

LymphomaToday

SUMMER 2025



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Kia ora, welcome to your latest edition of Lymphoma Today

This year marks a significant moment in our organisation's journey. After many years as Leukaemia & Blood Cancer New Zealand, we are becoming Blood Cancer NZ.

This new name reflects our commitment to serving the interests of every person affected by blood cancer across Aotearoa. Our new logo features eight blood drops, each representing an individual life and experience, symbolising how, together, we move forward as one.

As we make this transition, the need for our services is higher than ever before. Six months into our financial year, we have already supported more than 1,000 newly referred patients and whānau, a 10% increase on the same period last year. To meet this growing need, we've expanded our Support Services team so we can be there for people when they need us most. Whether it's practical support, financial help, guidance during treatment, or simply a caring voice in a difficult moment, our Support Services team is here to make sure no one faces blood cancer alone.

While we focus on supporting people diagnosed today, we are equally committed to improving

outcomes for tomorrow. Our advocacy work continues to build momentum, from setting out a bold 10-year vision for blood cancer care in New Zealand through our State of the Nation report, to championing improved access to modern treatments.

These efforts are grounded in the voices and experiences of patients, clinicians and experts who share our vision of a system that delivers the best possible care. Our research funding programme continues to accelerate efforts to discover new treatments and cures across a wide range of blood cancers.

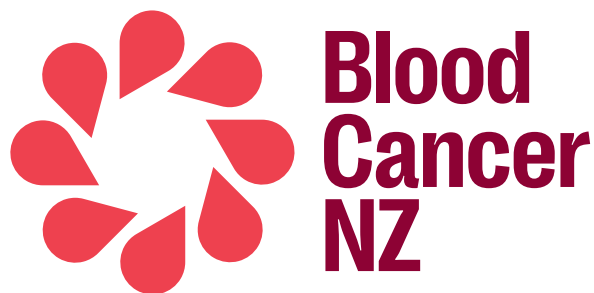
In recent months, I have joined the Pharmac Consumer & Patient Working Group, ensuring that the perspectives of blood cancer patients are well represented as Pharmac begins a period of reform.

Inside this edition, as well as updates on our advocacy work, you'll find stories and insights from across the lymphoma community. Whether you are newly diagnosed, in treatment, or supporting someone close to you, we hope these pages offer information, encouragement and connection.

Ngā mihi nui,

A handwritten signature in blue ink, which appears to read 'Tim Edmonds'.

Tim Edmonds
Blood Cancer NZ Chief Executive



Our new logo



State of the Nation: Progress Update

Blood Cancer NZ is continuing work on the State of the Nation report, the first in-depth look at how blood cancer care is provided across New Zealand.

The report will explore care across the full patient journey, from diagnosis and treatment through to recovery and palliative care. It will show where the system is working, where there are gaps, and what needs to change so that every New Zealander can access the best global standard of care.

The core research and engagement phases are now complete. We've heard from people right across the blood cancer community, including patients and whānau who shared their stories living with blood cancer, as well as clinicians, healthcare professionals and international experts. Their insights have helped build a clear picture of current performance and the key areas where system change is most needed. The findings confirm challenges patients have faced for years and reveal some new issues that need attention.

Over the coming months, we'll continue working with clinical leaders and government agencies to finalise the report's recommendations. Our goal is to make sure the suggested actions are evidence-based, practical in the New Zealand context, and focused on what really matters to people living with blood cancer.

The report will be published early next year. Alongside its release, Blood Cancer NZ will lead a coordinated advocacy effort to push for meaningful improvements in care. We look forward to sharing the findings and working to create lasting change for patients.



Valuing Life Summit: Building Momentum for Change

The Valuing Life Summit was held at Parliament on 14-15 October. It brought together patient organisations, clinicians, government officials and industry representatives to discuss New Zealand's access to modern medicines. The summit highlighted how delays in medicine access affect survival and quality of life, and the vital role that medicines play in an effective health system.

Blood cancer patients were strongly represented at the summit. Blood Cancer NZ Chief Executive Tim Edmonds contributed to a panel discussion, and Blood Cancer NZ Board Member Associate Professor Rodger Tiedemann shared a powerful example of how treatment options and outcomes differ between patients in Canada and New Zealand.

