



Impact Report
for year ended
31 March
2021

Resilience in challenging times.



Vision to Cure. Mission to Care.



Peter Fergusson,
Chief Executive Officer, Leukaemia
& Blood Cancer New Zealand

A YEAR THAT MEANT CHANGE WAS NEEDED QUICKLY, ALONG WITH A POSITIVE MINDSET

The 2020/21 year has, as you will see in the stories and outcomes reflected in this report, been a year of two halves but with successful results.

In a year that required adaptability, flexibility and an unwavering passion from our Board of Trustees and dedicated staff at Leukaemia & Blood Cancer New Zealand (LBC), we would not have been able to achieve all that we did. This commitment also goes for our supporters – donors, volunteers, partners and funders. It is down to everyone that we are closer to our vision to cure without compromising our mission to care. As a collective, we continue to do our vital work.

However, I must say that starting and ending the year in various states of lockdown has affected so many people's emotional and mental well-being. Witnessing people come together again to work differently and keep sharing essential information with kindness and compassion was heartening, as always.

With each wave in New Zealand, we had to respond quickly with a determination not to let COVID-19 defeat us. We weren't alone, as people from around the

country and the world were right there with us. By putting our patients, their families and whānau first, we were still able to deliver some essential support and continue key initiatives, including:

- Moving our Winter-Spring Webinar series; bringing the best information available to our communities
- We embraced the opportunity to join and collaborate in the Māori Cancer Community Hui with Te Aho o Te Kahu (Cancer Control Agency)
- We translated our main information booklet into seven languages, focusing on not leaving people behind due to a potential language barrier.
- Our financial support did not stop, nor did our patient support services.

Learning to adapt to do what we do and how that can impact us financially put us in a better position to deal with the uncertainties of the last year. And it is with heartfelt thanks to all our communities and teams. You have helped us achieve so much, but there is still a great deal for us to do. But together, we look forward to driving more significant progress in the future and help improve the lives of people affected by blood cancer through our research, support and care.

Front Cover:

Mariana and her family with Tim, our Support Services North Island Regional Manager, enjoy a day with Auckland Airport Emergency Services

STRATEGIC OBJECTIVES

Every day, an average of eight Kiwis will discover they have a blood cancer such as leukaemia, lymphoma or myeloma. With a vision to cure and a mission to care, Leukaemia & Blood Cancer New Zealand (LBC) is the national charity dedicated to supporting them.

OBJECTIVE 1

Deliver valued patient and family support services nationally

OBJECTIVE 2

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

OBJECTIVE 3

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

OBJECTIVE 4

Ensure future organisational success and financial sustainability



HIGHLIGHTS OF 2020/2021 YEAR: VISION TO CURE. MISSION TO CARE

We aim to ease the emotional and practical burden carried by patients and their families, and to invest in vital research to find a cure. We are not a government agency, meaning donations and fundraising are essential for the continuation of our life-changing work to find better treatments and cures. Heartfelt thanks to everyone for the support provided and for caring about blood cancer patients as much as we do.



CURE



CARE

5,673

Patients and their families supported by the LBC Support Services team

177,458

People using online resources

1,690

Support group attendees plus their family/whānau

\$398,810

Amount given in research funding and grants

\$102,750

Financial support provided to those needing it

175

Vital support groups held around the country

1,107

Patients supported with financial assistance

1,146

Referrals from across NZ for new patients and their families



OBJECTIVE

Deliver valued patient and family support services nationally

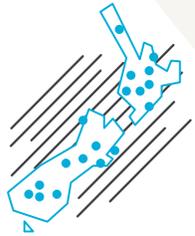


WHEN EVERYONE WAS CLOSING THEIR DOORS, WE HAD TO FIND A WAY TO KEEP SUPPORT GOING

Priority online shopping for our vulnerable patients

When faced with a national lockdown during the global pandemic from COVID-19, the Support Services team had the appropriate health and safety measures and guidelines in each support centre around the country. As the situation worsened, we made the call to cease all community patient support groups and then, soon

Natasha Donovan,
Support Services Coordinator
Northern Region



177,458

Total visits to www.leukaemia.org.nz



9,300

Information booklets and fact sheets viewed online or sent out



83,967

Information pages viewed



8,456

Support pages viewed



after, all face to face contact with patients – moving to online support. This meant when total lockdown happened, we were in a better place to shift gears into a fully online way of supporting our patients. The focus was always on how we can best support our patients and meet their changing needs while remaining within the boundaries of our service remit.

