

## About acute lymphoblastic leukaemia

Acute lymphoblastic leukaemia (ALL), also known as acute lymphocytic leukaemia, is a rare disease. While it can occur at any age, ALL is the most common type of childhood cancer and accounts for 75% of child cancer cases. It is more common in males than in females.

Each year in Australia, around 304 people are diagnosed with ALL and 60% of all cases are aged 0 – 14 years at diagnosis.

Although the survival rates for childhood ALL have improved dramatically over the past 20-30 years, transplantation offers the best chance of cure for a proportion of patients.



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## NOTHING WILL STOP LANE'S DETERMINATION TO BEAT LEUKAEMIA

**The story of Lane Martino's ongoing battle with leukaemia is one of sheer determination and resilience.**

According to his mother, Deborah, Lane, 22, was "a dedicated and gifted sportsman". He was in an Australian Rules development squad and one night when she picked him up from training he was tired and pale.

It was February 2003, Lane was 16 and had just started his final year of high school when he was diagnosed with acute lymphoblastic leukaemia.

After being told of the diagnosis, Lane took a couple of minutes to gather his thoughts before asking: "What's the first thing we have to do? Let's get on with it."

He breezed through the three and a half years of treatment with hardly a day's sickness, surfing regularly and even going overseas with friends. During the eight-week holiday he was responsible for taking his oral chemotherapy and he spent a couple of weeks travelling by himself.

In 2006 Lane started studying business at Notre Dame University, transferring in the second semester to the University of Western Australia to do commerce.

But a couple of months after completing his treatment program, in September that year, Deborah noticed one of Lane's eyes was half closed and he looked a bit pale.

"I think you need to go to see the haematologist again," she told him.

"He had relapsed and it was apparent he would have to have a bone marrow transplant."

Unfortunately neither Lane's brother nor his sister was a match but he was lucky



Lane Martino has his sights set on returning to his studies

that a Victorian man was found to be an unrelated match and Lane had a stem cell transplant in March 2007.

Leading up to the transplant Lane had complications including a fungal infection in his lung and a couple of weeks after the transplant he had respiratory failure and several allergic reactions to the medications.

"He was transferred to the intensive care unit, put on life support and we were told not to expect him to survive past that day," Deborah said.

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# MEETING THE NEEDS OF CHILDREN POST-TREATMENT

**An Australian research group is undertaking an in-depth study to develop support strategies for families whose children are about to complete cancer treatment.**

The Leukaemia Foundation awarded a \$70,460 Grant-in-Aid to fund the initial year of the four-year study led by psychologist Dr Claire Wakefield, a NH&MRC Postdoctoral Training Fellow at the Centre for Children's Cancer and Blood Disorders at Sydney Children's Hospital and the University of New South Wales.

This is one of the first Australian studies of its kind and uniquely includes interviews not only with children who have undergone cancer treatment but also with their parents and their siblings.

The study was borne out of ongoing anecdotal reports from concerned social workers and medical and nursing staff at the Sydney Children's Hospital that families with children who had finished cancer treatment were not coping.

The Hospital's long-term follow up clinic was also reporting a high incidence of families five years' post-treatment who were still struggling.

When Dr Wakefield looked at the literature, she found very little research had been undertaken internationally to understand the needs of families post treatment and only limited support was provided in Australia.

"When a child finishes his or her cancer treatment, it's a positive time and an opportunity for families to celebrate," said Dr Wakefield.

"It's also a time of uncertainty and lingering worries – families just don't know what's going to happen when they return home – there are concerns about relapse and settling back into their old life and for the first time

no one is there to help them in a professional capacity.

"While children can come out of the experience with a really strong sense of self worth, they can also find it difficult to fit back into school and re-establish friendships, as well as deal with over-protective parents," she said.

"This study is designed to uncover the key issues affecting families and allow us to develop strategies to help them cope."

The outcomes from the study will be used by Dr Wakefield and her team to suggest a range of practical improvements to services, as well as clear guidelines to inform government policy.



*Dr Claire Wakefield*

## NOTHING WILL STOP LANE'S DETERMINATION TO BEAT LEUKAEMIA

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Lane spent 31 days on life support before being transferred back to the bone marrow transplant unit where he battled graft versus host disease (GVHD).

The unit held a big party for him when he finally left in December 2007, as their longest-staying patient.

"His battle is far from over but his resilience is contagious and we keep going because he keeps going," said Deborah.

Lane has continued to fight GVHD for the last 12 months and was the first patient in WA to receive mesenchymal stromal cells (MSC), harvested from his mother, brother, Joel, and sister, Bianca.

"He receives the MSC regularly and studies overseas have shown they repair damaged organs and help the body with the effects of GVHD," Deborah said.

In mid-October last year, Lane was diagnosed with Shapiro's Syndrome where his body has no control over its body temperature and he has some memory loss. This is being controlled by medication.

"Lane hopes to return to some study next year and his brother and sister both got engaged recently so we have two overseas weddings to look forward to," said Deborah.

"Having normality back in our lives is something that we are working towards. Our goals, however small, like going for a drive, make up part of our 'big picture'."

### WHAT ARE MESENCHYMAL STROMAL CELLS?

**Mesenchymal stromal cells (MSC) are a form of stem or 'mother' cell found in the bone marrow and blood. The cells can be difficult to distinguish and their full function is still being determined. Present in small numbers only, MSC have the ability to differentiate or 'turn into' a range of cell types, including cartilage, bone and muscle. This allows them to help repair injured tissues. MSC also appear to play a role in the immune response and have been shown to have a localised ability to suppress immune cells.**

# JIM SELIM DONATED \$1 MILLION FOR CLL RESEARCH

**The founder of Pan Pharmaceuticals, Jim Selim, donated \$1 million to the Leukaemia Foundation in the first of his promised assistance to a range of charities and causes.**

Announcing the donation at Royal North Shore Hospital, the Foundation said it would help support continued research into chronic lymphocytic leukaemia (CLL), which Mr Selim contracted more than 20 years ago.

