Lymphoma news.

For people with lymphoma & their families

Leukaemia Foundation
VISION TO CURE
MISSION TO CARE

ISSN 2208-2034

August 2018 | leukaemia.org.au | 1800 620 420

David Young and his wife, Kate Platt.

Contents

David's "almost in full remission" thanks to zanubrutinib trial

David Young read about a new clinical trial, checked its availability and spoke to a principal investigator – all while having coffee one morning last year.

As a result, the lymphoma he was diagnosed with six years ago is now "pretty close" to being in remission.

During his "compulsory 'me' time", at his local café in Byron Bay last September, David received an email about a new international Phase III clinical trial for Waldenström's macroglobulinaemia (WM), comparing two targeted therapies – ibrutinib and zanubrutinib (previously known as BGB-3111).

By the time he'd finished his flat white, David had found out the trial was available at three Australian sites, including Brisbane.

"I read the criteria for signing up and it looked hopeful but there was still a bit of a question mark, so I noted the doctor's name at the Brisbane hospital and rang while I was still sitting there," said David.

"She was surprised to hear from me and said 'wow, we haven't even started the trial yet. How did you know about it?'

"She said if I wanted to be a part of the trial to get my haematologist to send in all my information, which I did.

"I was told I had a reasonable chance," said David, and just over a month later he was on the trial.

Step back 11 years, when David, now 61, started having yearly medical check-ups after his 50th birthday. David's doctor had noticed some anomalies in his blood results over a three-year period.

He was originally told he had MGUS* but after seeing a haematologist for the first time, David was diagnosed with WM, in 2012.

"I was told I had two to six years to live and that I should have strong dose chemotherapy (RCHOP) starting the next week!

"Within a month my blood levels were heading towards normal rapidly... "

"The first thing I did, after recovering from the shock of being given that information, was to go online and start researching WM.

"Lucky I did. I spent a couple of days doing that and discovered neither the prognosis nor the treatment seemed quite right.

"The international approach was 'wait and watch', rather than jumping straight in [to treatment], and my prognosis seemed better than had been suggested.

"I got a second opinion, luckily. That haematologist agreed with me and put me on watch and wait, with monthly blood tests.

"We kept a close eye on my symptoms and bloods.

"I was asymptomatic (had no symptoms) in the beginning but finally started to get fatigue, not have my usual energy and lost strength in my hands," said David, a commercial photographer who also runs a bed and breakfast with his wife of 25 years, Kate Platt.

"I also had leg and foot cramps at night. I was getting up, up to five times a night, and walking around for 10 minutes before going back to bed.

"At the time, cramps weren't recognised as a WM symptom but have since been added to the list."

David started treatment on chlorambucil in May 2014, which he had for a few months.

"They weren't expecting much to happen," he said, but it did mean he became eligible for rituximab.

"The Government didn't pay [for rituximab through the PBS] unless you had already had some other treatment," explained David.

Story continued on page 10.

National Blood Cancer Conference – September 8

The Leukaemia Foundation's first national Blood Cancer Conference for people living with blood cancer brings together leaders in blood cancer research, treatment and wellbeing.

They will share their knowledge and expertise on September 8 at the Melbourne Convention and Exhibitions Centre, so save this date as this conference is designed for you.

One of the speakers, Associate Professor Jake Shortt, will present an overview of non-Hodgkin lymphoma.

If you would like to be kept updated on information about the conference, please register your interest on our 2018 conference website here: **bit.ly/IfBCC18**

Even if you are not able to attend, we are committed to ensuring this important education opportunity is available to you as all the key conference sessions will be recorded and shared on our website.

To stay up-to-date with details about the day's program and key speakers, you also can join our Blood Cancer Conference 2018 Facebook group: **bit.ly/BCC18fb**

CAR T-cell therapy FDA approved for the most common NHL

The CAR-T cell therapy, Kymriah®, now has U.S. regulatory approval to treat adults with relapsed or refractory diffuse large B-cell lymphoma (DLBCL) – the most common form of non-Hodgkin lymphoma (NHL).

This includes people with DLBCL who have relapsed or are ineligible for an autologous stem cell transplant (ASCT).

This is the second indication for Kymriah (tisagenlecleucel, formerly known as CTL019) to be approved by the U.S. Food and Drug Administration (FDA), based on high response rates in patient populations with unmet medical needs.

And, according to Dr Stephen Schuster, the Robert and Margarita Louis-Dreyfus Professor in CLL and Lymphoma Clinical Care and Research and director of the Lymphoma Program at the University of Pennsylvania's Abramson Cancer Center, Kymriah is the CAR T-cell therapy "most likely to find its way into Australia".

In August 2017, Kymriah was the first personalised cellular therapy to gain FDA approval – for children and young adults with relapsed or refractory B-cell acute lymphoblastic leukaemia.

Then, in October last year, another CAR T-cell therapy, Yescarta® (axicabtagene ciloleucel), was approved by the FDA for adults with several types of relapsed and refractory NHL.

Long-term follow-up results from the first cohort of DLBCL patients treated with Kymriah – the international Novartis-sponsored Phase II JULIET study – were reported at last year's American Society of Hematology annual meeting in December.

It showed an overall response rate of 53% among the 81 patients infused with their own modified T-cells, with 40% of patients experiencing a complete response. And response rates were similar for those who had prior ASCT and those with double-hit lymphoma (a DLBCL subtype) who typically have poor outcomes.

Tim Murphy, the Leukaemia Foundation's General Manager – Blood Cancer Partnerships.

Of the study participants, 77% had Stage 3 or 4 disease, 47% had previously been treated with an ASCT and nearly all of them (95%) had at least two and, on average, three lines of prior therapy.

"We're proud to have developed this therapy through all phases of development and clinical trials in collaboration with Novartis," said Dr Carl June, the Richard W Vague Professor in Immunotherapy in the department of Pathology and Laboratory Medicine in the Perelman School of Medicine and director of the Center for Cellular Immunotherapies in the Abramson Cancer Center.

In Australia, Novartis is working through the registration and reimbursement processes with the Therapeutic Goods Administration and Department of Health.

The Leukaemia Foundation's General Manager – Blood Cancer Partnerships, Tim Murphy said access to innovative treatments was important.

"We encourage Novartis and the Australian Government to complete assessment and pricing discussions as soon as possible," said Mr Murphy.

World Lymphoma Awareness Day - 15 September 2018

September 15 is World Lymphoma Awareness Day, which brings together people who are living with lymphoma, their carers, supporters and healthcare professionals.

In 2018, the theme is Small Things Build Confidence. This new patient-centric campaign supports issues that have been identified by qualitative and quantitative research* to improve patients' experiences and outcomes.

People with a lymphoma diagnosis can feel uncertain as they face many questions, worries and doubts. These range from the fear of relapse, understanding the reasons for and realities of fatigue, and knowing which of the 100+ subtypes they have, which helps with making confident decisions.

Having access to information and support plays a vital role in positive healthcare experiences and outcomes for patients and to building confidence.

You are invited to join in and contribute to an Australia-wide conversation by sharing the small things that help you feel more confident on one of our lymphoma network Facebook pages:

facebook.com/groups/LymphomaLFA/
facebook.com/groups/WaldenstromsLF/

It's not one big thing, but many small things that add up to a person feeing more self-assured. And when we all start bringing the challenges and issues that patients face into the light, we can support, empower and help them build confidence.

** Global patient survey, see story on page 11.*

Improved diagnoses and therapies to come from DNA sequencing study

An Australian genetic sequencing study of selected high-risk lymphomas is paving the way for a new era of diagnostic medicine.

Project manager, Dr Gareth Gregory said the Victorian Government funded initiative, through the Melbourne Genomics Health Alliance, was identifying genetic variations in different lymphoma sub-types, which will be used to improve patient therapy.

