



Vision to Cure. Mission to Care.

Lifeblood

The difference *you* make

WINTER 2022



Fundraise
Your Way

p.2

The patient
voice

p.3

You're not
going home

p.4

You *never*
think it's
blood cancer

p.6

Supporting
life - saving
research

p.8

From Peter



Brrrr – we’re certainly in the thick of winter now!

I hope that you’re keeping warm, dry, and safe wherever you are. This season can be particularly difficult for vulnerable and immunocompromised people in our communities; don’t forget to check in on your friends and whānau who may need some TLC.

Speaking of the ‘C’ in ‘TLC’ – this edition of Lifeblood is all about blood cancer **care**. We’re talking about how we can fundraise to increase cancer care, the work that LBC is doing to advocate for better treatments – and the progress we’re making with research so that we can eventually turn the word ‘care’ into ‘cure’.

I’m reminded of the importance of our work when I read stories about people like Tai, and Megan and her young son DJ. I am sure that these stories will be a moving and meaningful read for you too – after all, we wouldn’t be able to support these incredible people without the generous donations we receive from supporters like you.

Peter Fergusson
Chief Executive

Fundraise

What can you do to make a difference?

Are you a keen baker, or the local knitting hero? Are you amazing at washing cars, or is stand-up comedy more your thing? Harness those skills and put them to good use by raising money to support Kiwis living with blood cancer.

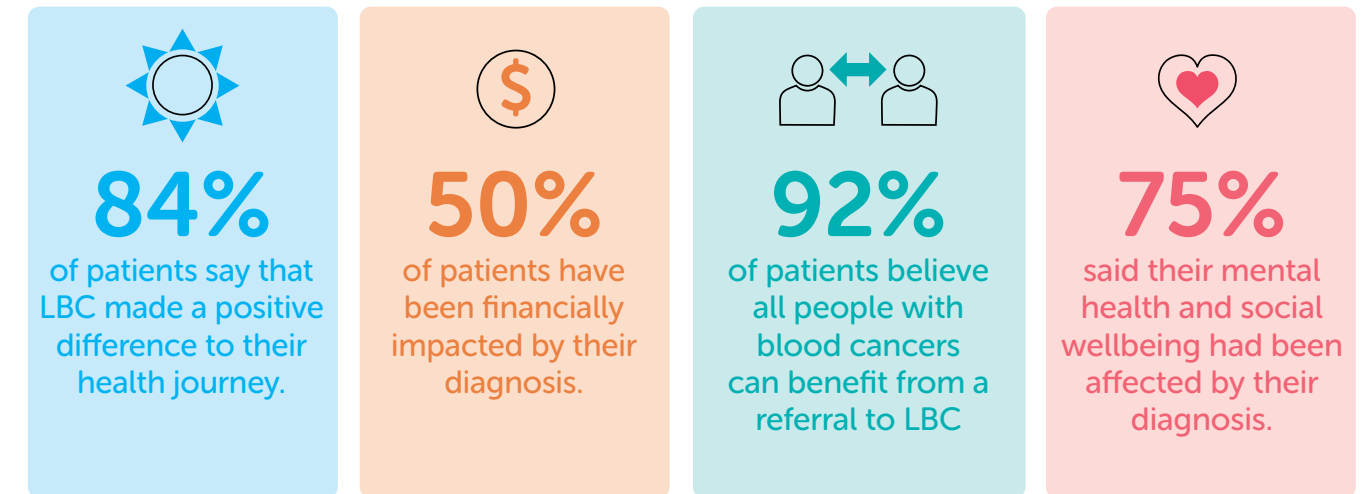
It’s now easier than ever before to fundraise for LBC – and the best part is, however you want to fundraise is totally up to you. Just visit **fundraise.leukaemia.org.nz** to get started.



The patient voice

You may be aware that LBC funds research, advocates for patient needs and raises awareness about blood cancer. But, the heart of our work is in the support and care of patients and their family/whānau.

That’s why we regularly survey our patients about the support they receive from LBC. Thanks to your generous donations, we can make a real impact on the Kiwis who need it most. Check out these results from a recent survey of LBC patients and their families.