The double challenge we had was meeting a new set of needs from our patients and doing it in a way that was different to the norm. We looked for new ways of doing things to support our patients across the country who were feeling increasingly more anxious.

“We needed to obtain Essential Service status to allow us to reach our most vulnerable people” Emma Barker, Head of Support Services & Operations. Emma went through a thorough process to get LBC set up to operate as an Essential Service throughout the lockdown levels. Getting support to patients was even more than important than usual.

When talking with patients/whānau, being able to get food delivered to their homes was important, although it was hard to get a supermarket time slot. We secured priority codes for our patients’ online shopping and set up ‘shop & drop’ services for our very vulnerable patients.



“LBC is amazing for sourcing the special shopping code for patients – it has been so useful for us and I have not had to step outside my home in these scary times. No one else has done this for us.”



Dr Robert Weincove

GETTING THE LATEST UPDATES OUT THROUGH OUR WINTER-SPRING WEBINAR SERIES

As everything was getting shifted online, we knew it was essential still to get information to our patients and their families/whānau

Access to medical and allied health experts meant we could pull together a complete webinar series covering important topics on disease management and treatment updates. It was also important to meet the delicate balance of support that would work online for mental health and wellbeing.

As many people could tell you, a national lockdown affects mental health, and we found the webinars had a far-reaching impact for our patients and their whānau. Tools and techniques to get through were beneficial to so many. Sourcing the right professional speakers and topics for the webinars was crucial, and from the results, it looks like we achieved that.

A couple of webinars that stood out were the updates on CAR T-Cell therapy, by Dr Robert Weincove. This is an area that we continue to update regularly. The other highlight was bringing to life balanced data and research from vitamin C studies, especially in the treatment of AML. University of Otago Research Professor Margreet Vissers presented a must-see

webinar outlining research into the role of Vitamin C in leukaemia treatment. Margreet has established an international reputation for her research work on Vitamin C in cancer and general health. Having connections to such people and getting the latest updates to people is crucial

