

MyelomaToday

Supporting people *living* with myeloma



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Advocacy Update

Kia ora!

Welcome to Leukaemia Today.

As I write this Advocacy Update, we find ourselves

in the middle of a dynamic political landscape, eagerly awaiting the outcome of negotiations that will shape our new Government structure. The mix of parties, ministers and portfolios holds the key to the areas where we may find traction in the coming years.

Despite the political uncertainty, we have maintained pressure on critical areas that require change. Recently, our focus has been on championing the core aspects that were brought to the forefront during the election. These include:

- **\$300 million for fast-track assessment and funding for cancer medicines:** We advocate for the allocation of \$300 million annually to establish a fast-track assessment and funding scheme for cancer medicines within a 12-month timeframe.
- **More funding for clinical research:** We push for an increased allocation in the government's health budget dedicated to clinical research, the implementation of trials nationwide, and the incorporation of cancer research Key Performance Indicators (KPIs).

- **Fully funded National Travel Assistance scheme :** We call for the establishment of a fully funded National Travel Assistance Scheme, recognising the financial burden that patients face when seeking crucial medical care.
- **Integrated workforce plan for all cancers:** We emphasise the need for an integrated workforce plan for all cancers that is future-focused, addresses urgent needs, and ensures a holistic approach to cancer care.

We continue to hold Pharmac accountable, and are hoping to see significant improvements in the near future.

As we navigate the uncertainty of our political environment, our dedication to advocating for change remains unwavering. We'll continue to be a voice for change and won't stop pushing for the transformation needed in our healthcare system.

Ngā mihi nui,

Peter Fergusson
LBC Chief Executive

CAR T-cell therapy

In November, we were delighted to hear that the Malaghan Institute's clinical trial on CAR T-cell therapy has shown positive results in Kiwi blood cancer patients. Three months after receiving the treatment, half of the 21 lymphoma patients, who were relapsed and refractory before the trial, showed no sign of disease. After proving the safety and initial efficacy of the treatment in phase 1, a phase 2 trial planned for 2024 will look at the effectiveness of the therapy in a larger group of patients. LBC has been proud to help support the trials by contributing to travel and accommodation costs for patients and their families.

Let's Drive Change



We are calling on the new Government to make much-needed changes to the National Travel Assistance (NTA) scheme by December 2024.

Head to www.letsdrivechange.org.nz to read, sign and share an open letter to the incoming Minister of Health.

The one that got me

"We had a number of close calls. One was the Pike River Mine tragedy. I was supposed to be down the mine that Friday; the day it blew up, but it had been rescheduled. We made it through both Christchurch earthquakes. And finally, myeloma. That was the one that got me."

Barry has lived in Christchurch for the past 36 years, along with his wife, Sandra, and their three adult children. He found out he had blood cancer in 2011 – but had been suffering from symptoms for three years before that.

"I'd had a sore back. Carrying a 6kg tool bag and fire extinguishers every day was becoming difficult. So my work sent me to a physio through ACC. I had a blood test done with a new doctor, which didn't show anything, then another blood test with our original family doctor, and... I knew within 24 hours."

"We both thought it was some kind of cancer – but no one wanted to say it out loud," Sandra says. "Neither of us had heard of multiple myeloma."

Barry was initially given just days or weeks left to live. He had to start treatment straight away.

"We just kept going with more and more medication and treatment. Everything was thrown at him."

Everything, including a successful stem cell transplant, later that year. Eventually Barry made it through 2011.

Sandra took on the role of his nurse at home, and kept Barry safe from sicknesses while he was at his most vulnerable. *"I couldn't even get a cold, so Sandra kept me in absolute lockdown."*

Sandra jokes, *"I needed him to get through this, because the lawnmower hates me!"*

It's clear that staying positive and having a good sense of humour is important to the couple.

"He was OK for a couple of years before it started to rear its head again. That's when they offered him the first clinical trial."



Barry speaking at LBC's Firefighter Sky Tower Challenge dinner

The couple are grateful to the hospital staff. *"They were always amazing – particularly his specialist."*

So, we signed the paper and hoped for the best.

They're also thankful for the support they received from LBC.

"The team down here reached out to us. Kate and Helen are great," says Barry, "We attend most of their LBC support meetings. And, back in 2019, we went up to Auckland to speak at the Firefighter Sky Tower Challenge."

Barry is now in remission after another clinical trial last year. *"The trials are very full on. But there are no complaints from me if it works, or will help someone else in the future."*

"A few weeks ago I saw my haematologist in person for the first time in six months, and he couldn't believe it. He opened the door and said, 'Look at you! You'd never know anything was wrong.'"

As hard as the journey has been, the couple has managed to make the most out of life, even fitting in the Otago Rail Trail with a group of friends between remissions and treatments.

