

the CARER

www.leukaemia.org.au

About AML

Each year around 715 people in Australia are diagnosed with acute myeloid leukaemia (AML).

This cancer affects the blood and bone marrow and is characterised by an overproduction of immature white blood cells.

AML is a rare disease. It accounts for 0.8 per cent of all cancers diagnosed and can occur at any age.

AML is more common in adults over the age of 60 years and occurs more frequently in males than in females.

Around 30 children (0-14 years) are diagnosed with AML each year.



**Leukaemia
Foundation**
VISION TO CURE
MISSION TO CARE

1800 620 420
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MIRACLE BABY BRYDON SAVED HIS MUM'S LIFE



De-Arn Clout says her son, Brydon, who was born in February 2004, saved her life. He was a miracle baby, conceived, carried and born healthy, despite all odds.

"I haven't looked back since I had him," said De-Arn who was diagnosed with acute myeloid leukaemia in May 2001, aged 19. At the time she had just started a new job and was "perfectly fine".

She went to her doctor with a bad back and some hair loss and a blood test showed very high iron levels and virtually no white blood cells. Within a week she had more blood tests, a bone marrow biopsy, was hospitalised, had a blood transfusion and began her first course of chemotherapy.

"The chemo really knocked me around," said De-Arn who got a fungal infection in her liver and spleen.

She was hospitalised for three months while her gall bladder and a slice of her liver were removed and it wasn't until September that De-Arn was strong enough for a second course of chemo. The planned bone marrow transplant

was postponed because she was too weak to handle it.

For two years De-Arn had to travel from her home at Dapto to Wollongong Hospital where she received treatment from 8am until 6pm as she continued to fight the infection. This really affected her lifestyle.

"I couldn't go anywhere or do anything, it was terrible. I really wanted to go out and have some fun," said De-Arn

who loved to sing.

The Leukaemia Foundation provided De-Arn with an IV pump so she could administer her own treatment and didn't have to go to hospital every day.

"I could sleep, it gave me some privacy and friends could visit me at home."

One night she went to a karaoke night and that's when she met Jonathan Hall who she married the following year.

"We weren't planning to have children. I'd been told there was a 99.9% chance I wouldn't fall pregnant so I didn't know whether to laugh or cry when I found out," said De-Arn who at the time was on treatment, had had x-rays, cat scans and an anaesthetic.

At 20 weeks pregnant De-Arn's health started to improve and she hasn't looked back since.

"Brydon helped take up the excess iron that had been feeding the fungus. He saved my life, I'm sure of it," said De-Arn who has since had a daughter, Nevaeh, and has been in remission for six years.

NEWS IN BRIEF

FIVE HAEMATOLOGICAL NURSING DISTANCE GRANTS AWARDED

New South Wales: Five cancer nurses have been awarded the Leukaemia Foundation's Haematology



One of the nursing grant recipients, Meredith Oatley.

Nurses Distance Education Grant 2007. This is the sixth consecutive year the grant has been offered to both metropolitan and rural/regional cancer nurses working with people with blood and bone marrow cancers.

The recipients are Meredith Oatley (RNSH, St Leonards), Dina Marissa

(POWH, Randwick), Catherine Brophy (Grafton), Narelle Zappas (Milton/Nowra) and Sharna-Marie Sutherland (JHH, Newcastle). The grant provides support for the educational and professional development of these nurses and enables them to undertake The College of Nursing Distance Education course, Haematology and Haemopoietic Cell Transplantation Nursing. The course normally runs over six months and each student is provided with tutorial support.

LOTTERIES GRANT ASSISTS PATIENT ACCOMMODATION

Western Australia: The Leukaemia Foundation received a Lotterywest grant to fit out three of the Foundation's accommodation units in the Perth suburb of Bassendean. Peta Fillery, general manager of the Foundation in WA, said the grant money would be used for building alterations, equipment and furniture including floor and window treatments, painting and installation of security screens. "The recently acquired units also will be fully equipped with lounge suites, electrical goods such as fridges, washing machines and TV's, as well as kitchen, bathroom and laundry utensils," Peta said. Lotterywest program co-ordinator, Josephine Buontempo, said the aim of Lotterywest grants was to assist community organisations, such as the Leukaemia Foundation, to turn their ideas into reality: "We see the grants we make as an investment, not only in the future of the Leukaemia Foundation, but in the future of the Western Australian community as a whole." Increasing the availability of accommodation means the Foundation can supply more options to families who travel from rural and regional Western Australia for treatment in Perth.

THE CATS SUPPORT THE FOUNDATION IN 2007

Victoria: The Geelong Football Club launched its partnership with the Leukaemia Foundation at its Family Day on Sunday 18 March at their home ground in front of thousands of CATS supporters. The community partnership program gives the Foundation access to players throughout 2007 to help raise awareness of the Foundation and its work in and around Geelong. CATS captain, Tom Harley, helped promote the *World's Greatest Shave* at Skilled Stadium with the help of four-year old leukaemia patient, Matilda Pretty. Regional fundraising manager, Meaghan Bush, said: "Geelong and surrounding areas have always shown tremendous support for the Foundation and this partnership is a fantastic way of continuing to create awareness and build our profile in the region. We are delighted with being nominated this year as one of their community partners."

NOW PATIENTS CAN SURF THE NET WHILE STAYING AT TRARALGON

Victoria: Patients undergoing treatment at the Latrobe Regional Hospital and their families who stay at the Leukaemia Foundation's Traralgon accommodation can now surf the Internet and send emails to friends and family. A leukaemia diagnosis turns the lives of patients upside down overnight and is sometimes a very unsettling period according to Samantha Schembri, support services manager. The introduction of state-of-the-art computer equipment into this supportive environment endeavours to give patients a semblance of normal life. "They no longer feel as isolated from their loved ones because they can jump on the computer and send an email," said Sam. The Leukaemia Foundation of Victoria/Tasmania thanks the Freemasons Lodge Cornucopia for providing the computer equipment and for their generous support towards the Gippsland accommodation, worth \$34,000.

LGCO DINNER DANCE RAISED \$20,000

Victoria: The Lead Generation Company (LGCo) raised \$20,000 for the Leukaemia Foundation at a spectacular dinner dance at the RACV Club in Melbourne in March. The 250 guests revelled in the dancing, live music, exciting auction, fantastic food and wine and interesting speakers. Special thanks to Edward Sedgely, Carey Anderson and Sarah Heyburn for co-ordinating the event which was supported by Melbourne businesses including Sportsbiz, Tishe Jewelry, Emagin8, Eve Nightclub, Glen Anderson Photography and Christian Schoeps. During their business slow-down period over December and January LGCo wanted to direct its full-time sales and marketing resources towards a noble charity to make a difference in the community, help build awareness of leukaemia and raise funds to help those with the debilitating disease.

