

SUMMER 2023

Leukaemia Today

Supporting people *living* with leukaemia



Advocacy
Update
p.2

A father's
fight
p.3

Blood Cancer
Patient Forum
2023
p.4

A second
chance
at life
p.6

Book
giveaway
p.8



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.

A father's fight



It's 11am on a Monday and Robert is receiving treatment for leukaemia. Hospital staff come and go as he talks about how he ended up here.

"I felt unwell for about a month. One day, I lost feeling in my hands and feet, and I felt dizzy. I rang my boss and he asked if I was well enough to finish the day, and I said yes. But towards the end of the day... he was like, 'Nah, go to the doctor.'"

Rob went to his doctor and had blood tests done. By 7pm, he received a call from an oncologist, who urged him to go to the ED as soon as possible.

"I was freaking out, and so I went to the ED, and the doctors were like, 'You have leukaemia,' and I was like, 'Huh? What is that?' They said it was cancer. I was pretty shocked."

"My sister-in-law had the same type of cancer as me – acute myeloid leukaemia (AML). And my old lady had breast cancer, so when I heard 'cancer', I just thought it was something to do with lumps in your body."

“But blood cancer isn't the type of cancer you can just chop out.”

Rob's wife was distraught. And his kids didn't really understand.

"They're all under six, so they thought – oh, Dad's just sick and he needs medicine."

Thankfully, after Rob's second round of chemo, he was told he was in remission.

Despite this good news, things are still hard. He still needs to finish two more rounds of chemotherapy, and treatment can feel incredibly isolating.

"It feels like fatherhood's been taken from me," he says. "All I want to do is be a dad. But I'm in here for four or five weeks at a time."

"My wife is so strong. She's looking after five kids by herself. And even though she lives an hour from the hospital, she still finds time to visit me. That's two hours of driving, plus wrangling the kids."

"People tell me that being here is helping everyone. But right now, I can't see or feel that. I just feel lazy and useless."

Rob is interrupted by the arrival of a haematology nurse. She asks him questions about a cut on his lip, his skin and his temperature. Then she asks him how he's doing mentally.

"Not good. I'm missing my kids. But I've got two of their birthdays this week, so I'll get to see them."

"The support here is awesome. But I'm a bit of a hard-headed person. I don't like pity," Rob laughs. "And I'm not good at asking for help."

That's why when Rob was visited by Deborah from LBC, he only wanted for his family to be supported. His wife was given petrol vouchers to aid the long drives to and from the hospital.

Putting his needs first has been a challenge for Rob. *"For the last 30 years of my life, I've been working and helping other people. This is the first time I've had to look after myself. I'm not used to it, and I don't like it,"* Rob laughs.

"This whole experience has just made me want to help people more."

Fast Facts: Acute myeloid leukaemia (AML)

- There are approximately 140 diagnoses of AML in NZ each year
- AML is an acute leukaemia that develops very quickly and requires immediate treatment
- AML is a cancer of the myeloid blood cells.

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.

A second chance at life

Josh Komen is 36 and lives in Greymouth with his wife Sibille and daughter Maja. A decade ago, at age 23, he was one of the fastest runners in New Zealand. But his body began to break down.

"I stopped running, entered a bike race... and then fell off my bike! I didn't know what was going on."

He went home, slept for a week, and developed night sweats. His doctor couldn't figure out what was wrong. It wasn't until Josh collapsed in front of his brother and was taken to the hospital that he learned he had acute myeloid leukaemia. Eight months of chemotherapy lay ahead of him.

"I didn't even know what leukaemia was, or that you could have cancer in your blood. I thought all cancers were an immediate death sentence."

Josh fell into a deep depression.

"Eventually, I got into remission, and LBC was a big support through it. Not just the financial support for fuel and parking, but also Helen was just amazing. She'd take me out for coffee, have a chat, and just be a supportive friend."

At the end of 2011, Josh reflected on what was next for him.

☞ I decided I'd achieve some of my childhood dreams, while I still could. ☹☹

Josh visited the Everest Base Camp in Nepal, and he remembers one moment in particular: watching kids playing barefoot in rubbish.

