

# CLL news.

For people with CLL or SLL & their families



Leukaemia  
Foundation  
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*Des Paddon with his daughter, Jessica O'Brien, and grandson, Harvey. When he visited them in Darwin in March last year, they spent a few days together at Katherine Gorge.*

## Clinical trial access to venetoclax – a lifesaver for Des

**Des Paddon has no doubt – a clinical trial he went on in late-2014 for the experimental therapy ABT-199 (venetoclax) saved his life.**

"I wouldn't be here now if the trial hadn't come up," said Des, 70, a retired builder, of Warrnambool.

In early-2014, seven years after being told he had CLL, Des was all out of treatment options. His CLL had mutated, chemotherapy had become ineffective and physically, he was "a wreck". He could hardly walk, was unable to drive, and at times was "very fuzzy" mentally.

"A lot has happened," said Des, describing his journey since being diagnosed with early-stage CLL in 2007.

He was on 'watch and wait' for two years before "it got really bad" and he started combination chemotherapy. Over the next five years, he had four "bouts" of FCR\* at his local hospital.

"The chemo stabilised the CLL and pulled it back sometimes, but it didn't stop it fully, then it just wasn't working," explained Des, who has two daughters and a grandson, and lives alone.

***"I wouldn't be here now if the trial hadn't come up..."***

"I was at the end at that point and very low when I found out 'something might be available'."

His haematologist, having heard about a venetoclax (Venclexta™) trial, was looking at getting Des on to it.

"I had to qualify, of course, which meant going to Melbourne to be tested. And I needed to have good kidney and liver function because the process kills a lot of cells very quickly and your body has a big job flushing out those dead cells," he explained.

Des was ecstatic to be accepted for the trial. He only found out recently that he was one of the first Australians to participate in the U.S.-run international study for the new oral anti-cancer therapy that was actually developed in Australia.

*Continued on page 6.*

## World-first liquid biopsy – new test for CLL

**People with CLL and other blood cancers could soon have access to a simple blood test to monitor their disease.**

How the innovative new test can be applied in clinical cases of CLL was published in two leading journals, *Nature Communications* and *Blood*, in March.

The world-first liquid biopsy for blood cancers was developed at the Peter MacCallum Cancer Centre (Melbourne) by Associate Professor Sarah-Jane Dawson and Professor Mark Dawson, with funding support from the Leukaemia Foundation.

It promises a new era of less invasive, more precise, and effective management of blood cancers including CLL, in place of painful bone marrow biopsies.

The test monitors tiny fragments of DNA that cancer cells emit 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 treatment, and enable rapid adjustments if a person with CLL relapses or fails to respond to therapy.

Associate Professor Sarah-Jane said this ctDNA test 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,” said Assoc. Prof. Dawson.

The liquid biopsy also addresses a major limitation in the current approach to managing blood cancers according to Professor Mark Dawson.

“We know that a single tissue biopsy from the bone marrow or lymph node does not accurately reflect the composition of the whole tumour,” he said.

“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



Associate Professor Sarah-Jane Dawson and Professor Mark Dawson.

comprehensive picture of how a patient is responding to their treatment,” Professor Dawson said.

Professor Mark Dawson has a Leukaemia Foundation Senior Research Fellowship of \$200,000 per year from 2013-2017.

## PBAC approves ibrutinib and SC rituximab but defers venetoclax

**At its meeting in March, the Pharmaceutical Benefits Advisory Committee (PBAC) recommended ibrutinib providing it is available only as a monotherapy for people with relapsed or refractory CLL and SLL.**

The PBAC also recommended rituximab solution for subcutaneous injection for CD20 positive CLL in combination with chemotherapy after being satisfied rituximab subcutaneous (1600mg) gave the same health benefit and was as safe as an intravenous course of rituximab at a dose of 500mg/m<sup>2</sup>.

A decision regarding venetoclax was deferred for those with relapsed/refractory CLL as the PBAC considered it more appropriate to compare the potential benefit, cost, and cost-effectiveness of venetoclax with ibrutinib and idelalisib rather than ofatumumab – the drug nominated in the submission.

## Light the Night

**Australia’s blood cancer community comes together each year to Light the Night at 100+ locations across the nation, to reflect and remember those who have or have had blood cancer.**

These Leukaemia Foundation events are held on October 6 in metro centres and on various dates but predominantly in October in regional and rural areas.

Those who attend raise money to help make a better future and to provide life-saving services, emotional and practical

support to those facing blood cancer and their families.