"Even though a number of lymphomas are classified according to their appearance under the microscope and their surface protein expression, we know the genetic landscape of these lymphomas is very broad," said Dr Gregory, a haematologist at Monash Health and Monash University (Melbourne).

"There can be very different causative genetic events in a patient's lymphoma cells, yet the cells can look very similar, and that's never directed our therapy before."

The DNA sequencing study could lead to new diagnostic testing, more successful salvage therapies for people who relapse, clinical trials for new drugs, and more.

Molecular haematologist, Dr Greg Corboy joined the project in September 2016. His role was to enrol people with aggressive lymphoma who were suitable to join the study, manage all testing and interpret the findings.

"These are cases where we anticipated sequencing would change the way we manage the lymphoma, particularly when the diagnosis is unclear or difficult to make," said Dr Corboy.

"Also, to identify therapeutic targets that conventional diagnostic testing might not detect.

"Lymphoma biology can be very complex. Confirming we have the correct diagnosis is important, since this underpins optimal management of the disease, including selecting the best therapy," said Dr Corboy.

The study is looking at people with high-risk (poor prognosis) B-cell lymphomas, including diffuse large B-cell lymphoma and Burkitt's lymphoma, and high-risk T-cell lymphomas (including cutaneous lymphoma and systemic lymphoma). They were recruited from three sites in Victoria – the lead site, Monash Health, Austin Health, and the Victorian Comprehensive Cancer Centre.

Molecular haematologist, Dr Greg Corboy.

DNA was extracted from lymphoma cells present in diagnostic lymph node biopsies, taken as part of the routine diagnostic process for the 91 study participants. A mouth swab was taken to provide normal DNA for comparison, and both tumour and normal samples were whole exome sequenced (WES).

"This means we can give patients more information about what's causing their lymphoma," said Dr Gregory, and this knowledge can direct clinicians regarding the next line of treatment should they relapse.

"Confirming we have the correct diagnosis is important... "

Most patients on the study have had CHOP*-based therapy.

"Unfortunately 50% of them will experience recurrent disease. They're the ones we're most interested in because they stand to benefit the most from this information," said Dr Gregory.

"If they are in that patient group, we will already know what their disease process is at a molecular level, which will better rationalise our ability to direct their salvage therapy to targeted or other therapies.

"That's particularly exciting because, historically, all our salvage therapies have been done according to standard diagnostic pathology parameters (looking under a microscope)."

Based on information from patients' tumours that have been sequenced, Dr Gregory said clinicians could better predict which targeted therapies could improve the activity of salvage treatments and also reduce the number of futile therapies being pursued in clinical trials.

"We're still analysing the data, but are seeing some exciting results," said Dr Gregory.

A multi-disciplinary team has reviewed data from each case. Reports have been released to the clinicians involved and will be shared with their patients during their routine clinic reviews.

"There's some very useful information for quite a number of patients," said Dr Corboy.

"We have clarified the prognosis for some people, altered or refined the diagnosis for some people, and identified potential therapeutic strategies that we might not have otherwise known about.

"This is a very fast moving field and part of this program is to ensure Australia keeps up. We want our patients to receive world-class treatment and this testing is going to be necessary to provide that."

** Cyclophosphamide, doxorubicin, vincristine and prednisone.*

Using gene sequencing data for precision medicine

Data from the gene sequencing study is being looked at now as a whole, from a precision medicine viewpoint.

Dr Greg Corboy said there were more than 100 subtypes of lymphoma and increasingly genetic alterations were included as part of the diagnostic process.

"You can accurately group diagnostic subtypes or groups of patients together because they have similar or the same genetic alternations. And these cohorts can be used in clinical trials in the search for better treatment outcomes or better ways to treat them," said Dr Corboy.

"Genetic testing is increasingly being incorporated into clinical trials to select trial participants, prospectively, and to look for predictive markers of therapy response, retrospectively."

Dr Gareth Gregory said another benefit from this study was the potential to discover new mutations that hadn't been described before.

"That would contribute to global knowledge in terms of the disease processes driving lymphoma.

"All patients on the WES study will be included on the Lymphoma and Related Diseases Registry, so a lot of information about the clinical aspects of their presentation and treatment course can be correlated with this valuable genetic resource," said Dr Gregory.

"The cost of genetic sequencing has come down significantly. We anticipate this being integrated into routine lab practice and in the not-too-distant future it will be part of standard diagnostic testing for patients with lymphoma and most blood cancers."

Dr Corboy said he hoped flagship data from the study was robust enough to have the test accredited through the National Association of Testing Authorities, Australia, for routine diagnostic testing.

"And one of my goals is to get more molecular testing funded through the Medicare Benefits Scheme, so it is more available to patients, so we can improve their treatment," said Dr Corboy.

Daniela's been through a lot and now takes every day as it comes

Daniela Kohutova was 24 and had recently immigrated to Australia when she was diagnosed with a rare and aggressive form of lymphoma.

The former teacher from Slovakia was working in a Brisbane restaurant and studying English when she got lower back pain and put it down to working 60-hour weeks. Then she started getting head spins and ended up in Emergency one night.

The following week, after her GP had ordered blood tests and got the results, he told her go straight to hospital. She had almost no white blood cells, red blood cells, or platelets!

She wasn't discharged until a month later, after being diagnosed with Burkitt's-like lymphoma on 3 December 2011, and her memory of this time is "very blurry".

"I had CT scans, biopsies and saw a fertility specialist, but storing my eggs wasn't an option as I had to start treatment," said Daniela, now 31.

"After only three days and lots of blood tests, I looked like a druggy with bruises up and down my arms.

"And before surgery to remove a lymph node, they had to cut me out of my underwear because I'd puffed up so much. I'd put on 20kg from all the fluids I'd been given to protect my kidneys from the treatment.

"I have lots of very funny stories."

Daniela went through almost seven months of treatment and spent most of that time in hospital, going home only for a few days between each of six cycles of intensive chemotherapy.

"Back home I was a biology teacher, I'd studied the human body and thought I knew about everything. Then I came to hospital and realised everybody hears about chemo, but nobody knows what it is.

"It's like, 'oh, chemo – just some juices they give you' – but the side-effects and what it does to you; that's a completely different story. I had no idea, I can tell you," said Daniela.

"I have lots of very funny stories."

"I was constipated for two and a half weeks as a side-effect of the chemo and literally wanted to die because of the pain."

At this time, her sister Katarina arrived from Sweden where she had been living and studying. She had transferred to a Brisbane university, to help care for Daniela.

"When she first saw me, she thought I was dying," explained Daniela.

"I had no colour. I was hallucinating from the pain, my hair was starting to fall out and I'd lost a lot of weight; I hadn't eaten in two weeks.

"To this day Katarina hates hospitals, but I loved it there. Hospital was my home for so many months. I had my own room, everyone on the ward knew me and I made friends with other young patients, as they came and went."

Daniela's treatment finished in May 2012.

"I was so scared to go home, and for several months I suffered depression and anxiety.

"I'm fine now," she said.

"You're discharged and expected to go back to normal life. Nobody tells you you'll never be normal. You can't go back to your old self, your old life. It's not possible.

"I was at home waiting to be my old normal self and it wasn't coming.

"... everybody hears about chemo, but nobody knows what it is."

"I ate, went for walks, but was very physically weak. My hair started to grow back but I was still puffed up from steroids (that lasted several years). And I had hormonal, physical and mental changes from the medications."

Daniela questioned why she got cancer, to work out what she needed to change in her life, and came up with the answer; being healthy was why she had survived.

By September 2012, Daniela was having "really bad" anxiety attacks.