YouTube – Winter-Spring Webinar Series



21

videos created



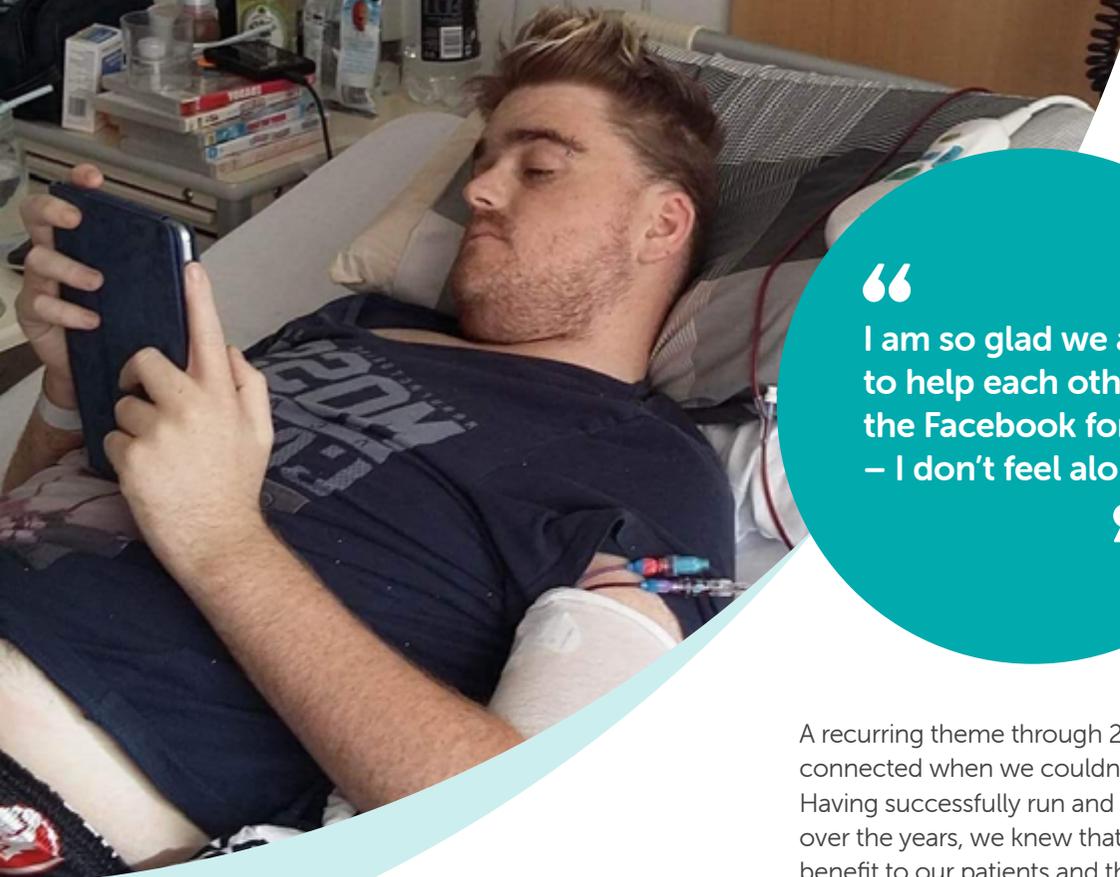
12,014

views



Top viewed

New data and insight from vitamin C studies Professor Margreet Vissers 5,088 views since posted and still viewed



“
 I am so glad we are here
 to help each other on
 the Facebook forum
 – I don't feel alone.
 ”

CONNECTING, BUT VIRTUALLY

Going through cancer treatment or having a family member go through it can challenge the most resilient person.

A recurring theme through 2020 was how to stay connected when we couldn't be together face-to-face. Having successfully run and developed support groups over the years, we knew that we had to get creative. The benefit to our patients and their families of connecting to other people in a similar situation is immensely important. We increased our Facebook groups to meet the needs of patients across all blood cancers. The numbers joining these groups grew significantly over the year.

We continued to look at ways we could meet our patients' needs online and introduced a very successful Ladies' online group to join our already growing Blokes with Blood Cancer online group.

"Thank you so much for sourcing such interesting speakers on our Blokes online chat! I have learnt about things I would never normally think of and it is making a big difference in my life".

"We attended online support groups, and my brother was lucky enough to do the Kids' Club zoom group which he loved." Sam



1,200

Views of Managing Stress and Anxiety during COVID-19 Shutdown



250

New subscribers during the year



162,629

Total views of our videos in the year



“
 These are amazing resources for our Tongan and Samoan patients. These will be well used!
 ”

EQUITY IN KNOWLEDGE AND TREATMENT

When it comes to information and advocacy we strive for equity for all those affected by blood cancer or serious blood conditions.

Someone’s background or understanding should not dictate a person’s outcomes, and knowledge of blood cancer and treatment journeys should not be restricted. This is very much at the heart of our vision and mission. LBC made headway translating our key publication, ‘Blood Cancer and Conditions’ into 7 other languages this year. Māori, Samoan, Tongan, traditional and simplified Chinese, Korean and Hindi. Building on the great work in the previous year, the Support Services team has continued to build knowledge within our diverse communities.



Taranaki Hui

Collaborating to maximise our reach

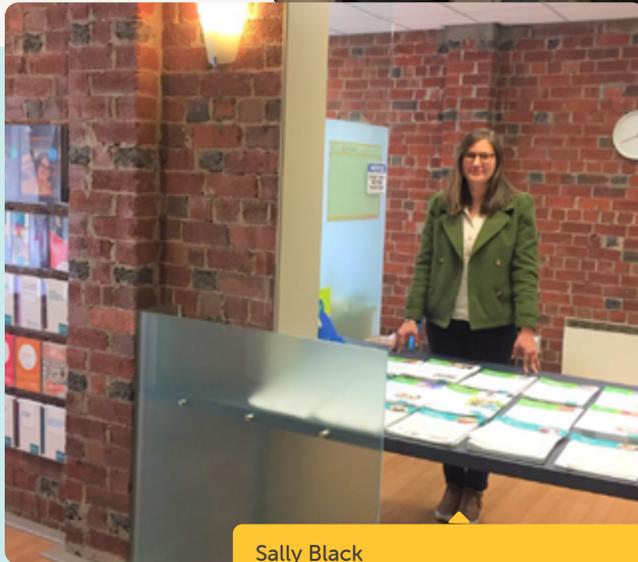
The Māori Cancer Community Hui with Te Aho o Te Kahu (Cancer Control Agency) kicked off at the beginning of 2021. As a committee member along with other Cancer NGOs, we seized the opportunity to participate in all the Hui, 15 across Aotearoa New Zealand. Although they ran through the entire calendar year, We started with Hui in Taranaki and Hawkes Bay and worked our way around the rest of the country.

