# ALL NEWS

For people with ALL & their families

Leukaemia Foundation
VISION TO CURE
MISSION TO CARE

ISSN 2202-2392

MAY 2019 | leukaemia.org.au | 1800 620 420


*Just prior to his diagnosis, Deyan Cashmere, left, with sister Amy, Cooper and Brandon Holgate, and sister, Jennifer Brown.*

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# DEYAN'S LAST OPTION – GOING TO THE U.S. FOR CAR T-CELL THERAPY

**When Deyan Cashmere relapsed in February, following a stem cell transplant, his only option was to go to the U.S. for potentially life-saving immunotherapy, at a cost of USD1 million.**

Even though CAR T-cell therapy was approved by the TGA in Australia last December, it is still several months away from being made available to people like Deyan who'd had an allogeneic transplant from a matched unrelated donor.

And he couldn't wait that long.

So, on March 16, Deyan, 20, went to Seattle with his parents, Kelly and Bruce, to have the procedure where his T-cells are harvested, re-engineered, grown up in large numbers, and given back to him.

It was his first overseas trip.

In the lead up to his diagnosis in March last year, and during the series of different treatments he's since had in Sydney in a bid to gain remission, Deyan has had a tough time.

And in those 12 months, he only got to go home once, when he spent three days at his parent's wheat property at Hillstone, 680km west of Sydney.

When Deyan was 19, and just months away from completing his welding apprenticeship at Griffith, he started feeling unusually tired and lethargic. He lost weight rapidly and the bones in his hips and legs ached.

"He'd come home to help with the harvest in November 2017 and felt a bit off," said his mum, Kelly.

"He went to the doctors numerous times and not once did they take a blood test, even though he asked for it," said Kelly, describing the months that followed, when he was working on another farm.

Then, on March 11 last year, Deyan was rushed to hospital in Griffith with severe appendicitis.

"They took some blood and found he had leukaemia as well! He had no white blood cells whatsoever," said Kelly.

"When they took out his appendix, they didn't think he was going to make it through the operation because he was so badly infected, and he also had a stroke while he was under the knife."

That night Deyan was flown to Sydney. He had sepsis "all through his body" and it was "touch and go for the next five days". He still has a stoma from another operation 10 days later when his bowel burst.

It took two months to get Deyan's infections under control and it was too risky to treat his ALL, so he didn't start chemotherapy until May.

The first round knocked his ALL down to 70% blasts. But a second, different chemo saw an increase, to 80% blasts. It was the third chemo that got him into remission.

*Continued on page 6.*

# CAR T-CELL THERAPY TGA APPROVED IN AUSTRALIA

**The Therapeutic Goods Administration (TGA) has approved CAR T-cell therapy for Australians with B-cell precursor ALL*.**

In December, tisagenlecleucel (Kymriah®) was given the go ahead to treat people, aged up to 25, who had relapsed after a stem cell transplant or were in second or later relapse.

Tisagenlecleucel is the first in a new generation of therapies that are manufactured for each individual patient using their own T-cells. CAR T-cell therapy involves extracting a patient's immune cells, genetically re-engineering them in the laboratory to recognise and fight the patient's cancer cells, then infusing them back into the body.

This treatment helps address treatment gaps and a significant unmet need for patients who relapse from standard of care therapies including chemotherapy, radiotherapy, targeted therapy or transplantation.

** The TGA also approved this treatment for people with diffuse large B-cell lymphoma who were relapsed or refractory.*

# NEW DRUG PBS-LISTED FOR B-ALL

**The life-extending ALL drug, inotuzumab ozogamicin (Besponsa®) was made available to treat Australians with B-cell ALL (B-ALL) on May 1.**

The announcement that this effective new treatment would be added to the Pharmaceutical Benefits Scheme (PBS) for reimbursement was made during last month's Federal Budget.

This decision reduces the cost of a course of treatment from $120,000 to $6.50 per script, making it affordable, more accessible and giving clinicians a further treatment option for their patients.

The PBS listing of inotuzumab ozogamicin is for the treatment of relapsed or refractory (not responding to treatment) Philadelphia chromosome negative CD22 positive B-ALL.