CANGO Campaign Update

CANGO, the alliance of New Zealand's cancer charities, is continuing its campaign to make medicine access a top priority in the lead-up to the next election. The group has chosen two partners who will help make this a success – a specialist creative agency will lead the public awareness campaign to highlight New Zealand's current medicine access gap, while a government relations agency will support with engaging political parties to push for change.

By raising public awareness and engaging with decision-makers, CANGO is helping build a future where all New Zealanders can get the treatments they need, when they need them.

Isaac's journey of hope



Thirteen-year-old Isaac lives with his mum and little sister in Methven. He's a keen skier who loves nothing more than hanging out with his friends and playing his favourite sports. So when he suddenly became too tired to play football, his mum, Kelly, knew something was wrong.

"It all started with influenza at the end of July last year," says Isaac. "I was sleeping a ton, and my stamina was super low."

"He lost about eight kilos," adds Kelly. "He would come home from school and go to sleep straight away. We were at the GP fortnightly – getting blood tests and weigh-ins, and we were at Ashburton Hospital quite frequently. We just kept getting sent away, being told it was mental health or an eating disorder."

As Isaac's symptoms worsened, Kelly made yet another doctor's appointment with a GP they hadn't met before. "I told her, 'You just need to see us as we are today.'"

The GP asked Isaac to lie down, and when he tried to, he couldn't breathe. She sent him straight to Christchurch Hospital.

"Everything went pretty crazy from there," says Kelly. "They did an X-ray, and all of a sudden the room was full, and the word cancer was spoken about. From there, our lives changed."

The X-ray showed that Isaac's chest was full of fluid and contained a large tumour. His heart had been pushed right over to the side, and only one of his lungs was visible. The medical team told Kelly that, based on the type of cancer they thought it was, there would be very few treatment options available.

"We had some pretty frank talks with the oncologist," Kelly says. "He said there was



nothing they could do. That was horrific."

Isaac and Kelly were flown up to Starship Hospital in the middle of the night. Kelly was told that if Isaac's heart stopped during the flight, they wouldn't be able to restart it.

Thankfully, they made it. But with Isaac heavily sedated, Kelly was entirely on her own, terrified about what was to come.

“Then all of a sudden, it turned out to be lymphoma,” she says, “so things turned around a bit.”

When Isaac woke up, Kelly was nervous to tell him he had cancer. “But he was actually quite relieved,” she says. “He was just like, ‘Oh, so I’m not making all of this up!’”

Isaac’s diagnosis was primary mediastinal B-cell lymphoma (PMBCL). He was started on chemotherapy and responded almost immediately. After two weeks at Starship, he was transferred back to Christchurch Hospital. “Then, midway through treatment, we got a not-so-good X-ray, so he got his chemo ramped up to the highest it could be. The higher dose made him really sick, but it did the trick.”

Isaac remembers those days clearly. “It was like having a cold but 100 times worse,” he says. “Like, sore throat, sore stomach, spit coming out of my mouth. I had headaches and was photosensitive, so I liked to be in the dark with the curtains shut.”

“He kind of just dug deep and got through every part of it,” says Kelly.

As well as dealing with side effects, Isaac had to cope with months away from home – missing out on school and seeing his friends.

Fortunately, during his stay in Christchurch Hospital, Isaac met Kate from Blood Cancer NZ. She could tell Isaac was missing his friends, so she visited his school to chat with his classmates about what was going on. She left a toy monkey in Isaac’s chair to keep his place until he was ready to come back.

“His friends really jumped on that,” says Kelly. “They took the monkey everywhere – it’s been on motorbikes, it’s been on the mountain, to sports games and sleepovers. It was an amazing thing that Kate did, and I think our whole journey would have been a lot different, especially for Isaac and his friends, if she hadn’t done that.”

Kate also made a connection with Isaac’s little sister, Bella. “She was going to school and battling all these things that were being said about her brother,” says Kelly. “So Kate even went into her school and talked to her class, which was amazing.”