"I used to play sports, was very physical and could rely on my body. I felt like my body had failed me. It was a really hard time."

Then one day, during an anxiety attack, Daniela thought – 'stop it'.

"That day was like – 'I'm done'. I decided then to take every day as it comes, to love myself the way I am. From that day, I had no expectations," said Daniela.

And that's when she started her 'mind exercise' based on there being at least one thing in each day to appreciate and be happy about.

Now more than five years have passed, Daniela is starting to feel herself again and the chance of the lymphoma coming back is very limited, but she lives with ongoing late effects.

"I have chronic sinus, which is my best friend, and I have no immunoglobulins, so if I get sick I need an infusion every month, which is a life sentence. And I need to sleep well and eat well."

Her biggest goal now is to set up a peer support group for people aged 25 to 40 to get together and talk about their experiences before and after treatment.

Daniela Kohutova during treatment after her diagnosis in late-2011.

Daniela, left, with friends at last year's Light the Night event in Brisbane.

For the last four years, Daniela has worked at the Lady Cilento Children's Hospital (Brisbane).

"I love it. It's given me purpose and puts my life in perspective," said Daniela, who also is a volunteer tutor for refugee children.

Daniela and the Leukaemia Foundation

Daniela's first contact with the Leukaemia Foundation was a visit from a blood cancer coordinator when she was in hospital.

"I was helped out with some bills while I was going through treatment, went to a support group, and found out about Light the Night which I went to for the first time with friends in 2013.

"It was really lovely. I loved the atmosphere and it was so stirring when the lanterns were all lit up. I felt that I belonged.

"I go and raise money every year and have been five or six times."

And in 2013, Daniela was among the first group of people to do the Leukaemia Foundation's Fit to Thrive exercise program.

"It was great. We were individually assessed and I went two to three times a week."

Developing new treatments for Burkitt's lymphoma

The Leukaemia Foundation is funding research aimed at advancing treatment for Burkitt's lymphoma (BL), thanks to the generous support of a major donor who has survived this aggressive blood cancer.

There is a need for alternative therapies for people with BL, according to Dr Gemma Kelly, a senior postdoctoral research scientist at the Walter and Eliza Hall Institute (Melbourne).

In January, Dr Kelly and Professor Andreas Strasser received a two-year grant-in-aid of $250,000 towards investigating a new anti-cancer drug to treat BL.

"Our research focuses on a group of lymphomas driven by abnormal expression of a gene called MYC of which Burkitt's lymphoma is the most well-known example," said Dr Kelly.

"It is a very aggressive disease. The good news is many patients with this disease respond well to conventional chemotherapy but they need aggressive treatment, which some people are unable to tolerate.

"And if the patients do not respond or they relapse, there are not many alternative therapeutic options for them," she explained.

"I work in Professor Strasser's lab and we are trying to understand the control of the pathways to cell death with the objective of manipulating them specifically with therapeutics to make lymphoma cells die.

"We have found that Burkitt's lymphoma cells are highly dependent on a pro-survival protein called MCL-1 and that if we take this protein away, using genetic tricks in the laboratory, the lymphoma cells die very rapidly.

"This finding identified MCL-1 as a therapeutic target for these particular lymphoma cells," said Dr Kelly.

"More recently, we have tested the efficiency of a drug that targets MCL-1 in our pre-clinical models of lymphomas and found it to be very efficient at killing Burkitt's lymphoma cells, and the side-effects to healthy tissues appeared manageable.

"A lot of our work has been in cell lines established from these Burkitt's lymphomas.

"We now want to generate pre-clinical models that allow us to test how efficient pharmacological MCl-1 inhibition is in primary biopsy samples from Burkitt's lymphoma patients and patients with other MYC-driven lymphomas and leukaemias," said Dr Kelly.

"This is the kind of research we want to conduct with the very generous donation we received from the Leukaemia Foundation.

"We do not know the answers to our biological questions; so we do not know what will happen," said Dr Kelly about the nature of research.

Dr Gemma Kelly.

"You get answers to the questions you set out to address, but such studies frequently also open up many more possibilities for further experiments, to address new important questions about lymphoma and leukaemia for which it will be exciting and important to get the answers.

"Excitingly, MCL-1 inhibiting drugs recently entered clinical trials, including in Melbourne, for the treatment of acute myeloid leukaemia and myeloma. Time will tell whether they will be successful in patients."

"We hope our research will really help to progress the search for alternatives for patients with Burkitt's lymphoma who are unable to tolerate chemotherapy and those who relapse with this disease," said Dr Kelly.

WhiMSICAL study provides new and interesting insights

International guidelines recommend a limited number of first-line treatments yet people with Waldenström's Macroglobulinaemia (WM) on the WhiMSICAL study list 37 different initial treatment protocols.

That's "quite remarkable" according to one of the lead investigators, Dr Ibrahim Tohidi-Esfahani, commenting on early findings.

WhiMSICAL is the only global registry for WM. It uses the ethically approved and secure database, CART-wheel.org, and enables people with WM to directly contribute their data to advancing research in this field.

Since June 2016, 308 patients from 14 countries – 25% of them from Australia – have provided their clinical data to this project, including details about their diagnosis, treatment, blood results, symptoms, side-effects, and psychosocial information.

Data from 279 patients, presented in a poster at the last American Society of Hematology annual conference, revealed that almost 50% of patients reported fatigue at diagnosis, and a major difference in the median time from diagnosis to first treatment – 48 days in the U.S. (where 31% of treatments are government-funded) and 122 days for the rest of the world (61% government-funded).

"This real-world data has not been seen before and shows the variation in treatments that patients receive and how they are accessed," said Dr Tohidi-Esfahani.

New data generated by WhiMSICAL, based on assessing symptoms for post-traumatic stress disorder (PSTD) resulting from a cancer diagnosis in WM patients, revealed that 12% of patients have symptoms consistent with a predictive value of 94% for PTSD.

"This finding suggests routine psychological support would be appropriate for people with WM," said Dr Tohidi-Esfahani.

"WhiMSICAL has great potential to advance WM research and provide new insights into the patient experience."

A further 30 questions are being added to the study, to collect critical information on how treatments affect quality of life.

The overall aim is for 1000 people around the world to be recruited to the study.

"This will provide the big data required to help develop new research pathways. Also, in providing much needed additional patient-reported outcomes and quality of life data, this information can assist funding bodies make decisions about which new therapies to fund."

A validation study compared data entered by Australian patients with data compiled by clinical teams at sites registered to the Lymphoma and Related Diseases Registry (LaRDR).

Looking at 'date of diagnosis', 'first treatment type', and 'date treatment started', 78-86% of the patient data matched clinical registry data.

"This demonstrates good concordance and the reliability of patient-derived data. With increased patient numbers, the patient voice and direct scientific contribution through WhiMSiCAL can be very powerful," said Dr Tohidi-Esfahani.

He recommends all WM patients join WhiMSICAL by registering at **www.cart-wheel.org**, providing their consent, and entering their data.

"For those already on the study, thank you for your contribution. Please return to ensure completion of your data entry, with regular updates every six months to maximise the strength of this research," he said.

For more information on WhiMSICAL, visit: **bit.ly/2N0sbvK** or email **whimsical@iwmf.com**

Q&A with Stephen Ansell

Dr Stephen Ansell was among 10 international speakers at the Leukaemia Foundation-hosted New Directions in Leukaemia Research (NDLR) conference in Brisbane in March. During his career the Chair of the Mayo Clinic Lymphoma Group (Minnesota, U.S.) has seen dramatic progress in understanding the biology of lymphoma.

Q How did you get involved in blood cancer research?

