Together, we will Cure and Care

Outcomes Report for year ended 31 March 2020

leukaemia & blood cancer NEW ZEALAND

Vision to Cure. Mission to Care

OUR VISION AND MISSION ARE NEEDED MORE THAN EVER

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

The 2019/20 year has, as you will see in the stories and outcomes reflected in this report, been enormously successful.

It would be appropriate to recognise both our passionate Board of Trustees as well as the dedicated staff of Leukaemia & Blood Cancer New Zealand (LBC) for these selfless life-changing efforts and heart-warming outcomes. Last and not least, our supporters – donors, volunteers, funders – without whom, we could not fulfil our vision to cure, and mission to care. Your ongoing support is the glue that holds all aspects of our work together.

However, it may also be understandable that my personal reflection on the past year has been clouded by two devastating events (at the beginning of each year) – the senseless loss of life at the Christchurch Mosque shootings March 2019 and the COVID-19 pandemic that is currently ravaging our world.

Both these events have highlighted truly admirable elements of human nature (our team of five million looking out for each other) and also our many human frailties. The pandemic, in particular, underlined the significantly greater risks that blood cancer patients (and their families) are exposed to.

We inherently knew that our mission to care would be tested. We have been challenged to adjust the way we deliver support to patients and families over the past year – while also ensuring our staff (and families) were kept safe. In addition, the critical fundraising events we rely on to fund essential services were being postponed – leaving a substantial hole in our current and future finances.

The team at LBC continues to work tirelessly to adjust the way we do things and maximise the care, support and practical help we give, especially to those who are most isolated and alone. Just a few examples of this work are:

- Increasing the individual help we give to the most vulnerable patients by keeping in close contact by phone, text and online.
- Providing emergency financial support to people who are struggling with the basics like nutritious food, help with transport to treatments and parking costs at hospital.
- Stepping in and organising deliveries of groceries and essentials to the most vulnerable patients.
- Providing online support groups and live Q & A sessions for patients and families with haematologists, pharmacists and other health specialists.

Maintaining this support comes at a financial cost, which is not clearly evident in this report (but will be reflected in future years) and we are doing all we can now to ensure our efforts and impact can continue – because as we all know, virus or no virus, cancer does not rest.

With sincere thanks for the support given over the past year, and in anticipation of continued support in the years to come.

STRATEGIC OBJECTIVES

Every day, an average of seven 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 cancers in New Zealand

OBJECTIVE 3

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

OBJECTIVE 4

Ensure future organisational and financial sustainability

HIGHLIGHTS OF 2019/20 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. With no direct government funding, 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

4,465
patients and their families supported by the LBC Support Services team

249
support groups held around the country

2,730
people attended our support groups

13,269
patient and family contacts were made

CARE

$151,090
given in financial support

1,525
patients were given financial assistance

$494,603
given in research funding and grants

1,267
new patient and family referrals from all over NZ

OBJECTIVE

Deliver valued patient and family support services nationally

Tamsin's son, Alex, diagnosed with acute myeloid leukaemia

A MISSION TO CARE

No blood cancer diagnosis is the same: that's why we provide personalised services for our patients and their families. Donations enable our mission to care – thank you.

Diagnosis

A blood cancer diagnosis can feel devastating – and we believe that no one should have to face this diagnosis alone. That's why our Support Services team is right here to help patients and their families understand and deal with some of these unique challenges. From having someone to talk to, to finding practical help, to providing financial assistance and information about specific diseases and treatments, we're only a phone call away.

> **We met for coffee and Deb gave me advice and literature and suggested I attend a support group. I'm glad I went, it was helpful to rationalise what I was going through with others on a similar journey."**
> **– Tamsin Yarnell**

Tests and treatment

Once a patient has been diagnosed with blood cancer or a blood condition, their specialist medical team will discuss treatment options and possible side effects.

Matt Eby, Regional Manager Support Services, South Island

Blokes with Blood Cancer

As its name suggests, Blokes with Blood Cancer is a group phone call for men affected by blood cancer. "It's a chance to ask questions, share tips, or talk about what's going on in your life", says host Matt Eby. He hosts regular group calls nationwide.

> **It's a bit of banter with blokes experiencing similar stuff. And it's all on the phone – you don't even have to leave your house – just take the call in your pyjamas. So don't be shy!"**
> **says Matt**

Wellbeing Wednesdays

Blood cancer patients in Auckland hospital have a new reason to smile thanks to a mid-weekly event called Wellbeing Wednesdays. Hosted by Tim and Natasha from the Support Services team, this initiative is designed to add a little fun and connection to the weekly hospital schedule.