"They smiled at me with these beautiful smiles. And I thought, holy moly. I'm pretty lucky to suffer in such good conditions here in New Zealand."

"We have fantastic doctors, nurses and a good healthcare system. I had adequate food, a comfortable bed and my Mum who looked after me."



Josh with his family – wife Sibille and daughter Maja

Another dream Josh had was to skydive. *"I wanted to overcome my fear, jump out of a plane, and land on the ground. And I did, and it was the most freeing moment of my life."*

But that freedom was short-lived, because he then relapsed.

Josh always knew there was a chance the cancer could return. But he didn't expect it to be more painful the second time.

"I had even more chemo, and I slipped into a 10-day coma. My family were told I may never wake up. Thank goodness I did."

Next, Josh had an allogeneic stem cell transplant. There was only a short window in which it could happen, as his donor was a young girl in Germany. Again, he was told there was a high chance he would die. It took an entire year for his body to accept the transplant.

"I was able to fly to Germany to meet my donor. And... words weren't really enough to thank her."

"But by the time I got back, I had developed this horrific thing called trigeminal neuralgia, an extremely painful condition that affected the trigeminal nerve in my face. I was on every pain medication you could think of."



Josh breaking NZ's unofficial record for the longest time in an ice-bath

By now, it was 2017 and Josh was 28. He had developed a severe chronic graft versus host disease, or GvHD, which meant he needed to go to Melbourne for specialised treatment.

"I was so far from my friends and family, and it felt like my life had been taken away. I fell into depression again."

Josh started having frequent heart attacks, and he was flying back and forth between Melbourne and New Zealand every two months for treatment.

"One day, I was on a plane that was full apart from one seat, between me and a woman from Switzerland. We started talking, and she mentioned that she was backpacking around New Zealand and Australia."

"I asked her about her work, and she said, 'I'm an oncology cancer nurse.' I smiled, and said, 'Well I'll tell you why I'm in Australia.'"

The woman was interested in his treatment at the Peter McCallum Cancer Centre. So, as Josh calls it – his 'pick-up line' – was to ask if she wanted to come and see the Centre.

They agreed to meet at the Centre at 10am, but Josh was asked to come back three hours later. *"We spent the morning together, getting to know one another, and then went back to the Centre. Then we spent the rest of the week together."*



"That's how I met my wife, Sibbs."

"I didn't have a job, I was on the sickness benefit, living with my parents, and she moved all the way over to New Zealand for me. She got a job here, and after a couple of years, I started working too, and we bought a house together."

Josh and Sibille had their first daughter, Maja, born through IVF from a sperm sample that Josh gave when he was first diagnosed.

"Thanks to LBC, I can live life to the fullest. They played a pivotal role in my wellbeing and support. I can't speak highly enough of Helen – she did so much for me."

Now, at 36 years old, Josh isn't the fastest runner in New Zealand. He isn't travelling the world or skydiving out of planes. He's just grateful to be alive and to have his family with him.

"I've got a life I couldn't even fathom when I was 23. As you can see, I've been pretty lucky."

Fast Facts: Graft vs host disease (GvHD)

- GvHD is a side effect of an allogeneic stem cell transplant, affecting up to 80% of patients. GvHD happens when T-cells in the donated stem cells or bone marrow attack the patient's own body cells. Some GvHD may be a good thing, because it means that the new immune system is working and is likely to be attacking any remaining disease cells
- GvHD can be controlled with medication and in most acute cases it will stop
- Chronic GvHD can be severe and long term, lasting a few months or a lifetime.

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

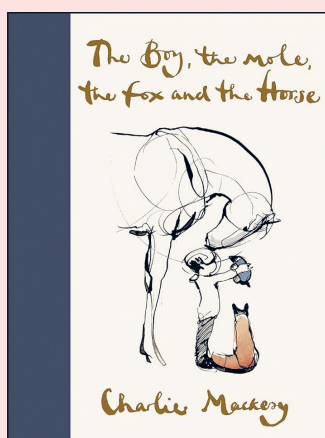
We have three copies of Charlie Mackesy's book *The Boy, the Mole, the Fox and the Horse* to give away!

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!



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