“I know LBC are there for me if I need to talk about things. I loved that the local support person came and visited me while I was navigating my treatment. They really care.”

“Vouchers have been a big help, because parking at hospital is horrendously expensive. It’s a really supportive gesture.”

Ask the Chief Executive

Q The recent report from Te Aho o Te Kahu Cancer Control Agency, ‘Understanding the Gap’, received mixed reactions from a number of NGOs working in cancer care. What is LBC’s stance on the report?

A The report takes a much-needed look inside the funding of cancer drugs in New Zealand – and it is a small (but meaningful) win, that the Government has finally identified and accepted that there are a range of significant life-improving treatment gaps right now. LBC has advocated about this for many years.

However, a glaring failure in the report is the absence of blood cancer treatments in the validated ‘gaps’ that they did identify. This reflects a wider, international problem with the lack of a validation tool for blood cancer treatments. We’ve actively engaged and have addressed this with Te Aho o Te Kahu.

We understand that 26 blood cancer treatments fit the criteria to be considered a significant ‘gap’ – of which seven are considered curative. If this is confirmed – that would make the number of unfunded blood cancer treatments greater than that

identified for solid tumour cancers combined, in Aotearoa.

This underlines the disappointing underfunding of treatments in New Zealand. We’re working behind the scenes to address this with urgency. It requires courageous leadership from Government and Pharmac to improve, and ultimately save, the lives of many tens of thousands of New Zealanders facing their cancer journey.

Peter Fergusson
Chief Executive

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.



You're not going home, you're staying here



"You didn't really know what was going on, aye?"

Megan Aramoana says this to her 14-year-old son DJ, who is scooped under her arm on their living room couch. It's a warm afternoon, and yet DJ is wearing a hoodie.

"We spent the first night in Starship on Level 5, and then we were taken up to Level 7. DJ knew he had acute lymphoblastic leukaemia (ALL), but it wasn't until he saw the sign on the ward... he was like, 'Do I have cancer?' and his oncologist said yes."

Despite going up to Level 7, Megan felt like she was falling. Level 7 was for cancer patients. What would that mean? Would the elevator doors open to a giant black abyss? It was terrifying, but there was no other option – DJ needed treatment. "It basically cemented what was wrong. We would have to face it. It would make it real."

When Megan says 'it', she means the horrific idea that her 9-year-old son could die.

“Oh, you're not going home. You're staying here.”

"So we're on Level 7, and they show us around. They're like, so...this is where you put your food, the fridge and the kitchen are here, and you can cook in here."

"I was like, 'Why would I want to do that?' I just didn't get it. Then they go, 'Oh, you're not going home. You're staying here.'"

They didn't know it, but 'staying here' would mean that the hospital would become their second home for the next five years. School was out of the picture and it was replaced with chemotherapy, multiple relapses and transplants, seizures and surgeries.

***E kore au e ngaro, he kākano i ruia mai i Rangiaētea
I shall never be lost, for I am a seed sown from Rangiaētea***



DJ with his siblings, Megan and friend Matt

But, for everything that DJ's blood cancer took from his life – there were just as many layers of support added to it, like LBC's Tim Maifeleni who met the family early in DJ's treatment.

He facilitated a 'Monkey In My Chair' for DJ – where a soft monkey toy sat in DJ's school seat; collecting messages from DJ's classmates for him to read in hospital.

DJ's siblings also had the opportunity to get therapeutic support and meet other kids in similar situations, thanks to LBC's Kids' Club.

Megan remembers being told there was nothing left for DJ.

"They were sending him overseas for CAR T-cell therapy, but his cancer mutated and he wasn't eligible anymore. That was it. They said, 'Chemo doesn't work, we can't do radiation and he can't have immunotherapy because he had a seizure on it.'"

"There was just no more." The abyss was growing bigger by the second – and Megan couldn't see any way out. She was upset, and DJ was too. Why was this happening to their family? It didn't make any sense.

“We kinda needed space to process things on our own without feeding off each other.”



DJ climbing the Sky Tower in firefighter gear

This is when Tim from LBC stepped in. "We weren't really in a good headspace, aye?" DJ shakes his head. "So I said to Tim, 'Can you please come and get DJ?' We kinda needed space to process things on our own without feeding off each other."

