

LymphomaToday

Supporting people *living* with lymphoma



2023 in
focus
p.2

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

Should
that be
there?
p.4

OK, let's
go for it
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.

S**t. Should that be there?

Ron and his wife Rachel are sitting together on the couch, while a storm rages on outside their West Auckland home. They're wearing hoodies, with Rachel in pink and Ron wearing one that is half-zipped up. His head is snug inside a beanie.

They're sitting on opposite edges of the couch, just close enough for their hands to touch - or, more likely, for someone's leg to be slapped for making a cheeky joke. That happens a lot on Ron's side of the couch. For example, when Ron describes his hair loss due to chemotherapy:

"I lost every hair on my body – legs, under arms, my bum..."

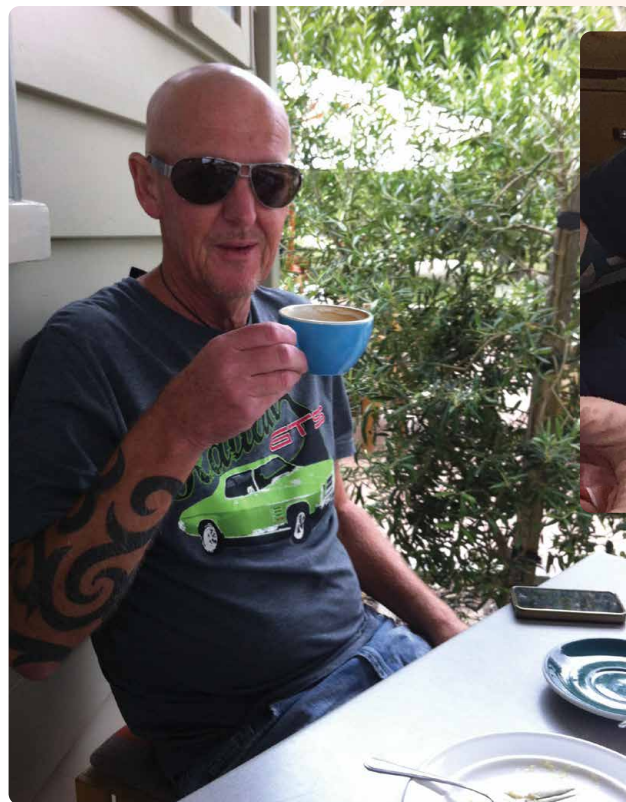
Rachel turns to him, and with a funny look on her face, she says: *"Excuse me, you don't need to go that far!"* *"What? We've all got bums!"* Ron chuckles back.

The couple have adult children - a son and a daughter, both in their 40s, as well as a 16-year-old grandson and a 2-year-old granddaughter. *"We've been together since we were 13 and 14. We've got a couple of kids who have left home."*

Between the two of them, they have worked all kinds of jobs throughout their life - from managing a fast food restaurant, to driving buses, to operating a health food company. *"I stopped working after the second cancer."*

It all started 10 years ago. Ron had been feeling slightly unwell - but he didn't think anything of it until he noticed a small bump under his arms.

*"I was in the shower, washing under my arms and I noticed a small bump. I thought, s**t. Should that be there? So I showed Rachel, and she thought I should go and see my GP."*



Ron and Rachel enjoying a day out together

They went to a private hospital, and had all kinds of tests and a biopsy done. Rachel says, *"They virtually told me to take him to Auckland hospital immediately."*

"It grew to become a 9kg mass under my arm. It split all of my skin open, and they couldn't take it away - they just said I needed to have a lot of drugs."

By now, Ron had been diagnosed with Burkitt's lymphoma and he immediately started on a journey of six months of intense treatment, in and out of hospital. Ron says, *"My kids were a massive support. My daughter did a lot of homemade cooking for me, because I couldn't eat hospital food."*

Eventually, Ron improved, and after six months post-treatment, Ron showed no sign of any cancer left in his body.

Ron says, *"At 5 years with no cancer, they say that you're pretty much cured and don't come back. But after 5 years... I got another dose of lymphoma and this time, it was Large B-cell lymphoma."*

Rachel chimes in, *"It was almost five years to the day, in fact. He had been unwell for a while, and his neck was sore. The GP treated him for different infections... but his weight was dropping off quickly. We had a private MRI, and that picked up a mass in the back of his nose and throat. Then, we were immediately back in haematology."*

The haematologist told Ron that if he didn't do something about it, he'd have roughly 6-8 weeks left to live. He could get palliative care to extend that time... or he could receive some intense chemo.

