leukaemia & blood cancer
NEW ZEALAND
Vision to Cure. Mission to Care.

Lifeblood

The difference *you* make

SPRING 2023

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Kia ora

There is a popular whakataukī (Māori proverb) that I have been thinking about lately:
Mā whero, mā pango, ka oti ai te mahi - with red and black, the work will be done.

Red and black are the colours used in traditional kowhaiwhai, or Māori art, that you can see displayed in marae all over New Zealand. This whakataukī is a beautiful way of describing how we can achieve great things when we work together as a community.

And, what a community we have at LBC. There is the wonderful LBC Support Services team, who work tirelessly to support patients every day. There are the researchers, medical students and health professionals we invest in. And, our staff who are committed to advocating for patients and raising awareness.

And finally, there is you – our generous donors. Our mission to care and vision to cure wouldn't be possible without you. In other words, you are the red to our black.

Thank you so much for your support and I hope you enjoy this edition of Lifeblood.

Peter Fergusson
Chief Executive

Lighting the path toward a cure

This July, we held our first-ever Light the Night event, in which we encouraged Kiwis to fundraise at least $100 to receive a free LED-based lantern. The lantern colour options included gold, white and teal – depending on whether you were living with blood cancer, or in support or in memory of someone else.

Tim from LBC and Velvet, mum of patient Vanessa

Everyone was invited to the live-streamed event on Saturday 22 July, hosted by David Downs and joined by people from all over Aotearoa. Together, we lit our lanterns for those living with blood cancer. With lots of positive feedback, we are looking forward to next year's event already.

Ava, supporting her cousin living with leukaemia

Have *twice* the impact this Giving Day

As a valued member of our LBC whānau, chances are you're aware of the work we do to support patients, advocate for them and invest in research to find a cure. But every year, it gets harder and harder to ensure that we have the resources we need to continue doing this important work.

Please donate on or before Thursday 28 September, 2023 and your gift will be doubled thanks to some generous supporters. For every $1 donated, another $1 will be gifted to LBC.

Thursday 28 September

If you, or someone you know with blood cancer, needs support please get in touch - we are here to help.

☎ 0800 15 10 15 ✉ info@leukaemia.org.nz @LBCNZ www.leukaemia.org.nz

The ABCs of change

Advocacy is a core part of our work at LBC, and if you or a loved one is living with blood cancer – you know exactly why we must advocate for patient needs. Here are just three ways that we actively advocate for change:

A – Amplifying the patient 'voice'

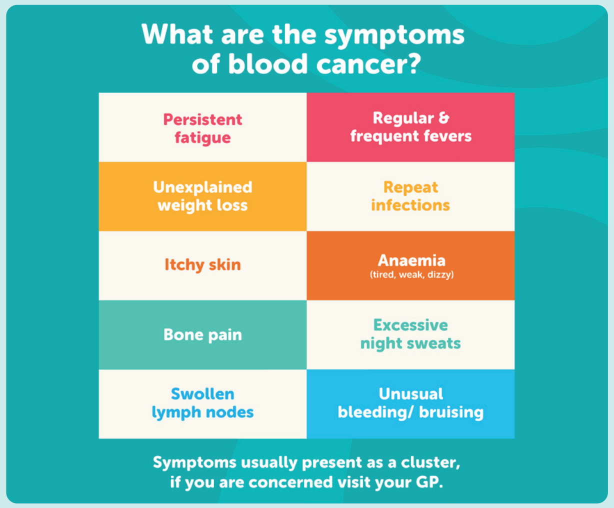
We maintain a strong presence in two key groups that directly influence government:

- We are involved with The Haematology Leadership Group, which assists Te Aho o Te Kahu (Cancer Control Agency) with knowledge, feedback and direction to advise the Minister of Health.
- Peter Fergusson, LBC CEO, is a member of CANGO (Cancer Alliance of Non-Government Organisations), a group of 9 NGOs focussed on ensuring the concerns and needs of cancer patients are heard, seen and considered by decision-makers.

Blood Cancer Awareness Month

Once again, we're joining organisations all over the world to raise awareness this September about blood cancer.

How many blood cancer signs and symptoms from the list below did you know?



What are the symptoms of blood cancer?

Persistent fatigue
Unexplained weight loss
Itchy skin
Bone pain
Swollen lymph nodes
Regular & frequent fevers
Repeat infections
Anaemia (tired, weak, dizzy)
Excessive night sweats
Unusual bleeding/ bruising

Symptoms usually present as a cluster, if you are concerned visit your GP.