# PBAC SUBMISSION FOR BLINATUMOMAB



**The Leukaemia Foundation made a submission in February to encourage the Pharmaceutical Benefits Advisory Committee (PBAC) to recommend the availability of a new treatment for ALL*.**

The submission, considered by the PBAC at its March meeting, supported the reimbursement of blinatumomab (Blincyto®).

There is a high unmet need for adults diagnosed with ALL according to Emily Forrest, the Leukaemia Foundation's Head of Policy and Advocacy – Blood Cancer Partnerships.

"Only about a third of people with ALL between the age of 45-54 are alive five years after their diagnosis with ALL, and for those aged 75 or older, the five-year survival rate is 10% or less.

"For these people, relapse and death is common, often within a short period of time," said Emily.

Our submission supported the latest application by the drug's manufacturer, Amgen, for PBS listing of blinatumomab for people with B-cell precursor ALL who are in complete remission with minimal residual disease (MRD) following chemotherapy.

When assessing the blinatumomab application, the PBAC considered the role of MRD in survival outcomes and treatment options.

*Emily Forrest: "There is a high unmet need for adults with ALL".*

"As we also learn more about the role of MRD in ALL treatment outcomes, the literature we have seen on blinatumomab is encouraging," said Emily.

"Achieving an MRD-negative status is desirable in terms of survival, reducing the chances of relapse, and affects an individual's suitability for allogeneic stem cell transplantation (SCT).

"This means new treatments that help people living with ALL to reach a deeper and more effective MRD response are welcomed," said Emily.

Before Amgen's first submission to the PBAC, in 2016, the Leukaemia Foundation surveyed a group of people about their personal experiences with blinatumomab.

"Their responses indicated blinatumomab increased survival, improved quality of life and reduced side-effects," said Emily.

For all of them, the impact of having ALL was major and enduring, and their lives had completely changed since their diagnosis. Those who were working or studying had to stop these activities and most had not been able to return to their previous employment or education.

They had been through debilitating chemotherapy treatments, experienced a loss in physical and cognitive abilities, and their emotional wellbeing and mental health was impaired. They also suffered great financial stress and reported stress on their families and relationships.

Those treated with blinatumomab in a clinical trial reported significant benefits from the treatment compared to chemotherapy. Their responses to the drug were quick, durable and improved their suitability for transplantation.

The Leukaemia Foundation's priority is to ensure all Australians living with blood cancer have access to the best therapies and treatments available.

** Each year around 350 people are diagnosed with ALL, an aggressive disease and the most common type of childhood cancer. Young children, up to the age of 14 years, make up 60% of all cases of ALL and most of them can be cured of their disease. Survival rates decrease with age.*

# SHARING THE ALL EXPERIENCE CENTRAL TO HEALING FOR SANDRA

**Psychologist, Sandra Evans, penned her powerful memoir, *Eight Seasons*, to share her family's journey following the diagnosis of her daughter, Tahlia, with childhood leukaemia at the age of four.**

Tahlia, now 17, was treated for ALL during 2006-2008 and *Eight Seasons* was first published in 2010. This honest, often heart-breaking account of life with childhood leukaemia, told through the eyes of a parent, can give guidance and comfort to others on the same journey.

"I hope the book normalises the experience and parents can see that we had intense emotions, went through many challenges and made it out the other side," said Sandra, who reflects here on the book's main themes.

### Honesty is the best policy...

"We only have to think of ourselves as adults and how we like to have a sense of what's going on; how much is this going to hurt, how long am I going to have to take this for, when will it stop?'. It's all about giving your child a feeling of control when so much is outside of theirs."

### Analogies and stories are gold...

"All the terms are so medical and grown up, so try and pare it back to something simple your child can understand. In the book, I talk about a 'weeding analogy' that I used to describe the importance of maintenance treatment to Tahlia."

### Steroids and behaviour management...

"The line between normal childhood boundary pushing and steroid-induced behaviour can become blurred. When a child is on chemotherapy, it's hard to figure out what's what, because those steroids can be so personality changing. Accept that medications have the potential to alter your child's behaviour in some way and ride it out. It's also about knowing your child and when they're pushing the boundaries."

### Parents often feel the trauma more than the child...

"A good thing for parents to remember is that we are the ones who carry much of the trauma and worry. Very young children tend not to recall their treatment experience with the same detail as their parents, so it can feel worse for parents; remembering the invasive procedures; worrying your child is missing out on things or not able to be 'normal'."

