

**About acute myeloid leukaemia**

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, at a rate of 3.7 per 100,000 of the population.

AML can occur at any age but is more common in adults over the age of 60 years. It occurs more frequently in males than in females and around 50 children (0-14 years) are diagnosed with AML each year.

For more information on AML visit:

[www.leukaemia.org.au](http://www.leukaemia.org.au)



**Leukaemia Foundation**

VISION TO CURE  
MISSION TO CARE

1800 620 420

[www.leukaemia.org.au](http://www.leukaemia.org.au)

**RARE LEUKAEMIA TAKES NT PATIENT TO MELBOURNE FOR CLINICAL TRIAL**

**Robert Wall is patient number four in the first stage of a clinical trial that is assessing new drug combinations for mature-age patients with acute myeloid leukaemia (AML).**

After being diagnosed with a rare form of AML in late-April this year, Robert had to choose one of three options – palliative care, conventional treatment which is considered too toxic for elderly patients, or taking part in the trial.

He chose the research program headed by Dr Andrew Wei at The Alfred Hospital. This meant Robert and his wife, Hilary, who live in Darwin, had to move immediately to Melbourne for several months.

Hilary described her husband's diagnosis with a serious disease as a "total shock". It came out of nowhere as blood tests he'd had in February were clear.

In April while playing golf with workmates, Robert felt dizzy and faint. He went to the doctor the next day and was due to visit a cardiologist a few days later.

"We thought he'd had a mini heart attack, that he had a blocked valve and maybe needed a stent," explained Hilary.

The electrical engineer, 69, continued working but had to come home each day because of extreme fatigue. The third day this happened, he went to hospital and after a series of blood tests and a bone marrow biopsy, was told he had acute megakaryocytic leukaemia, a rare subtype of acute myeloid leukaemia resulting from the overproduction of cells responsible for platelet development in the blood.

He was immediately given four units of blood and two units of platelets and after deciding to take part in the research program received more blood and platelets to make the early-morning flight to Melbourne.

It's still early days, and despite a minor setback due to a chest infection, Hilary said Robert was doing well on the trial.

He takes a drug called RAD001 daily for 12 months and is given mini-chemotherapy subcutaneously in the stomach twice a day for 10 days. "And a team of merry men come around and look at him," said Hilary.

Then, after a three-week break, Robert begins another 10-day treatment.



Robert Wall with his grand-daughter, Eleanor Cavanaugh

"We have a very positive outlook and the Leukaemia Foundation has been wonderful. They have arranged accommodation for us in an apartment close to the hospital and we're very grateful."

Hilary said they didn't know anyone in the area but during their first month in Melbourne, their children and grandchildren and other members of their family, from Hobart, Canberra and Sydney, visited them in Melbourne.

While the treatment program is for 12 months, Dr Wei told the Walls they may be able to go home to Darwin after four to six months. They would then travel to Melbourne each month for Robert's treatment and tests.

**Dr Andrew Wei's study is testing low dose cytarabine (a treatment commonly used for older patients with acute myeloid leukaemia) in combination with everolimus (a drug which has shown to be effective in laboratory models of acute myeloid leukaemia) in a clinical trial. The purpose of this study is to record the safety and tolerability of the new drug everolimus at three different doses (2.5mg, 5mg or 10 mg daily for up to 12 months) given together with low dose cytarabine. The study will also do surveys assessing patient quality of life prior to and during everolimus/cytarabine drug treatment. Early studies have shown that everolimus can be given safely and with potentially less side-effects than intensive chemotherapy. The trial is suitable for patients with newly diagnosed acute myeloid leukaemia over the age of 55.**

# NEWS IN BRIEF

## FOUNDATION AMONG TOP 5 ORGANISATIONS

The Leukaemia Foundation of Australia was named one of the top five 'Best Practice' not-for-profit organisations in Australia by the Givewell Good Giving Guide Charity Awards which reviewed some of Australia's most prominent charities against strict criteria including:

- ability to deal with significant social problems in tangible ways
- demonstrate best practice organisational and financial management
- have strong fundraising and financing mechanisms providing the organisation with the capacity to deliver to its constituency.

Peter Cox, Leukaemia Foundation of Australia CEO, was delighted with the recognition which he said places the Foundation in the league with some of Australia's most respected not-for-profit organisations: "Recognition such as this helps raise awareness of the Foundation and goes a long way to helping support the 25 Australians who were told today that they had a blood cancer. On a daily basis the Foundation strives for excellence, not only with providing practical care to our patients and families, but in being a 'preferred partner' with our corporate supporters."

## HILTON HOTEL SELECTS FOUNDATION AS NOT FOR PROFIT IN AUSTRALASIA

To make a significant difference in their respective communities, Hilton Hotels in Australasia is channelling all its philanthropic efforts to the Leukaemia Foundation of Australia. The partnership agreement, signed in March by Ashley Spencer - Vice President, Hilton Hotels Australasia and the Foundation's CEO, Peter Cox, runs until 31 December 2010. Hilton Hotels hopes to maximise the financial and non-financial contributions to ensure the activities have a positive impact on people with blood cancers. Hilton Hotels will host events on behalf of the Foundation across Australia, donate short stays at Hilton Hotels to be used by the Foundation as prizes and provide spa or restaurant gift certificates for the Foundation. Hilton Hotels also will actively encourage staff volunteering involvement in the Foundation's projects and in-room flyers at all Hilton Hotels will recognise the partnership.



Ashley Spencer, left, and Peter Cox

## FIRST CLINICAL TRIAL IN DARWIN BENEFITS NT LYMPHOMA PATIENTS

The first clinical trial for blood cancer patients in the Northern Territory began at the Royal Darwin Hospital in November last year. It follows the successful application by haematologist, Dr Ferenc Szabo, for funding by the NT Government to establish a trial centre in the Top End. The study involves using a drug called enzasturin to lengthen remission in patients with diffuse large B-cell lymphoma. Treatment will span three years and the progress of participating patients will be followed for a further five years. Teresa Hyatt,

Support Services Co-ordinator in the Northern Territory, said that until now only a few lymphoma patients from the Territory could participate in trials and receive the latest treatments because of the high cost of travelling to participate in trials in other cities. The trial is still recruiting suitable lymphoma patients. For more information, contact Teresa on 08 8927 9611.

## ANTARCTIC EXPLORER'S BOOK RAISES FUNDS

Environmental scientist, explorer, film-maker and author, Tim Jarvis, became a Leukaemia Foundation ambassador following his friendship with an inspirational young man who later passed away from acute myeloid leukaemia, aged 20. Tim, who wrote *The Unforgiving Minute* (2004), replicated the Douglas Mawson Antarctic Expedition of 1912 with similar meagre rations, primitive clothing and equipment, to uncover what happened to Mawson physically and mentally. The documentary, *MAWSON: Life and Death in Antarctica* followed this journey and premièred on the ABC in May. Tim Jarvis' book, *MAWSON: Life and Death in Antarctica*, captures the same adventure in 200 pages of compelling text and stunning photographs. Purchase a copy through the Leukaemia Foundation for \$40 (plus postage), and the Foundation receives a \$20 donation. To order, contact Rebecca Goodman on 08 8273 3511 or [rgoodman@leukaemia.org.au](mailto:rgoodman@leukaemia.org.au).



