



Vision to Cure. Mission to Care.

Lifeblood

The difference *you* make

AUTUMN 2024



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Introducing Tim Edmonds

In January, LBC welcomed Tim Edmonds as our new CEO. We sat down with Tim to learn a bit about where he's come from and what he's focused on as he starts this new chapter.

Tim, can you tell us about your background?

Over the past 20 years, I've worked closely with researchers and clinicians on funding solutions that help translate new ideas into community impact. This has been the common thread throughout my career.

Since returning from the UK in 2012, I've held leadership roles with health charities focused on improving child health outcomes (Cure Kids & Cure Kids Fiji) and improving patient care through innovation in the hospital and community care setting (Well Foundation).

Health charities play an incredibly important role in matching generosity with opportunities to improve patient outcomes. I've been fortunate to see that impact realised across a wide range of health challenges, including mental health, rheumatic heart disease, newborn and infant care, and cancer.

Why are you excited to join LBC?

I'm excited about the scope of impact LBC has for blood cancer patients. While meeting the immediate needs of patients through our support services, we're also making progress towards our bigger-picture goals of transforming blood cancer patient outcomes through research and advocacy.

We've got an incredibly talented and committed team and we're very fortunate to receive generous support from New Zealanders across the country. This allows us to always be focused on what more we can be doing for blood cancer patients.

Over the past year, we have supported more patients, provided more information, and funded more research than any other in our 47-year history.

But there is still so much more LBC can do for blood cancer patients. I'm excited to be part of developing these opportunities, sharing them with our supporters, and extending our impact.

You mentioned transforming blood cancer patient outcomes through research. How can LBC make this happen?

It's an exciting time for blood cancer research internationally. New Zealand researchers and clinicians make an important contribution to both the global discovery of new advancements, and bringing the benefit of new discoveries to New Zealand patients.

As the only dedicated funder of blood cancer research in New Zealand, we provide support to a wide range of potential innovations, including new diagnostics, treatments and novel therapies. We also support the careers of promising scientists and clinicians.

With the support of LBC's donors, we have provided \$6m in grants to accelerate the work of our research community on behalf of patients. Yet, every year, there are projects that have the potential to benefit blood cancer patients that go unfunded. We're focused on bridging that gap by raising the additional funds needed, and we are grateful for every dollar donated.

Looking ahead...

Firefighter Sky Tower Challenge – Saturday, 18th May

This massive annual fundraising event is the ultimate challenge for firefighters from all over Aotearoa and overseas, and this year we're celebrating its 20th anniversary! This May, more than 1100 firefighters will give it their all and climb Auckland's Sky Tower to support Kiwis living with blood cancer.

Step Up Challenge Sky Tower – Sunday, 4th August

It's not just the firefighters who can get involved! The Step Up Challenge Sky Tower is a chance for Kiwis to experience the ultimate stair climb and fundraise to make a difference.

Blood Cancer Awareness Month – September

Throughout the month of September, we'll be raising awareness around blood cancer. These are often invisible diseases – they tend to cause a range of vague symptoms that are often overlooked or misdiagnosed, so spreading awareness of the conditions is vital.

Shine for a Cure – Saturday, 21st September

In 2023, we launched an online lantern event. This year, we're taking it out into the community!

Introducing: Shine for a Cure. On 21st September, we'll be taking over Auckland Domain and Hagley Park in Christchurch with a sea of light. If you can't make it to one of the two in-person events, you're still encouraged to do your own, or even join online.

LBC will provide each participant who raises over \$100 a lantern in one of three colours: gold, representing those who are no longer with us; white, showing support for all those affected by cancer; or teal, symbolising a personal journey with cancer.

Blood Cancer Patient Forum 2024 – 27th & 28th September

Over two days in September, we'll be hosting a wonderful line-up of speakers who will cover a range of topics across the different blood cancers. The Blood Cancer Patient Forum will be held in Auckland this year and is shaping up to be another great opportunity to connect and learn!

