Blood Cancer NZ

Leukaemia Today

WINTER 2026



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Kia ora, welcome to your latest edition of Leukaemia Today

Blood cancer can change life very quickly. For many people, diagnosis comes with little warning. Suddenly, there are tests and appointments to navigate, treatment decisions to make, and worries about family, work and the future.

At Blood Cancer NZ, we want every person affected by blood cancer to know they don't have to face these challenges alone. Supporting and connecting our community is at the heart of what we do, and this newsletter is one of the many ways we help people stay connected and informed.

Our work is guided by three commitments: supporting patients, advocating for better access to treatments, and changing outcomes through research. These priorities are closely connected. Support helps people through the realities of diagnosis and treatment. Advocacy works to improve care and influence access to medicines. Research creates opportunities for clinical trials, better treatments and, over time, more people living longer and better lives.

Over the past year, Blood Cancer NZ has reached more than 3,500 patients, whānau and support people across New Zealand. Some were newly diagnosed and looking for trusted information and advice. Others needed practical or financial support during treatment, or were seeking counselling or connections with people who could truly understand what they were going through. Each person's situation is different, and our role is to respond to what matters most to them.

We know that many of you also value the role we play in advocating on your behalf for better access to modern treatments that remain unavailable through New Zealand's public health system. The recent launch of our *State of Blood Cancer in New Zealand* report has helped bring the realities of blood cancer into sharper focus for decision-makers and strengthened the case for coordinated national planning. You can read more about this in Rosie's advocacy update on the next page.

We're looking forward to opportunities for our community to come together in the months ahead. On 11 and 12 September, our Patient Forum in Wellington will bring together patients, whānau, clinicians and advocates to share knowledge and evidence to improve care. And on 19 September, during Blood Cancer Awareness Month, Shine for a Cure will bring people together across the country to remember loved ones, show support, and help fund research that can change the future for people affected by blood cancer. We'd love to see you there if you're able to join us.

Inside this edition, you'll find stories and updates from across the blood cancer community. I hope they leave you with a sense of both the strength that comes from connection and of the progress we can make together.

Ngā mihi nui,



Tim Edmonds
Chief Executive
Blood Cancer NZ



Advocacy update

Rosie Shaw,
Head of Advocacy

Things are heating up ahead of the General Election in November, and Blood Cancer NZ is working hard to ensure our future Government understands the needs of the blood cancer community and is committed to meaningful change.

In April, we launched our *State of Blood Cancer in New Zealand* report in Parliament. The report is the first comprehensive look at blood cancer in New Zealand, combining national data with the experiences of 744 patients and carers. It highlights the realities of living with blood cancer, and the challenges patients face accessing timely diagnosis, specialist care, and modern treatments.

The findings confirm what many patients and families already know: blood cancer is a significant and growing health challenge. Around 3,000 New Zealanders are diagnosed with blood cancer each year, approximately 27,000 people are currently living with the disease, and it is now the third leading cause of cancer death in New Zealand. Yet despite its impact, blood cancer has historically received less attention than many other cancers.

At the heart of the report are patient voices. Every story shared helps to turn blood cancer from something people know little about into something they can connect with and understand. Those stories were central to the report launch, where patients stood alongside clinicians, advocates, and policymakers to highlight both the progress being made and the challenges that remain.

It was great to see health leaders from across the political spectrum attend the launch. And we were encouraged to see the Minister of Health, Hon Simeon Brown, announce the establishment of a dedicated blood cancer oversight group in response to the report's key recommendation.

This group will bring together experts from across the health system to help improve planning, coordination and decision-making for blood cancer care. For patients, this is an opportunity to ensure blood cancer receives the focused attention it needs, and an important step towards building a future where no lives are needlessly lost to blood cancer.

To further support the goal of improving access to modern therapies in New Zealand, Blood Cancer NZ is also leading a coordinated campaign involving 17 patient organisations. Taking place in Auckland on 24-25 July, the campaign will feature a public installation highlighting medicines that New Zealand patients still cannot access. It aims to spark public, media and political discussion about what it will take to ensure that all New Zealanders can access the medicines they need.