From left: Tim Jarvis, Mark Pharoah (Senior Collection Manager, Mawson Centre), Simon Matthias (Leukaemia Foundation General Manager SA/NT,) and Andrea Shaw (Marketing Manager, URS). Photo: courtesy asbcreative

## INTERLYMPH 2008 CONFERENCE TO BE HELD IN SYDNEY

Australians interested in the causes of lymphoma can attend the seventh annual meeting of the international consortium of lymphoma researchers, known as InterLymph. The consortium, which comprises epidemiologists, research scientists and clinicians who are involved in lymphoma research in North America, Europe and Australia, is gathering in Sydney at the Menzies Hotel on July 29 – 31. International experts will present the latest findings on the causes and risk factors involved in developing non-Hodgkin lymphoma, Hodgkin disease and multiple myeloma. The program includes presentations on lifestyle and environment risks, such as hair dyes, obesity and sun exposure; immunity and infection risks; and pathology and survival, including genetic and environmental determinants. In addition, there will be an optional extra one-day scientific symposium, *New Insights into the Causes of Lymphoma*, on July 28. While the deadline for registrations was in May, late registrations are welcome. To download the registration form visit [www.epi.grants.cancer.gov/InterLymph/call\\_for\\_abstracts.html](http://www.epi.grants.cancer.gov/InterLymph/call_for_abstracts.html).

## CORRECTION

On page 8, *The Carer* (Autumn 2008) in the story, *Unravelling the Mystery of Inheriting Haematological Cancers*, people were invited to email Dr Graeme Suthers regarding a familial cancer study. Please note, the correct email address for Dr Suthers is: [graeme.suthers@cywhs.sa.gov.au](mailto:graeme.suthers@cywhs.sa.gov.au).

# AML RESEARCH FURTHERED BY YOUNG SA MOTHER

**The generosity of a young mother who lost her husband to leukaemia has led to the purchase of equipment researchers hope will increase survival rates for others in the future.**

South Australian mother of three, Natalie Morgan, will never forget the Wednesday in January 2006 when her husband, Stephen, 34, was diagnosed with a very aggressive type of acute myeloid leukaemia (AML). Four days later, he died.

Natalie, who was seven months pregnant with their third child at the time, went to the Leukaemia Foundation with questions about why this happened to Stephen and concerns about the risk of blood cancer developing in her children.

Natalie is passionate about research and she raised \$20,000 by participating in the *World's Greatest Shave* in 2007. With the support of the Leukaemia Foundation, a bioanalyser was purchased for the Institute of Medical and Veterinary Science (IMVS) in Adelaide and dedicated to the memory of Stephen Morgan in a ceremony on May 30 this year.

The bio-analyser is a timesaving piece of equipment that enables researchers to quickly assess the suitability of samples to conduct further research on the role of two genes identified as potentially important in the



Simon Matthias (Leukaemia Foundation General Manager SA & NT), Dr Anna Brown (Researcher, IMVS), Natalie Morgan and Dr Richard D'Andrea (Head, Acute Leukaemia Laboratory, IMVS)

development of AML. It is the first unit of its kind at the IMVS.

"I'm so proud to have the bioanalyser dedicated in Stephen's name. He was a wonderful man with a gorgeous spirit," said Natalie.

"There are no positives that will ever justify not having Stephen in our day-to-day lives, but it is comforting to have his memory honoured in this way and encouraging to think the bioanalyser will assist researchers to one day answer some of the many questions about acute myeloid leukaemia."

## IMPROVING STEM CELL TRANSPLANT SURVIVAL

**The Leukaemia Foundation is funding five very different research projects that focus on improving stem cell transplant survival rates.**

While up to 75% of blood cancer patients are cured by a stem cell transplant, the procedure can be limited by serious complications including graft-versus-host disease (GVHD) and post-transplant infection.

A stem cell transplant involves replacing the patient's bone marrow stem cells (the 'mother' cells which produce white and red blood cells as well as platelets) with healthy stem cells from a genetically similar donor.

GVHD develops when the donor stem cells attack the body. It occurs in 50 - 70% cent of patients, with up to 50% dying as a result of the disease. In 2008, the Leukaemia Foundation awarded three grants to researchers investigating GVHD.

Dr Simon He was awarded a Clinical Fellowship to undertake GVHD research at The Royal Melbourne Hospital. Dr He is designing a clinical trial for a new treatment regimen, combining the drug rituximab with low-dose irradiation, to treat chronic GVHD.

PhD scholarships were also awarded to Renee Robb and Therese Seldon to undertake GVHD research in Brisbane at the Queensland Institute of Medical Research (QIMR) and Mater Medical Research Institute, respectively.

Ms Robb is developing a targeted treatment to prevent GVHD, while Ms Seldon is developing a GVHD vaccine based on dendritic cells – a subset of white blood cells which may play a pivotal role in GVHD.

Post-transplant, patients' immune systems are severely compromised leaving them vulnerable to common viral infections such as cytomegalovirus and varicella zoster virus. These infections can cause serious illness or death in transplant patients.

The Foundation awarded Clinical Fellowships to haematologists Dr Siok-Keen Tey (QIMR) and Dr Emily Blyth (Westmead Millennium Institute) to improve patient survival from infection post-transplant.

Dr Tey is studying how the immune system rebuilds itself after a transplant, how this affects the risks of infection, and what can be done to improve a patient's ability to fight viral infection.

"If we can predict which patients will be at risk for disease post transplant, we can target pre-emptive anti-viral therapy," said Dr Tey.

Dr Blyth is trialing the use of donor immune cells to help patients fight viral infections post transplant. According to Dr Blyth, improvements in the treatment of infectious complications would improve long term outcomes for transplant patients.

# RESEARCH FOCUS FOR PATIENT EDUCATION DAY

**More than 120 patients, carers and health professionals attended the Leukaemia Foundation's 3rd Annual Patient Education day in Adelaide in May.**

Prof Bik To, Head of Haematology at the Royal Adelaide Hospital, spoke about treatment advances over the last 10 years and Dr Mark Guthridge, Head of Cell Growth and Differentiation Laboratory at the Institute of Medical and Veterinary Science in Adelaide, highlighted current research on curing leukaemia.

The Leukaemia Foundation's National Manager – Vision, Dr Susan O'Brien, explained the Foundation's role in funding research projects and nurturing the next generation of leading researchers.

In the afternoon, patients opted to attend various sessions including a talk by retired media specialist and lymphoma survivor, Professor Garry Phillips, a session on rebuilding the immune system, and a discussion of issues faced by carers.

This year the Foundation celebrates 10 years in South Australia. This milestone provided an opportunity to recognise the contribution of the volunteers.



*Denis Pitcher and Dr Mark Guthridge at the patient education day in Adelaide*

Two of the first volunteers who are still with the Foundation today spoke about the "early years".

In the words of one patient: "I gained a sense of hope for future treatments and cures and a greater appreciation of the Foundation and what it does".

## HELPING GP'S DIAGNOSE LYMPHOMA

**WORLD LYMPHOMA AWARENESS DAY - 15 September**

**The symptoms for lymphoma are often very ordinary and similar to the common symptoms of less serious or minor conditions such as having the flu or being run-down or stressed.**

It is a common experience for patients to know they're not well but to take some time before going to their doctor, and often they find it hard to describe what's wrong. It also can take several visits to their GP and to other specialists before lymphoma is diagnosed.

Educating GP's to assist in the early diagnosis of lymphoma is the aim of *World Lymphoma Awareness Day 2008* on 15 September.