LYMPHOMA'S NOT GENETIC BUT DEAN AND HIS DAD HAVE BOTH BATTLED THE DISEASE



Dean Papadopoulos with his dad, Lucky, right, his mum, Zoi, left, and his fiancée, Elena, at his engagement party.

When Dean Papadopoulos, 26, was diagnosed with lymphoma, he believes the shock of this news caused his father, Lucky, to relapse with the same disease.

Dean's dad was 50 when he was diagnosed with non-Hodgkin lymphoma five years ago. It was in his spleen and after oral chemotherapy he was given the all clear and for a couple of years he was cancer-free and lived a normal life.

Then symptoms of a bloated tummy turned out to hail the return of the lymphoma and after having six litres of fluid drained from the lining of his stomach he had a combination of chemotherapy and MabThera (called RCHOP), and went into remission again.

When he recovered, Lucky had his stem cells collected in case they were needed down the track for a transplant.

"They did say that at some stage it (lymphoma) will most likely come back," explained Dean who went on a seven-month world trip with his fiancé in May last year.

They'd backpacked through China and Europe and were in the USA when Dean was diagnosed in October. He hadn't been sleeping because of back and shoulder blade pain, then he discovered blood in his sputum, which is why he went to hospital in Santa Monica where x-rays revealed a large white blur on his chest.

"After a catscan they said they were 99.9% sure it was lymphoma and that basically was the end of our trip," said Dean who had to break the news to his folks back home.

"I called dad on the mobile and asked him to tell mum."

Dean had lots of problems with his travel insurance organising a flight home, so his mum and sister flew to the US to be with him and to travel back with them.

"Eventually I got on a flight but we had to wait at the check-in counter for four hours and I was in no shape to be standing," said Dean who travelled from the airport straight to hospital in Melbourne.

The next problem he encountered was getting his medical results from the US and he was in a wheelchair ready to have another chest biopsy when they finally arrived.

The next day Dean started RCHOP treatment. After four months he started radiotherapy in March and his final treatment was in mid-April.

At one stage, in November last year, when Dean was at Box Hill Hospital, his father was downstairs at the same time having tests and blood transfusions because his cancer had come back a third time.

"A regular check-up in late-September showed he was in remission but a week later I was diagnosed and we strongly believe Dad's relapse was from being so upset about me," explained Dean.

"Strange stuff, because apparently there's no connection and all the studies show there's no genetic link."

Lucky is now in remission for the third time and Dean too has been given the all clear.

"I've come to terms with the whole ordeal and I'm slowly getting back into work and getting on with my life," said Dean, a data analyst, who is planning to marry in March next year.

"The Leukaemia Foundation was unbelievable and did heaps for me.

"Sam (Schembri), from Support Services was great. She'd come over and have a chat and answer my questions about treatment and how I was feeling.

"They also paid my mobile phone bill and Internet which was a great help because I'd gone from a good income to zero.

"It's an emotional roller coaster and it's pretty hard but without the Leukaemia Foundation and Sam it would have been a much rougher ride."

NEW NATIONAL AUSTRALIAN BLOOD CANCER REGISTRY

Blood cancers such as lymphoma, leukaemia and myeloma are a significant health concern in Australia. They account for 10% of all cancers and non-Hodgkin lymphoma is the fifth most common cancer.

State cancer registries have collected broad incidence and mortality data but the lack of a central repository to consolidate information on treatment patterns and patient outcomes, to optimise clinical decision-making, has been a gap in the management of blood cancers.

To address this unmet need, the idea of developing a national registry was conceived with the goal of providing complete, accurate data on the management of trends and outcomes of Australians with blood cancers and related disorders.

Clinical haematologists and consumer organisation representatives formed a project management group and following a research and consultation phase, the first stakeholder meeting, Working Towards An Australian Blood Cancer Registry, was held in Sydney in September 2005.

There was unanimous support for the registry concept by delegates including representatives from consumer organisations, clinicians, researchers, academics, cancer registries, government, pathology laboratories, the pharmaceutical industry and software developers.

Since then the Australian Blood Cancer Registry (ABCR) has made inroads into repository development, funding and standards setting and has embarked on various projects such as implementing and piloting data collection via the Lymphoma Wizard Project (see page 6), communicating the development of the ABCR with key stakeholders while garnering clinical and financial support to bring the vision of the ABCR to fruition.

In November 2006, the ABCR's second annual stakeholder meeting in Sydney was attended by nearly 60 delegates and received unanimous support for the registry's work to date and a strong commitment from stakeholders to continue supporting future initiatives.

The ABCR is collecting detailed and accurate information on blood cancers. This information will be used to improve the capacity of clinicians, patients, their families, carers and governments to make informed and timely decisions on the management of blood cancers.

The ABCR will provide clinical haematologists and oncologists with accurate and detailed information to improve survival and treatment outcomes and set standards to achieve best practise in clinical care.

Since January 2007, the Leukaemia Foundation has provided its services as Secretariat for the ABCR.

YOU CAN JOIN SAM'S FAMILY AND FRIENDS BY BUYING WINE TO HELP THE LEUKAEMIA FOUNDATION

Sam Harris was diagnosed with acute myeloid leukaemia in mid-February after a sudden illness that was originally thought to be pneumonia.

Blood tests showed otherwise and he was rushed from Rockhampton to Brisbane. At the Mater Hospital Sam had two rounds of chemotherapy and achieved remission so he could spend more time with his wife, Bec and children, Sophie, seven, and Annie, six, in the lead-up to having a transplant.

His older brother, David, flew to Brisbane from Adelaide in April to donate his stem cells for Sam's transplant later that month.

"While we've been in Brisbane the Leukaemia Foundation has been an amazing support," said Sam.

The family's 'home away from home' is an apartment at ESA Village in South Brisbane, the girls are enrolled at the Mater school, near the village and transportation is provided when needed.

Many of Sam and Bec's friends asked how they could help so Sam's sister-in-law, Jane Harris, who lives in Adelaide organised a fundraiser for the Leukaemia Foundation where the profits from the sale of wines through Adelaide Cellar Door and its website are

donated to the Foundation Australia-wide.

