



2024 Annual Impact Report



leukaemia &
blood cancer
NEW ZEALAND

Vision to Cure. Mission to Care.

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Executive Summary from the CEO and Board Chair

As we reflect on the past year, we are incredibly proud of the impact that Leukaemia & Blood Cancer New Zealand (LBC) has made in the lives of those affected by blood cancer. Our commitment to supporting patients and families, advocating for improved treatment options, and funding vital research remains unwavering and is only possible through the generosity of our supporters – thank you.

Patient Support

Our Support Services Team continued to make a profound difference in the lives of thousands of New Zealanders living with blood cancer. With 1,383 patients and whānau supported and 323 patient support groups held both in person and online, we reinforced our commitment to ensuring that no patient faces their blood cancer journey alone. Key initiatives such as the Blood Cancer Patient Forum, Winter Workshops, and the launch of our booklet for adolescents and young people have strengthened our ability to reach and support diverse patient groups.

Advocacy

Advocacy remains a key pillar of our impact. In 2024, we took a significant step by embedding it into our organisational strategy. We appointed a dedicated full-time advocacy lead, who is now driving advocacy efforts in partnership with our patient and clinical community. We also established the Blood Cancer Alliance in collaboration with other advocacy groups and haematologists. This has helped unify and amplify our collective voice as we engage Government and health system decision-makers. Our advocacy included contributing to Pharmac’s decision to retain funding clause 8.1b for paediatric oncology treatments.

Research and Innovation

This year marked a decade of impact from the Leukaemia & Blood Cancer Research Unit (LBCRU). Our investment of over \$3 million in cutting-edge research at the LBCRU has significantly enhanced personalised treatment approaches for blood cancer patients in New Zealand. The advancement in genetic testing, increasing from just 3 genes in 2019 to 111 genes in 2023, has helped improve treatment decisions for 20% of acute myeloid leukaemia patients. With ongoing research, we look forward to future discoveries and their translation into improved patient care.

Sustainability

The sustainability of LBC is critical to our ability to deliver impact for patients now and in the future. Our fundraising initiatives continue to grow, with the launch of our Shine for a Cure lantern walk, the return of the Step Up Challenge, and the continued success of the Sky Tower Firefighter Challenge, Shave for a Cure, and Spirit to Cure. As a charity that relies 100% on donations to deliver our impact, the generosity of New Zealanders is being felt now more than ever. With five offices around the country, we continue to enhance our operational efficiency as we extend our patient reach and community engagement.

Looking Ahead

We remain committed to our vision to cure and our mission to care. Our vision is strengthened by the generosity of our donors, the dedication of our partners, and the unwavering spirit of our patients and their families. Together, we will continue to drive impact, innovation, and hope for all those affected by blood cancer in New Zealand.

With gratitude,



Tim Edmonds
Chief Executive Officer



Pene Milne
Chair, Board of Directors

Our Objectives

Support

Deliver valued patient and family support services nationally.

Advocacy

Advocate for access to the best global standard of treatment for New Zealand patients.

Research

Proactively drive research into the prevention, cure and care of blood cancer in New Zealand.

Sustainability

Ensure future organisational success and financial sustainability.

Numbers Snapshot

1,383

Total number of referrals

\$842,922

Total patient related support

323

Total number of groups held (online and in-person)

1.9m

Facebook reach over the year

Thank you to all of our wonderful partners



Farmers

sky CITY

Auckland Airport



SUNCORP

SUZUKI

Support

LBC Support services team support thousands of patients like John who has been living with Myeloma for 8 years. Our LBC Support Services Coordinator provided John with help and support during his transplant and when he was recovering at home. John attended regular support groups including our online Blokes with Blood Cancer group. He attends our education events, online webinars and patient forum. Once through treatment he engaged in the LBC's Employment workshops to assist in navigating getting back to work. John continues to attend our support groups and finds value in our newsletters and disease specific publications.

Haematology health professionals learning about Chinese culture in healthcare.



