



leukaemia &
blood cancer
NEW ZEALAND

Vision to Cure. Mission to Care.

Lifeblood

The difference *you* make

WINTER 2023



Be in to
WIN
p.2

The
Heartbeat
of LBC
p.3

The *voice*
for patients
p.4

Finding *joy*
and meaning
p.6

Investing
in *future*
clinicians
p.8

Kia ora



Welcome to your Winter 2023 edition of Lifeblood.

This edition is chocka! It's incredible to see all of the activity that we're doing listed together on the opposite page - 'The Heartbeat of LBC'. It's a busy year for the team but it's absolutely worth it. We love supporting patients.

Speaking of heart, I feel very touched by Jacky's story. As a father myself, I know how special it is to have a close relationship with your child - especially when you're going through a tough time.

It's easy to take these relationships for granted, so this is a great reminder to keep your family close. I encourage you to go and hug someone that you love today.

And, think of this message from me as a 'verbal hug' itself. Because, thanks to you and your generous donations, we're able to go above and beyond with supporting patients. Your help is so needed, and appreciated.

Peter Fergusson
Chief Executive

Be in to WIN

We're giving away 5 packs of fundraising goodies!

Simply complete the word search below, take a photo of it, and email it to marketing@leukaemia.org.nz OR send the photo to us as a message on Facebook to go in the draw.

Please enter the competition before Monday 31 July 2023.

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BLOOD CANCER SUPPORT	HELP EDUCATION ADVOCACY	EQUITY RESEARCH GENEROSITY
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The Heartbeat of LBC

Check out what is coming up at LBC for the rest of the year.

JUNE

- World Blood Donor Day**
14 June 2023
- Winter Workshop Auckland**
15 June 2023
- Winter Workshop Christchurch**
22 June 2023
- Winter Workshop Hamilton**
29 June 2023
- Winter Workshop Wellington**
6 July 2023
- Light the Night (just announced)**
22 July 2023

JULY

- 10th Anniversary of Leukaemia & Blood Cancer Research Unit** 26 July 2023
- Winter Workshop Palmerston North**
27 July 2023
- Winter Appeal**
July

AUGUST

- Winter Workshop Dunedin**
3 August 2023
- Step Up Challenge Sky Tower**
6 August 2023
- Blood Cancer Patient Forum**
Welcome event: 15 September 2023
- Blood Cancer Patient Forum**
Main event: 16 September 2023
- Giving Day**
28 September 2023
- Blood Cancer Awareness Month**
September (all month)
- Lifeblood Spring Edition**
September

SEPTEMBER

- Giving Tuesday**
27 November 2023
- Bridgestone Drive for a Cure**
November (all month)
- Christmas Appeal**
November

NOVEMBER

- Grief Awareness Week**
4 December 2023

DECEMBER

Our highlights from 2023 so far...



**Just Announced:
Light the Night**

Show your support for blood cancer patients. Sign up today:

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](https://www.facebook.com/LBCNZ) | www.leukaemia.org.nz

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



The voice for patients

The LBC Consumer Advisory Board (CAB) play a crucial role in advising LBC from a blood cancer patient's or caregiver's perspective.

This year, we farewell several of our original members who have been with the CAB since it was created in 2017. Please join us in wishing them well and read on to hear about how they have helped shape LBC today.

Maree Fredericksen

Maree is a support person for her husband who has lymphoma. He has been on 'watch and wait' for 9 years. *"I've valued the opportunity to participate in CAB. I think that by bringing together LBC's dedicated team, and the experience of patients, we have broadened and improved how LBC supports the blood cancer community."*

Maree found that coming up with ideas for LBC's Blood Cancer Patient Forum was very rewarding and she is impressed with how LBC has managed to strengthen their online services recently.

"The goal with CAB has been to bring the best possible service to those affected by blood cancer, and I think it has been a great success – it can only get better from here. I wish everyone the very best and thank you, LBC, for giving me the opportunity to share and participate."

Naomi McRae

Naomi is a Hodgkin lymphoma survivor, who is passionate about using her professional skills to help support current and future blood cancer patients. Outside of CAB, she leads the charitable arm of PwC (PwC Foundation).

"Being a part of CAB has been eye-opening. I've had real insight into the challenges LBC faces and I've enjoyed giving my recommendations to help continue to improve and develop resources for future blood cancer warriors."

Naomi is particularly proud of the 'Work it Out' employment programme that she co-designed and rolled out nationally to blood cancer patients to help them gain a better understanding of their employment rights and responsibilities while undergoing treatment.

"I'm delighted to be able to continue supporting LBC through my recent appointment to LBC's Board of Trustees. Thank you for the opportunity to give back to the blood cancer community."