This year the Leukaemia Foundation plans to raise the profile of lymphoma and position this increasing health problem onto a GP's radar, so they 'think lymphoma' and the correct tests are conducted earlier on, to either

eliminate lymphoma or provide early detection. (It is usual for these symptoms to be due to other conditions, not lymphoma.)

Treatments for slow developing, less aggressive (indolent) forms of lymphoma have changed over recent years. The previous 'watch and wait' protocol has been replaced with a 'treat up front now' approach.

### **DID YOU KNOW?**

- ***The incidence of lymphoma has doubled in the last 20 years in western countries for unknown reasons.***
- ***More than 5000 cases of lymphoma will be diagnosed this year in Australia.***
- ***There are two major groups – Hodgkin lymphoma and non-Hodgkin lymphoma, but each group has many subtypes, especially NHL (30 subtypes).***

## SIGNS AND SYMPTOMS OF LYMPHOMA

**Lymphoma is difficult to diagnose due to an entire suite of 'quite ordinary' symptoms.**

**For many patients their symptoms are atypical and the disease is not always evident in the blood.**

**Predominant presentations can include:**

- Feeling run-down, stressed and in need of a holiday, especially if this feeling persists for more than two weeks
- Having enlarged lymph nodes (swollen glands) anywhere in the body, but usually in the neck, under the arms or in the groin, which aren't painful
- Regular and frequent fevers
- Excessive sweating, sometimes more often at night
- Unintentional weight loss
- Persistent fatigue and lack of energy
- Generalised itching.

# DANTE HAD LYMPHOMA FOR TWO YEARS BEFORE BEING DIAGNOSED

In 1996, Dante St James had the dream job in IT in Brisbane. He was being paid “quite nicely” and doing “really well”, all at the ripe old age of 22.

Then the golden boy developed some “strange symptoms”. It wasn’t until he got a wart-like growth in the corner of his mouth that he went to the GP who promptly removed it. The growth grew back within a week and his GP removed it again. When it reappeared, Dante’s GP decided to do a biopsy.

Over the next month Dante was referred to a radiologist, a pathologist, then an oncologist. He had PET and CAT scans, an MRI and “blood test after blood test after blood test” before being diagnosed with non-Hodgkin lymphoma. It was stage four which is very advanced.

Dante was told he’d had lymphoma for up to two years. Looking back, he realised the kidney pain, stomach problems, skin rashes, itchiness on his scalp and several instances of night sweats were all indicators for lymphoma.

“I’d been living with fatigue, but put it down to long hours and a high stress environment and thought it was normal,” said Dante.

He was in shock when he checked into the Royal Brisbane Hospital to start radiation treatment.

“I didn’t get much of a response, so I went onto oral chemo,” said Dante who was getting really sick at this stage. He was bloated, suffered skin redness and abdominal pain.

“This is when things got really blurry. I couldn’t work, my hair fell out and the lymphoma still wasn’t responding to stronger treatment.”

Dante was told he had six months to live and he still hadn’t told his family in Sydney of his diagnosis.

Then he was offered an experimental treatment as part of a clinical trial.

“I was too out of it to know what they were putting into me but it was some kind of chemo and it was partially funded by the Leukaemia Foundation,” he said.

Within two weeks Dante had a major response. The five different tumours he had all started shrinking in size so they could be removed surgically, one of them along with the kidney to which it was attached.

At age 23, Dante was given the all clear.

“When you get that close to death you see things differently and several things happened.”



*Dante St James, right, broadcasting live with co-host, Tori Hodgman*

He saw that he was selling himself short for a high stress career, he lost his taste for Diet Coke, his hair went from blond and straight to dark and curly and he grew a lot of body hair.

He decided to do something more meaningful, volunteered for a radio station on the Gold Coast and took to it like a duck to water. Two years later he was “picked up” by a radio station in Darwin to host an FM morning program.

“It was so much fun and I miss Darwin terribly. It is such a great lifestyle, especially if you have a philosophical view of life.”

Last year while in Darwin, Dante developed some familiar symptoms.

“I had itchy skin again, my stomach started playing up and I started puffing up.”

He was referred to Brisbane for tests that showed his lymphoma was in the early stage of returning. After a week of “minor radiation” he was back to normal again and he accepted a job offer in Tasmania where he is a breakfast presenter at 7HOFM in Hobart.

He’s also done a stand-up comedy course, started his own IT business and mentors 15 year-old students at a local high school.

His five-year plan is to return to the Top End, retire and spend the rest of his days fishing for barramundi.

“I’d be happy to be bored doing that, but right now it’s not looking likely for the end of 2009!” said Dante, 34.

# LEADING SCIENTISTS UNCOVERING GENES CAUSING BLOOD CANCER

Internationally renowned cancer researchers, Professor Neal Copeland and Professor Nancy Jenkins, recently visited Australia to present their research on blood cancers at the *New Directions in Leukaemia Research* conference.

The husband and wife team are ranked among the world's top biomedical scientists and have published more than 750 publications in 30 years.

They are highly respected for their pioneering work in developing a new technique, known as Sleeping Beauty (SB), to efficiently identify cancer-causing genes. Using SB, they have modelled many different types of human cancers in mice.

SB is an altered transposon from fish, a piece of 'jumping' DNA, which inserts itself into or between genes and then mutates the gene, contributing to the disease process. Using the transposon as a 'tag', scientists can clone and identify many of the genes mutated in a particular tumour.

The hope is that by identifying all the genes that are mutated in cancer, better targets for therapeutics will be identified and better drugs will be available for treatment.

"Cancer is caused by multiple gene mutations which interact to induce disease," said Professor Copeland.

"Exactly how many genes are cancer genes remains to be determined although there are surely going to be hundreds if not thousands.

"Using Sleeping Beauty, we can select tumours that share histological features in common with humans and then go after the genes in mice.

"Recently, we mobilised Sleeping Beauty in mice to induce blood cancer and were able to identify several genes and signalling pathways important for blood cancer.



Husband & wife cancer researchers, Professor Copeland & Professor Jenkins

"And we know that we are finding genes that also cause blood cancer in humans. As an example, the Notch1 gene was mutated in 50 per cent of mice with T cell lymphoma induced by Sleeping Beauty.

"The same gene is mutated in about 50 per cent of people with a similar type of cancer," he said.

Professors Copeland and Jenkins and their colleagues are studying genes causing tumours not only in leukaemia and lymphoma but also in the brain, melanoma, and breast, among others. They hope to improve treatment options for these cancers, as well.

## CAREER HISTORY

**2006-current:** Executive Director of The Institute of Molecular and Cell Biology (IMCB), Singapore (Copeland); Deputy Director, Genetics and Genomics Division, IMCB (Jenkins).

**1985–2006:** Director, mouse cancer genetics programme, and head, molecular genetics, oncogenesis section, National Cancer Institute, USA (Copeland). Head, molecular genetics, development section, National Cancer Institute, USA (Jenkins).

**1983–1985:** Associate professors, University of Cincinnati College of Medicine, Cincinnati, Ohio.

## DISEASE-SPECIFIC NEWSLETTERS FOR PATIENTS & FAMILIES

The Leukaemia Foundation has developed a range of disease-specific newsletters that focus on issues and information relevant to each disease.

The articles include personal stories, advice on practical issues, research updates and the latest news and information.

Each year the Foundation publishes two issues of *Myeloma News*, *Leukaemia News* and *Myelodysplastic Syndromes News*; three issues of *Lymphoma News*; and an update on the Australian Blood Cancer Registry.

The newsletters are posted to patients personally and each issue can be downloaded from [www.leukaemia.org.au](http://www.leukaemia.org.au), *About the Diseases* section.

