

Leukaemia Today

Supporting people *living* with leukaemia



2023 in
focus
p.2

What's *next*
for Te Aho o
Te Kahu
p.2

You're not
looking up
p.4

60 trips
since
diagnosis
p.6

Save the
Date: Patient
Forum
p.8



2023 in focus

Peter Fergusson, LBC Chief Executive

Kia ora! Welcome to Leukaemia Today.

I'm so proud of the hard work that our Support Services team has put into supporting and caring for patients and families - you will read more about that in some of the stories shared in this edition.

However, patient support is only one side of the mahi we do at LBC to make our mission to care and vision to cure, become a reality. A key part of that future vision to cure, comes from our advocacy work.

LBC is a key member of the Haematology Leadership Group that assists Te Aho o Te Kahu (Cancer Control Agency) with providing the knowledge, feedback and direction to advise the Minister of Health.

A small number of these advisory Leadership Groups exist (8 in total) however across all these, LBC is the only patient body

represented – which elevates our input, responsibility and intent to ensure that your 'voice' is heard at the highest level.

In addition, I currently chair CANGO (Cancer Alliance of Non-Government Organisations), a group of 9 collaborative cancer-focussed NGOs in New Zealand. This year, CANGO is focussed on the 2023 General Election, ensuring the concerns and needs of cancer patients are documented, heard and considered by all political parties.

We also work closely with a range of key organisations that advocate regularly - including:

- Australasian Leukaemia & Lymphoma Group (ALLG), which deals with submissions, research and clinical trials
- Haematology Society of Australia and New Zealand (HSANZ), an influential clinician led ally
- Adolescent/Young Adult Cancer Services (AYA)
- National Child Cancer Network (NCCN).

However, LBC also has a voice of its own. Already this year we have formally submitted on a number of key issues:

- Daratumumab - reviving the discussion on funding this important myeloma treatment and pleased to be working alongside Multiple Myeloma NZ to further this important cause
- Therapeutic & Natural Health Products Bill - raising our critical concerns
- Paediatric Cancer Treatment – the proposed changes to children's cancer treatment access
- A co-signatory to the CAR-T National Service Framework application.



What's next for Te Aho o Te Kahu

We sat down with Cushla Lucas, Regional Manager at Te Aho o Te Kahu (Cancer Control Agency) to talk about what the changes to Te Whatu Ora (Health New Zealand) and Te Aka Whai Ora (Māori Health Authority) mean for blood cancer patients.

Q: How have the recent health reforms affected Te Aho o Te Kahu?

Our role, as a standalone government agency, is to provide high quality advice to the Government on what the needs and priorities are for New Zealanders with cancer. We also play an important role in shaping the environment for cancer care by listening to people and whānau who experience cancer and by supporting decision makers and providers to deliver care. This role hasn't changed as part of the health reform.

In everything we do, our core values to be person-and-whānau-centred, equity-led, knowledge-driven and outcomes-focused are at the forefront. It's early days for the

reforms, but we are optimistic about the changes and recognise that the previous structure of having multiple independent providers made it complicated to address variation in healthcare across the motu, or to provide seamless care for people who have to travel for cancer treatment.

One of the significant changes has been the establishment Te Aka Whai Ora – Māori Health Authority bringing the issue of inequity in Māori cancer outcomes into the spotlight. This is a really positive step.

There is a lot more to do but we believe it's important to be focused on moving forward.

Q: What is the Te Aho o Te Kahu vision for cancer care in Aotearoa?

Te Aho o Te Kahu has a three-prong vision for New Zealand's cancer care:

1. Fewer cancers - which starts with better community health, but also includes some cancer screening activities.
2. Better survival - which is about national screening and early detection of cancers, access to more timely diagnostics and high-quality treatments.
3. Equity for all - we know that inequity exists at all stages of the cancer continuum, especially for whānau Māori.

And we know that New Zealand's health system could do more for those with cancer, and we acknowledge the advocacy of LBC and other NGOs in this space.

Q: What about blood cancer specifically? What can blood cancer patients expect?

