada, Germany, Belgium]



Demographics

European	70.2
Māori	16.5
Asian	15.1
Pacific peoples	8.1
Middle Eastern/Latin American/African	1.5
Other ethnicity	1.2



Māori health model



- Taha wairua - spiritual
- Taha hinengaro - psychological
- Taha tinana - physical
- Taha whānau – extended family

Brain tumours in New Zealand

Malignant primary brain tumours

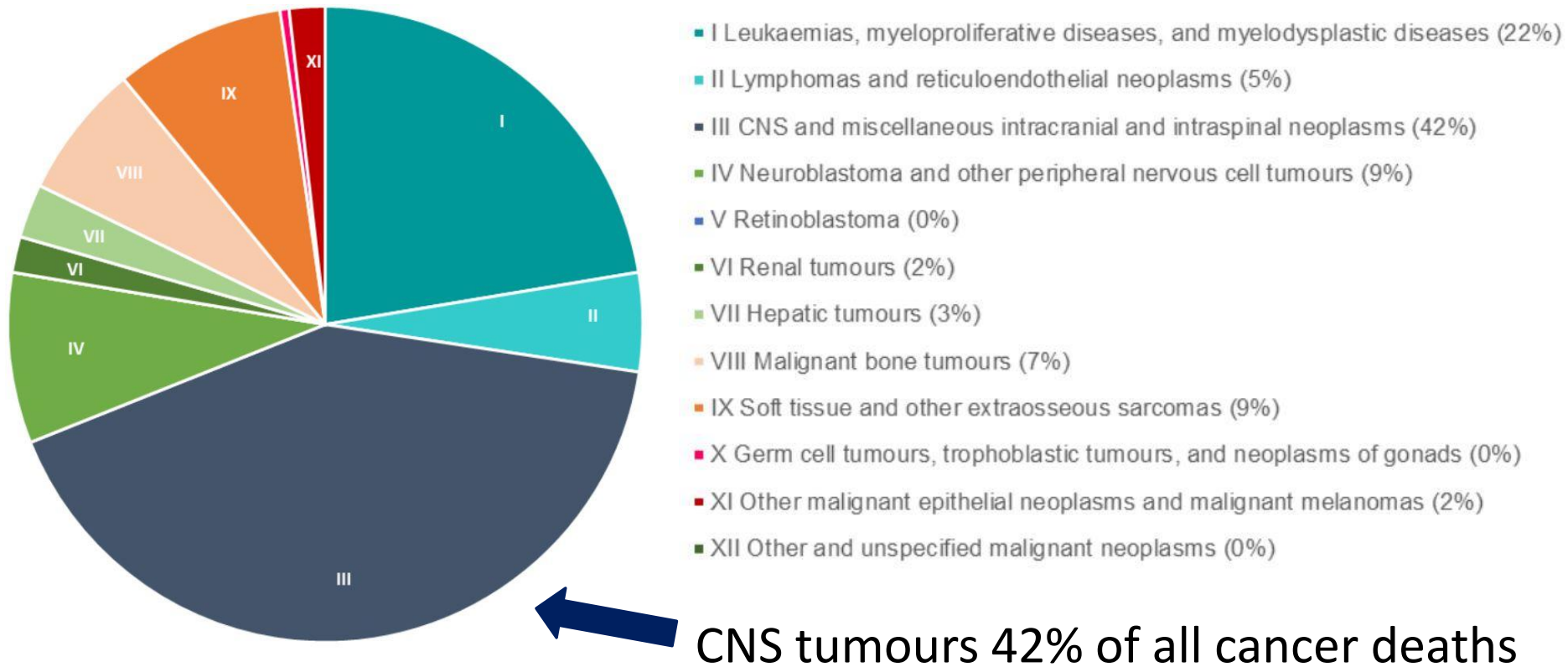
- 337 cases (all ages, annually)
- 278 deaths (all ages, annually)