It was fortuitous. I grew up in South Africa and when I was called up to the military, I was volunteered to do oncology at the university – the only member of the Eastern Cooperative Oncology Group outside the U.S. It was really interesting and ECOG did a lot of cutting edge clinical trials which interested me, so I stayed on, trained in oncology and did a PhD in clinical epidemiology. Then I wrote to the top 10 places in the U.S about an international fellowship. The Mayo Clinic interviewed me and gave me a slot in 1994. I was interested in proteins that stimulate the immune system and did an extra research year as part of the fellowship. I got involved with a lab and did work around cytokines [small proteins that are important in cell signalling].

Q What is your main area of work?

Anything with the word 'lymphoma' in it, and particularly the biology of these diseases. We're interested in what happens outside the tumour cell. If we take a lymphoma cell from a patient and culture it, it doesn't grow very well in a test tube, yet it grows inside the patient just fine. So... what's facilitating its growth, and can we block and prevent that? We've also found a lot of the cells around the cancer cell in lymphoma are immune cells. So... why are they right next to the cancer cell but ignoring it? How can we wake them up and make them target the tumour cell? We are developing strategies to wake up the immune system and have it target the cancer cells and kill them.

Q What was the topic of your NDLR conference presentation?

Barriers to a good immune response – understanding why the immune cells present in lymphoma aren't killing the cancer cell. Some of the reasons are that many suppressor cells are present in the tumours that inhibit the immune response, and many of the immune cells that could be useful in fighting the cancer are functionally exhausted and worn out. I shared some strategies that have been tried to prevent the suppression and to activate the exhausted cells. Some are really promising. The key is to understand why it works for some patients and not for all.

Q What biologic therapies are you developing for lymphoma?

Rather than putting new immune cells into the patient, we're taking the patient's existing immune cells that are present in the tumour and using them. Antibody treatment used for lymphoma to date has largely targeted the cancer cell and has only indirectly engaged the immune system. By developing antibodies that go after receptors [little messaging systems within the immune system] on immune cells, we're directly engaging the immune system by blocking the negative signal that suppresses the immune response. We're doing this by putting an antibody in the way of a suppressive signal or using an activating antibody that stimulates the cells and gives them a positive signal. Examples of blocking antibodies are treatments that block PD-1 signalling, like nivolumab (Opdivo®) and pembrolizumab (Keytruda®), which have been pretty effective, particularly in Hodgkin lymphoma (HL). Activating antibodies include dacetuzumab that targets CD40 or varlilumab that targets CD27, both of which signal positively through each of those receptors.

Q Are the immune cells that sit around the tumour cells 'normal'?

Yes, usually. If we sequence them for genetic mutations, they have none – they are normal cells. The sad part is, they have been drawn there by the cancer cell but conditioned to be suppressive [dormant] as the tumour cell creates its own microenvironment. It's like a good kid being dragged into bad company and trained to tolerate bad behavior. Our job is to bring out the good part of the good kid, and have the child revert to what its mother taught it to do and do the right thing.

Q How do biologic therapies differ from traditional lymphoma treatments?

We've treated lymphoma in the past using chemicals that kill cancer cells, usually by damaging the cancer cells' DNA, which shuts the cells down. In contrast, biologic treatments do no direct damage at all. They create either a positive or a negative stimulatory message to the immune cells in the cancer. This differs in two ways: it doesn't target the cancer cell, it targets the cells around the cancer cell, and it doesn't kill the cells, it activates them. That's why the side-effects of these drugs are different – not your typical low blood counts or hair loss, but immune symptoms like diarrhoea, or shortness of breath, cough, and skin rashes. How well these treatments are tolerated depends on the severity of these symptoms. Anything severe is not easy to tolerate. This happens in a minority of patients and cortisone-type treatments like prednisone can suppress these symptoms.

Q How many biologic therapies are underway and how accessible are they in Australia?

It's the beginning of a massive wave of new immunotherapies. Nivolumab and pembrolizumab are approved by the FDA in the U.S. and are rolling out in Australia. In HL patients, more than 70% have an excellent response even after failing lots of other treatments. Clinical trials now are looking at treatment combinations to wake up the immune system and get rid of the cancer cells. In HL, brentuximab vedotin (an antibody drug conjugate) is very effective on its own with a response rate of 75%, but combined with nivolumab (an immune blocking antibody), the response rates are 90+%. The thinking down the road is to do away entirely with chemotherapy and use targeted and immune therapies. These are being tested in elderly patients as the very first (front-line) treatment because elderly patients don't do well on ABVD* and get lots of side-effects. HL is a significant success story using immune therapies, particularly PD-1 blocking antibodies like nivolumab and pembrolizumb. However, the results are more sobering in the other lymphomas. In follicular lymphoma or large cell lymphoma, the response rates to the PD-1 blocking antibodies are far lower and we really don't know why. We have a lot of work to do to understand how the immune system differs in these diseases compared to HL.

Q What clinical trials do you have underway in different lymphomas?

We have trials in large cell lymphoma and high-grade B-cell lymphomas (like Burkitt's lymphoma) including one using varlilumab (an immune stimulating antibody) plus nivolumab (a blocking antibody) in people who are third-line (relapsed/refractory). You can't test brand new treatments until potential curative treatments have been tried, so patients need to first receive standard chemotherapy and a stem cell transplant before they can go on this trial. The challenge is – their immune system is often beaten up after chemotherapy, so it may not be the best time to test these treatments. While we don't have a choice as to the patient population on whom we can start these treatments, if we get really good results the treatment will rapidly leapfrog to the front-line. While responses to immune treatment are promising, the key factor is time, to see if people are truly cured. If people are still in remission after five years of follow-up, it's likely to be a curative therapy. Everyone would love a chemo-free world, and I'm all for that, but you never want to favour the use of immune treatment at the expense of more people failing treatment or not being cured. Chemotherapy still cures a high percentage of people, so the new treatments have to beat that.

Q Have these trials been international and are Australians on these trials?

Many of these immunological therapies are in early Phase I trials, done at a small number of centres and unfortunately not available in Australia as we are still learning about the safety of these drugs. The reason for limiting the number of centres is that good communication is needed, so monitoring can be optimised. If something bad happens, you need to tell people about what's happening in short order. The early Phase I trial for nivolumab in HL was only at five centres but when it rolled out to Phase II, it was a multinational trial and included Australia. Once you know you can do a trial safely, you can take it to lots of different places.

Q What are immunomodulators?

They're exactly what they say: 'immune' meaning they target the immune system (not the cancer) and 'modulator' meaning they change immune function. They modulate in two directions, up or down (more positive or more negative) like a rheostat. An immunomodulator gives the immune system more of one signal or more of a different signal. We try and work out what's wrong with the cell – does it need more or less of something? Then, we work out how to dial the immune system up or down. Often, it's getting too much of an inhibitory signal that tells it – 'it's all good, go home'. However, if you take that signal away, the immune system responds, 'no it's not good' and goes after the cancer cell. On the other hand, what sometimes happens is like 'crying wolf'. The immune system hears 'trouble, trouble, trouble' all the time until eventually the immune system responds with 'I'm done with this' and ignores the message. However, when you take away that persistent signal, the immune system has a chance to reactivate and takes danger signals more seriously.

Q What are immune checkpoint inhibitors?

The immune system has several normal checks and balances. After immune cells take care of an infection, you want them to calm down. If kept activated, they'll cause problems with auto-immunity. At some point the immune system gets shut down – the 'checkpoint', typically with PD-1 signalling. When the cell gets activated, it puts a little receptor (a docking site) on its surface (often PD-1) and if it gets a negative message through PD-1, it'll shut the immune cell down. The problem is, cancer got smart and exploits that by putting all these negative messages on its surface indicating to the immune system that 'it's all fine, you can go home'. An immune checkpoint blockade prevents the negative signal that comes through this immune checkpoint that keeps the cell active.