Introducing LBC's 'Guide to Blood Cancer' booklet for adolescents and young adults.



kids' club

Play therapy at LBC's Auckland Kids' club.

Forum

The 2023 Blood Cancer Patient Forum held in Christchurch was a huge success with 160 patients and family members attending. We had 22 sessions across the day with a selection of disease updates and survivorship topics from expert speakers in the haematology field.

Winter Workshops

The 2023 Winter Workshop series was a great opportunity to network with our health professional stakeholders while providing a valuable education opportunity benefitting our patients across New Zealand.

Dr James Jap presented on the Care of the Chinese Patient, widening our understanding of Chinese cultural norms.

AYA booklet launch

In March we launched our new AYA Blood Cancer booklet – aimed to help adolescent and young adult patients navigate their way through diagnosis, treatment and recovery. This booklet is proving to be an important resource for our patients.

Kids' Club

LBC offers a wide range of support for paediatric patients and children whose loved one has a blood cancer. Our Kids' Clubs were held regularly through the year in 4 main centres, with special online groups available for those children not able to get to our centres, as well as for patients in the hospital.

Our annual patient survey had a great response.

Tracy King's closing speech on Living well with and beyond blood cancer.



Key Findings

92%

of patients and whanau agree that referrals to LBC should be automatic (with the option to opt out).



Online services that are most appreciated are the education webinars and disease specific support groups.

Online OR hardcopy resources – patients and whanau prefer both.

58%

of patients say they have been either moderately or severely impacted financially by their diagnosis



Of all LBC services, information booklets and factsheets remain the most useful, followed by in-person support groups, and our disease specific publications.

83%

said LBC made a positive difference to their health journey



Our staff and their specialised knowledge rated highest for what makes LBC unique

Research

The Leukaemia & Blood Cancer Research Unit – celebrating 10 years

In 2023, we celebrated 10 years since the opening of the Leukaemia & Blood Cancer Research Unit (LBCRU) in the Faculty of Medical & Health Sciences at the University of Auckland Waipapa Taumata Rau.

Back in 2013, the LBCRU was opened as a collaboration between LBC and the university to support innovative blood cancer research to improve patient outcomes. It was the first of its kind in New Zealand.

The University of Marburg’s Professor Stefan Bohlander joined Dr Peter Browett, Professor of Pathology at the University of Auckland and LBC’s Medical Director as co-directors of the LBCRU – positions that they still hold today.