The newsletters are produced with support received as unrestricted education grants from a number of pharmaceutical companies.

### MULTIPLE MYELOMA NEWS

CARING FOR PATIENTS WITH MYELOMA AND THEIR FAMILIES

www.leukaemia.org.au June 2008

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#### ALLAN'S OK AND DOING WHAT HE LOVES – TRAVELLING

Since the age of 16, Allan Webb worked continuously at his life until he was diagnosed with multiple myeloma... and he hasn't worked a day since. His job as a coal miner ended suddenly in mid-2004, aged 55, when he crushed a vertebra in his back when lifting a heavy box. The next day, he was told he had multiple myeloma. It's a 'tag' of a just nothing of any significance, and that's why his GP decided more tests were needed. A bone marrow biopsy revealed Allan had myeloma – a disease he had never even heard of. He started oral chemotherapy treatment – a combination of cyclophosphamide, idarubicin and doxorubicin, as well as drugs to help strengthen his bones – ostein, calcium, bisphosphonates and more. Allan can recite the details as he has kept a diary of all his treatment, procedures and medical appointments over the last four years. "It comes in handy at times," said Allan, who had to give up driving as his vision blurred during treatment due to the side-effects of one of the chemo drugs. "I got the idea of having a serious case log book while on the chemo," explained Allan, who suffered mood swings and his sight was affected. As his wife, Susan, doesn't drive, the Leukaemia Foundation helped out by giving Allan a lift from their home at Camden, south-west of Sydney, and taking him to Liverpool Hospital for treatment and back, once a month. His initial treatment protocol hadn't been as effective as hoped, so at the end of 2004 Allan started on thalidomide. Six months later, he had a relapse. In his head, the drug was doing nothing after a couple of months and he returned to his original protocol. Around this time, a friend who had had relapsed and had kept his head with through a haematology support group, died from myeloma. "That brought things home a bit as I thought, 'he had what I've got. It was a bit of a wake-up call,'" Allan said. In January 2005, he spent a week in hospital having kidney function tests and he had a kidney transplant in July that year so he could receive kidney dialysis, should that be necessary down the track. Since then, thankfully, his kidneys have stabilised, and Allan hasn't needed dialysis. Allan continued on maintenance treatment – cycles of oral chemo, and took thalidomide again for a couple of months. "I'm going pretty good at the moment," said Allan, who had another two friends to myeloma, in June and December 2007. "This is one of those diseases where there is no cure. It affects different people in different ways. Some can have smouldering myeloma for 15 years and for others, it can kill you in a year. "I've had it for four years and I'm doing okay, although it has been very tough at times both physically and emotionally. "You try doing what you can when you can."

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Allan and Susan Webb on their travels.

Towards the end of 2008 his energy levels had dropped, his tongue was feeling enlarged, and he was diagnosed with amyloidosis. In November he started treatment with a new drug, Velcade, combined with doxorubicin but his bones and feet became numb and increasingly painful. It was decided that Allan's only option was a stem cell transplant. His stem cells were harvested in February 2007 and his transplant was in April that year. "While the stem cell transplant did have the desired result, it was very rough going," said Allan who hasn't received any treatment since then. "I've had to take a break from work to help with my blood cell production, which Susan administered. The side effects for food and his neurotoxicity, which has improved, and every couple of months he has a blood test and sees the doctor. "Things are going pretty good at the moment," said Allan, who had another two friends to myeloma, in June and December 2007. "This is one of those diseases where there is no cure. It affects different people in different ways. Some can have smouldering myeloma for 15 years and for others, it can kill you in a year. "I've had it for four years and I'm doing okay, although it has been very tough at times both physically and emotionally. "You try doing what you can when you can."

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LEUKAEMIA FOUNDATION SUPPORT SERVICES
Ph: 1800 620 420

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# NEW DIRECTIONS IN LEUKAEMIA RESEARCH

**Leading scientists and clinicians got together earlier this year to discuss and debate current concepts in understanding the molecular basis of leukaemia.**

International and national speakers covered the spectrum of 'bench to clinic' leukaemia research at the Leukaemia Foundation's second biennial *New Directions in Leukaemia Research Conference*.

Discussing new paradigms and breakthroughs at the forefront of bone marrow cancer research and emerging therapies for treatment were integral to this forum, held on the Sunshine Coast from March 30 – April 2.

Presentations highlighted the complexity of the regulation of normal and malignant blood cell development and the great heterogeneity in each of the major subtypes of leukaemia.

The Leukaemia Foundation also supported five Student Travel Scholarships, worth \$1000 each, which were open to students enrolled in post-graduate studies (e.g. Honours, Masters or PhD).

The recipients, who had the opportunity to attend the conference and present their research in either



From left to right: Laura High, Jane Engler, Kathryn Roberts, Daniel Thomas and Lynette Chee

a poster or oral session, were Laura High, Children's Cancer Institute of Australia, University of Sydney; Jane Engler, Institute of Medical and Veterinary Science (IMVS), University of Adelaide; Kathryn Roberts, School of Biomedical Sciences, University of Newcastle; Daniel Thomas, IMVS, University of Adelaide; Lynette Chee, Peter MacCallum Cancer Centre, University of Melbourne.

## EDUCATIONAL DISEASE-SPECIFIC DVDS



**Accessing haematologists/oncologists to speak at education and support programmes for regional and rural patients and their families has been an ongoing challenge for the Leukaemia Foundation's support services teams.**

To resolve this issue the Foundation's Support Services Manager Victoria/Tasmania, Samantha Schembri, and her regional support services team developed a DVD pilot project.

This new educational tool, funded by the IOOF Foundation, is a valuable resource for health professionals to use to facilitate disease-specific seminars to provide patients, especially in rural and remote settings, with information from leading haematologists, to whom they otherwise would not have access.

The six disease-specific DVDs empower patients and their families by providing accurate, up-to-date information regarding their diagnosis, management and treatment of their disease, including new and emerging therapies. The 30-minute DVDs are:

- *Understanding Acute Leukaemias* - presented by haematologist, Dr Andrew Wei.
- *Understanding Chronic Leukaemias* - presented by haematologist, Dr Dennis Carney.
- *Understanding Non-Hodgkin Lymphoma* - presented by haematologist, Associate Professor John Seymour.
- *Understanding Myeloma* - presented by haematologist, Professor Miles Prince.
- *Understanding Myelodysplastic Syndromes* - presented by haematologist, Dr Melita Kenealy.

The disease-specific presentations are supported by the final DVD:

*Living with Leukaemia, Lymphoma, Myeloma & Related Disorders* - which explores the emotional journey experienced when these diseases are diagnosed, presented by psychologist, John Boyle.

The Leukaemia Foundation has supplied a complimentary set of the DVDs to haematology treating centres across Australia. Health professionals can purchase the set for \$25 from <http://shop.leukaemia.com>.

Samantha presented the educational DVDs as a new innovation at the *Cancer Nurses Society of Australia 11th Winter Congress* on the Gold Coast in June. With membership of more than 600 registered nurses dedicated to excellence in patient care, research, and education in cancer nursing, the Society's acceptance of the disease-specific DVDs extract at the Congress was a significant achievement for the Foundation.

# FOUNDATION FUNDS NEW RESEARCH IN 2008

The Leukaemia Foundation will invest \$2.8 million in research this year because it believes cures will be made sooner by supporting innovative research and fostering the careers of our talented researchers.

