A world-first “liquid biopsy” partly funded by the Leukaemia Foundation means that Australians with a blood cancer could soon have access to a simple blood test to monitor their disease.

Developed by Associate Professor Sarah-Jane Dawson and Professor Mark Dawson at the Peter MacCallum Cancer Centre in Melbourne, the blood test promises a new era of less invasive, more precise and effective management of blood cancers, in place of painful bone marrow or lymph node biopsies.

The test monitors tiny fragments of DNA emitted from cancer cells into the blood stream, called circulating tumour DNA (ctDNA).

Unlike traditional biopsies, ctDNA tests track disease status throughout the body; can be used at any time over the course of cancer treatment; and enable rapid adjustments if a patient relapses or fails to respond to a particular therapy.

Assoc. Professor Sarah-Jane Dawson has helped pioneer the development of ctDNA tests for solid tumours in breast and other cancer types, which now guide the treatment of some 500 patients from across Australia who are part of her research program.

Assoc. Professor Dawson said this world-first ctDNA test for blood cancers will also help to more rapidly advance the availability of new precision medicines and targeted therapies as these are developed.

“Not only does this new test promise clinicians and patients a more timely and accurate understanding of whether a cancer treatment is working, it gives scientists the ability to quickly and effectively evaluate how clinical trial patients are responding to new life-saving therapies,” she said.

Professor Mark Dawson said the liquid biopsy also addresses one of the major limitations of the current approach to managing blood cancers.

“We know that a single tissue biopsy from the bone marrow or lymph node does not accurately reflect the composition of the whole tumour as there is significant variation – so called intra-tumour heterogeneity – that exists between the individual cells that make up any cancer,” he said.

continues on page 2 ➤

At the Leukaemia Foundation, we are privileged to talk to many people from a variety of different backgrounds, all who are willing to share their story about how blood cancer has affected them.

You’ll find this issue is packed with such stories, each one offering a unique perspective – whether it’s tips for getting back into exercise, motivation for completing a daunting task during treatment, or just a simple motto for dealing with life’s setbacks.

When we asked you for feedback about whether you want to see more patient stories, the answer was a resounding “yes!”, so we hope you enjoy reading these sources of inspiration.

This issue also has some exciting research stories, including our cover story – about a world-first liquid biopsy, which could mean an end to painful invasive biopsies – as well as updates from around the globe.

And don’t forget to flip to the back, where you’ll find dates for upcoming seminars and support sessions.

We hope you enjoy this issue and find the information in it helpful.

Remember, further support is just a phone call, email, or mouse click away. Contact us on 1800 620 420, qldsupport@leukaemia.org.au, or visit leukaemia.org.au.

Barbie Hartigan
Manager of Support Services, Leukaemia Foundation in Queensland

"Because cancer cells from all disease sites within the body shed their DNA into the bloodstream, we found that ctDNA collected from a routine blood sample more accurately mirrors the disease across all parts of the body.

“This ctDNA test for blood cancer therefore provides a much more comprehensive picture of how a patient is responding to their treatment.”

The emergence of liquid biopsies as precision cancer trackers could significantly reduce costs to our health system. For example, the Peter MacCallum Cancer Centre currently conducts some 800+ bone marrow biopsies each year at around $2,500 per test, while patients undergoing the procedure are required to stay in hospital for at least six hours each time.

The ctDNA tests will be available to patients within Australia from July and are expected to become a standard clinical tool in the near future.

The Peter MacCallum Cancer Centre will continue to develop its ctDNA expertise and technology so the tests can be further refined and applied across more cancer types.

This research was supported by the National Health and Medical Research Council of Australia; Leukaemia and Lymphoma Society USA; Victorian Cancer Agency; National Breast Cancer Foundation; Leukaemia Foundation Australia; Snowdome Foundation; and the Haematology Society of Australia and New Zealand. Core technologies for the research are supported by the Australian Cancer Research Foundation and Peter MacCallum Cancer Centre.

WHAT DOES THIS MEAN FOR BLOOD CANCER PATIENTS?

Caroline Turnour, the Leukaemia Foundation’s General Manager, Research, Advocacy & Services said the test is excellent news for better personalising the care and treatment blood cancer patients receive.

“These new tests will ensure patients will receive more personalised treatment, not just what historically is known to work for a disease,” she said. “This will mean less treatment-related toxicity and more patient-driven clinical care.”
POWERFUL NEW PATH FOR BLOOD CANCER THERAPIES

Researchers at Monash University and Peter MacCallum Cancer Centre in Melbourne have identified for the first time how a new class of epigenetic drug engages with the immune system to kill off cancer cells.

The research, published earlier this year in *Cell Reports*, offers powerful new pathways for enhanced blood cancer therapy.

The research looks at BET-inhibitors, which are a relatively new class of drug that work to "switch off" important cancer-causing genes expressed within tumour cells.

The team at Monash and the Peter MacCallum Cancer Centre have demonstrated the potential for combining ground-breaking epigenetic and immune-based treatments for more potent results.

The experiments conducted as part of the research have showed that immune-competent mice with lymphoma had a far greater response to BET-inhibitors than their immune-deficient counterparts.