Light the Night fundraisers receive a coloured lantern to carry during the event’s ceremony and the short lantern walk that follows. They are celebrating what has been achieved for the 60,000 people currently living with a blood cancer diagnosis and the 35 additional Australians who are diagnosed each day.

Gold lanterns remember loved ones lost to blood cancer, white lanterns are held by those who have had a blood cancer diagnosis, and their friends, family and the community carry blue lanterns as a show of support.

Join a Light the Night event near you today at [lightthenight.org.au](http://lightthenight.org.au).



# LF-funded research advancing and improving CAR T-cell therapy

**A clinical trial, expected to open in Sydney later this year, will test advancements in chimeric antigen receptor (CAR) T-cell therapy developed in Australia and funded by the Leukaemia Foundation\*.**

CAR T-cells are a revolutionary form of treatment for B-cell malignancies. In people with previously incurable CLL, CAR T-cells have resulted in complete response rates of approximately 50% across multiple clinical trials.

Yet access to CAR T-cells remains limited to clinical trials at only a few centres, due to the cost and complexity of CAR T-cell generation.

Dr David Bishop, a specialist in adult clinical and laboratory haematology, is completing his PhD, funded by the Leukaemia Foundation's National Research Program, on the development of CAR T-cells for the treatment of B-cell malignancies.

His research, part of the Leukaemia Cell Therapies Group at the Westmead Institute for Medical Research, University of Sydney, has investigated new methods of generating CAR T-cells to address these issues and also to improve CAR T-cell safety.

Leukaemias and lymphomas that arise from a subset of white blood cells called B-cells are among the most common forms of blood cancer.

Standard treatment for these conditions involves chemotherapy and rituximab, a monoclonal antibody that specifically targets the B-cells and leads to their destruction. People with high-risk disease or who relapse may go on to have a bone marrow transplant.

"Unfortunately, despite these treatment options, a subset of patients with highly aggressive leukaemia or lymphoma will have incurable disease," said Dr Bishop.

In recent years, a groundbreaking new form of treatment for B-cell malignancies has been developed – CAR T-cell therapy.

"The normal role of a T-cell is to provide immunity against foreign invading pathogens, like bacteria and viruses. Because cancer cells arise from normal body tissue, naturally occurring T-cells have difficulty recognising them as abnormal," Dr Bishop explained.

"To overcome this problem, a synthetic CAR can be introduced into a naturally occurring T-cell by genetic modification, which enables it to recognise markers on the surface of B-cell leukaemias and lymphomas, and destroy them.

"Despite the astounding success of this form of immunotherapy, patients can only access CAR T-cells in clinical trials run in only a small number of centres worldwide.

"Factors contributing to this situation include the cost and complexity of CAR T-cell generation. My research has investigated new methods of generating CAR T-cells to address these issues, and also to improve CAR T-cell safety," said Dr Bishop.

"The manufacturing process of most CAR T-cells to date has utilised expensive systems incorporating modified viruses to deliver the CAR gene into the T-cells.

"Instead, we have developed a process that essentially cuts the CAR gene from a DNA template and pastes it into the T-cell genome.

"This has enabled us to reduce the cost of CAR T-cell production by 10-fold, to approximately US\$10,000 per patient.

"The structure of the CAR itself also has been optimised within this system in preclinical studies, to improve leukaemia eradication and CAR T-cell persistence.

"We expect to open a clinical trial of these CAR T-cells at Westmead Hospital later in the year, for the treatment of patients with relapsed or refractory B-cell malignancies following allogeneic bone marrow transplant."

Dr Bishop said the trial will be open to paediatric patients as well as adult patients and will run out of both the adult's and children's hospitals at Westmead.

*"... it's very satisfying to see your ideas progress from a pre-clinical setting to being translated to the clinic..."*

The trial will be led by Dr Kenneth Micklethwaite, who is supervising Dr Bishop's doctoral research, along with Professor David Gottlieb.

