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lifeblood

News from Leukaemia & Blood Cancer New Zealand



our mission is to care, our vision is to cure

leukaemia.org.nz



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YOU SPOKE, WE LISTENED

Thank you to everyone who took part in our 2018 Community Survey.

We wanted to know a little more about you as a supporter of Leukaemia & Blood Cancer New Zealand (LBC), and about what you like reading about in Lifeblood. Results showed us that you want to read about patient stories, research updates and about our wonderful fundraisers.

You also told us that you want to know about the impact of your donation, and how your support makes a difference to haematology research, and to the lives of thousands of Kiwis living with blood cancer.

We hope that you enjoy reading this edition of Lifeblood, and we are delighted to announce that our 2018 Impact Report 'Rising to the Challenge' is now available at www.leukaemia.org.nz

Do you have any feedback, or have a story you'd like to share in an upcoming issue of Lifeblood? Please get in touch with the team on **0800 15 15 10** or at info@leukaemia.org.nz

LBC is proudly supported by



YOUR SURVEY RESULTS

HOW DID YOU HEAR ABOUT LBC?

53%
I know someone living with blood cancer or a blood condition



19%
I took part in an event



13%
I donated to a friend's fundraising page



WHAT MOTIVATES YOU TO SUPPORT LBC?

64%
I believe in research to find better treatments and cures



57%
I believe that no-one should have to face blood cancer alone



52%
I'd like the services to be there should I or a loved one need them in future



WHAT INTERESTS YOU MOST?

63%
Research news



44%
Patient stories



35%
Fundraising updates



PATIENT STORY

Colleen Taylor was diagnosed with multiple myeloma on the day of her partner Julie's graduation.

"I was receiving treatment for osteoporosis, when I had a fall and fractured my sternum" said Colleen. "I asked my doctor if that meant that my medication wasn't working, and she ran some blood tests to see if there were any underlying problems".

"We were in Auckland for Julie's graduation when I took the call. I decided to wait until the next day to tell Julie, as I didn't want anything to spoil her special day – she had worked so hard for it"

Myeloma (also known as multiple myeloma or plasma cell myeloma) is a cancer of the plasma cells that usually arise in the bone marrow. In the early stages there may be no symptoms, and myeloma may be detected by coincidence during a routine blood test, as was the case with Colleen.

"My GP told me that while there was no cure for myeloma, there are treatments that can help with the progression of the disease" said Colleen.

"When Colleen told me that she had blood cancer there was a lot of crying" said partner Julie. "Living in a rural area, we felt very isolated, and got in touch with LBC to register for local support groups and connect with others going through something similar".

Colleen's treatment included chemotherapy and a stem cell transplant. It was during her course of chemotherapy that Colleen began to lose her hair. In solidarity, Julie organised a Shave for a Cure event with colleagues at the



SUPPORT FOR PATIENTS AND FAMILIES



"Feelings of isolation when living with a serious illness can be very common. Not just for the patient, but also their families or caregivers. Recently a patient with follicular lymphoma came to his first support group in Christchurch. Prior to attending this support group, he had felt like the only person in the world with this particular condition."

Donations from communities around the country means that we can run support groups while providing individually tailored one-on-one support, and do all that we can to make sure that no-one has to face blood cancer or a blood condition alone. Thank you"

Matt Eby,
Support Services Team Regional Manager

school where she is a teacher, in December 2015.

"Even though you are there with your loved one on their cancer journey, sometimes you can feel so useless," said Julie. "You try to act normal, but it's so hard knowing that there is nothing that you can do to make them well again"

"Knowing there was nothing I could do about Colleen's actual illness, I wanted to raise awareness and fundraise for LBC to make sure that their services are there for everyone who needs them. It's also important to me that funding is available for research into better treatments and even a cure one day"



Colleen and Julie kindly shared their story, and Julie 'braved the shave' once again to help raise awareness for Shave for a Cure 2019.

Find out more about Shave for a Cure at www.shaveforacure.co.nz

BIG BOOST FOR BLOOD CANCER RESEARCH AT OTAGO UNIVERSITY

Two top researchers at the University of Otago have both received national research grants, totalling over \$130,000, in LBC's 2018 funding round.

Both Professor Dr Ian Morison and Associate Professor Dr Julia Horsfield work in the Department of Pathology, Dunedin School of Medicine but they are tackling very different research areas with their funding.

Dr Morison is investigating myeloma which is one of the most common blood cancers and is currently an incurable cancer of the plasma cells.

"Our goal is to develop an improved biomarker as part of a wider programme of research into myeloma" states Dr Morison. "As drug treatments improve, previous biomarkers used to see how well the body responds are insufficiently sensitive for this new era."

