

Lifeblood

The difference *you* make



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From Peter

Hen's teeth

Advocating on behalf of blood cancer patients and bringing about political change to improve health outcomes is endless and can feel like extracting teeth from chickens.

However, some of those teeth were successfully extracted over the last year with the creation of the NZ Cancer Agency and the announcement of a Cancer Action Plan - how well the agency will meet expectations, and what the plan will deliver, remain to be seen

With your support, LBC's priorities remain convincing Government of the need for earlier access to improved medicines, increased budget allocation for cancer treatments, greater access to clinical trials, and the need to reduce the inequities in cancer health care that exist across the country.

There have been some wins with successful submissions for funded treatments including Ruxolitinib, Lenalidomide, Rituximab, Venetoclax and Bortezomib – great news for some patients. We'll continue advocating for other critical treatments including Ibrutinib, Carfilzomib, Pomalidomide, Daratumumab, Midostaurin, Obintatuzumab and CAR-T.

LBC has also made submissions in support of a Rapid Access Scheme for new cancer medicines. In addition we've joined the call for a formal review of Pharmac in relation to budget and its focus on financial savings – rather than saving lives. These continue to be significant issues and will be in our 'cross hairs' for 2020 and beyond.

LBC is part of a collective advocacy group (CANGO) that represents a broad range of cancer organisations – this group has developed a comprehensive manifesto and a shared voice on key cancer issues that are designed to inform Government thinking and benefit the patients and families we support.


Thank you to each of you whose donations make this advocacy work possible.


Peter Fergusson
Chief Executive
Leukaemia & Blood Cancer New Zealand




Peter has a close shave with LBC's Head of Support Services and Operations, Emma Barker during "Shave the Boss"

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

 0800 15 10 15

 info@leukaemia.org.nz

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 www.leukaemia.org.nz



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

Support during lockdown

COVID-19 has added an additional level of anxiety and vulnerability for many blood cancer patients and their families. LBC's priority at all COVID-19 alert levels is to ensure patients and families are well supported in a safe way.

During Level 2 and higher, all community patient support groups took place online whilst face-to-face contact with patients was minimised. Instead support staff concentrated on phoning, texting, emailing and providing online support to the most vulnerable people.

A key focus during COVID-19 was ensuring reliable and up-to-date information on managing blood cancer and health was available to all patients.

LBC provided a range of interactive seminars on health and psychological well-being to help patients through these difficult times.



LBC's Support Services team prioritised staying in touch with the most vulnerable patients during COVID-19

Continuing to deliver emergency financial support like grocery vouchers or help with transport to treatment was a top priority. In addition LBC secured priority assistance for online grocery shopping for patients by supplying them with a special code.

All of this additional help is made possible by the gifts LBC receives from people who choose to donate. Thank you to everyone who has helped blood cancer patients and families get through COVID.

A problem shared...

Q Since having cancer treatment I've noticed my memory isn't as good as it used to be and I sometimes struggle to focus, is this normal?

A Many people who have been through cancer treatment describe forgetfulness or difficulty concentrating - this is often called "Chemo brain".

It can be a frustrating side effect and it's important to let your doctor know if it is impacting on daily life as they may be able to identify and correct medical problems that could be causing the condition.

Behavioural and lifestyle changes can also help including relaxation techniques, gentle exercise or using planners and smartphones as ways to keep track of important tasks or as a memory aide.

To receive the 'Chemo brain' factsheet or for more information and support call 0800 15 10 15 or visit www.leukaemia.org.nz/information

Sally Black, Senior Support Services Coordinator Central Region, has worked within the health sector in family support and community social work roles for many years before joining the LBC team. Sally has a passion for people and ensuring they are well resourced, informed and supported during challenging times.



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



Emotional support the most important thing

LBC not only supports patients and families going through blood cancer, but also those facing a myriad of other debilitating blood conditions such as aplastic anaemia, sickle cell anaemia and thalassaemia.

Dad of two Anthony McQuoid has been living with his blood condition all his life.