### Talking to someone who gets it...

"The beauty of talking to Leukaemia Foundation staff is that they can listen to all those difficult emotions related to grief and anger and understand it's about the journey, not just the prognosis. It's all those little moments that you need help to get through, and ongoing fear was something I never had to explain because it was implicitly understood."

### Accept that some people may distance themselves...

"A couple of my friends found it hard to hear about the realities of what I was going through and they became uncomfortable with the intensity of my emotions. In the end, I accepted that everyone is at a different stage in their life's journey. People do the best they can at the time. I learned not to have regret or wish for it to be different, but to accept what was.

### The healing power of storytelling

The process of writing the book, as well as the editing, re-reading, re-writing, and connecting with readers has been Sandra's best therapy.

"I resolved many things about my relationships, my reaction and my grief. Throughout the process of recording your experience, something changes and you discover something new every time you revisit the journey.

"The essence of feedback I receive from readers is the unrivalled value of shared experience. Sharing stories often allows for the articulation of emotions that some people find hard to explain to their families or people around them."

### Tahlia's come full circle

Tahlia is now in her senior years of high school and has high hopes for a career in oncology social work. Recently, she and Sandra met another mother whose child has ALL.

"As soon as we sat down, this mum burst into tears. I started saying... 'I know it's really tough and you're at a difficult point and the drugs are really awful'," said Sandra.

"Then she turned to Tahlia. 'Can you remember anything?' she asked, and Tahlia replied, 'you know what, I can remember some parts... '.

"I let them talk and this mum's anxiety decreased as Tahlia shared her experience of chemotherapy as a young child. The hope and promise gained from seeing and hearing that Tahlia had come through it, gave her more possibility and a process to get through the upcoming months."

***Eight Seasons*: *our family's journey with childhood leukaemia* is available at our Patient Accommodation Villages and from our Blood Cancer Support Co-ordinators. The third edition (with chapters on life post-treatment) can be bought online from Book Depository: https://bit.ly/2Ov1npp**

*The Evans family – Randall, Tahlia, Lauren and Sandra Evans.*

# INHERITED GENETIC VARIATION LINKED TO RISK OF CHILDHOOD T-CELL ALL

**A novel risk variant associated with T-cell ALL (T-ALL) has been identified in a study by St. Jude Children's Research Hospital (U.S.) with the findings published in *Journal of the National Cancer Institute*.**

Senior investigator, Dr Jun Yang said the inherited genetics underlying this rare leukaemia subtype were largely unknown prior to our study.

"Now, we have definitively identified a gene associated with increased odds of developing T-ALL," said Dr Yang.

In a genome-wide association study, researchers analysed the inherited (germline) DNA of more than 1000 children with T-ALL and more than 12,000 control samples. The ALL cases were treated at St. Jude and through clinical trials run by Children's Oncology Group, the world's largest cooperative paediatric cancer research organisation.

The study identified a novel variant of the USP7 gene played a role in increasing the risk of developing T-ALL. This USP7 risk variant is found more often among people of African ancestry and may help explain why T-ALL is more common in this group.

### Understanding the function of USP7

There is a genetic subtype of T-ALL that is characterised by overexpression of TAL1. Building on previous research at St. Jude, Dr Yang and his team found that genetic changes in USP7, either inherited or in the DNA of the cancer cells, occur in 56% of TAL1 overexpressed T-ALL, more than any other T-ALL subtype.

"These findings confirm that T-ALL is very different from other types of leukemia, with its unique set of genetic risk factors," said Dr Yang.

"This work adds evidence to support the notion that USP7 plays an important role in the development of T-ALL."

# WHAT CAUSES CHILDHOOD LEUKAEMIA AND HOW TO PREVENT IT

**In a breakthrough discovery, our modern germ-free lifestyle, particularly our high level of cleanliness, has been found to contribute to the formation of childhood leukaemia.**

Patterns of infection characteristic of developed societies is the major cause of ALL, and it's not infection, but a lack of infection early in life that is the problem, according to Professor Mel Greaves, of the Institute of Cancer Research in London.