Matched Giving Day – Thursday, 28th November

For 24 hours, all donations made to LBC's Giving Day will be matched, thanks to some amazing supporters who are matching every gift. Mark 28th November in your diary, and we'll send out more information in the next edition of Lifeblood.

If you're looking for more ways to get involved, remember that **Shave for a Cure** is now a year-round event. You can sign up to shave your head in support of Kiwis living with blood cancer at shaveforacure.co.nz.

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  www.leukaemia.org.nz

Your support funds research to help find a cure for blood cancers.



Day 97

Christchurch resident Bryan is 63 and lives with his partner Ruth. He has two grown-up children and has recently retired from running his own company in the spatial mapping industry. He's always enjoyed an active lifestyle, getting around on his bike and going for bush walks whenever possible.

A few years ago, Bryan began to notice he was slowing down a bit on his bike but didn't think anything of it. *"I just put it down to age."*

Shortly after celebrating his 60th birthday, Bryan went to his GP for a check-up.

"The doctor did a routine blood test, and something was a bit low." This abnormal result was the first real sign that anything was wrong. After 18 months of repeated blood tests and ruling out other causes, Bryan finally received a diagnosis: myelodysplastic syndrome (MDS).

He started on a chemotherapy drug called azacitidine, which worked well at getting things under control. The next stage of treatment was an allogeneic stem cell transplant. In May 2022 Bryan received the transplant, which used stem cells collected from his son. In the period that followed, everything seemed to be going smoothly – until day 97. Just three days short of the 100-day mark, Bryan's stem cell graft failed.

🌀 On day 100 you're normally safe. 🌀

Bryan was due to receive a second transplant at the end of 2022, but devastatingly, he relapsed in November and was no longer well enough to go ahead with it. *"The offer of a second transplant was taken off the table."*

In August 2023, Bryan received the life-changing news that his diagnosis had progressed from MDS to acute myeloid leukaemia (AML). *"That was when it started to take off, full steam ahead."*



He receives weekly blood transfusions to top up the blood components that his body can't produce enough of on its own. After being declined funding through Pharmac, Bryan is now self-funding a new drug called enasidenib to treat the AML.

While the medication is working at the moment, Bryan is realistic about what the future holds.

"This is certainly not a cure. It's just prolonging the inevitable."

"The leukaemia is just really racing to go, and this drug's holding it back. It sort of reminds me of the All Blacks versus South African scrum," Bryan says. "Eventually, I guess the enasidenib will be the first to move, but at the moment it's extending my life."

🌀 If things go wrong, I might only have two or three weeks. You know, they thought I might have three months, and that was probably a month ago. 🌀



Bryan with his artworks he donated to the Christchurch Hospital haematology ward.

Bryan's biggest supporter through all the challenges has been his partner, Ruth. *"She's been an absolute rock,"* he says. *"I think sometimes the journey is harder for the partner than for the patient."*

"Things like when you get chemo brain and they tell you something, and it doesn't stick, and you have to ask again and again. And with the fatigue, you know, she's just having to get up and do everything around the house."

LBC has also been there for Bryan throughout his journey. He's had one-on-one support from Helen, one of LBC's Christchurch-based Support Services Coordinators, and he attends the Blokes with Blood Cancer group, as well as an online support group for patients receiving allogeneic stem cell transplants.

He's enjoyed attending LBC events in Christchurch. *"They'll have a morning tea event and have a speaker – it might be a pharmacist, a nurse, or a psychologist. They've been good."*

Ruth has also found support through the LBC Support Person Connect Facebook page.

Throughout the difficulties of the past several years, one constant in Bryan's life has been art. *"I've been an artist since about the year 2000, mainly working with pastels."*

Over the years Bryan has entered art competitions and had his work exhibited in galleries. Following one exhibition, he had some unsold artworks sitting in his studio. Instead of letting them sit there and collect dust, Bryan had the idea of donating them to the haematology ward. He suggested it to the hospital staff. *"I said, 'Don't feel like you have to take any of them, and don't be embarrassed by taking all of them.' And they took all of them."*

Bryan's art now takes pride of place on the hospital walls. *"They hung them really nicely around the ward. They seem to be universally liked by staff and patients."*

It's a powerful way for Bryan to give back and show his appreciation for the healthcare workers who have looked after him during his journey. *"I'm always very grateful for the care that I've received,"* Bryan says.