CLL, the most common form of leukaemia, is a slowly progressing condition that affects the blood and bone marrow.

"I have and continue to receive excellent treatment for my condition and I am committed to assisting the Foundation in any way I can to find a cure," said Mr Selim who last year was awarded \$50 million in damages from the Commonwealth Government and four senior officers of the Therapeutic Goods Administration (TGA) for their part in forcing the closure of Pan in 2003.

The Commonwealth consented to judgment on charges of negligence and misfeasance of public office. The TGA was found to have acted maliciously and outside its statutory mandate.

Following his court victory Mr Selim pledged to donate much of the damages awarded to charities and other causes he supports.

"There are a number of causes with which I am involved and I intend to continue supporting them," Mr Selim said.

"Because of my particularly close relationship with the Foundation and its work, I would like it to be the first recipient of a donation arising from the recent court victory."

The donation to the Leukaemia Foundation coincides with the visit of Australian-born world authority on CLL, Dr Michael Keating, now Professor of Medicine in



*Jim Selim, centre, presenting his donation with, from left, Stuart Allen, Dr Michael Keating, Dr Stephen Mulligan and Warren Lippiatt*

Hematology at the University of Texas' M.D. Anderson Cancer Centre.

Dr Keating has been integrally involved in Mr Selim's treatment regimen.

Leukaemia Foundation CEO, Peter Cox, said the Foundation was committed to funding innovative research into developing new treatments and cures for blood cancers.

"We sincerely thank Mr Selim and his family for this kind donation. A gift such as this is a vital step forward and helps us fund CLL research through our National Research Program and through our partnership with the CLL Australian Research Consortium," said Mr Cox.

This year the Foundation will invest \$3.1 million nationally to support research, via Australia's best scientists and research institutes, into the causes, diagnosis and better treatments for leukaemias, lymphomas, myeloma and related blood disorders. (see pages 8 and 9)

## FAMILIAL HAEMATOLOGICAL STUDY INTO CLL

**The Baker family\* from New South Wales is the largest known family with multiple members affected by chronic lymphocytic leukaemia (CLL), as reported in Spring 2008 issue of *The Carer*.**

This family became the subject of a familial study published in May 2008 in the *British Journal of Haematology*.

Professor James Wiley, Professor of Haematology at the University of Sydney, is currently treating sisters, Julienne Baker and Sue Andruskin. In 2008 he received funding of \$90,000 from the Leukaemia Foundation's National Research Program to investigate the familial links further: *CLL in an extended family pedigree*.

In investigating the inheritance of CLL in the Baker family, Professor Wiley hopes to identify which regions of DNA are linked to the disease and to identify subclinical expressions of the disease which may represent a precursor to developing CLL.

His team will study DNA from up to 200 potentially affected family members to establish a link between having CLL and a specific part of the three billion base pairs that make up human genetic material. Currently there is only limited data on the susceptibility genes implicated in familial CLL, despite extensive study of the mutations that result in development and progression of CLL.

Professor Wiley's research may lead to new approaches to the diagnosis and treatment of CLL.

This project is an ongoing collaboration with Dr Richard Houlston, Institute of Cancer Research, at Royal Marsden Hospital, Surrey, UK.

*\* Sisters, Julienne Baker and Sue Andruskin, both have CLL and their father, grandfather and great grandfather all died of leukaemia. One of their father's brothers has CLL and his two sons have precursors to the disease. Another of their father's brothers who died of skin cancer also had CLL and his son has CLL.*

# RESEARCHERS REPORT ON LYMPHOMA CAUSES

**Lymphoma researchers from North America, Europe and Australia recently met in Sydney to share their latest findings at the seventh annual meeting of InterLymph.**

The Leukaemia Foundation-sponsored event provided an invaluable opportunity for the world's leading lymphoma researchers to gather together, according to the Foundation's General Manager - research advocacy and patient care, Dr Anna Williamson.

"The incidence of lymphoma\* has risen dramatically in developed countries during the past 50 years and it's now the fifth most common cancer in Australia, so an international effort to understand the causes is essential if we are to develop better treatments and cures," said Dr Williamson.

"At the symposium, research results from 40 studies were presented, with severe infection and diseases of the immune system appearing to be the most important risk factors for patients developing lymphoma."

Lymphomas, particularly, non-Hodgkin lymphoma (NHL), are known to be caused by inherited immune disorders, immunosuppressive drugs, viruses such as Epstein-Barr virus, many chemicals (such as pesticides, organic solvents, persistent pollutants, hair dyes and chemotherapy), as well as lifestyle factors such as diet.

InterLymph researchers reported that specific gene variations could make people more susceptible to these

risk factors, while environmental factors could explain incidence variations between different countries.

Concentrating on the risk of hair dyes, Dr Yawei Zhang from Yale School of Public Health and his research colleagues analysed the personal hair dye use of more than 4500 NHL patients. The team found that women who began colouring their hair before 1980 had a greater risk of developing NHL.

After 1980, many cancer causing hair dye chemicals were changed, however, Dr Zhang found that women who started dying their hair after 1980 also had an increased risk of developing follicular lymphoma. Frequency and duration of use as well as permanent, dark colour dyes could place women at greater risk.

