Blood Cancer NZ

LymphomaToday

WINTER 2026



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Kia ora, welcome to your latest edition of Lymphoma 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

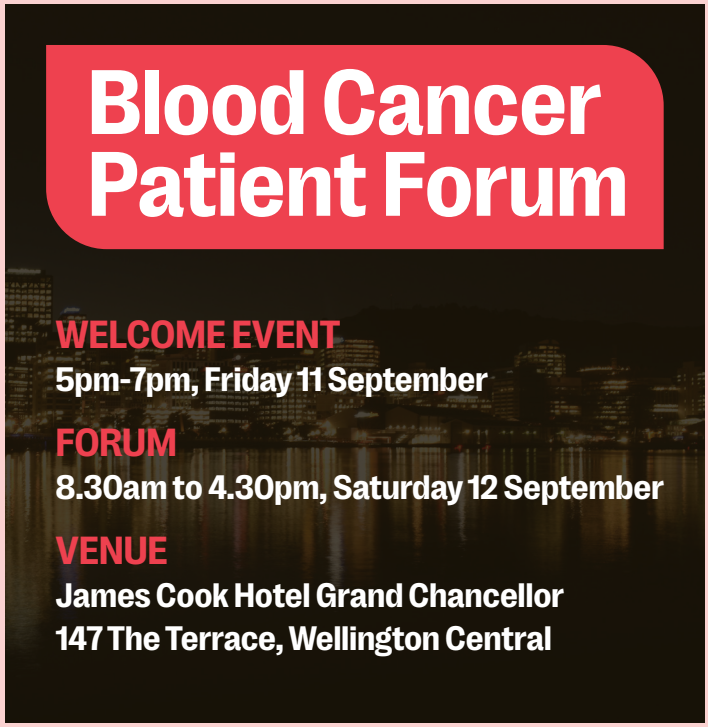
On the horizon

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 voice of reassurance

In 2010, after a long career working as an engineer on planes and trains in England, Trevor moved to New Zealand with his wife, Pat. The couple spent the first year living with their daughter's family before eventually buying a parcel of land and settling in Warkworth.

Life looked very different from the one they had left behind. Retirement allowed them to slow down and enjoy the simple things. Mornings often began with sheep grazing outside their window and ducks from the nearby pond tapping on the glass at breakfast time.

But in the midst of their idyllic new life, Trevor's health started to decline. In 2015, he underwent surgery for bladder cancer, followed by a second operation the following year when it returned.

Fortunately, the cancer remained in remission after that. But in October 2018, Trevor noticed something was off again.

"I was just feeling really rough," he recalls. "I'd go out the front door and start walking, and I couldn't even get to the top of the hill."

Concerned by his lack of energy, Trevor visited his GP.

"I said, 'I don't know what's wrong, but I'm just feeling really lethargic and tired.' She did a good check-up and said, 'Do you know you've got a lump in your neck?'"

He was sent across the road for a scan. Later that same afternoon, his GP called to tell him it looked like cancer.

Over the following weeks, the lump in Trevor's neck grew rapidly, from the size of his thumbnail to the size of an orange. Three biopsies eventually confirmed a diagnosis of follicular lymphoma. Eight weeks after first seeing his GP, he began six rounds of rituximab and bendamustine treatment.



Throughout his journey, Trevor has focused on trying to stay positive

"I was fine for the first three doses," he says. "Then on the fourth dose, I had a temperature spike."

Trevor was admitted to hospital and started on antibiotics. The same thing happened during his fifth round of treatment.

"Then before the sixth lot, the consultant came in and told me I wasn't actually getting any bugs, I was just intolerant to the chemo – but they were going to give it to me anyway!"

Despite the setbacks, Trevor completed treatment and gradually recovered. It took another six or seven months for his blood results to return to normal.

"But they said, 'If it's worked, you'll get a good six years in remission.' And believe it or not, six and a half years later, I got out of bed one morning and had pains all down my side, and a tight feeling across my chest."

> 20 minutes later, the doctor came back with the results of the blood test and a letter, saying, ‘Take this to the hospital – and I suggest you take an overnight bag.’

Because it was early December, Trevor decided it was best to get checked before Christmas. He visited his doctor and had a blood test.

“20 minutes later, the doctor came back with the results of the blood test and a letter, saying, ‘Take this to the hospital – and I suggest you take an overnight bag.’”

Trevor and Pat assumed his heart was playing up. But the next morning, after an X-ray and CT scan overnight, he was told he had a large tumour. “It was six and a half centimetres in diameter, 19 and a half centimetres long, and was wrapping itself around my aorta,” Trevor says.

He was told that he would need to start treatment on December 30th. “We’d thought eight weeks to starting treatment was quick the first time, but this time it was only three weeks!” he says.

Trevor underwent six rounds of R-CHOP, each three weeks apart.

“The side effects of that, compared with the previous lot, were quite a nuisance,” he says. “This time, my hair did fall out, including my beard and my eyelashes. I also had nausea, and it lowered my blood pressure.”

But more than anything, Trevor found the fatigue difficult to adjust to. Having never been someone who slept during the day, regular nana naps soon became an essential part of his routine.

Throughout both diagnoses, Trevor and Pat have drawn strength from the support of family and friends. They have also found encouragement and connection through Blood Cancer NZ’s support group in Orewa.

“The first time I got lymphoma, I’d started chemo in December, and we went to our first meeting in February. I introduced myself and said that I’ve got follicular lymphoma and I’ve just had my first round of treatment,” Trevor recalls.

“There was this old guy sitting across the room, and he could probably tell I was a bit down, and he said, ‘I’m 84, I had that 17 years ago, and I’m still here.’ And that was the biggest perk, because I thought to myself, ‘Well, if he’s been here for 17 years, I really haven’t got to worry.’”