Q What different therapy combinations are being investigated?

Using positive and negative signals in combination with other immune treatments like CAR T-cells is one strategy – activating the immune response and then preventing the immune cells from being switched off. A second strategy is using standard chemotherapy plus immune checkpoint therapies, to try and get a more favourable balance in the tumour – you kill the cancer cell to prevent it from suppressing the immune cells and activate the immune system at the same time. A third way to do it is with small molecule treatments, like ibrutinib, that block messaging systems within the immune cells – you're changing the function of the immune cell to make it more tumour-targeted. Using ibrutinib and an immune checkpoint blockade may be a good way to go because you can change the way in which the T-cell functions and keep it activated by using the immune checkpoint blocking antibodies. However, one of the challenges with these combination trials is there are almost too many decisions, too many potential trials and too few patients. We have to be smart about this and find ways to rationally move the field forward without having to test every single one of these strategies.

Q What's the most exciting thing you're working on?

Targeting macrophages. All the immune therapies we've been using to date target T-cells and we've ignored the innate immune system that is dependent on macrophages – the trash collectors of the immune system! Macrophages are not very sophisticated but are big and tough and mean. The answer to the question – could you use them in a better way? – is yes. The challenge is... tumours don't want to get into trouble with the macrophages either. To protect themselves from the macrophages, they put a little protein, called CD47, on their surface. It's the 'don't eat me' signal which says 'I'm normal, I'm part of the immune system, leave me alone'. But that's not true and if you get rid of that signal, the macrophages look over the tumour cells with a greater degree of interest. We have trials with an anti-CD47 antibody, specifically a decoy receptor that effectively blocks the signalling. The 'don't eat me' signal is removed so the macrophages eat the tumour cells. This immunotherapy uses the innate immune system and so is an innate immune checkpoint. We have a Phase I clinical trial that's accrued patients with a variety of haematological malignancies. This treatment looks very promising in T-cell lymphomas and diffuse large B-cell lymphoma.

Chemotherapy still cures a high percentage of people, so the new treatments have to beat that.

Q What's your career Holy Grail?

I'd like to see most, if not all, lymphoma patients cured of their disease. It's gratifying to see patients really benefitting from new treatment – particularly immunological therapies. I like to talk about a 26-year old patient, who had exhausted all treatment options, who went on a nivolumab trial and six weeks later was in a near complete remission. He's still in remission now, five years later. I'd like to see that to be true for everybody.

** The chemo regimen: doxorubicin, bleomycin, vinblastine, dacarbazine.*

Guadecitabine trial for T-cell lymphoma

An Australian pilot trial for a new drug – not used before to treat lymphoma – has opened and aims to recruit 20 patients over the next two years.

Principal investigator, Associate Professor Jake Shortt, said this first application of a drug of its class in a prospective trial of this nature "was very exciting".

In June, the first patient was signed on to the STELLAR Phase II investigator-initiated trial at Monash Health (Melbourne).

Associate Professor Jake Shortt.

The drug is guadecitabine, also known as SGI-110, and the trial is for T-cell lymphoma, which Dr Shortt said was often more rare and harder to treat than the more commonly diagnosed B-cell lymphomas.

T-cell lymphomas still affect "hundreds of Australians every year" and this trial offers treatment to two quite different groups:

- young, fit patients people with T-cell lymphoma who have not responded to treatment or relapsed after standard of care (high dose chemotherapy and stem cell transplantation); or
- older or frail patients, who are unfit or unable to tolerate conventional chemotherapy. For them the trial drug may be used in the early treatment setting.

"Outcomes with traditional standard of care chemotherapy for T-cell lymphoma haven't really changed in a long time, so this is an area of unmet need," said Assoc. Prof. Shortt, haematologist and Head of Haematology Research at the Monash Health Translation Precinct.

Guadecitabine is a new generation drug, similar in its mechanism of action to azacitidine, which is used to treat myelodysplastic syndrome (MDS) and acute myeloid leukaemia (AML).

"Guadecitabine... hasn't been tested in lymphoma patients."

"The advantage of guadecitabine over azacitidine is that it is more stable in the patient's body," said Assoc. Prof. Shortt.

"It has stronger and more uniform effects on the methylation of genes and cancer cells, which is how azacitidine works.

"Guadecitabine is currently being evaluated in a large randomised Phase III study (ASTRAL-1) in AML patients who are unfit for induction therapy.

"The Phase II data reported with guadecitabine in AML was promising and the Phase III data is keenly awaited.

"Guadecitabine seems to be well tolerated and what's being evaluated now is whether guadecitabine has advantages over azacitidine in MDS/AML.

"Guadecitabine isn't generally considered to be a lymphoma drug and hasn't been tested in lymphoma patients," said Assoc. Prof. Shortt.

However, we now understand more about the genetic changes that are present in T-cell lymphoma and there are similar mutations to what is seen in MDS.

"Even though they look like completely different diseases, they may be more closely related than we had previously thought. Indeed, some patients with T-cell lymphoma also present with MDS at the same time," said Assoc. Prof. Shortt.

"For that reason, there are reports of patients who have been given azacitidine for MDS who also had T-cell lymphoma, and the lymphoma has gone into remission.

"We feel lucky to have been able to access guadecitabine for this study, as its improved stability may translate into clinical advantages over azacitidine.

"We are not aware of any other trials using guadecitabine for lymphoma, so in that sense it will be a world first trial.

"Monash Health is the trial sponsor and we have secured funding from [the manufacturer] Astex Pharmaceuticals to perform the trial. Despite the support from Astex, the trial concept and design have been entirely the product of our teams at Monash and our collaborators at Concord Hospital in NSW," said Assoc. Prof. Shortt.

The dosing of guadecitabine is similar to azacitidine in that it is injected under the skin of the abdomen, but in a much smaller volume of fluid. It is given once a day for five days, with the cycle repeated every 28 days.

The length of the trial is two years and the first person to be treated on the trial has angioimmunoblastic T-cell lymphoma.

Assoc. Prof. Shortt said the trial was open to "people with any form of T-cell lymphoma (including skin lymphoma), where the disease is not responding to the standard of care, or intensive chemotherapy is not appropriate".

For latest details about this trial, visit the ClinTrial Refer ANZ mobile app* and search for STELLAR.

** The ClinTrial Refer ANZ app can be downloaded from the App Store (iPhone, iPad users) or Google Play (Android users).*

New treatment option for T-cell lymphoma

People with T-cell lymphoma have a new treatment option following the listing of pralatrexate (Folotyn®) on the Pharmaceutical Benefits Scheme (PBS) on April 1.

This medicine is showing remarkable results and will help around 440 people with peripheral T-cell lymphoma (PTCL) each year. Its availability is an important step towards ensuring all Australians living with PTCL have access to the treatment they need.

Pralatrexate is a form of chemotherapy used to treat people aged 18 years and older with PTCL who have had previous treatments that have not worked (refractory) or have stopped working (relapsed).

PTCL is a rare form of non-Hodgkin lymphoma that accounts for approximately 7% of all cases of NHL. While it commonly affects people over 60 years, it can be diagnosed at anytime in adulthood. It is slightly more common in men than in women.

Jeffrey says therapeutic vaccine "saved my life"

When somebody survives cancer against all odds, there is often a remarkable, compelling story to be told.

So begins the description on the back cover of Jeffrey Deslandes' book, *From Cancer Good Things Grow*, which he self-published in 2012.

Lymphoma News first told his story back in our July 2009 issue.

Jeffrey, who celebrated his 70th birthday this year, was diagnosed with Stage 4 follicular mixed small and large cell non-Hodgkin lymphoma in May 1999, when he was 51.

