

2018

RISING

TO THE

CHALLENGE ▶



our mission is to care, our vision is to cure



CONTENTS

▶ Support services	4
▶ No barriers to care	6
▶ Access to information	8
▶ Survivorship	9
▶ Research	10
▶ Amazing fundraisers	12
▶ Planning for the future	14

2018 HIGHLIGHTS

OUR MISSION IS TO CARE. OUR VISION IS TO CURE.



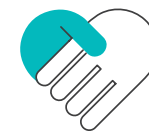
\$424,471
given in research
funding and grants



\$141,001
given in financial
assistance



46,404
generous donors



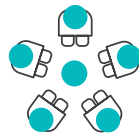
18,725
patient and family
contacts were made



4,687
patients and their families
supported by the LBC
Support Services team



4,097
Kiwis took part in
events & fundraised



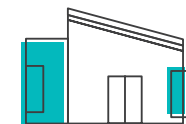
3,302
people attended 330
support groups



2,039
patients were given
financial assistance



1,385
new patient and family
referrals from all over NZ



1
new support service
office opened in Dunedin,
supporting the whole
southern region

SUPPORT

SERVICES

Every blood cancer diagnosis is unique in its challenges. Your donations keep our individually-tailored services free of charge for patients and their families every step of the way.

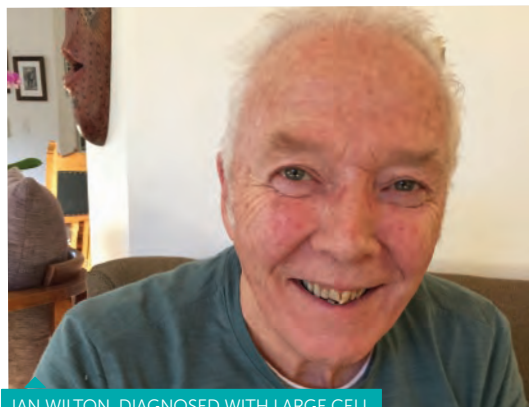


Diagnosis

A blood cancer diagnosis can affect every aspect of life. We believe no-one should have to face this diagnosis alone, and our Leukaemia & Blood Cancer New Zealand (LBC) Support Services team are right there to help patients and their families to meet some of these challenges. Our services range from having someone to talk to, to sourcing practical help and providing financial assistance and information about specific diseases and treatments.



Our LBC Support Services Coordinator, Ady, was so approachable and warm and she helped my wife Alison and me understand what medical terminology meant. My wife has a background in nursing, but even she needed help with some specific terms.” – Ian Wilton



IAN WILTON, DIAGNOSED WITH LARGE CELL FOLLICULAR NON HODGKIN LYMPHOMA



JACKIE TOO HILL, DAUGHTER MACKENZIE & FAMILY



Tests and Treatment

After a patient has been diagnosed with blood cancer or a blood condition, their specialist medical team will discuss treatment options and possible side effects. At this time there can be financial strain, especially when a patient is undergoing long-term treatment, or their caregiver can no longer work. We can ease this financial burden by providing food or petrol vouchers, or help with unexpected expenses. Each case is individually assessed.



My daughter Mackenzie and I moved to Christchurch for an urgent stem cell transplant. Funds were tight, but our LBC Support Services Coordinator organised petrol vouchers and grocery vouchers to help when my husband and other children came to visit. I don't know many people in Christchurch so to have someone regularly calling, texting or dropping by the ward to take me for a coffee became so important.” – Jackie Toohill



Home from Hospital

Recovery from treatment is both physical and mental. Resuming a normal life while managing new medication and side effects can be unsettling and sometimes lonely. LBC support groups help patients and families connect with others on a similar journey, and find ways to live well when they are home from hospital.



If you don't have a caregiver who understands what is going on with you, you can become your own worst enemy. I'm very grateful for the support and information that LBC has given to me and my husband." – Tae Mason



TAE MASON, DIAGNOSED WITH ACUTE MYELOID LEUKAEMIA IN 2015



FIONA BECK, DIAGNOSED WITH ACUTE PROMYELOCYTIC LEUKAEMIA (APL) IN 2016



Survivorship

Survivorship is an area often under-funded by health agencies. We offer on-going education and support, nutrition and exercise groups, employment workshops and mentoring, and psychosocial support to help patients and families make adjustments to a 'new normal'.