He conducted a meta-analysis, combing through 30 years of medical literature and gathering data from colleagues around the world. His search included research on genetics, epidemiology, immunology and cellular biology.

And in putting together so many disparate puzzle pieces, he eliminated false causes which included chemicals in the environment, ionising radiation, electromagnetic waves, and the influence of high-tension wires (electrical cables).

Prof. Greaves' analysis, published in the journal, *Nature Reviews Cancer*, also concluded that ALL "is probably a preventable disease".

"The immune system has evolved to fight infections. Natural infections in the first weeks and months of life prime the immune system," he said.

The research study strongly suggests that ALL has a clear biological cause and is activated by a variety of infections in predisposed children whose immune systems have not been properly primed.

"Children born with a certain genetic mutation, that takes place by accident in the womb, have merely the potential for developing ALL," said Prof. Greaves.

"This mutation will remain latent until the second 'hit' comes, when the immune system fails to encounter enough microbes during the first year of life to prime it."

A healthy amount of germ exposure that's benign and safe allows the immune system to learn how to deal with pathogens correctly.

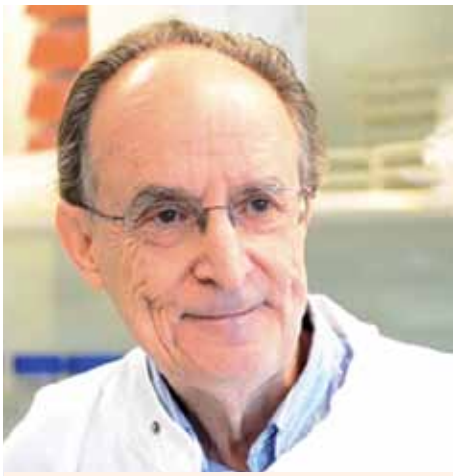
"If the infant grows into childhood without exposure to microbes from the environment or other children, they may develop ALL," said Prof. Greaves.

"But it takes a run-of-the-mill infection later on to ultimately trigger this form of leukaemia and the risk is low. All told, full-blown ALL only occurs in 1% of cases where the mutation is present.

"The absence of pathogens as a factor explains why this form of childhood leukemia is common in wealthy, developed countries, but nearly absent in developing ones," he said.

Some of the disparate pieces of the puzzle Prof. Greaves put together to formulate this discovery, was an outbreak of swine flu in Milan, which resulted in seven children developing ALL.

Another clue was that infants born vaginally, when compared to cesarean section, have a lower risk of developing ALL.



*Professor Mel Greaves, of the Institute of Cancer Research in London.*

"Infants who pass through the vaginal canal are exposed to more microbes than those born through c-section. Also, infants who are breastfed have less of a risk, as they often pick up healthy bacteria this way.

And animals, particularly mice, when living in an environment devoid of pathogens, often develop leukaemia.

Prof. Greaves urges parents not to worry too much about keeping a clean house. His tips for preventing the disease include being less concerned about normal, run-of-the-mill infections and allowing young children to play with other children, especially older ones.

"I'm reasonably optimistic, in a five to 10-year timeframe, we'll see this research translated into some real benefit and may help prevent the onset of other autoimmune disorders, including type 1 diabetes and allergies."

# FIRST FAMILIAL CLINIC SEARCHES FOR FAMILIES WITH MULTIPLE BLOOD CANCERS

**All cancers have a genetic component according to Dr Chris Hahn, a researcher at the University of South Australia and SA Pathology, who heads Australia's first multi-disciplinary blood cancer clinic.**

And for around 10% of cancers, there is some sort of familial basis.

"We think that figure may be higher; we just don't understand all the players," said Dr Hahn who leads a team of haematologists, geneticists, genetic counsellors, research nurses and research scientists at the new Australian Familial Haematological Cancer Clinic (AFHCC).

The clinic is being established in Adelaide with a grant from the National Health and Medical Research Council and is expected to begin mid-year. They will use the latest DNA sequencing technologies to identify families carrying genetic mutations that could increase their risk of developing blood cancers.

The AFHCC will expand on research that began in 2004 when professors Hamish Scott and Richard D'Andrea started the Australian Familial Haematological Cancer Study (AFHCS). Their aim was to find families in Australia and New Zealand with predisposition to blood cancers and identify the genetic cause. There are currently more than 130 families on the study database with the causative genetic mutation having been identified in more than 30 families so far.