So far friends and family have bought their wines online and passed on the word to their friends, but many more supporters are needed to reach the fundraising target of at least \$20,000.

To help, visit: www.adelaidecellardoor.com.au and click on Leukaemia Foundation under the heading Fundraisers.



Sam Harris with his daughters Sophie and Annie.

FIVE-YEAR OLD BEN'S A CHAMPION FIGHTER

The day before five-year old Ben Clark was diagnosed with leukaemia he told his mum, Kris, that his head hurt and she noticed a bruise on his shoulder.

It was Christmas Eve and the family was driving from Melbourne to spend the festive season with family in Sydney. As there were no other indications that anything was wrong, Kris thought she'd have him checked out when they arrived.

But Ben complained about stomach pain in the car, he went quiet and wasn't hungry, and when they arrived at Goulburn he said: "Mum, my wee wee is red." They called an ambulance and Ben went straight to Goulburn Hospital where a blood test showed a significant white blood cell count. He then was rushed to Westmead Hospital, an hour away in Sydney.

"All of a sudden bruises started appearing on his skin, it happened in front of our eyes, and his liver expanded three times in size," Kris said.

Ben was diagnosed with acute lymphoblastic leukaemia Philadelphia+ which is a chromosome fault, had a Hickman's catheter inserted that night and began chemotherapy. He did extremely well, the family flew home, and he was admitted to the Royal Melbourne Children's Hospital on New Year's Eve. Ben responded well to treatment, is in first stage remission and due to have a transplant in August. There's a 98% chance his two-year old brother, Josh, is a match.

"Ben's a champion. He's handling it all fantastically well and for the majority of the time, he's felt good. He's playing football and riding his bike and the only thing he's missed out on is kinder."

Kris said the Leukaemia Foundation was fantastic. In Sydney, they were provided with lots of information and cab fares to the airport.

"We were trying to take in all the terminology and information and then we found out it was even worse. The Philadelphia+ just blew us away and Fiona (from support services) was fantastic. She went through it with us slowly, had the most up-to-date info and was very reassuring and positive," Kris said.



Ben Clark with his mum, Kris.

SUPPORT NOW OFFERED IN THE ILLAWARRA REGION

Wollongong City Mayor, Alex Darling and the Leukaemia Foundation's NSW/ACT general manager, Stuart Allen welcomed the Leukaemia Foundation to the Illawarra region with the opening of the Wollongong office in March.

In 2006, the Foundation supported 110 patients and families in the area and support services co-ordinator, Steve Dunn, said the Illawarra office would build on this work.

It will run free disease-specific and general education programs to empower patients and carers with information regarding diagnosis, treatment and recovery, and provide an opportunity to hear from specialist doctors and allied health professionals.

"Regional offices such as Illawarra are set up to provide all residents in NSW with equity of access to our programs and services," said Steve.

Former patient, De-Arn Clout, shared her inspirational story (see page 1) with the 50 guests at the opening, including local health professionals, Leukaemia Foundation volunteers, local business owners, media, and current and past patients.

This year more than 9000 Australians are projected to be diagnosed with leukaemia, lymphoma or myeloma, the equivalent of nearly 25 people per day.



Leukaemia Foundation general manager (NSW/ACT), Stuart Allen, and Wollongong City Lord Mayor, Alex Darling.

RECOVERED PATIENT TURNS PROFESSIONAL

Danielle Tindle, 27, changed the course of her career as the result of her experience with lymphoma and has gone from being a patient, to a professional in the field.

She was 22 and living in Sydney, studying a Masters degree in international relations, when she found a lump in her neck while at the uni canteen.

"I thought my tiredness was from being rundown, from studying a lot, working and partying, but then I realised my concerns were more serious," said Danielle who was taking iron tablets for anaemia at the time.

She skipped lectures, took herself off to the Prince Alfred Hospital where she had some tests and was on the bus home when she received a call asking her to go back in to hospital.

When Danielle said she couldn't because she was on a flight to Brisbane that night to visit her parents and boyfriend, they told her she had Hodgkin lymphoma.

"I jumped on the plane in a state of shock and when I told my parents I had something to tell them, they thought I was pregnant!"

She had further diagnostic tests at the Princess Alexandra Hospital in Brisbane the next day, began six months of chemotherapy, followed by a month of radiotherapy, then was given the all clear.

Three months later, she'd restarted her Masters degree in Brisbane and was just back from a holiday in New Zealand when she relapsed with a tumour the size of a football in her chest, neck and abdomen.

"So they had to bring out the big guns," said Danielle, who spent much of the next six months in hospital fighting infections.

But that treatment didn't work, so she had a course of experimental aggressive treatment followed by a stem cell transplant just before Christmas 2003, and didn't leave hospital until April 2004.



Danielle Tindle with her mum, Elizabeth.

"I was zonked out most of the time on morphine, was wheelchair bound, couldn't walk, stand or eat, weighed 34 kg and was close to death. I can laugh about it now but it got pretty scary.

"My survival instinct kicked in and I had such incredible support. The team of clinicians cared for me above and beyond normal medical treatment."

The rest of 2004 was spent recovering, in 2005 Danielle finished her Masters and in 2006 she approached the Leukaemia Foundation, because she felt there was no support for people her age who were going through treatment.

She drew up a plan of ideas that was instrumental in the formation of the Revive Young Adults Program and last August the Foundation appointed her as project officer to research major issues affecting the 18 – 35 year age group and to develop the program.

Danielle was awarded one of five Australian scholarships by CanTeen to study an online Postgraduate Certificate in Cancer Care of Adolescents and Young Adults at Coventry University in the UK, to academically back her practical knowledge in developing the Revive program.

LYMPHOMA WIZARD HELPS BOTH PATIENTS AND DOCTORS

Lymphoma patients may soon have greater involvement in their treatment decisions as well as better survival rates due to new desktop blood cancer software.

The Australian Blood Cancer Registry's (ABCR) Lymphoma Wizard* is a desktop pilot computer program that supports clinical haematologists in their daily clinical practice. The aim is to explore and improve the capacity of clinical haematologists to make informed, accurate and timely decisions on the diagnosis and management of blood cancers and to efficiently provide data for the ABCR.

The Lymphoma Wizard helps with the planning of treatment for lymphoma and collects the necessary clinical data for a clinical registry to go along with

the electronic pathology request. The clinical data can then be sent along with the pathology report to the registry providing that patient privacy is protected. The Wizard allows clinicians to keep electronic records of pathology and treatment for their lymphoma patients.

