leukaemia & blood cancer
NEW ZEALAND
Vision to Cure. Mission to Care.

Lifeblood

The difference you make

AUTUMN 2025

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Kia ora,

The stories of patients and their families guide everything we do at LBC. I recently spoke with a woman whose husband had been diagnosed with blood cancer. She told me that, for months, it felt like the floor had vanished beneath her feet. Everything she thought was solid suddenly wasn't. But she also shared what helped her through: *"In that moment, it was the kindness of strangers that held us up."*

Over the past year, our support team has stood alongside thousands of people impacted by blood cancer, including 1,700 patients and whānau accessing support for the first time due to a recent diagnosis. Our support has reached more people than in any 12-month period in our 48-year history. We're humbled not just by the trust people place in our support services, but because it has only been possible thanks to the generosity of others. Behind every person and family is a story of courage, connection, and community – and each one is touched by your support.

In this issue, we're sharing stories not just of the challenges blood cancer patients face, but of the support that lifts them, the research offering new hope, and the health system changes we're working hard to achieve. From raising political awareness of the unique needs of blood cancer patients to advocating for a fairer, more responsive medicine access system, LBC continues to be a strong and proactive voice for those who too often go unheard.

There's a quiet strength that grows when people know there are others beside them. Whether you are a patient, a loved one, a donor, or an advocate – thank you. We all have a part to play in holding one another up through kindness.

Ngā mihi,

Tim Edmonds (LBC Chief Executive)

Driving Political Awareness of Blood Cancer

LBC has been working hard to raise awareness of blood cancer among policymakers. Unfortunately, the funding for broader cancer care only partially trickles down to those with blood cancer, and many politicians do not yet recognise that blood cancer patients have specific needs that must be addressed in health system planning. For many blood cancers, access to modern medicines offers the best chance of survival, yet chronic underinvestment in medicines leaves patients missing out. This has been central to our government engagement, including meetings with Health Ministers, and remains a key advocacy focus.

Shaping the Future of our Medicine Access Landscape

Through active participation in Pharmac consumer workshops and direct engagement with decision-makers, LBC is advocating for a more transparent, patient-centred approach to medicine funding. We are pushing for changes that ensure faster access to new blood cancer treatments, align New Zealand's processes with international standards, and give patients a stronger voice in decision-making. With the Minister setting bold expectations for Pharmac and a new Chief Executive soon to be appointed, this is a critical moment for change. LBC is proud to be a strong and informed voice in these discussions, ensuring blood cancer patients are not left behind.

On the *horizon* in 2025

Firefighter Sky Tower Challenge – Saturday, 24 May

After a massive 20th anniversary last year, the Firefighter Sky Tower Challenge is back again for 2025! Firefighters from across Aotearoa and beyond will push their limits for Kiwis living with blood cancer by climbing Auckland's iconic Sky Tower. Keep an eye out for your local brigade fundraising in your community!

Winter Workshops – July and August

Throughout winter, we'll be running a series of educational workshops for haematology professionals all over the country. These sessions are designed to enhance the care patients receive through a holistic and cultural lens.

Step Up Sky Tower Challenge– Sunday, 3 August

The firefighters aren't the only ones who get to take on the Sky Tower! The Step Up Sky Tower Challenge invites everyday Kiwis to experience the ultimate stair climb while supporting those living with blood cancer. Registrations will open soon.

Online Blood Cancer Patient Forum – September

Throughout September, we'll be holding an online webinar series for patients and their support people. These sessions will cover haematology healthcare updates in 2025, with the aim of supporting patients to navigate and get the best out of the healthcare system.

Shine for a Cure – Saturday, 20 September

Following two successful events in Auckland and Christchurch last year, Shine for a Cure is making a return this September. Auckland Domain and Hagley Park will once again be lit up by a sea of colourful lanterns as patients, support people and the wider blood cancer community walk together for a great cause.

Participants who raise over $100 for LBC will receive a lantern in the colour of their choice: gold to represent those who are no longer with us, white to show support for all those affected by blood cancer, or teal to symbolise a personal cancer journey.