Childhood brain tumours

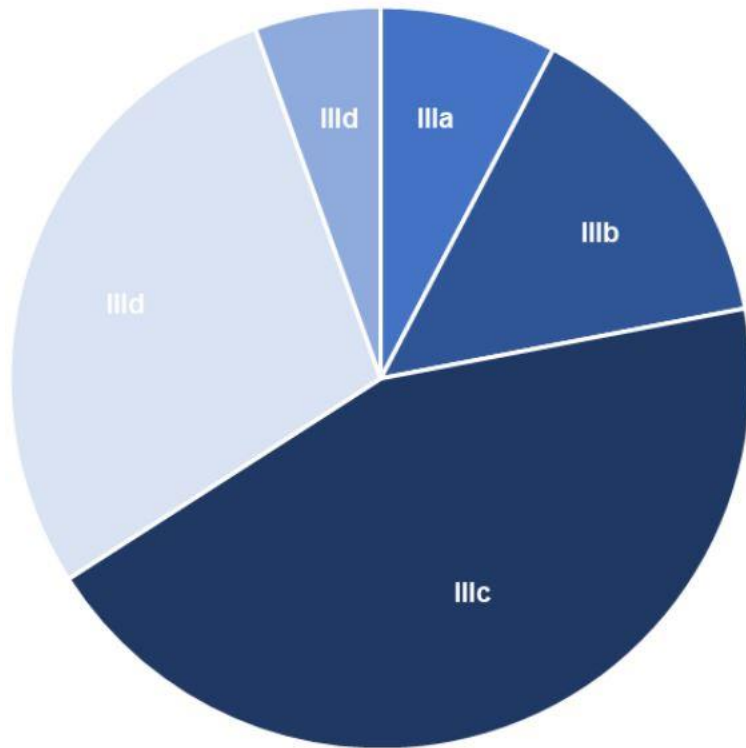
- 36 cases (aged 0–14 years, annually)
- 9 deaths (aged 0–14 years, annually)



Childhood cancer deaths in New Zealand



Childhood brain tumours in New Zealand



- III.a Ependymomas and choroid plexus tumours (3%)
- III.b Astrocytomas (6%)
- III.c Intracranial and intraspinal embryonal tumours (18%)
- III.d Other gliomas (12%)
- III.e Other specified intracranial and intraspinal neoplasms (0%)
- III.f Unspecified intracranial and intraspinal neoplasms (2%)

Paediatric treatment centres



Starship Children's Hospital,
Auckland



Child Haematology and Oncology
Centre (CHOC), Christchurch



Brain Tumour Support NZ



Mandy Bathan
Dx Oligodendroglioma 2017



Gavin Starling
Partner Natalie dx GBM 2017



Chris Tse
Wife Lynda dx GBM 2006

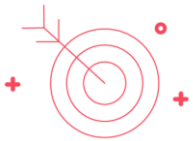


- Formed as a charitable trust in June 2019
- Registered with Charity Services in September 2019

Our Vision, Mission and Values



Our Vision is that people affected by a brain tumour feel less afraid, less alone and more empowered.



Our Mission is to inform, support and advocate for everyone in Aotearoa New Zealand affected by a brain tumour.



Our Trust is founded on values of inclusivity, compassion, integrity and respect.

Medical Advisory Board



Dr Steve Delaney, medical oncologist, Nelson
Dr Catherine Han, medical oncologist, Auckland
Dr Salina Iupati, palliative care physician, Wellington
Dr Melissa James, radiation oncologist, Christchurch
Mr Simon John, neurosurgeon, Christchurch
Mr Andrew Parker, neurosurgeon, Wellington
Dr Frank Saran, radiation oncologist, Auckland
Dr Clinton Turner, neuro-pathologist, Auckland
Caroline Woon, nurse educator, Wellington

Medical Advisory Board

Information and support



Website



Patient Guides



Brain Boxes



Email Newsletter



Social Media



Support Friends
(Peer Support)