"The connection and friendships that I have made with my fellow CAB members will stay with me for life. It has been a privilege to serve alongside them."

- Fatumata Bah



Eric Neary

"I was encouraged by my late wife Debbie to join CAB as a 'carer' representative when approached by LBC in early 2017. We'd been involved with LBC since early 2011 when Debbie was first diagnosed with blood cancer and we both agreed that if I joined CAB, we could give back something constructive to LBC and blood cancer patients."

Eric has felt delighted to represent carers in his role in the CAB over the last six years. He has particularly enjoyed how LBC has grown over this time, from expanding their support services team throughout Aotearoa, to increasing their blood cancer patient advocacy.

"Another great achievement has been LBC's Blood Cancer Patient Forum, and the quality of speakers and varied subjects that are presented. They're well worth attending!"

Karen Ell

Karen is a proud Cantabrian who was diagnosed seven years ago with Burkitt's lymphoma.

Eternally grateful for the outstanding medical team and regular support from LBC during her hospital journey, Karen was eager to help others by paying it forward – as soon as the brain fog cleared! Karen immediately agreed to join CAB once the initiative was created.

Throughout her time with LBC, Karen sought to raise awareness about the importance of holistic wellbeing and accessibility to resources. She also mentored a cancer patient with free monthly on-demand career coaching for a year. (Karen has a Graduate Diploma in Career Development and several years of experience as a Career Consultant.)

"It's been a privilege to be involved with LBC and the inspiring CAB members."

Fatumata Bah

During her last two years of university, Fatumata was very unwell with sickle cell disease. *"I received a lot of support from LBC during this time. And this support enabled me to push through and finish my studies. Joining CAB was an opportunity for me to give back to LBC."*

Fatumata has especially enjoyed contributing to LBC's Blood Cancer Patient Forum, and meeting other patients and their carers.

We also thank Sally Xu who finished her term with the CAB in 2022. And, we are grateful for current members Matt Smith, Raewyn Moss, Ian Scott, Ian Laban and Mile Nafatali for their continued service.

*Me mahi tahi tatou mo te oranga o te katoa.
We work together for the wellbeing of everyone.*

Finding joy and meaning

Jacky's diagnosis came out of the blue in 2010. Health problems were nothing new as Jacky and her son, Zak, both developed myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) in 2000 after a bad bout of influenza. This resulted in Zak being home schooled. At the start of what was Zak's last year of schooling he took up guitar and they incorporated music into his curriculum.

Jacky was never bothered by the loud music that filled the house. On the contrary, their shared love of music helped form their unbreakable bond, especially as Jacky's husband had passed away four years earlier.

In August 2010 Jacky took Zak to a guitar festival in New Plymouth. With so many big names performing it was hard to resist. However, while in Taranaki Jacky began to feel a bit unwell with a lot more fatigue than she was used to. The exhaustion continued when she returned back home to Dunedin, and she decided to have it checked out.

"I went off to the doctor and they did a blood test. It came back showing an anomaly. The lab picked up the shape of my red blood cells, which is what tipped them off. It was quite serendipitous, if a cancer diagnosis can be described by that."

After a JAK2 gene test which was positive and a bone marrow biopsy they told Jacky that she had primary myelofibrosis – a rare type of blood cancer where too many abnormal blood cells are produced and scar tissue forms in the bone marrow.

Her son was by her side when she got her initial blood test back.

"I continued to be upfront with him because I'd rather he knew what was going on. But I was really worried at the beginning, because when I asked the haematologist what my prognosis was, he said 'Five years plus.' That was scary!"



Subsequently another haematologist calculated her prognosis at around eleven years which has extended further after a two year drug trial. This was a more hopeful scenario for Jacky and her son.

Ironically the fatigue that had been problematic in New Plymouth dissipated after a few weeks, but within a few months Jacky's spleen became enlarged and she began treatment with hydroxyurea. Luckily she had few of the possible side effects, and the plus was that it alleviated the severity of her ME/CFS symptoms.

Thankfully, Jacky has received unwavering care and support from her Zak, who remains a constant source of strength throughout her journey. Their shared passion for music has proven to be a powerful force, allowing Jacky to embrace life to the fullest. They have had lots of adventures travelling around New Zealand on holidays and attending rock concerts. *"He's my best buddy. He takes over the lounge a couple of nights a week with his friends and the band strikes up. Some of his friends call me mum, which is really nice. I like having lots of young people around the house. I think it's good for me."*

Despite the fear and uncertainty that accompanied her diagnosis, Jacky remained determined to make the most of the time she had left. By 2014 she felt well enough



"I felt like an orphan. There was no one else to talk to."

to get out in the community with more people again. To that end she enrolled in an Age Concern tai chi class. It was not long before she was hooked and by 2016 she had become a certified tutor and was teaching a class of her own each week. Along with the health benefits of tai chi came finding some new friends who shared her interests.