The value of us attending is immeasurable; it is an opportunity to present LBC’s services, make important connections with Māori health providers and patients and whānau, and cement relationships with potential referrers. In addition, we got to be the NGO voice to shine the light on the gaps we fill where the DHBs or the National Travel Assistance scheme fall short. Our impact at these Hui was to support the organisers to help them become familiar with the cancer NGOs available to help with our Māori patients, as well as to make connections with local Māori health providers to reach patients and whānau.

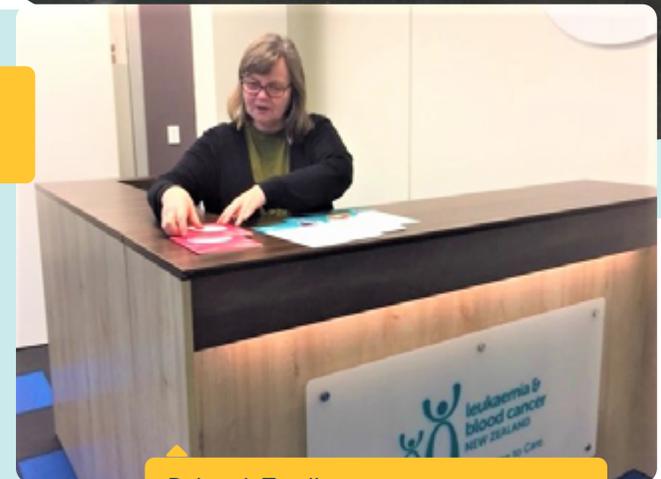
NEW PLACES, MORE FACES

We continue to build our team, and with growing referrals, and subsequent demand, in our Central region, we were pleased to add another experienced health professional, registered nurse Nicki Roy, to our Wellington based team.

2020 also saw us move offices in both Dunedin and Wellington. Both moves mean we now have the space and facilities in our support centres to better accommodate our patients' needs, and run groups and education sessions.



Sally Black
Senior Support Services Coordinator
Central Region



Deborah Tomlin
Senior Support Services Coordinator
Southern Region



ADVOCACY AND AWARENESS

OBJECTIVE

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



SPEAKING UP FOR PATIENTS

Despite recent challenges with COVID-19, advocacy remains a major focus for LBC. This work is carried out in two ways: collaboration with likeminded organisations, and direct support of Clinician-led submission for trials/drugs/medication.

To shift Government thinking, LBC together with other representative cancer groups adopt a shared 'voice'. In 2020, this collective of cancer agencies presented a set of 10 key concerns to ministers. These concerns ranged from ensuring access to world-class care, medicines, and clinical trials, to improving cancer diagnosis methods, to sharing the cancer strategy with NGOs.

The NZ Cancer Agency, Te Aho o Te Kahu, provided a welcome channel for proactive input, feedback, and information around the delivery of the National Cancer Plan. LBC also took the opportunity to submit proposals on Early Access Funding Schemes (the formal review of Pharmac).

Some progress was made during 2020/21 – however investment in ongoing advocacy, awareness and agitation is needed.



Members of CANGO meeting at LBC Head Office

THANK YOU TO ALL OF OUR WONDERFUL PARTNERS



ENABLING EQUITY FOR BREAKTHROUGH CAR T-CELL THERAPY

Leukaemia & Blood Cancer New Zealand (LBC) has always had a close relationship with the Malaghan Institute of Medical Research – New Zealand’s world-leading and independent biomedical research institute based in Wellington.