Barry also enjoys spending time at the Rolleston Men's Shed, where they call him the Energiser Bunny.

Sandra says, *"I can't see him slowing down any time soon. He's a great number eight wire man!"*

Blood Cancer Patient Forum 2023

This September we held our Blood Cancer Patient Forum 2023 in Christchurch. We were pleased to host over 200 delegates, with speakers covering 20 topics on all the different blood cancers, along with treatment updates and survivorship support. We had updates on research and CAR T-cell treatment in New Zealand, an insight into the workings of Pharmac, advice on how to navigate the online world and much, much more. We chose three of the topics from the Forum to highlight here.

Stress less with the breath



Josh Komen's workshop on breathing was a huge hit at our recent Blood Cancer Patient Forum. We asked Josh if there was one message we could pass on, and the simple message was: "THE BREATH IS BEST AND THE NOSE KNOWS!"

AND THE NOSE KNOWS!"

We start life with a single breath. This innate process happens automatically for the rest of our lives. It continues without any thought at all. However, this automated breathing pattern we adopt may not actually be the optimal way to breathe for our physical and mental health.

What if we could consciously take control of our breathing pattern? Bringing more awareness to our breath to improve our health and wellbeing, and to manage stress and anxiety.

Wow, it sounds like a wonder drug... And it's free! There is no cost whatsoever – no catch – all you need to do is take conscious awareness to your own breath.

Here's how: *Breathe a slow inhale through your nose for 2-4 seconds*
Exhale slowly through your nose for 2-6 seconds
Make the exhale slower than the inhale

Yes, your nose knows best! The human nose was designed for breathing. Nasal breathing warms, humidifies and purifies the air we breathe in. When we focus on a slower exhale than inhale, we can slow the heart rate down, and activate the parasympathetic nervous system which calms and relaxes the body. Start with this small yet powerful breathing pattern. You might want to sit in a quiet space and close your eyes so you can focus.

Why participate in clinical trials: It's not about being a guinea pig



Dr Alwyn D'Souza gave a great presentation on clinical trials – and why participating in them is not about being a guinea pig.

Clinical trials are how we learn to advance medical treatments, and Dr D'Souza would like them to be of higher importance in New Zealand.

They are used to test new management and treatment strategies, with the goal of better outcomes for patients.

Dr D'Souza explained the differences between phase 1 and 2 trials. Phase 1 involves a smaller number of patients, focusing on how to give the drug safely and what side effects occur. A phase 2 trial is larger, confirming the drug's safety and toxicity risks, and looking at how effective the new drug is, usually in comparison to standard care.

Dr D'Souza stressed that all trials have thorough patient safeguards in place, are voluntary, and participants can withdraw at any time. A physician can also withdraw a participant if it's deemed in their best interest.

Benefits of being involved were discussed. These include:

- Gaining access to novel agents or treatment combinations that might make a difference to the management of the disease.
- Participants' anonymised data is reviewed by international experts, and some patients feel reassured by the extra safety checks and monitoring.
- Knowing that your participation will help patients in the future.

Dr D'Souza finished by talking about the process of getting a trial started in the hospital and how patients get approved to participate. He reflected on how nice it is for the hospital staff and the patients to get to know each other so well during the trial process.

For more information on clinical trials, watch the full talk via the link, or scanning the QR code, below.

Many of the topics from this year's Patient Forum were recorded. To watch the videos, scan this QR code or go to lbcnz.link/forumvideos.



Living well with and beyond blood cancer



In this must-see talk from Tracy King, the concept of living well with and beyond a blood cancer was discussed through the eyes of Max – a myeloma patient.

Living well is all about quality of life. It's a subjective concept that is different for everyone, but does have some common components:

- It needs to be considered from the point of diagnosis.
- Components to consider include good nutrition, exercise and sleep. Visit the LBC website for fact sheets on these topics.
- It involves strategies for resilience – the ability to bounce back from a stressful experience and adapt to the situation without lasting consequences.

Tracy's talk encouraged patients to remind themselves what matters most to them – things like family, being social, working – and to acknowledge that they may need to relearn how to live well after a cancer diagnosis. Tracy stated that most people have developed skills throughout life that can assist with this, such as realistic goal setting and breaking a task into manageable steps.

Tracy offered practical tips on how to interact with medical teams and families, to help patients live well their way and to become an active participant in their own journey. She also recommended patients try identifying what they can and can't control and suggested some strategies to manage stress and anxiety.

To watch the full talk, please go to the link above, or scan the QR code.

I can overcome this

"Lotomau is my name, or Lotto for short. Not that I've ever won the lottery, though," Lotto laughs heartily. "I'm from Samoa, and I used to work in the telecom industry."