B – Bringing our expertise to the table

Over 2022/2023, LBC has formally submitted on many key issues, including:

- Reviving the discussion on funding Daratumumab, an important myeloma treatment; and working alongside Multiple Myeloma NZ to continue this advocacy
- Raising critical concerns on the Therapeutic & Natural Health Products Bill
- Paediatric Cancer Treatment – commenting on the proposed changes to children's cancer treatment access to ensure our patients' needs are met
- The CAR-T National Service Framework application (as a co-signatory)
- Bone Marrow Transplant Model of Care – contributing to the development of 'A Model of Care plan for Stem Cell Transplant & Cellular Therapy (TCT) Services'.

C – Collaborating with like-minded organisations

To maximise impact, we work closely with several organisations who advocate for change in the cancer space, 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).

Your support funds research to help find a cure for blood cancers.

Is this our life now?

"I used to look after my grandparents when they were sick, and I remember receiving the news that they had cancer. So, I knew how things worked; you know, the whole – "pulling you aside" – thing. Doctors never pull you aside to tell you good news."

Tupou was at Auckland's Middlemore Hospital with her 9-year-old son Taalili, who was in the other side of the room with a play therapist. They had just rushed here after their GP urged them to go straight to the hospital, having examined a strange lump on Taalili's neck that looked serious.

And when this doctor at the hospital asked Tupou to step aside for a moment, she knew exactly what they were about to say to her. She was distraught.

*"When they said that he had blood cancer, I just broke down. The very first thing that ran through my mind was... **my son is going to die.**"*

Tupou pauses, as she struggles to find the words. *"I was heartbroken. All I remember was screaming, 'No, not my son! **Please, not my son.**'"*

But, it *was* her son. It was Taalili, the child quietly playing in the corner. The bubbly, caring, sport-loving young boy with his whole life ahead of him. He was the one who had a life-threatening blood cancer called acute lymphoblastic leukaemia (ALL).

The doctor assured Tupou that they would start treatment immediately, and that they would do everything they could to help Taalili. But, Tupou was still anxious.

This was when Tim from LBC reached out to Tupou. Tim told her about some of the ways that the family could be supported, which Tupou appreciated. And later in Taalili's journey, he would join LBC's Super Kids' Club, where he would have the chance to connect with other children with blood cancer and receive support from trained play therapists. His siblings also had the chance to join in, as coping with their brother's blood cancer was hard on them, too.

> **"Why are you all treating me like a baby?"**

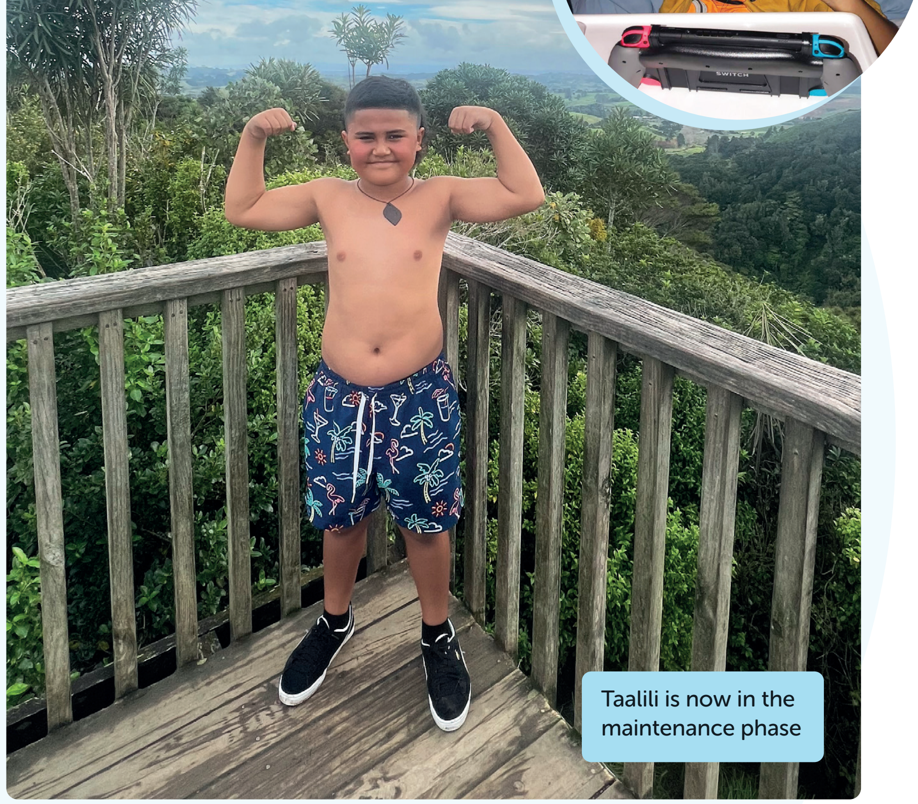
But for now, the family were just focused on getting through it.