The institute has been working for some time on the development of CAR T-cell therapy in New Zealand with the potential to target different cancers. The therapy works by re-directing a patient’s own immune cells (T-cells) in the lab to directly identify and attack the cancer cells before returning the modified cells to the patient.

In 2020, the institute, which is based in Wellington, commenced a phase 1 trial called ENABLE for people with certain types of relapsed and refractory B-cell non-Hodgkin lymphomas who have exhausted other treatment options.

This is being managed by Dr Robert Weinkove, the Malaghan Institute’s Clinical Director, who is also on LBC’s Medical and Scientific Committee.



OBJECTIVE

Proactively drive research into prevention, cure and care of blood cancers in New Zealand

Referrals can come from all over New Zealand so LBC has entered into an arrangement to support accommodation and travel costs for patients who live outside the Wellington Region. In some cases, this can be extended to their care-giver or a family member as well to ensure good support is in place for the patient no matter where they live.

Gail Marshall, Head of Communications at the Malaghan Institute has said, “We continue to hugely value and appreciate the contribution LBC makes to the Institute’s progress and achievements.”

The data collected from the exploratory, early phase clinical trial will help to understand the effectiveness and safety of the CAR T-cell therapy with the potential to move to a phase 2 trial where patients are tested with a set dose with more targeted results. All trial participants will be monitored for 5 years within the trial, and lifelong within a Cell Therapies Registry.

LBC is pleased to play its part in ensuring that eligible patients can have the opportunity to take part in this cutting-edge cancer immunotherapy.

Malaghan Institute researcher

Child cancer specialist on a mission

This year, LBC’s Medical and Scientific Committee awarded two substantial national grants. \$48,742 was approved for Dr Andrew Wood to support his study into targeting mesothelin in paediatric AML (acute myeloid leukaemia). Mesothelin is a protein found on the surface of certain types of cancer cells with an unusually high number in childhood AML. Dr Wood is an internationally renowned childhood cancer specialist now based at the University of Auckland. His research overall is focused on developing safer, more gentle treatments with less adverse side effects and improved survival for paediatric AML patients.

Professor Ian Morison from Otago University was awarded \$27,984 for his research into familial Immune Thrombocytopenia.

LBC, with a vision to cure, continues to be firmly committed to funding targeted blood cancer research.

FUNDRAISE TO CURE AND CARE



FUNDRAISE TO CURE. FUNDRAISE TO CARE

Throughout New Zealand every year, thousands of people give time, energy, commitment and donations to enable LBC's support of blood cancer patients. Together, these caring Kiwis have contributed \$4m this year, sharing the vision to cure and mission to care.



Happy Birthday Farmers

2020 was LBC's Principal Partner, Farmers, 111th birthday! That's an impressive number and we were looking forward to celebrate it in August before COVID-19 disrupted plans. In fact, lockdown restrictions were also in place for their annual Shave for a Cure and Queens Birthday Weekend Life-Changing Small Change fundraisers. However, this didn't stop Farmers from continuing to support LBC with generous donations throughout the year from staff, shoppers and Head Office. Thank you Farmers for being such an outstanding partner.

Firefighters rise to the Challenge

When our Firefighter Sky Tower Stair Challenge, scheduled for May, had to put on hold due to the COVID-19 restrictions, we were concerned that there would be no climb in 2020.

However, the firefighting community, already underway with fundraising and training, was determined to make it happen. And thanks to the support of SkyCity Auckland, LBC was able to secure a mid-November date.

As a result, we had an impressive turnout and over \$800,000 was raised by brigades throughout the country.



Firefighter passes the Sky Tower dedication wall



Kimbleton firefighters making the crossing

We also welcomed a new sponsor onboard – Rosenbauer. Despite not being able to attend the event in person (their regional office is in Brisbane), they honoured their commitment and provided our top fundraiser with an impressive new firefighting outfit.

