



Vision to Cure. Mission to Care.

Lifeblood

The difference *you* make

SPRING 2024



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Kia ora,

Welcome to your Spring 2024 edition of Lifeblood! This issue is packed with updates on what's been happening around the country. Our support services team has been busier than ever, and we've also been working behind the scenes to push for health system change that will benefit blood cancer patients in Aotearoa.

A major area of focus has been amplifying the needs of blood cancer patients in political decision-making. Access to medicines has been a hot topic since National's pre-election pledge to fund 13 cancer medicines – a promise that notably left out blood cancer treatments. In response, Leukaemia & Blood Cancer New Zealand (LBC) has helped form the 'Blood Cancer Alliance', bringing together patient advocacy groups and consultant haematologists.

The aim of the Alliance is to provide health system decision-makers with greater awareness and understanding of the needs of blood cancer patients in medicine policy and other aspects of patient care. Our collaborative efforts have included media campaigns and engagement with Ministers to ensure blood cancer patients are not forgotten. We're pleased the initial '13 Medicines' policy has progressed to a significant increase in the Pharmac budget, which includes funding of medicines for four different types of blood cancer. In recent months, Pharmac has indicated that it plans to widen funding for the following medicines for blood cancer:

- Pembrolizumab (Keytruda) for relapsed or refractory Hodgkin lymphoma
- Bendamustine for relapsed or refractory chronic lymphocytic leukaemia
- Lenalidomide and pomalidomide for multiple myeloma.



Tim Edmonds (CEO), Hon Dr. Shane Reti (Minister of Health), Pene Milne (Board Chair), Assoc. Prof. Rodger Tiedemann (Consultant Haematologist) and Prof. Peter Browett (Medical Director) at their meeting in August

We recently met with the Minister of Health, Hon Dr. Shane Reti, and emphasised to him the importance of access to modern medicines for blood cancer treatment. There is still a long road ahead to improve medicine availability in Aotearoa and we will persist with these advocacy efforts for as long as it takes to see change for patients.

Another key initiative is our work towards a roadmap for best practice blood cancer care in Aotearoa. To do this, LBC is forming partnerships with central government organisations and healthcare providers. This roadmap will include a comprehensive analysis of blood cancer patient data, treatment outcomes, and international benchmarking. It will guide an action plan for best practice care, including medicine funding models and the clinical services needed to deliver important new treatments such as CAR T-cell therapy.

The voice of blood cancer patients and supporting communities will be central to this initiative, and we are looking forward to sharing details of how you can get involved in the coming months.

As always, I am so grateful for your generosity – none of the work LBC does would be possible without your support.

Ngā mihi nui,

Tim Edmonds
Chief Executive

P.S. We'd love you to join us on Saturday, 21 September for our new lantern event, Shine for a Cure. It's an opportunity to bring our community together as we show our support for those living with blood cancer, acknowledge a personal blood cancer journey, or honour those who are no longer with us. Head to shineforacure.org.nz for more details.

Making strides in education

As well as pushing for access to the best possible blood cancer care in New Zealand, LBC is committed to educating patients and healthcare professionals on blood cancer and supportive care topics. This year we've been making strides in our education programmes and increasing knowledge about blood cancers in all corners of the country.

Throughout June and July, we were busy hosting our yearly Winter Workshops for blood cancer health professionals across Aotearoa. The workshops were attended by haematologists, nurses, psychologists and social workers, and we were very lucky to have Josh Komen speaking. You might remember Josh from an earlier edition of Lifeblood – he has an incredible story of facing acute myeloid leukaemia (AML). Josh came on the road with us across six regions around New Zealand to meet and educate healthcare professionals about his experience, and to pass on his survival tips so that other patients will benefit.

In August, we ran a series of webinars for primary healthcare practitioners. These covered the basics of blood cancers and blood conditions, active monitoring (watch and wait), navigating post-treatment care and stem cell transplants, and emergency management of haematology patients in the community. As these were hosted online, they were available to primary care professionals in even the most remote areas.

These sessions ensure that healthcare professionals in the community can confidently recognise and manage blood cancers and blood conditions. They provide primary healthcare practitioners with the skills and knowledge needed to make speedy diagnoses, and allow them to offer better treatment and supportive care back in the community. The webinars are accredited by the Royal New Zealand College of General Practitioners, meaning they meet rigorous standards and count towards professional development hours.