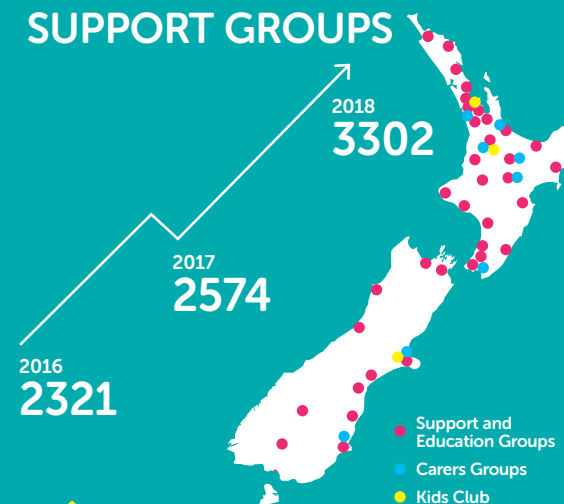


Luckily I responded well to the treatment, but when it ended I was a little at a loss. LBC's Wellington Support Services Coordinator Sally, was great. From providing information in the early stages to sessions like the Blood Cancer Patient Forum, it's all been so helpful. Sharing your thoughts in meetings helps you cope and look out for one another." – Fiona Beck

Your support meant that we were able to increase the number of support groups to meet the growing number of patients across the country.



SUPPORT GROUPS



INCREASE IN PATIENT REFERRALS 2018

	2018	2017
New Patients	816	635
New Family / Caregivers	569	336
TOTAL	1385	971

NO BARRIER

TO CARE

Your donations reach across barriers such as financial constraints, location and cultural differences to make sure that no-one has to face blood cancer alone.

Breaking down the cost barrier

"I recently met a female patient in her late 20s who had been unwell for over a year, but who kept missing haematology appointments in Christchurch. She was a mother with a young child, and while her partner was working full time, the family was struggling financially. She felt that she could not justify the cost of petrol to get to her appointments."

"Patients in the Otago region often have to travel long distances for treatment and financial hardship is sometimes the biggest barrier to accessing treatment."



Strong donor support in our community means that I am able to provide financial assistance when it is most needed – in this instance petrol vouchers so that this patient could travel to Christchurch for her much needed treatment.”
– Deborah Tomlin



DEBORAH TOMLIN, SOUTHERN REGION SUPPORT SERVICES COORDINATOR

Over
\$140,000
in financial support
given in 2018 to
2,039
patients experiencing
financial hardship

Support for everyone

Blood cancer can affect anyone, at any time, and at any age. 2018 saw an increase in patient referrals, particularly among children and ethnic communities.



Generosity of donors meant that in 2018 we ran our first support groups for Maori and Pasifika and their whanau, with great attendance. Blood cancer survival rates can be lower among Maori and Pasifika, so it's really important to provide support and raise awareness among these communities.” – Tim Maifeleni



TIM MAIFELENI, NORTHERN REGIONAL SUPPORT SERVICES MANAGER

Support for siblings



THE LBC KIDS CLUB IS FOR CHILDREN AGED BETWEEN 5 AND 12 WHO HAVE A PARENT OR SIBLING WITH A BLOOD CANCER

Luca's sister Devyn was diagnosed with acute lymphoblastic leukaemia at two years old. Devyn spent a lot of time in hospital, which was tough on the family and in particular on five-year-old sister Luca.

“In the first month of treatment, either my husband Ryan or I were in hospital with Devyn, which meant that Luca never had us all together at home,” says mum Bianca. “Luca became anxious and worried that she would get leukaemia too.”



When we heard about the LBC's Kid's Club for children affected by a diagnosis in the family, we thought it would be good for Luca. We were so happy that she could take part in activities, talk about feelings, learn about cancer and treatment, and most importantly to meet other children going through a similar experience.”



INCREASING OUR REACH

In 2018 we saw a significant increase in the number of patient referrals from children and ethnic communities across the country.