The months ahead will be critical in shaping the future of blood cancer care in New Zealand, and Blood Cancer NZ will continue to champion the voices of patients and whānau every step of the way.



Blood Cancer NZ staff present the *State of Blood Cancer* report in Parliament

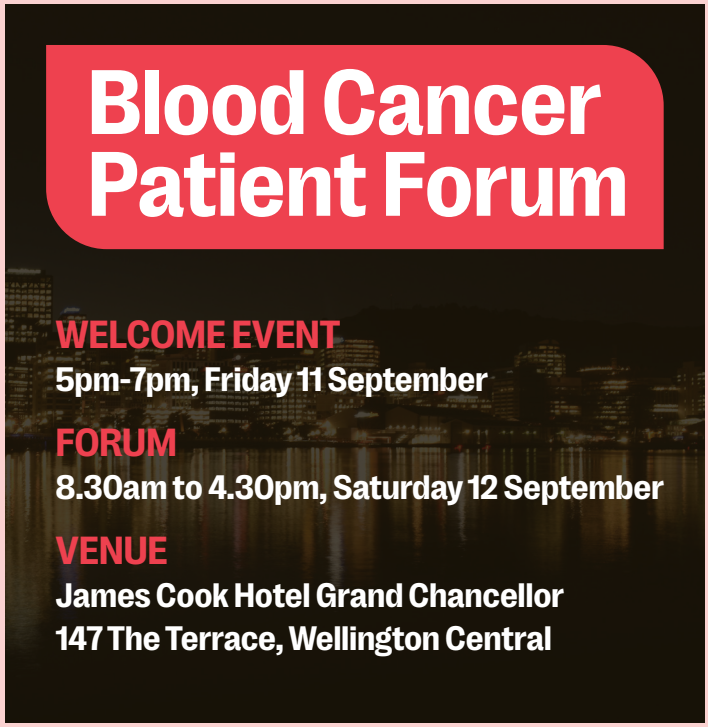
On the horizon

As we look ahead to the rest of 2026, there are still plenty of opportunities to learn, connect with others, and feel supported on your blood cancer journey. Here are two events we'd love you to be part of.

2026 Blood Cancer Patient Forum

Whether you're newly diagnosed, on active monitoring, or well into your post-treatment journey, the Blood Cancer Patient Forum is a wonderful opportunity to connect with others, hear from leading experts, and leave feeling informed and supported. The Forum is a special event open exclusively to patients living with a blood cancer and their whānau, and this year's Forum will take place in Wellington on 11-12 September. It brings together an inspiring line-up of speakers covering everything from the latest treatment developments to living well with and beyond blood cancer.

Registrations are now open. Visit **bloodcancerpatientforum.org.nz** to find out more.







Shine for a Cure

On Saturday, 19 September, join people in Auckland, Christchurch and across the country as we come together to honour loved ones, reflect on our own journeys, and shine a light on everyone affected by blood cancer – all while raising money for life-saving research.

It's completely free to register and come along. There's no pressure to fundraise, but if you'd like to, you'll receive a free lantern when you raise $100 or more. The three lantern colours represent why you're taking part – teal symbolises a personal journey with blood cancer, gold is to remember those who are no longer with us, and white shows support for all those affected by blood cancer.

Can't make it to Auckland or Christchurch? You can still take part by hosting your own lantern event wherever you are in the country and joining the live stream online.

Head to **shineforacure.org.nz** to register!

Understanding your full blood count

People living with blood cancer often have regular blood tests, especially around diagnosis, treatment, and follow-up. One of the most common blood tests is a full blood count (FBC), also called a complete blood count (CBC). It measures the levels of different blood cell types and provides information about how your bone marrow is working.

Your results may include abbreviations, numbers, and "normal ranges". These ranges can vary between laboratories and may also be influenced by your age, sex, treatment, and other health conditions. Your treatment team are the best people to explain what your results mean for you.

Red blood cells and haemoglobin

Red blood cells carry oxygen around your body using haemoglobin (Hb). Low haemoglobin is called anaemia and can cause tiredness, weakness, dizziness, shortness of breath, or looking paler than usual.

Your report may also include haematocrit (HCT), which measures the proportion of your blood made up of red blood cells, and MCV, which describes the average size of your red blood cells.