In addition to their primary function, the research showed the BET inhibitors were able to "switch off" a protein called PD-L1, which is used by tumour cells to hide from the immune system.

This resulted in the BET-inhibitors making tumour cells more sensitive to attack from the immune system.

The power of an activated immune system in eliminating tumour cells has previously been proven with drugs such as Keytruda and Opdivo, which also target the PD-L1 pathway.

This study builds on this knowledge, and confirms that combining the BET-inhibitors with other immune therapies work better in treating lymphoma, rather than just using either therapy alone.

Based on laboratory research performed at the Peter MacCallum Cancer Centre, the Monash team is currently trialling a combination of a different epigenetic drug called Dinaciclib with the anti-PD1 therapy, Keytruda in relapsed lymphoma, myeloma and chronic lymphocytic leukaemia.

Further clinical trials for combination therapy are likely to emerge as a result of this research.

ADEM CROSBY CENTRE OPENS

On March 21 Lu Crosby was the first patient to be treated in the new, state-of-the-art Adem Crosby Centre at the Sunshine Coast University Hospital.

Now in remission from breast cancer, Lu was receiving her first out-patient treatment in the facility named after her late son Adem, an avid Leukaemia Foundation supporter.

The centre will offer expanded cancer care services including medical oncology, radiation oncology, haematology, and specialised help for inpatients.

Stay tuned for our next issue of *Blood Cancer News*, where we’ll profile the centre and what it means for blood cancer patients.

Lu and Brent Crosby in the new cancer centre
When Gold Coast man Peter Hardwick had open heart surgery in 2005, he thought that would be the most difficult thing he would ever encounter.

But in 2010, 44-year-old Peter faced another fight for his life.

“After my heart surgery I got back to cycling and in 2010 completed the Mt Tamborine Challenge, a tough ride,” Peter said.

“When I finished I was totally exhausted and just didn’t recover, constantly picking up flus, viruses as well as pneumonia.”

His wife Vicki finally convinced Peter he needed to find answers, and a trip to the emergency department ended in news that neither of them were prepared for.

Peter was diagnosed with stage 4 B-cell follicular non-Hodgkins lymphoma.

“Our heads went into a spin,” Peter said.

“They wanted to admit me straight away but it was my daughter Megan’s birthday party the next day and we couldn’t disappoint her.

“We had the party and when it finished we told some close friends what was going on and then headed to hospital for admission.”

Peter had his first round of chemotherapy in May 2011.

“I had six months off work and was well on my way to remission when I went back to work full-time at the end of 2011,” he said.

Peter works for Queensland Health as a Biomedical Technology Consultant, developing maintenance strategies for medical equipment and providing consultation for the purchasing of this equipment.

“All was going well until a lump appeared on the right side of my neck in January 2013. I had relapsed and commenced my next regimen of chemotherapy,” he said.

“I continued full-time work and after chemo finished was given the all clear.”

Abdominal pain in November 2014 was the first sign that Peter’s lymphoma had returned.

An ultrasound resulted in the removal of his gall bladder and he began chemotherapy for the third time the following week.

“I spent almost every day, except Christmas Day, at the clinic getting platelets, fluid and other medications until the end of March 2015,” he said.

During this time Peter and his family moved to the Gold Coast for Vicki’s work.

This meant many hours of travel to and from treatment in Brisbane but Peter said their amazing group of friends and family helped out.

“Don’t underestimate the importance of family and friends during this time, particularly your spouse, the primary care giver, who is often forgotten and underappreciated.

“Without all these people it would have been a lonely, scary journey.”

With Peter’s autologous transplant scheduled for June 2015, he kept active in the lead up to the procedure, walking and riding when he could.

“When the stem cell transplant day came it all felt like a bit of a non-event, a 30-45 minute infusion, all done, easy!”

Peter started to feel fatigued around this time, but knowing it was important to keep active, he set himself daily targets.

“Two or three laps of the ward, not as easy as it sounds, along with some gentle stretches and exercise took care of my body,” he said.

Peter says that finally leaving the hospital had its own set of challenges, too.

“It’s the second hardest part. Keep yourself moving, motivated and busy,” advised Peter.

“Take up a hobby or start reading, or start planning a holiday for when you’re well.

“You will have down days and this is normal. Don’t get overly concerned, but if they string together talk to someone.”

Peter is now back at work and is looking forward to going on his first holiday since 2013.

“Stay positive and live for the future – don’t let it beat you!”
Life-saving Hodgkin lymphoma drug now on PBS

A drug used to treat a rare form of Hodgkin lymphoma is now widely available through the national Pharmaceutical Benefits Scheme (PBS), saving patients thousands of dollars.

The PBS listing of brentuximab vedotin gives Australians access to potentially life-saving treatments that previously cost up to $16,100 for one course.

The Leukaemia Foundation presented comprehensive consumer submissions to assist the Pharmaceutical Benefits Advisory Committee (PBAC) in its consideration of the two applications for brentuximab vedotin.

The submissions contained information from two Leukaemia Foundation surveys about the quality of life for people living with relapsed or refractory Hodgkin lymphoma.

Survey respondents provided insights into the severe and debilitating impact their diagnosis, or that of a loved one, had on their life, work and career.