Bella also joined Blood Cancer NZ’s Kids’ Club, and continues to receive one-on-one support to help her process everything that’s happened.

After a frightening start to his journey, Isaac has now finished treatment and is back home. “He just rang the bell two weeks ago,” says Kelly, “and his haematologist has said he’s just a miracle, really.”

“He’s still having three-weekly scans, because there’s still a tumour,” she explains. “That tumour is likely to stay there forever. It’s right in the centre, so they’re not going to operate.”

Isaac says he’s already feeling a lot better than he did. “I’m regaining my strength quite quickly and my hair is growing back quite a bit.”

He’s going to regular physio appointments and has taken up surfing. The family have also welcomed a new puppy, and they’re looking forward to a ski holiday in Japan – something Isaac planned throughout the hardest days in hospital.

Kelly laughs, “We’re not wasting any time in getting life underway!”



Fast facts: Primary mediastinal B-cell lymphoma (PMBCL)

- PMBCL is a rare type of non-Hodgkin lymphoma affecting mainly young adults. There are approximately 13 diagnoses each year in New Zealand.
- It develops specifically in the mediastinum (the area between the lungs in the chest), often causing cough, chest pain, shortness of breath, or superior vena cava syndrome.
- Despite being aggressive, PMBCL has excellent outcomes with modern treatment (chemotherapy like R-CHOP plus radiation), with cure rates of 70-90% or higher.

Welcome to our growing team

We're excited to share some staffing updates as we continue to expand our support for patients and their whānau.



Rachel joins our Auckland team

We're delighted to welcome Rachel Donegan to a new part-time role supporting people in West Auckland, Waitākere Hospital and Auckland City Hospital.

Rachel has many years of experience as a Clinical Nurse Specialist in haematology at Middlemore Hospital, where she also worked as a Transfusion Nurse Specialist. She has a deep understanding of patient care and working with Māori and Pasifika communities – values that align with our commitment to equitable healthcare access.

Rachel is particularly excited about moving into the NGO sector, where she can use her clinical expertise to support our community.



Rochelle returns from maternity leave

We're equally excited to welcome back Rochelle Mills to our Hamilton-based team following her maternity leave. Rochelle will focus on supporting our online activities and helping develop new resources for patients and families.

Healthcare Compass: Haematology Updates

In September, we hosted a 4-part webinar series to help patients, whānau and caregivers learn more about blood cancer care in Aotearoa.

Experts shared updates on new treatments, the future of care in New Zealand, and practical advice to help you navigate your journey.

The series at a glance:

The Future of Blood Cancer Care in Aotearoa

Rosie Shaw, Blood Cancer NZ Head of Advocacy, explored the pathway to delivering world-class care in New Zealand. She discussed current challenges and opportunities in blood cancer treatment and support.

Self-empowerment from Hospital to Home/Community Care

Wendy Jar, Clinical Nurse Specialist in Haematology, shared tips for managing the often-daunting transition from hospital to home and feeling empowered in this process.

And Now What...? Navigating the Practical and Emotional Challenges of Cancer

Lauren Bradley is a social worker and Regional Lead of the Cancer Psychological and Social Support Service. In her talk, she addressed the practical and emotional complexities that come with a cancer diagnosis and ongoing treatment.

CAR T-cell Therapy in New Zealand

Dr Philip George, Consultant Haematologist, and Petra Minehan, Clinical Trials Research Nurse, discussed this groundbreaking treatment innovation and its current use in New Zealand.

Watch Now

All four webinars are now available to view on our YouTube channel. You can catch up on any missed sessions or revisit key information at bloodcancernz.link/webinars.

Educating our health professionals



The team behind the Winter Workshops

Winter Workshops: A Transformational Journey of Healing

Over winter, we ran a workshop series in six cities around New Zealand. Around 300 healthcare professionals who work with blood cancer patients attended.

The workshops featured Vonda Nepia, an AML patient and passionate advocate. She shared her powerful personal story, “A Transformational Journey of Healing: Restoration of Mana & Tapu”.