White blood cells

White blood cells help protect your body from infection. The total white cell count (WBC) includes several different cell types that all play different roles, and some blood cancers affect particular types of white blood cells.

A white cell count can be high or low for many reasons, including infection, treatment, and blood cancer. Your healthcare team will look at patterns and trends rather than at a single result.

Neutrophils

Neutrophils are white blood cells that help fight bacterial infections. Low neutrophils are called neutropenia and can increase your risk of serious infection, particularly during or after treatment.

If you have been told your neutrophils are low, or you have recently had chemotherapy or intensive treatment, contact your treatment team immediately if you:

- develop a temperature
- have chills or shivering
- feel suddenly unwell
- notice signs of infection.

If you are very unwell or cannot reach your team, call 111 or go to your nearest emergency department.

Platelets

Platelets help your blood clot. A low platelet count can cause easy bruising, nosebleeds, bleeding gums, tiny red or purple spots on the skin, heavier periods, or bleeding that is difficult to stop. Tell your healthcare team if these occur.

During treatment, some people need platelet transfusions as a temporary "top-up" while the bone marrow recovers.

Reading your results

It can be worrying when a result falls outside the normal range, but for people with blood cancer, changes are often expected during treatment. Trends over time are usually more important than a single number.

If you would like help understanding your results, speak with your haematology team, specialist nurse, GP, or pharmacist.

Test	What it does	Typical adult range*
Haemoglobin (Hb)	Carries oxygen around the body	Men: 130–175 g/L; Women: 115–155 g/L
Neutrophils	Help fight bacterial infections	2.0–7.5 × 10^9/L
Platelets	Help blood clot and prevent bleeding	150–400 × 10^9/L

*Your results should always be interpreted alongside the ranges on your laboratory report and your clinical situation.

A mother's fight

Eight years ago, Moana and her whānau moved to Hamilton for a fresh start. Life was going smoothly for the mum of three boys – until suddenly everything changed.

At the beginning of last year, the 48-year-old began noticing unexplained bruises on her arms and legs. When she went to have her teeth cleaned at the dentist, her gums bled for days afterwards.

But it wasn't until she was in excruciating pain that alarm bells started to ring. "I felt this pinching feeling going down my legs," she says. "It was so painful, like someone was tearing my veins out."

Not able to sleep from the pain, Moana went to hospital the next day.

It wasn't long before she received the news that turned her world upside down: Moana had acute myeloid leukaemia.

"I freaked out," she recalls. "I said, 'Could I die from this?' and they said, 'Yes, you could.'"

Her first thought was her children. "I was just worried about my kids growing up without a mum," she says.

Breaking the news to them was devastating. "They were shattered," she says. "They felt like I wasn't going to come home. But I told them, 'We have to believe in this, we've got to try.'"

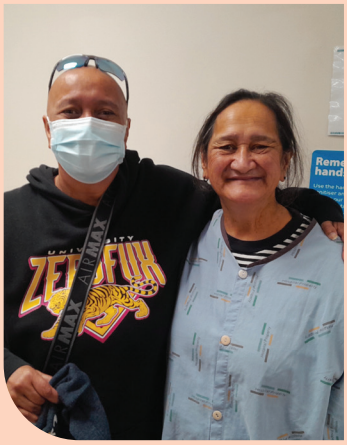
The medical team started Moana's treatment straight away. She spent half a year getting chemotherapy, with five of those months spent as an inpatient at Waikato Hospital.

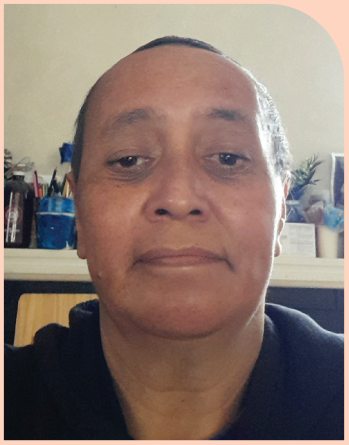
Moana's eldest son had to step into the role of looking after his two teenage brothers. "He was only 22. It was hard for him," she says. "All the cooking, cleaning – he was so stressed out."