Tim took DJ to the Breakers basketball team headquarters, where he met with the players and the owner, Matt, who would become another friend for DJ, like Tim had.

DJ also enjoyed having a PlayStation 4 in his room, which Tim organised as part of a bigger project on behalf of the team at LBC, who were working hard to get funding for all the kids on the ward to get PlayStations too.

Megan turns to DJ. "That was how you met Charlie, wasn't it?" Charlie was another child on the ward.

We are heartbroken to share that DJ passed away on 2 June 2022 at the age of 14. DJ touched the lives of many people; making friends wherever he could and devoting his time and talents to help others. People often commented that they would leave an interaction with him feeling grateful for their life. This is what made DJ such a remarkable young man. Our deepest condolences go to his mum Megan, his whānau and everyone who had a connection with DJ throughout his life.

"I woke up at 1 am one day and DJ wasn't in bed. And I was like, where is he? I went and looked through the window in Charlie's room and they were in there, just chatting away and playing a game." Tragically, Charlie passed away in 2019.

*"It's been a s**t journey. But, we've met some cool people and done some cool things."*

DJ is in a much better place now. He has blown away all of his nurses and doctors. It's no wonder Megan calls him her 'Lil' Warrior'.

"One year..." DJ says, with a big smile on his face, "LBC let me do the last bit of stairs of the Firefighter Sky Tower Challenge, with the full firefighter gear on; like the tank and helmet and stuff."

"Did you carry the tank?" Megan teases, "I'm pretty sure one of the firemen carried your tank. You just put it on before you came out the door in front of everyone."

"Nah!" DJ's smile turns into a toothy grin, and his mum laughs. She looks at him for a while, as if she's taking a mental snapshot of this moment to save for later.

Megan has stood by her Lil' Warrior this whole time. And, vice versa, whether lounging at home, lost in the abyss or holding hands throughout a relapse, DJ has been there for his mum too.

"It's taught our family so many things. We're all in this together."

You never think it's blood cancer

Tai Agnoletto is so in touch with nature, that if the earth had a beating heart – it would probably be in sync with her heartbeats. Each beat would rise to a tall mountain that she has climbed, and then lower to a deep glacier that she's photographed.

"I am a complete mountain and snow person, and I never knew that until I moved to Queenstown"

It was also in Queenstown, in February 2021, that Tai discovered something else about herself that would change the course of her life. After two months of back and forth between her GP, several clinics and her haematologist – she was diagnosed with Hodgkin lymphoma.

"But before that, even when I was traveling in Japan two years ago, I had cancer and I didn't even know. I'd put all the symptoms aside and say, 'hey, I'm having night sweats – but I'm just stressed at the moment.' Or, 'I'm super fatigued, but that's because I'm working 70 hour weeks"

Tai is a hard worker, and to compensate for that – she also has a lot of fun. Tai loves travelling the world, chasing auroras and being around nature. This is how she spent her early thirties.

She had no idea that deep inside, her body was fighting a serious battle and she was gravely ill.

"See, it's funny with blood cancer... you always find an explanation for your symptoms. You never think it's blood cancer, you think it's something else."

It's funny with blood cancer...you always find an explanation for your symptoms. You never think it's blood cancer, you think it's something else.

But, by now, Tai knew exactly what she was dealing with. She had accepted her diagnosis and she went head first into treatment. It wasn't easy.

"My haematologist told me that I wouldn't be able to have kids after the treatment."

This was because of the effects of the chemotherapy. She suggested to Tai that they could look into freezing her eggs, but advised caution when considering this, as it would delay the treatment by 2-3 weeks.

Tai agreed. *"I'm like, 'I'll tell you what. Things happen the way they should. If I am to be a mother, then that will happen for me, somehow. I'm not going to worry about that right now."*

It's remarkable how Tai can accept a challenging situation with grace and kindness to herself. Sometimes, she can even have a little fun with it.

"I was always visualising things. I'd look at my PICC line (the tube inserted into your skin to give medications), and I'd think, what if I was in X-Men? Like, imagine if I was a bionic human being!"