Dr Hahn said the clinic will regularly bring together geneticists and haematologists to discuss patient cases, decide if they are likely familial, screen for mutations and recruit them to the research study of families for surveillance, more comprehensive genetic analyses and follow up.

"We're planning to use a panel of ~200 genes – mainly myeloid, with some lymphoid and some Pan-Cancer genes as well," said Dr Hahn.

"By identifying genetic mutations, we can better monitor family members at risk, and counsel those affected with the aim to improve outcomes by early detection.

"Bone marrow transplantation is a potential cure for blood cancer and knowing a patient's predisposing mutation will enable us to screen family members as potential bone marrow donors and rule out those carrying the mutation," said Dr Hahn.

The first predisposition gene for blood cancer, RUNX1, was reported in AML in 1999, and there are now more than 15 known predisposition genes.

"There's been lots evidence of families where it's obvious a CLL or AML runs in a family but we haven't been able to determine the predisposition gene or genetic cause," said Dr Hahn.

It wasn't until 2016 that the World Health Organization (WHO) made work practice recommendations in the blood cancer field, changing the ruling for inherited myeloid leukaemias.

"WHO published recommendations suggesting clinicians screen for the familial genes RUNX1, GATA2, DDX41, ETV6, ANKRD26 and CEBPA where indicated," said Dr Hahn.

***".. DNA sequencing will identify families carrying genetic mutations that could increase their risk of developing blood cancers."***

"There are still no recommendations for lymphoid genes. We know of very few lymphoid predisposition genes."

In 2015, Dr Hahn and colleagues contributed to a paper, primarily run out of St Jude Children's Research Hospital in Memphis (U.S.) that published PAX5 as a predisposition to ALL in children.

"Since then, familial cases with mutations in ETV6, IKZF1, RUNX1 and TP53 have been reported for ALL," said Dr Hahn.

"It's not that we're not looking. We don't have a lot of families with multiple ALLs; only two or three.

"We know we are missing a number of familial cases of blood cancer just because routine screening for such cases is not available in the clinic.

"We're trying to find those, to find out how many there are, and ultimately to report so that governments recognise that screening is an important part of [health] funding," said Dr Hahn.

*Dr Chris Hahn.*

Dr Hahn said the AFHCC will encourage haematologists to look more closely at the family history of their blood cancer patients.

"An amended questionnaire our geneticist uses for enrollment into AHFCS will be used in the clinic for haematologists to provide to their patients," said Dr Hahn.

"Our research nurse will go through the questions with patients. This helps in gathering important information and provides counselling support if needed immediately.

"Hair is the best sample (better than blood) for hereditary searches because it maintains the genetics you were born with. And it's easy to get," said Dr Hahn.

"Identifying new predisposition genes has potential to benefit families around the world. If a family has a mutation in the same gene as another family's mutation, that's extra evidence that that gene may be involved. Hence the importance of the international collaborations we have with researchers in the U.S. and UK."

**Dr Hahn is interested to hear from clinicians of families with multiple cases of ALL or cases of ALL with other blood cancers.**

# CONTINUED: DEYAN'S LAST OPTION – GOING TO THE U.S. FOR CAR T-CELL THERAPY

This was followed by three days of full body radiation before his stem cell transplant in October 2018. His donor – one of three potential donors in Australia – lived in Queensland and was a 10 out of 10 match.

But six weeks later, the cancer was back in his bloodstream at 0.001% and within another three weeks, it was back up to 100%. Deyan had relapsed. That was on February 4 this year.

"He was told there was nothing else they could do for him and that he had three to six months to live without any further treatment," said Kelly.

During Deyan's transplant, she'd read a news article about CAR T-cell therapy in America, which she discussed with his haematologist in October.

"She said 'yes, we're looking into that, in about January, if he relapses'. She had a fair idea he was going to relapse," said Kelly.

The week after Deyan's relapse, the Cashmeres looked into access to CAR T-cell therapy and fundraising, to pay for it.

"I wrote a letter to Greg Hunt [the Health Minister] in Canberra to say what had happened and that we needed assistance," said Kelly.