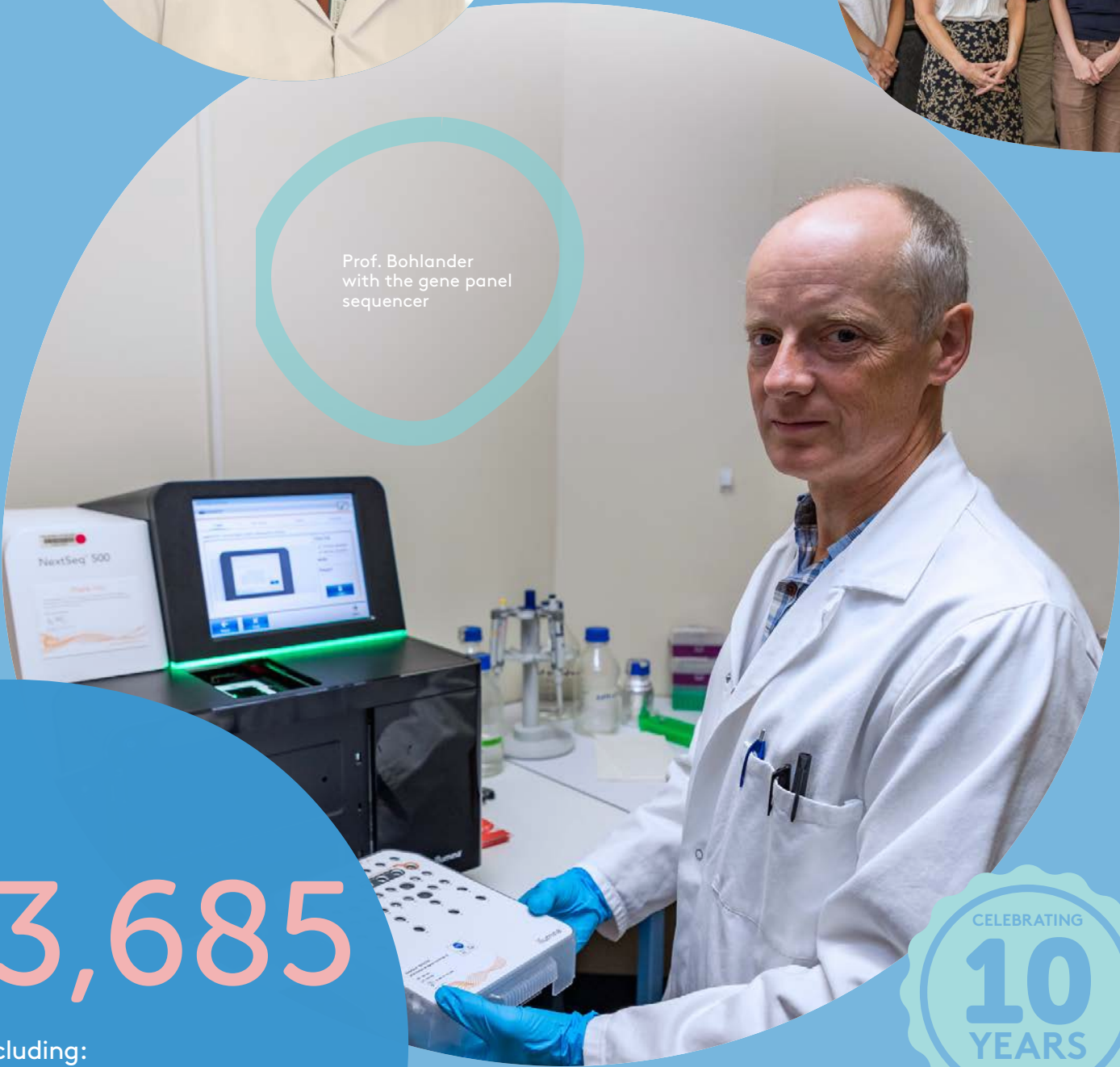
LBC has now contributed over **\$3 million** toward the LBCRU’s research on a highly personalised approach to blood cancer treatment – finding specific genetic mutations in a patient’s blood cancer that would result in improved treatments and outcomes for that patient. LBC has continued funding toward the LBCRU every year and the unit has continued to make great progress and strides.



Mariam Alhilali ,
our 2nd John Waller
PhD Scholar



The team of the
Leukaemia & Blood
Cancer Research
Unit



Prof. Bohlander
with the gene panel
sequencer

In 2019, blood cancer patients had only 3 genes out of a total of 22,000 routinely tested at Auckland City Hospital, and about 50-60% had to be treated the same way. But by 2023, thanks in part to the LBCRU, blood cancer patients can now have 111 genes tested. Leukaemia cells of every single acute myeloid leukaemia patient are now analysed at Auckland City Hospital. No two patients have been found with the same pattern of mutation.

In about 20% of cases, clinicians have changed their treatment approach for AML patients as a result – sometimes avoiding the need for a stem cell transplant. These tests are now being made available throughout New Zealand.

We celebrated a decade of success with a LBCRU open day – an opportunity for LBC donors, supporters and Board members past and present to listen to an engaging presentation by Prof. Bohlander, followed by a walk-through of the Research Unit.

A short video, highlighting the gene panel research, was produced and has been viewed many times since as an impactful, visual example of the difference that blood cancer research has made on the lives of AML blood cancer patients in the past few years.

We look forward to what the next decade will bring and the potential for further advances in personalised haematology research.

