

Lifeblood

The difference *you* make

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From Peter

Let's take a breath – what a whirlwind of a year we've had so far. I know most of you are still dealing with the effects of the recent lockdown levels. I hope you're hanging in there.

LBC's Support Services team has done an amazing job of staying connected with patients during the various challenges of alert level restrictions. Our Blood Cancer Patient Forum still went ahead as an online version and was a real highlight. Shave for a Cure is up next.

I'd like to sincerely thank you for your continued support, as you help us touch the lives of Kiwis living with blood cancer. Even in these uncertain times, a virtual forum, digital hug, or a check-in phone call goes a long way.

Peter

Peter Fergusson
Chief Executive
Leukaemia & Blood Cancer New Zealand

Amazing Fundraising!

A warm thank you and ngā mihi to all our fundraising superstars! Whether you're shaving, cycling, bowling, or supporting LBC with a donation – your support makes a huge difference.

Thank you to...

- Blenheim Bowling Club for their annual tournament in memory of Kevin Gallop.
- Freddie Gillies, Arthur Gillies and Sean Wakely who recently published a photo book about their worldwide bicycle trip in support of LBC.
- Everyone who has stepped up or Shaved for a Cure this year!



The show must go on

Entering lockdown without warning was hard for many Kiwis, especially patients and their families. With only two weeks until our Blood Cancer Patient Forum in Christchurch, it was critical that we responded quickly to ensure we were able to still provide this event via an online platform.

Friday's Welcome event with David Downs was an instant hit. We were pleased to also be joined by members from LBC's Consumer Advisory Board. The group's charming humour and the messages of hope were a much-appreciated ray of sunshine in lockdown.



On Saturday, we presented 20 talks from experts across Aotearoa. This included disease and treatment updates, plus Dr Robert Weinkove's talk on Haematology and the COVID landscape. We also had a range of talks about living optimally with a blood cancer – from managing late effects to tips on increasing energy levels.



You can watch the recorded talks on YouTube at lbcnz.link/bcpf_videos

Some of the highlights included:

- Professor Peter Browett and Professor Ian Morison – Genes, Genetics & Familial Blood Cancers
- Dr Richard Doocey – Navigating Access to Unfunded Drugs
- Dr Graeme Kidd – Self-empowerment and living well with blood cancer
- Dr Myra Ruka – Updates and Activities at Te Aho o Te Kahu, the Cancer Control Agency

We want to thank the ANZ Staff Foundation for their support, which ensured the Forum went ahead.



A Problem Shared...

Q I'm struggling to get a good night's sleep since being diagnosed and starting treatment. What can I do?

A Receiving a blood cancer or blood condition diagnosis can be very traumatic and emotionally distressing. Pain, anxiety, side effects of treatment, as well as routine and lifestyle changes can all lead to poor sleep.

It can occasionally develop into insomnia. The term 'insomnia' is usually used when specific sleep problems last longer than a month. These problems include difficulty falling asleep, being wakeful in the night and waking early.

We recommend you practise good 'sleep hygiene'. This refers to a variety of things you can do to support better quality sleep. Some practical recommendations include:

- Create a relaxing routine prior to bedtime and ensure your bedroom is dark, quiet and the temperature is cool.

- Avoid watching TV, or using a computer or mobile device before bed as exposure to blue light can stimulate your brain activity and make it hard to switch off.
- Establish a regular bedtime and get-up schedule.
- Don't nap for more than 30 minutes during the day, and avoid napping late in the afternoon or evening. Use an alarm to wake you if necessary.
- Where possible, try to get out in the fresh air and get some exercise during the day.

- Avoid caffeine and alcohol close to bedtime.

For more information and tips, download our Sleep factsheet at lbcnz.link/sleep

Deborah Tomlin, Senior Support Services Coordinator Southern Region, is a registered nurse originally from the UK. Deb ensures she is there for blood cancer patients going through difficult times and can often be seen travelling in her LBC car around the Southern Region.



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

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



Where flowers bloom, so does hope

Five years ago, on her daily bike ride to work as an ESOL literacy tutor, Celia Hope felt a throbbing discomfort in her abdomen. She didn't take too much notice of the pain; she was fit from cycling for many years.

But over the following weeks, she experienced dizziness and bloating when she ate.

"I couldn't eat much at mealtime. I was so uncomfortable I told my husband, Tim: 'something isn't quite right; I think I need to get this looked at.'"

After Christmas, her GP ran blood tests and sent her for an ultrasound which picked up the enlargement of her spleen and liver. From there, she was referred to haematology and had a CT scan and bone marrow biopsy.