They also highlighted the significant inequities in accessing the latest available treatment: while some people were provided with it on compassionate grounds, others had to raise substantial funds.

Those who could access brentuximab vedotin reported less disruption to their lifestyle as a result of fewer side effects.

Leukaemia Foundation CEO Bill Petch said the decision to list brentuximab vedotin on the PBS ensures equal access to the life-saving treatment for all Australians who require it.

“This is wonderful news for people with Hodgkin lymphoma and this achievement demonstrates a successful united-front approach,” he said.

“Together we can help elevate the vital needs of people impacted by a blood cancer diagnosis and achieve great outcomes for more Australian families.”

The Leukaemia Foundation is committed to improving the lives of people living with blood cancer and this is a great example of how collaboration is helping to make a real difference.

*Patients with relapsed or refractory CD30 + Hodgkin lymphoma following autologous stem cell transplant (ASCT), and patients with relapsed or refractory CD30 + Hodgkin lymphoma following at least two prior therapies when ASCT or multi-agent chemotherapy is not a treatment option.

Study turns blood cells into cancer killers

An experimental gene therapy in the US has seen one third of non-Hodgkin lymphoma patients showing no sign of the disease six months after a single treatment.

Called CAR-T cell therapy, it involves filtering the patient’s blood, removing key immune system soldiers called T-cells.

The T-cells are then given back to the patient intravenously and multiply in the body, turning into an “army” that fights the disease.

The therapy was developed at the National Cancer Institute, and official results will be published this year.

Potential new Burkitt & DLCL therapy

Scientists at the Spanish National Center for Cardiovascular Research in Madrid have identified a possible therapeutic target for Burkitt lymphoma and diffuse large cell lymphoma.

The study was published in Blood earlier this year and looks at the potential of a microRNA, miR-28, being developed as a therapy.

The study’s results could lead to human clinical trials.

Support from the comfort of home

Dates have been set for this year’s free lymphoma telephone forums, where you can chat to others with lymphoma and hear from health professionals.

Forums cover general lymphoma topics, as well as cutaneous lymphoma, Hodgkin lymphoma, and Waldenstrom’s Macroglobulinaemia.

All forums are hosted by a Leukaemia Foundation staff member. Visit leukaemia.org.au or call 1800 620 420 to find out more.
In October 2011 Michael O’Gorman was admitted to hospital with 24 broken bones.

Doctors had never seen a case like it. "I was diagnosed with advanced stage 3 myeloma and told to get my affairs in order," said the Sunshine Coast resident.

The next day Michael began an intense course of chemotherapy and radiation.

It was devastating news for Michael’s 11-year-old daughter Taylor and his wife, Lynne; however the O’Gormans resolved to beat the cancer together.

Michael, a keen triathlete, knew something about determination and persistence and it was this spirit that carried him through his blood cancer fight.

It was while watching the 2012 Olympics in hospital following his bone marrow transplant, that Michael made Taylor a promise to get strong enough to complete the Noosa Triathlon.

"I said, ‘You just watch me, I will compete in the triathlon next year and prove to you how well I am!’," Michael said.

While Michael was in Brisbane receiving treatment, he and his family stayed together at the Leukaemia Foundation’s Clem Jones-Sunland Village in Brisbane.

"The support it provided my wife and daughter when I was in hospital gave me great comfort," he said.

After 10 months of gruelling treatment, Michael was able to go home.

He held true to his promise and started training for the 2013 Noosa Triathlon, signing up as soon as entries opened.

"I walked to the end of the driveway and back a couple of times and put it in my training journal," Michael said.

"My determination to keep going was to show all of the people who supported us that their prayers and positive thoughts made a difference."

Two years on, Taylor and Lynne were waiting at the Noosa Triathlon finish line.

"When dad came in, he embraced us and whispered ‘I did it, I beat it’. It was then I knew my dad wasn’t going anywhere for a long time," Taylor said.

Since then, Michael has completed 10 triathlons, including a 70.3 Ironman (1.9km swim, 90km bike, 21.1km run).

He now has his sights on completing a full Ironman (3.8km swim, 180km bike, 42.2km run) next year.

"The motivation to keep going is an affirmation of health. But I mainly do this for me and my family. Each time I cross the line my daughter smiles and doesn’t worry about me. That makes me happy."

Michael O’Gorman and daughter Taylor

Michael crossing the finish line

MYELOMA

Michael had so many broken bones before he was diagnosed because myeloma increases bone breakdown, and decreases the formation of new bones.

Bone pain is a very common symptom of myeloma, with pain usually felt in the back or chest, although it can occur anywhere in the body.

Remember though, myeloma symptoms can be different for everyone, so it’s always wise to speak to your doctor if you’re concerned about bone pain.
The Australasian Leukaemia & Lymphoma Group (ALLG) are currently recruiting for a new myeloma trial ‘MM17’ at a variety of hospital sites around Australia, including at the Princess Alexandra Hospital in Brisbane.

The trial is looking for patients who have been newly diagnosed with myeloma and who are fit enough for an autologous stem cell transplant.

Participants must also be currently treated with bortezomib-based induction for tumour reduction, before moving to stem cell collection and a transplant.