\$503,685

Given to Research, including:

- Annual support of the LBCRU
- Research grants
- Summer Studentship Grants
- Travel Grants
- John Waller PhD Scholarship





Advocacy



Embedding Advocacy at LBC

At LBC, we keep the voice and perspective of patients at the forefront of every conversation. In 2023-24, we set a goal to enhance our patient advocacy efforts and embedded advocacy into our organisational strategy.

To build the capacity required to deliver a more proactive and comprehensive approach, we introduced a new full-time 'Advocacy Strategy Manager' role that is now driving advocacy efforts across the organisation.

Strengthening advocacy networks

Successful advocacy relies on partnering with like-minded groups to amplify our message and drive change. Early in 2024, we formed the Blood Cancer Alliance, comprising other patient advocacy groups (Chronic Lymphocytic Leukaemia Advocates New Zealand and Myeloma New Zealand), along with consultant haematologists. As a collective, we have engaged with Ministers and have achieved improved recognition across Government on the importance of delivering timely and quality blood cancer care.

LBC also collaborates with a variety of organisations to drive change, including:

- The Alliance of Cancer Non-Governmental Organisations (CANGO)
- Australasian Leukaemia & Lymphoma Group (ALLG)
- Haematology Society of Australia & New Zealand (HSANZ)
- Adolescent/Young Adult Cancer Services (AYA)
- National Child Cancer Network (NCCN)

Driving change

In 2022-23 LBC submitted to parliamentary enquiries and health sector consultations on a range of issues, and in 2023-24 we saw our responses inform decision-making and result in positive outcomes for the blood cancer community, including;

In 2023, Pharmac proposed removing funding clause 8.1b that allows paediatric oncologists to provide treatments to children without requiring Pharmac assessment. The damaging impact of this change on patient outcomes was highlighted to Pharmac, who subsequently agreed to retain the clause.

Concerns raised on the Therapeutic Products Bill were widely shared by respondents in public consultation, and the Act is expected to be repealed by the end of 2024.

LBC's response to Pharmac's consultation to fund a shingles vaccine (Shingrix) for immunocompromised people was supportive, highlighting the benefit this offers blood cancer patients. In April 2024, Pharmac confirmed the decision to widen funded access to this group.

#ThisIsBloodCancer

LBC once again joined forces with our sister organisations from Australia, UK and Canada for Blood Cancer Awareness Month in September 2023. Building on previous years, we continued to promote the signs and symptoms of blood cancer, as well as the impact it has on patients and their families.

Content was published across Instagram/Facebook/LinkedIn and through key news media, including raising awareness to healthcare professionals, via NZ Doctor. We want to always encourage them to look out for signs and symptoms too.



Sustainability



Getting ready for our new lantern event

Touching hearts and minds with our Lantern celebration

Peer to peer fundraising is a core component of LBC's fundraising. We seized the opportunity last year to launch a new fundraising campaign that we had been considering for some time – an evening lantern festival.

Donors were invited to fundraise and then take part in a very special lantern lighting ceremony at dusk in July. Once they had raised a minimum of \$100, they received from us a beautiful silk lantern to keep. They could choose gold to remember someone who had passed away, teal for your own cancer journey or white to show support for all those affected by cancer.

Patients and their families were especially keen to join in. Many still had concerns about close personal contact and so, as this was our first year, we chose to run a virtual event with an online live and pre-recorded programme of messages and support before everyone was asked to switch on their lanterns at exactly the same time.

The evening went very well and the feedback was positive so we look forward to expanding the scope to include an in-person event in 2024.



Increased efficiency with new CRM

After 18 months of intense preparation, in mid 2023, we launched Salesforce.org as our new CRM with the Nonprofit Success Pack application providing special features with a fundraising focus.

We had been aware for some time that a new CRM was required in order for the organisation to improve our efficiency, our reach, our fundraising goals and our ability to better engage with our donors – and those we support.