Patients in the same ward don't always get to meet each other, so Tim and Natasha host social activities where they can bond and connect, such as card games and Nintendo. Other activities are more therapeutic, such as creating vision boards about their treatment to help patients express their emotions.

> **It really puts a smile on their faces. Patients can feel quite isolated in a hospital environment, so Wellbeing Wednesdays breaks down those barriers by building connections. The more emotionally stable you are, the more resilience you have in treatment." – Natasha Donovan, Support Services Coordinator Northern Region**

Natasha Donovan, Support Services Coordinator Northern Region

Kent, diagnosed with stage 4 lymphoma

Home from hospital

Recovering from treatment takes time and lots of support. Returning to a normal life can be challenging, especially while managing new medication and side effects. That's why our support groups help patients find ways to get back into life once they're home from hospital – including connecting patients and their families with others who are going through similar challenges.

> **The support group was therapeutic. It was a relief to meet other patients with a deep understanding and compassion. I didn't feel like I was alone any more. It's okay for men to talk about their feelings. If you don't, then pent-up emotions will surface in all sorts of unhealthy ways." – Kent**

Advanced care planning

Our Support Services team are trained in providing advanced care planning and are able to help patients plan their end of life experience, both in terms of the experience and also the more practical aspects such as having their affairs in order.

Advanced care planning unfortunately is a reality for many blood cancer patients and discussing it can be challenging. However, doing so can make it a much more positive experience for both the patient and their family.

> **There are two sides to advanced care planning: the practical aspects such as having a will in place, and then there is planning the end-of-life experience a patient wishes to have. This can be a much more difficult conversation but is equally important. Dying is a natural part of life and we try and support our patients to have peace of mind and a say on how they want this experience to be." – Tim Maifeleni, Regional Manager Support Services, Northern Region**

OBJECTIVE

Deliver valued patient and family support services nationally

Tim Maifelene, Regional Manager Support Services, Northern Region

THE NEEDS OF PATIENTS ARE UNIQUE: SO ARE WE

We know patient care isn't one size fits all, so we customise our programmes to meet the needs of each individual patient, for as long as is required.

Justin's five-year fight for survival

Justin Waipouri's story began with a lump on his leg and 'fevers and shakes'. Weeks later, Justin was dangerously ill and doctors were stumped: eventually he was diagnosed with Non-Hodgkin's Lymphoma.

Justin was too unwell to work, and with a young family to support, finances were tight. Thanks to the generosity of LBC's supporters, Justin and his family received practical and emotional support to help him get through his cancer, including petrol vouchers, visits and information, plus his young children were enrolled in LBC's Kids Club. Justin is doing well and has recently had another child with his partner, Skye.

> **"LBC helped me out big time – especially how they helped me to get to my treatments and to my appointments – it definitely helped a lot," says Justin**

Individual care

At LBC, we aim to provide an ongoing, wrap-around service that meets the unique needs of blood cancer patients – emotional, financial, relationship and practical. Our patients and their families can use our services for as long as needed through all stages of their journey – from diagnosis to treatment to recovery or advanced care planning.

LBC works closely with other health professionals ensuring a holistic service, including counselling or WINZ assistance. This fills gaps in state support and fulfills LBC's mission to care.

> **"No matter where our patients and their families are at in their cancer journey, we do everything we can to ensure we're here for them."**

Deborah Tomlin, Support Services Coordinator, Dunedin

OBJECTIVE
Deliver valued patient and family support services nationally

Tim shares how Monkey in my Chair works

CHILDREN AND YOUTH

Blood cancer can affect anyone at any age, including children. In 2019, we saw an increase in patient referrals, particularly among children and ethnic communities.

Monkey business

Monkey in my Chair is a wonderful programme designed to keep young patients connected to their classmates while they're undergoing treatment.

When a child is away from school, Big Monkey sits in their chair, while Small Monkey keeps them company in hospital or at home. Their classmates are encouraged to include Big Monkey in lessons and send messages and news to their friend using Big Monkey's bright yellow backpack.

Each Monkey in my Chair kit comes with a range of educational books, teacher guides and LBC resources. Our Support Services staff also talk with patients, parents and schools about blood cancer and how classmates can help to keep their friends safe when they return to school.

Helpful books for big worries

Kids can get very worried and anxious when they, a sibling or a friend are undergoing treatment for blood cancer. That's why we offer a series of children's haematology books on our website, in both English and Te Reo Māori.