An Australian research team reported that people with asthma or hay fever are up to 25% less likely to develop B-cell lymphoma, the most common type of NHL. It was also reported that recreational sun exposure (which stimulates vitamin D production) may reduce NHL risk.

Former Leukaemia Foundation research grant recipients, Associate Professor Andrew Grulich and Dr Claire Vajdic from the University of New South Wales played a key role in organising the InterLymph symposium.

For more information visit [www.leukaemia.org.au](http://www.leukaemia.org.au)

*\* The incidence of lymphoma worldwide appears to have been levelling out since 2000.*

## INTERNATIONAL LYMPHOMA COALITION TO BECOME AN INCORPORATED NOT-FOR-PROFIT

**At the annual general meeting of the international Lymphoma Coalition, held in San Francisco last December, members voted unanimously to incorporate the organisation.**

Its status will be changed this year to become an international charity, registered in Belgium.

This will give the organisation more credibility and will help with fundraising, according to the Leukaemia Foundation's General Manager - research advocacy and patient care, Dr Anna Williamson.

At the meeting, held in conjunction with the American Society of Hematology meeting, Dr Williamson was voted onto the Board of Directors.

The Lymphoma Coalition was formed in 2001 and now has members from 40 countries. In 2008, Venezuela, Slovenia, Denmark, Uruguay and Mexico were the latest countries to join the organisation.



*Dr Anna Williamson at the International Lymphoma Coalition annual meeting*

# FITNESS DISGUISED THE SYMPTOMS THEN ASSISTED JONATHON'S RECOVERY FROM RARE LYMPHOMA

**Jonathon Degner believes being extremely fit disguised the symptoms of lymphoma, which doctors believe he potentially had for years before his diagnosis.**

He also feels that his level of fitness helped him through his treatment and that exercise is of benefit to all bone cancer patients.

An avid cyclist, Jonathon, 35, of Mt Barker in the Adelaide Hills, used to ride with a bunch at weekends and was always among the first cyclists to reach the summit. He also rode by himself during the week, covering several hundred kilometres each week.

In December 2005 Jonathon started to notice he couldn't keep up once the bunch left flat ground and hit the Adelaide Hills. In March of 2006, he was struggling to catch up, and by July he was 20 minutes behind everyone.

"I was probably anaemic but I could process oxygen very well because my heart and lungs were strong," Jonathon said.

"Embarrassingly, I was in an advanced stage four," said Jonathon of the "very very rare" form of mantle cell lymphoma he was diagnosed with in August 2006. His spleen was enormous and filled his entire abdominal cavity.

But the production manager of a company going through a Therapeutic Goods Administration audit was so focused on his job at the time that he had ignored everything else.

Jonathon finally went to his GP at the behest of his wife, who knew something wasn't right because he complained about his lack of fitness, what his stomach looked like, and his pallor was pasty.

"The doctor had a good idea from talking to me and feeling my stomach and he was alarmed at the enlarged lymph nodes all over my body," he said.

"My white blood count was through the roof and I had abnormal lymphocytes.

"It took a while to work out what they were and in the end they treated it like mantle cell lymphoma which was considered incurable.

"My best option was a stem cell transplant because I needed a new immune system."

In the lead-up to the transplant, Jonathon had eight cycles of combination chemotherapy, called CHOP\*, plus MabThera® over the next 10 months.

While he was sick for a day or two after each round of chemo, he continued to work full-time and to cycle, completing the 140 km Challenge Tour in January 2007.

During his stem cell transplant, in May 2007, Jonathon got on the treadmill every day during the six weeks he was in isolation.

He spent a year off work after the transplant, returning in September 2008.



*Jonathon Degner didn't stop cycling during his lymphoma treatment*

"My resistance and immune system was too compromised to go to work, or to a shopping centre," explained Jonathon, but he continued to walk and cycle.

Treatment has left him with a form of neuropathy (nerve damage) that has affected his feet, knees and wrists.

"It can take two kilometres of running for the pain to go away but I can push through that and go on for another five to seven kilometres," he said.

"I'm in quite good shape. I'd like to be faster because I'm a competitive person but I'm happy with my recovery.

"I was determined to keep moving through my treatment. Even when my haemoglobin was low, I could walk four kilometres."

In October 2008 Jonathon competed in eight different events at the Transplant Games in Perth in cycling, track and field and volleyball. He brought home three gold and two silver medals but what was more important to him were the people he met and the inspiring stories they shared.

"I made a lot of friends there," he said.

**Jonathon was "quite self-sufficient" and didn't require a lot of the services the Leukaemia Foundation offers. However, one of the first faces he saw when he was in hospital for his first chemo was support services manager, Steve Marshall, who has continued to keep in touch. Jonathon described the information pack that Steve provided as "invaluable".**

\* CHOP is a combination of cyclophosphamide, doxorubicin, vincristine and prednisone.

# NEW NATIONAL LYMPHOMA CO-ORDINATOR ROLE

## Many lymphoma patients are unaware that the Leukaemia Foundation's services are available and tailored specifically to them.

The Foundation's education, support, practical assistance and research funding covers all the blood cancers and are for people not only with leukaemia, but also lymphoma, myeloma and the related blood disorders.

Approximately 5000 people will be diagnosed with lymphoma this year and the Foundation is working hard to ensure its services are known and available to this patient group.

To help facilitate this, the Foundation has created a new position - National Lymphoma Co-ordinator – and Tania Cushion, a senior member of the Support Services team in Melbourne, takes up this role this month.

Tania is an experienced haematology nurse with a great passion for working with people affected by lymphoma. She will continue to be based in Melbourne and education, support and collaborating with related health organisations are part of her initial focus.

This year more than 50 education and support programs will be provided to lymphoma patients nationally by the Foundation's highly trained support services team.

