

LeukaemiaToday

SUMMER 2025



**Grace's journey,
one step at
a time** p4

Advocacy updates, p3
Expanding our support, p6
Amelia's strength through setback, p8
Steroids and blood cancer, p10
Shine for a Cure 2025, p11



Kia ora, welcome to your latest edition of Leukaemia 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.

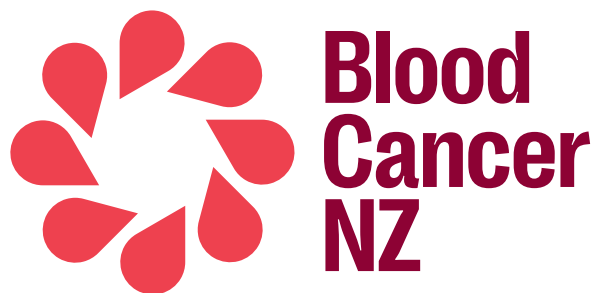
In recent months, I have joined the Pharmac Consumer & Patient Working Group, ensuring that the perspectives of blood cancer patients are well represented as Pharmac begins a period of reform.

Inside this edition, as well as updates on our advocacy work, you'll find stories and insights from across the leukaemia 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, appearing 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.

Grace's journey, one step at a time



In 2023, four-year-old Grace began complaining of sore legs during her gymnastics class. Her mum, Kaye, was worried something was wrong – but other parents reassured her it was probably just growing pains.

At the time, life was busy for the young family. Kaye and her husband, Liam, were dairy farming in rural Canterbury while raising two little ones – Grace and her younger brother, Axel. Kaye had recently returned to work, and both children were in daycare part-time.

That winter, the family travelled to Ireland to visit Liam's relatives. When they returned home, everyone came down with a virus. "But then Grace just didn't really recover," says Kaye. "We were getting up in the night to give her ibuprofen and Pamol, and in the mornings she'd be limping and so tired she'd fall asleep on the couch."

Concerned, the family's GP spoke to a paediatrician, who suspected Grace might have a type of arthritis. When X-rays came back clear, she was placed on a waiting list for a specialist appointment.

"Two months later, we finally saw the paediatrician and got follow-up blood tests – and they showed that things hadn't improved," says Kaye. It was at this appointment that leukaemia was first mentioned as a possibility.

"We were sent up to CHOC [Child Haematology and Oncology Centre] in Christchurch that following week, and then we had a diagnosis in a couple of days: B-cell acute lymphoblastic leukaemia."

Although the news was devastating, Kaye says it was also a relief to finally have some answers and a treatment plan after months of uncertainty.

The family were allowed to return home for the weekend to pack their bags and prepare



“We were getting up in the night to give her ibuprofen and Pamol, and in the mornings she'd be limping and so tired she'd fall asleep on the couch.”

themselves. On Monday, Grace was admitted to the hospital and began treatment.

“They put her port in and started lots of different chemo, plus a month of high-dose steroids,” says Kaye. “The steroids made her gain a lot of weight, and she became almost unrecognisable.”

The hardest part for Grace, though, was losing her hair.

“That was really hard for her, especially as a kid who loves Frozen and Barbies with long hair,” says Kaye. “Before that, she could go out, and no one really knew anything was wrong. She wasn’t considered different – and then she was.”

Soon after they arrived at Christchurch Hospital, the family were visited by Kate from Blood Cancer NZ. She gave them a book called “Joe has Leukaemia” to help explain Grace’s illness in a way the kids could understand.

“Both Grace and Axel would actually pick it out as a bedtime story,” Kaye says. “It helped explain some of the things Grace was going through.”

Kate continued to check in on the family throughout Grace’s treatment, offering emotional support and practical help like petrol and grocery vouchers when things were tight.

“She also organised Monkey in My Chair for Grace’s class,” says Kaye. “Grace has the wee monkey here, and there’s a big one that sits in her chair at school. Kate actually went in on Grace’s birthday and brought cupcakes for her class, and Grace was pretty thrilled with that.”

“I think it was good for her classmates, as well, just to get a little bit of understanding around what’s happening with Grace.”

Grace’s initial treatment lasted nine months before she transitioned to maintenance therapy. “You expect that maintenance treatment will be a little easier,” says Kaye, “but it hasn’t really been that way for us. She’s been quite sick off and on, with hospital stays and lots of coughs and bugs. It’s been challenge after challenge.”

Grace turned five in April last year but didn’t start school until several months later, after the winter illnesses had passed. Even now, she often only manages half a day here and there.

“She loves school – playing and learning and reading and counting,” says Kaye. “It’s hard for her not to be there every day.”

Reflecting on their journey, Kaye says one of the most valuable things has been connecting with other families who understand. “You kind of end up in a club that no one wants to be in,” she says, “but it’s really helpful talking to other parents going through similar things.”