It’s been shown that the level of response to induction therapy is a powerful predictor of patient outcome, with a deeper level of response being linked to longer survival rates.

This study proposes to switch therapy in those patients who demonstrate a suboptimal response to bortezomib-based induction, to a potentially more effective regimen.

MM17 will look at evaluating the efficacy and safety of a combination of carfilzomib, thalidomide and dexamethasone (CarTD) in trial participants.

The hope is that a better response will be produced prior to transplant.

It has been a busy time for myeloma trials, with ‘MM16’ also recruiting earlier this year.

MM16 is a phase II study assessing the effect of carfilzomib treatment on early free light chain kinetics, in myeloma patients who have renal impairment.

MM16 participants will include patients who have newly diagnosed, relapsing, or progressive myeloma.

The study will determine whether patients taking carfilzomib respond to the drug, as well as the length of time until the myeloma progresses.

It will also be carried out at the Princess Alexandra Hospital.

For more information about MM17, MM16, or other myeloma clinical trials, visit allg.org.au/current-trials.html, clinicaltrials.gov, the ClinTrial Refer ANZ app, and speak to your haematologist about your eligibility for any current myeloma trials you are interested in.

Myeloma patients in Ireland have become the first in the world to trial a new drug, daratumumab (DARA).

The 2.7 million Euro (~$3.8 million AUD) early stage clinical trial of DARA has recently begun, and is a research initiative of Science Foundation Ireland and the Irish Cancer Society.

The trial involves testing whether the addition of DARA to standard chemotherapy can help those recently diagnosed with myeloma.
MYELOMA

MYELOMA MOTIVATED ME TO GET MY DOCTORATE

When Harvey Westbury and his wife were on holiday in St Petersburg, Russia, in 2008, they were not expecting a cancer diagnosis.

“My wife Jo and I were visiting as tourists, and I became progressively less well while we were there,” Harvey said.

“Jo called the hotel doctor after I collapsed in our room with general weakness, severe back spasms, and gastro-intestinal problems.”

The myeloma had also caused end-stage kidney failure, forcing Harvey to fight for his life for several weeks in hospital in Russia.

Harvey was subsequently air-ambulanced to a more specialised hospital in Frankfurt, Germany, where he was finally stabilised. After a few weeks he was air-ambulanced to the Wesley Hospital in Brisbane.

After an autologous stem cell transplant, chemotherapy, and haemo-dialysis (which he still undertakes), Harvey went home to Noosa on the Sunshine Coast.

“My treatment plan ultimately saved my life, but I found I was unable to do many of the activities I enjoyed before. I needed something else to keep me occupied,” Harvey said.

Harvey had previously spent most of his career working in veterinary research, primarily studying animal infectious diseases caused by viruses.

“Following my diagnosis, I was unable to do much physical activity without tiring very quickly. However, I still had my mental facilities and thought I needed an appropriate challenge to keep me going,” he said.

Consequently, he enrolled to undertake the onerous and demanding requirements for the Doctor of Veterinary Science (DVSc) degree at the University of Sydney.

“I was required to write and submit for examination a very detailed scientific thesis concerning the virus diseases of animals,” Harvey said.

Harvey says he had “ups and downs” during the three years it took him to write his thesis, along with further hospital admissions for health complications.

“Doing the research and writing for my thesis was certainly challenging, but I persisted despite the setbacks – I was determined to finish it,” he said.

Harvey’s determination paid off last year, when he was awarded his DVSc for his thesis titled ‘Studies on endemic, exotic and emerging diseases of animals caused by viruses’.

Harvey said the staff at the Noosa Hospital Renal Unit helped him during his study, as they encouraged patients to do things they may never have contemplated before.

He found further support with the Leukaemia Foundation’s newsletters, which he has received for several years.

“I really enjoy reading them, particularly the stories about people facing the challenge of life-changing events. They help provide inspiration – if they can do it, so can I!”

Harvey has a few words of inspiration of his own to share with others.

“Get involved in something that you reckon you can do, preferably something that’s challenging,” he said.

“This creates, in my opinion, a very positive attitude and immunises you against negative thoughts and any feelings that life is not worthwhile.”

Harvey is now keeping busy with researching his family tree, and taking part in community activities. He’s also still “basking in the satisfaction” of finishing his DVSc.

“What seemed improbable, in the first instance, turned into reality. Dreams do come true, even under difficult circumstances.”
Life post-transplant is even better

Life was good for Richard and Heinke Butt before his diagnosis with acute myeloid leukaemia (AML) and now two years post-transplant, he believes it’s even better.

Since retiring in 2006, they’d walked the Inca Trail to Machu Picchu, successfully reached Mt Everest Base Camp, and ticked another trip off their bucket list when they returned from a trek up Mount Kilimanjaro in mid-2014.

They were enjoying a quiet camping holiday with their two working dogs in July 2014, when Richard got a call from his GP that cut short their trip.

“She wanted to see me to discuss my most recent blood results,” said Richard, 65.

Two years earlier he had been diagnosed with essential thrombocythaemia* (ET), and had routine monthly blood tests to monitor his platelet level.

His latest blood result had picked up blast cells and, due to the possibility of ET transforming to AML, Richard was referred to a haematologist in Brisbane.