It seeks to provide information and guidelines on best practice models and as a result, improve the survival rates of patients with lymphoma. While the project is focused on lymphoma, if successful, it will be extended to other blood cancers.

** A clinical desktop wizard to support specialists' diagnosis and management of blood cancers, supported by the Australian Government through the Information Technology Online Program of the Department of Communications, Information Technology and the Arts.*

EDUCATION AND SUPPORT FOR YOUNG ADULTS

Young adults affected by cancer are a vastly understudied population with special needs who, until recently, have been neglected.

Increasing numbers of adolescents and young adults are being diagnosed with cancer and despite their survival rates improving less than any other age group, the number of survivors aged 18 to 35 years old is rising.

Yet minimal resources have been invested in finding better treatments for them and there is little support or facilities for their specific requirements.

The Leukaemia Foundation received \$25,000 from the Royal Children's Hospital Foundation (Brisbane) to extensively research the issues and needs of this group.

From the findings, a program was developed called Revive, for young Australians affected by leukaemia, lymphoma, myeloma and related blood disorders, to assist with their transition back to normal life.

The Gandel Charitable Trust also has supported Revive, providing \$50,000 to produce a young adults' information booklet and develop an interactive website to assist in the delivery of the program.

The Foundation is training young people in each state to facilitate face-to-face meetings and peer support programs to increase awareness within the medical community of the needs of this age group and the quality of age-specific care, and ultimately to increase relevant scientific research and clinical trial options available to young adults.

The Revive Young Adults Program addresses the physical, social and emotional issues that many young people face during the tumultuous period of diagnosis and treatment. This often results in a range of unique and ongoing psychosocial issues such as problems with self-esteem, issues of fertility and sexuality, and coping with the fear of relapse.

Many survivors of five or more years report that they continue to experience negative effects from the cancer and/or treatment, such as fatigue or depression, in their daily lives.

The Foundation is ensuring that the need for education and support for this minority group is no longer neglected and is collaborating with organisations such as LiveStrong Youth Alliance, CanTeen and Cancer Council Australia to avoid duplication of services or resources.

YOUNG RESEARCHER RECEIVES FIRST HONOURS SCHOLARSHIP

Dana Ihdayhid was awarded the Leukaemia Foundation's inaugural Dominic Di Giacomo Honours Scholarship for 2007.

The 12-month funding enables the young Western Australian researcher to investigate 'mesenchymal stem cells for allogeneic stem cell transplantation'.

This scholarship and its project focus could form an important component in the Foundation's commitment to finding cures and improving treatments for blood and bone marrow cancers.

Dana was delighted to receive the scholarship, the latest in a long list of achievements.

"This is a fantastic opportunity for me to contribute to the scientific community and develop my skills as a research scientist within the field of haematology," said Dana who graduated from the Curtin University of Technology in Western Australia in 2006 with a Bachelor of Science (Medical Science) majoring in haematology, medical microbiology and clinical biochemistry.

"I'm really looking forward to exploring my topic further with the support of the Leukaemia Foundation in WA and to seeing the effects and results of my project topic."

Dana is based at the Royal Perth Hospital, at the newly created Ray & Bill Dobney Cell and Tissue Therapies WA facility, and is already hard at work on her project.

The Dominic Di Giacomo Scholarship was created

in honour of Mr Dominic Di Giacomo who lost his battle with acute myeloid leukaemia in 2006. His wish was to set aside funds from his death policy to further research into a cure for leukaemia which has developed into the scholarship.

Mr Di Giacomo's wife, Lia, was delighted to learn of the awarding of the inaugural scholarship.

"My family is very pleased to be able to support the Leukaemia Foundation in WA by providing funding to support young researchers such as Dana," Mrs Di Giacomo said.

"I am sure that with talented researchers across Australia, a cure for leukaemia is getting closer every day."



Scholarship recipient, Dana Ihdayhid.

WORLD'S GREATEST SHAVE 2007

The World's Greatest Shave 2007 attracted record numbers of Australians who shaved or coloured their hair in support of the Leukaemia Foundation between March 15 -17. More than \$9 million has been raised to date, which is a phenomenal effort. These funds will greatly assist the Foundation in its care and support of patients and families across Australia and research into better treatments and cures. Congratulations to everyone who participated and special thanks to our Top 30 fundraisers.

Best friends stick together and in North Queensland, nine-year old Cody, right, raised a whopping \$1700 in honour of his friend, Calvin, also nine, who has been diagnosed with leukaemia.



Qantas Club employee, Katrina Berry, shaved her waist-length locks and raised more than \$25,000 for her courageous effort. She dedicated her shave to her auntie who was diagnosed last year with terminal lymphoma.

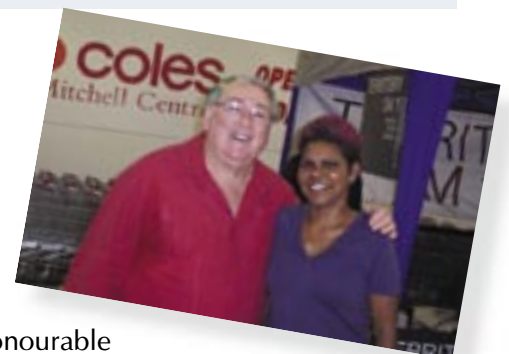


The National Top 30 Supporters:

- 1 PricewaterhouseCoopers
- 3 GIO/Suncorp
- 2 BHP Billiton Mitsubishi Alliance
- 4 Laing O'Rourke Mine
- 5 Rio Tinto
- 6 NAB
- 7 Barrick Gold of Australia Limited
- 8 Mitchell & Partners
- 9 Aon
- 10 Old Geelong Football Club
- 11 BHP Billiton
- 12 Onkaparinga Valley FNC Club
- 13 Loquat Valley School
- 14 Bank of Queensland
- 15 Crescents of Brisbane
- 16 OneSteel
- 17 Prime Health Group
- 18 ANZ
- 19 Westpac
- 20 Oscar's Friends
- 21 Macquarie Bank
- 22 Investa Property Group
- 23 UBS AG, Australia Branch
- 24 Lend Lease, Jacksons Landing
- 25 AeM & CBH Groups
- 26 Ahrens Group
- 27 IGA
- 28 Marilyn Simmons
- 29 Tarong Power Station Mine
- 30 Priceline/Priceline Pharmacy



In Queensland, **Mitchell's Media Agency** took part in the *World's Greatest Shave* for the second year running and in 2007 raised more than \$65,000. Left to right in back row: Sean Ryan, Richard Hunwick, Ash Dunn, Troy Allingham, John Droulers, Dave Bauer, Matt The. Second row: Jon Cole, Trish Eustace, Sue Robinson, Sharon Clarke, Liam Daly. Front: Daniela Lacovella.