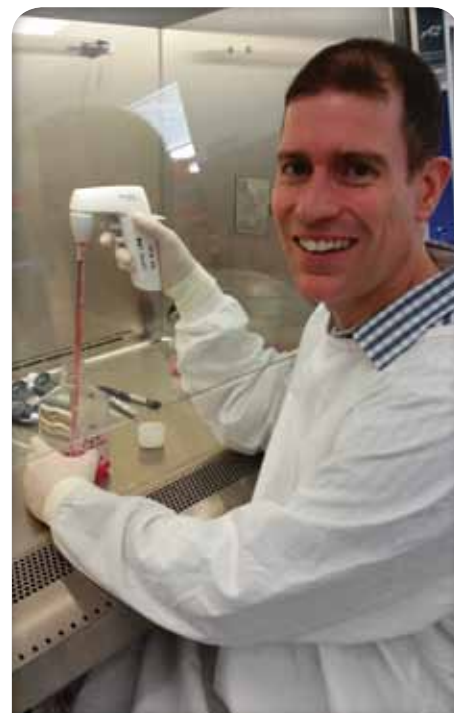
Dr Bishop said another factor contributing to the cost of CAR T-cell therapy was the current need for every patient to have an individualised product, generated from their own T-cells.

"The main reason for this is to avoid graft-versus-host disease that could occur if CAR T-cells were generated from donor T-cells.

"Because any potential cross reaction is brought about by the native T-cell receptor found on the surface of all T-cells, my research also has investigated eliminating the expression of this molecule on CAR T-cells.

"This would make the donor CAR T-cells safe and enable the formation of CAR T-cell banks, so one, ready-made product is suitable for many patients."

Because CAR T-cells, like any treatment, may have unwanted side-effects, Dr Bishop said it would be useful to be able to selectively eliminate them in the event of unacceptable toxicity.



Dr David Bishop.

"My research has explored incorporating a 'suicide gene' into CAR T-cells that sensitises them to the drug rituximab," he said.

"When exposed to this drug, virtually all CAR T-cells expressing the suicide gene are eliminated, but ordinary T-cells are left untouched.

"Our group is evaluating several other candidate suicide genes before deciding which to incorporate into our CAR T-cell products for use in clinical trials."

Dr Bishop said the CAR T-cell field was rapidly progressing globally.

"It is an incredibly exciting area of research to be involved in, and it's very satisfying to see your ideas progress from a pre-clinical setting to being translated to the clinic where they can potentially have a meaningful impact on patient care.

"My personal goal for the future is to combine practise as a clinical haematologist with a translational research career, and I would love to be part of a team that can develop a new treatment that improves the outcomes of our patients with haematological malignancies.

"With a PhD scholarship, the Leukaemia Foundation has enabled me to take the first steps towards that goal by providing funding to undertake high quality research and share my findings with the world at international conferences," said Dr Bishop.

\* Dr Bishop has a Leukaemia Foundation PhD Scholarship (Clinical) supported by the NSW Community Foundation, N&P Pinter, of \$60,000 per year from 2014-2017 (Immune cell therapies for lymphoma, leukaemia and post-transplant viral infections).

## CLL Horizons 2016 conference – improving outcomes

**People with CLL experience psychological stress and high levels of anxiety from the contradiction of having leukaemia but not being treated at the time of their diagnosis.**

That was the take home message from CLL Horizons 2016 for the Leukaemia Foundation's CLL My Way Coordinator, Sheila Deuchars\*. She attended the first international conference for organisations representing people with CLL, in Serbia last November.

"I gained a deep understanding of the major cognitive dissonance (mental discomfort) that occurs for CLL patients when they are told 'you have leukaemia, however, you don't need treatment' and 'we will just keep an eye on you for as long as possible,'" said Sheila.

"Patients report a high level of anxiety and concern that they are 'living with cancer' but they can't do anything other than 'staying positive and living normally'.

"Often they are not referred to support services at their initial diagnosis because they aren't having treatment, yet this is a critical time when they report feeling vulnerable and concerned that they could be 'doing something' rather than 'waiting for something to happen'.

"Some patients refer to 'active surveillance' as 'watch & worry' rather than 'watch & wait', as it is referred to by haematologists," she said.

Sheila, who represented the Leukaemia Foundation of Australia, was among attendees from 25 countries from Europe, and the U.S., Canada and the UK.

The delegates were health professionals supporting people living with CLL as well as patients and their partners/advocates. They gathered to learn, share and start to think about how to help improve outcomes for CLL patients globally. There was a strong focus on patient advocacy with advocacy sessions each day.

The pre-meeting session, *CLL 101*, was an overview of the disease by Dr Brian Koffman (U.S.) MD, educator and clinical professor turned patient when he was diagnosed in 2005, and Dr Kostas Stamatopoulos (Greece).

*"... they could be 'doing something' rather than 'waiting for something to happen'..."*

The first medical session was on CLL biology, diagnosis and prognosis by Dr Ben Kennedy (UK), Dr Stamatopoulos and Professor Christopher Fegan (UK).