She spoke about weaving Te Whare Tapa Whā cultural principles into healthcare, and how this supported her wellbeing. Healthcare professionals learned how honouring mana and tapu in clinical settings can improve the experience and outcomes for patients and their whānau.



Dr David Scott presents at the Summit

Lymphoma Summit NZ 2025

On 3-4 October, Blood Cancer NZ supported and hosted the first Lymphoma Summit NZ at the Napier Conference and Events Centre, in partnership with the Lymphoma Network of New Zealand (LNNZ).

Around 90 healthcare professionals gathered to learn about the latest research and treatments for lymphoproliferative disorders, including CLL and lymphomas.

The summit featured international experts Dr David Scott and Dr Kerry Savage from Canada, alongside leading Australian and New Zealand specialists. The programme included scientific presentations, clinical discussions, case-based learning, and networking opportunities.

These initiatives show our commitment to supporting the healthcare professionals who care for our community. Together, we are working to ensure that blood cancer patients across New Zealand receive compassionate, evidence-based and culturally responsive care.

Taking the days as they come



At 70, Warwick describes himself as someone who has always enjoyed good health. Living in Lower Hutt with his daughter, he continued to work throughout his sixties and hardly ever got sick. “I hadn’t had a day off work for two years!” he says.

So when he suddenly began to feel unwell, it wasn’t something he took lightly. “I was just feeling yuck all the time,” he says. “I ended up going to the doctor every month for six months in a row.”

Despite the regular visits, he wasn’t getting any answers – but his symptoms were becoming harder to ignore. He was exhausted, struggling through each day. “I was going to work, and going through the motions, but I wasn’t actually doing anything,” he says.

His boss did what he could to help, encouraging Warwick to sit while he worked. But as the fatigue got worse, even that wasn’t enough. Eventually, Warwick’s employer made the difficult decision to let him go. “I wasn’t upset, really,” says Warwick. “I knew that my ability to do the work was almost zero.”

By then, Warwick had lost 30 kilograms and was feeling increasingly frustrated by the lack of a diagnosis. Determined to get to the bottom of what was going on, he asked to see a different GP. “I talked to him for five minutes, and he said I needed to go to the hospital. Just like that.”

At the hospital, doctors took a biopsy of a lymph node in his neck. “But it wasn’t sufficient, so then I had to go back three weeks later, and they had another shot.”

After that, it was a waiting game. “It was probably about a week and a half later,” Warwick says. “The thing came back and said, ‘Yes, you’ve got mantle cell lymphoma.’”



The diagnosis was hard to take in. “I couldn’t believe it,” Warwick recalls. “I thought, ‘This can’t be right. Cancer – no, not me.’ I just couldn’t believe that I could have cancer.”

But things moved quickly. Within weeks, Warwick had started chemotherapy.

He soon realised he wasn’t alone in his journey. Every treatment day was a reminder of how many others were facing similar challenges. “All the chemo sessions I went to, all but one chair was full. I was surprised at how many people were there.”



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His treatment took place at Wellington Hospital, and travelling back and forth from the Hutt Valley was tough. Despite this, Warwick was grateful for how smoothly the chemo itself was going. Apart from some nausea from one of the medications, he experienced very few side effects.

Part way through treatment, however, he faced an unexpected complication: his heart began to fail, and his blood pressure dropped dangerously low. “At one stage, my blood pressure was down to about 54/45,” he says. He was hospitalised for monitoring and treatment, adding another layer of uncertainty to an already challenging year.

Thankfully, Warwick responded well, and his health gradually stabilised. He completed six rounds of chemo and moved on to maintenance medication.

Unfortunately, recovery hasn’t been as quick as he imagined. “I’m getting my energy back slowly,” he says, “but it’s taken a lot longer than I expected.” He used to love reading books, but says he now finds it too hard to focus on them.

Throughout his journey, Warwick stayed connected with Blood Cancer NZ Support Services Coordinators Melody and Nicki. They regularly checked in with him over the phone and at the hospital, offering information and a listening ear.

Blood Cancer NZ’s local support groups have been another great source of support. “I’d recommend them to anyone who’s interested,” he says. “If you have the opportunity, go along just to have a look, and you’ll find someone to talk to.”