The Honourable Ted Egan AO, Administrator of the Northern Territory and Minister for Arts, Marion Scrymgour, took part in *WGS* in the Northern Territory.



Priceline's marketing services manager, David Glenn, was among the local residents whose heads were shaved or coloured at Frankston's Bayside Shopping Centre in Victoria.



At a press conference, the Treasurer, the Honourable Peter Costello, shaved the head of Senator M. Ronaldson staff member, Andrew Elsbury, to encourage all Australians to get behind the *World's Greatest Shave*.



The CEO and doctors were among five staff members of **Hobart Pathology** who shaved. From left to right in back row: Michelle Berry, Rob Lister, Joe Lohrey, Eddie Jones, Graham Collins (practice manager) and Trish Weston. Front row: Lawrie Bott (CEO) and Daniel Owens (medical director).



Network Ten's, Mark Aiston, and Rebecca Goodman, sporting a 'new look' after taking part in the shave event at Adelaide's Rundle Mall.



The teams at long-term *WGS* supporter, **Iluka Resources**, raised nearly \$16,000. Left to right in front row: Jim White, Belinda Minogue, Mike Crosby, Ben Ash. Back row: Mark Adam, Bek Pickering, Glen Holland and Carly Hilton.



The Leukaemia Foundation's ambassador, Gina Jeffries, shaved **PricewaterhouseCoopers** (PwC) managing partner, Tom Fenton, at PwC's Sydney shave event, one of nine events held at PwC offices around the country. For the fourth year in a row PwC was the *World's Greatest Shave's* highest fundraiser.

Bill MacLeod, senior plant pathologist for the **Department of Agriculture and Food**, shaved his head and coloured his beard purple for *WGS* in Western Australia.



MYELOMA HAS CHANGED ROLAND'S OUTLOOK

If Roland Reid had been told that one day he'd be meditating and doing yoga he would have laughed at the suggestion.

Yet not only has Roland, and his wife, Sandra (both pictured right), returned recently from a workshop that included these practices, they have given Roland hope and the confidence that he can take control of his own recovery.

In March last year, Roland, 52, was diagnosed with multiple myeloma, something he'd never heard of before.

Nothing showed up on x-rays to explain his back and rib pain, so he opted for massage treatment and this resulted in a broken rib so he gave up his work as a building contractor for a few weeks. Further x-rays, for lower back pain, detected a lesion on a rib, and blood tests and a cat scan showed he had myeloma. He had a four-month program of chemotherapy, then a stem cell harvest leading up to a transplant last November.

"It was a very big year and everything went fine although I suffered badly through the chemo and apart from back pain now, you wouldn't think there was anything wrong," said Roland who is in a plateau state.

"Myeloma is, at present, medically incurable, but treatable, and some patients have a transplant which

hopefully delays the return of the disease. Some people are still running around 15 years later.

"I had enough stem cells harvested for three transplants and I'm hoping it is at least five years before I need another one. My prognosis is five to 10 years, but everyone is individual.

"My plan now is to get out and do what we can while I am well and fit enough and you never know if a cure may be around the corner."

The Leukaemia Foundation provided the Reids with accommodation while Roland was being treated at Newcastle and they have attended several seminars.



VITAL SUPPORT FROM TRUSTS AND FOUNDATIONS

Charitable trusts and foundations continue to show confidence in the work the Leukaemia Foundation carries out in its vision to find a cure for leukaemias, lymphomas and myeloma, and its mission to provide the highest quality care for patients and families.

From July 2006 to March 2007, the Leukaemia Foundation received \$535,000 in grant funding from a range of private and corporate charitable trusts and foundations.

Patient and family education and support services (\$227,000)

Funding from the following trusts and foundations is being invested in running our patient and carer workshop and peer support programs and to assist in developing a new program for young adult blood cancer survivors.

- Aon Charitable Foundation
- Gandel Charitable Trust
- IOOF Foundation
- Newcastle Permanent Community Foundation
- Perpetual Trustees
- RACV Foundation
- Tasmanian Community Foundation
- The Marian & E H Flack Trust Trust Company of Australia Limited
- The Raymond E Purves Foundation
- Trust Company

Delivery of patient services to regional areas (\$112,000)

These trusts and foundations have provided funds to deliver comprehensive patient support services in regional Victoria and Tasmania.

- John T Reid Charitable Trusts
- The William Buckland Foundation

Patient and family accommodation (\$138,000)

Patient accommodation in Melbourne and Perth is being refurbished and patient accommodation is being purchased in Melbourne with funds from:

- Eldon & Anne Foote Trust (Lord Mayor's Charitable Fund)
- Lord Mayor's Charitable Fund
- Lotterywest
- The Freemasons Public Charitable Foundation
- The William Angliss Charitable Fund

Research (\$58,000)

These two trusts have provided funding for research into the treatment and cure of haematological diseases.

- Bennelong Foundation
- W C F Thomas Charitable Trust

The Leukaemia Foundation appreciates the wonderful support provided by these Australian trusts and foundations.

LEUKAEMIA HAS GIVEN LOUISE OPPORTUNITIES

The day before Louise Mackay was to start Newcastle University, she was diagnosed with acute lymphoblastic leukaemia (ALL).

"I became really exhausted and fatigued," explained Louise who was 18 and working for a pizza outlet at the time. One night she walked up three levels for a delivery before realising she'd forgotten the drink, so she had to go down and back up again.

"My boss was concerned and thought I had glandular fever, so I had a blood test and when my doctor came around to tell me I had anaemia, I told mum I had amnesia. I was a bit vague," said Louise whose haemoglobin* was only 36.

"My doctor wondered how I was delivering pizzas and going to nightclubs when I shouldn't even have been able to lift my arm!" said Louise who went into hospital that night.

"They said I either had a virus or cancer and when they told me I had leukaemia I went into shock for a little while, then my first concern was that my hair was going to fall out.

Louise would never have guessed that she'd feature in a calendar wearing a dress she'd made and with no hair! She was Miss November 2006 in the Leukaemia Foundation's Nude Nuts fundraising calendar.