141% increase in referrals among children (under age 18)



60% increase in referrals among Maori



105% increase in referrals among Pasifika

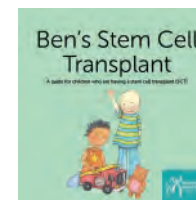
ACCESS

TO INFORMATION

Confidence is often built on information and support, and plays a big part in a person's treatment journey. We make sure that patients, families and medical professionals can access the information they need through awareness campaigns, workshops, online resources, fact sheets and booklets. These are designed to:

- ▶ Raise awareness of the signs and symptoms of blood cancer
- ▶ Help health professionals offer wrap-around services for their patients and families
- ▶ Reach out to higher risk communities, in particular, Maori and Pasifika
- ▶ Describe how to manage symptoms and live well with blood cancer
- ▶ Keep patients, families and caregivers up to date with news and developments in the fast-paced blood cancer research field.

Information booklets are available in Te Reo Maori, Cook Islands Maori, Samoan, Tongan, Niuean, Hindi, Chinese and Korean. A series of children's haematology books are available in English and Te Reo Maori. They are all available on our website.



Patient Forum

The Blood Cancer Patient Forum gives blood cancer patients and their whanau opportunities to share their experiences and hear the latest information from experts.

Keeping health professionals up to date

In a fast-developing field, donations fund regional GP education workshops and 'Winter Workshops' for health professionals each year to share the latest on the management of blood cancer and blood conditions.

Our patients voice

Ten patients and carers from around the country represent the voice of patients for LBC as members of our Consumer Advisory Board. LBC regularly seeks its views on anything from writing information materials to planning our workshops and Blood Cancer Patient Forum.



SURVIVORSHIP

Surviving a serious illness brings its own set of challenges. We address the long-term impact of patients' and their families' diagnosis through:

- education programmes
- nutrition and exercise groups
- employment workshops
- mentoring
- ongoing psychosocial support

Transforming transplant recovery

Donor support in 2018 meant that we could launch our first ever post-transplant wellness programme. This 8-week course is run in collaboration with health professionals, and is for patients who have undergone a bone marrow transplant. It focuses on exercise, nutrition, and recovery.

Return to work programme



The LBC Return to Work Mentoring programme, powered by Randstad, connects survivors of blood cancer back into the workforce. The programme identifies and closes knowledge gaps, looks at new opportunities and pathways to new careers. Practical skills include CV writing, technology training and professional development.

Randstad recently matched a young masters degree graduate, who lost a great job prospect following his diagnosis of Hodgkin lymphoma, with an experienced mentor who has also survived blood cancer. Together they secured that young man a new role. They both learned new skills and plan to stay connected as the new career unfolds.



NAOMI McRAE

Working it out



I was diagnosed with Hodgkin lymphoma just before my 30th birthday. I never expected to get cancer at such a young age. There are so many things you suddenly have to think about. What is lymphoma? What does this mean for my friends and family? What does this mean for my career?

My employers, PwC, were so understanding and together we came up with a plan to manage my involvement at work while I had treatment.

I know not everyone is so fortunate, and I decided to use my knowledge as a HR specialist, my relationship with LBC, and my experience as a patient to develop resources for patients who are dealing with employment issues related to their condition.

With the support of the PwC Charitable Foundation and LBC, we've held workshops around the country and produced resources about engaging with employers, and employment rights.

It's wonderful to be at a point where my own diagnosis doesn't consume me, and where I can support others."

Naomi McRae

Create access to best practice standard
of care for New Zealand patients



RESEARCH

THE LEUKAEMIA & BLOOD CANCER RESEARCH UNIT SITS WITHIN THE FACULTY
OF MEDICAL AND HEALTH SCIENCES AT THE UNIVERSITY OF AUCKLAND

In just five years, blood cancer research has become a leading light of cancer research in New Zealand, thanks to generous donations to LBC.

LBC's \$1,250,000 commitment to establish the Leukaemia & Blood Cancer Research Unit within the University of Auckland's Faculty of Medical and Health Sciences in 2013 coincided with an explosion of opportunities created by genomic sequencing.

New, low-cost gene-sequencing technology has given cancer researchers an unprecedented high resolution view of cancer cells, which is translating into dramatic improvements in survivability, and low-impact treatment.

Twenty years ago, the life expectancy of a patient with chronic myeloid leukaemia (CML) was four to five years. Now a 50-year-old with that diagnosis has the same life expectancy of any other 50-year-old.

The 13-strong team is identifying blood cancers' molecular markers that will allow more targeted treatment, avoid aggressive treatments when they are not necessary and pave the way to new treatments.



Donations to research channelled through LBC now total \$7 million since the first grant in 2011. They remain the main source of haematology research funding in New Zealand."