For Trevor and Pat, that moment explains why they have continued attending the group all these years. As much as they value hearing from others who understand what they are going through, they also know that Trevor can now be that source of reassurance for someone newly diagnosed.

Now, nine weeks after completing R-CHOP treatment, Trevor is waiting for a PET scan to confirm whether his cancer is in remission. In the meantime, life is beginning to return to normal. He’s back in the garden, keeping the neighbours supplied with fresh vegetables and sharing homemade jams, pies and pickles.

“The secret is positivity,” Trevor says. “You can either lie in bed and say, well, I’ve got cancer, and that’s the end of it. Or you can say bugger this – I’m going to get through it!”

Fast facts: Follicular lymphoma

- Follicular lymphoma is a type of non-Hodgkin lymphoma affecting approximately 190 New Zealanders each year
- It gets its name from the circular arrangement of lymphocytes inside the lymph nodes
- Follicular lymphoma usually grows slowly over months or years.

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.

Lily's journey of determination

In April 2025, Lily had just finished her first year at university. A passionate and hard-working student nurse, she was looking forward to the next stage of her training. She had no idea she was about to experience healthcare through the eyes of a patient.

By then, the sports-loving 19-year-old had been dealing with unexplained symptoms for almost a year.

"Around June 2024, I started feeling really tired every day," Lily recalls.

A visit to her GP revealed low iron levels, and she began taking supplements. But the fatigue continued, and other symptoms soon followed.

"I started losing quite a lot of weight," she says. "I was wheezing and coughing every day, but I thought maybe I was just getting asthma."

Night sweats and recurring sinus infections followed, but each issue seemed easy to explain away.

It wasn't until Lily went for an unrelated scan that the real cause of her symptoms became clear. "In April, I was at the hospital getting a scan on my brain," she says. "While the X-ray was above me, they saw a mass next to my heart. It was pressing on my windpipe."

Lily was admitted to hospital, where an oncologist explained that she suspected lymphoma. A biopsy was taken, and Lily was sent home to await a PET scan the following week.

Determined not to jump to conclusions, she tried to stay positive while waiting for answers. But just a few days after the scan, everything changed.

While out for a walk, Lily received a call from her oncologist asking her to come in for an appointment the following morning.



Between treatments, Lily was determined to carry on with life as normal

"I asked if she could just tell me the results over the phone," Lily says. "So she did – she said it was Hodgkin lymphoma."

The diagnosis was difficult to process.

"It was weird," she says. "I knew I had cancer, but it didn't seem like it was happening to me."

The news came just before Lily's nursing placement was due to begin. Rather than putting her life on hold immediately, she was able to complete the placement while waiting for treatment to start.

"It was a good distraction," she says. "It kept me busy."

Soon after, she had a port inserted, underwent treatment to preserve her fertility, and began eight rounds of chemotherapy on a fortnightly cycle.

“I felt tired and quite nauseous for the first day or two after each round,” Lily recalls. “By the fifth or sixth round, I started vomiting.”

Despite the side effects, Lily was determined to keep living life as normally as possible. “I was still doing everything,” she says. “I was working, going to nursing school and going to the gym.”

Then one Tuesday morning, she woke up struggling to breathe. With classes she didn’t want to miss, Lily pushed through and carried on with her day, even working that evening.

“I was still short of breath, and I was getting sharp chest pain,” she says. “I probably should have done something about it then, but I was worried that I’d go in and it would be nothing.”

By the time she attended her next chemotherapy appointment on Thursday, she was feeling awful. A chest X-ray revealed pneumonia, and she was admitted overnight before being sent home on antibiotics.

“Then the next day, I felt like I couldn’t breathe, so I called, and they told me to come in again. They wanted to keep me in for the night, but I wanted to go home because I had an exam the next day.”

Hospital staff encouraged her to stay, reassuring her that she could leave temporarily to sit the exam.

“I stayed the night at the hospital and left at 8.30 in the morning to sit my exam, which was just across the road, and then I came back. It was so weird – I was sitting in my exam with my hospital bracelet still on under my hoodie.”

While balancing cancer treatment with study wasn’t easy, Lily found comfort in some unexpected places. One of the highlights of her chemotherapy appointments was the friendships she formed with other patients.

“When I went for chemo, I’d always sit next to this lady in her 70s,” Lily recalls. “We were on La-Z-Boy chairs, and it just felt like we were at the nail salon getting manicures or something, talking and laughing the whole time. It was really nice. I would look forward to it.”

Lily also found support through Kate from Blood Cancer NZ, who provided information about her diagnosis and connected her with other people affected by blood cancer through support groups and the Young Adults closed Facebook group.

“It was so nice to talk to people who were going through something similar,” she says, “because none of my friends could relate.”

Today, Lily is cancer-free. She still has a chest X-ray every three months to keep an eye on things, but so far, every result has been positive.

As she works towards completing nursing school, Lily hopes to get a job in oncology, supporting others through the challenges of cancer treatment. Having experienced life as both a patient and a future healthcare professional, she knows just how much compassionate care matters.

“In a way, I’m grateful that it happened, because I learnt a lot from it,” she says. “It’s made me appreciate life more.”





Fast facts: Hodgkin lymphoma

- Hodgkin lymphoma makes up roughly 10% of all lymphomas with about 130 diagnosed in NZ each year
- The majority of those diagnosed are aged between 15 and 35
- Hodgkin lymphoma is the name given to lymphomas that have a special kind of cancer cell, called a Reed-Sternberg cell.

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)

Call us toll free on 0800 15 10 15
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Blood Cancer NZ