Multiple health professional education forums will be conducted as part of Leukaemia Foundation's role in commemorating World Lymphoma Awareness Day (15 September 2009).

To support lymphoma patients who live in regional and remote parts of Australia, a lymphoma telephone discussion forum will be established in 2009. Facilitated by a trained lymphoma nurse, this valuable service will enable lymphoma patients to offer advice and support for each other within a safe environment.

The Foundation is also committed to working collaboratively with the health industry and related organisations to provide the best care and support for patients with lymphoma and their loved ones.

- In a partnership deal with Cancer Australia, the Foundation will increase its funding to lymphoma research to improve patient outcomes;
- The Calvert Jones Foundation has partnered with the Leukaemia Foundation to produce a DVD that will outline treatment options for people with lymphoma and;
- The Foundation has collaborated with the Late Effects Clinic at the Peter MacCallum Cancer Centre to fund a haematology late effects nurse co-ordinator for three years. This clinic supports survivors of lymphoma and other blood cancers who find they are having side-effects from their treatment years after being 'cured'.

For more information on the Leukaemia Foundation's 2009 national lymphoma program, please contact Tania Cushion by email on [tcushion@leukaemia.org.au](mailto:tcushion@leukaemia.org.au) or call your local support services co-ordinator on 1800 620 420.



*Tania Cushion and the 'tree of hope' covered in messages of support to patients with lymphoma*

## JUNE SAYS THANKS TO THE FOUNDATION WITH A BEQUEST

### June Judd had just bought a house and had started a new life in the Yarra Valley when she was diagnosed with non-Hodgkin lymphoma.

While in hospital for chemotherapy June was referred to the Leukaemia Foundation by her haematology nurse.

Support services staff provided June with information about the free services the Foundation provides. This made June feel as though somebody was by her side and was interested in her journey with blood cancer.

While June only used the Foundation's patient transport service once during her treatment, she was comforted by the fact that other services such as accommodation and emotional assistance were available.

"It really gave me a peace of mind knowing that these wonderful and necessary services were provided by the Leukaemia Foundation for people with blood cancer," said June.

To say thank you for being there for her June has left a bequest for the Leukaemia Foundation in her will.

"I felt as though I had somewhere to go if I needed to and that was a comforting feeling during treatment, when I didn't want to rely on my children all the time," June said.

"I'm very grateful and leaving a bequest in my will is my way of saying thank you."



*June Judd has made a bequest to the Foundation*

If you are considering making a bequest in your will to the Leukaemia Foundation, please call the General Manager - donor relations, planned giving and bequests, Alana Kenny, on 07 3866 4067 or 0408 981 092 for a confidential discussion.

# TO SECURE HIS FUTURE JAMES NEEDS A BONE MARROW MATCH

**It took James Thuo three visits to a GP and a Sunday night trip to emergency before a blood test showed he had acute myeloid leukaemia (AML).**

His symptoms were feeling tired, nosebleeds and headaches and because he'd visited his home country, Kenya, earlier in the year it was suggested that he may have had malaria or AIDS.

After his diagnosis with AML in August 2006, James began a regimen of three sets of chemotherapy, finishing this treatment just before the birth of his daughter, Ella, on October 30 that year.

Over the next 12 months visits to his haematologist gradually reduced from every two weeks, to every month, then every three months, but in November 2007 James, 32, of Perth relapsed.

He began another program of treatment leading up to a bone marrow transplant in May 2008, using his own bone marrow harvested while he was in remission.

"I'm going alright and can't complain," said James who returned to work as a storeman last October, doing light duties for six hours a day, four days a week.

James has a long list of people he would like to thank: "God, my creator, my wife, Betty, and Ella my daughter, my wife's and my family, friends who have done the test, my employer, Metcash, my workmates and the union.

"I want to thank the Leukaemia Foundation too for helping me with transport to hospital, helping out with some bills sometimes and sending me information. They made a difference."

Tests last December showed James is in remission, but to



James Thuo with his wife, Betty and daughter, Ella

secure a healthy future, James really needs to find a bone marrow match in case he needs to have another bone marrow transplant.

Despite having two sisters and two brothers, James does not have a bone marrow match within his family, including his mother, father, aunty and uncle.

"I'm reaching out to the African community as I am wishing to get a match in the future," said James.

"If I can find a complete match that would be great."

## PARTNERSHIP WITH CANCER AUSTRALIA TO BENEFIT LYMPHOMA PATIENTS

**The Priority-driven Collaborative Cancer Research Scheme (PdCCRS) is an Australian government research-funding program to help reduce the impact of cancer in the community and improve outcomes for people affected by cancer.**

To support PdCCRS, the Leukaemia Foundation and Cancer Australia will become formal research partners this year, with a focus on lymphoma.

The Foundation has identified lymphoma as a significantly under-funded disease in proportion to its incidence in the Australian community. Cancer Australia agrees and will list lymphoma as a key research priority for the PdCCRS in 2009 and beyond.

This is an excellent outcome for the Foundation and the 5000 Australians diagnosed with lymphoma each year.

In Australia, lymphomas are the most common form of haematological or blood cancer, they are the fifth most common form of cancer and the sixth most common cause of cancer death. Their incidence has more than

doubled over the past 20 years for no known reason.

The partnership between Cancer Australia and the Leukaemia Foundation will ensure at least one project to the value of \$200,000 per year for three years will be funded for collaborative, outcomes-based research into the agreed research priority - *Innovative approaches to improve outcomes in human lymphoma.*

The call for research applications is now open and closes on March 17. After selection of the best projects, funding will begin in late-2009.