She described the first three months of treatment as "one big blur". She was in hospital a lot with fevers, treatments, transfusions and infections. Louise went into remission after six months, but because she is a little older than most people who get ALL, the length of her treatment was extended to two and half years. Her last treatment is due three weeks before her 21st birthday, in September, and she is looking forward to celebrating with a drink.

"I was told I probably wouldn't go to uni for at least a year but I started studying six months into my



Louise Mackay and her boyfriend, Ben Purser.

treatment," said Louise who, since she was 16, has wanted to work for Dolly magazine and help people with health issues. In August 2005 she had a story published in Dolly about her experience with cancer.

"One of my biggest inspirations is Delta Goodrem. I read an article on her which was very helpful as there were no other young women having treatment and I couldn't talk to anyone," said Louise who said she went through some depression.

"At first I was very angry and I didn't really have anything to blame but so many opportunities have come out of the experience. I'm starting to see it as a thing that was supposed to happen, to get me to where I want to be.

"I've got a lot of wisdom, met some really great people and got great skills in event management and PR."

** If your haemoglobin is under 80, you need a blood transfusion. A normal healthy woman's is over 120.*

WA CARERS PAMPERED AND INFORMED AT WEEKEND RETREAT

Patients and carers enjoyed a weekend of workshops, programs and support at a Carer's Retreat at Wandoo Hill Retreat, east of Perth, in February.

Carers had some time to themselves and were pampered as well as participating in the 'Learn Now; Live Well' education program which provides skills to help care for someone at home and improve their quality of life and comfort.

Support services manager for the Leukaemia Foundation in WA, Sandy McKiernan, said the retreat was a great success.

Anna Pettersen facilitated a creative workshop and managed the art therapy program. Lisa Booth spoke about nutrition and encouraged participants to attend a pilates session and SolarisCare Foundation volunteers provided complementary therapies

including reiki, reflexology and chi breathing. Wandoo Hill Retreat continued its support for the Foundation by subsidising the venue.



Art therapy at the Carer's Retreat.

JUDITH CELEBRATES LIFE AS A LONG-TERM SURVIVOR

When Judith Ade was diagnosed with lymphoma at the age of 42, she didn't think she'd celebrate her next birthday, let alone her 50th.

Now aged 52, Judith is a long-term survivor and last year she became a grandmother.

In October 1997 she was shocked by her diagnosis with non-Hodgkin lymphoma (NHL).

"The chemotherapy changed me. I gained weight and I felt it aged me. Now I'm a lot slower than I used to be, but I am very glad to be alive," she said.

"I never thought something like this would ever happen to me. I was healthy, I didn't smoke, nor was I overweight."

Judith had felt "unwell" for some time and her GP was unable to diagnose what was wrong with her.

"I knew I was sick," explained Judith who had experienced pain in her neck, chest and abdomen and other symptoms.

A chest x-ray and ultra sound finally revealed she had low-grade NHL.

"It is a slow growing type of lymphoma which I had probably had for several years. My GP was surprised to find out I was quite ill.

"I was in absolute shock and wanted to take my time to think about what I was going to do," said Judith, who decided against going on a recommended trial after reading about the side-effects.

In January 1998, she opted to begin six cycles of chemotherapy, approximately three weeks apart, and went into remission until 2001 when pain in her back turned out to be lymphoma. It was successfully treated with radiotherapy.

Then in 2002 Judith relapsed again. She was treated with a combination of chemotherapy and MabThera.

"I have been in remission since that time but I do expect to have further treatment at some time in the future as a permanent cure has not yet been found for this type of lymphoma."



Judith Ade with her grand-daughter, Natalie.

AON SELECTS FOUNDATION AS ITS FIRST CHARITY PARTNER

The Aon Charitable Foundation has selected the Leukaemia Foundation as its first charity partner and has committed to providing \$50,000 a year for the next three years.

The partnership creates opportunities for Aon Australia staff to become involved with the Foundation and in their first activity they raised more than \$50,000 in this year's *World's Greatest Shave*. More than 80

staff around the country took part and sections of the Sydney, Melbourne, Adelaide and Perth offices were converted into temporary barber shops. In other cities and regional centres, Aon staff joined participants at public shave locations.

Aon Charitable Foundation manager, Lyn Munday, was overwhelmed by both the number of staff who participated and the generosity of the staff who sponsored them.

"This means that in 2007 the Foundation will receive more than \$100,000 from Aon and we certainly look forward to further developing our partnership with the Foundation," Lyn said.

Leukaemia Foundation CEO, Adrian Collins, is excited about the new relationship with Aon, the largest insurance broking and consulting operation in the Australia Pacific region: "We are pleased to be in partnership with the Aon Charitable Foundation and their first *World's Greatest Shave* event with us has achieved outstanding results. This, along with their three year commitment, means we can further our care and support of patients and families around the country."



PETER'S LIFE-ALTERING EXPERIENCE WITH CML

Peter and Ingrid Pempeit had two young children and were at that stage of life where they were planning an overseas holiday, assessing future job prospects and considering a range of investments.

Then, on Christmas Day last year, Peter, 41, noticed a "little bump" on his forearm but didn't think much of it.

Over the next few days it grew. It was initially thought to be lipoma – a benign fatty tumour, but it swelled up and turned purple. Peter was given antibiotics to treat a possible infection, but it quickly got worse.

He returned to work after New Year but his arm swelled up so badly on his first day back that he lost all mobility and Ingrid took him to the Emergency Department at the Geelong Hospital.

They did a blood test and three hours later Peter was told it looked as if he had leukaemia.

"It was a major shock," he said.

"I didn't know much about leukaemia but I knew it was serious and that it was fatal so it was very distressing."

A bone marrow biopsy the next day confirmed it was chronic myeloid leukaemia and looking back, Peter reckons he'd had leukaemia for at least 12 months and possibly two years.

"I had aches in my joints, legs, ankles and hips, night sweats, headaches, nose bleeds that wouldn't stop and I was fatigued and lethargic.

"At the time I thought these were all isolated issues and I couldn't see how they were related."

The first week of treatment was a pretty rough time for Peter but he felt well enough to go home, although he went back to hospital each day for transfusions



Peter Pempeit in hospital in January.

and treatments. His condition, however, quickly deteriorated.

"My legs really started to hurt and it got to the point where I couldn't walk anymore. Ingrid had to do everything for me until she couldn't handle it and she called an ambulance to take me back to hospital.

"The next three days were the worst days so far. I had to learn to walk again. I had to use a walking frame and felt like an 85 year old person with arthritis.