We're also thrilled to have this year's

Blood Cancer Patient Forum

coming up at the end of September. This is an opportunity for people living with blood cancer to come together, share insights, and listen to experts speak on a range of topics. This year, there will be sessions on life after stem cell transplant, financial resilience, medicine decision-making in New Zealand, immunotherapies, a seated movement workshop, plus many more!



Josh Komen presenting to healthcare professionals at an LBC Winter Workshop

If you or someone you know with blood cancer needs support, please get in touch - we are here to help.

0800 15 10 15 | info@leukaemia.org.nz | [@LBCNZ](https://www.facebook.com/LBCNZ) | www.leukaemia.org.nz

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



A long road to diagnosis

Emma lives in Lower Hutt with her husband, Jamie, their dogs, and the two international students they look after. She has a big, close-knit family and is the eldest of five. After living in Japan as a student, Emma spent 10 years working as a flight attendant in the United States, before moving to Christchurch and eventually settling back in her hometown.

"When I moved up here, I started working at a home for pregnant teens and young mums. I did that for three years – until I became too unwell."

It was in the United States that Emma's health journey began. She was told by her GP that her white blood cell count was low, so she sought out a haematologist, who regularly tested her blood for eight weeks. *"They said it was chronically low, but I was otherwise healthy, so they weren't going to test my bone marrow."*

In 2012, things began to ramp up. *"I was working as a flight attendant in Boston, and I developed a necrotising fasciitis inside my neck – flesh-eating bacteria."*

Emma knew her immune system was compromised, so she told the doctors at the hospital and asked if she could have antibiotics for the infection. *"That's not what they did, so it got worse. I had emergency surgery and was put in a coma for two days. I spent a total of nine days in ICU and then was in and out of hospital for the better part of that year."*

During this process, Emma's bone marrow was finally tested. *"They discovered it was myelodysplastic, meaning all the cells in the marrow were odd shapes and sizes. So even the ones I had weren't working properly."*

Emma's siblings were all tested to see if they might be a match for a bone marrow transplant, in case she needed one in the future. *"But in my mind, that was extreme – I thought, 'I'm never going to need that!' And I just carried on."*



Emma with her pup, Mojo



Emma is thrilled that international adventures are back on the cards



The day Emma received her transplant

Emma and her husband moved back to New Zealand in 2016. They had been providing respite foster care for several children, but after a horrendous bout of the flu and pneumonia, Emma became too unwell and had to give this up. Not long afterwards, she was diagnosed with pulmonary hypertension.

"Over those next few years, I declined severely. I went from being really independent, managing my house, doing the shopping – all of that – to not being able to do anything."

“I was in a wheelchair and lost sight in both my eyes.”

Emma held out for as long as she could, but eventually she had to give up work.

Finally, in 2020, Emma received an official diagnosis of GATA 2 deficiency, a rare genetic condition that was only discovered in 2011. *"There's perhaps one other person that has GATA 2 in New Zealand. It's not common at all."*

After years of dealing with constant infections and spending increasingly more time in hospital, an immunologist suggested that Emma try Privigen, an IV antibody therapy. *"That was a turning point. Since then, I've had it every three weeks and I've hardly had any infections on that. It's remarkable."*

But even with the infections under control, Emma's health was in bad shape. She had been struggling with breathlessness and was using supplemental oxygen overnight. When her usual haematologist returned from maternity leave in November 2022, their first appointment was not the catch-up Emma had been expecting. *"She sat me down and said, 'If you don't have a transplant, you're not going to make it through the year.'"*

It was reconfirmed that Emma's brother was a match, and in April 2023, Emma received her stem cell transplant. She spent four weeks in the hospital recovering, keeping busy with knitting, Lego and podcasts to try and distract herself from how awful she felt.

When she returned home from the hospital, Emma began to struggle, especially as her visits to the day ward became less frequent. *"I got really low. I didn't have a rhythm, and I didn't have the energy to go out and do normal things. It was winter, and it sort of all just caught up with me – the enormity of it. I'd been in fight or flight mode for so long."*

"To sit with your inner thoughts and have everything around you go quiet – it's really confronting. There has to be a level of acceptance where you come to terms with your reality, and that you might die."

During this period, Emma was admitted back into hospital five times for various complications, including a collapsed lung and fluid around her heart.