"His secretary sent through a Medical Treatment Overseas Program* application. I filled it out and sent it in and we got approved.

"It's wonderful to have this opportunity. It's taken the weight off our shoulders.

"We would have had to mortgage the farm, and were ready for that," she said.

"$1 million is a lot of money and we don't have to worry now about how we pay that back when Deyan gets home."

In addition to the treatment cost, the Commonwealth government is paying for Deyan and Kelly's return flights, passports, visas and taxi fares to and from the airport.

One of Deyan's two sisters, Jenny, set up 'Deyan's dash to the USA' GoFundMe campaign which raised $76,000 in a month.

Kelly said this money would pay for Bruce's airfares, and accommodation and living expenses for the three of them in Seattle during Deyan's 12-week CAR T-cell treatment. And to help when they return to Australia. Deyan will spend another three months in Sydney being monitored and having follow-up treatment.


*Deyan Cashmere, in Seattle for CAR T-cell therapy last month, with his parents, Kelly and Bruce Cashmere.*

"Whatever is left, we will donate to the Leukaemia Foundation, which has been very generous," said Kelly. *(See adjacent story.)*

On Friday night, March 1, the Cashmeres received word of Deyan's eligibility for government funding.

"Deyan's spirits have picked up since they gave him that option," said Kelly.

"He's probably the best he's ever been in the last 12 months, even though he's full of cancer.

"He took his diagnosis hard at the start, but he's willing to keep going. He's not given up yet.

"He's looking forward to it [CAR T-cell therapy] actually. He just wants to get over there and get it done," said Kelly.

Deyan was about to leave for Seattle when *ALL News* spoke to Kelly. But his departure was delayed based on the results of his last bone marrow biopsy. His response to three doses of inotuzumab ozogamicin (Besponsa®) "to get him overseas" was better than expected.

"It worked too well and knocked out all his cells," said Kelly.

Deyan needed to have transfusions every couple of days over the following week or two until he was ready to travel.

When Deyan returns from the U.S. and he has fully recovered, he's keen to get back to work and has a job waiting for him at Hillstone. And he can't wait to be back with his friends and to go fishing and pig chasing and shooting.

** The Medical Treatment Overseas Program (MTOP) provides financial assistance for Australians with a life-threatening medical condition to receive proven life-saving medical treatment overseas where effective treatment is not available in Australia.*

## OUR ACCOMMODATION IN SYDNEY HELPED KELLY COPE

In Sydney, the Leukaemia Foundation provided the Cashmeres with accommodation at Waverton, six kilometres from the hospital where Deyan had appointments, blood transfusions and treatment, mostly as an outpatient.

"If we hadn't had this free accommodation, it would have been even harder on us," said his mum, Kelly Cashmere.

"It's made a huge difference. It's saved us a lot of money. They're great little units.

"Most of the time, it's just me and Deyan. Bruce comes and goes from the farm but it's shut down at the moment.

"Neighbours have said they'll put the crop in for us this year if it rains, because we'll have no money this year if we don't. We've been in drought for two years. We got no crop last year either."

Kelly said she had adapted well to living in Sydney.

"I've had some rough spots, especially when Deyan had his transplant. He was very sick and in a lot of pain all the time. But I got over that hurdle and everything's been going alright.

"When I get bad news, it hits me for a little while, but I get over it pretty quickly. You just have to keep going until the end."

# ALL9 TRIAL ADDRESSES LOW SURVIVAL RATE ISSUES

**A new clinical trial, aimed at improving the treatment of Australian adolescents and young adults with CD19 positive B-lineage ALL, will be launched later this year.**

The study, called ALL9, will add a new immune-based therapy (blinatumomab) to the BFM-2000-based standard chemotherapy treatment regimen for ALL, to improve eradication of minimal residual disease.

This is one of the first trials in the world to incorporate this level of treatment according to the CEO of the Australasian Leukaemia & Lymphoma Group (ALLG), Delaine Smith.

"ALL9 is the only proposed ALL trial option in Australia for young people and is specifically designed to address the issues that result in low survival rates," said Delaine.

"This important new trial will lead to a better understanding of how to successfully incorporate immune-based therapy into standard of care protocols, as well as having a significant impact on the outcomes of young patients with this type of leukaemia.