The Foundation's National Manager for Vision, Dr Susan O'Brien, said the new partnership was a fantastic opportunity for the Leukaemia Foundation and Cancer Australia.

"This is a significant research initiative which will enable collaboration between Australia's leading lymphoma experts and we believe it will make a major contribution to improving outcomes for lymphoma patients."

# FOUNDATION INVESTS MILLIONS IN BLOOD CANCER RESEARCH IN 2009

**The Leukaemia Foundation is awarding \$3.1 million in grants this year to innovative Australian researchers undertaking studies into better treatments and cures for blood cancers such as leukaemia, lymphoma and myeloma.**

The success of fundraising programs in 2008 has enabled the Foundation to increase its research funding by 10%.

Leukaemia Foundation of Australia Chief Executive Officer, Peter Cox, said the Foundation was the only national not-for-profit organisation in Australia dedicated to funding research into blood cancers.

"We received 85 expressions of interest from Australian research groups to fund new research projects as well as applications for grants or fellowships and scholarships, which indicates the high level of interest in the Foundation's program," said Mr Cox.

"Blood cancer research is essential – only one generation

ago the majority of children with leukaemia died but today, with advancements in treatments, most survive. However, some blood cancers still have the worst survival rates of any cancer and some of our best treatments are extremely toxic, so it is essential we develop better treatments."

The Foundation extended funds to 20 existing research projects – including nine PhDs and a clinical trial run by the Australasian Leukaemia and Lymphoma Group – and 21 new research projects (nine Grants-in-Aid [see table below], three Fellowships, eight PhD scholarships and one Honours scholarship).



*2009 Leukaemia Foundation Grant-in-Aid recipient, Associate Professor Lin Fritschi*

In summary: New Grants-in-Aid for 2009

Chief Investigator(s)	Research project
Associate Professor Lin Fritschi – Western Australian Institute for Medical Research	The risk of developing a second cancer after leukaemia or lymphoma
Dr Louise Purton and Dr Maria Askmyr – St Vincent's Institute, Melbourne	Understanding how blood cell diseases form
Dr Andrew Wei – Alfred Hospital, Melbourne	Molecular targeting of the bone marrow microenvironment in acute leukaemia
Dr Matthew McCormack and Dr David Curtis – Royal Melbourne Hospital	Determining the causes of T-cell acute lymphoblastic leukaemia
Associate Professor David Ashley, Dr Nicholas Wong, Dr Richard Saffery and Dr Jeff Craig – Royal Children's Hospital, Melbourne	Investigating the factors that cause and determine outcome of childhood leukaemia
Associate Professor Ricky Johnstone and Professor Mark Smyth – Peter MacCallum Research Institute, Melbourne	Developing new treatments for blood cancer
Professor Geoff Hill – Queensland Institute of Medical Research	Development of therapy for chronic graft versus host disease (GVHD) after bone marrow transplantation
Associate Professor Alison Rice and Dr David Munster – Mater Medical Research Institute, Brisbane	Method to prevent GVHD after transplantation
Professor Tom Gonda – UQ Diamantina Institute	Development of drugs to block the MYB 'cancer gene' in human leukaemia

*If you are interested in supporting a research project or would like to receive more information about funding options please contact Alana Kenny, General Manager - donor relations, planned giving and bequests on 07 3866 4067, 0408 981 092 or [akenny@leukaemia.org.au](mailto:akenny@leukaemia.org.au). Trusts and Foundations interested in Foundation funded research should contact Cathy Bryson, General Manager - trusts and foundations on 03 9949 5815, 0434 366 692 or [cbryson@leukaemia.org.au](mailto:cbryson@leukaemia.org.au).*

## YOUNG PHD SCHOLAR PRESENTED HER RESEARCH ON WORLD HAEMATOLOGY STAGE

**Jane Engler, a Leukaemia Foundation PhD scholarship recipient, was probably the youngest researcher to present an oral session at the world's largest haematology conference late last year.**

Prior to the American Society of Hematology (ASH) annual meeting, Jane, 24, submitted an abstract on one of her research projects for peer-review. When it was accepted for presentation at the four-day meeting in San Francisco last December, she was overwhelmed.

"It was absolutely exciting and gratification for all the years of work I have put in," said Jane who is part of an internationally-renowned Australian chronic myeloid leukaemia (CML) group.

Jane's PhD supervisors, Timothy Hughes and Deborah White, along with Susan Bamford, were also among around 40 Australians who presented at the 50th ASH Annual Meeting.

In 2006 Jane received a one-year Honours Scholarship from the Foundation for her research at the Institute of Medical and Veterinary Science in Adelaide. When she began her PhD in 2007 she received a three-year scholarship from the Foundation.

She is investigating the expression and function of the OCT-1 protein within the more primitive CML cell population to identify possible reasons why these cells are resistant to two drugs used to treat CML – imatinib

# IMMUNOTHERAPY – THE NEXT FRONTIER IN BLOOD CANCER TREATMENT

**Blood cancer researchers in Australia and overseas are exploring new treatments, known as immunotherapy, which harness the body's immune system to systematically wipe out cancer cells.**

Currently, antibody immunotherapy treatments are being used clinically, while last year U.S. clinicians at the Fred Hutchinson Cancer Research Center announced they had used another form of immunotherapy to cure a skin cancer patient.

The researchers had isolated some of the patient's T-cells, a type of white blood cell, and then 'trained' these cells in the laboratory to recognise cancer cells. The T-cells were re-infused back into the patient in large numbers, where they killed all the cancer cells.

Although clinicians have had some success with this technique, its use is likely to remain limited, according to 2009 Leukaemia Foundation research grant recipient and Mater Medical Research Institute (MMRI) Senior Research Fellow, Associate Professor Alison Rice.