“That late evening consultation is a moment in my life I will never forget. The transition from normal life to complete turmoil was instantaneous,” Richard explained.

The following week, he got the results of a bone marrow aspirate, which confirmed he had AML.

“What I did know was we were going to beat this disease and a steely determination welled up inside me from that moment,” he said.

Richard chose to start chemotherapy immediately in the lead-up to his stem cell transplant.

Prior to the transplant, he made a concerted effort to get physically and mentally fit.

“I’ve always been active and I wanted to ensure my cardio and muscle strength were at peak levels, to give myself every conceivable chance,” said Richard, who played squash, jogged every day, swam, and rode his horse.

“I even took meditation classes which I found a benefit at times of stress and pain and helped me through the worst of times.

“On December 11, I received my life-giving stem cells from my donor and the long road to recovery began.”

Soon after his transplant Richard ended up back in hospital with high temperatures when his Hickman catheter became infected.

And in January this year, Richard got pneumocystis pneumonia, which also put him back in hospital.

“It cleared up quite quickly but knocked me around and it took me a while to claw back my physical state after that,” he said.

Now two years post-transplant, Richard said he feels excellent.

“In some respects my life has taken a turn for the better because I tend to appreciate everything I do. I look at life through different eyes and don’t take anything for granted.”

He and Heinke are now looking at tackling another goal on their bucket list, one they were working towards when the news came in that Richard had AML: high altitude trekking to Aconcagua, a peak in South America.

“I’m feeling ultra-positive about everything. I’ve been given a very rare second chance at life and I ain’t going to squander it!

“It’s a shame it takes something like this to give you this different outlook on life, but that’s the way the cards have fallen.”

*Essential thrombocythaemia (ET) is a blood disorder in which too many platelets are produced in the bone marrow. The risk of transforming to AML is less than 1%.

SUPPORT “MADE A HUGE DIFFERENCE”

When the Butts were in Brisbane for Richard’s transplant, the Leukaemia Foundation provided them with accommodation at Clem Jones-Sunland Village.

“We were fortunate to get a self-contained unit where we stayed for five months. It made a huge difference,” Richard said.

“Apart from the financial aspect, to be in a facility with its own network of patients and carers who are in a similar situation was huge.”

Richard Butt
New anti-cancer drug, venetoclax which has the power to “melt away” advanced forms of chronic lymphocytic leukaemia (CLL) was recently granted approval by the Australian Therapeutic Goods Administration (TGA).

The drug will be marketed as Venclexta and is approved for Australians with relapsed or refractory CLL with 17p deletion, a mutation that makes the disease resistant to standard treatment, as well as for people with relapsed or refractory CLL who do not have any other treatment options available.

How did this discovery come about?
In 1988, researchers at Walter and Eliza Hall Institute (WEHI) in Melbourne discovered BCL-2, a protein that enables cancer cells to survive. Since then a team of scientists worldwide has been working to find a way to “hit” BCL-2 in order to stop cancer cell survival.

Venetoclax was discovered and developed with scientists from US pharmaceutical companies AbbVie and Genetech, as part of an international collaboration with WEHI. Thanks to our supporters, the Leukaemia Foundation contributed to early work on the development of venetoclax (formerly called ABT-199).

This research was undertaken by Dr Kylie Mason, Professor Andrew Roberts and collaborators at WEHI through the Leukaemia Foundation’s National Research Program Grants-in-Aid in 2010 and 2012.

How does venetoclax work?
The drug works on the protein BCL-2 that prevents CLL cells from dying. Because these cells don’t die and continue to be made in the bone marrow, they begin to crowd out the blood, bone marrow and organs.

The protein also protects the malignant CLL cells from chemotherapy, making them resistant to treatment.

Venetoclax switches off the BCL-2 protein, allowing the CLL cells to die naturally and making them susceptible to chemotherapy, so it is more effective in killing cancer cells.

Will this drug target other blood cancers?
Venetoclax is being combined with other approved drugs in Phase II and Phase III clinical trials in other blood cancers.

It is hoped venetoclax in combination with other drugs could benefit other hard to treat types of blood cancer, but further research is necessary.

Associate Professor Steven Lane and his team at QIMR Berghofer Medical Research Institute in Brisbane are searching for better ways to treat acute leukaemia in older people. Their aim is to develop personalised leukaemia treatments to reduce relapse rates amongst this patient group.

“Today, 85% of children with leukaemia can be cured, but the outlook for patients over the age of 60 is bleak, with only 10% surviving their disease,” Assoc. Professor Lane said.

“The reason is that in older patients the cancer adapts to become resistant to treatment with chemotherapy.”

Assoc. Professor Lane has developed a model to rapidly profile the genetics of different types of leukaemia.

This allows him to map the effectiveness of chemotherapy treatments against the genomes of individual cancers, then to tailor treatments to individual patients.

“We plan to identify new drug targets and test whether we can use existing drugs to treat resistant types of leukaemia,” he said.

Assoc. Professor Steven Lane was awarded three grants-in-aid (in 2012, 2013, and 2014, totalling $300,000) from the Leukaemia Foundation’s National Research Program.