Having relapsed from conventional treatment in 2000, 2004, 2005 and 2006, he attributes his survival to an experimental therapeutic vaccine, developed in Brisbane.

"I had become aware of research for this technology in Queensland and a Brisbane haematologist had a clinical trial for the vaccines in melanoma.

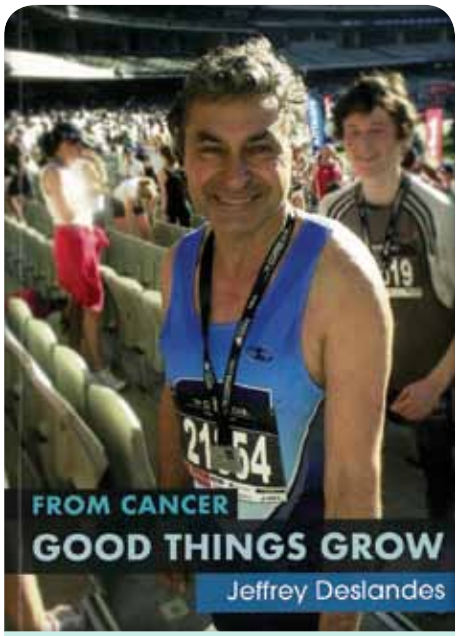
"I approached him out of the blue and asked him to make a vaccine for me – apparently I was very persistent and persuasive.

"I just knew it was going to work," said Jeffrey, who paid $35,000 to have the personalised vaccine made.

He had 52 doses over nine years and has remained in remission since early-2015, when his supply ran out.

"My vaccine was an exact antibody to the cancer," said Jeffrey about the idiotype dendritic cell vaccine produced to specifically fight his lymphoma.

It was manufactured in the laboratory using a diseased lymph node, surgically removed from Jeffrey's groin and some immature dendritic cells, extracted from his blood. There were 33 doses, each containing five million antibodies, which were stored in liquid nitrogen.



The cover of From Cancer Good Things Grow.

Jeffrey Deslandes with daughters, Sara and Melanie Deslandes.

In May 2006, Jeffrey flew to Brisbane from his home in Frankston (Victoria) to have the first dose, by injection into the dermis in May 2006.

"It helps re-educate your immune system to recognise and see the cancer as a threat, then to destroy it," he said.

Jeffrey became disease-free after the first eight injections. He continued to have a booster shot every two months and has had "absolutely no side-effects" from the treatment.

> *"I just knew it was going to work."*

He had a second batch of vaccine made in 2011 and the last of those 19 doses was in January 2015.

Having the treatment meant Jeffrey travelled to Brisbane 52 times!

"That's halfway to the moon!" he said.

"The jury is still out on cancer vaccines," he said by way of a disclaimer.

"It's not proven. It appears to work in about half of cases. Some people get an immune response and some people don't and it's not known why.

"Every now and again, someone defies the odds and survives cancer against all medical prognoses. That has happened to me.

Do I sit on my hands and say nothing or do tell my story? I chose the later."

Jeffrey scribbled out the plan for his book on 10 sheets of A4 paper early one morning in late-2011. Then, over the next six weeks, he expanded this framework.

"It was pretty easy really," he said.

And last year, Jeffrey released the second edition, which included a new chapter: *Vaccine Therapy – Ten Years Disease-Free... and Still Counting*.

His intention is "to open people's eyes about vaccine treatment".

"Ask your doctor if there are any vaccines available, get on the net. It's worked for me. It saved my life."

Postscript: As this issue went to print, Jeffrey was still lymphoma-free but in May he was diagnosed with a different rare cancer – a neuroendocrine tumour (NET).

"No-one in Australia is making vaccines at present, as far as I can ascertain," he said.

"So I am travelling to Japan to have a vaccine made specifically for my NET cancer."

When Jeffrey had surgery in June, the surgeon reserved a sample of his tumour for this purpose.

From Cancer Good Things Grow is available from: **ebay.com.au**; **www.facebook.com/FromCancerGoodThingsGrow/**; or **jdeslandes@optusnet.com.au**

Continued: David's "almost in full remission" thanks to trial

His first course of rituximab "improved everything apart from the cramps".

"I felt almost normal again for 18 months, then another course of rituximab lasted about a year," said David, who continued to be proactive in his research on WM and the latest drugs.

"Everyone was getting excited about ibrutinib, hoping and praying clinical trials in Australia would go through quickly, and the government would pay for it. It was a slow process." [Ibrutinib was listed on the Pharmaceutical Benefits Scheme on December 1 last year.]

Before setting up two general cancer support groups, which he facilitates at Byron Bay and Ballina, David regularly travelled to Brisbane to go to the Leukaemia Foundation's WM support groups.

"They were great. Speakers come and you hear about the latest treatments."

He is also on WM online forums – an Australian one and another based in the U.S. and that is how he found out about the randomised clinical trial he started in November last year.

"I would have been really happy to go on either arm but I think, moving forward, zanubrutinib may be even more effective," said David, who discovered he was on the zanubrutinib arm.

"It's the newer of the two drugs – probably slightly better and with less side-effects.

"The effects are pretty amazing. Within a month my blood levels were heading towards normal rapidly and now I'm almost in full remission. And, wonderfully for me, my cramps have stopped during the night, which has made a big difference.

"I've got 100% of my normal energy back and all my bloods show I'm pretty close to remission."

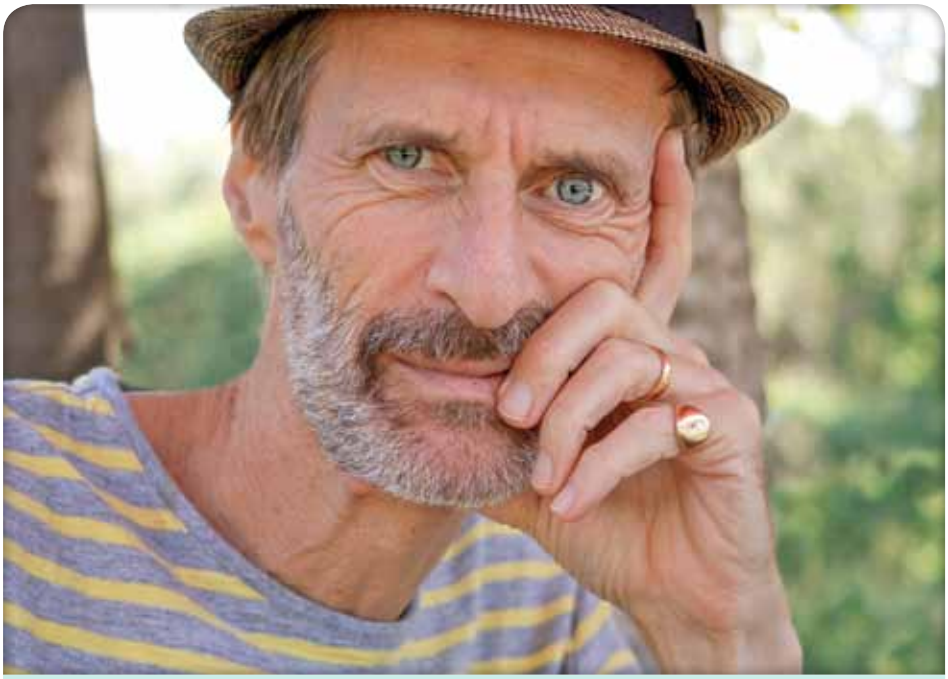
The trial involves taking four pills a day – two in the morning and two at night.

"I saw somewhere that ibrutinib was about $187,000 a year cost-wise, when it first came out, which if I relate to my tablets is about $128 a tablet! When I think of that, I say 'thank you' to the pharmaceutical industry," said David, who is on the trial at no cost to him.