And while things were a struggle at home, they were just as tough for Moana in the hospital. She lost her appetite completely and was surviving



Moana treasures spending quality time with her three sons





> "I just kept on fighting. All I could say to myself was, 'You've got to beat this. You have to do it for your boys.'"

on water and ice chips to get her through. "The chemo was pulling me down," she says, "but I just kept on fighting. All I could say to myself was, 'You've got to beat this. You have to do it for your boys.'"

"But I really did love the people up there," she says. "There were a lot of us going through it. I could walk around with no hat on, free as a bird with a baldie."

During this time, Moana also met Sean from Blood Cancer NZ. "He has been a wonderful support through my journey," she says. "I'm so glad I formed that bond with him."

After finishing chemo, Moana had to go up to Auckland for a stem cell transplant. "My sister was my donor," Moana says. "She was a perfect match. I told her she's my hero for life."

Although it was an incredible gift from her sister, the months in Auckland Hospital for Moana's transplant were beyond anything she could have imagined.

In an isolation room and with no whānau able to be there with her, Moana felt totally alone. She couldn't eat and had to be fed through a tube. The line in her chest got infected, and she had terrible gut issues.

"I would voice call my sons from hospital instead of video calling, because I didn't want them to see what I looked like," she says.

When Moana felt like she just couldn't handle it anymore, she called Sean in tears. "I told him I've got no one to talk to here and I need support. He guided me through it and had someone from Blood Cancer NZ in my room within half an hour."

Finally, Moana was allowed to return home. It was just a week before Christmas. "It was like a joy I'd never had before," she says. "We got to put up the Christmas tree together, which is a special thing for me and my boys."

Although she's glad to be back home, she still has to travel to Auckland for medical reviews, which is costly in terms of both time and money. Fortunately, Sean from Blood Cancer NZ has provided petrol vouchers to help ease the burden and ensure she can get to appointments.

Moana says, "I'm not a person who likes to ask for help. I'm so independent, and I find it really hard, but I'm trying to learn how to accept help when people offer."

She's still facing the after-effects of her transplant and is currently dealing with graft-versus-host disease (GVHD). "The transplant is battling it out with my liver and my kidneys at the moment," she says. "I'm dry in my mouth and throat, and I've started to lose my toenails and fingernails."

She also struggles with her energy levels and is limited in what she can do around the house. "I find it very hard, because the things I used to do – like mow the lawns and weed the gardens – I can't do them anymore," she says.

Fortunately, her boys have stepped up, helping make sure that everything gets done.

Moana admits she gets bored easily, so while she's still recovering at home, she's taught herself to make flowers from ribbons. "My niece had said, 'Auntie, how about crocheting?' And I said, 'No, thank you, I'm not that old – not yet!'"

Despite everything, Moana is just grateful to be done with her treatment and to be home with the people she loves most. And she knows her boys are grateful, too. "As long as they get to see their mum, they're happy."

Fast facts: Acute myeloid leukaemia (AML)

- Abnormal white blood cells rapidly multiply in blood and bone marrow, crowding out healthy cells, leading to symptoms like fatigue, frequent infections, and easy bleeding.
- Around 150 New Zealanders are diagnosed each year, mainly older adults.
- AML progresses quickly and needs immediate treatment. There are multiple subtypes and different genetic variations.

An update on your Support Services team

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



A new face in the Wellington office

In March, we were pleased to welcome Stephanie Waterbury to our Wellington Support Services team. Stephanie is an experienced registered nurse who enjoys building meaningful connections with people and making sure their needs are heard and addressed.

Stephanie began her nursing career in Washington State, USA, as a medical oncology and haematology infusion nurse. In 2021, she moved to Wellington, where she has since gained further experience in hospice and clinical oncology nursing.

Stephanie has taken over from Nicki Roy, who was a valued member of the Blood Cancer NZ Support Services team for five years before recently moving away from Wellington with her family.



Extra support in Christchurch

We are delighted to share that Nish Mohun has recently joined our Upper Southern Support Services team in a newly created role.

Nish is a certified health coach and health and disability advocate, bringing a wealth of experience to the team. Most recently, she spent five years at the Nationwide Health and Disability Advocacy Service. She will be working alongside Helen and Kate to support patients and whānau across the region.