"I'm fortunate I've got this disease now and not 10 years ago when my statistical survival rate would have been a lot lower.

"I'm still very early in my treatment and I don't know what the future holds for us. We can't plan long-term at the moment so right now we're in a holding pattern."

ON-LINE SUPPORT FORUM FOR PATIENTS AND FAMILIES

Talk Blood Cancer* is a moderated on-line information and support forum for patients and families living with leukaemias, lymphomas, myeloma and related blood disorders.

Being diagnosed and treated with a blood cancer like lymphoma can be confronting and at times overwhelming. It presents patients and families with many challenges. Being in contact with other people who have experienced or are going through similar, complex feelings associated with the disease is useful.

Talk Blood Cancer is designed to help in understanding and managing the practical and emotional issues that are part of the journey through diagnosis, treatment and recovery.

This safe, supportive, informative environment, moderated by four of the Leukaemia Foundation's support service staff, enables people to share ideas, opinions, helpful and practical advice and personal experiences.

Registration is free and participants can remain anonymous. To participate is easy.

1. Visit www.talkbloodcancer.com
2. Click on 'register'
3. Provide a username (for public viewing) and your email address and a password (not public)
4. Take part by posting messages, participating in polls and reading on-line discussions

This service is part of the Foundation's commitment to increasing the delivery and reach of world-class support to patients and families. Talk Blood Cancer is an alternative source of support and information and it is particularly helpful for people who live in regional and rural areas and those who are not able to attend the Foundation's face-to-face support groups.

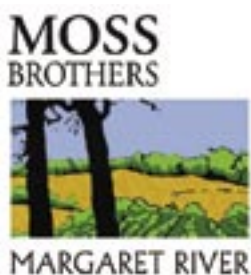
** Talk Blood Cancer is supported by financial assistance from the Australian Government through the Cancer Support Groups Program.*

EXCLUSIVE WINE OFFER FROM MOSS BROTHERS

The Leukaemia Foundation has partnered with Moss Brothers Winery of Margaret River, Western Australia to develop an exclusive wine offer.

Purchase a case or more from this popular winery with free delivery to anywhere in Australia and the Foundation receives \$15 per case. This offer is valid only while stocks last, so place your orders now to avoid missing out.

There are four wines to choose from - 2004 Drummond Hill White, \$132 per dozen, 2004 Autumn Harvest Cabernet and 2005 Moses Rock Rose, both \$153 per dozen and 2004 Verdelho, \$164 per dozen.



Leukaemia Foundation supporter, Gail Simpson, who bought a case of Moss Brothers wine in a previous wine offer last Christmas said: "I was delighted to be able to support the Leukaemia Foundation and order my wine for the festive season at the same time."

"The wine was delivered promptly to my door and most importantly the quality of the wine itself was really lovely. I enjoyed sharing it with my family and friends and the case was finished very quickly."

Gail who lives at Northam, outside the Perth metropolitan area was also pleased with the free delivery.

"Living in regional Western Australia often means delivery charges are an added expense, so with the free delivery from Moss Brothers, I will definitely purchase more cases through this new offer," she said.

Moss Brothers Vineyard and Winery lies in the heart of the prestigious Margaret River wine growing region, called Wilyabrup Valley which is considered by many as the region's jewel in the crown. Established, owned and operated by the Moss family since 1984, the vineyard and winery is committed to quality and its exceptional fruit has earned a reputation for producing some of Margaret River's finest wines.

For orders call the Leukaemia Foundation on (08) 9272 9332.

LUCKY BEAR'S GRANT

A significant one-off grant from the Channel 7 Telethon Trust benefits children in the Lucky Bear's Club program by funding a 12-month program of workshops and activity days.

The club is for children with a parent, sibling or grandparent who is affected by leukaemia, lymphoma, myeloma or a related blood disorder. This has a significant impact on the family unit and environment and can lead to major psychological changes in children and their ability to cope, according to Peta Fillery, the Foundation's general manager in WA.

"This grant will make a significant difference to children in the 14 families who are diagnosed with leukaemias and related blood disorders every week here in Western Australia and means we can expand the program to include 12-15 year olds who were previously not included due to budget constraints," said Peta.

Telethon Trust general manager, Rudi Gracias, said Telethon trustees recognised the need for the Lucky Bear's Club and its program of workshops, activity days and annual Christmas party.

The age-specific workshops focus on child centred play therapy, professionally facilitated by play therapists, health professionals and counsellors and offer children the opportunity to form links with



Piwiki and Raewyn Kingi.

people of similar ages who are experiencing similar challenges. Play is used as a way of expressing feelings and communicating in a safe, nurturing environment. The activity days focus on 'time out' for children from the day-to-day stresses of dealing with a seriously ill parent or sibling. They are fully supervised and have included visits to the Perth Zoo and Perth Museum.

At the most recent Lucky Bear's Club activity day, during the Easter school holidays, Piwiki Kingi, 10, and his eight-year old sister, Raewyn, were among children who watched Arthur and the Invisibles at a private cinema, played games and ate pizza and Easter eggs.

LEAVE A LASTING LEGACY FOR THE FUTURE

Include a Charity is a collaborative research and awareness campaign, launched by four of Australia's largest charities, to promote the importance of having an up-to-date will and including a bequest to a favourite charitable cause.

New research undertaken by Include a Charity shows that it is estimated only 8% of Australians make charitable bequests.

These bequests, when realised, provide funding that contributes to research into cures and better treatments, as well as information and support for patients and families affected by diseases such as blood cancers.

According to the Leukaemia Foundation's national trusts, foundations and planned giving manager, Ralph Roath, leaving a bequest to a favourite cause is in no way intended to deprive family and friends.

"After making due allowance for loved ones, a bequest of a specific amount or a proportion of the residue of their estate is a wonderful way for our supporters to leave a real and lasting legacy to future generations," Ralph said.

Another interesting finding from the research is that solicitors appear to be far more philanthropic and community minded than their stereotypical reputation

suggests, with Australian solicitors more likely to leave a bequest in their will than the rest of the population.

Two years of extensive research and interviews with 150 solicitors found that 75% of solicitors support the idea of leaving a bequest in their will compared to 51% of the general public.

"Our organisation receives no ongoing government funding so we rely heavily on donations and our fundraising campaigns to continue our support of patients diagnosed with leukaemias, lymphomas or myeloma and their families, as well as our research into cures for these diseases," said Ralph.