Although life was good, after about eight years Jacky realised in some ways it was a very lonely life.

"I felt like an orphan. There was no one else to talk to. Nobody else had what I had. Even now, I've come across very few people in New Zealand with it."

At first she found some Facebook groups. There were still not too many people like her but she did learn more about myeloproliferative diseases and the need to be your own advocate. Then in 2019 she also joined the LBC patient support group

Through LBC, Jacky was put in touch with Deborah from the LBC Support Services team. Deborah offered a listening ear, practical help, and reassurance.

"Deborah's always there if I need someone to talk to," Jacky says. *"It's nice to have people who understand, and I like how all the correspondence comes addressed to me and my son, as he's my support person. It's a really nice touch."*

"I just love what LBC has done for us. We have regular lunches, we've done art therapy, and a jewellery class. It's just little things that help to give you another outlook on life."

It didn't take long before Deborah discovered that Jacky was a tai chi teacher and approached her to run a class for LBC in Dunedin. Jacky was happy to do so as a way of giving back to the organisation that does so much for its members. The class is now into its third year.

"It was a great way to get to know other members. And, it made the other activities more enjoyable as I wasn't completely alone there."

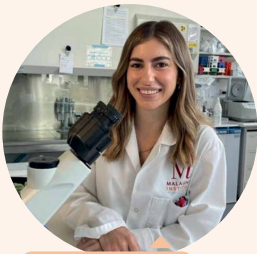
It's been 12 years since Jacky was told she might only have five years left to live. And although her future remains uncertain, changing to interferon treatment in 2019 has kept things very stable and she continues to find new things that bring her joy and meaning.

"I've got a really nice group of friends. We go to music concerts, we can go to the movies, we meet up and do crafts and things. I've never actually had a social life like that before. So, life's pretty perfect, at the moment"



Fast Facts: Myelofibrosis (MF)

- Approximately 55 people are diagnosed with MF each year in New Zealand
- MF is where abnormal cells in the bone marrow cause scarring, also known as fibrosis
- The most common gene that is affected in MF is called JAK2.



Yasmin Nouri

Investing in future clinicians



We sat down with Yasmin Nouri, our 2020 John Waller doctoral scholarship recipient to hear about what's next for this bright young professional.

What is your academic background?

In Wellington I did a biomedical science degree specialising in genetics. Then I did my Masters in Dunedin, which involved cancer genetics, and that's when I fell in love with cancer research. I received the John Waller scholarship after applying for my PhD.

How did you hear about the John Waller scholarship?

First, I heard about a clinical trial at the Malaghan Institute of Medical Research which sounded amazing, so I talked to Rob Weinkove and Graham Le Gros and decided to join - the best decision I ever made!

I moved back to Wellington to work on the trial and start my PhD. But I had another problem. Doing a PhD can be financially difficult. Rob told me about the John Waller scholarship, and the timing was perfect, so I applied and I was successful.

I couldn't have done my PhD without the scholarship. It's been so helpful.

What did the scholarship allow you to do with your studies?

My project was focussed on CAR T-cell therapy – the overarching question was, *How does CAR T-cell therapy work?* CAR T-cell therapy stands for Chimeric Antigen Receptor T-cell therapy which is a treatment that aims to redirect a patient's own T-cells (their immune cells) to target and kill cancer cells in the body. We knew that it does work, but not exactly how. I did this alongside the clinical trial so it was a really exciting time.

How do your studies translate in the real world to blood cancer research?

We know that chemotherapy works for a lot of people – but for many people it doesn't, and it also causes really awful side effects for many patients. There's been a big movement for gentler treatments, and that's where CAR T-cell therapy comes in.

CAR T-cell therapy has minimal side effects, it's really targeted and it improves your immune system so that it can continue to keep the cancer away in the future. It's a pretty incredible treatment and it's been working well overseas for over 10 years, but it's taken longer to get to New Zealand. The Malaghan Institute's main goal is to get it more accessible in Aotearoa and we're almost there – which is great for Kiwi blood cancer patients.

“The results are really promising.”

What's next for you?

I love research and I think CAR T-cell therapy has so much potential, so the Malaghan Institute has funded me to come to Australia and continue developing my knowledge at Melbourne University for the next 2-3 years.

Will you be coming back to New Zealand?

Absolutely! Once I'm done studying here, I will come back to New Zealand, and back to the Malaghan Institute to bring everything I have learned and continue my cancer research in Aotearoa.



Vision to Cure. Mission to Care.

If you would like to get in touch:

Call: 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