As part of the implementation process, we built unique platforms for our inbound grants programme and our Support Services as well as one to integrate our many revenue streams and provide customised reporting

Salesforce.org offers all the capabilities of Salesforce.com but tailor-made to meet the needs of the not for profit/for purpose community and at greatly reduced fees.

The LBC team clearly came up to speed with the new functionality quickly and we are all commenting on our ability already to work faster and smarter with the new CRM system.

More FM Breakfast host, Lana after climbing the Sky Tower



Workplace Teams Race to the Top

After a couple of years of disruption due to the impact of the COVID epidemic, it was great this year to once again hold our Auckland Sky Tower Step Up Challenge.

This is an iconic fundraising event giving everyone a "bucket list" challenge to climb the Sky Tower. We have a fundraising expectation of \$1,103 for everyone – the same number as the steps taken to reach the finish line on level 51.

In the past, this event typically attracted workplace teams. This year, we found that this was no different, meaning that we focused on reaching out to businesses and community groups to reach our participation target. It is a great event for our partners too, looking for an engaging way to get staff and stakeholders fundraising for us.

At the summit, teams waited for everyone in their group to cross the finish line before celebrating with their medals. There was great camaraderie and plenty of colourful costumes as well.

Our thanks to SkyCity as the principal partner and we congratulate the More FM team led by Lana Cochrane-Searle as our top fundraisers.



Finisher at the Christchurch Adventure Park Spirit to Cure walk

Suncorp NZ's Spirited Fundraising

After a successful series of challenge fundraising events in 2022, Suncorp NZ confirmed that they would like to continue with their Spirit to Cure campaign in 2023 and that LBC would once again be the main charity partner.

We repeated the same core stepping events in the 3 main centres – Eden Park Stadium in Auckland, Sky Stadium in Wellington and the Port Hills' walk within the Christchurch Adventure Park.

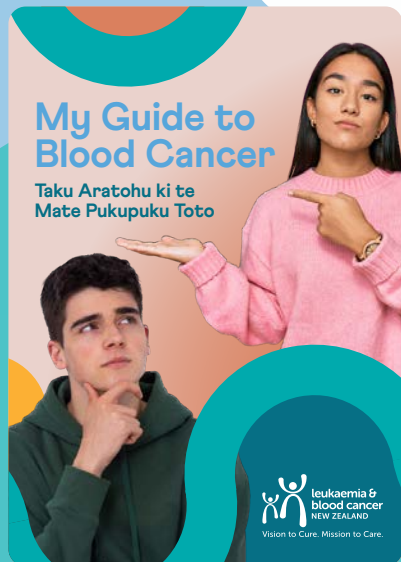
It is always a concern when asking the same group to fundraise again, and so soon, that there will be donor fatigue but Suncorp and its many business partners, rose to the challenge and raised even more funds in the 2nd year.

We heard stories of some very creative fundraising including selling pies, quiz nights and an online auction filled with sponsors' products. We acknowledge the generosity of everyone involved – not only with donations but with the volunteer time as well. The events were very enjoyable – blustery and wet unfortunately in Wellington and Auckland but it didn't dampen the banter and laughter throughout.

Grants



Kate with a Monkey in My Chair



Front cover of "My Guide to Blood Cancer" for AYA patients

Keeping Kids Connected

Our **Monkey in My Chair** programme is a successful therapeutic resource to keep young patients, teachers and classmates connected in a positive, supportive and compassionate way.

Thanks to a grant from the Chenery Memorial Trust, we were able to purchase a number of these kits this year, ready to be used when a child is diagnosed and will be absent from school for some time.

The Monkey in My Chair kit comes with two adorable fluffy monkeys plus a range of educational books, teacher guides and LBC resources.

When a young person is away from school, the bigger of the two monkeys sits in the student's chair, while the smaller monkey keeps the patient company while they undergo treatment and are missing their friends at school.

Classmates are encouraged to include the big monkey in lessons and send messages and news to their friend using Monkey's bright yellow backpack.