*"Life after the diagnosis was like, **'Is this our life now?'** You see people go through cancer in movies and stuff, but when it actually hits you in real life - it's just a whole other world."*

And no one knew that world better than Taalili himself.

"Why are you all treating me like a baby?" – This is what he said to a room full of hospital staff, after being transferred to Auckland City Hospital. He was frustrated, having been poked and prodded and having had various tests done on him by well-meaning nurses and doctors.

"Ever since he first found out, he didn't want to be kept in the dark about anything. From the get-go, any news we've had throughout his journey, we've always told him in words that he can understand. Taalili has been really brave throughout this whole process."



Taalili is now in the maintenance phase

"Even when we went through hurdles, and he was going through so much pain. Even when the medication was hard to take. He kept saying to us: he's going to keep going. He knew, deep down... 'If I'm going to beat this. I have to do what I need to do.'"

Taalili's friends and whānau are all immensely proud of him. Their support helped keep his spirits high and motivated during the tough times.

"And, we met other families going through a similar blood cancer journey. It was cool to be able to relate to them, and talk to them too. Like, saying to another parent, 'Oh, Taalili was at that stage last year, too.'"

Today, she also recommends that other parents of children with blood cancer reach out to LBC for support.

Over a year and a half later, Taalili is in the maintenance phase. He has been given an estimated 'End of treatment' date, and their family are very grateful to be here.

> **He knew, deep down... *'If I'm going to beat this. I have to do what I need to do.'***

"Often, we do things, and he'll be like 'Oh man, I couldn't do this when I was in hospital.' Last year, he would have to watch his brother's rugby games online. But now, he can actually go and be there in person."

"He's even joined a Muay Thai kick-boxing group. He really wants to be active again."

Taalili has been eager to return back to school. Initially, after finishing treatment, he was allowed to go back to the regular school routine.

But, he now gets tired very easily. And, with a weakened immunity, he also often comes home from school sick.

It has been hard for the family to balance her son's social and learning needs - while also making sure he's as safe and healthy as possible.

"There's no manual for how to have a child with blood cancer. We've been learning throughout the way. Now, we're just grateful for life."

Fast Facts: ALL in children

- The most common type of leukaemia in children, accounting for 82 % of leukaemias
- Children undergo a treatment regime of at least 2 years
- 5-year survival rate is 93% **
- More common in males (on average 68% male)

**Source: National Child Cancer Network

A letter from Josh

My name is Josh Komen, I'm 36 and I live in Greymouth with my wife and daughter.

In 2011, at age 23, I was one of the fastest runners in New Zealand. But, my body started deteriorating. I stopped running and entered a bike race… and then fell off my bike! I didn't know what was going on. When I finished the race, I went home, slept for a week, and developed night sweats. My doctor couldn't figure out what was wrong.

One day, I collapsed and my brother took me to hospital. I was diagnosed with leukaemia – later, I learned it was specifically acute myeloid leukaemia. I had to go through about 7-8 months of chemotherapy.

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. It may as well have been, because when I told my family, I saw their tears, and the concern on their faces. It was killing them – and yet I was the person dying (or so I thought).

I fell into a deep depression. I even contemplated taking my life.

It took a lot of work, but I saw a counsellor and learned some good coping mechanisms. Eventually, I got into remission. LBC was a big support through it all. 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, I left the hospital and reflected on my life. I went back home, read books, visited the beach, went on walks and I thought a lot about my purpose.

I fell into a deep depression.

I decided I'd achieve some of my childhood dreams, while I still could, like visiting the Everest Base Camp in Nepal. I remember seeing these kids in Nepal; some naked, some only wearing jocks, 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.

Josh with his family – wife Sibille and daughter Maja

We have fantastic doctors, nurses and a good healthcare system. I had adequate food, a comfortable bed and my Mum who looked after me. So, how could I have wanted to take my life?

I watched the sunrise over Mount Everest, which was a special moment in my life. It's like when you're going through a hard time… perhaps you feel like you have a 'mountain to climb'. But, when you reach the top, and you see that beautiful view, that sunrise… that's the good in life.

Another dream I had was to skydive. I wanted to overcome my fear, jump out of a plane, and land on the ground with my own two feet. And I did, and it was the most freeing moment of my life. But it was short-lived because then I relapsed.