PROFESSOR STEFAN BOHLANDER AT THE LBCRU



Molecular test breakthrough for AML patients

In 2018, the gene panel, developed by the Leukaemia & Blood Cancer Research Unit (LBCRU), for testing myeloid leukaemia patient samples became available to cancer clinicians in Auckland. Now all adult patients with newly diagnosed and relapsed acute myeloid leukaemia have samples collected for DNA preparation and analysis using this 70-gene myeloid panel.

HK, a man aged 57, was diagnosed with acute myeloid leukaemia (AML) in August 2015. Molecular studies showed that his leukaemia cells had two abnormal genes: the NPM1 mutation and the FLT3 ITD mutation. The second carries a high risk of relapse so, in addition to chemotherapy, this is usually addressed with a bone marrow transplant.

But transplants are risky. The LBCRU estimates that between 15 and 20 percent of patients are at risk of dying in the first year from complications. It also commits the patient, family and caregivers to four weeks in hospital and two months of follow up care. It's usually a year before they resume a normal life.

As HK was in remission after the first of four treatments, instead of going straight to a transplant, his blood and bone marrow were re-tested using a super-sensitive new test at three-monthly intervals. Using the NPM1 marker, which is seen in about 30 percent of AML cases, the team's new molecular test can find one leukaemia cell in 100,000 normal cells.

Every test after treatment was negative. Clinicians say HK is probably cured. However, if the tests had turned positive, a transplant could have been arranged before a relapse without the need for further chemo or radiotherapy.

Soon all adult patients diagnosed with AML could be tested using the same 70-gene myeloid panel, meaning many more New Zealanders will share in HK's success story.

Big boost for blood cancer research at Otago University

Two top researchers at the University of Otago both received national research grants, totalling over \$130,000, in LBC's 2018 funding round.

Both Professor Dr Ian Morison and Associate Professor Dr Julia Horsfield work in the Department of Pathology, Dunedin School of Medicine but they are tackling very different research areas with their funding.

Dr Morison is investigating myeloma which is currently an incurable cancer of the plasma cells.



Our goal is to develop an improved biomarker as part of a wider programme of research into myeloma" states Dr Morison. "As drug treatments improve, previous biomarkers used to see how well the body responds are insufficiently sensitive for this new era."

Dr Horsfield's project focuses on Acute Myeloid Leukaemia (AML) and the need to understand how leukaemia emerges from specific genetic mutations.

This investigation is significant not only because the global incidence of AML is increasing but also that strikingly, New Zealand now has one of the highest incidences in the world. Although cure rates for AML are gradually improving, results for older patients, who cannot tolerate intensive chemotherapy, remain poor.

AMAZING FUNDRAISERS

TAKE A BOW!

In 2018, generous people all over the country ran, climbed, cycled, baked, jumped, swam and shaved to care and to cure. Together they made literally the biggest contribution to funding research and LBC support services.

Thank you!

Brave the Shave!

Hundreds of freshly-shaven heads were out in force in March as Kiwis banished their bad hair days for Shave for a Cure.

The annual week saw brave individuals, businesses, schools and community groups shave and raise an incredible \$1.38 million to support our vital work.

Thank you to all who took part, and special thanks to Farmers, who held shaves at 18 stores across the country.



Farmers' Life Changing Small Change

Our long-term partners Farmers once again ran a fantastic fundraising campaign over Queen's Birthday Weekend – Life Changing Small Change, which raised \$104,000!

The campaign ran in Farmers stores across the country, encouraging generous customers to donate their small change and make a huge difference to the lives of the families we support.

In 2018, over 4,000 people took part in fundraising events for LBC, and together raised an incredible \$4.8 million dollars.

A Record Breaking Year for our Firefighters

In 2018, firefighters taking part in the Firefighter Sky Tower Stair Challenge raised more than \$1.25 million for LBC. Thank you to the nine hundred and fifty firefighters from communities around New Zealand, as well as Australia and the USA, who took on the 1103 steps of Auckland's Sky Tower wearing up to 25 kilograms of firefighting kit.



THANK YOU TO OUR WONDERFUL FIREFIGHTERS



CLARE REILLY ON THE EL CAMINO WALK

Clare's Soulful Journey

Clare Reilly planned to walk the El Camino in Spain with her life partner Max, before he was diagnosed with CNS lymphoma. Max was an avid walker and had been given a pair of walking poles when he left his job after 30 years as a librarian at the University of Canterbury.