Partner gives kids the support they need

Support for children whose loved one (sibling, parent or grandparent) has been diagnosed with a blood cancer or blood condition is very important, which is why we have our Kids Club for five to 12 year olds. Run by a professional therapist, the groups provide a safe and supportive environment for children to discuss their feelings and ask questions about blood cancers while meeting other children going through a similar experience. These discussions are based around creative activities and games.

Kids Clubs are held in Auckland, Christchurch and Wellington thanks to the support of our partner, Fidelity Life – and also in Hamilton.

Fidelity Life is also paying for the hoodies given to every child in Kids Club – these have a very special Kids Club logo designed last year by children themselves taking part in the sessions.

> **“Kids Club is run by a psychologist, and she was like my guardian angel – for the first time, my daughter was opening up and expressing her emotions.” – Sonia**

fidelity life

OBJECTIVE

Deliver valued patient and family support services nationally

Johnny Duncan

SURVIVORSHIP

Surviving a serious illness can be hugely challenging for both patients and their families. LBC addresses the ongoing impact of diagnosis through education and well-being sessions, employment workshops, mentoring and ongoing psychosocial support.

The path to employment

Supported by Randstad, LBC's Return to Work mentoring programme helps blood cancer survivors connect with the workforce, helping them investigate opportunities and pathways to new careers and close any knowledge gaps.

John Duncan (Johnny) was finalising his thesis for his Masters in Marketing when he was diagnosed. He completed the thesis, but it was sometime before he could seek his first job. He joined the Randstad mentoring programme and was paired with a career coach who supported him throughout the job-seeking process – from how to write a CV, to learning skills and techniques for job interviews.

> **“My mentor was brilliant. She was there every step of the way and coached me throughout the process. My goal had always been to join a graduate programme on completing my thesis and with the help of my mentor, I achieved that goal.” – Johnny Duncan**

Sonia (diagnosed with leukaemia) with her family

Survivorship

Survivorship (i.e. getting back into normal life) is an area that's often overlooked and under-funded, yet it's vitally important. LBC's assistance can help patients and their families work towards a 'new normal'.

> **“I learned to make jewellery at the beading workshops, it was part of my healing. I felt a kinship with the other women living with blood cancer and lasting friendships were formed.”**
>
> **– Sonia**

Work It Out workshops

Liz has myeloma. A radiographer, she's extremely thankful to work for a very supportive employer and that she was already familiar with the health system. Last year, Liz attended LBC's Work It Out employment workshops in Hamilton.

"I decided to attend the workshops to find answers to all those questions that having cancer while in the workforce throws at you. The session was great – so comprehensive and informative. I came away with so many practical tips, especially on how to deal with a career gap due to illness." Liz said the other unexpected benefit was engaging with others of a similar age and life stage. This successful programme was developed with the PwC Foundation.

> **Myeloma is most common in older people, so I am quite young – however, all of the people at the workshop were also in the workforce. We had a lot in common: we all had a blood cancer and were all working. I found that enormously supportive." – Liz**

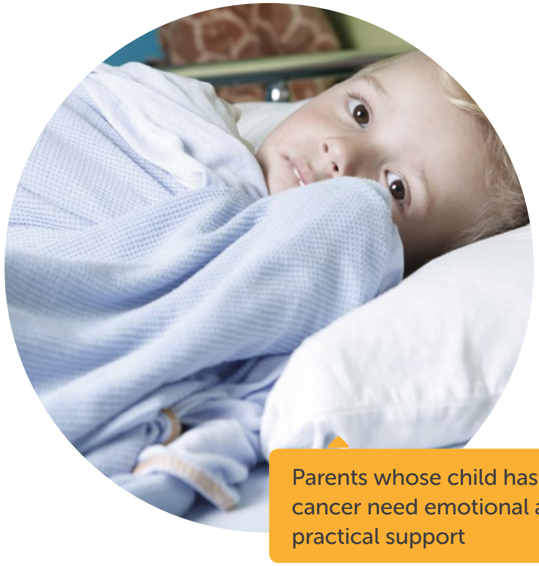
Liz Leavins attended the Work It Out workshop

Parents find strength together

There are few things more devastating than your child being diagnosed with cancer. Often children need to spend long periods of time in hospital and undergo difficult and distressing treatment with mum or dad by their side. This is an enormously stressful time for the whole family, and parents in particular can really feel the strain.