"The fact that solicitors are so supportive of bequests means that hopefully, the number of Australians considering bequests will increase in time as solicitors are so intrinsically involved in the will preparation process.

"We hope our supporters will consider the option of a bequest to help us ensure a future free of these diseases," he said.

For further information about including a bequest to the Leukaemia Foundation in your will, call us on our Freecall number 1800 620 420, contact Ralph Roath on (03) 9949 5815, or email: rroath@leukaemia.org.au. All enquiries are treated in the strictest confidence.

FOUNDATION LAUNCHES NEW NATIONAL FUNDRAISING EVENTS

The Leukaemia Foundation will launch two new national fundraising programs next month – *Lavender for Leukaemia* and the *Leukaemia Foundation Doorknock Appeal*. Both are designed to raise funds at the local community level to help the Foundation continue to provide care and support to patients and their families, and to fund vital research into better treatments and cures.

Lavender for Leukaemia, from July 2 – 8, features the sale of lavender-scented goodies from just \$3. From lip balm to potpourri and teddy bears to lapel pins, the lavender range features great gift ideas and collectables and all funds raised go to the Foundation.

From July 21 to August 4, don't ignore a knock at your front door as the Leukaemia Foundation's *Doorknock Appeal* is trialled in selected areas across Australia. The face of the *Doorknock Appeal* is Brisbane's 10 year-old Georgina Thomas who is urging Australians to give generously.

"Hi, I'm Georgina. When I was three I was diagnosed with leukaemia. I was really sick back then, and had to have chemotherapy for two years. I spent a lot of time in hospital and lost my hair. But now I'm 10 and glad to say I don't have leukaemia any more. I love to do all the things most 10 year olds do – I love going to the beach, fishing, shopping....I'm even learning to snorkel and play the trombone.

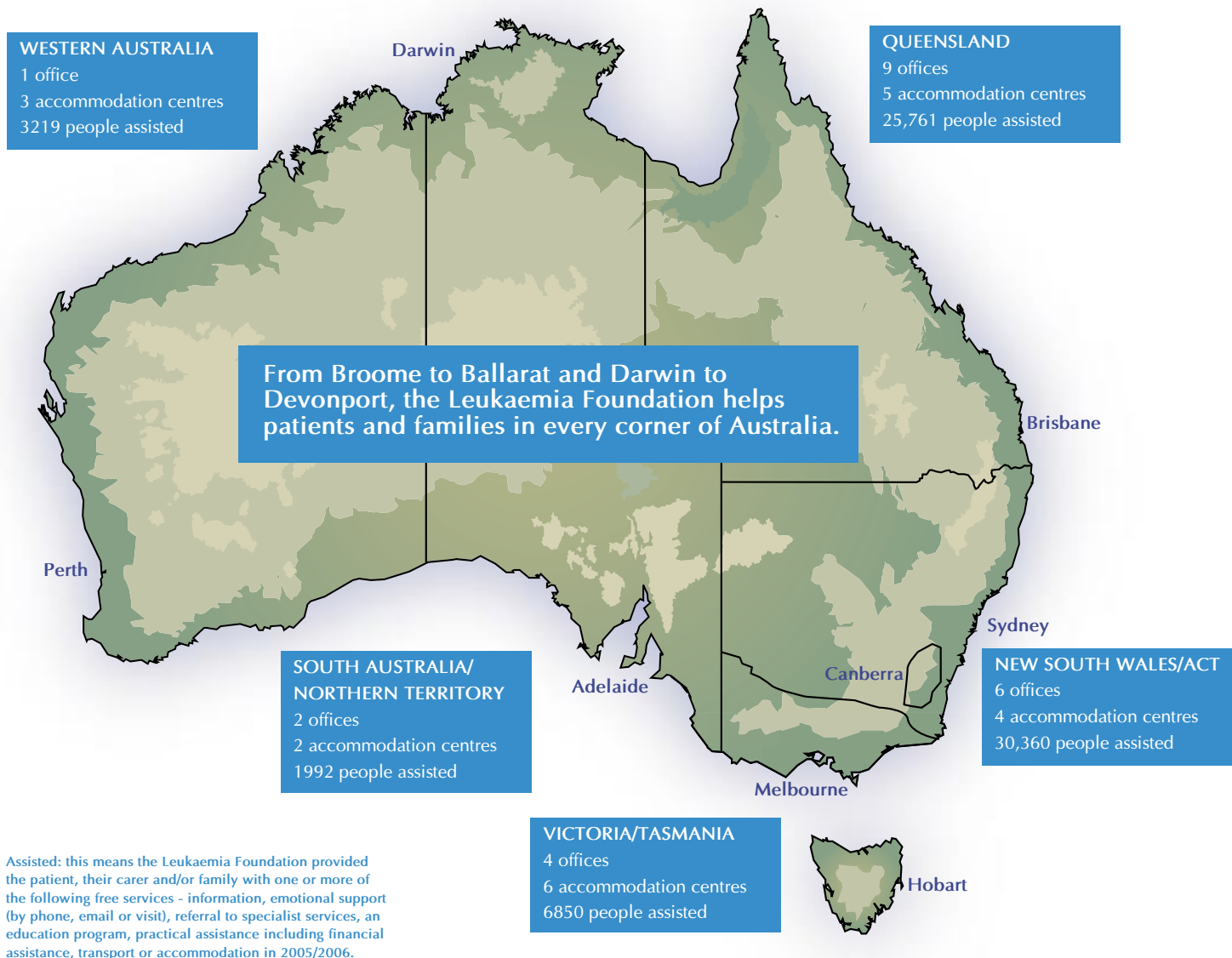


"With your help, everyone with leukaemia may be cured like me and look forward to a bright future. Please help the Leukaemia Foundation by supporting this year's Doorknock Appeal."

To register as a volunteer for this year's *Doorknock Appeal*, to donate, or for more information, please call 1800 152 211.

OUR SUPPORT EXTENDS ACROSS ALL METROPOLITAN AND REGIONAL AREAS

The Leukaemia Foundation is a national organisation dedicated to helping all patients, carers and their families, regardless of where they live. We have offices in every state and territory and our world-class support extends across metropolitan, regional and rural communities.



CONTACT US

Freecall 1800 620 420 (call will go through to your local office)

Email: info@leukaemia.org.au

Mail: GPO Box 9954 in your capital city

Website: www.leukaemia.org.au

The Leukaemia Foundation is the only national not-for-profit organisation dedicated to the care and cure of patients and families living with leukaemias, lymphomas, myeloma and related blood disorders.