We'd like to see people and whānau with blood cancer have better access to services and information, experience greater consistency across the system and experience better outcomes.

A key piece of work for us has been looking at cancer journeys that describe, end-to-end, an optimal pathway for people with blood cancers – covering aspects such as what does advanced care look like? Or, survival aspects? Prevention or earlier diagnosis? As well as what treatments / medications are appropriate and how to support and coordinate care across all the steps.

Better and more timely access to services is critical for people with blood cancer. For many people, this treatment may not be close to home and that's where access to the best possible support and partnerships with

groups like LBC is really important.

One key project this year has been to work closely with hospitals that provide stem cell transplants – who are facing growing demands and need to grow capacity for the future. We have supported processes for people and whānau to travel between centres, where needed, and to build business cases and models of care for the future so we can be better prepared.

Of course as part of that future, we are also aware of the CAR T-cell trials that are currently happening in Wellington. CAR T-cell therapy may be more of a standard of care overseas, but it is new for New Zealand and it's going to be an exciting time to see what next for this treatment.

So a lot is happening in the blood cancer space.

You're not looking up

After Brian's 7-year-old son Liem was diagnosed with leukaemia, Brian's life fell apart. He struggled at work. A close friend died in a motorcycle crash. His own brother passed away tragically, and even Brian had his own cancer scare. Brian's heart was starting to break and the only thing keeping it from being broken, was his drive to be a rock for Liem.

"My counsellor said, 'Your brain has all this trauma going on, and you've put it to one side because you're totally focused. You're in this glass bottom boat, paddling around, and all you can see is Liem – the fish in the ocean. You're not looking up.'"

"One day, Liem's treatment will end, he will be OK, and you'll eventually look up and see the rest of the world around you."

Brian was stuck in his "boat" for a very, very long time.

He has an online photo album titled 'Hell n back', which includes 191 photos and videos, dating from June 2020-June 2022. As Brian scrolls through the photos, you can see Liem getting sicker and sicker. There's Liem lying in hospital beds, his PICC lines, odd bruises and cuts and hair loss, among other symptoms of acute lymphoblastic leukaemia (ALL).

"I've got brain fog, so I can't remember much. That's why I've got these photos."

Brian pauses on an early photo of Liem with a nurse by his side. "I remember these nurses with purple gowns holding a bucket labelled 'TOXIC', to give chemo to Liem. I was like, 'What is going on? Chemo, for my boy?'"

"As a parent, I wanted to defend and protect my child. And then, this thing, this disease, gets him and... I was just totally helpless, I was a bystander."

Next, Brian studies a photo of Liem lying down, with his shoulders up to his ears and his chest sunken into his hospital bed. Liem is looking off to the side of the camera, with a blank stare.



"This was the hardest conversation I had with him. There were all these people in the room trying to help... the play therapist, nurses, and I was there as well. They were trying to give him Dexamethasone, which just tastes disgusting."

"Liem was just crying, getting confused, and it was all just too much. I told everyone in the room, 'Get out - everybody, GET OUT', and I said, 'Liem-'"

Brian sighs. He leans back, covers his eyes and apologises. He doesn't want to get upset, but this is a difficult memory. "I said to him, look, Liem. You've got to take these medicines. If you don't take them, you might not come home."

Thankfully, just a few photos later, Liem is sitting down with a plate of crushed up pills and a glass of water.

But in the next photo, Brian has his fingers cupped together, holding a small clump of hair, above a page of hand-written medical notes.

"This is when he started to lose his hair."

"I remember saying to the doctor one day; I think we've dodged a bullet! He hasn't lost any hair. And then one day I stood behind him, and I ran my fingers through his little hair and a big clump came out. I was like, 'Oh. S**t.'" This is when it really hit home that Liem had blood cancer.

His hair loss wasn't the only side-effect. In another photo, Liem is in a pram, even though he is clearly too big for it at his age. He looks exhausted. "The chemo affected his legs, so he couldn't walk very well."

"But you know what, he's been awesome."

Brian takes out his phone and plays a video of him talking to Liem in hospital:

'Liem, how are you feeling about all this?'