Through its National Research Program, the Foundation is committed to funding innovative research into the causes, diagnosis and treatment of leukaemias, lymphomas, myeloma and related blood disorders.

The program includes grants for research projects, scholarships and fellowships to encourage and support young researchers and foster cutting edge research to improve our understanding of leukaemias and related disorders in the short and long term.

The Foundation also funds research facilities such as the PricewaterhouseCoopers Leukaemia and Lymphoma Tissue Bank and the Leukaemia Foundation Research Laboratory at the Queensland Institute of Medical Research.

The Leukaemia Foundation is pleased to announce the following new research projects funded this year across Australia.

## NEW SOUTH WALES

**Dr Michelle Henderson** (Children's Cancer Institute Australia) \$93,500 *Improving treatment outcomes for infants with ALL*

**Ms Claire Wakefield** (Prince of Wales Hospital) \$70,460 *Familial psychological adjustment and needs on childhood cancer treatment completion*

**Prof. James Wiley** (University of Sydney) \$90,000 *Susceptibility to CLL in an extended family pedigree*

**Dr Margaret Blyth** (Westmead Millennium Institute) \$100,000 *The use of cytotoxic T cells for immunotherapy of viral infections post allogeneic stem cell transplantation*

**Dr Scott Brown** (Children's Cancer Institute of Australia) \$40,000 *Gene trap mutagenesis to identify cellular mutations that contribute to the development of leukaemia*

**Dr Sylvia Ling** (Centenary Institute of Cancer Medicine and Cell Biology) \$40,000 *Understanding and predicting the response of MM to proteasome inhibitors*

## QUEENSLAND

**Dr Mayer Ghandi** (Queensland Institute of Medical Research) \$100,000 *A novel mechanism of immunosuppression in B-cell lymphomas*

**Dr Raymond Banh** (Princess Alexandra Hospital) \$100,000 *Molecular prognostication in CLL*

**Ms Renee Jessica Robb** (QIMR) \$40,000 *Targeted modulation of antigen presenting cells in graft versus host disease*

**Mr Diwakar Pattabirar** (University of Queensland) \$40,000 *Targeting Myb in human leukaemia*

**Ms Therese Seldon** (Mater Medical Research Institute) \$40,000 *Development of dendritic cell biomarker antibodies and applications in leukaemia*



## SOUTH AUSTRALIA

**Prof. Timothy Hughes** (Institute of Medical & Veterinary Science) \$81,225 *Studies of imatinib-resistant CML patients to characterise the causes of resistance and to predict response to second-line therapy*

**Ms Hui Peng Lim** (Institute of Medical & Veterinary Science) \$10,000 *Identification of prognostic markers and therapeutic targets in AML*

**Ms Theresa Sadras** (Institute of Medical & Veterinary Science) \$10,000 *Dissecting the role of B-catenin in FLT3 ITD AML*

## VICTORIA

**Dr Lorraine Robb** (The Walter and Eliza Hall Institute of Medical Research) \$66,163 *The role of the homeobox gene *Mixl1* in leukaemia*

**Dr Ruth Mackinnon** (St Vincent's Hospital) \$100,000 *A new oncogene in AML and myelodysplastic syndromes*

**Dr Catherine Carmichael** (The Walter & Eliza Hall Institute of Medical Research) \$97,759 *Investigation of the physiological role of the transcription factor *Erg* in haematopoietic development and disease*

**Dr Simon He** (The Royal Melbourne Hospital) \$50,000 *New therapeutic approaches in acute leukaemia & transplant*

**Dr Jake Shortt** (Peter MacCallum Cancer Centre) \$40,000 *Therapeutic inhibition of the cell cycle checkpoints mediated by *CHK1**

**Ms Lina Hoppo** (University of Melbourne) \$40,000 *The impact of *BH3*-only genes on the response of murine lymphoma to anti-cancer therapy*

## WESTERN AUSTRALIA

**Mr Lawrence Liew** (Royal Perth Hospital & Curtin University of Technology) \$10,000 *Immune dysregulation in myelodysplasia*

## MOST COMMON LEUKAEMIA CAN RUN IN THE FAMILY

**Chronic lymphocytic leukaemia (CLL), the most commonly occurring leukaemia in developed countries, has a three to five-fold increase in incidence among closely related family members.**

As part of its \$2.8 million funding for blood cancer research in 2008, the Leukaemia Foundation has awarded Sydney University Professor of Haematology, James Wiley, a \$90,000 grant to begin a study of an extended family in which CLL runs through five generations.

In an attempt to discover the inherited genes that contribute to the development of CLL, Professor Wiley has traced 200 members of the family which has 11 confirmed leukaemia patients, and a further five have a precursor form of this leukaemia. It is the largest pedigree ever described for familial CLL.

Professor Wiley will collect blood samples from members of the family to analyse their DNA as part of a systematic search for the inherited genes contributing to the development of this leukaemia.

This family could help scientists uncover the genes that predispose people to the world's most common form of leukaemia.



*Professor James Wiley and Dr Stephen Fuller*

"Identifying the gene or genes which are responsible for members of this family developing CLL may lead to new approaches in the diagnosis and treatment of this leukaemia," said Professor Wiley.

The study is one of nine pioneering blood cancer studies by New South Wales researchers which the Leukaemia Foundation is funding in 2008.

Professor Wiley is collaborating on this project with Dr Richard Houlston from the Institute of Cancer Research in the United Kingdom and Dr Stephen Fuller from The University of Sydney.

The project has received previous funding from The University of Sydney Cancer Research Fund.

### APPLICATIONS OPEN FOR 2009 RESEARCH GRANTS, FELLOWSHIPS & SCHOLARSHIPS

Researchers investigating the causes, diagnosis, treatment and care of people living with blood cancer are invited to apply for the Leukaemia Foundation's 2009 round of funding through its National Research Program. Expressions of interest for grants-in-aid for research projects as well as Clinical and Postdoctoral

Fellowships are due by July 25. Applications for PhD and Honours Year scholarships close on September 26. Researchers must be based in Australia.

For more information, visit [www.leukaemia.org.au](http://www.leukaemia.org.au) or call Dr Susan O'Brien on 07 3866 4038.

## JAMES REYNE HAS TAKEN UP THE LEUKAEMIA CAUSE

**One of Australia's most successful musicians, James Reyne, accepted the Foundation's invitation to become an ambassador for the leukaemia cause because of his own personal loss due to cancer.**

James' father died from throat cancer in 1996, around the same time fellow Australian Crawl guitarist, Brad Robinson, lost his three-year battle with non-Hodgkin lymphoma. And right now one of his good friends is recovering from breast cancer.

"I've seen how cancer has affected my family and friends, how insidious a disease it is, and I'd like to help however I can," said James who has been an integral part of the music scene for 30 years.

In April, the singer songwriter took part in the Great Walk to Beijing fundraising walk where he spoke to oncologists and found out about the lack of funding for research. This has inspired James' determination to raise awareness and highlight the need to fund research.



"I thought it was time to put money where my mouth is," said James who will perform at a fundraising event he is helping to organise for the Foundation.

# NURSES WEEKEND RETREAT POPULAR ANNUAL EVENT

**Twelve haematological nursing staff from Perth's major treatment centres jumped at the chance to attend a nurse's retreat, held for the third consecutive year by the Leukaemia Foundation in Western Australia.**

The nurses from Sir Charles Gairdner, Royal Perth, Fremantle and Princess Margaret hospitals and four members of the Foundation's support services team spent two days at Wandoo Hills Retreat, at Toodyay, two hours east of Perth.