The next day started with a second medical session on the early management of CLL. Professor Arnon Kater, clinical haematologist (The Netherlands) covered *Watch & wait: when to treat, why to treat, when not to treat*, and Professor Christopher Fegan spoke about the psychological impacts and managing access to information and support.



CLL My Way Coordinator, Sheila Deuchars.

The third day of the conference featured first line treatment, clinical trials, trial uptake and availability, and the final medical session focused on relapsed and refractory CLL and future strategies.

\* Sheila's travel, accommodation and registration costs were sponsored by CLL Advocates Network.

## Blood Buddies – an especially useful form of CLL support

**The Blood Buddies phone-based peer support program is particularly beneficial for people with CLL – the most common form of leukaemia.**

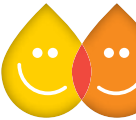
This is because people diagnosed with CLL are living with a chronic illness, says Chloe Nunn, the Leukaemia Foundation's Blood Buddies Coordinator.

Often, CLL can be a relatively slow-growing disease initially.

"Some people may never require any treatment for their disease, while others who are being treated may be seen mainly in outpatient settings where they may not meet another person with the same diagnosis," said Chloe.

"And it can be difficult for people with CLL to attend support groups, education sessions and telephone forums if they are still working or live in regional areas.

"Therefore, having a Buddy can be particularly powerful in reducing the sense of isolation and in providing reassurance and support," she explained.

Leukaemia Foundation  
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 BUDDIES

"It also can be helpful to speak to someone who has experience living with a chronic illness about managing the anxieties that can come from watch and wait, and managing any side-effects related to treatment."

Blood Buddies matches and connects people diagnosed with blood cancer with trained volunteers who have had one of the blood cancers themselves.

"We are excited that the Blood Buddies program has had a high level of interest since its launch in 2015, and we recently connected the 280th person with blood cancer to a trained 'Buddy'.

"So far there are 180 fully qualified Buddies including 12 CLL Buddies and 1 SLL Buddy and there have been 23 matches between those more recently diagnosed with CLL or SLL and others who are further down the track," Chloe said.

"As people have a diverse range of experiences and treatment approaches, we are keen to recruit and train more Buddies who have been diagnosed with CLL or SLL and there is an urgent need for volunteers with hairy cell leukaemia (a subtype of CLL) to train as a Buddy so we can offer this important support service to even more people.

"If you feel you can offer short-term one-on-one support to someone else at an earlier stage of this disease experience than you, please let us know you're interested in the program," Chloe said.

For more information and to register your interest in becoming a Blood Buddy, or being matched with a Buddy, email: [bloodbuddies@leukaemia.org.au](mailto:bloodbuddies@leukaemia.org.au) or call 1800 007 343.

## Having a Buddy helped Terese's fear of the unknown

**Terese Saunders feels much more relaxed about the future now, having had several conversations with her Blood Buddy, Martin Lowthe.**

"I'd never heard of CLL, and to be told you've got a form of blood cancer is devastating news," said Terese, 55, a retiree, of South Gippsland (Vic).

It's more than five years since her diagnosis and she hasn't had any treatment or medical procedures.

"I'm on watch, wait and worry," she explained.

"I couldn't understand why you wouldn't be given drastic and savage treatment to kill it (CLL) then and there, to fight it with all your worth while you're young and healthy.

"I couldn't get my head around – you actually just wait.

"You never stop worrying about it and I couldn't push it on to the back burner," she said.

***"You gain something from helping someone else..."***

"When I read about Blood Buddies in *CLL News*, I wanted to join and be hooked up to a Buddy.

"I live in a small country town and don't have a great deal of contact with anyone else with CLL.

"I thought it would be nice to talk to somebody, who was a bit further down the track than me, about what treatments and procedures they've had."

Terese was matched with Martin Lowthe, 71, of Northam, west of Perth. He didn't

need to start treatment until two years ago and he's had CLL for 14 years.

"I was aware of having CLL, but it didn't bother me. I had no symptoms and ignored it," said Martin.

"I tend to live for the day rather than worry about what happens in the future, or the past," said Martin.

"You may never need treatment, so why worry about something that may never happen."

When Martin read about the Blood Buddies program on the Foundation's website ([leukaemia.org.au](http://leukaemia.org.au)) he thought it would be a good idea to give something back.

"Especially as I have been through a lot and am retired," said Martin, who has been a Buddy to two people.

"You gain something from helping someone else, and you help yourself at the same time.

"The Blood Buddies training course is very good. You learn a lot about yourself. I go back to it now and again to refresh my memory of it," he explained.