Matched Giving Day – Thursday, 27 November

For 24 hours, every donation made to LBC will be DOUBLED, thanks to some incredibly generous supporters who are matching every gift. This means that every dollar donated during this period will go twice as far for Kiwis living with blood cancer. Mark the date in your calendar and we'll share more information in the next issue of Lifeblood.

Your support funds education for healthcare professionals working with blood cancer patients.

care

Back to square one

“I’ve always been a very healthy guy,” says Richard. The 62-year-old university professor lives in Christchurch with his wife, Martha, and has dedicated much of his life to keeping fit and active.

“As a young fellow, I was a competitive athlete. I specialised in an event that most others thought was close to madness – the 400m with hurdles.” Even when it came time to call it quits on competing, Richard kept up a strict training schedule.

“So I was quite surprised when, one day in 2021, I started having massive pains in my chest. And, of course, when a 59-year-old has pains in his chest, everybody assumes it’s a heart condition. But I really didn’t think so.”

Despite his doubts, his wife rushed him to the hospital to get checked over. He was diagnosed with pneumonia and prescribed antibiotics.

Two months later, Richard was back at the hospital for a CT scan to check that his pneumonia had cleared up. *“My lungs were fine,”* he says. *“But the scan showed that further down my torso, there was something else. The report described it as ‘potential lymphoma’.”*

> “It didn’t take too much online research for my wife and I to discover this meant ‘potential cancer’.”

When a biopsy at the end of January 2022 confirmed Richard had stage 3 follicular lymphoma, his life changed dramatically. *“It only took them two or three days after the biopsy results to get me directly onto the chemotherapy ward.”*

Treatment with RCHOP chemotherapy brought a whole host of issues. As well as dealing with side effects like insomnia, nausea and constipation, Richard had to face his lifelong fear of needles head-on. *“I have quite a phobia around that.”*

Richard received treatment at Cytecare Hospital in Bangalore, India

Fortunately, Richard has had good support throughout his journey. Martha has been by his side through all the ups and downs, and he’s had LBC to lean on when needed.

Richard was first introduced to LBC when his local Support Services Coordinator, Kate, visited him at the hospital. *“She gave me some pamphlets and information and asked me if I’d like to come to the meetings,”* Richard says.

Since then, he’s stayed in touch with Kate and has continued to attend his local LBC support group. *“I go as often as I can. It’s nice to swap stories with other patients. I hope that the conversations I have there are helpful to some of the other people, too.”*

These vital connections are only possible thanks to supporters like you. Your kindness means we can run support groups throughout the country and continue to be there for patients for as long as they need us.

Martha has been by Richard’s side through all the ups and downs

Richard made it through six rounds of chemo, at which point a scan showed that about 80% of the lymphoma was gone. His haematologist decided to stop treatment for the time being and monitor him closely.

“That would have been July, and I was back in trouble early the next year. I started having symptoms again in late 2022, and by the end of March 2023, I was essentially back to square one.”

This time, a more aggressive form of chemotherapy called GDP was used. *“The first week of GDP was a living hell for me,”* says Richard. *“It really hit me hard, to the extent that I was seriously doubting whether I could continue. My body weight plummeted until I was little more than a bag of skin and bones.”*

One night during this treatment, Richard suffered a huge internal bleed. He was rushed to the emergency department and needed to have over five litres of blood transfused. He remembers being told by the hospital staff that they’d never seen someone lose so much blood and survive.

After finishing his GDP treatment and then going through a gruelling stem cell transplant, a further scan revealed there were still areas of active lymphoma in Richard’s body. His haematologist gave him two final treatment options, but admitted that neither of them was perfect – one would be very risky, and the other was not a long-term solution.

The haematologist had, however, mentioned a newer type of treatment called CAR T-cell therapy, which had shown promising results for lymphoma patients like Richard. The only catch? CAR T-cell therapy wasn’t available in New Zealand, and Richard would have to self-fund the treatment overseas. *“My haematologist talked about it being a million-dollar treatment.”*

Still, hopeful that this might be his best chance of survival, Richard and his wife looked into it. Through their research, they discovered that India offered a state-of-the-art CAR T-cell programme that was much more affordable than those offered in countries such as Australia or the USA. By May 2024, the couple were on a flight to Bangalore for Richard to begin treatment at Cytecare Hospital.