The retreat, developed to support the staff who provide care to patients who the Foundation also assists, achieved several outcomes for participants.

Facilitated by Dr Martin Philpot and Mr Ross Appleton from Notre Dame University, the key topics were managing stress, preventing burnout, developing strategies for self-care and being self-aware.

The nurses capitalised on their new skills by enjoying a massage by Martin Booth, a trainee from TAFE at the end of this popular annual weekend event.



*From left, Suzanne Momber (Princess Margaret Hospital), Marla Reid (Fremantle Hospital) and Ann-Marie Brennan (Support Services Co-ordinator)*

## NEW LARGER REGIONAL OFFICE OPENED AT NEWCASTLE

**The Leukaemia Foundation officially opened a new, larger re-fitted office at Mayfield in Newcastle in May to strengthen its regional presence and meet growing demands in the Hunter region.**

Community relationships and administration functions have been added to the office, which accommodates local permanent and volunteer staff and has an onsite education room for patient and family disease-specific education sessions.

In the last 12 months the Foundation assisted 115 new

patients and transported 440 patients to and from their appointments in the Hunter region and the need for bigger premises became crucial.

Leukaemia Foundation General Manager NSW/ACT, Stuart Allen, said the Foundation was committed to providing a high standard of service, expanding its reach in regional areas and ensuring the Foundation becomes an integral part of the local community. Special thanks to Ross Howard for volunteering Graph Building for the office re-fit project and Geoff Kirby, the project manager.

## SUPPORT TEAM EXPANDS AT ALBURY WODONGA

**The Albury Wodonga regional office has two new support services team members - Sallianne Brown and Carmel Duck. Appointed as Support Services Co-ordinators in the Victorian Hume region, they are based in the Albury and Riverina region of New South Wales.**

Sallianne supports patients treated through the Wodonga, Wangaratta and Shepparton cancer centres, and those who have further treatment in Melbourne. She has 15 years acute oncology experience, having worked as Clinical Nurse Consultant at Goulburn Valley Health Day Chemotherapy Unit in Shepparton.

Carmel has a strong background with 28 years in nursing, including six years of oncology nursing. Her role is to support patients treated through the Albury, Wagga and Griffith cancer centres, and those who have further treatment in Sydney.



*Sallianne Brown and Carmel Duck. Photo: courtesy of the Border Mail*

Sallianne and Carmel will work closely with the Foundation's metropolitan-based support services team to ensure those who need to go to Sydney or Melbourne for ongoing advice or treatment experience a seamless transition from the rural to metropolitan settings.

# AFTERMATH OF BONE MARROW TRANSPLANT — A RARE AND PAINFUL SEVERE SKIN CONDITION

**No-one could have foreseen the complications Serina Dosen would suffer several years after her successful bone marrow transplant (BMT) in late-2002.**

She went to her GP with what she thought was a cold in August that year. Blood tests revealed she had a low white blood cell count and Serina was suddenly and unexpectedly diagnosed with acute myeloid leukaemia.

Serina immediately began treatment at the Royal Perth Hospital but she had a severe reaction to the chemotherapy and spent eight days in intensive care. It was decided, that as she had two matching donors, a transplant was her best option.

Her brother, Antun, was her donor, and the transplant went well. But it took Serina six months to recover and return to part-time work. She loves writing and had always wanted to go to uni, so she also started a degree in English at Murdoch University, which she is still completing part-time.

In early-2005, Serina slowly started to develop a skin condition. It began with a patch on her chest, progressed over the next six months to cover her entire body, and she lost her hair again.

"The doctors had never seen this condition before and couldn't understand what was causing the reaction," said Serina.

She had multiple skin biopsies and flew to Melbourne to check if she had T-cell lymphoma, before finally being diagnosed with folliculitis mucinosis, a severe and rare form of graft versus host disease (GVHD).

Many different medications were prescribed at varying times and in various combinations and doses to try and treat the condition which caused a very painful burning sensation due to her body overproducing mucin, a natural substance that keeps the skin soft and supple.

When Serina returned to her consulting BMT specialist last year, it was discovered that most of the cells in her skin were male donor cells, which pointed toward GVHD.

From November 2007 through to March this year, she took part in a trial of a new drug, depsipeptide, which was only available at the Peter MacCallum Cancer Centre in Melbourne.

"It hasn't worked long term and I had a lot of terrible side-effects," said Serina. "But I was very grateful to have the opportunity to try it and the Leukaemia Foundation was very supportive, providing air tickets and accommodation."

She is now doing ok on a low dose combination of the immunosuppressive, cyclosporin, and steroids.

"I can tolerate the lower doses which seems to be working, but my hair isn't growing back," said Serina, 35.



*Serina Dosen*

"I had gorgeous hair and now I don't have any and wear a wig. Sometimes I get bit upset about this. I'd like to get my hair back."

In mid-May, Serina's BMT specialist discussed another possible treatment option with her for the first time.

"It's a type of stem cell that can be manufactured," Serina explained.

"It's administered by IVF drip, involves no chemo and has been successful in attacking the graft cells.

"Next time we catch up, I'll find out if I fit into the selection criteria. If it's an option, I'd love to try it, but it's a very expensive procedure.

"If it works and alleviates me being on medication it would be amazing," said Serina, who's main concern is to have the opportunity to try everything that's available.

"I am appreciative of everything the Leukaemia Foundation has done and grateful to the doctors at the Peter MacCallum Cancer Centre and the Royal Perth Hospital for everything I've been given.

"People have really gone out of their way to help me and I feel very well looked after."

# REVIVE MEETS NEEDS OF ADOLESCENTS AND YOUNG ADULTS

**In contrast to younger and older patients, improvements in the treatment outcomes of cancer in young adults have not increased over the last 20 years.**

Yet the rising number of adolescents and young adults diagnosed with cancer means the population of survivors also is increasing. These young survivors may have many years ahead of them to cope with the impact of their cancer experience and any long-term side-effects.

Diagnosis and treatment during young adulthood often results in a range of unique and ongoing psychosocial issues including problems with self esteem, issues of fertility and sexuality, and coping with the fear of relapse.

The Leukaemia Foundation has developed a new education and support program, called *Revive*, specifically for young people, aged 18 to 35 years, and their friends and families, because young adults affected by cancer are an unsupported population.

Their survivorship issues are yet to be fully addressed by the medical community and the Foundation hopes its comprehensive *Revive* program will address this gap in support services for patients and families living with leukaemias, lymphomas, myeloma and related blood disorders.

*Revive* aims to:

- establish a knowledge base about young adult cancer-related care
- provide a forum to support young cancer patients during and after their cancer experience
- empower survivors to confront life positively after facing death

## \$50,000 ALLOCATED TO LATEST SUPPORT SERVICES GRANT PROGRAM

**The Leukaemia Foundation works closely with health professionals to provide a continuum of care for patients and their families and funds innovative Australian research, fellowships and scholarships.**

In the 2007/2008 Support Services Grant Program, the Foundation allocated nearly \$50,000 across Australia in three different types of grants:

- **Haematology distance education grant for nurses** (\$1000 each): allows haematology nurses to undertake a certified or postgraduate course in a field directly related to haematological nursing.
- **Hospital resource grant** (\$2500 each): promotes a more comfortable and functional environment for patients, carers or family members who spend long periods of time in hospital wards or clinics.
- **Professional development grant for nurses and allied health professionals in rural and regional settings** (\$2000 each): allows regional and rural health professionals to spend time in their relevant tertiary referral institution to gain further knowledge and skills to enhance their rural/regional clinical practice in caring for people with blood cancers.