LBC's Support Services Coordinators work with a patient's parents and school to use the kits in a way which is easy, fun and helpful for everyone involved.

A Young Person's Guide to Blood Cancer

Being told you have a blood cancer at a young age can come as a huge shock. One of the aims of LBC is to provide resources with a health literacy lens and this includes reaching young adults and adolescents (AYA patients).

We partnered with The Lindsay Foundation this year and received funding to produce an updated blood cancer resource specifically for this age group.

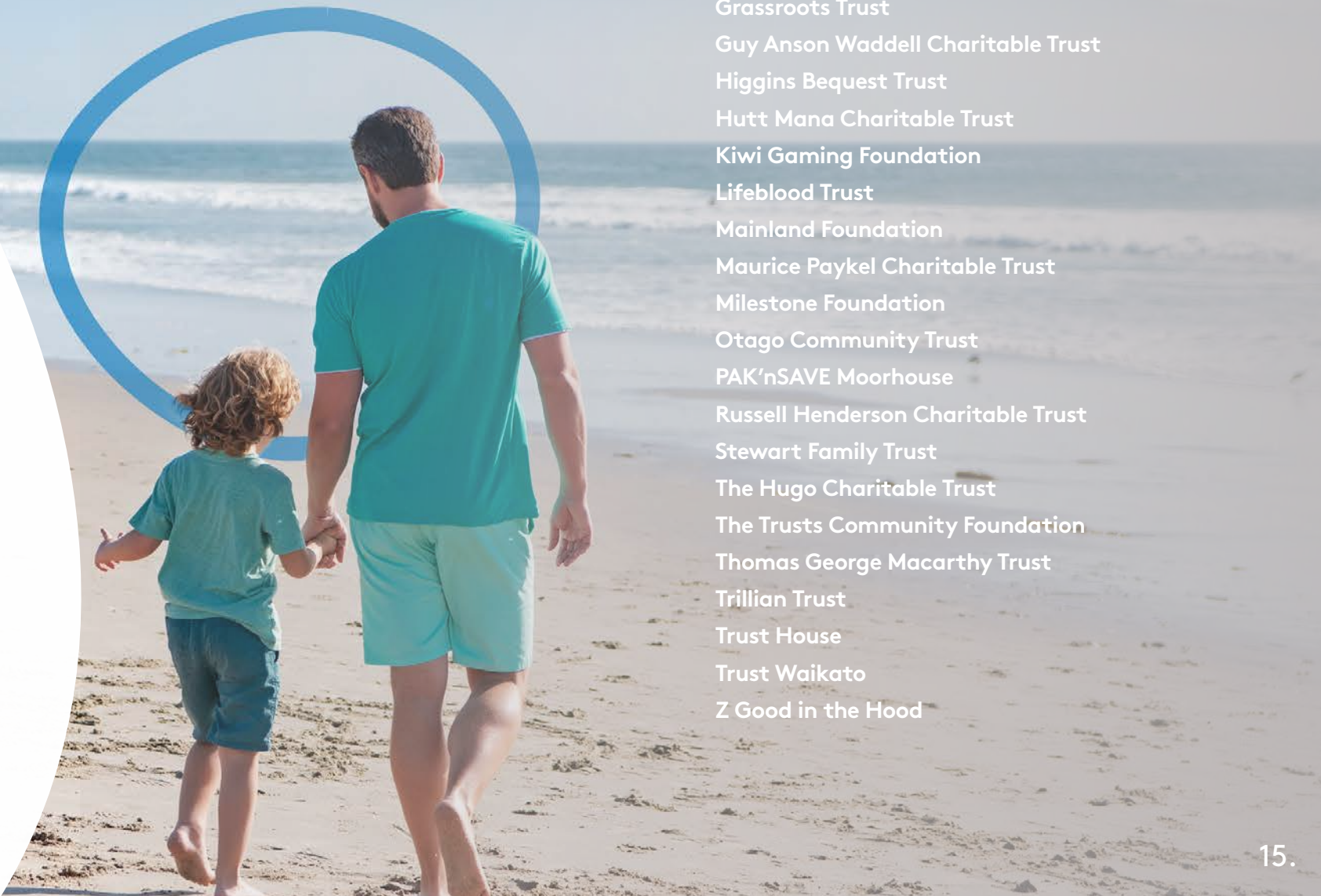
My Guide to Blood Cancer – Taku Aratohu ki te Mate Pukupuku Toto – is a booklet written to help to describe to this age-group what blood cancers are and speaks to the challenges that they are facing in a language they relate to.

