

LymphomaToday

Supporting people *living* with lymphoma



Advocacy
Update
p.2

Can we
start *this*
afternoon?
p.3

Blood Cancer
Patient Forum
2023
p.4

My
worst-case
scenario
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.

Can we start this afternoon?

Marion and her husband were both high school teachers before they retired together at the end of 2020.

"We didn't want to become sit-on-the-couch type of people, so we bought ourselves e-bikes and planned to do lots of gardening. That's why I felt so frustrated when I started to get a sore back, in late 2020... I thought I must have injured it when I was outside, so I didn't do anything about it."

The initial COVID-19 lockdowns had ended, and the couple were enjoying getting out and doing things. But back pain and fatigue started to get to Marion. *"And I often felt faint – one day, I actually did faint at a friend's house... that's when they said to me, Marion, it's time to do something about this."* By this point it had been six months of hoping things would improve and Marion agreed it was time to see her doctor.

Marion's doctor immediately reassured her. *"He said to me, 'We'll figure this out.'"*

Marion had some tests done and was referred to haematology in Dunedin. She learned that she had Follicular lymphoma, a type of non-Hodgkin lymphoma, and would need to begin treatment soon.

"I said to the haematologist, 'OK, can we start this afternoon?' and she smiled and said, 'Er, no, not this afternoon but we won't be slow about this.' Sure enough, just a few days later I was back there getting treatment."

It was there in hospital that Marion was visited by Deborah from LBC. Deborah explained some of the ways that she and the team at LBC could support her, such as providing information resources, support meetings and vouchers. Marion knew she couldn't go through this without help.



"I wasn't the sharpest at that stage, and I relied on my husband a lot. I remember thinking, 'This would be so much harder if I were alone, or if my children were small.'"

"I felt so encouraged by having my family around, and my friends... I had people who'd help clean my house, provide lovely meals, pray for me and drive me around.... I feel like one of the lucky ones."

She's also grateful to the doctors and nurses who treated her.

"I was a real person to them, not just a 'case' in hospital."

Now, thanks to them, Marion is back enjoying life. *"The biggest tumour I had has shrunk a lot,*

and they've called it 'partial remission'. It means I can live a pretty normal life. Regular infusions of rituximab are keeping the cancer under control. So I'm happy."

Marion's loved ones are thrilled for her too.

"During our first big trip on our bike after chemo, we sent a photo to our family WhatsApp group. Everyone in the chat responded with smiles and hugs, because they understood what that meant."

"I may not be as fit as I used to be, but I can do the things I want to do. I can make choices about how I spend my life again."

Fast Facts: Follicular lymphoma

- Follicular lymphoma is a type of non-Hodgkin lymphoma affecting approximately 195 New Zealanders each year
- It gets its name from the circular arrangement of lymphocytes inside the lymph nodes
- Follicular lymphoma usually grows slowly over months or years.

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.

My worst-case scenario

“Before I was diagnosed, I had no clue what lymphoma was. There’s no history of cancer in my family, and I didn’t really have any medical issues before that.”

Li’e and her husband moved from their Auckland home to Sydney in July of 2022. They had been there for less than six months when a close family friend passed away, just before the New Year, and so Li’e flew back to Auckland in January.

While in Auckland, Li’e went to the doctor to get a second opinion about a lump on her neck. She had already had it examined in Sydney, but as a Kiwi abroad, visiting the doctor was expensive.

“The doctor was pretty concerned with the lump, and they said that I shouldn’t leave the country. They referred me to a radiologist, who then did an ultrasound on it. They told me it didn’t look good – but I had to wait for the doctor to find out more.”

Li’e called her husband, who immediately booked tickets to Auckland to join her on the journey she was about to go on. Li’e was then referred to yet another specialist in Manukau, who did two biopsies, and confirmed it for her: she had Hodgkin lymphoma, stage 2.