"I could be on the trial for two to three years and have been told I can keep taking the drug after the trial**.

"I keep an eye on American and European research on these targeted therapies and get Google to send me results once a week with anything on ibrutinib and zanubrutinib.

"There's no cure for WM at this point, and the interesting thing about these targeted therapies is how long they are going to last. My understanding is... the jury is still out on that."



David Young: "I intend to die of something else".

David goes to Brisbane once a month for blood tests, to see the trial doctor and make sure everything's good.

"They're keeping a close eye on me and I have a CT scan every three months.

"One of the things I've always demanded is that I get all my blood results emailed to me, so when I'm talking to my haematologist, I know the important ones for WM and those are the ones I keep an eye on.

"I've been looking at all those results for six years. Now I don't feel the need to watch them quite so diligently and just have a look every so often to make sure everything's right.

"I feel pretty confident with where I am with my health outcomes, and where the science is going enables me to feel fairly confident about my long-term prognosis.

"I intend to die of something else," said David.

** Monoclonal gammopathy of unknown significance, which has a small risk of developing into myeloma or a related blood disorder.*

*** Providing David is responding to the treatment.*

Changes David has made since his diagnosis

"You hear a lot of people with cancer say they've gained a lot of insights and are actually happier now than before their diagnosis. I'm definitely in that category.

"Emotionally, it was a big shock initially but I coped pretty well. I have a positive attitude but it was hard. My wife also was in shock and we both struggled for a while.

"I was a busy person and realised I should work at lowing my stress levels. I decided I had three jobs – the B&B, photography and me, and I needed to devote equal time to those three things.

"I made sure I was doing enough exercise and slowed down my mornings which feels healthy. I don't rush into the day. I read the paper and make a big effort to have an hour's break at my local café in Byron Bay. I zip down there and back on the electric bike I bought and it all feels good.

I cut down on alcohol, not that I was a big drinker and I tend not to drink during the week. Luckily I'm married to a great cook who makes lots of interesting and healthy food mostly using a lot of fresh ingredients. And I still like to eat 'soul food' – chocolate, cakes, that sort of thing.

And there's my attitude to life. I appreciate the small things in life more than I did before and I think I'm happier than before I got cancer. It's a reminder to everyone that it's good to slow down and to appreciate everything."

David's advice to help people help themselves

"I've realised from my own experience and insights, and stories of other people's experience in the health system, that it is definitely an advantage to be well educated, have a fair dose of common sense, some business acumen and computer skills, and to be proactive or 'pushy' as I call it.

"My advice is – take responsibility for finding out everything you possibly can about your disease, keep doing research, and take charge."

Global survey report of lymphoma impact on Aussie patients/carers

To better understand the impact of lymphoma treatment and care, the Lymphoma Coalition has conducted a global patient survey every two years since 2008.

In the 2018 survey, almost 4% (253) of the 6631 participants were from Australia, with the split Down Under being 85% lymphoma patients to 15% caregivers.

Most of the Aussie respondents (67%) were female, with 84% aged 41 years or older, and the breakdown of where they lived was 66% suburban, 18% urban and 16% rural. More than half (53%) were diagnosed in the six years from 2011-2016, with 26% diagnosed last year, and 15% from 2006-2010. *(See accompanying pie chart for the breakdown of lymphoma diagnoses.)*

Patient information, guidance and support

Analysis revealed most Australian respondents, while aware of their lymphoma subtype, found the characteristics of their particular subtype difficult to understand. There were 44% of them who wanted additional information and searched for information (59%), mostly immediately after their diagnosis and their main sources were doctors and websites.

The Australian survey cohort mainly searched for support 1-3 months after diagnosis (34%).

They said having adequate information had a positive influence on their feelings of confidence in determining the trustworthiness of information about their health condition and treatment choices. It also had a positive effect on communication with their doctor, such as feeling they had the right to take the doctor's time to discuss their concerns.

Respondents' interest in services included: downloadable materials and treatment information. When asked to rate the service types that they had already used, they specified patient organisations and counsellor/psychologists were the services they found most helpful.

Living with side-effects

The most frequently reported physical conditions were fatigue, changes in sleep patterns and trouble concentrating. During treatment, the most commonly reported medical conditions were neutropenia and tingling, and after treatment, numbness and tingling were the most frequently reported medical issues.

Changes in relationships with loved ones, friends or co-workers/social life and anxiety were the most commonly reported psychosocial issues during treatment.

The experience of medical issues, physical conditions and psychosocial issues was diverse and lasted for various lengths of time after treatment.

Most Australian respondents have experienced changes in their lifestyle and almost half reported changes in their independence, as a result of having lymphoma.

Fear of relapse

The fear of relapse was experienced by respondents during treatment and was most common after treatment, when levels peaked significantly. Some even reported this fear 8+ years after treatment. Fear of relapse was associated with feelings of anxiety, depression and isolation, which were not often discussed with their doctor.

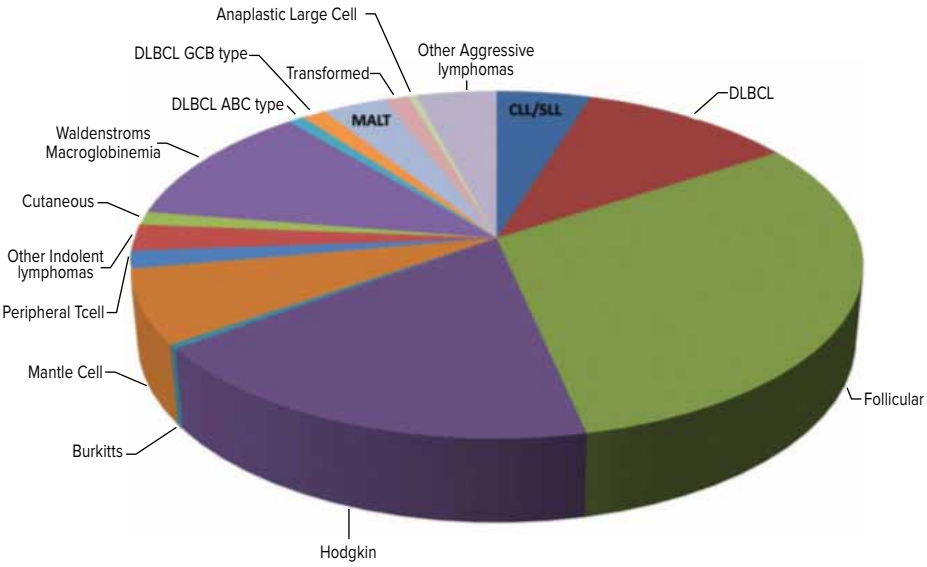
Fatigue

Fatigue, which affected respondents' independence but more so their lifestyle, peaked immediately following treatment, and was reported at 3-5 years and even 8+ years after treatment.

Barriers and impediments

Australians commonly reported finances as a barrier to treatment along with access to a treatment centre/prohibitive travel.

Barriers also were found to be associated with where they lived. For example, the availability of a specialist physician locally was identified as a barrier more frequently by respondents living in rural areas compared to in metropolitan areas.



About the survey

There were two versions of the 2018 Global Patient Survey on Lymphomas and CLL – patient and caregiver – and the data from both were merged for the analysis.

The survey had 29 questions, was available in 19 languages, and could be completed online from January to March 2018. For the analysis, the surveys completed by patients and carers were merged.