'Happy.'

'Happy? What do you mean; happy that you're sick?'

'No. I'm happy because I get presents. And being here is like being in a hotel!'

'And what about the bad things?'

'I just don't think about them.'

"I had chats like that with him a couple of times. One day he just said to me, 'I'm not worried, daddy, because you're dealing with it.'" And, Brian had a huge amount of support behind him to help him deal with it too.

"The nurses were bloody brilliant. Starship was the best place that he could be, I knew he was in good hands. And LBC was great too - LBC's picture book, Joe Has Leukaemia, was really good to help explain to Liem what happened to him, plus the Monkey In My Chair, which Tim did with his class."

"Tim was also the one who encouraged me to go see that counsellor."

"Because, people just don't get it. And it's not their fault, you know, 'End of treatment', sounds like a great name for what it is, but it doesn't mean what you think it means. They've taken away the only medicine that has kept the leukaemia away, and now we have to wait and see if it's worked. You're still watching every nosebleed, every bruise. It doesn't just mean you're cured."

"That's kinda why I got so tired of people asking 'How are you?' just because they thought that it was all over once he had finished treatment, but it wasn't. So I became a bit of a recluse, I'd get on the ferry and I'd sit right at the back, away from everyone. I didn't want to talk to anyone."

But as Brian scrolls through more photos - Liem's first day back at school, Liem winning an adversity award at his school's prizegiving, visiting the zoo as a family, modelling a shirt that details his cancer journey - you can hear the pride in his voice, and the relief that his little boy got through it.

The last photo in the album was taken in June 2022. It's been over six months, and things are better now. Brian finally has a chance to breathe and 'look up', to jump off the 'glass bottom boat' and feel stable ground underneath his feet. Liem is OK.

Fast Facts: Acute lymphoblastic leukaemia (ALL)

- Approximately 75 New Zealanders are diagnosed with ALL each year
- Majority of cases are under 5 years of age but can be in adults too. It is more common in males (68%)
- ALL is an acute leukaemia affecting immature white blood cells. It usually requires immediate treatment.

60 trips since diagnosis



Rob and friend,
Giraffe Manor, Kenya.
November 2019

"I'm one of the lucky ones; no question."

At 75, Rob has seen every corner of the world, and kept travelling even after getting diagnosed with chronic lymphocytic leukaemia (CLL). In fact, he's travelled over 60 times since then.

"I've had blood tests in Tanzania, Zanzibar, South Africa - and Canada. I've even spent 4 nights in a hospital in Alaska."

And, having spent 22 years of his life with a blood cancer, he has experienced incredible advancements in treatment and technology.

"When I was told I had CLL, the average life expectancy was 8 years. I thought, well, bugger this. I don't want to die before 60."

Rob was diagnosed on September 20 2001, the day before his partner Joan's 50th birthday the next day. *"We cancelled the party we had planned; we were too upset."*

"I heard 'leukaemia' but I didn't hear a thing"

Rob's blood type is O-Negative, which made him a universal blood donor. He had proudly donated his blood 72 times. *"But, number 72 was bizarre. I received a letter saying that I should make an appointment at what is now the Blood and Cancer Centre in Wellington. That's when I got told I had CLL."*

"I thought they'd just tell me I was low in iron or something, so I didn't think to bring Joan. I just had this shockwave through my body - I heard 'leukaemia' - but I didn't hear a thing."

Rob believes that if he hadn't donated blood, his CLL might not have been discovered so early. *"Although CLL is not hereditary, I tell my son that he should donate blood. Not only can it save lives, but it can save our life as well."*

Rob has tracked every blood test and CLL drug he has ever taken. *Over the years Rob has had FCR (Fludarabine, cyclophosphamide, and rituximab) treatment 11 times, plus 7 additional rounds of rituximab alone.*

"I started on 80mg a day of prednisone, and this was back in 2006. I was awake for 23 hours a day! This was before Netflix, so I would get DVDs of TV shows and watch them on my laptop to pass the time."