Developing our online services

After almost 10 years working in the Blood Cancer NZ Support Services team, Rochelle Mills has recently moved into a new role as our Online Support Services Specialist.

In this role, Rochelle will be working to strengthen and expand our online services, helping us reach more patients and whānau throughout New Zealand. She will be running a quarterly post-treatment workshop series (see details below), hosting regular webinars, and overseeing our disease-specific online groups and closed Facebook groups.

New post-treatment workshop series

As part of our growing online support services, we're pleased to launch a new post-treatment workshop series for people with blood cancer who have completed treatment within the past year – often referred to as the 'survivorship' phase.

The six-week online programme will run four times a year. It includes a one-hour Zoom session each week and is designed to help you navigate life after treatment, build practical knowledge, and connect with others who understand your experience.

Topics include:

- Nutrition to support recovery
- Fatigue reduction and exercise
- Psychological wellbeing
- Self-empowerment and ongoing care
- Redefining "normal"
- Exploring the question "what now?"

To register your interest, please email **rochellem@bloodcancer.org.nz**



Protecting your immunity this winter

As we roll into the cooler months, many of us are more aware of the coughs, colds and flu bugs going around. People with blood cancers or blood conditions are often classified as immunocompromised. While this does mean you're more vulnerable to infection than other people, it does not mean you're destined for illness.

Taking a proactive approach can empower you to feel safer this winter. Here are some practical steps you can take to help prevent getting sick this season:

- **Eat plenty of fruits and vegetables.** This will help keep your immune system in tip-top shape. Eat a variety of colours so that your body can use nutrients, minerals, and antioxidants to give your infection-fighters the fuel they need.
- **Prioritise rest and sleep.** While this is not something people commonly think about when boosting their immunity, 7-9 hours of regular sleep can help your body heal and recover from the stress of the day.
- **Stay active.** Exercise (within moderation) can promote the circulation of immune cells and reduce stress hormones. As a bonus, moving your body also helps lessen fatigue. Consider gentle yoga or walking to start out.
- **Talk to your haematologist or GP about vaccines** that can keep you safer this season. These recommendations may change depending on your age, medical conditions and what treatments you're on.
- **Always use hand hygiene.** Remember to wash or sanitise your hands before eating or touching your face, and after using the toilet. Keep a travel-size sanitiser gel in your bag or purse for easy access.
- **Consider wearing a mask** in crowded situations like on public transport or at large events. Remember, a well-fit N95 will give you more protection than a surgical mask.
- **Tell your sick loved ones to please stay home** to prevent illness from spreading to you and the wider public.

Remember that everyone is different. People have different bodies, treatments, conditions and risk factors. There may be points when you are more or less vulnerable to infection. If you feel unwell, please seek advice from your medical team. Keep in mind that it's impossible to never get sick – but by making proactive decisions, you can reduce your risk, stay connected to your loved ones and continue to take part in your community.

If you decide to take any supplements, let your treatment team know. They can make sure that what you're taking won't interact with any treatment you're receiving.

Lyn's second chance at life

In 2021, Lyn had recently retired after a long and varied career in the business world. She and her husband had moved to Lincoln and were looking forward to enjoying this next stage of their lives.

Then Lyn's health took a turn. Between thyroid issues and a cough she just couldn't shake, it wasn't the start to her retirement she'd hoped for. She began having all sorts of investigations to figure out what was going on.

"I had a blood test a week before Christmas," Lyn says. "They were monitoring my thyroid because I was quite ill – like a zombie, really."

In the lead-up to Christmas, she felt as though she might be coming right. But then things went south. "On Christmas Day, I was just a mess, and on Christmas night, I saw angels," she says. "I nearly died."

Her husband went to ring the ambulance, but Lyn stopped him, promising she would go to the medical centre the next day.

On Boxing Day, she was started on antibiotics. When she saw her regular GP a few days later, he ordered urgent blood tests and rang her soon after with the results.

"He asked how I was feeling, and I told him I felt really lousy," Lyn recalls. "He said, 'You're going to haematology tomorrow. You're having a bone marrow biopsy, a scan, blood tests – the whole works.'"