So far, Terese and Martin have had five conversations.

"I had a list of questions to ask on our first discussion," said Terese.

"I'm not so terrified of the unknown now – the 'when' and 'if' it'll happen to me.

"I'm more relaxed about the future. It might not be so dreadful after all! Martin keeps saying: 'you may not need any treatment'.

"I know every case is very individual\* and it's good to know Martin is still so positive.



**Martin Lowthe: "You may never need treatment, so why worry about something that may never happen".**

"He is getting on with life and living, and is up and at 'em," she said.

"His life hasn't been robbed from him. He's mowing lawns and isn't bedridden and sickly.

"I feel good and I try to keep as healthy as I can. I go for a fast walk of a morning, rarely eat junk food and don't add sugar to anything. I eat lots of fresh fruit and veges and steer away from deep fried and fatty food.

"And I'd just like to say what a wonderful program the Foundation's Blood Buddies is," said Terese.

*\* Earlier this year Martin found out his CLL had changed to Hodgkin lymphoma. He is currently having treatment for this form of blood cancer.*



**Terese Saunders: "I'm not so terrified of the unknown now..."**

## Continued: Clinical trial access to venetoclax – a lifesaver for Des

During the six months leading up to the trial, Des, who was still recovering from his final cycle of FCR, was monitored and given antibiotics and transfusions.

While he wasn't well when he had his first dose of venetoclax on 17 November 2014, Des said his bloods showed improvement within 48 hours.

Over the next week he was closely monitored in Melbourne before going home to Warrnambool. At first, friends and family helped out by driving him the 750km to Melbourne and back. Initially his appointments for blood tests, CT scans and bone marrow biopsies were every week, then monthly, and now are four times a year.

"My youngest daughter, Naomi, drove me down and later, when I'd catch the train there and back, my sister, Yvonne would pick me up from the station and take me to the hospital.

"Over the last 2½ years, she has come with me to every appointment with my specialist in Melbourne.

"Now I make the trip myself in a day. I leave at 3am and arrive in Melbourne in time for a blood test at 7.30am. My medical appointment is at 11am, then I have lunch with family and drive back," said Des who gets home around 7pm.

"It's a pretty easy drive once I get out of town and I am grateful and thankful to be going to Melbourne for the treatment."

After 18 months on the trial, Des was told he was "totally clear" – there was no longer any sign of leukaemia in his bone marrow!

"I'm very happy with the results and haven't noticed any physical side-effects from the tablets that I can put my fingers on.

"You are not cast as cured, the CLL is just under control," he explained.

The trial has now officially ended but Des continues to take his tablets every morning and is still monitored at the Melbourne hospital every three months.

Des has faced many challenges, mostly while he was having chemo, and he joined the Leukaemia Foundation's Blood Buddies program to share his experiences with others.

Once, between cycles, he was hospitalised for two weeks after breaking out in blisters all over his body in a reaction to the chemo. And during his last cycle of FCR he started having convulsions when his PICC line became infected. It was removed and he spent another fortnight in hospital having antibiotics.

In another incident, three days before his eldest daughter's wedding on 15 March 2014, Des got "really sick" and ended up in hospital again.

"My whole body had crashed and the doctor said, 'if we can't turn this around, you don't walk out of here'. It was pretty serious. All the family came down and I got the lawyer for my will," said Des.

But he was not thwarted and when he showed signs of a slight improvement Des asked his specialist if he could go to the wedding.

"He wasn't too happy about that and he gave me six hours but I had to have a blood transfusion in the morning and another one before they let me out (of hospital)," he said.

*"I'm very happy with the results and haven't noticed any side-effects..."*

"I gave Jessica away and went to the reception, but didn't last. It took a lot out of me, but I was there, and I danced with her before going back to hospital where I stayed for another 10 days, and Jessica delayed her honeymoon for two weeks.

"I survived, and soon after that I got the okay to apply for the venetoclax trial."

When Des was first diagnosed he made a decision that alongside the medicos, who looked after his treatment, he would look after his health; that was his job.

"I took a great deal of care in what I was eating and gave up all sugars and bread and processed food and any rubbish," said Des, who has been on cleansing diets, went vegan for a while, fasts from time to time, and drinks fresh rainwater.

Since finishing chemo, when he could only walk 30 metres, Des has gradually built up to walking five kilometres.... on the beach, along the cliffs and up and down

Tower Hill (an extinct volcano and nature reserve near his home). He also believes weight-resistant exercise is important and regularly goes to the gym.