The Leukaemia Foundation has developed a new wellness program to inform, support and empower people with chronic lymphocytic leukaemia (CLL).

CLL My Way is run by specially trained staff.

It includes motivational counselling, a closed Facebook group to help peer support, seminars and support groups, and a telephone forum.

CLL My Way has been generously supported by Janssen and the CLL Australian Research Consortium.

For more information, contact Sheila Deuchars on 1800 002 244 or visit leukaemia.org.au/cllmyway.
Christmas Day 2004: while most people were opening presents and relaxing poolside with family, five-year-old Will Wright was about to undergo a stem cell transplant.

Two years prior, in January 2002, Will was diagnosed with acute lymphoblastic leukaemia (ALL) while he and his family were living on their cattle property in Baralaba, 140km from Rockhampton in Queensland.

“We saw a specialist doctor in a nearby town, had blood tests, and the next day it was confirmed Will had ALL,” said his dad Jacko.

“We were told not to let him bump his head or cut himself, as his blood would not clot and he may die.”

Thus began a rigorous travelling and treatment schedule for Will, forcing him and his family to go back and forth between Brisbane and Rockhampton for the next two years.

Will had his first surgery – a bone marrow aspirate and port-a-cath inserted – and started his first round of chemotherapy on his third birthday.

“We eventually relocated to Brisbane for Will’s treatment, but I was constantly travelling back and forth to the property as we were in drought, pumping water and feeding cattle,” Jacko said.

After finally being allowed to go home in August 2002, Will continued chemotherapy for the next 13 months before relapsing in September 2003, forcing the family to move back to Brisbane for more treatment and surgeries.

Once they were able to leave Brisbane again, the family moved to Rockhampton which enabled Jacko to travel back to the property, and for Will to receive treatment in Rockhampton and Brisbane.

In October 2004, Will relapsed again and the family were told he had a 10% chance of surviving.

“We packed up again and moved back to Brisbane,” Jacko said.

“After lots more chemotherapy, radiation and surgeries we found an unrelated bone marrow donor in the UK and his transplant was scheduled for Christmas Day 2004.”

Will’s parents said their son never complained about anything and would never even say he was sick.

Amazingly, they have also been told that Will was the only child to complete a bone marrow transplant without morphine or a nasal gastric tube.

While in isolation following his transplant in December 2004, he rang in Christmas (his second Christmas spent in the hospital) and his fifth birthday (his third birthday spent in the hospital).

Over the following years Will had dozens of surgeries related to complications from his treatment, around 70 plus procedures to date.

He has had to travel to Brisbane every few months for further treatment and surgeries, which has required stays in nearby hotels and motels, which the Leukaemia Foundation has provided assistance with.

On one Brisbane visit in August 2016, Will’s specialist found abnormal cells in his thyroid that were unrelated to his transplant.

It was recommended that Will undergo surgery to remove his thyroid.

“We decided to hold off on the surgery as Will was in grade 12 and wanted to graduate and enjoy his 18th birthday first,” his mum Jennifer said.

Will’s surgery is scheduled for April. He plans to start university shortly after, studying a degree in environmental science and ecology.

Despite his setbacks Will has a positive outlook on life, and has found solace in the phrase “hakuna matata”, from the Disney movie The Lion King.

“Hakuna matata is to be brave in the face of adversity and have the courage to go on even when you are scared to do so,” Will said.

“Let the bad times roll on and enjoy the good times that are ahead.”
Many people with a blood cancer or related blood disorder, like MDS, require blood transfusions at some point during treatment.

People who suffer from chronic anaemia, either as a result of MDS or its treatment, may become reliant on regular red blood cell transfusions.

Transfusions help to alleviate symptoms of anaemia such as fatigue, lethargy, poor concentration and physical weakness.

However, repeated blood transfusions over a period of time can lead to iron overload.

What is iron?
Iron is an important mineral in our body. It helps to maintain our bodies function and our immune system, and is responsible for ensuring that oxygen is transported around the body by the red cells. This oxygen is used by the body to create energy.

How does iron overload happen?
Red blood cells contain iron, so every time you get a red blood cell transfusion, you are putting more iron into your body.

As the red blood cells break down over time, the iron in the haemoglobin is released.

Because your body doesn’t have an efficient way to get rid of this extra iron, the iron can build up in your vital organs and could injure them over time.

Where does the iron accumulate?
Excess iron can accumulate in the liver, spleen, and bone marrow, as well as other organs that don’t normally store iron, like the pancreas, joints, and skin.

What are the symptoms of iron overload?
You may not experience any symptoms for a while, or you may experience tiredness, weight loss, or joint aches.

The symptoms of severe iron overload are often easier to spot and can include diabetes, grey-coloured or bronze-coloured skin, and a shortness of breath.

How do I find out if I have iron overload?
A blood test known as a serum ferritin level is used to test for iron overload. Serum ferritin can indicate if there is too little or too much iron in your body.

An elevated serum ferritin level over a period of time may be indicative of iron overload. However, serum ferritin levels can also be influenced by other factors such as inflammation.

Each treating centre has its own policy on the management of iron overload.

Therefore, it is important to discuss this with your doctor or nurse if you are having regular blood transfusions.