Dr Horsfield's project focuses on Acute Myeloid Leukaemia (AML) and the need to understand how leukaemia emerges from specific genetic mutations.

This investigation is significant not only because the global incidence of AML is increasing but also that strikingly, New Zealand now has one of the highest incidences in the world. Although cure rates for AML are gradually improving, results for older patients, who cannot tolerate intensive chemotherapy, remain poor.



HOW YOUR DONATIONS FUND RESEARCH



Some of the team at the LBCRU, led by Professor Peter Browett and Professor Stefan Bohlander

Your donations to research, channelled through LBC, now total \$7 million since the first grant in 2011. Your donations remain one of the main sources of haematology research funding in New Zealand.

The Leukaemia & Blood Cancer Research Unit (LBCRU) sits within the University of Auckland's Faculty of Medical and Health Sciences, and was established in 2013 with an initial commitment of \$1,250,000 from LBC.

The team is identifying blood cancers' molecular markers that will allow more targeted medical care, avoid aggressive treatments when they are not necessary, and pave the way to new therapies for blood cancer and blood conditions.

MOLECULAR TEST BREAKTHROUGH FOR AML PATIENTS

Earlier this year, the gene panel developed by the LBCRU for testing acute myeloid leukaemia (AML) patient samples became available to cancer clinicians in Auckland. Now all adult patients with newly diagnosed and relapsed AML have samples collected for DNA preparation and analysis using this 70-gene myeloid panel.

HK, a man aged 57, was diagnosed with AML in August 2015. Molecular studies showed that his leukaemia cells had two abnormal genes: the NPM1 mutation and the FLT3 ITD mutation. The second carries a high risk of relapse so, in addition to chemotherapy, this is usually addressed with a bone marrow transplant.

But transplants are risky. The LBCRU estimates that between 15 and 20 percent of patients are at risk of dying in the first year from complications. It also commits the patient, family and caregivers to four weeks in hospital and two months of follow up care. It's usually a year before they resume a normal life.

As HK was in remission after the first of four treatments, instead of going straight to a transplant, his blood and bone marrow were re-tested at the LBCRU using a super-sensitive new test at three-monthly intervals. Using the NPM1 marker, which is seen in about 30 percent of AML cases, the team's new molecular test can find one leukaemia cell in 100,000 normal cells.

Every test after treatment was negative. Clinicians say HK is probably cured. However, if the tests had turned positive, a transplant could have been arranged before a relapse without the need for further chemo or radiotherapy.

HK's good news story will soon be that of many New Zealanders living with blood cancers thanks to this new molecular test for a common leukaemia.



Research at the LBCRU is funded by your generous donations



Professor Stefan Bohlander using the gene sequencing machine at the LBCRU

THE GOOD DEED FEED

A good news round up from around New Zealand

Christchurch head shave brings in the dollars

The locks fell and the dollars rose as boys at Christ College, Christchurch raised \$12,500 for Leukaemia & Blood Cancer New Zealand (LBC).



The stage in the Assembly Hall became a hair salon as the willing candidates lined up for a number one from professionals Rana Thomas and Victoria Beattie from Haircuts for Haircuts who donated their time and expertise.



Top fundraising honours went to Louis Gunn whose enthusiasm for the cause saw him receive sponsorship of \$1,440. Our thanks go to all who took part.



Same Shirt, Different Day

Whakatane local Owen Vaughan, has just completed walking the Te Araroa Trail, a 3,000km pathway from Cape Reinga to Bluff, while raising funds for LBC. Owen is a member of The Rotary Club of Whakatane, which is helping him to reach his \$10,000 fundraising target. Head to Owen's Facebook page 'Same Shirt Different Day' to find out more about his incredible challenge.

The Big Bike Trip finishes in Taupo

After cycling through Asia for 12 months, Freddie and Arthur Gillies and Sean Wakely have finished their epic adventure at the Lake Taupo Cycle Challenge. The three friends have raised over \$34,000 for LBC, and our thanks go to the team for all the riding and to The Beauty Collective for being such a great sponsor and LBC supporter.

Spring into Summer in Rotorua

In October, over 200 people supported the annual Quota International of Rotorua's 'Spring into Summer' fashion show, to raise an incredible \$9,000 for LBC. This event is one of the Rotorua branch's biggest fundraisers of the year, and showcased the spring collection from Parrots on Hinemoa, along with a raffle that was supported by generous Rotorua businesses. Our thanks go to all members of the club for their time and effort into making this such a successful event.



Donal and Tim from the LBC Support Services team proudly show off their teal caps on the LBC car!

THANK YOU TO EVERYONE WHO 'PUT A CAP ON IT' FOR BLOOD CANCER.