- raise general awareness about young adult cancer in order to provide support in the community (eg. job networking)
- work with other organisations with complementary interests, such as CanTeen and The Cancer Council Australia, to avoid duplication of services or resources to this age-specific group
- raise awareness about, and provide access to, clinical trials involving this age group.

The Leukaemia Foundation conducted a national research survey to increase the knowledge base and understanding of best practice regarding young people's needs. From this research, an information booklet, *Young Adults with a Blood Cancer*, was published in line with the Foundation's educational series.

The *Revive* program was launched on July 1 with an online educational and interactive website, [www.teamrevive.com](http://www.teamrevive.com), which is a portal for young people to access information and contacts, share stories and network.

2008 professional development grant recipient, Elaine Carey, who is an oncology nurse at the North Coast Cancer Institute, Port Macquarie, spent two and a half days on placement at the Peter MacCallum Cancer Centre and the Tattersall's Cancer Centre (Epworth Hospital) attending meetings and observing treatments.



Elaine Carey

"I wanted to enhance my knowledge of the practices and processes of other radiotherapy services and now have a better understanding of the disease processes involved in these malignancies," said Elaine. "Now I am better able to educate patients on toxicities and management which would not have been possible without the support of the Leukaemia Foundation."

Applications for the 2008/2009 grants close in February 2009. For more information: <http://www.leukaemia.org.au/web/professionals.php>.

# SURVIVING LEUKAEMIA SEES AMANDA SUPPORT THE CAUSE

**Amanda Magarey was an energetic 35-year old who ran her own thriving dog-walking and pet-care business and practiced the sports she loved – sailing and skiing ....until August 2006.**

Then, three weeks after returning from a skiing holiday with a painful rib injury, she was diagnosed with a very aggressive form of acute lymphoblastic leukaemia (ALL).

Amanda was spending some time with her parents when her father, Gus, a retired GP, realised something was seriously wrong as the pain in his daughter's chest worsened and spread to her legs and spine.

She had a blood test done and was admitted to Sydney's Royal North Shore Hospital the same day. The initial diagnosis, non-Hodgkin lymphoma, was changed as it turned out Amanda had a more aggressive form of leukaemia, ALL.

She began three months of chemotherapy and was told she would need a bone marrow transplant to prevent the disease from coming back. A bone marrow donor was found in Melbourne and Amanda was admitted to St. Vincent's Hospital for the transplant on December 15, after three days of total body irradiation.

"I spent an extremely quiet, but also extremely painful Christmas in isolation, but my bone marrow soon started to show signs of recovery and I was discharged in an amazingly short period of time," Amanda said.

Throughout her treatment, Amanda had the support of her family and friends, especially from the sailing and skiing fraternities, and the Leukaemia Foundation.

"The Foundation was always there for me. Bright and

## PATIENTS TAKE TO THE SKY

**Around 80 patients and family members who are supported by the Leukaemia Foundation in South Australia were treated to joy flights at a family fun day in March.**

Rugged up against the elements, they gathered at the Aldinga Aero Club, south of Adelaide, to enjoy scenic flights over the coast and McLaren Vale wine region.

This experience was possible due to the generosity of club members who donated their time and aircraft. The day also provided an opportunity for patients to meet others, share stories and offer support over a relaxed barbecue lunch. SA Support Services Manager, Steve Marshall, said blood cancer patients were often cautious about going to public events because of the possible risks of infection.

"The family fun day was a fantastic way for patients to get to know others living with blood cancers and many



*Amanda Magarey with her dad, Gus, and nephew, Thomas*

positive people came in to say 'hello' and they told me if I needed anything, to let them know. There were helpful books and leaflets, transport and accommodation, if required."

Amanda, now 37, is still on multiple medications and her energy is returning. Having sailed for 17 years, she is again enjoying weekly opportunities to go sailing with her friends.

To thank the Foundation for its support, she is raising money for much needed research, providing support for other leukaemia patients and is a spokesperson for their cause. Earlier this year Amanda raised \$44,000 when she held a beach barbecue at Middle Harbour Yacht Club in Sydney.



*Angela Aston with Sue, Renee and Geoff Schaffer*

patients said they had been looking forward to the outing for weeks," Steve said.

The Leukaemia Foundation thanks the Aldinga Aero Club and LJ Hooker Aldinga for their support.

# BLOOD CANCER SURVIVORS BECOME FIRST DARWIN VOLUNTEER DRIVERS

**Alan Peterson and Derek Chin are moving forward as blood cancer survivors by becoming Darwin's first Leukaemia Foundation volunteer drivers.**

Alan was diagnosed with non-Hodgkin lymphoma in March 2007. He said dealing with the cancer, which involved spending seven months in Adelaide away from his family, was an emotional roller coaster. While in Adelaide, Alan used the patient transport service two or three times a week. The volunteer drivers made him feel safe and he enjoyed his contact with them.

"It was good not to have to worry about booking taxis or bus routes. I just called the Foundation to book a car and could focus my energy on getting better," said Alan who was inspired to become a driver himself, to deliver the same service to others that played such an important role in his treatment.

Derek was diagnosed with acute myeloid leukaemia in November 2000 and like Alan, needed to relocate to another state for treatment. He was treated at the Royal Brisbane Hospital and stayed in one of the Foundation's

accommodation units in Brisbane for several months. In June 2001, he received an allogeneic transplant from his brother and now believes he's cured.

Derek also understands the importance of the transport service for patients.

"I know how tiring and exhausting it can be during treatment and many people couldn't do it without the transport help. I have always wanted to be a volunteer driver and believe that talking to others and being able to show them real empathy helps them a great deal," Derek said.



*Volunteer drivers, Alan Peterson and Derek Chin*

## BOOST FOR ADELAIDE PATIENT TRANSPORT SERVICE

**Hundreds of patients across Australia are driven to hospital appointments each week by volunteer drivers who operate the Leukaemia Foundation's free patient transport service.**

Last year, in South Australia alone, the Foundation's four cars clocked up 200,000 km.

A call for more volunteer drivers in the Royal Automobile Association of South Australia's magazine, *SA Motor*, resulted in hundreds of enquiries, the induction of 35 new drivers, and the introduction of half-day driving shifts.

The Foundation's General Manager SA/NT, Simon Matthias, said demand for the patient transport service was growing: "We wanted to extend our hours of

operation without increasing the burden for volunteers and were overwhelmed by the generosity of South Australians in coming forward. We even have a waiting list."

The service now operates in the greater Adelaide area between 8am and 6.30pm with the last pick up from hospitals extended beyond the previous cut-off time of 4pm.

In addition to ongoing support by GM Holden and Bridgestone, the Leukaemia Foundation in SA acknowledges the support of RAA in donating two new child seats and four booster seats, and City Holden which has washed the patient transport cars free-of-charge since late 2007.