"The trial is expected to accrue patients until 2022 with results expected by 2025."

She said the trial would give at least 47 people with ALL, aged 15-40 years (including 29 aged between 15-25) access to a novel immunotherapy during induction.

"This should translate to improved long-term outcomes that result in fewer patients requiring allogeneic transplantation and the reduction in quality of life that is associated with this procedure," said Delaine.

The ALL9 study also is expected to affect the way future clinical trials in ALL are designed and translated into clinical practice.

# RESOURCE HUB ONE-STOP SHOP FOR EVERYTHING BLOOD CANCER


**An online Blood Cancer Resource Hub, launched recently by the Leukaemia Foundation, is a dedicated information source for people living with blood cancer that covers all aspects of their disease.**

The hub sits on the Leukaemia Foundation's website and is the 'go to' for everything you may need to navigate your way on the blood cancer journey, from diagnosis, through treatment and on to life after blood cancer.

The hub's extensive and diverse range of information resources, downloads and videos includes:

- **information booklets** and **fact sheets** for ALL and the other blood cancers
- *ALL News* and all our other **disease-specific newsletters**, which are packed full of inspiring patient stories, latest research and treatment news
- up-to-date **facts** and **statistics** about blood cancer
- **patient stories** shared by people with ALL and other blood cancers
- **informative videos** presented by haematologists, researchers and patients about the disease and disease experience
- a list of other **useful websites** with further information on specific blood cancers
- a **glossary of terms** including a breakdown and explanation of commonly used medical terms and abbreviations
- **Q&As** with Australia's leading blood cancer researchers
- resources for **health professionals** such as books brochures and DVDs.

**Our blood cancer resource hub is updated regularly and can be accessed by visiting: bit.ly/LFresourcehub**

# GLOBAL SURVEY TO HELP DRIVE IMPROVEMENTS IN QOL

**You can take part in a global survey that addresses an urgent need to better understand patients' quality of life (QOL) at different points in their acute leukaemia journeys.**

The survey is run by the Acute Leukaemia Advocates Network (ALAN) – a Swiss-based independent global network of patient organisations dedicated to changing outcomes for patients with acute leukaemia by strengthening patient advocacy.

Anyone with an ALL diagnosis is encouraged to take part in the survey which will generate data to help in understanding issues and gather information on the current and emerging treatment landscape and patient experiences.

The results will be used to:

- form evidence about QOL at different points in the acute leukaemia patient journey;
- aid patient advocates and advocacy groups to inform and influence stakeholder communities, industry and policy makers;
- help identify and communicate the varying levels of information, care and support available for patients and caregivers; and
- support education and information tools and programs for healthcare professionals.

Once the survey is completed, ALAN aims to publish the results in professional medical journals and present them at haematology meetings and congresses.

**To read more and take part in the survey visit: myonlinesurvey.co.uk/ALAN/**

# WHAT'S ON NEAR YOU

## NSW & AUSTRALIAN CAPITAL TERRITORY

| Location | Date | Disease group | Event type |
|---|---|---|---|
| Bowral | 29 May | All blood cancers | Support group |
| Concord | 29 May, 26 Jun | All blood cancers | Support group |
| Dubbo | 1 May, 5 Jun | All blood cancers | Support group |
| Kogarah | 27 May, 24 Jun | All blood cancers | Support group |
| Gosford | 30 May, 27 Jun | All blood cancers | Support group |
| Liverpool | 18 Jun | All blood cancers | Support group |
| Mudgee | 13 Jun | All blood cancers | Support group |
| Newcastle | 4 Jun | All blood cancers | Coffee & chat |
| Newcastle | 7 May | All blood cancers | Support group |
| Orange | 2 May, 6 Jun | All blood cancers | Support group |
| Penrith | 6 Jun | All blood cancers | Coffee & chat |
| Port Macquarie | 8 May, 12 Jun | All blood cancers | Support group |
| Randwick | 15 May, 19 Jun | All blood cancers | Support group |
| Shoalhaven | 13 May, 10 Jun | All blood cancers | Support group |
| St Leonards | 3 May, 28 Jun | All blood cancers | Support group |
| Tamworth | 21 May, 17 Jun | All blood cancers | Support group |
| Wollongong | 1 May, 5 Jun | All blood cancers | Support group |
| Westmead | 29 May, 26 Jun | All blood cancers | Support group |