"Expanding cells out of body is really interesting but time consuming," Associate Professor Rice said.

"It can take four weeks to grow the immune cells, which is just too long for some blood cancer patients, and there are a whole of lot contamination issues associated with the process.

"I believe the next 'holy grail' for many immunotherapy researchers will be developing vaccines which trigger the immune system when cells become cancerous."

Associate Professor Rice's research is directed towards improving survival rates from stem cell transplants by developing immunotherapy treatments.

With funding from the Leukaemia Foundation, Associate Professor Rice's PhD student, Andy Hsu, made significant progress towards developing a vaccine to prevent patients relapsing with acute lymphocytic leukaemia (ALL) following a stem cell transplant.

The vaccine, which was made from the specialised white blood cells known as dendritic cells, successfully stimulated the immune system to attack leukaemia cells in pre-clinical trials.

"Andy's work was very exciting – this type of

immunotherapy could help dramatically improve survival rates for patients with ALL because unfortunately nearly half relapse after a transplant," said Associate Professor Rice.

"We're now seeking funding to continue this research project and hopefully develop a vaccine for clinical use."

*Leukaemia Foundation research grant recipient, Associate Professor Alison Rice*



## WHAT IS IMMUNOTHERAPY?

*By Dr Constantine Tam*

**Blood cancers are being increasingly treated with immunotherapy (also known as immune therapy). This relatively new form of treatment uses the body's own immune system to attack cancer and, importantly, gives doctors a new way to treat chemotherapy resistant cancers. Also, because the treatment is targeted and affecting cancer cells only, the side-effects from chemotherapy are greatly reduced.**

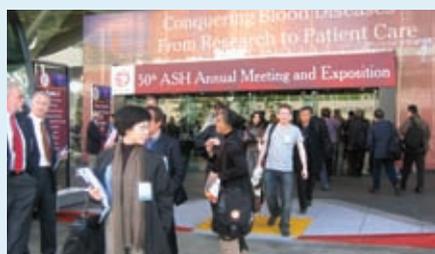
**Stem cell transplants, where an entirely new immune system is imported from a donor into the patient, are an extreme form of immune therapy used to treat blood cancers. However, in the past decade a new class of antibody treatments has emerged, including campath and rituximab. (Antibodies are produced naturally by the immune system.) Rituximab in particular has substantially increased the cure rate of diffuse large cell lymphoma and extended the lifespan of patients with chronic lymphocytic leukaemia, follicular lymphoma and mantle cell lymphoma.**

(Glivec®) and second generation tyrosine kinase inhibitor, nilotinib (Tasigna®).

Jane said being a part of the ASH meeting, along with 23,000 clinicians, scientists and others from around the world, was "huge".

"It was a wonderful meeting. It's great to hear what else is going on, to discuss the different procedures other labs are using, and meet some of the bigger names in the area."

Jane was able to attend the four-day meeting as part of her funding from the Foundation.



*Left: The ASH annual meeting in San Francisco*

*Above: Jane Engler, one of the youngest researchers to present at the ASH annual meeting in 2008*

# AUSTRALIAN SCIENTIST UNCOVERING ROLE OF BLOOD CANCER GENE

**A Melbourne-based scientist is at the forefront of international research into a gene thought to play a key role in blood cell formation and potentially blood cancers.**

In 2008, the Leukaemia Foundation awarded a three-year Postdoctoral Fellowship to Dr Catherine Carmichael from the Walter and Eliza Hall Institute (WEHI) to study the role of the gene, Erg.

Erg belongs to a gene family that is known to be a key regulator of haematopoiesis – the formation of blood cells.

Every day the stem cells in our bone marrow produce billions of blood cells. However, if the genes involved in this process are damaged in any way, diseases such as leukaemia may develop.

While Erg has been indirectly implicated in haematopoiesis, definitive proof has remained elusive. However, a new animal model recently developed by WEHI researchers has made it possible to study the role of Erg, according to Dr Carmichael.

“Over the last few years there has been a lot of interest in Erg worldwide, but WEHI is the only institute that we know of with an animal model for this gene,” Dr Carmichael said.

“This places us in a fantastic position to understand the

normal function of Erg, and how perturbation of this normal function can lead to leukaemia development.”

To date, Dr Carmichael has analysed data derived from this model to identify genes that Erg may be regulating during normal haematopoiesis.

Several of the genes identified have no currently known role in haematopoiesis and will require in-depth research to discover their function as well as their interaction with Erg.

“This project involves some intensive research but at the end of it I hope to have identified some true gene targets as well as gained some insight into what Erg is doing in leukaemia and blood cell formation,” said Dr Carmichael.

“I’ve been interested in the Erg gene for several years and if I could help shed some light on what this gene does during normal blood cell development, as well as generate some information that could be used to develop potential new treatments for people with blood cancers, that would make me really happy.”