Earlier this year, Grace became a big sister to baby Millie. It’s a bright new chapter in what has been a long journey for the family. Now, as Grace nears the end of her treatment, her family are looking forward to seeing her get stronger and healthier – and to simply enjoy being a kid again.



Fast facts: Acute lymphoblastic leukaemia (ALL)

- Approximately 75 New Zealanders are diagnosed annually. It is the most common childhood cancer, typically affecting ages 2-5, but also occurs in adults.
- High cure rate – modern chemotherapy achieves 80-90% long-term survival in children.
- Treatment duration – requires 2-3 years of multi-drug chemotherapy regimen.

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.

Amelia's strength through setback



When Amelia began having severe pain in her stomach last year, she didn't panic at first.

The mum-of-three had recently come back from an extended family holiday in Australia and Bali, and aside from the pain, everything was going well.

"We were just a happy family living in Upper Hutt," she says. "The kids were two, four and six at the time. We were all in good health, and I actually had a good immune system, so I'd rarely get coughs and colds."

But over time, the pain in her stomach got worse. She was struggling to keep food down, and soon she couldn't even keep water down. "That's when the emergency department took me seriously," she recalls.

A PET scan initially suggested ovarian cancer that had spread to her stomach. But more tests uncovered the real cause of her pain – acute lymphoblastic leukaemia (ALL). Amelia was rushed to Wellington Hospital to begin urgent treatment.

"It was straight into some quite intense chemo," she says. "I was hospitalised for about a month and a half."

While still coming to terms with her diagnosis, Amelia was visited by Nicki from Blood Cancer NZ. "She was easy to talk to and very supportive," Amelia says. "It was always so nice when she would pop in for a chat."

Even when she was eventually allowed home, Amelia spent much of her time back at the day ward for treatment. "It was exhausting," she recalls. "And I really struggled with not being there for my kids."

During this time, Amelia was thankful for Blood Cancer NZ's Kids' Club. It gave her children a place to have fun and connect with other kids going through a similar journey.





Get help if you need it. And even though it's hard, just try to take it one day at a time.



After a few more months of treatment, Amelia was relieved to hear she was in remission. But when a follow-up PET scan showed three active areas, her heart sank.

"They said it looked like the leukaemia was back."

Thankfully, a repeat scan brought good news. "All of the three areas had gone – it turns out it was just an infection."

The next step was an allogeneic stem cell transplant. Finding a donor seemed impossible at first, until her mum reached out to Amelia's biological father and her two half-siblings. "One of them wasn't a match, but the younger one was," Amelia says. "So I had bone marrow donated by my brother, who I'd never even met. I'm very grateful to him."

Her transplant went ahead in June this year. While it was an important milestone in her treatment, the recovery was incredibly tough.

"It was a rocky road," she says. "I ended up staying in hospital for three months. I had so many infections, and the worst was toxoplasmosis, which attacked my brain. I literally can't remember a couple of days – apparently, I had a seizure. My thoughts were addled, and I was very confused. But I'm so thankful for the hospital stuff. The nurses were amazing."

Through it all, Amelia's family have been an incredible source of support. Her in-laws moved in to help with the kids while she was in hospital, and her mum never left her side. "Mum stayed with me every night after my transplant," Amelia says. "She's been really exceptional." She was also grateful for her community, who prayed for her and provided an endless supply of frozen meals.

As the weeks in hospital dragged on, Amelia found that the small things made a big difference. "Getting sunlight helped me so much," she says. "If your bed isn't by the window, ask to go somewhere you can access sunlight. And then as you get better, getting fresh air outside really helps."

She also used the hospital's psychology service, which she would recommend to other patients who are struggling. "It was a helpful place to vent, and it gave me some strategies for reframing my worries."

After three long months, she was finally discharged from the hospital. Coming home in spring brought an extra lift for Amelia, who loves nature and lives next to a river reserve.

Although it was amazing to be back with her family after so many months away, it was also challenging in ways she hadn't expected.

"I wasn't sure what my role was anymore," she admits. "I couldn't jump straight back into being a stay-at-home mum, doing everything for the kids around the house. I just don't have the energy. But it's fantastic being together as a family again, spending time with the kids, making sure they know they're loved."

As Amelia adjusts to life after her transplant, her advice for others living with leukaemia is simple but powerful: "Get help if you need it. And even though it's hard, just try to take it one day at a time."



Fast facts: Allogeneic stem cell transplant (ALLO)

- Replaces the immune system – completely rebuilds patient's bone marrow and blood-forming cells.
- Uses donor stem cells from matched or partially matched donors, rather than the patient's own cells.
- Hospital stay can be between 6-8 weeks and often longer post ALLO, with main risks being infections and acute graft vs host disease (GvHD).

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)