Tim Maifeleni, LBC's Northern Regional Manager of Support Services, identified a gap in support for parents, with many feeling isolated and overwhelmed and in need of an opportunity to share stories, learn and connect. So Tim enlisted the help of Dr Deb Perrott, a psychologist with Lifespan Counselling and Rehab, and together, they've created a monthly support group for parents.

This programme is also funded by Fidelity Life as part of their ongoing support of blood cancer patients throughout New Zealand.



Parents whose child has blood cancer need emotional and practical support

> **The shared learning within the group is really powerful: it's a safe place for parents to talk about their fears, anxieties, hopes and adjustments to having a child with cancer. The resources shared between parents are incredible. One dad developed a list called 'coping skills', which listed all the local cafés that served beer so parents could have a real break!" – Dr Deb Perrott**

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


Peter Fergusson, CEO, at a CANGO meeting

ADVOCACY AND EDUCATION

Your support helps us deliver on our goals of advocating for better funding for cancer patients, and educating healthcare professionals about the symptoms and treatment of blood cancers around New Zealand.

CANGO's collective voice is being heard

Formed in 2007, CANGO (Cancer Non-Governmental Organisations) is an alliance of prominent New Zealand cancer charities, including LBC, which was created to increase collaboration among cancer charities and advocate on behalf of cancer patients and carers. In essence, it represents the voices of the 23,000 New Zealanders diagnosed with cancer every year.

In 2019, CANGO called for the development of a Rapid Access Scheme that would provide a swifter process for funding new, innovative treatments, such as targeted therapies and immunotherapy that are the standard in comparable OECD countries.


CANGO members

The great news is that the power of the collective voice is starting to be heard. Working together has opened doors to meeting both the Health Minister and Pharmac to discuss:

- the Rapid Access Scheme
- a formal cancer plan for New Zealand
- a dedicated cancer agency
- a review of Pharmac's remit and funding of medicines.

LBC will continue to play an active role in CANGO, lobbying for best access treatment for blood cancer patients.

Educating GPs in rural areas

LBC's Deborah (Deb) Tomlin is a registered nurse and just the kind of person you want in your corner if you're going through blood cancer. Deb is tenacious in her approach and dedicated to working with other health providers to ensure patients can get the best possible outcomes.

Deb and her colleague Julie Smith, a Clinical Nurse Specialist, identified a need for more education and support for GPs serving rural communities and those areas of New Zealand without permanent haematology services.

In the absence of specialist services, GPs in these communities were managing more and more aspects of blood cancer patient care. But without specialist training, they were becoming concerned about a lack of equity for their patients.

Deb set about organising education evenings for GPs and nurses in Southland, delivered by a consultant haematologist who gave up her time to ensure GPs have access to the latest clinical information and were more able to support blood cancer patients in their care.

The evenings were accredited under The Royal New Zealand College of General Practitioners continuing professional development scheme and were very well received by all those who attended. So far, 80 GPs and nurse practitioners have been through the programme and Deb plans to extend it to other parts of the South Island, with LBC colleagues also implementing the scheme in other parts of the country.

Rural GPs pass on valuable information to their patients with blood cancer

> **The feedback we've had has been really positive with GPs saying the sessions have helped them provide better care and information to patients," says Deb. "They also have a better understanding of how the haematology service is set up, so they know how to go about asking for help on behalf of their patients."**

2019 Winter Workshops

LBC supports the education of health professionals with our annual Winter Workshops. Held around New Zealand, these are designed for haematologists, nurses and clinicians in District Health Boards working with patients living with a blood cancer or a blood-related condition. It's an opportunity for health professionals to keep up to date with the latest research and developments in the fast-paced field of managing blood cancer. The objective is to provide better health and well-being outcomes for those facing a diagnosis of myeloma, leukaemia or lymphoma. The most recent session in 2019 featured Dr Richard Egan, who advised on spiritual and emotional well-being for the health professional and the patient.

> **Gave tips and tools that can be used in practice immediately. Provided resources in terms of references for follow-up. Good discussion and affirmation of what we already do and a reminder of the need to recognise and explore spirituality in every interaction with patients and colleagues." – Winter Workshop 2019 attendee**

Winter Workshop August 2019. Due to COVID, no 2020 Winter Workshops ran.

OBJECTIVE

Ensure financial, organisational and financial sustainability

Julie Harper-Taylor shaved in memory of her partner Colleen

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, sharing the vision to cure and mission to care.