For Des, health is a lifetime approach to food control and physical exercise, and counselling is a vital part of the mix.

"Don't be afraid to ask for help," he said.

"When I first walked into the Melbourne hospital for the trial, it totally freaked me out – floors of people everywhere, with every cancer you can think of.

"I needed help, and had counselling straight away because I wasn't coping. I think cancer therapy should go hand-in-hand with counselling.

"It's up to you to take control. The simple choice is how well or how badly you want to live your life. Concentrate on yourself, treat yourself as No. 1 and look after yourself," said Des, who is looking forward to the birth of his second grandchild next month.

The Leukaemia Foundation provided funding for early work on the precursor to ABT-199. This research, undertaken by Dr Kylie Mason, Professor Andrew Roberts and collaborators at the Walter & Eliza Hall Institute (Melbourne) through the Foundation's National Research Program Grants-in-Aid 2010 and 2012, assisted in the development of venetoclax.

\* FCR: fludarabine, cyclophosphamide and rituximab



Des Paddon with his younger daughter, Naomi Paddon, at Jessica's wedding reception in March 2014.

## Wellness program support – a comfort for Dulcie

**Dulcie Hooper, 86, of Bargara (Qld), has returned to her quilter's group, is back playing mahjong every week, and walks for an hour early every morning.**

She also does her own grocery shopping and has stopped getting Meals on Wheels because she is cooking for herself again.

"I haven't felt this well in a long time," said Dulcie, who started a new medication, ibrutinib\*, in February.

"I just feel a lot better since I've been on this drug. People tell me I'm looking good and that's how I feel."

Dulcie was diagnosed with CLL in October 2011 and started chemotherapy the following May (2012). In October 2015 she went on to a more intense treatment regimen. This involved going to Brisbane for the first of the four cycles, the rest she had in Bundaberg.

At the end of last year, after 10 months when she was medication-free and just monitored with blood tests, a bone marrow aspirate showed she still had leukaemia cells.

*"It's comforting to know someone who cares and understands CLL will ring you, and to know help is there if you need it..."*

So earlier this year, Dulcie was put on ibrutinib (Imbruvica®) and her haematologist suggested she take part in the Leukaemia Foundation's CLL My Way pilot program. (See next story.)

She receives regular phone calls from CLL My Way Coordinator, Sheila Deuchars,



*Dulcie Hooper with her daughter, Jan Bradford, and grandsons, Nicholas, left, and James, right, on Mother's Day.*

who checks in on Dulcie, to ensure she is taking her medication every day and to talk about her diet and levels of fatigue and how she is feeling.

"It's comforting to know someone who cares and understands the condition (CLL) will ring you, and to know help is there if you need it," said Dulcie.

"I'm beginning to feel a lot better, I've got more energy and don't have any side-effects.

"I'm going along really well at the moment and am back to what I was doing before I started chemo.

"Long-term, I could be on these capsules for the rest of my life.

"I have them after my morning walk each day – it's just a routine. It doesn't worry me taking them – they're doing me good," said Dulcie, who describes herself as a positive person who doesn't dwell on having CLL.

\* Supplied on compassionate grounds by the manufacturer, Janssen. Ibrutinib is not yet PBS-listed but has been approved by the PBAC as a monotherapy for patients with relapsed or refractory CLL/SLL who meet certain conditions.

## CLL My Way program update

**Sixty people in New South Wales and Queensland enrolled in a pilot program, called CLL My Way, aimed at informing, supporting and empowering people with CLL.**

The Leukaemia Foundation developed the wellness program, with support from Janssen and the CLL Australian Research Consortium.

It is based on providing motivational counselling and one-on-one support to help people with CLL live with the challenges of long-term and changing treatments. These treatments include emerging oral therapies, which require patients to take medications strictly as they are prescribed for the rest of their lives.

Caroline Turnour, the Foundation's General Manager, Research, Advocacy & Services, said the chronic nature of CLL meant personalised support was vital to assist people to stay on track with treatment and take steps towards a healthier life.

"CLL My Way takes a holistic approach and promotes the benefits of regular exercise, a healthy diet, stress reduction and managing fatigue," Ms Turnour explained.

The program involves regular face-to-face, telephone or online support provided by a trained CLL My Way coordinator.

At the first CLL My Way telephone forum in March, Dr Cecily Forsyth spoke about CLL and its treatment and answered questions.