## HOME LOANS THROUGH AUSTRALIAN MORTGAGE BROKERS PARTNERSHIP SUPPORTS FOUNDATION

The Leukaemia Foundation has signed an ongoing agreement with Australian Mortgage Brokers (AMB). AMB will provide the Foundation with a portion of the upfront commission and on-going income received from loans secured as a direct outcome of the partnership between the two organisations. AMB has operations in all states and its team of mortgage consultants are among the most experienced, professional and best trained in the mortgage industry. To take advantage of this partnership, contact AMB and mention the relationship during the home loan process. When your loan settles, AMB will donate 10 per cent of the upfront commission directly to the Foundation and each month that the loan continues,



**australian**  
mortgage brokers

AMB will donate 30 per cent of the ongoing commission paid to AMB by the lender. For example, a single loan of \$350,000 established under this partnership will generate approximately \$1025 for the Foundation over five years. Call Adam Hindmarch on 0400 400 515 or email [lfdonation@amortgage.com.au](mailto:lfdonation@amortgage.com.au).

## BEREAVEMENT SUPPORT GROUP A LIFELINE FOR MICHELE

**One of the first and ongoing attendees of the Leukaemia Foundation's first bereavement support group in Bunbury, Michele O'Sullivan, has found it an invaluable help in managing her grief.**

She regularly attends the monthly meeting of the group, started by the Leukaemia Foundation's Bunbury regional office early this year.

Michele's husband, Patrick, was diagnosed with acute myeloid leukaemia in October 2005, and following treatment for three months, was in remission until the disease reappeared in September 2007.

Around this time, the Foundation contacted the couple to offer support. Patrick was undergoing treatment at Royal Perth Hospital and to visit him, Michele travelled three hours each way between Perth and Australind.

Patrick fought a brave battle during his relapse but sadly he passed away in Perth last Christmas Eve, the day before his 65th birthday.

Michele turned to the Foundation to help her through this difficult time: "I felt that I really needed to meet and talk to other people going through the same experience as me."

The Foundation believed the bereavement support group would form an important link in the local community and it certainly has for Michele. Most of



*Michele O'Sullivan, front left, with the Bunbury bereavement support group*

her family do not live in Bunbury and she found the Foundation was on hand to support her after Patrick's death.

"It is very easy to feel isolated, both geographically and emotionally, when you experience this type of journey, but meeting different people of different ages in my local community who have suffered the same loss has really made a difference," said Michele.

"People may think that it's too much for them to go to a bereavement support group, but everyone is living with their own grief and by sharing stories on how they cope with their own situation helps. Sometimes those tears turn to laughter and I'm sure that's good for everyone."

## LIGHT THE NIGHT TO REMEMBER, CELEBRATE AND GIVE HOPE

**In September the Leukaemia Foundation will launch an Australian first to support its Vision to Cure and Mission to Care, called *Light the Night*.**

This year, *Light the Night* will be piloted in South Australia, Western Australia and Queensland with plans to make the event national in 2009.

*Light the Night* will bring families, friends and co-workers together to remember loved ones lost, celebrate blood cancer survivors and give hope for a brighter future.

During the evening, participants each receive a coloured balloon containing a glowing light, each with a special meaning. Gold balloons remember a loved one, white balloons celebrate being a blood cancer survivor and blue balloons give hope as a supporter. In a magical finale, participants walk together for approximately three kilometres, helping to 'light the night' with their balloons.

In the weeks leading up to *Light the Night* corporate supporters, neighbours and friends will form teams and gather donations to support the estimated 25 Australians who are diagnosed each day with leukaemia, lymphoma, myeloma or a related blood disorder.

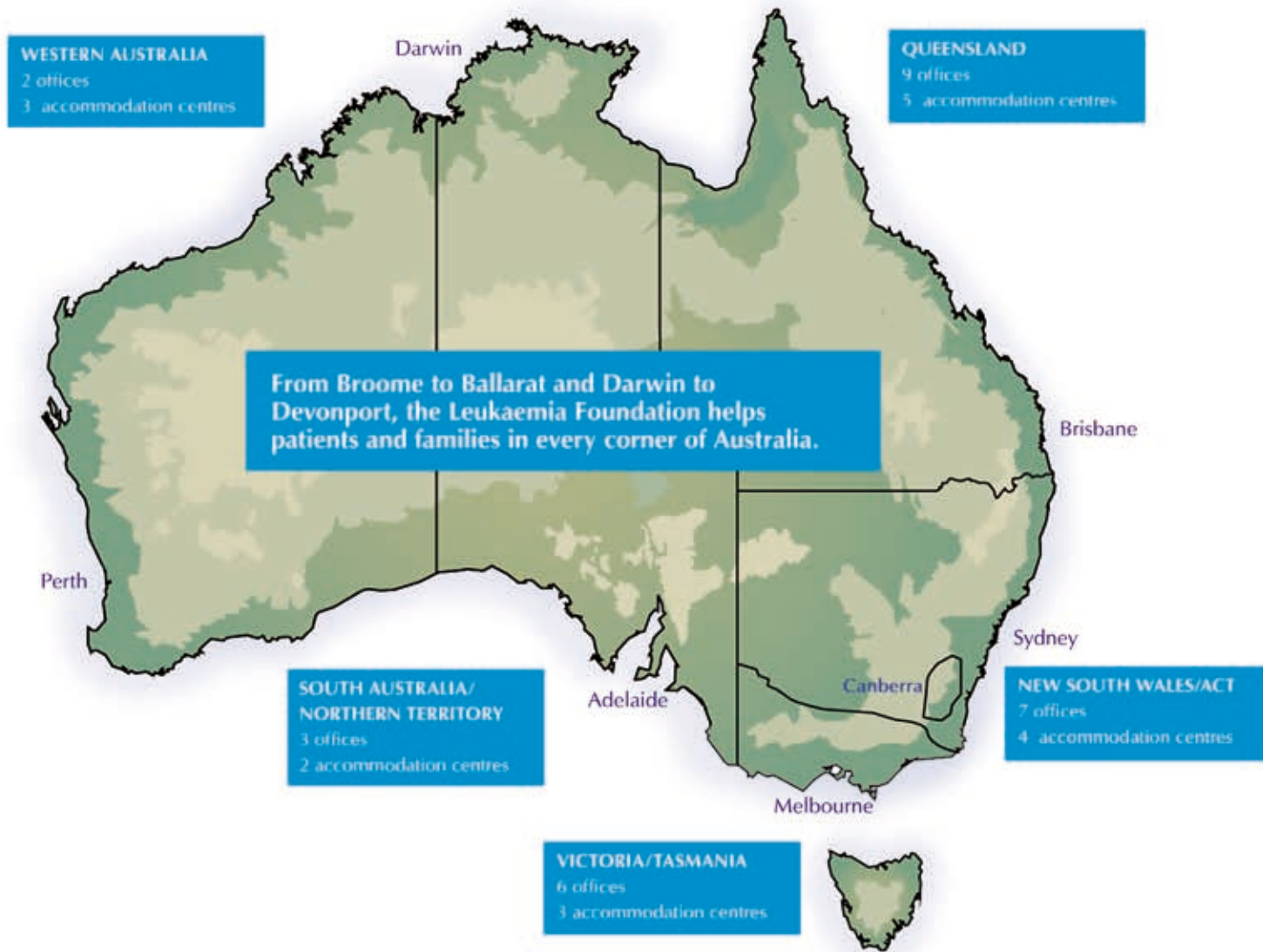
You can be one of the many hands that make 'light' work by joining *Light the Night* on 17 September in



South Australia or Western Australia and 18 September in Queensland. For more information or to register to participate, go to [www.lightthenight.org.au](http://www.lightthenight.org.au) or call 1800 500 088.

# 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](mailto:info@leukaemia.org.au)

Mail: GPO Box 9954 in your capital city

Website: [www.leukaemia.org.au](http://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 leukemias, lymphomas, myeloma and related blood disorders.