*Leukaemia Foundation post-doctoral scholarship recipient, Dr Catherine Carmichael*

# FOUNDATION HELPS FUND VITAL NEW TISSUE BANK ROBOT

**The PwC Foundation Leukaemia and Lymphoma Tissue Bank is a national resource established by the Australasian Leukaemia and Lymphoma Group (ALLG) in conjunction with the Leukaemia Foundation in 2002.**

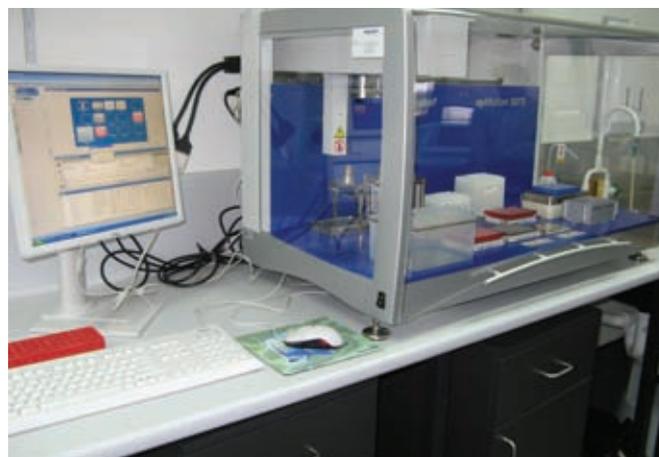
The ALLG conducts national multi-centre clinical trials in blood cancers and has 70 member institutions throughout Australia and the Tissue Bank collects, processes and stores tissue samples from blood cancer patients.

It currently stores more than 21,000 samples from more than 900 patients for use by researchers in scientifically approved projects around the country.

The Tissue Bank has outgrown the capacity to manually process samples. To overcome increasing delays in the supply of tissue due to the rapid increase in requests for tissue by researchers, a state-of-the-art robot has been purchased.

The robotic extraction equipment, called the Eppendorf EpMotion 5075, automates the extraction of products such as DNA and RNA from tissue samples and other time-consuming tasks, cutting labour time for tissue processing by 75%.

It also improves efficiency, improves the consistency of end product quality and adds flexibility that allows tailored sample processing to meet the specific needs of each research project with high quality sample products generated rapidly and supplied to researchers without delay.



*The Eppendorf EpMotion 5075*

The ‘EpMotion’ equipment will assist a large range of research collaborators utilising human tissue from the Tissue Bank in their research into the causes and diagnosis of blood cancers and the development of new treatments.

This instrument was purchased with an enabling grant from the National Health and Medical Research Council, funding from sponsors, PricewaterhouseCoopers and the Leukaemia Foundation, and a top-up grant from the Ramaciotti Foundation.

The Leukaemia Foundation thanks the Princess Alexandra Hospital and Queensland Health – Pathology Queensland for their continued support and for housing the Tissue Bank and Eppendorf EpMotion 5075.

# EVERYTHING IS GOING OKAY FOR CML PATIENT

**In the 12 months before Samantha Freeman's diagnosis with leukaemia in January 2007, a lot had changed in her life.**

She'd gone from a part-time home-based job in childcare, to a new full-time job managing a general store. It was physically demanding and involved carrying, shifting and loading, as well as standing all day on a concrete floor. She felt this was why she was constantly tired.

She also had changed her diet to food that was low in saturated fat and she shed 16 kilos – around 10 kilos more than she needed to lose.

It was when she starting feeling bone pain in her femur (upper leg) for the second consecutive month, when menstruating, that Samantha went to her doctor.

"I had a blood test and it was quite obvious apparently that I had a leukaemia," said Samantha, 40, of Margate, south of Hobart.

"It was really quite devastating," said the single mother whose daughter, Hannah, was 15 at the time.

"My mum, Hannah, my family and friends have stepped up beautifully and I attend a couple of the Leukaemia Foundation's education and support group luncheons each month.

"I've really enjoyed going along and meeting people in the same boat – it's understood we've all got something we're battling with, and I get advice from Jane (a Foundation support services co-ordinator) because the body does really quirky things when you're on chemo."

When diagnosed, Samantha started oral chemotherapy right away and had more tests including cytogenetic testing. Once it was confirmed that Samantha had chronic myeloid leukaemia (CML) she went onto Glivec®, a molecularly targeted oral chemotherapy that targets the abnormality that causes CML.

"It's nearly \$6000 for a month's supply and to get Medicare funding I needed proof from a bone marrow biopsy that I had CML," explained Samantha who has been on the drug for two years.

"It is very slowly putting the CML into remission," said Samantha. Her BCR-ABL gene, which was at 67% when diagnosed, is now 0.15%.

"They want four or five zeros after the decimal point before they'll say I'm in remission.

"Everything is going okay. It's just a waiting game at the moment."

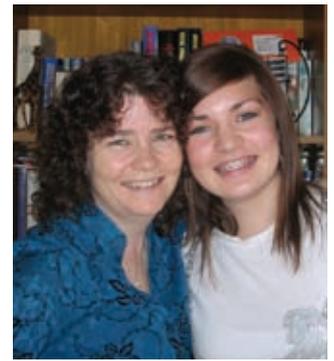
Samantha stopped full-time work when diagnosed: "My body just crashed with the shock of everything.

"I do feel better now. My weight has gone back to normal and I am generally free of bone pain, but I am still constantly tired, although it is a different sort of tired, and I have dry eyes and I get really cold, even on hot days."

The treatment is leaching potassium out of her body: "This is an uncommon side-effect so I take six potassium tablets each day and three Glivec tablets.

"The biggest thing for me is not having a secure future for myself and my daughter mainly because I don't know how long I'll be on Glivec, and being on the Glivec limits my ability to work full-time."

*Samantha has raised more than \$6000 for the Foundation by holding two quiz nights and organising a group to participate in World's Greatest Shave.*



*Samantha Freeman and her daughter, Hannah*

# FRUITS AND HERBS INTERFERE WITH CML TREATMENT

**Commonly consumed fruits and herbal remedies can interfere with the drugs used to treat chronic myeloid leukaemia (CML).**

Treatment for the slow progressing CML, which commonly affects people in their 60s, was revolutionised in the last decade by the release of imatinib mesilate (Glivec®). More recently, dasatinib (Sprycel®) and nilotinib (Tasigna®) have been developed to treat those patients resistant to or intolerant of Glivec.