How is iron overload treated?
Treatment of iron overload is known as iron chelation therapy.

This works by binding to the iron and allowing the body to excrete the bound particles.

Iron chelating agents come as a dissolvable tablet, Exjade, or as a slow infusion, desferrioxamine, under the skin or intravenously.

Iron chelation therapy is not suitable for everyone, so you should broach the subject with your doctor or nurse.

**MDS Day: July 12**

Mark your calendars: Wednesday, July 12 is National MDS Day.

There will be seminars and support groups running across the country, where people affected by MDS can come together to get support and learn more about treatments and research.

For information on events near you, visit leukaemia.org.au or contact our support team on 1800 620 420.
Nathalie Cook has worked tirelessly over the last six years campaigning for interferon alfa-2a (Pegasys) to be added to the Pharmaceutical Benefits Scheme (PBS).

It's now one step closer to being added, as it was discussed at a Pharmaceutical Benefits Advisory Committee (PBAC) meeting in March.

Nathalie herself was diagnosed with the MPN essential thrombocythaemia in 2008, which progressed to another MPN, polycythaemia vera, in 2010.

Seeking more information about her diagnosis and treatment, she attended the MPN doctor-patient conference at the Mayo Clinic in the US in 2011.

She learned that the newer form of interferon – Pegasys – was easier to tolerate compared to some other drugs, with fewer adverse side-effects.

However, Pegasys was not listed on the PBS.

“On the flight home, I made a decision – to try to get Pegasys on the PBS for people with MPN in Australia,” Nathalie said.

Nathalie attended the conference again in 2013 and 2015 and in this time continued to send annual letters to the drug company Roche documenting her experience with interferon.

In 2015 Nathalie submitted a letter to the Senate Enquiry on the Availability of New, Innovative and Specialist Cancer Drugs in Australia, proposing the government include Pegasys on the PBS.

She also met with her local MP who suggested she write to the Health Minister and also contacted Melbourne haematologist, Associate Professor Constantine Tam, to ask about clinical trials.

In October 2016, Nathalie met Professor Andrew Wilson, Chair of the PBAC.

“He listened to my story with great interest. I also asked if I could write to him directly.”

In January 2017, the Department of Health advised that her submission to Prof. Wilson was being considered at the March 8 meeting of the PBAC.

The next step is to register the drug on the Therapeutic Goods Authority, which must be done by a pharmaceutical sponsor (in this case, Roche).

“We keenly await the outcome of this meeting and are committed to working with the government and Roche to overcome any barriers that may stop it being listed,” said Caroline Turnour, the Leukaemia Foundation’s General Manager, Research, Advocacy & Services.

MPN ABSTRACT
THE ‘BEST OF ASH’

Associate Professor Steven Lane’s Brisbane-based research lab has received rave reviews for their abstract about genetic progression in MPN.

The abstract was featured in the 2016 American Society of Hematology (ASH) annual conference’s ‘Best of ASH’, a session that features the 10 best talks that reflected the key themes and groundbreaking new research of clinical importance.

“MPN is driven by key genetic mutations, such as JAK2 V617F, MPL W515 and CALR,” Assoc. Prof. Lane said.

“Different patients have different types of disease such as polycythaemia vera (PV), essential thrombocythaemia (ET) or myelofibrosis (MF).

“Some of this might be explained by the differences between JAK2, MPL and CALR mutations but we still don’t understand how other mutations, such as DNMT3A, ASXL1 and EZH2, affect disease.

“We have used a new technique to change or edit the genes in Jak2 V617F cells to generate additional changes, such as loss of Dnmt3a. We have found that Dnmt3a loss changes the type of disease that develops to become more like MF.

“We can use this model to understand the pathways that induce MF.

“This is likely to identify ways to stop those patients developing MF, or a potential treatment for people with MF that has developed from ET or PV.”
Last December Anita Cox, third winner of the Adem Crosby Haematology Nursing Award, used her award funds to attend the first Global Adolescent and Young Adult Cancer Congress in Edinburgh.

One of the conference sessions covered the importance of young people with cancer linking with others in similar situations for support.

Anita, the Youth Cancer & CNS Nurse Consultant at the Gold Coast University Hospital, explains the challenges people in their teens, 20s, and early 30s with blood cancer can face, and why having a like-minded support system can help.

Helping to ease the stress

“For some patients, it can be a real help to know that someone else has been in the same situation as them, experiencing similar side effects and they can understand how hard treatment can be. It may feel easier to ask tough questions to a fellow patient rather than a doctor or family member,” Anita said.

“The support from others who have been there, done that, and real life answers about coping with the illness, treatment, stress and normal life challenges can be really valuable.

“Having new friends to talk to about their experience of their diagnosis, treatment and side effects can also ease some of the stress caused by the whole situation.”

A different set of challenges

“When some young people struggle with losing their independence. Some may have to move back home when they have previously lived with friends or a partner. This can be a mixed blessing as they’re happy to have the support of their families but they also feel sad that they’re not able to support themselves just as they were starting to become self-sufficient,” she said.