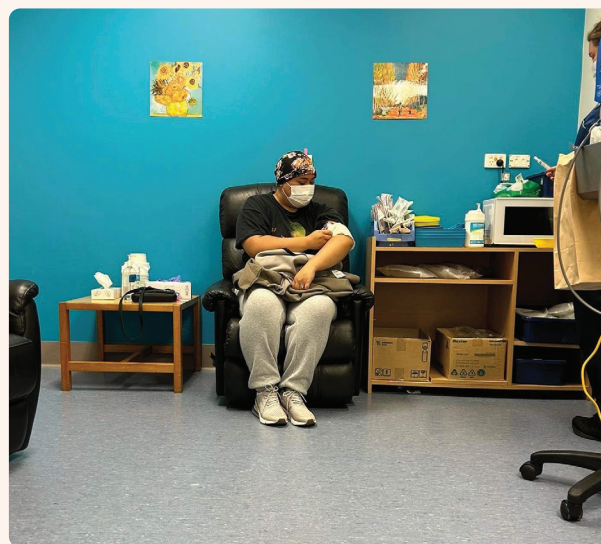


“I was with my family when I got the results. It was life changing. It definitely didn’t sit well... but I think it affected my family more than me. I was more prepared for it. I had already had this lump on my neck, plus itchy legs and night sweats.”

Li’e had tried to protect her family from worrying about her while she went through the process of being diagnosed, until she knew for sure what was going on. *“I knew it wasn’t looking good, and that was my worst-case scenario – finding out that it was cancer.”*

“We had a fair idea of what it could be... we were just hoping it wasn’t.”

Because she was only 25, Li’e was offered two options for chemotherapy. *“I could either have the treatment catered to kids, where we’d do chemo for three or four months with the hope of avoiding radiation. Or, the other option – the adult option – as I call it, was to go full steam ahead with both chemo and radiation.”*



Li’e was lost. Not only had she not heard of lymphoma before, but she wasn’t familiar with chemotherapy either; what it looked like or how it worked. *“I asked my haematologist what to do, and he thought the best option was the kids one, to avoid radiation. And in the end, that was definitely the best option for me.”*

Li’e went through four months of chemotherapy and dealt with some difficult reactions to it. *“These included neuropathy, achy joints, constipation and low white blood cells. I also had to have blood transfusions, and I ended up being hospitalised after each round of chemotherapy. Managing things at home during my treatment was hard – especially coming off steroids.”*

Li’e is grateful for the support of her husband, family and close friends. *“They’ve supported me unconditionally during one of the hardest trials I have faced.”*

Tim from LBC played a key role in helping Li’e manage, too. *“I got in contact with him. He was super helpful. He supported me and visited me in hospital, gave me petrol vouchers. Even after treatment, he was able to connect me with another girl who had Hodgkin lymphoma.”*



“That was cool because she was around my age, she was about 23 or 24 and we could talk about our experiences. Like, losing our hair – for me, that was really hard to go through and to accept that that was part of chemo. It was nice to talk to someone who understood what that was like.”

Li’e still has regular check-ups with her haematologist, and she’s happy to report that, as of recently, she’s almost all-clear from blood cancer. After moving overseas, then being forced back home due

to such a serious illness – the news that she is OK is bittersweet.

“This whole past year has been about looking after myself and just surviving through treatment. That’s all I knew. So re-learning how to go back to normal life has been interesting. Eventually, my husband and I want to return to Sydney, go back to our jobs and back to our lives.”

“My body got so drained and overwhelmed during treatment, and now that I have my energy back, I want to get back out there and bring awareness to what people like me go through with blood cancer.”

Fast Facts: Hodgkin lymphoma

- Hodgkin lymphoma makes up roughly 10% of all lymphomas with about 135 diagnosed in NZ each year
- The majority of those diagnosed are aged between 15 and 35
- Hodgkin lymphoma is the name given to lymphomas that have a special kind of cancer cell, called a Reed-Sternberg cell.

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

Giveaway

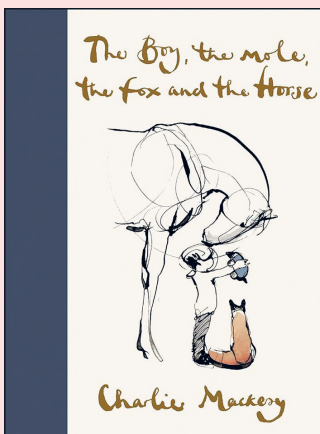
We have three copies of Charlie Mackesy's book *The Boy, the Mole, the Fox and the Horse* to give away!

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!



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