Brave Shavers

Vital funds were raised by over 1,000 people who supported Shave for a Cure. In 2019/20, $1.3m was raised by young primary school pupils and senior schools, work colleagues and people whose lives have been touched by blood cancer. Our heartfelt thanks to all Shavees and their supporters on behalf of blood cancer patients throughout New Zealand.

> "St Thomas of Canterbury College together with Villa Maria College, raised over $20,000 for Shave 2019 – this is a fantastic effort," says Peter Fergusson, CEO

Students celebrating their shaves and amazing fundraising results

LBC is reliant on fundraising to deliver services and to maintain and grow a sustainable organisation. In 2019/20, fundraisers and donors together contributed an amazing $4m dollars to fund research and provide services to blood cancer patients and their families. Without this commitment, a vision to cure and a mission to care would not be possible. Together, we achieve sustainability now and in the future.

Sharing the Vision to Cure and Mission to Care

For many years LBC's business partners have gifted in many ways, enabling blood cancer patients to receive much-needed help. The 2019/20 year was no exception, with Farmers running its Life Changing Small Change in-store campaign over Queen's Birthday weekend. This raised $71,000 from customer donations. LBC thanks all Farmers staff and generous customers from communities all over New Zealand for this wonderful contribution.

Our firefighters smashed records

Particularly memorable from the 2019 event was DJ (aged 11) who has acute lymphoblastic leukaemia and became an honorary fireman for the day. He wasn't able to climb all 1,103 steps himself, so completed a portion of the challenge accompanied by fire fighters from Waiuku and Auckland Airport Rescue Fire Brigade.

For 15 years, firefighters from across the country come together in May for the Firefighter Sky Tower Stair Challenge in solidarity with people affected by blood cancer. In the months leading up to the event, these same firefighters are committed fundraisers in their communities. The generosity of time, fitness and funds raised is inspirational.

Says DJ, "It was challenging and fun and I want to do it again when I get better. I want to train to be a fireman so I can join the Waiuku brigade and be in this event running 51 floors with them."

A massive $1.38m was raised in the 15th year.

DJ and Phil

Dave & Tom Barker during their epic ride

From Cape Reinga to Bluff

We often hear those words but how many of us have traversed the length of New Zealand? For father and son Dave and Tom Barker, December 2019 was a very special month. With other family members all travelling overseas, Dave and Tom enjoyed a big adventure, riding for 32 days and raising an amazing $7,000! They braved all types of weather, met wonderful people and saw some of New Zealand's most beautiful sights. A trip of a lifetime, father and son said the most special part was knowing they were helping people with blood cancer through LBC's support services. To Dave, Tom and all generous donors – our grateful thanks.

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


Dr Rhea Desai, Research Fellow, Leukaemia & Blood Cancer Research Unit, University of Auckland

CREATING A LEGACY TO FIND A CURE.

When established in 2013, the Leukaemia & Blood Cancer Research Unit at the University of Auckland was a significant step in LBC's commitment to care for and cure those diagnosed with blood cancers. Since then, the Research Unit has created a body of world-renowned research and built a pre-eminent research team.

Seven years on, the Research Unit continues to thrive under the skilful leadership of co-directors Professors Peter Browett and Stefan Bohlander, who lead a team of 20 scientists and clinicians researching the causes of leukaemia and personalised medicine for blood cancer patients.

"Great research becomes brilliant research through a robust process of discussion and critical thinking," explains Browett. "By its very nature, groundbreaking research is a team effort. A collaborative culture where researchers are empowered to lead their own projects not only ensures better outcomes, but also the unit's long-term sustainability. In turn, this means we can continue to attract exceptional talent in the future."

Talent such as research fellow, Dr Rhea Desai. Originally from India and having studied in Glasgow, Dr Desai joined the Unit as a PhD student. She recently established a significant research project modelling how leukaemia is caused by genetic mutations or 'spelling mistakes' in the DNA, and now leads a team of PhD students working on the project.

"Attracting this calibre of researchers has been made possible by your generous funding. We're forever grateful for the continued support as we work to create better outcomes for blood cancer patients, and ultimately a cure."

Research to care. Research to cure.

The Research Unit's work has two main elements. The Personalised Haematology Project aims to improve the quality of care blood cancer patients receive. Currently available only to leukaemia patients in Auckland, the immediate priority is to make this available in the other main centres and include other blood cancers such as myeloma and lymphoma.