“In the end, in my particular case, the cost of the entire journey to health ended up being somewhere around a couple of hundred thousand dollars, which I financed by cashing in my Kiwisaver and taking out a sizeable loan.”

The entire process took about two months and went surprisingly smoothly, with very few side effects. Just before he was due to fly home, Richard had his final scan and received the best possible news.

“The lymphoma was gone. The haematologist said, ‘You’re in total remission.’”

Now back home, Richard is feeling well. He’s started up his training again and has even managed to take a trip to Florida with his wife. Of course, he doesn’t know what the future holds – but as he awaits his next scan in June, Richard is hopeful for many years of good health ahead.

Richard was thrilled to find out he was in complete remission

Rolling with the punches

Juliet has spent her life searching for adventure. After a trip to New Zealand in 1997, she and her husband decided to leave their home in the UK and move here permanently for a change of pace. *"We lived on the South Coast in Wellington, which was just stunning. We had two kids, who are now 24 and 26."*

When their youngest left home a few years ago, the empty nesters decided it was time for their next big adventure. They sold their house in Wellington and moved down to the beautiful shores of Lake Hāwea. *"We'd actually only been down here once,"* Juliet laughs. *"The kids thought we were slightly nuts!"*

Not long after settling into their new home, Juliet had a serious mountain biking accident. *"A dog ran into the back wheel of my bike. I ended up with five fractures and a nasty concussion."*

The concussion didn't improve despite trying several different treatments. *"My health actually seemed to be deteriorating, and I was getting more and more worried about it."*


Juliet has always embraced an active, adventure-filled lifestyle

Juliet soon learned there was something else at play. Blood tests revealed her platelet levels were slowly rising, and she was eventually diagnosed with essential thrombocythaemia (ET), a type of blood cancer that falls into a group called myeloproliferative neoplasms (MPNs).

Suddenly, Juliet had an explanation for all the strange symptoms that had been plaguing her for years. The intense fatigue, migraines, vision problems, nausea and tingling feet – *"They're all ET symptoms!"*

While Juliet loves her rural lifestyle, she does miss the ease of accessing healthcare in the city. She's had to pay for things like blood tests and scans out of pocket because it's too far to drive to a main centre where she could get them for free. And attending appointments requires a lot of forward planning, particularly if she wants her husband to join her.

"For hospital appointments, I have to travel to Dunedin. It's a four-hour drive each way, and it's a pretty intense drive, so it's too much to do in a day. It's a one-night trip at a minimum."


Juliet and her husband love living in the South Island, but their remote location has posed some challenges

Although living rurally has posed challenges in Juliet's treatment, it hasn't stopped her from getting support through LBC. After coming across LBC online, Juliet reached out and was put in touch with Deborah, her local Support Services Coordinator.

"Deborah has been fantastic," says Juliet. *"She gave me some really good independent advice, and she was just easier to communicate with about some of the sensitive subjects."*

Juliet has also enjoyed going along to her local LBC support group in Cromwell, and she was relieved to finally connect with several other ET patients in New Zealand through an online support group run by LBC. *"I'm really grateful to finally find some other people out there with ET – you know, we're rare, but we are out there!"*

She says it's been great speaking with them about the challenges of ET – particularly the severe fatigue, which is a common effect of the condition and its treatment. *"The fatigue is real. I often feel really tired and very flat – I do have some days I can't get off the couch,"* Juliet says.

She's currently also dealing with low white blood cell counts, which means her immunity is compromised. After speaking to her haematologist, she's taking time away from her job at the local school to lower her risk of infection.


Despite her fatigue, Juliet does what she can each day

As Juliet navigates these uncertain times, she knows that LBC has her back. It's thanks to people like you, our wonderful supporters, that we can be there for Juliet and other Kiwis like her when they need us.