"It was during one of the returns to hospital that I met Nicki from LBC. And she met me probably at my lowest, or close to it."

Although Emma wishes she had been referred to LBC earlier in her illness, she's grateful to have the support from Nicki now. *"We have a good yarn. I can text her when I'm going to be in the day ward getting my treatment, and if she's around, she'll pop in. She's very compassionate, and she'll have suggestions, but mostly she'll listen."*

Getting hooked in with LBC's support groups was also a big relief.

“During my recovery, although it took a lot of effort for me to go to those support groups, I really prioritised it.”

"A lot of the people at the groups have gone through stem cell transplants or are about to. Plus we're on a lot of the same drugs, or have the same doctors."

Emma is now more than a year on from her stem cell transplant, and things are a lot brighter. *"I've been able to start looking after my nieces and nephews, and just feel like I'm part of things again – I can do things for other people. I'm in the gym most days and I volunteer at the Red Cross."*

On the day I spoke to Emma, she'd just been to a job interview, after two years of being too unwell to work. *"It's pretty exciting to be in a position to be looking at work again."*

And as someone who used to travel for a living, Emma is thrilled that international adventures are back on the cards. *"I had resigned myself to the fact I probably wouldn't get overseas again... But I've got a new passport, so the future is bright!"*

“He just knew I needed support”

It was a day that should have been filled with happy memories. But last year, on her son's second birthday, Tiffany's world was turned upside down.

“Tommy was really sick on his birthday,” the mum-of-four recalls. “He wouldn't move, and he had fevers that weren't coming down with Pamol. The day after his birthday, every time I picked his legs up to change his nappy, he'd scream in pain.”

Tiffany called an ambulance, and her little boy was taken to Waitākere Hospital. After tests and a transfer to Starship, Tommy received a diagnosis no parent is ever prepared for – acute lymphoblastic leukaemia (ALL).

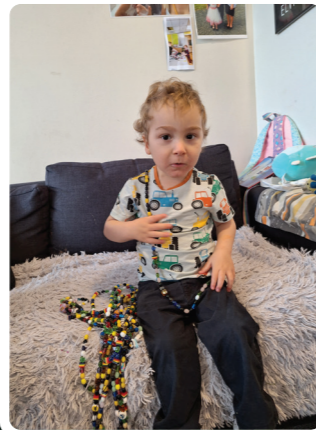
Tommy was started on intense chemotherapy straight away. Later, when the treatment caused him to lose his hair, it meant there was no escape from the reality they were living through.

“For me, that was the most upsetting bit,” Tiffany says. “When Tommy had hair, on the days he wasn't sick, you could look at him and almost forget he had cancer. But when he had no hair, it was always a visual reminder.”

When Tommy eventually finished his treatment and began maintenance chemotherapy, Tiffany felt like the worst was over. But it wasn't long until the family was thrown another curveball – this time, a serious fungal infection in Tommy's lungs. The two-year-old was back in hospital for seven weeks while the infection was brought under control. “I've never had more anxiety in my entire life than when we were waiting to see if the antifungal was working.”

Tiffany struggles with all the things Tommy is missing out on due to his weakened immune system. “We've basically been living in a cancer bubble for his whole treatment,” she says. “We can't go to playgrounds where Tommy can play with other kids. We've got to keep driving until we see a playground with nobody on it - it's sad.”

One person who has made the journey less isolating is Tim from LBC's support services team. “Tim is wonderful. He's there any time we need. He was the one that helped me through Tommy's fungal infection. There were points where he must have noticed I went quiet, and he'd reach out – he just knew I needed support.”



Tommy with his mum and sister

Tommy's sister, Charley, has also been supported by LBC. She attends Kids' Club, which is a support group for children who have a sibling or parent with blood cancer.

Tiffany has found comfort in connecting with others in LBC's

Facebook groups, and is grateful for grocery vouchers provided by LBC, which have made a difficult time more manageable.

With Tommy now back on maintenance chemo, he's due to start kindy soon – which both he and his mum are very excited about.

“I'm feeling positive. Things are back on the right track!”

Supporting life-saving cancer research



We recently spoke to Paul Owaci, recipient of the 2024 Leukaemia & Blood Cancer New Zealand and HSNZ PhD Scholarship. He told us about the exciting project he's working on at the Malaghan Institute of Medical Research, and what this could mean for blood cancer treatment in New Zealand.

What's your academic background?