For Warwick, the groups offer connection and understanding. “It’s quite a social thing – but if you want to talk about cancer, everyone’s prepared to do that,” he says. “Talking to other people is wonderful. You realise in some ways how lucky you are, and in other ways, perhaps you’re a little bit unlucky as well.”

Now on the other side of active treatment, Warwick has a realistic outlook. “I’m very aware that it could be a click of my fingers and I could be right back where I started,” he says. “And I know that, because I’ve talked to other people who’ve been there.”

He’s also found himself wanting to give back. “One thing that’s come from this is there are so many people helping you that it rubs off, and you actually want to help other people.”

Instead of planning too far into the future, Warwick is taking things day by day. “It might be a self-preservation thing that I’m not thinking too far ahead,” he says.

“We’ll just take the days as they come. And when I wake up, it’s a good day.”



Fast facts: Mantle cell lymphoma

- Mantle cell lymphoma is a rare and aggressive type of non-Hodgkin lymphoma, affecting approximately 40 New Zealanders each year.
- Often advanced at diagnosis – most patients present with widespread disease involving lymph nodes, bone marrow, and often the gastrointestinal tract.
- Treatment outcomes are improving – newer therapies have significantly extended survival in recent years, particularly with intensive chemotherapy followed by stem cell transplantation.

Steroids and blood cancer



What are steroids?

Steroids play an essential role in managing some blood cancers and blood conditions.

These medications are man-made versions of substances our bodies naturally produce. They help control essential functions like blood pressure, inflammation, metabolism, and immune responses.

The steroids used in cancer care are usually corticosteroids, which mimic the steroids made by our adrenal glands. Examples include dexamethasone, prednisone, methylprednisolone, and hydrocortisone. They may be prescribed alongside other cancer treatments or on their own.

How steroids can help

Steroids have several benefits in cancer treatment:

- Directly kill cancer cells and make other treatments more effective
- Reduce inflammation and help prevent allergic reactions to certain chemotherapy drugs
- Help to prevent complications after a stem cell transplant by reducing the body's immune response
- Improve appetite and help ease nausea and vomiting caused by treatment

Side effects

While steroids are an important part of treatment, they can cause temporary side effects that usually improve once treatment ends. Everyone's experience is different, and side effects can vary depending on other treatments being received.

Common side effects:

- Stomach discomfort such as indigestion or heartburn (can often be eased by taking steroids with food or milk)

- Raised blood sugar levels (regular monitoring is important, especially for those with diabetes)
- High doses or long-term use can suppress the immune system, increasing infection risk (try to avoid people who are unwell and practise good hand hygiene)

Other side effects may include:

- Increased appetite and weight gain
- Swelling in the feet, legs, or abdomen
- Difficulty sleeping
- Feeling anxious, restless, or having difficulty concentrating
- Changes to skin, hair, or face (more body hair, thinning scalp hair, rashes, or facial puffiness)
- Muscle weakness, fatigue, and vision changes

If you're worried about any side effects, speak to your medical team. They may be able to adjust the dose or timing of your steroids.

Important safety considerations

Always follow your medical team's instructions carefully.

- Taking high doses of steroids stops your body from making its own supply, so it's dangerous to stop suddenly
- If you've been taking steroids for more than three weeks, your dose must be reduced gradually under medical supervision to avoid serious complications
- Steroids can interact with other medications, supplements, and certain foods and drinks
- Always tell your medical team about anything else you're taking, whether prescribed or over-the-counter, along with any allergies or existing health conditions

For more information, see the Steroids and Cancer Treatment factsheet on the Blood Cancer NZ website.

Shine for a Cure 2025

In September, Shine for a Cure lit up the night in Auckland and Christchurch – a celebration of hope, remembrance and togetherness for the blood cancer community.

Now in its second year, this special event brought together patients, families and supporters from across Aotearoa to walk side by side and shine a light on blood cancer. Everyone who raised over \$100 received a lantern, and together participants raised an incredible \$135,000 for blood cancer research.