"And, he chose chemo," Rachel says, *"Thank God, he chose chemo."*

Ron thinks about it for a moment. *"Yeah. It wasn't an easy choice, but I didn't want to mess around with it. I didn't really want to die. That would be such a nuisance."*

"Yeah," Rachel smiles, *"Such a nuisance."*

☝ Thank God, he chose chemo. ☝

It was at this point that the couple met Melody from LBC on the hospital ward. Melody invited them to their first support group. *"I had to drag Ron to the first one,"* Rachel laughs, *"He really didn't want to go - but he got so much out of it that now he's the first one to ask, 'When's the next one?'"*

"Yeah," Ron says, *"It just helped me so much because I got a huge lift. Even though I felt awful, it gave me hope. And now I'm there in case someone else needs hope."*

"There's just something in here -" Ron touches his chest, and says, *"In my heart - it's something that I just feel - I've come this far, so I can help someone else and tell them what I've learned."*

Incredibly, Ron finished his treatment 2 years early. *"The consultant was like, 'I don't think we need to keep seeing you. I really think it's gone, our door is always open but let's finish early.'"*

That was over 5 years ago, and now Ron only needs to see his GP for a checkup once a year.

"Sometimes even now, I think in the shower – 'Today, am I going to find a bump that shouldn't be there?' But, I'm OK. I've got plenty of bumps. But..." Ron says with a cheeky grin, *"That's just body fat."*

Fast Facts: Burkitt's lymphoma

- Burkitt's lymphoma is a rare and very aggressive type of non-Hodgkin lymphoma, accounting for around 1% of all lymphoma diagnoses
- Approximately 15 New Zealanders are diagnosed each year
- It is more common in men and children.



Share your story ideas.
Email info@leukaemia.org.nz

Register for Blokes with Blood Cancer
group phone chat on 0800 15 10 15



OK, let's go for it



On 28 October, 25-year-old Makayla was driving home from work when she noticed her neck was swollen. Once home, Makayla noticed a lump just above her collarbone.

Makayla also had a persistent cough, but she had already been sick for a month before that - so she assumed her swollen neck was related. She went back to work the next day. *"I showed a client, who used to be a nurse, the lump, and he said I needed to get it seen straight away."*

In a few days, Makayla saw her regular GP, had an ultrasound done, confirmed that she had an abnormal mass in her neck, and had a CT scan. She was glad to get a break then, as her family went on a holiday to the West Coast.

"I was pretty sick, but I really wanted to go. We don't get to go on many holidays."

When she got back home, she saw an Ear, Nose and Throat specialist who noticed her chest was swollen too. The specialist wanted to schedule a biopsy but Makayla needed to be in Auckland for a work conference.

"Later that day, he said he could do it tomorrow. Then, miraculously, he said he could do it now! I was like oh, jeez, OK! I didn't even know what was happening, or what a biopsy was, but I said OK, let's go for it."

Makayla had the biopsy done in her neck. She was in Auckland at her work conference when she received the phone call.

"Hearing that I had Hodgkin lymphoma was emotional. I was glad that I was in Auckland and could distract myself."

"I came home and saw the haematologist who told me how serious it was, and that she didn't know how I was still going with having stage 4 Hodgkin lymphoma. I had to stop working - and that was a big shock! In the movies, people with cancer still work and do activities. But I had to isolate, and I couldn't even go to church."

Makayla also had to think about IVF, as the treatment could impact her ability to have children. She never thought this would be something she'd have to think about at 25.

Makayla found ways to cope with, and make treatment more bearable. At her chemo appointments, she asked her friends and family to vote on 'colour polls', and choose a colour she could theme her chemo visit around. So far, she's worn clothes and painted her nails orange, purple, and green, to name a few. Some people have joined in with the colour themes too.

She also had help from LBC's Deb. *"Deb sent us petrol vouchers to help me get to my appointments, and food vouchers too. She visited me in hospital when I was having one of my chemo infusions and gave us information packs to read. She's been really helpful."*

Makayla is still going through her treatment, but feels positive about where her journey is headed.

"My faith is the most important thing in my life. I've just given it all to God and said to myself, 'I know that He will be my strength when I'm weak. I have a lot of peace about it, and I'm very grateful for everyone that is helping and supporting me through this journey."

Fast Facts: Hodgkin lymphoma

- Approximately 130 New Zealanders are diagnosed each year
- It has 5 sub-types and has a special kind of cancer cell called a Reed-Sternberg cell
- It is most common in people aged 15-30.

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

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)

Available online OR in-person

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

Mail: PO Box 99182, Newmarket, Auckland 1149

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