"Within a month, I was diagnosed with splenic marginal zone lymphoma (SMZL). It's a mouthful."

SMZL can be very difficult to diagnose as it's rare (accounting for roughly 1% of non-Hodgkin's lymphoma cases) and it can look like other types of lymphoma.

"That was a shock. It was difficult, because my mother's health was deteriorating, and she passed away within a couple of days of my diagnosis. A double whammy."

After immunotherapy treatment, the haematologist told Celia she was in remission. She spent the next year in relatively good health.

"In 2018 I felt really good. It was coming up to my 60th birthday, and I thought, I want to do something significant. I did a fundraiser for LBC! My plan was to cycle, cumulatively, 600km over the month of October, and raise \$2,000."



Kowhai flowers on the first 'Tree of Hope' planted by Celia in her local park on the anniversary of Tim passing away.

"Tim believed I would get through it, he was there to support me and would often leave me little encouraging notes."

One of the hardest parts of her treatment was that she couldn't join Tim for the bike rides they loved so much. "He'd pick flowers out on his rides and bring them home for me."

Flowers were part of a tradition between Celia and Tim, who met on a bicycle tour across Canada in 1997 – back then, Tim helped Celia decorate her bike with daisies he had picked.

"He's amazing. He was always there when I had the infusions. Once we got into lockdown, he couldn't come anymore, but he was always there to pick me up - in both senses of the word."

But on a Sunday morning in June, Celia's life turned upside down once again:

"I was still trying to cycle a bit. We biked our usual route to the farmer's market in Hamilton. On our way there, Tim was hit by a truck and was immediately unconscious. He spent five days in the hospital. He didn't make it."

"That was my biggest tragedy, yet I still had to get through treatment - that was my focus. I knew that Tim would have wanted me to do that."

The grief was overwhelming, and chemo left her with terrible wrist pain from the IV. But Celia's two brothers, cousin, sister, neighbours, friends, her dog Lucky and the LBC team gave her the support she needed.

After Tim's death, Celia got a phone call from Zoe, an LBC Support Services Coordinator:

"That was just amazing. She was so caring. She helped me through the last treatment and put me in touch with the nurse specialist that I felt most comfortable with."

Today, Celia feels healthy and positive about the future, and hopes to get more involved in advocating for cycling safety.

"At the end of January, I had a memorial gathering for Tim in our garden and had a memorial seat made. It's outside our house, on the roadside and daisies are just starting to bloom beside it"



Fast Facts: Splenic Marginal Zone Lymphoma (SMZL)

- Rare, making up only about 1% of non-Hodgkin lymphomas.
- SMZL is an indolent (slow growing) B-cell lymphoma.
- SMZL occurs most often in the spleen as well as the bone marrow and blood.



Your support provides ongoing care for people living with blood cancers.



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

Overcoming all obstacles

In early 2020, Mile Nafatali had soreness in his shoulder. The 22 year-old, who worked as an Administrator at a medical centre, just thought it was from playing sport.

When he began coughing up blood, he decided to get it checked out. After a visit to the GP, they found a lump in his chest. A biopsy a few weeks later confirmed it was Primary Mediastinal large B-cell lymphoma Stage 4B.

The diagnosis came as a huge shock to Mile and his family:

"I was quite healthy, active and feeling well. Because the cancer was mostly in my bones, I wasn't in pain... I couldn't believe it."

Over the next six months, he had six rounds of chemotherapy. A scan to check its progress found the chemo wasn't working, so he was given a higher dose of three more rounds.

After nearly a year of chemo, Mile needed a Stem Cell Transplant (SCT). By the time he travelled from Dunedin to Christchurch with his mum and sister, he could barely walk. A PET scan showed the lymphoma had progressed rapidly. His SCT was cancelled.

Mile remembers the moment clearly:

"My doctors said I had no more options left; I only had a few months to live. I was in total shock. I was put in a wheelchair, because they said the cancer would break my bones. I was sent home to be with my family and basically prepare to die."

Despite the devastating news, Mile's family were not giving up. After meeting to discuss what they could do, they immediately reached out to the top clinics around the world to see what their options were.

Eventually they got in contact with the Peter McCallum Cancer Research Centre in Melbourne. Doctors there offered a potentially



life-saving treatment called CAR T-cell therapy, which involves taking blood and modifying the "T-cell" from the white blood cells before reinserting it into the blood system.

"The only catch was the cost," Mile laughs. "I thought it wouldn't be possible. But incredibly, my doctor helped push through special funding to cover the costs. I was so thankful."

His excitement quickly shifted to worry. Just as he was preparing to travel to Melbourne, New Zealand went into lockdown.