As a young child Anthony experienced severe anaemia - but doctors weren't able to identify the cause. It was only later, after multiple tests and ongoing transfusions that Anthony was told he had a blood condition called Haemoglobin Volga. As Anthony's wife Meredith explains:

"It's a very rare, chronic condition which means Anthony's blood can't carry enough oxygen around his body, he's the only person in Australasia to have it which has made it especially hard to deal with."



Maia, Meredith, Bella & Anthony enjoying family time



LBC's Kids Club really helps Maia and Bella cope with their Dad's illness

Anthony's condition damaged some of the small blood vessels in his body – this affected blood flow to his brain. Four years ago, at the age of just 38, he started to experience multiple strokes and had to have urgent brain surgery to re-route blood flow to parts of his brain. It was a very difficult time for the whole family, as Meredith explains:

"Anthony being so ill was especially hard on Maia because she was that little bit older, she knew more about what was going on – it was a really scary time for all of us."



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



Meredith's nursing background means she can help interpret complex medical information for Anthony



“Anthony being so ill was especially hard on Maia because she was that little bit older, she knew more about what was going on – it was a really scary time for all of us.”

“We are so grateful for the support we receive from LBC – especially for Bella and Maia. LBC helps families with lots of different things like getting to appointments, parking at hospital or food vouchers...plus emotional support which for us was the most important thing. LBC's Kids Club really helps our girls - we've had a couple of really tough years and LBC has been able to make it a bit easier for us.”

The support that helps families like the McQuoids is not funded by the Government but by thousands of warm-hearted Kiwis - thank you to everyone who chooses to help.



Fast Facts: Haemoglobin Volga

- A very rare blood condition affecting haemoglobin
- Haemoglobin is a protein molecule in red blood cells that carries oxygen from the lungs to the body's tissues and returns carbon dioxide from the tissues back to the lungs
- Symptoms include severe anaemia and damage to small blood vessels

Thankfully Anthony made it through his brain surgery but it has left him with lasting side effects, in addition, his condition means he is on a relentless cycle of treatment every six weeks where he has to go into Auckland City Hospital to receive a transfusion of red blood cells, as he explains:

“I get hooked up to the machine on the Friday and it takes me until Sunday to recover and then by Monday I am feeling OK again. By the fourth week I start going downhill and it becomes a struggle - by week six I'm hanging out for the treatment and the cycle begins again.”

Anthony's condition has been hard on the whole family - a few years ago things started to get really tough so Meredith got in touch with LBC:

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Your donations made the difference

Last year, when Christchurch resident Tori was just 17 years old she developed a sore neck, little did she know the path that lay ahead:

"After a couple of weeks when my neck didn't get better I went to the doctor - she tried a few things but nothing helped. I was starting to worry because I could feel lumps in it so I requested a different doctor. He felt my neck and straight away rang the hospital specialist - they recommended an ultrasound."

The ultrasound showed that Tori's lymph nodes were enlarged, she was referred for a biopsy:

"When the doctor told me I had Hodkin lymphoma it didn't feel real. Mum was working on the West Coast at the time but came back to Christchurch to be with me - that's when it dawned on me that it was serious."

Tori was referred to LBC and Matt Eby, one of the Support Services team got in touch. Matt was able to answer Tori's questions and provide booklets to share with her family. As she explains:

"It was easier to talk to Matt about my cancer because I didn't have to worry about his feelings like with family. I knew what he told me was reliable and specifically made for people like me."

Tori had six months of chemo - it was tough. At times she felt unwell but was determined to continue working in her hospitality job:

"The more chemo I had, the worse I felt. I got about half-way through and felt so rubbish I had to cut my hours down - my boss said I could build them up again when I was feeling better ... then COVID hit and I lost my job!"



Tori with her portacath during treatment

“ I want to say thank you to all the people who donate to LBC - it's a great thing you are doing and it definitely helped me when I was struggling.”

LBC was able to provide Tori with practical help like taxi vouchers to get to appointments and grocery vouchers to buy healthy food. After treatment finished she had a scan during Level 4 lockdown restrictions - it was tough as she had to go by herself whilst her mum waited in the car. It was a nervous wait for the results:

"Because of COVID I had to get my results by video chat which felt weird. When the doctor told me I was in remission I was shocked... it didn't feel real."