Mentally, I was OK as I was prepared; I knew there was a chance the cancer would come back. But this was more painful. I had even more chemo, and I even slipped into a 10-day coma. My family were told I may never wake up. Thank goodness I did.

Next, I had my allogenic stem cell transplant. There was a short window in which it needed to happen, because my donor was a young girl in Germany. Again, I was told there was a high chance I would die. It took an entire year for my body to accept the transplant.

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

My family were told I may never wake up.

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.

By now, it was 2017 and I was 28. I had developed a very severe chronic graft versus host disease, or GvHD, which meant I needed to go to Melbourne for specialised treatment. It took 5 years, and it was horrendous.

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

I started having these frequent heart attacks, and I ended up going to the Peter McCallum Cancer Centre in Melbourne, and then a hospital over there. I was flying back and forth between Melbourne and New Zealand every 2 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 I said, 'Well I'll tell you why I'm in Australia.'

Naturally, she was interested in my treatment at the Peter McCallum Cancer Centre. So, this was my pick-up line – I asked if she wanted to come and see it.

We agreed to meet. I thought she was just being nice, but she actually showed up! So, we went there at 10am – and, never before had they been delayed – but this time, they asked us to come back at 1pm.

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, Sibs.

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. We had our daughter, Maja, who is 1 now. She was born through IVF, from a sperm sample I gave 11 years ago when I was first diagnosed.

Thanks to organisations like LBC, I can live my life to the fullest. You guys have played a pivotal role in my wellbeing, and my support. I can't speak highly enough of Helen – she did so much for me with what she had.

And now, 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: AML

- Approx. 130 Kiwis are diagnosed with AML each year
- Most are over 45 with slightly more men than women affected
- AML is the most common acute leukaemia in adults
- Treatment is required immediately

Celebrating 10 years of the Leukaemia & Blood Cancer Research Unit (LBCRU)

This year, we're pleased to celebrate the 10th anniversary of the Leukaemia & Blood Cancer Research Unit (LBCRU), a leading haematology research unit in the Faculty of Medical & Health Sciences in Waipapa Taumata Rau | The University of Auckland.

The LBCRU was first opened in 2013, as a collaboration between LBC and Waipapa Taumata Rau | The University of Auckland to support innovative blood cancer research to improve patient outcomes.

The University of Marburg's Professor Stefan Bohlander joined Dr Peter Browett, Professor of Pathology at Waipapa Taumata Rau | The University of Auckland and Leukaemia & Blood Cancer (LBC) Medical Director as co-directors of the LBCRU – positions that they still hold today.

LBC has now contributed over $3 million toward the LBCRU's research on a highly personalised approach to blood cancer treatment – finding specific genetic mutations in a patient's blood cancer that would result in improved treatments and outcomes for that patient.

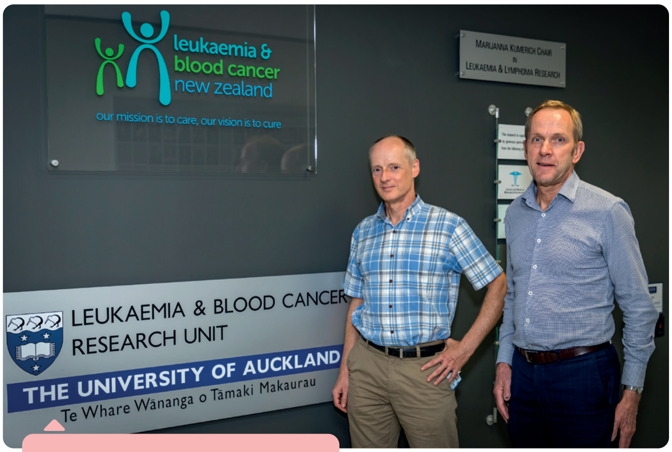
Since then, LBC has continued funding toward the LBCRU every year and the unit has continued to make great progress and strides.

In 2019, blood cancer patients had only 3 genes out of a total of 22,000 routinely tested at Auckland City Hospital, and about 50-60% had to be treated the same way.

But by 2023, thanks in part to the LBCRU, blood cancer patients can now have 111 genes tested. Leukaemia cells of every single acute myeloid leukaemia patient are now analysed at Auckland City Hospital. No two patients have been found with the same pattern of mutation.

In about 20% of cases, clinicians have changed their treatment approach for AML patients as a result – sometimes avoiding the need for a stem cell transplant.

These tests are now being made available throughout New Zealand. We look forward to what the next decade will bring and the potential for further advances in personalised haematology research.



LBCRU Co-directors Professor Stefan Bohlander and Dr Peter Browett

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