"When I was 15, I fell from a mango tree in Samoa. Since then, I've had problems with my hip. I needed to have a hip replacement in Samoa in 1988."

Three years later, in 1991, Lotto moved to New Zealand. When he arrived here, he looked for a job in the telecom industry. *"But New Zealand's telecoms were in the process of becoming privatised and it was hard to find work. So I got a job in the wiring industry instead... but then I was laid off after seven months."*

Struggling to find ways to make ends meet and provide for his wife and five children, Lotto looked at other options. He decided to start his own taxi business. He used the money from his redundancy package to buy a taxi, began driving and made a decent living. He eventually moved on to driving buses in 2006, after his kids had grown up.



Lotto with his wife

On the surface, things were finally looking up for Lotto.

"But I still had a hip problem. I was limping. That whole time, I was still dealing with a sore hip. I ended up going to have a check-up on it, because the joint I had from my operation in Samoa had started to wear out."

Lotto remembers vividly the day that everything changed.

"It was in 2016, and I was driving the bus – and when I started work, I was sharp as – but later that morning, I bent down to grab a coin that had fallen on the bus floor. And I felt a snap in my back. It was really painful."

Lotto tried to keep going and finish his shift – but by lunch time, he couldn't take it anymore. His back was so sore he couldn't drive. He went to his doctor, who gave him pain killers and sent him home. But by that night, he couldn't even walk. The next morning, he was in so much pain that even getting out of bed seemed impossible.

"I reached out of my bed and shook the shelf with my phone on it, so it would fall for me to pick up, and I rang 111. An ambulance came and took me to the hospital."

After three weeks of tests, the hospital doctors finally diagnosed Lotto with myeloma. *"I remember the doctors telling me about the treatment, but I told them that I needed some time to think about it. I was crying so much, I felt like that was the end of the world for me."*

“When you hear the word ‘cancer’, you just think you’re not going to live anymore.”



Lotto with Tim from LBC

"I didn't know what to do with myself. But I agreed to go with the treatment in the end."

Lotto was put on radiation treatment for a week and a half. This was followed by chemotherapy which was injected into his stomach. Finally, he was put on the waiting list to receive a stem cell transplant – which he received in 2016.

"I was really weak, and my hair started to fall out. My teeth fell out, too. I have hardly any left now. And when I was going through the blood regeneration process, I couldn't eat. I lost about 14kg. I couldn't work anymore, and I had to learn how to walk again, too."

It was hard for Lotto, who was used to working hard and keeping himself busy with projects. *"I'm not the type of person who likes to just sit around and do nothing. I'm always outside looking for things to do – painting, gardening; doing what needs to be done."*

Despite the challenges of treatment, Lotto appreciates the people who looked after him in hospital. *"Everybody, in every department – radiation, chemo – the staff were all awesome. I have no complaints!"*

Thankfully he also had support from people like Tim, from LBC, who visited Lotto at home and gave him encouragement throughout his journey. Lotto knew Tim was always available for a chat if he needed it. But Lotto is most grateful for his family.

"My wife dropped everything when she found out about my diagnosis. On the morning I first went to hospital – my son came home and I wasn't there, and hadn't left a message for him. He rang around every single hospital in Auckland until he found me."

Lotto hasn't been dealt the easiest cards in life. But he has a loving family, a roof over his head and a wife that has never left his side.

Just as importantly, Lotto has hope he can get back to living the life he wants. *"I think I can overcome this."*

Fast Facts: Myeloma

- Myeloma is a cancer of the plasma cells, which become abnormal and multiply, causing damage in the body - most commonly in the bone marrow and different bones
- Approximately 430 New Zealanders are diagnosed with myeloma each year
- The majority are over the age of 40 years old and it is more common in men.

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)

Giveaway

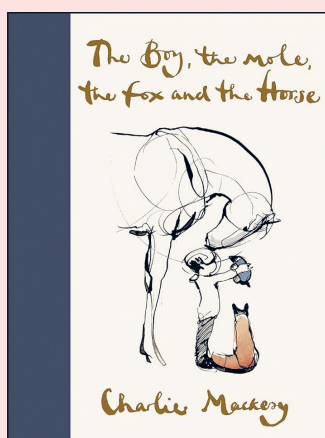
We have three copies of Charlie Mackesy's book *The Boy, the Mole, the Fox and the Horse* to give away!

In her talk at the Blood Cancer Patient Forum 2023, Tracy King recommended this powerful story of four unlikely friends who go on an adventure together and learn some important life lessons along the way.

To be in with a chance to win a copy, email us at marketing@leukaemia.org.nz with your name and top tip for getting through the tougher moments.

Winners will be selected at random and notified on December 14, 2023.

WIN!



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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