> "I'm just so grateful to have LBC, and access to Deborah and her knowledge."

For the time being, Juliet is taking care of herself and listening to her body. Depending on her energy levels each morning, she does what she can with the day – walks her dog, swims in the lake, potters in her garden, or gets out in the beautiful Otago landscape – and tries not to beat herself up if it's a couch day. *"I just have to roll with the punches!"*

Our Support Services team is Growing!

At LBC, we are committed to supporting Kiwis living with blood cancer and related conditions. As more patients turn to us for help, we rely on the generosity of donors like you to continue providing essential care and resources.

In the past year, we've seen a 15% increase in new patient and whānau referrals. We've increased support across a range of areas, including emergency financial assistance like petrol vouchers to help patients get to treatment, and counselling support to help patients navigate the psychological challenges of a blood cancer diagnosis.

To meet this need, our nationwide team is growing. We're excited to welcome Tina to our Support Services team in Hamilton, where she'll expand services and improve equity in the region. We will continue to build our team of Support Service Coordinators over the coming year to make sure we meet the increasing needs all around the country.

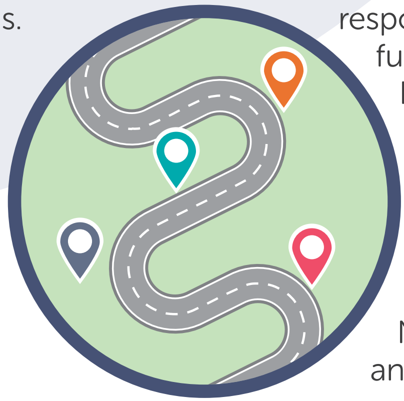
Your generosity is vital in helping us provide life-changing support to those who need it most. Together, we can ensure that every Kiwi facing blood cancer has the care they deserve. Thank you for being part of this important mission.

State of the *Nation*

At Leukaemia & Blood Cancer New Zealand (LBC), one of our top priorities is ensuring that every person affected by blood cancer receives the best possible care and support. To make this possible, the first step is to gain a clear understanding of where things stand in Aotearoa – how many people are affected by blood cancer, how the health system is performing, and what outcomes patients are experiencing.

Currently, health system decision-makers don't have access to this type of data. Without this, the health system cannot plan effectively, invest wisely in new treatments, or ensure equitable care for all those living with blood cancer. Thanks to the generosity of our supporters, we have been able to take the first step in addressing this.

Blood cancer is the fourth most common cancer in New Zealand – but unlike many solid tumour cancers, it doesn't benefit from screening or prevention programmes. Patients are often diagnosed late, need complex and prolonged treatment, and face lifelong impacts. These challenges make accurate data, system planning, and access to innovative treatments even more important.



We don't have to look far to see what's possible. Across the Tasman, Leukaemia Foundation Australia has produced its own State of the Nation report. Over there, this work has helped to make blood cancer a national health priority. It has guided policy and funding and has unlocked access to critical, life-extending treatments.

LBC is now embarking on the New Zealand equivalent of this work, in partnership with Deloitte and the University of Auckland. The goal is to fill a critical information gap and pave the way to achieving our aspiration of zero lives needlessly lost to blood cancer.

The University of Auckland team is carrying out a thorough analysis of blood cancer statistics in New Zealand. This research will provide, for the first time, accurate national measures of blood cancer incidence, prevalence, and survival rates. At the moment, government agencies responsible for health planning and funding decisions simply don't have access to these important statistics.

As well as painting a picture of the current landscape, the report will look at international best practice. It will compare New Zealand's performance and identify what's getting in the way of Kiwis receiving optimal care. It will provide a roadmap for the future that focuses on improving outcomes, exploring opportunities for innovation, and highlighting emerging treatments and technologies. Finally, it will recommend practical steps for achieving change. These will be informed by conversations with patients, whānau, and healthcare providers.

Ultimately, this is about ensuring that every Kiwi diagnosed with blood cancer has the best possible chance of survival – with access to world-class treatment, equitable care, and outcomes on par with the best in the world.

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