This year the survey specifically sought to gain insights into:

- patient awareness and understanding, sources and level of information and support, support from healthcare professionals (HPs), and the impact this has on the patient experience; how a patient 'feels' when they have the information, and support they perceive they need;
- trends in patient 'fear of relapse' to ensure that patients are getting enough proactive psychosocial support during/after the treatment process;
- a variety of fatigue-related issues and demographics, and to determine how often patients are communicating these issues to their HPs;
- issues around physical/medical/psychosocial side-effects; and
- availability and efficacy of services by country and by area (rural/urban), and determine if/how that affects the patient experience (communication, side-effects, information-seeking, etc.)

NEW SOUTH WALES & AUSTRALIAN CAPITAL TERRITORY

Sydney Metro

21 Aug	10am-12pm	Liverpool Blood Cancer Information & Support Group (also 18 Sep, 16 Oct, 20 Nov)
27 Aug	10-11.30am	St George Blood Cancer Education & Support Group (also 24 Sep, 29 Oct, 26 Nov)
29 Aug	11am-1pm	Westmead Blood Cancer Education & Support Group (also 26 Sep, 31 Oct, 28 Nov)

Australian Capital Territory & Southern New South Wales

13 Aug	11am-1pm	Goulburn & Surrounds Blood Cancer Support Group (also 10 Sep, 8 Oct, 12 Nov, 10 Dec)
14 Aug	10am-12pm	Canberra Blood Cancer Support Group (also 11 Sep, 9 Oct, 13 Nov, 11 Dec)
23 Aug	4-6pm	Bega Valley & Sapphire Coast Blood Cancer Support Group, Merimbula (also 18 Oct)
28 Aug	5.30-7.30pm	20/30 Chat, Garran (also 27 Nov)
21 Sep	1.30-3.30pm	Moruya & Surrounds Blood Cancer Support Group (also 16 Nov)

Central Coast

30 Aug	10-11.30am	Gosford Blood Cancer Education & Support Group (also 27 Sep, 25 Oct, 29 Nov)

Central West & Far West

9 Aug	10.30am-12pm	Mudgee Blood Cancer Education & Support Group (also 11 Oct, 13 Dec)

Hunter

7 Aug	10am-12pm	Newcastle Blood Cancer Education & Support Group, Mayfield (also 2 Oct, 4 Dec)
14 Aug	10am-11.30am	Port Stephens Blood Cancer Education & Support Group (also 9 Oct, 20 Nov)
4 Sep	10am-12pm	Newcastle Blood Cancer Education & Support Group, Shortland (also 13 Nov)

Illawarra & Shoalhaven

1 Aug	10.30am-12.30pm	Wollongong Blood Cancer Information & Support Group, Fig Tree (also 5 Sep, 3 Oct, 7 Nov, 5 Dec)
13 Aug	10am-12pm	Shoalhaven Blood Cancer Information & Support Group, Bomaderry (also 10 Sep, 8 Oct, 12 Nov, 10 Dec)
26 Sep	10am-12pm	Bowral Blood Cancer & Support Group (also 28 Nov)

Mid North Coast

20 Aug	10-11.30am	Port Macquarie Blood Cancer Education & Support Group (also 17 Sep, 15 Oct, 19 Nov, 17 Dec)
23 Aug	11.30am-1pm	Coffs Harbour Blood Cancer Education & Support Group (also 27 Sep, 25 Oct, 22 Nov)

New England

14 Aug	10.30am-12pm	Armidale Blood Cancer Education & Support Group (also 11 Sep, 9 Oct, 13 Nov, 11 Dec)
21 Aug	1.30-3.30pm	Tamworth Blood Cancer Education & Support Group (also 18 Sep, 16 Oct, 20 Nov, 18 Dec)

QUEENSLAND

Brisbane Metro

4 Aug	9am-12pm	It's all about me, Nutrition (also 3 Nov)
11 Aug	9am-3pm	It's all about me, Exercise & Relaxation (also 17 Nov)
22 Sep	12-3pm	20/30 Chat
2 Nov	10am-12pm	Waldenström's Macroglobulinaemia Coffee, Cake & Chat
16 Nov	10am-12pm	Lymphoma Coffee, Cake & Chat

Regional Queensland

13 Aug	10am-12pm	Coffee, Cake & Chat, Mackay
23 Aug	10am-12pm	Coffee, Cake & Chat, Ingham
30 Aug	10am-12pm	Coffee, Cake & Chat, Gold Coast (also 15 Nov)
6 Sep	10am-12pm	Coffee, Cake & Chat, Ayr
7 Sep	10am-12pm	Blood Cancer Coffee, Cake & Chat, Toowoomba (also 7 Dec)
12 Sep	10am-12pm	Coffee, Cake & Chat, Sunshine Coast (also 9 Nov)
13 Sep	10am-12pm	Lymphoma Coffee, Cake & Chat, Townsville

SOUTH AUSTRALIA

Adelaide Metro

15 Aug	10.30am-12.30pm	Strathalbyn Support Group (also 19 Sep, 17 Oct, 21 Nov)
21 Aug	10am-12pm	Northern Adelaide Support Group, Evanston (also 16 Oct)
28 Aug	10.30am-12.30pm	Men's Group, Adelaide (also 30 Oct)

Regional South Australia

6 Aug	5.30-6.30pm	Mount Gambier Support Group (also 8 Oct, 3 Dec)
14 Aug	10am-12pm	Port Lincoln Support Group (also 9 Oct)

TASMANIA

Northern Tasmania

14 Aug	10.30am-12pm	Blood Cancer Support Group, Launceston (also 9 Oct)

Southern Tasmania

8 Aug	10.45am-1.30pm	Hobart Blood Cancer Wellbeing Forum
16 Aug	10.30am-12pm	She Shed (also 20 Sep, 22 Nov)
10 Oct	10.45am-1pm	Stem Cell Collection and Transplantation Seminar
5 Dec	11am-1.30pm	Hobart Christmas Party

VICTORIA

Metro Melbourne

2 Aug	10.15-11.45am	Bone Marrow & Stem Cell Transplant Support Group, Hawthorn (also 1 Nov)
8 Sep	8am-5pm	Leukaemia Foundation Blood Cancer Conference, Melbourne
1 Oct	10.15-11.45am	Bone Marrow Stem Cell Support
16 Oct	10.15-11.45am	Northern Suburbs Blood Cancer Support Group, Hawthorn
9 Nov	10-11.30am	Berwick Support Group

Barwon & South West

14 Aug	10-11.30am	Barwon Blood Cancer Support Group (also 9 Oct, 11 Dec)
5 Sep	10-11.30am	Warrnambool & South West Blood Cancer Support Group (also 28 Nov)

WESTERN AUSTRALIA

Perth Metro

20 Aug	1-3pm	Perth Metro Blood Cancer Support Group

Regional Western Australia

2 Aug	10:30am-12pm	Bunbury Regional Blood Cancer Support Group
8 Aug	10am-12pm	Albany Blood Cancer Support Group
23 Aug	10.30-12pm	Peel/Port Kennedy Regional Blood Cancer Support Group, Greenfields

WORLD LYMPHOMA AWARENESS DAY 2018 EVENTS

12 Sep	10.45am-1.30pm	WLAD seminar, Hobart
12 Sep	10am-1pm	WLAD seminar, Brisbane
13 Sep	11am-2pm	WLAD seminar, Sunshine Coast

Light the Night

October 2018

Light the Night is the Leukaemia Foundation's beautiful evening lantern walk, where Australians come together and transform the darkness into a sea of glowing light to beat blood cancer.

For dates and details across Australia: **lightthenight.org.au**

Join the Lymphoma Network and WM Network closed groups on Facebook: facebook.com/groups/LymphomaLFA/ and facebook.com/groups/WaldenstromsLF/
Visit leukaemia.org.au for our latest Education and Support Program Event Calendar.
To register for an education or support event, freecall 1800 620 420 or email info@leukaemia.org.au

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