But, Tai knew that she wasn't really bionic. Like many people in her position, she needed support and when Deborah from LBC came to visit her with open arms, Tai graciously accepted her help.



I understood that my body would be rebuilding, little by little, and I'd need to be patient.

"I was like, give me everything! If I don't need something, I'll press pause, or stop. But at this stage, just throw at me whatever you have and we can go from there."

The most practical support that Tai was grateful to receive from LBC was fuel vouchers, because she was constantly driving in and out of Clyde – a town over an hour away from her home for treatment.

And LBC's support groups were the most meaningful. Tai remembers one session in particular; *"They all realised that I was still actively going through chemo and they were looking at me like I was a ghost! They said, 'Are you serious? You drove here?'; It was really funny."*

"They were like – 'look at your hair! Is that a wig?' and I said, 'No, it's my hair.'; They couldn't believe it!" Their feedback gave Tai a huge boost of confidence.

Perhaps, her motivation to get outdoors again had something to do with it.

"Throughout my whole treatment, I had a plan of the hikes that I wanted to do after finishing treatment. It would be a progression – I understood that my body would be rebuilding, little by little, and I'd need to be patient."

Tai has spent a lot of time reflecting on her cancer journey.

She's no longer going to accept 70 hour work weeks. *"If I die tomorrow, I don't want my epitaph to say, 'She was a duty manager at a hotel. I want it to say... 'She was a dreamer, she was a hiker, she was a snowboarder,'"*

She's already made her next travel plans for Iceland, and she's also looking forward to visiting her parents back home in Brazil.

"You live so much more intensely after cancer, because you really understand the meaning of the phrase, 'you never know about tomorrow.'"



Fast Facts: Hodgkin lymphoma

- 120 people are diagnosed each year
- Majority are adolescent and young adults - 15- 35 years old
- A key difference from non-Hodgkin lymphoma, is the presence of Reed-Sternberg cells (unusually large, malignant mature B-cell lymphocytes) in Hodgkin lymphoma patients



Your support provides ongoing care for people living with blood cancers.



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



Supporting life – saving research

We couldn't do this important work without your generous donations.

Your support allows LBC to invest around \$500,000 each year in haematology research, which includes \$250,000 to the Leukaemia & Blood Cancer Research Unit.

The LBC Medical & Scientific Committee meet four times each year to approve research, travel and conference grants to upskill and keep haematology professionals up to date with global research.

In the last year, LBC has funded research for:

- University of Otago, Professor Ian Morison – Genetic determinants of myeloma and its precursor in Māori and Pasifika
- University of Otago, Elizabeth Ledgerwood – Calreticulin mutations and cellular stress responses in myeloproliferative neoplasm
- The University of Auckland, Kathryn Burns – Activation of 4-hydroxycyclophosphamide within lymphocytes: an additional mechanism for the immunomodulatory behaviour of cyclophosphamide
- 2 Summer Studentship grants
- Support with CAR T-cell trials at the Malaghan Institute
- Third year of funding the John Waller PhD Scholarship
- Scholarships for AYA cancer practicums for nurses.



Ee Jin Goh

Supporting future clinicians

2021 Summer Studentship recipient Ee Jin Goh is originally from Singapore and she studies medicine at The University of Auckland.

What is the LBC Summer Studentship?

It's a grant for students involved in current haematology research. I applied for it after I heard about the KIWI Trial.

What is the 'KIWI Trial'?

It's a study to analyse the effectiveness of a chemotherapy drug called Kryprolis (Carfilzomib) for newly diagnosed and transplant-eligible multiple myeloma patients.

What was your role?

I helped make it easier to accurately analyse our results by cleaning up the raw data collected, and keying it into a system that tracks patients.

Do you think this study might influence future funding of Kryprolis in New Zealand?

I do, it's very promising as we know it induces remission early in patients. I'm interested to see the Trial with DNA PCR results, as that one may solidify what comes out of this report.

What did you get out of the grant?

I was really grateful for this opportunity. Not only did it add to my skillset as a future clinician, but having that behind-the-scenes picture of what haematology looks like and seeing real results translated into patient medicine, was pretty cool.



Vision to Cure. Mission to Care.

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