Online Support
Groups



Facebook
Groups

Not reinventing the wheel



International research



Pediatric
Brain Tumor
Foundation®



Identifying the unmet need

- Mid-2021 Held parent focus group
- Feeling dumbfounded, overwhelmed
 - Gaps in support following clinical treatment, eg. back to school
 - Existing information not specific to brain tumours or not made for New Zealand
- Aug 2021 Appointed project lead
- Aug 2021 Recruited paediatric neurosurgeon to MAB
- Sep 2021 Met with paediatric neuro-psychology team at Starship Children's Hospital



Moira Coatsworth

Producing the guide

Oct 2021

Scope the document

- Who is it for?
- What age children should it cover?
- New Zealand relevant

Oct-Dec
2021

Put advisory in place

- Ministry of Education
- Regional Health School
- Starship paediatric neuro-psychologists
- Paediatric neurosurgeon
- Parents advisory group

Aug 2022

Launch!



The finished product

- Family friendly
- Two copies in each Brain Box
- Distinctly New Zealand flavour
- Collaborative input
- Positive tone - strengths focused



Lessons learned

- 🗨️ Do your research
- 🗨️ Don't try and do everything at once
- 🗨️ Be targeted and focused
- 🗨️ Be realistic, play to your strengths
- 🗨️ Seek expert advice, collaborate



Since the launch



Brain Box 4 Kidz
Launched August 2022



Parents Facebook group
Launched January 2023

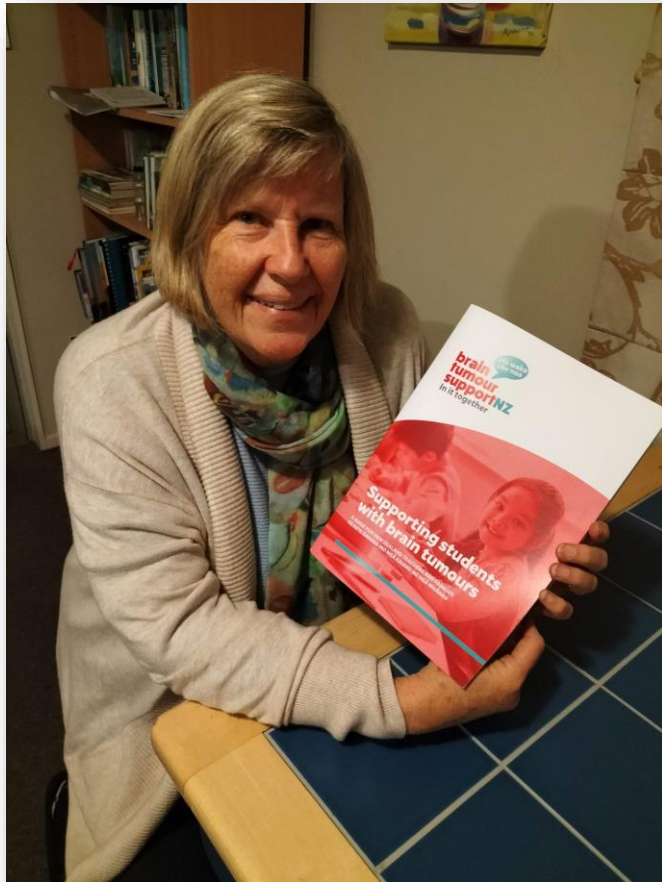


Download a copy of the Brain Tumour Support NZ education guide: “Supporting Students with Brain Tumours” here:



<https://bit.ly/btsnz-education-guide>

Thank you!



- Brain Tumour Support NZ: Moira Coatsworth, Mandy Bathan, Marie Waterhouse
- Starship Children's Hospital, Auckland
- Child Haematology and Oncology Centre, Christchurch
- Child Cancer Foundation
- Ministry of Education
- Northern Regional Health School
- FRANKiE4 and Hothouse Creative
- Children, parents and families