Last year, Bridgestone once again urged New Zealanders to 'put a cap' on blood cancer, raising over \$37,000 for LBC.

New Zealand's support for LBC, and we loved to see all the creative ways people 'put a cap on it' to help beat blood cancer – from farmers and tractors, to kids and their bikes or tradies and their wheelbarrows."

Specially designed teal blue valve caps were sold by Bridgestone for \$2 each, with the sole aim of funding the support, research and advocacy work conducted by LBC.

We would like to thank everyone who got behind the cause and 'put a cap on it' by demonstrating support on anything that needs tyres: cars, bikes, wheelbarrows, trucks, golf carts, or prams to name just a few.

"While \$2 a valve cap may sound insignificant, collectively amazing individuals around the country raised over \$37,000 to support blood cancer patients and their families" said Bridgestone Director of New Zealand Business, John Staples.



"The teal caps are a great visual representation of

Bridgestone New Zealand launched its partnership with LBC in 2017, and since then has raised more than \$80,000 through the sale of blue caps. The Bridgestone team have raised a further \$50,000 by taking part in other LBC fundraisers Shave for a Cure, Stadium Climb Wellington and the Step Up Sky Tower Stair Challenge.

Te Haana Rikia and Melissa Tia (the Bridgestone Stair Bears Team) at Stadium Climb Wellington 2018



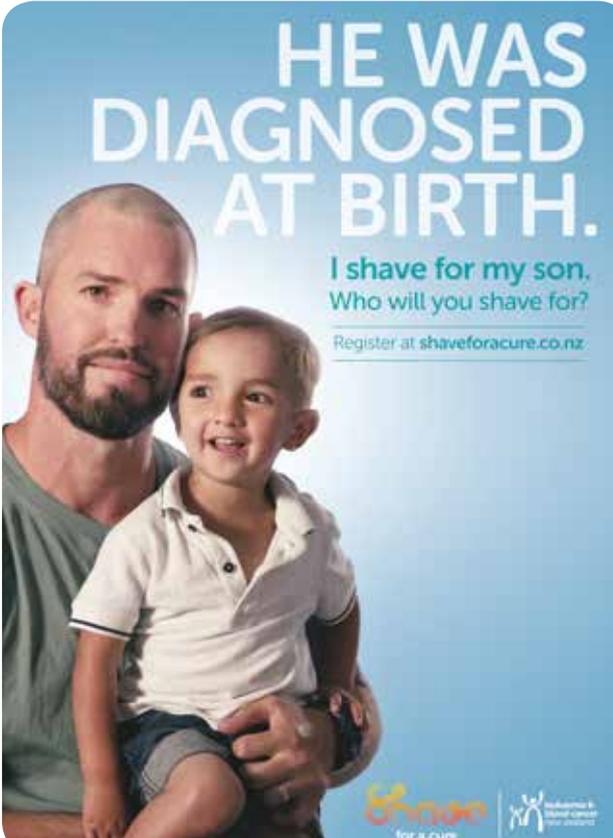
NOTICEBOARD

Dates for your diary

- 18 May** Firefighter Sky Tower Stair Challenge, Auckland
- 9 August** Step Up Sky Tower Stair Challenge, Auckland
- 2 – 8 September** Trek the Outback for blood cancer, Northern Territories, Australia
- All year round** Shave for a Cure, Nationwide
- COMING SOON** Stadium Climb
Dunedin & Wellington
www.stadiumclimb.co.nz

Find out more about all of our upcoming events at www.leukaemia.org.nz/get-involved

Want to organise your own fundraiser for LBC?
Contact Rebecca in our Community Fundraising team on 0800 15 15 10



HE WAS DIAGNOSED AT BIRTH.

I shave for my son.
Who will you shave for?

Register at shaveforcure.co.nz

Shave for a Cure | Leukaemia & Blood Cancer New Zealand



TREK THE OUTBACK FOR BLOOD CANCER

Join us in September 2019 for an incredible adventure. The Larapinta Trail is one of Australia's premier walking tracks.

From the old Alice Springs Telegraph Station to the peak of Mount Sonder, the trail stretches along the backbone of the West MacDonnell Ranges. This challenge will see

you trek over 60km of the famous trail. By fundraising and taking part in the unique experience you will be supporting patients and their families living with blood cancer throughout New Zealand.

For more information and to register your interest please visit www.inspiredadventures.co.nz/events/lbcnz-outback-2019

Support Services offices in:
Auckland
Christchurch
Dunedin
Hamilton
Wellington

For information about LBC's support services, plus a full list of our upcoming support groups in your area, please visit www.leukaemia.org.nz/support or call our Support Services Team on 0800 15 10 15.

Leukaemia & Blood Cancer New Zealand (CC24498) is a registered charity under the Charities Act 2005