I did my Bachelor of Biomedical Science, majoring in Molecular Pathology, and then my Master of Clinical Immunology – both at Victoria University of Wellington. During my Master's, I was fortunate to complete my practicum with the Malaghan Institute of Medical Research within their cancer immunotherapy programme.

How did you find out about the LBC and HSNZ PhD Scholarship?

It was a recommendation from my supervisor. There had been discussions about pursuing a PhD, but obviously, the financial aspect of this can be a big hurdle. I'm grateful for the opportunity to be supported by Leukaemia & Blood Cancer New Zealand and the Haematology Society of Australia and New Zealand (HSANZ).

Can you explain your research project to us?

My project focuses on a type of immunotherapy called CAR T-cell therapy, which is a personalised cellular treatment. Basically, the patient's own immune cells (T-cells) are taken out, genetically modified in the laboratory to identify and attack cancer cells, and then returned to the patient. The manufacturing process currently takes anywhere from two to six weeks.

The Malaghan Institute recently completed Aotearoa's first CAR T-cell clinical trial. That phase 1 trial ('ENABLE-1') showed promising safety and effectiveness for certain relapsed lymphomas. A phase 2 trial to confirm this ('ENABLE-2') has recently started. However, we know from international trials that some people's lymphomas do not respond to, or relapse after, CAR T-cell therapy, and that CAR T-cell therapy rarely works for solid cancers. One reason for this could be 'exhaustion' of CAR T-cells. My project seeks to explore alternative CAR T-cell manufacturing processes that could help reduce exhaustion, and to re-engineer CAR T-cells to knock down genes linked to exhaustion.

What difference will this make for Kiwis living with blood cancer?

Although my PhD research doesn't affect the current ENABLE-2 trial, it might contribute to our development of future CAR T-cell products. For example, we may be able to shorten the time it takes to manufacture CAR T-cells, allowing treatment of more patients and earlier treatment of patients with aggressive disease. Alternatively, we might be able to make CAR T-cells that remain fully active for longer, which could further improve CAR T-cell effectiveness for blood cancers or other conditions.

We would love you to join us on **Saturday, 21 September** as we light our lanterns and walk together to raise money for blood cancer research.

Head to shineforacure.org.nz or scan the QR code for more information.

Free to register!



shine
FOR A CURE

Together, we can light the path to a cure for blood cancer



Auckland Domain



Hagley Park, Christchurch



Or host your own event

This is for you, Dad!



"On the 9th of June 2022, after a long and brave battle, I lost my dad to follicular lymphoma – a form of blood cancer. Dad was an incredible man. He was smart, witty and he loved his life, but above all, he loved his family. His journey with cancer was tough, with many large hurdles and a few small wins. Leukaemia & Blood Cancer New Zealand were among the dedicated professionals that supported Dad and our family."

It was the tragic loss of his dad in 2022 that prompted Brad to take on the hardest physical challenge of his life. He wanted to do something that would honour his dad's memory while also raising vital funds for Leukaemia & Blood Cancer New Zealand. Brad secured his spot and began training for the Coast to Coast – a gruelling two-day multisport event that requires participants to run, cycle and kayak across the entire width of the South Island.

The training was a big commitment. In the final three months before the event, Brad spent 18 hours a week training on top of working full-time.

"The 4am starts for training sessions were made much easier because they had a purpose."

Brad's whole family got behind him in the lead-up to the competition. Someone who was with him all the way was his mum. *"Mum and Dad were inseparable,"* he says. *"It was their 42nd wedding anniversary not long after Dad passed, and they'd always just been best mates. Mum cared for Dad from start to finish. So with this journey, I sort of felt like I was doing it with her, too."*



Although it was incredibly tough at times, Brad found strength in keeping his dad front of mind. *"Knowing that I was doing it for Dad made it a lot easier – especially on race day, because there are some dark moments out there when you're sort of four or five hours into a run, and you're thinking, 'What have I done here?'. I also kept in mind that what I was going through in that moment was nothing compared to what he'd had to go through over those nine years."*

Brad had initially set a fundraising goal of \$5,000, but in the end, he was thrilled to raise more than \$9,000 for LBC.

"It's an organisation really close to my heart, and it was good to be able to give back. Mentally it helped me a lot."

"People keep telling me that Dad would be proud, and I have no doubt that they're right. This was for you, Dad!"