“The physical side effects of treatment can be devastating, as for many people they come at time when they’re trying to develop relationships. Hair loss, weight gain and loss, pale skin, rashes and surgical scars can all impact on confidence and self-esteem and can affect how they interact with friends, family and the world outside of the hospital environment. Although the physical side effects may ease over time, waiting for things to go back to normal sooner than their body allows can be a frustrating time.”

Life after treatment

“Regardless of how easy or hard people have found their treatment, life will be different after therapy,” Anita said.

“Some young people cope very well during treatment and yet when they try to return to work or study, they find that they are not as sharp, as energetic or even as interested in what they did before their diagnosis. This can cause stress at a time when they should be enjoying getting their life back on track.

“Some people decide to change careers and need to start again in terms of training and education. This can be difficult if finances are tight or if they don’t know where to look for advice or guidance.

“Emotionally, young people may have coped well with their treatment but the enormity of their diagnosis may not impact them until they try to return to their ‘normal’ life - suddenly, normality becomes hard to cope with!”

Connecting with others

“Talking to other young people in a social environment is a much more normal setting than attending a formal support group. Young adults have unique issues and only they can understand how treatment impacts them physically, psychologically, emotionally, financially and spiritually. Hearing other people’s stories may help bring some further understanding or support when they don’t know where else to turn,” Anita said.

“The 20/30 Chat program run by the Leukaemia Foundation is a great opportunity for young people to meet others who have similar issues, at a time when they need questions answered or just someone to listen and understand.”
UPCOMING 20/30 CHAT
The next 20/30 Chat will be in Brisbane on June 24.

Nicole Douglas, one of the coordinators of 20/30 Chat, said the sessions are very popular.

“Younger patients are finding it’s a great opportunity to catch up and chat about issues that are unique to them,” she said.

“It’s a very informal environment too, so it’s also a lot of fun and the chance to feel like you’re just chatting with friends.”

For more information about the next 20/30 Chat, contact Nicole on 1800 620 420 or email ndouglas@leukaemia.org.au.

SCHOOL, UNI, AND CANCER

Many younger people affected by a blood cancer worry about how their diagnosis and ongoing treatment can impact on their schooling.

Secondary school
The treatment for blood cancers, as with many types of cancer treatment, will inevitably change your everyday routine. This can limit the time and effort you can put into school or college work.

Someone (a parent, another relative, a social worker, nurse, or even yourself) will need to liaise with your school about any special requirements you have. The contact at your school may be a school nurse, counsellor, or a designated teacher with whom you feel comfortable.

You can decide who knows about your illness. However, you should bear in mind who needs to know.

For example, if there is a rule about not wearing hats at school, it would be useful to let the teachers know why you would like to wear one in advance to avoid any uncomfortable misunderstandings.

You can discuss with your teachers/tutors a plan for your education while you are being treated. It may include flexible timetabling so you only have to go to school for core subjects or if you are preparing for exams then you can devise a schedule to attend the most important lessons, or when you feel that you are able.

Throughout the entire treatment process, you are still part of your school/college, even if you are not there all the time.

Friends from school/college can provide a great support network, helping to keep you on the ball with your studies.

Tertiary
Treatment may cause a disturbance to your everyday routine but that doesn’t mean you will have to give everything up. Universities have a reasonably flexible timetable and usually much of the study can be carried out with minimal guidance.

It is essential to keep your personal tutor informed so that they can offer you the greatest amount of support possible. The student union can be a good place to look for advice and support too.

If you’re at uni, you may like to consider deferring for a year. While this may appear daunting, there will be many other people in a similar position, as many students defer for a variety of reasons.

You can order a copy of the book from our support team, or download it from our website. Call 1800 620 420 or visit leukaemia.org.au.

YOUNG ADULTS WITH A BLOOD CANCER
This free booklet, compiled by the Leukaemia Foundation, aims to help younger patients and their families understand more about blood cancers and disorders.

The book contains information about blood cancer and diagnosis, as well as information about treatment and side effects that are specific to the concerns of this age group.

There are also tips on managing work and study, and further resources specifically for young people.
## WHAT’S ON

Find out more about an event near you by contacting us on 07 3055 8233 or qldsupport@leukaemia.org.au. We will send out invitations closer to each event.

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**CONTACT US**

**BRISBANE**
Support and information: 07 3055 8233
Accommodation booking and enquiries: 07 3055 8200

**GOLD COAST**
Suite 4, 36 Harvest Court, Southport Qld 4215
Support and information: 07 5503 1270

**TOWNSVILLE**
Support, accommodation and information: 07 4727 8000

**CAIRNS**
52B Comport Street, Portsmith Qld 4870
Support and information: 07 4051 3355

We don’t receive any direct government funding and rely on the generosity of the community to support patients when they need it most. If you would like to make a donation to help others affected by blood cancers, visit leukaemiaqld.org.au.

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Would you like to receive this newsletter or invitations to our seminars via email? We would also love to know what you think about Blood Cancer News.

**Contact us:**
- 1800 620 420
- leukaemia.org.au
- qldsupport@leukaemia.org.au

Disclaimer: No person should rely on the contents of this publication without first obtaining advice from their treating specialist. If you do not wish to receive future editions of this publication please contact the Leukaemia Foundation Support Services Division on 07 3055 8233.