"That was on Friday, and by Tuesday, I needed to be in Melbourne to start treatment. Since flights weren't available, the only way I could get there was a private Medivac helicopter, costing \$80,000."



“My doctors said I had no more options left; I only had a few months to live. I was in total shock”

He reached out to LBC who sprang into action straight away.

"It was incredible - within a few hours, they reached out to Seven Sharp, who were very supportive and geared up to run a story to raise the funds. But then David Downs, a lymphoma survivor himself, stepped up. He found some private donors to cover the cost...I couldn't believe it. I was headed to Melbourne with my mum."

In March 2020, Mile started two long months of treatment, and then waited for 30 days to see if it worked. His partner, and sister came out to support him and were there on the day he got the good news:

"The scan showed the cancer was completely gone. That was the greatest day ever."

On May 1st, 2021, he headed back home to Dunedin and reunited with his family.

Today, Mile is in remission and is focussed on staying healthy:

"Physically, a year and a half of chemo and treatments took its toll. I'm currently in rehab with my physio, getting my body into shape and regaining lost muscle. At this stage my goals are to get back into work full time or possibly going back to study."

He's looking forward to spending more time with his friends, celebrating birthdays, and going on trips. He joined LBC's Consumer Advisory Board to give feedback on support services and resources. A new David Downs documentary featuring Mile's inspiring story is coming out soon.

Mile has a new outlook on life, and credits his resilience to the amazing people who helped him get through:

"I realised how precious life is, how we take things for granted. I'm so grateful for the huge amount of love and support from my family, my doctors, and the incredible LBC Support Services team who looked after and cared for me."



Fast Facts: Primary Mediastinal large B-cell lymphoma (PMBCL)

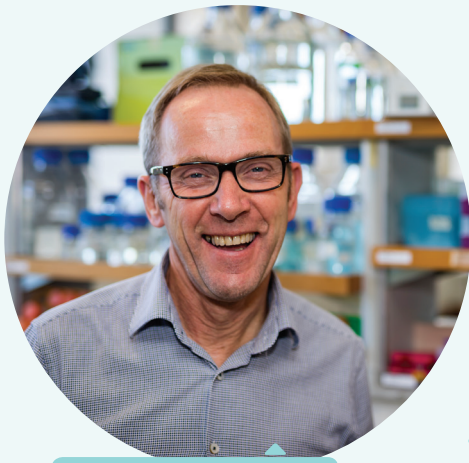
- A rare type of B-cell lymphoma making up around 1-3% of all non-Hodgkin lymphomas.
- PMBCL is a fast-growing lymphoma and needs to be treated quickly.
- PMBCL affects lymph nodes in the mediastinum, the central part of the chest between the lungs.



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Personalising medicine for blood cancer patients

Professor Peter Browett
LBCRU co-director

Current research from the Leukaemia & Blood Cancer Research Unit (LBCRU) at The University of Auckland has focused on increasing understanding of leukaemia genomics and how this information affects patient care and outcomes.

The research shows that most mutations which are relevant for blood cancer can be found in about 78 genes. Up to two years ago, only 3 genes were routinely analysed for mutation in blood cancer patients at Auckland City Hospital, giving limited insight into what was going on for each patient. This can have important consequences for the clinical course and the best treatment options for an individual patient.

Supported by Leukaemia & Blood Cancer New Zealand, the LBCRU has developed a comprehensive test that looks for mutations in all 78 genes using a “*Next Generation Sequencing*” platform.

Over 300 patient samples have been tested including 101 with AML using an “*Auckland Myeloid Gene Panel*”, which showed that no two AMLs are alike as no patients with identical patterns of mutations had been encountered.

This new diagnostic test has far-reaching results. Knowing which mutations are present means that the disease can be diagnosed correctly according to World Health Organisation criteria. It means better targeted treatment with specific drugs.

A more accurate prognosis allows predictions for the severity of the disease and likelihood of success with standard treatment, or whether more intensive therapies like bone marrow transplants are required.

Unexpectedly, in some case, mutations are found not only in the cancer cells but in all cells of the patients suggesting an inherited predisposition to blood cancer. This is an important discovery as familial mutations have implications not only for the patient but for other family members as well.

LBC’s Medical Director, Professor Peter Browett is Head of the Department of Molecular Medicine & Pathology at The University of Auckland as well as LBCRU’s co-director. He describes the results of the gene panel testing for physicians as “*bringing light into a previously dark room and enables them to make more informed decisions about patient management*”.



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facebook.com/LBCNZ/groups**



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

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LBC has Support Services offices in Auckland, Hamilton, Wellington, Christchurch and Dunedin