Now that he's retired, Bryan has had more time to spend on his art. At the moment he's doing some paintings for his son. *"It's reasonably sedentary and I can do it in small goes."*

His focus now is on tying up loose ends and making things easier for his family once he's gone. He's planned and paid for his funeral and is sorting through all his belongings. Bryan laughs, *"Your kids don't want your s**t, basically!"*

Despite the enormity of what lies ahead, Bryan has held on to his sense of humour and maintains an optimistic attitude. *"I'm sort of philosophical and positive in my outlook."*

He's intent on giving back and supporting other patients who are on a similar journey. *"It's what you put into it that matters. I always support what I can – even if it just makes a difference to one person."*

When talking to Bryan for this story, it was clear he was a man passionate about life and with a deep love for his family. It's with heavy hearts we share the news that Bryan passed away on February 2, 2024, just before his 64th birthday. Our thoughts are with his partner Ruth, his whānau, and everyone who had the privilege of knowing Bryan.

The wake-up call

"I'm a classic man – I didn't really listen to my body," Nic laughs. He's at his parents' house in Geraldine, telling the story of how he came to be diagnosed with blood cancer at only 23 years old.

Nic was living in Napier at the time, getting back into work as a white water rafting guide after shoulder surgery. He'd been feeling short of breath and had a persistent cough, but put it down to a recent bout of COVID-19. When his symptoms continued, Nic went to the GP and was diagnosed with asthma.



Nic working as a rafting guide

"Then I started waking up with night sweats," Nic says. But he assumed he was just wearing too many layers in bed.

He'd also lost his appetite and his weight had plummeted to under 50kg. **"I was having one bite of anything and that was filling me up."**

The wake-up call came when Nic's boss started asking him if he was okay. Nic insisted he was just tired, but his boss could tell something was wrong. After taking a couple of days off work, Nic decided it was time to find out what was really going on.

He drove to a 24/7 clinic in Napier and was seen by a doctor who agreed his cough sounded like asthma. **"But he said, 'We'll do an X-ray – just on the off-chance it's something else.'"** As soon as the X-ray was done, Nic was pulled into the doctor's office and told to sit down.

“I said, 'Ohh jeez, I'm getting told off.' And he said, 'No, you've got cancer.'”

The doctor couldn't tell whether it was lung cancer or lymphoma, and Nic was sent to Hastings Hospital for more scans.

The next few hours brought more bad news. After finding out he had Hodgkin lymphoma, Nic was told he had fluid around his heart and a large growth in his chest. **"I had a 16 to 18-centimetre mass sitting on top of my heart and lungs, and around the main vein going to my heart. So everything was getting squashed – I had 15% function in my left lung."**

He was moved to the intensive care unit immediately and told he might not make it through the night.

“Mum and Dad were travelling from Geraldine up to Hastings to, at that stage, say goodbye – because that's what we got told.”

It's clearly hard for Nic to tell this part of his story.

"In the morning, they put a drain in, and by 11 o'clock they'd drained a litre of fluid out of me."

That same day, Nic was airlifted down to Christchurch Hospital.

After being stabilised and starting chemotherapy, Nic was able to go home. He stayed with his parents in Geraldine and continued fortnightly chemo at Timaru Hospital. At first, the treatment was effective.

"But then I relapsed in January. The cancer mass started growing again."



“The support LBC gives to people is incredible... It helps people who are going through the journey to not feel so alone.”

Following Nic's relapse, he was started on a different kind of chemotherapy, which he responded to

well. To give Nic the best possible chance, this was followed by a stem cell transplant. **"After that, I got sent home, and they said, 'See you in three months for a scan and a check-up.' And I've been in remission ever since."**

Nic is grateful for the part LBC played in his journey. Kate, a Support Services Coordinator, was a huge source of support for Nic during his treatment. **"She was my best buddy. We'd message or phone each other when treatment was happening. She'd often come to the ward and say hello. We'd just have a catch-up and she'd see how I was doing."**

As well as providing one-to-one support, LBC invited Nic to participate in support groups in his area. And he was given petrol vouchers to help with the costs of travelling back and forth from the hospital.