"We had 10 precious months filled with love and special times before Max died peacefully on July 20th 2017."



Going on the journey that we had planned together with a team of LBC supporters in 2018, was my opportunity to walk on his behalf, carrying his walking poles every step of the way. I am grateful for all the support from friends and family to have raised over \$5000 for others living with blood cancer."

Bridgestone Put a Cap on It!

Last November and December, people around the country could buy great looking teal coloured valve caps for their cars, trucks, bikes, tractors, or even their wheelbarrows and make a small but noticeable contribution to people living with blood cancer.

"We are proud of our partnership with LBC, which we launched in 2017. Since then we have raised more than \$100,000 by taking part in fundraising events such as Shave for a Cure and the Step up Sky Tower Challenge. This year we have expanded the sale of valve caps into a new campaign called 'Put a Cap On It'.



While \$2 a cap may sound insignificant, collectively these small contributions make a big difference, and seeing these teal caps everywhere will be a great visual representation of New Zealanders caring for each other!" – John Staples, Bridgestone New Zealand General Manager



KIWIS AROUND THE COUNTRY PUT A CAP ON IT FOR BLOOD CANCER



PETER FERGUSSON AT STADIUM CLIMB WELLINGTON IN 2018

PLANNING

FOR THE FUTURE

A mission to care and a vision to cure remains the driving force at the heart of our planning for the future. Add an ever changing environment to that altruistic intent and we are endlessly changing to ensure the very best for patients and their families.

One of those emerging trends is increasing referrals, partly due to greater awareness and better diagnosis – we can take some pride in our effectiveness here – which challenges us to improve and meet those increasing demands.

Part of the answer includes greater access to information, support and resources across the country. With this in mind we have opened a new branch in Dunedin and recruited two new support services coordinators. The LBC Endowment Fund will help create a sustainable financial base for the organisation and support key services into the future.

Research remains a critical component of our intent to cure. Our long-term commitment and investment into the Leukaemia & Blood Cancer Research Unit, in collaboration with the University of Auckland, is a great example of the growing capability to detect molecular markers and use them to guide therapy, monitor response and improve patient outcomes.

Advancements in technology continue to create exciting insights into the treatment of blood cancers. It is gratifying to see better options, diagnosis and treatment as a result of this work and the increasing survivorship that this generates.

All said and done, we are here for others. In the great words of John Bunyan,

BB

You have not lived today until you have done something for someone who can never repay you."

That sentiment is reflected by every one of our beloved sponsors, partners, volunteers, donors, event participants, firefighters, community fundraisers, shavers, and regular givers. We wish to offer you our heartfelt thanks for helping LBC to support others.

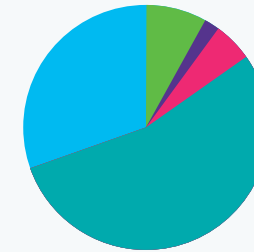
PETER FERGUSSON
Chief Executive Officer

TONY WILDING
Chair

2019 Focus

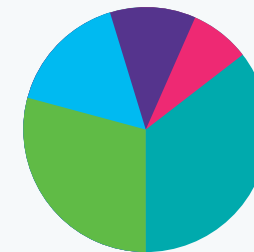
- ▶ Deliver valued patient and family support services nationally
- ▶ Proactively drive research into the prevention, cure and care of blood cancers in New Zealand
- ▶ Advocate for access to the best practice global standard of treatment for New Zealand patients
- ▶ Ensure future organisational and financial sustainability

WHERE OUR INCOME COMES FROM



55%	fundraising events
30%	tissue typing funding and overseas bone marrow & search receipts
8%	donations
2%	bequests
5%	trusts & foundations

HOW YOUR DONATIONS ARE USED



36%	patient support & advocacy
29%	bone marrow tissue typing, donor search and recruitment
16%	engagement & fundraising
11%	administration & support service office costs
8%	research

LBC receives no 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.



LBC has been a huge part of our family making it through this past year, and we would not have been able to stand so strongly without such a huge support system behind us.”

Support Service Centres

Auckland
Christchurch
Dunedin
Hamilton
Wellington

**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.

**THANK YOU TO ALL
OF OUR WONDERFUL
PARTNERS IN 2018!**



BELL GULLY



FidelityLife
THE NEW ZEALAND LIFE COMPANY

randstad



our mission is to care, our vision is to cure