In April, 20 people on the CLL My Way program who live in south-east Queensland attended a CLL mindfulness seminar in Brisbane, called *Adapting to Life Changes*. The same information session also was held in Sydney last month as part of the Foundation's Sydney Blood Cancer Education Conference.

On July 19, a CLL My Way seminar will be held in Brisbane, with a presentation and Q&A session on CLL treatments by Dr Sally Mapp. A special Q&A session with Dr Mapp will be filmed and made available for viewing on the Leukaemia Foundation's YouTube channel.

One participant described the program as "an exceptionally good learning experience" and another said "it's lovely to have access to these support mechanisms".

To connect people on the program and enable them to contact each other throughout the pilot, the Foundation established a CLL My Way members-only Facebook group. It has 26 members and here's a snapshot of comments posted by group members:

*"Great to be able to read other's experiences."*

*"Thanks for giving us the opportunity to 'meet' others."*

*"The telephone forum was very informative."*

**For information on CLL My Way, contact Sheila Deuchars on 1800 002 244 or visit [leukaemia.org.au/cllmyway](http://leukaemia.org.au/cllmyway).**



**NEW SOUTH WALES & AUSTRALIAN CAPITAL TERRITORY**

**Sydney Metro**

17 Jul	10am-12pm	Liverpool Blood Cancer Education & Support Group (also 21 Aug, 18 Sep, 16 Oct, 20 Nov)
19 Jul	2-4pm	Randwick Blood Cancer Education & Support Group (also 16 Aug, 20 Sep, 18 Oct, 15 Nov, 13 Dec)
26 Jul	11am-1pm	Westmead Blood Cancer Education & Support Group (also 30 Aug, 27 Sep, 25 Oct, 29 Nov)
28 Jul	10am-12pm	North Sydney Blood Cancer Education & Support Group (also 25 Aug, 29 Sep, 24 Nov)
31 Jul	10-11.30am	St George Blood Cancer Education & Support Group (also 28 Aug, 25 Sep, 30 Oct, 27 Nov)
11 Aug	10am-12pm	Concord Blood Cancer Education & Support Group (also 8 Sep, 13 Oct, 10 Nov, 8 Dec)

**Central Coast**

25 Jul	2-3.30pm	Wyong Blood Cancer Education & Support Group (also 29 Aug, 26 Sep, 31 Oct, 28 Nov)
27 Jul	10-11.30am	Gosford Blood Cancer Education & Support Group (also 31 Aug, 28 Sep, 26 Oct, 30 Nov)

**ACT & Southern NSW**

27 Jul	4-6pm	Bega Valley Support Group (also 21 Sep, 16 Nov)
8 Aug	10am-12pm	Canberra Blood Cancer Education & Support Group (also 12 Sep, 10 Oct, 14 Nov, 12 Dec)
11 Sep	11am-1pm	Goulburn Blood Cancer Education & Support Group (also 9 Oct, 13 Nov, 11 Dec)

**Hunter**

8 Aug	10am-12pm	Newcastle Blood Cancer Education & Support, Mayfield (also 5 Sep, 10 Oct, 14 Nov, 12 Dec)
15 Aug	10-11.30am	Port Stephens Blood Cancer Education & Support (also 12 Sep, 21 Nov)
5 Sep	10am-12pm	Newcastle Blood Cancer Education & Support, Shortland (also 14 Nov)

**Illawarra & Shoalhaven**

26 Jul	10am-12pm	Bowral Blood Cancer & Support Program (also 27 Sep, 22 Nov)
2 Aug	10.30am-12.30pm	Wollongong Blood Cancer Education & Support Group, Figtree (also 6 Sep, 4 Oct, 1 Nov, 6 Dec)

**Mid North Coast**

18 Jul	10-11.30am	Port Macquarie Blood Cancer Education & Support Group (also 21 Aug, 18 Sep, 16 Oct, 20 Nov, 18 Dec)
27 Jul	11.30am-1pm	Coffs Harbour Blood Cancer Information & Support Group (also 24 Aug, 28 Sep, 26 Oct, 23 Nov)

**New England**

18 Jul	1.30-3pm	Tamworth Blood Cancer Information & Support Group (also 15 Aug, 19 Sep, 17 Oct, 21 Nov, 19 Dec)
19 Jul	2-3.30pm	Armidale Blood Cancer Education & Support Group (also 16 Aug, 20 Sep, 18 Oct, 15 Nov, 20 Dec)