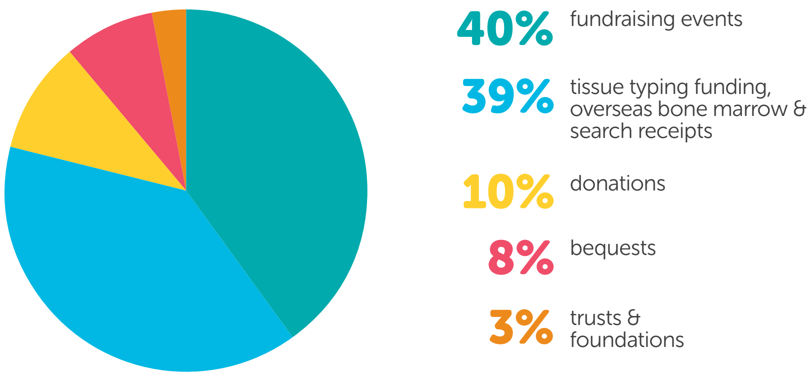
The second element is purely scientific research that focuses on understanding the causes of leukaemia and the steps in its development. Professor Browett explains, "We received international recognition of the animal models we established over the last 18 months, which is the bedrock of our future work in this area."

LBC has donated over $1.75 million to the LBCRU since it began in 2013.

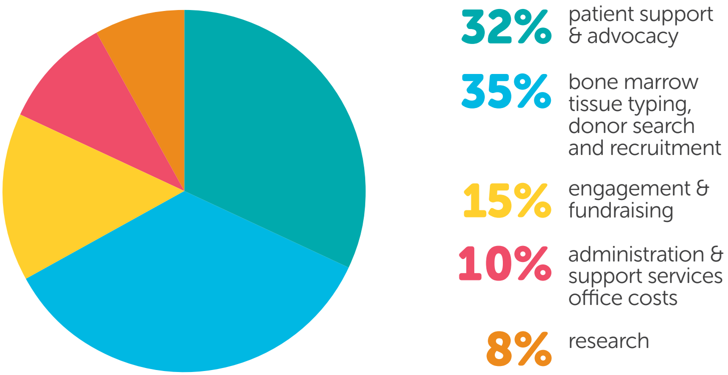
THANK YOU TO ALL OF OUR WONDERFUL PARTNERS

Without the kindness of people all over New Zealand, blood cancer patients would experience a much tougher journey. The generous grants received from multiple trusts and foundations, as well as the valued support from LBC's partners, directly fund services and support for patients. This makes the vision to cure and mission to care real and tangible every day – thank you.

Income sources this year



How income was spent this year



Financial year to 31 March 2020

LBC receives no direct government funding, and everything we have achieved is because of the generosity of our supporters.

The LBC Endowment Fund sits separately to our existing fundraising efforts to enable us to future-proof our services and research funding, and safeguard the care and support of the people who need us most. It's a significant step forward for the sustainability of our work.

A LASTING LEGACY FROM A VERY SPECIAL PERSON

Through a generous donation received following the passing of Angela Sunkel, LBC has set up Angela's Fund to provide extra comfort and support for blood cancer patients in the Waikato. Last year we were thrilled to join Waikato Hospital staff to celebrate the many new fittings and furnishings on the Haematology and Oncology Ward – including giant murals of local scenery and a new wardrobe in every room – and to remember Angela and the difference that this marvellous gift is making. Approximately $100K was invested from Angela's Fund into the improvements.

> **"Angela was a genuine person who made such an impact and a difference to people when she was with us – and today that marvellous gift continues through the funding that was entrusted to LBC's care."**
> **– Peter Fergusson, LBC CEO**

Some of Waikato Hospital's Ward M5 staff attending a special event to recognise Angela Sunkel's donation.

Support Services Centres
Auckland
Hamilton
Wellington
Christchurch
Dunedin

Support Services & General Enquiries
0800 15 10 15

Fundraising & Events
0800 15 15 10

info@leukaemia.org.nz
leukaemia.org.nz

National Office
PO Box 99182
Newmarket
Auckland 1149

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

WE GRATEFULLY THANK THE FOLLOWING TRUSTS FOR THEIR GENEROUS SUPPORT

- Bendigo Valley Sports and Charity Foundation
- Estate of Ernest Hyam Davis
- Hutt Mana Charitable Trust
- Joyce Fisher Charitable Trust
- Lottery Community Fund
- Matamata Leukaemia Research Trust
- Dry July Foundation
- The Ted and Mollie Carr Endowment Trust
- The Southern Trust
- Trust Waikato

leukaemia & blood cancer NEW ZEALAND

Vision to Cure. Mission to Care.