## VICTORIA & TASMANIA

| Location | Date | Disease group | Event type |
|---|---|---|---|
| Ballarat | 21 May | All blood cancers | 18-65yo support group |
| Ballarat | 18 Jun | All blood cancers | 65yo+ support group |
| Bendigo | 3 Jun | All blood cancers | Support group |
| Berwick | 10 May | All blood cancers | Support group |
| Burnie | 10 May | All blood cancers | Support group |
| Croydon | 23 May | All blood cancers | Support group |
| Hamlyn Heights | 25 Jun | All blood cancers | Support group |
| Hawthorn | 27 Jun | Bone marrow transplant | Support group |
| Hobart | 15 May | All blood cancers | Wellbeing seminar |
| Hobart | 20 Jun | All blood cancers | Support group |
| Kensington | 13 Jun | All blood cancers | Support group |
| Launceston | 14 Jun | All blood cancers | Support group |
| Mildura | 17 Jun | All blood cancers | Support group |
| North Melbourne | 15 May | All blood cancers | Young adults (20-40yo) |
| Warrnambool | 29 May | All blood cancers | Support group |

## WESTERN AUSTRALIA

| Location | Date | Disease group | Event type |
|---|---|---|---|
| Bunbury | 6 Jun | All blood cancers | Coffee & chat |
| Greenfields | 16 May, 6 Jun | All blood cancers | Coffee & chat |
| Innaloo | 6 May, 3 Jun | New diagnoses | Support group |
| Innaloo | 20 May, 17 Jun | All blood cancers | Coffee & chat |
| Spencer Park | 8 May | All blood cancers | Support group |

## QUEENSLAND

| Location | Date | Disease group | Event type |
|---|---|---|---|
| Brisbane *(Paddington)* | 11 May | All blood cancers | 20s & 30s chat |
| Bowen | 14 Mar | All blood cancers | Coffee, Cake & Chat |
| Buderim | 15 Mar, 21 Jun | All blood cancers | Coffee, Cake & Chat |
| Cairns | 16 May | All blood cancers | Coffee, Cake & Chat |
| Toowoomba | 7 Jun | All blood cancers | Coffee, Cake & Chat |
| Townsville | 29 May | All blood cancers | Coffee, Cake & Chat |

## SOUTH AUSTRALIA & NORTHERN TERRITORY

| Location | Date | Disease group | Event type |
|---|---|---|---|
| Lightsview | 7 May, 4 Jun | All blood cancers | Carer's support group |
| Lightsview | 25 Jun | All blood cancers | Men's support group |
| Mount Gambier | 5 Jun | All blood cancers | Support group |
| Noarlunga Downs | 9 May, 13 Jun | All blood cancers | Support group |
| Port Lincoln | 24 Jun | All blood cancers | Support group |
| Strathalbyn | 15 May, 19 Jun | All blood cancers | Support group |
| Torrensville | 1 May | All blood cancers | Women's support group |

**Education and support events for July-December 2019 will be available soon on our website: bit.ly/lfcalendar**

# LISTEN TO OUR ONLINE CONTENT

**The Leukaemia Foundation has installed a 'text to speech' service on our website so people visiting leukaemia.org.au can listen to our webpages and online PDF and Word documents.**

From our research, we understand that during treatment many people experience some difficulties with concentration, reading and information retention (often known as 'chemo brain').

The Leukaemia Foundation has installed an online product called ReadSpeaker so people can now choose to listen to information about all the different blood cancers including ALL. Also, our support services, our disease information booklets, even this issue of *ALL News*!

The listening tool is not only useful for those affected by chemo brain, but also people with low literacy, vision impairments, English as a second language, and others who just prefer to listen to our content rather than read it.

To activate ReadSpeaker, click on the 'Listen' icon; usually found at the top left of the page you want to read. When in 'play' mode, the words that are being spoken are highlighted.

You can also download the audio as an MP3 file, or highlight text and listen to a translation through Google translate.



Leukaemia Foundation
VISION TO CURE
MISSION TO CARE

**Join the ALL Network closed group on Facebook: https://www.facebook.com/groups/ALLLFA/**
**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**

## CONTACT US

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