**NORTHERN TERRITORY**

26 Jul	6-8pm	Men's Shed, Darwin (men only support group) (also 30 Aug, 27 Sep, 25 Oct, 29 Nov)
27 Jul	10-11.30am	Alice Springs Blood Cancer Support Group (also 31 Aug, 28 Sep, 26 Oct, 30 Nov)
8 Aug	6-8pm	Women's Group, Darwin (also 4 Sep, 2 Oct, 6 Nov, 4 Dec)

**QUEENSLAND**

**Brisbane Metro**

19 Jul	10.30am-1.30pm	CLL My Way seminar, Yesterday, today & tomorrow
17 Aug	10am-12pm	Brisbane Coffee Cake & Chat (also 16 Nov)
26 Aug	12pm	20/30 Chat (also 25 Nov)

**Regional Queensland**

8 Aug	10am-12pm	Ingham Patient Information Seminar
23 Aug	10am-12pm	Gold Coast Coffee Cake & Chat (also 22 Nov)
14 Sep	10am-12pm	Toowoomba Coffee Cake & Chat (also 7 Dec)
19 Oct	10am-12pm	Innisfail Coffee Cake & Chat
30 Oct	10am-12pm	Charters Towers Patient Information Session
9 Nov	10am-12pm	Cairns Paediatric Information Session

**SOUTH AUSTRALIA**

**Adelaide Metro**

31 Jul	10am-12pm	CLL/CML Support Group (also 25 Sep, 27 Nov)
1 Aug	10am-12pm	Women's Group (also 5 Sep, 3 Oct, 7 Nov)
10 Aug	10am-12pm	Southern Adelaide Support Group (also 14 Sep, 12 Oct, 9 Nov)
15 Aug	10am-12pm	Northern Adelaide Support Group (also 17 Oct)
29 Aug	10.30am-12.30pm	Men's Group, Adelaide (also 31 Oct, 19 Dec)

**Regional South Australia**

19 Jul	10.30am-12.30pm	Strathalbyn Support Group (also 16 Aug, 20 Sep, 18 Oct, 15 Nov)
8 Aug	10am-12pm	Port Lincoln Support Group (also 10 Oct)
6 Sep	5.30-6.30pm	Mount Gambier Support Group (also 1 Nov)

**TASMANIA**

**Northern Tasmania**

8 Aug	10.30am-12pm	Launceston Blood Cancer Support Group (also 10 Oct)
10 Aug	10.30am-12pm	Burnie Blood Cancer Support Group (also 7 Dec)
17 Nov	11am-1pm	Stem Cell Collection & Transplantation education seminar, Launceston
5 Dec	11.30am-2pm	Christmas Party, Launceston

**VICTORIA**

**Metro Melbourne**

22 Aug	10.15-11.45am	Northern Melbourne Blood Cancer Support Group, Preston (also 14 Nov)
24 Aug	10-11.30am	Eastern Blood Cancer Support Group, Croydon (also 23 Nov)
29 Aug	10.15-11.45am	BMT Support Group, Hawthorn (also 31 Oct)
31 Aug	10-11.30am	South East Melbourne Blood Cancer Support Group, Berwick (also 3 Nov)
2 Sep	9am-4pm	Annual Blood Cancer Conference
10 Sep	10-11.30am	Melbourne Man Cave (also 22 Sep)

**WESTERN AUSTRALIA**

**Perth Metro**

17 Jul	1-3pm	Perth Metro Blood Cancer Support Group (also 21 Aug)
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**Peel**

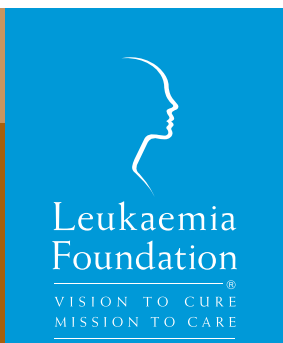
20 Jul	10.30am-12pm	Peel Region Blood Cancer Support Group, Mandurah (also 17 Aug)
25 Aug	1-2.30pm	Port Kennedy Blood Cancer Support Group

**Great Southern**

26 Jul	10am-12pm	Albany Blood Cancer Support Group
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**Bunbury**

3 Aug	10.30am-12pm	Bunbury Regional Blood Cancer Support Group
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Visit [leukaemia.org.au](http://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](mailto:info@leukaemia.org.au)

Contact us

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- [leukaemia.org.au](http://leukaemia.org.au)
- LeukaemiaFoundation
- LeukaemiaAus
- LeukaemiaFoundation

Disclaimer: No person should rely on the contents of this publication without first obtaining advice from their treating specialist.