Tori continues to be in remission and, inspired by her cancer journey, has started studying towards a Bachelor of Medical Imaging. She really appreciates the support she received - made possible by donations:

"I want to say thank you to all the people who donate to LBC - it's a great thing you are doing and it definitely helped me when I was struggling."



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Cancer triple blow

As many of us know, life can change in an instant. For Coleen, everything changed 11 years ago when she was first diagnosed with leukaemia.

Thankfully chemo put her leukaemia into remission but just a year after finishing treatment, Coleen was diagnosed with Non-Hodgkin lymphoma.

Getting through cancer once was tough enough, for Coleen facing this second blood cancer was incredibly difficult. She began another regime of chemo followed by a stem cell transplant - her lymphoma was put into remission. However the good news was short lived – within 15 months Coleen was back in Dunedin Hospital, as she explains:

"It was a roller coaster... after the transplant I was feeling better and we thought the cancer was gone...but then I started to feel unwell again and went back for more tests – that's when they told us it was back."

More rounds of chemo put her lymphoma back into remission, but just two weeks later Coleen was delivered yet another blow. She was diagnosed with advanced bowel cancer:

"It was a shock but my philosophy is to take each day as it comes – when I first had my lymphoma I was really unwell and the doctors didn't expect me to live - you just do what you can and carry on as best you can."

Thanks to the generosity of Kiwis who choose to donate, LBC is able to provide crucial support to help patients and families get through cancer, as Coleen explains:

"At the start we didn't realise how important LBC's support was going to be....It was good to have someone who was so knowledgeable and who could answer all our questions – it really helped."

Coleen's battle with lymphoma isn't over but despite it all she maintains a positive attitude:

"LBC's support through all this has been really important. When I am well enough we attend the support groups – it's good to meet other people going through similar situations. We're all in the same boat and I try to help where I can.... I always try to be positive and make people laugh."



Dunedin - new Support Services office



Leukaemia & Blood Cancer New Zealand's Dunedin Support Services office has recently moved to a new location in the Harvest Court Mall in George Street.

The new office is designed to provide a welcoming space and will enable LBC to continue to run support groups, education sessions and meetings - providing vital help and support to blood cancer patients and families.

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Gene sequencing – a Vision to cure



Members of the research team in the LBCRU lab

Blood cancers, like all other cancers, are caused by mutations in genes (the building blocks of our cells).

Studies have shown that the type and number of mutations can vary greatly from patient to patient even though their cancer cells may look almost identical under the microscope.

Identifying particular mutations in an individual's blood cancer is critical as it dictates how the cancer behaves, and how it will respond to treatment.

A year ago, only three genes were routinely analysed for mutations in blood cancer patients in most New Zealand hospitals. This meant that doctors had very limited insight into the spectrum of mutations that might have important consequences for the clinical course of the cancer, and help identify the best treatment plan for their patients.

With the support of donations from thousands of caring Kiwis, scientists at Leukaemia and Blood Cancer Research Unit (LBCRU) have developed a new test, which looks for mutations in 78 genes using a "Next Generation Sequencing" platform.

More than 100 patient samples, including 70 with acute myeloid leukaemia (AML), have been tested. So far results have shown that no two patients have exactly the same mutations even though their clinical symptoms may be similar.

The research team have successfully implemented the Myeloid Gene Panel for Auckland patients and are working to make the test available for all New Zealanders with myeloid blood cancers. As part of the ongoing research project they are also planning to develop a gene panel for patients with lymphoid blood cancers.

It is hoped that rolling out the gene panels to patients across New Zealand will enable doctors to make more informed decisions about patient treatment and ultimately lead to better outcomes for patients.



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Vision to Cure. Mission to Care.

If you would like to get in touch:

Call: 0800 15 10 15

Email: info@leukaemia.org.nz

Visit: www.leukaemia.org.nz

Mail: PO Box 99182, Newmarket, Auckland 1149

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