The booklet has a focus on wellbeing, survivorship and living well into the future with blood cancer.

A printed version is available nationwide and is also available to be read or downloaded through our website.

We gratefully thank the following trusts and foundations for their generous support

- ANZ Staff Foundation
- Aotearoa Gaming Trust
- Estate of Ernest Hyam Davis and The Ted & Mollie Carr Endowment Trust
- Joyce Fisher Charitable Trust
- Lion Foundation
- Pub Charity Ltd
- Birch Family Charitable Trust
- Clinton and Joy Whitley Fund with Auckland Foundation
- Community Trust South
- David Ellison Charitable Trust
- Dunedin Casino Trust
- Eastern and Central Community Trust
- Estate of Gordon Lindsey Isaacs
- Foodstuffs (South Island) Community Trust
- Four Winds Foundation
- Frimley Foundation
- Grassroots Trust
- Guy Anson Waddell Charitable Trust
- Higgins Bequest Trust
- Hutt Mana Charitable Trust
- Kiwi Gaming Foundation
- Lifeblood Trust
- Mainland Foundation
- Maurice Paykel Charitable Trust
- Milestone Foundation
- Otago Community Trust
- PAK'nSAVE Moorhouse
- Russell Henderson Charitable Trust
- Stewart Family Trust
- The Hugo Charitable Trust
- The Trusts Community Foundation
- Thomas George Macarthy Trust
- Trillian Trust
- Trust House
- Trust Waikato
- Z Good in the Hood



2023/2024

Financial Snapshot

Financial year to 31 March 2024



- 2% Bequests
- 9% Trusts & foundations
- 17% Donations
- 72% Fundraising events



- 13% Research funding awarded
- 14% Administration & support services office costs
- 19% Engagement & fundraising
- 54% Patient support & advocacy



Jimny Clipit, our fun Shavemobil, out at the Gibbs Farm fundraiser.

Jimny Clipit grows awareness with an arty return

Awareness of our Shave for a Cure campaign is extremely important all year round.

We were therefore thrilled that our major partner, Suzuki NZ, not only offered us the use of a Jimny this year but also paid for the artwork designed to catch the eye and promote our Shave event.

Inspiration for the design came from the “Anime” drawing style – creating a vehicle that looks at first glance as if it’s hand drawn animation. As a result, it can blend in with graffiti in the background. And we also re-installed the orange Mohawk that has been so popular in the past.

The result is eye-catching graphics that are turning heads wherever we go. Affectionately named “Jimny Clipit”, we have taken the vehicle to many different events in the Upper North Island.

This included a new fundraising event for LBC – the opportunity for guests to visit Gibbs Farm in the Kaipara Harbour. This is an open-air sculpture park with major artworks commissioned from some of the world’s most significant artists.

Our guests enjoyed an exclusive day walking through the park – and they would have noticed our Jimny artfully parked on the route, perhaps looking like another exhibit and supporting LBC’s Shave for a Cure Campaign!

Support Services Centres

Auckland

Hamilton

Wellington

Christchurch

Dunedin

National Office

PO Box 99182, Newmarket
Auckland 1149

Support Services &
General Enquiries

0800 15 10 15

Fundraising & Events

0800 15 15 10



Vision to Cure. Mission to Care.

Leukaemia & Blood Cancer New Zealand
(CC24498) is a registered charity under
the Charities Act 2005