With more than 2,000 people joining us at Auckland Domain, and another 500 people in Christchurch's Hagley Park, the energy on the night was powerful. Lanterns in gold, teal and white created colourful ribbons of light through the parks. Some walked in memory of a loved one, others to honour their own journey, and many to simply show support for those living with blood cancer.

Adding to the magic of the night, walkers were treated to a surprise 'hidden choir' along the route in each location.

Shining across the country

Those who couldn't join us in Auckland or Christchurch were invited to host their own local community event, and we were blown away by the effort and creativity shown by supporters across the country.

In Balclutha, locals came together for a special walk in honour of seven-year-old Aaliyah, who

was diagnosed with leukaemia earlier this year. The event was a great success – with face painting, a Mr Whippy van, a head-shaving fundraiser, and even an auction. Together, the community raised more than \$3,300 to help fund life-saving blood cancer research.

Be part of it!

We'd love you to join us for Shine for a Cure 2026. Keep an eye out from June for details on how to register.



A 'hidden choir' surprised participants in each location



More than 2,500 people came together to shine a light on blood cancer

We're here for you



Talk to our team

Our dedicated Support Services team is here to help you, your family and your support people.

We can answer questions, listen to your concerns, connect you with practical or financial help, and provide clear information.

If you ever need support, please reach out to your local Support Services Coordinator and they will be happy to help.

Education and support programmes

We offer support groups for patients and their whānau across the country – both in person and online. These groups are a safe space to share experiences, learn from others, and build connections with people who understand what you're going through.

Our programmes are designed to help you make informed choices about your condition, treatment and lifestyle.

Find a support group near you at bloodcancernz.link/groups

Information

Reliable information can make a big difference when you're navigating a blood cancer diagnosis. We offer a wide range of free booklets, factsheets and online webinars covering a variety of topics.

Our latest factsheets cover:

- Steroids and Cancer Treatment
- Immunotherapy and Cancer (in collaboration with the Malaghan Institute)
- Acute Promyelocytic Leukaemia (APL)

Explore our full library at bloodcancernz.link/info, or contact your local Support Services Coordinator to request printed copies.

Kids' Zone

We also provide dedicated programmes and resources for young people affected by blood cancer.

Our Super Kids' Club supports children living with cancer, while our Kids' Club helps those with a parent or family member diagnosed with blood cancer. Both are facilitated by play therapists and psychologists, giving children a safe space to talk, learn, and connect with others in similar situations.

We also offer picture books for kids, as well as a range of other initiatives. Head to bloodcancernz.link/kidszone to find out more.

Stay connected

Follow [@BCNZ](https://www.facebook.com/BCNZ) on Facebook for updates on our research, advocacy and awareness work, as well as support opportunities.

You can also join one of our closed Facebook groups to connect directly with other patients and support people who understand the challenges of blood cancer.

Support for specific cancers and conditions:

[@BCNZLymphoma](https://www.facebook.com/BCNZLymphoma)
[@BCNZMyeloma](https://www.facebook.com/BCNZMyeloma)
[@BCNZChronicLeukaemia](https://www.facebook.com/BCNZChronicLeukaemia)
[@BCNZAcuteLeukaemia](https://www.facebook.com/BCNZAcuteLeukaemia)
[@BCNZBloodDisorders](https://www.facebook.com/BCNZBloodDisorders)
[@BCNZHaemochromatosis](https://www.facebook.com/BCNZHaemochromatosis)
[@BCNZMPN](https://www.facebook.com/BCNZMPN)

Support for young adults and parents:

[@BCNZYoungAdults](https://www.facebook.com/BCNZYoungAdults)
[@BCNZParentsGroup](https://www.facebook.com/BCNZParentsGroup)

Further support pages:

[@BCNZSupportPersonConnect](https://www.facebook.com/BCNZSupportPersonConnect)
[@BCNZBereavement](https://www.facebook.com/BCNZBereavement)
[@BCNZCARTTherapy](https://www.facebook.com/BCNZCARTTherapy)
[@BCNZConnect \(Blood Cancer NZ & Health Professionals Connect\)](https://www.facebook.com/BCNZConnect)