"In 2018, my current specialist, Rob Weinkove, one of New Zealand's top specialists leading the charge in CAR T-cell therapy, said that I might be eligible for a clinical trial of Venetoclax monotherapy. I looked it up overseas and it cost about \$105USD per pill. I had to take 4 a day!"

Rob is happy with his life, living with his partner Joan at home in Otaki. He's very grateful that his blood cancer journey has been managed

so well, and he hasn't lost that lust for travel!

While it currently seems impossible to get travel insurance to cover CLL (partly because the insurance companies are working on updating policies to be in line with modern maintenance treatments), Rob is confident he can get cover for his other conditions.

"I was born on the 4th of July - I couldn't be more independent, if I tried."

Fast Facts: CLL

- The most common leukaemia affecting around 300 Kiwis each year
- It affects developing B-lymphocytes and usually develops slowly, not always requiring treatment straight away
- Most patients are over 45 years.

Support for you, where you are

LBC Support Services cover every corner of Aotearoa – no matter where you are, or your situation, we can be there for you. Check out of some of the ways that our team has supported Kiwis throughout New Zealand.



"It can be wonderfully therapeutic for patients to meet other people that have gone through a similar disease process, at one of our support groups."

Annette Cody and Sharon Verrall, Northern Region



"Some people in our region travel over 4.5 hours to get to their treatment, we often send petrol vouchers to help with these journeys."

Natasha Donovan and Tim Maifeleni, Northern Region



"We facilitate bi-monthly haematology patient groups in six different towns/cities across our region."

Sean Reeves and Rochelle Mills, Midland Region



"We run 58 in-person support groups throughout the Central Region each year."

Sally Black and Nicki Roy, Central Region



"Our area covers 9 hospitals where we do in-service education to the staff."

Helen McDermott, Upper Southern Region



"Families travel from all over the South Island to Christchurch for transplants."

Kate McHardy, Upper Southern Region



"I regularly provide support to patients in 5 hospitals/ treatment centres in the lower South Island and travel approximately 20,000kms per year."

Deborah Tomlin, Lower Southern Region



"We have supported over 6,000 patients and family members all over New Zealand in the last year."

Emma Barker, Head of Support Services



Resources & Support Corner



Connect & Learn

Available online OR in-person

For adults:

Join a personalised support group and share your experiences, advice, and wellbeing tips and meet other people living with blood cancer.

Learn more at an education group with health professional speakers covering a variety of wellbeing and survivorship topics.

Get support with finding work at an Employment Workshop, designed for patients who are looking for new work, re-entering the workforce, or planning ahead due to gaps in employment.

More information for all of the above can be found at lbcnz.link/groups

For children and families:

Check out Kids' Zone for all the resources, support and programmes that LBC has to offer for children and their families affected by blood cancer.

More information: lbcnz.link/kids_zone

Get social:

Follow @LBCNZ on Facebook for updates on LBC's research, advocacy and awareness work, as well as support opportunities.

Join a closed Facebook group to connect with other patients or support people who understand the challenges of blood cancer.

Support for specific cancers and conditions

@LBCLymphoma
@LBCMyeloma
@LBCChronicLeukaemia
@LBCAcuteLeukaemia
@LBCBloodDisorders
@LBCHAemochromatosis
@LBCMPN

Support for young adults and parents

@LBCYoungAdults
@LBCParentsGroup

Further support pages

@LBCSupportPersonConnect
@LBCBereavement
@LBCNZConnect
(LBC & Health Professionals Connect)

2023

Blood Cancer Patient Forum

SAVE
THE
DATE

WELCOME EVENT

Friday 15th September
5 to 7pm

FORUM

Saturday 16th September
8.30am to 5pm



The RYDGES, Latimer Square, Christchurch



leukaemia &
blood cancer
NEW ZEALAND

Vision to Cure. Mission to Care.

Call us on: 0800 15 10 15

Email: info@leukaemia.org.nz

Visit: www.leukaemia.org.nz

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LBC has Support Services offices in Auckland, Hamilton, Wellington, Christchurch and Dunedin