Nic is also grateful for the research made possible by LBC funding. **"Cancer is in everyone's lives now – it's such a common thing. Donating to LBC helps put research towards finding better treatments for people and a better chance of survival."**

Now that he's eight months on from the end of his treatment, things are getting back to normal for Nic. He still struggles with fatigue but is back at work on a casual, part-time basis.

When asked if there's anything he'd like to add, Nic says he wants to stress the importance of watching for unusual symptoms and getting regular check-ups.

His message is clear: **"Listen to your body."**



Nic having chemo

A legacy to change lives

Have you thought about the difference you could make for Kiwis like Nic by leaving a gift to LBC in your Will?

A gift in your Will, no matter what the size, paves the way for LBC to create a better future for all New Zealanders – one where nobody faces blood cancer alone, and where one day our ultimate goal of finding a cure becomes a reality.

We've recently partnered with **Gathered Here**, a trusted online Will provider, to offer access to a free online Will. Gathered Here has made it as easy as possible for people to include a gift to charity in their Will – and it won't cost a cent.

Head to lbcnz.link/giftsinwills or scan the QR code to create your free Will today. A gift to LBC, big or small, will make a real difference in the lives of Kiwis living with blood cancer.





Innovation through research



We sat down with Mariam Alhilali, the recipient of the 2023 John Waller Doctoral Scholarship, to hear about her research and what it could mean for Kiwi blood cancer patients.

What's your academic background?

I did my undergraduate degree at Otago University – I majored in microbiology and minored in genetics. I've always known that I wanted to continue and do research. I'm originally from Auckland, so I came back and did my Honours degree at the University of Auckland, also in molecular biology. Since then, I've been working at the university as a research technician, and decided it was time to do a PhD.

How did you hear about the John Waller scholarship?

It was through the research mailing list at university. I'd been thinking about doing a PhD, but obviously the financial side of things is something you really have to think about. The scholarship was exactly in my area of interest, which is blood cancers, and our lab already receives funding from LBC. So my supervisor was excited for me to apply. All the pieces came together in terms of the project, the supervisor and the scholarship. I ended up here in Professor Stefan Bohlander's lab, which is great! When I was at school and university, I always participated in fundraising for cancer charities – and it's amazing to be on the other side of that now; to see how helpful that money is and how it's being used.

What is your research about?

We're looking at a new method of detecting residual disease in patients with acute myeloid leukaemia (AML). With AML, relapse is quite common, and each successive relapse reduces the overall likelihood of survival. So it's really important for the doctor treating the patient to know how well the treatment is working, and to be able to monitor the recurrence of cancer cells afterwards. My research project focuses on developing a method to count the small amount of cancerous cells left over after treatment, which we call measurable residual disease (MRD). Currently, this is not routinely measured for most AML patients. My research project will establish a method employing next-generation sequencing for the sensitive, routine testing of MRD.

What difference will it make for patients?

By using this new method, we're expecting to be able to measure MRD in most AML patients. This should provide more prognostic accuracy when we're treating and monitoring AML.

Traditional methods of measuring MRD just aren't very sensitive – so by the time we can detect the cancer cells, treatment may be less effective. If we can detect it earlier, we're hoping it makes the patient's journey a bit easier. That's what I love about this project – I can see the direct impact it's going to have on people.

LBC is also proud to be supporting Paul Owaci, recipient of the HSANZ LBC PhD Scholarship. Paul starts his PhD this year at the Malaghan Institute.



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If you would like to get in touch:

Call: 0800 15 10 15

Email: info@leukaemia.org.nz

Visit: www.leukaemia.org.nz

Mail: PO Box 99182, Newmarket, Auckland 1149

LBC has Support Services offices in Auckland, Hamilton,

Wellington, Christchurch and Dunedin