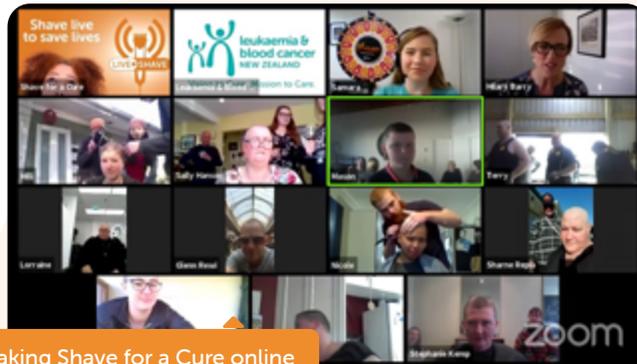
Changing Alert levels meant that some brigades made the call not to travel to Auckland to do the actual climb and get inventive instead. Members of the Rangiwahia, Kimbolton and Apiti brigades set themselves a different goal and completed the 30km Ruahine Alpine Crossing in full firefighting gear. This impressive feat raised \$14,880 for LBC.

Taking shaves online

Every year, thousands of Kiwis brave a shave as part of our Shave for a Cure campaign. But with COVID-19 restrictions in place, many shaves, including those in schools, workplaces and in Farmers stores throughout the country, were unable to take place in 2020. The LBC fundraising team did some quick thinking and created a new opportunity – Live Shave online

Now shavees, wherever they were, could take part in a national shave from their own kitchen or back-yard and be part of something much bigger. With Hilary Barry – a wonderful LBC supporter – as the MC, we held two Live Shaves in 2020. Anyone could watch the events from their homes as simultaneous shaves took place on screen from Kerikeri to Invercargill and everywhere in-between. Hilary “dropped in” on different shaves to have a chat and to find out the motivation for the shave. This was a great opportunity for everyone to share their wonderful stories with everyone who was watching across the country.

Our thanks to all these shavees, to Hilary and to everyone who fundraised and then shaved for LBC in 2020 despite the lockdown challenges.



Taking Shave for a Cure online



Marie Dwyer's scrumptious morning tea

Tasty treats raise spirits and funds

Many LBC supporters choose to fundraise their own way. We actively encourage this as it's a great way to get behind our cause doing something that you enjoy or taking on a personal challenge while raising vital funds.

For Marie Dwyer, in South Taranaki, a yummy morning tea was both a celebration of her 70th birthday and her way of honouring her daughter, it was her wish that it be a happy occasion, despite Jacq's diagnosis of multiple myeloma and the start of her stem cell transplant treatment. Over 120 guests paid to come along and enjoy the morning – well done Marie!



HELPING TO PAY THE BILLS

A blood cancer diagnosis has a significant financial impact on patients and their families. LBC's emergency support includes providing supermarket and petrol vouchers – a need that increased exponentially this year with many struggling with a reduced income as a result of the impact of Covid-19.

Thanks to funders such as the Hutt Mana Charitable Trust, LBC was able to apply for and receive grants specifically for the purchase of these vouchers and for taxi chits to help patients get to vital appointments and treatments.

For Hutt Mana CT, it was important that support was given to patients in the Hutt Valley, Porirua and Wellington North (Mana) area. LBC was able to provide not only the numbers but also a local story of how these vouchers made such a difference to a family struggling financially with their sole income earner having to give up their job to care for a parent with blood cancer.

Our heartfelt thanks to Hutt Mana CT and all the trusts who assisted us in purchasing vouchers over the past 12 months.



Nicki Roy and Sally Black
Wellington Regional Office

Lion Foundation keeps the LBC doors open

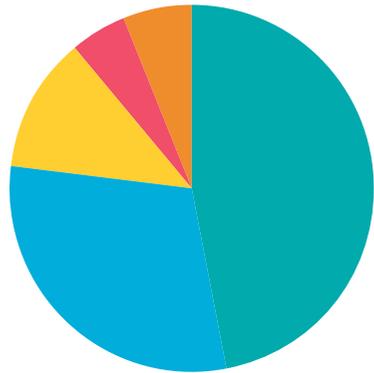
In 2020, LBC developed a new strategy to seek grant funding from Trusts and Foundations. We now reach out and apply to granting organisations nationwide for a wide range of expenses, including salaries, resources, printing and operational costs.

We were very pleased to receive a substantial grant of \$60,000 from The Lion Foundation to support the leases and day to day expenses in our five Support Centres around the country. Our mission to care can't be done without a roof over our heads.