At the hospital, a doctor took Lyn and her husband into a room. He explained that within just one week, one of her blood results had gone from being in the normal range to showing over 70% blasts, indicating she had acute myeloid leukaemia (AML).



Lyn is grateful for every Christmas she gets to spend with her family

> "He said, 'You're going to haematology tomorrow. You're having a bone marrow biopsy, a scan, blood tests – the whole works.'"

"I said to him, 'What's the treatment?' and he told me there wasn't one," Lyn says. "He told me that, in my case, being over 65 meant I wasn't eligible for a stem cell transplant."

"So I asked, 'How long have I got?' and he told me five to eight weeks."

Before Lyn and her husband could fully take in the news, they were visited by another specialist who spoke to them about a clinical trial for a new drug. "They said this trial had just started, and that I would be eligible to go on it, but I would need to start very quickly," Lyn recalls.

> They said this trial had just started, and that I would be eligible to go on it, but I would need to start very quickly...

It seemed like the only option available, and Lyn didn't need any convincing. She didn't know it at the time, but she was signing up for the first New Zealand trial of venetoclax.

Just days later, Lyn was back at the hospital to begin treatment. At first, it made her very sick. "It was just the combination of everything at the start – with the chemo injections, the venetoclax and the antibiotics," she says. "It was all a shock to the body. I was eating very little, and I was up to the toilet every five to ten minutes."

Lyn was given a break to allow her body to recover, then put back on the venetoclax at a lower dose. She was told that even with this treatment, she might still only have 11 months left to live.

"I didn't think I'd see Christmas," she recalls.

Lyn was desperate to talk to someone about how she was feeling. She researched what support was available and ended up connecting with Kate, her local Blood Cancer NZ Support Services Coordinator.

"Kate was brilliant," Lyn says. "I caught up with her one day, and she was just lovely. I told her that even my friends couldn't grasp what I was going through. She was really good."

Lyn also regularly attends Blood Cancer NZ support groups. She enjoys hearing from the different speakers that come along, and she's made a good friend who also has AML. "He and I have a lot of contact," she says. "It's good to have somebody to talk through everything with."

It has now been four and a half years since Lyn was diagnosed. "I've been extremely blessed," she says. "I'm fortunate that it has worked so well for me. And overall, I've had so few side effects."

The venetoclax trial has now ended, and Lyn is on a 10-week treatment cycle, which involves two weeks of venetoclax and 10 days of chemo injections. She has blood tests before the start of each round.

Although the treatment is still working, Lyn's haematologist recently reminded her that this is not a cure, and it's likely her leukaemia will come back at some stage.

Lyn has no idea how long it'll be before that day arrives, but she is glad to have taken part in the trial, and that venetoclax is now funded for Kiwis in her situation – giving people an option where previously they wouldn't have had any.

She finds that during chemo weeks, she needs to take things day by day. "I might get stomach cramps or feel lethargic, and I'll just want to crash a bit," she says. "It's unpredictable, so I don't plan anything during that time."

But otherwise, she feels quite good. "Most of the time, I can still carry on quite normally, but I do have to pace myself. Although I say to people, 'If you take me out shopping, I'll cope!' I can always handle an afternoon of shopping."

Her diagnosis has been life-changing in ways she didn't expect. Knowing she may be short on time has given her a greater appreciation of life, and she says it's also made her more direct with people.

"Sometimes that doesn't go down well," she laughs. "But I just don't hold back!"





How we can help

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 booklets include:

- Blood Cancers in Primary Health Care
- Blood Cancer Awareness for New Zealand's Rural Sector

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 **@bloodcancernz** 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
@BCNZMyeloma
@BCNZChronicLeukaemia
@BCNZAcuteLeukaemia
@BCNZBloodDisorders
@BCNZHaemochromatosis
@BCNZMPN

Support for young adults and parents:

@BCNZYoungAdults
@BCNZParentsGroup

Further support pages:

@BCNZSupportPersonConnect
@BCNZBereavement
@BCNZCARTTherapy
@BCNZConnect (Blood Cancer NZ & Health Professionals Connect)

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Blood Cancer NZ