The Lion Foundation is one of New Zealand's oldest and best known charitable trusts. Its commitment is to local communities but there is a huge demand on available funds – and this increased considerably during the Covid-19 lockdowns.

So we were delighted that our application was successful and we look forward to developing a longer term relationship with the foundation and with other trusts that have a shared vision to support those less fortunate.

Income sources this year



47% Tissue typing funding, overseas bone marrow & search receipts

30% Fundraising events

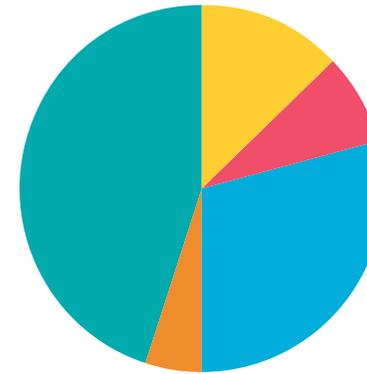
12% Donations

6% Trusts & foundations

5% Bequests

Financial year to 31 March 2021

How income was spent this year



45% Bone marrow tissue typing, donor search and recruitment

29% Patient support & advocacy

13% Engagement & fundraising

8% Administration & support services office costs

5% Grants/Research

WE GRATEFULLY THANK THE FOLLOWING TRUSTS AND FOUNDATIONS FOR THEIR GENEROUS SUPPORT

Estate of Ernest Hyam Davis & The Ted & Mollie Carr Endowment Trust

Lion Foundation

Joyce Fisher Charitable Trust

Lottery Community Fund

Southern Trust

Community Capability and Resilience Fund

Pub Charity Limited

Awhero Nui Trust

Blue Waters Community Trust

Clinton and Joy Whitley Fund with Auckland Foundation

Community Awareness and Preparedness Grant Fund

Community Food Response Grant Fund

Community Trust South

Dunedin Casino Trust

Eastern and Central Community Trust

Estate of Gordon Lindsey Isaacs

Four Winds Foundation

Freeman Fund (Nikau Foundation)

Frimley Foundation

Grassroots Trust

Guy Anson Waddel Charitable Trust

Helen Stewart Royle Charitable Trust

Higgins Bequest Trust

Hutt Mana Charitable Trust

John Beresford Swan Dudding Trust

Life Blood Trust

LW Nelson Charitable Trust

Maurice Paykel Charitable Trust

Milestone Foundation

Mount Wellington Foundation

Otago Community Trust

Rata Foundation

The Trusts Community Foundation

Thomas Bevan Charitable Trust

Trust House

Trust Waikato

W. Duncan Bickley Trust

BATTLE BUS BONANZA BEATS ISOLATION BLUES

Former paediatric nurse and now LBC Northern Regional Manager, Tim Maifeleni, knows only too well the loneliness felt by young blood cancer patients in hospital and isolated at home for long periods of time.

A keen gamer, Tim developed a unique new event – a Fortnite tournament hosted from the Sky Sports Breakers E-sports Headquarters in Auckland.

Tim was encouraged to organise the event by a young patient he has been supporting for some time. DJ knows all about spending long periods in isolation in hospital and home - and also happens to be a keen gamer and Breakers "super fan".

It brought together patients from Starship Hospital and the Christchurch Children's Haematology Oncology Centre (CHOC), together with doctors, nurses, siblings and parents, as well as Breakers players, radio DJs and professional e-sport gamers.

It proved so successful that Battle Bus Bonanza was born – an ongoing opportunity for children to play together wherever they are. Tim has continued to coordinate these events, creating an atmosphere where the children are gaining confidence in themselves and are enjoying "hanging out" while they remain in isolation.



DJ playing the first Fortnite tournament in the Sky Sport Breakers Dojo

“
When people are happy
and when they have
their friends and social
interaction, they cope
better with treatment.
”

– Tim Maifeleni,
LBC Regional Manager

Support Services Centres

Auckland
Hamilton
Wellington
Christchurch
Dunedin

Support Services & General Enquiries

0800 15 10 15

Fundraising & Events

0800 15 15 10

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



Vision to Cure. Mission to Care.