All three drugs specifically target and inhibit an abnormal gene found in the majority of CML patients. However, interactions with other drugs and foods can alter the concentration of the drugs, reducing their effectiveness and potentially exacerbating side-effects.

Patients should avoid, or use with care, a range of common drugs, including quinine and painkillers such as codeine, paracetamol (e.g. Panadol®) and ibuprofen (e.g. Nurofen®).

A range of herbs interfere with the drugs and patients should check with their doctor or pharmacist before taking

any herbal medicines. In particular, Saint John's Wort can reduce Glivec levels in the blood by up to 30%.

Several fruits can also cause problems and patients should not drink grapefruit juice or eat grapefruits. Other fruits available in Australia which should be avoided include star fruit, mulberries and pomegranates.

For more detailed information please talk to your doctor or visit <http://en.wikipedia.org/wiki/CYP3A4> (this site lists drugs that interfere with the body's ability to metabolise the drugs).

## WHY GRAPEFRUIT INTERFERES WITH GLIVEC

**Chronic myeloid leukaemia patients being treated with a tyrosine kinase inhibitor (TKI), such as Glivec®, are warned not to eat grapefruits or drink grapefruit juice. Grapefruit is one of several fruits and herbs which can stop TKIs from working. Grapefruit juice induces the lining of the stomach to produce cytochrome, which in turn metabolises the drug before it can reach the blood system.**

# CHEERS TO U.G.L.Y. BARTENDERS' \$88,000 EFFORT

**In the Leukaemia Foundation's quirky new fundraiser, U.G.L.Y. Bartender of the Year, 20 Northern Territory bartenders with big hearts raised \$87,804 in 2008.**

U.G.L.Y. stands for 'understanding, generous, likeable, you' and bartenders across the Northern Territory hosted fundraising events in their pubs last November in the hope of becoming U.G.L.Y. Bartender of the Year.

That honour went to Tania Bird from the Howard Springs Tavern who raised \$17,046 and won a trip for two to Bali, thanks to Frangipani Holidays, and a \$1000 tab at her pub to thank her local supporters.

"I couldn't believe it when the Leukaemia Foundation phoned. It's very, very exciting. Thanks to all the locals and bar staff at the Howard Springs Tavern and the other businesses who generously supported me," Tania said.

Among the more creative fundraisers by the U.G.L.Y. Bartenders was a bikini carwash, a slave auction and an 'UGLY Betty' theme night inspired by the TV show. Two bartenders also put their official "I'm U.G.L.Y. I need help" T-shirts to great use. One issued fines to those who teased her for wearing the T-shirt and the other sold her T-shirt at auction for \$1000.

Simon Matthias, Leukaemia Foundation General Manager SA/NT, said the event had exceeded all expectations: "We set a \$24,000 fundraising target for U.G.L.Y. Bartender of the Year and to have that figure more than tripled has left us speechless!

"Our sincere thanks to Australian Hotels Association NT, Frangipani Holidays and Lion Nathan for supporting this new fundraising campaign. As for all the U.G.L.Y. Bartenders and their supporters, thanks for having the



The inaugural U.G.L.Y. title went to Tania Bird from the Howard Springs Tavern

sense of humour needed to prove that it's a beautiful thing to be U.G.L.Y!" he said.

## THE 10 MOST U.G.L.Y. BARTENDERS!

1. Tania Bird, Howard Springs Tavern - \$17,046
2. Jody Ranie, Noonamah Tavern - \$14,298
3. Leigh Pryse, The Vic Hotel - \$12,493
4. Jessica Panov, Dolly O'Reilly's - \$8303
5. Kayleen Stevens, Lazy Lizard Tavern - \$5338
6. Oliver Martin, All Seasons Oasis - \$4333
7. Kelly Newsham, The Firkin & Hound - \$4258
8. Jodie Stafford, Jabiru Golf Club - \$4250
9. Angie SurrIDGE, Tennant Creek Memorial Club - \$3800
10. Paul Vandenbosch, Shenannigans - \$2310

# VOLUNTEER DRIVER CHRIS IS AN UNSUNG HERO

**Chris Lawless is a volunteer driver for the Leukaemia Foundation who dedicates many hours to driving patients to medical appointments in Canberra and Sydney.**

In more than two years volunteering for the Foundation Chris has never declined a job asked of him. He provides his services at the drop of a hat and is described as the 'ultimate giver' by his peers.

Chris helped the Foundation transport and house 180 families in the ACT and surrounding areas last year. The transport program is a vital courtesy service for patients and families living with leukaemias, lymphomas, myeloma and related blood disorders.

Patients' immune systems are severely weakened during treatment so catching public transport can be dangerous due to the high risk of infection. They also may feel weak from treatments or anaemia. Chris helps ensure these patients get to and from treatment safely and comfortably.

Not only is the service convenient, it relieves pressure on families and carers and takes away the burden of the potentially enormous expense of taxi fares and hospital parking.

During chemotherapy treatment, some patients may need to go to and from hospital for treatment three times a



Volunteer driver, Chris Lawless, and a Leukaemia Foundation patient transport vehicle

week according to Stuart Allen, the Foundation's General Manager NSW/ACT.

"Having a friendly kind face like Chris' to greet you before and after makes a big difference. It makes the service very personal, which the patients really appreciate," Mr Allen said.

"Knowing they have safe transport allows our patients to focus on what's most important, getting well."

Chris was a state finalist in the 2008 Independent Grocers Association competition, Unsung Heroes. He also volunteers for the State Emergency Service.

## BRIAN'S FLIGHT PLAN APPROACH TO HIS JOURNEY WITH MYELOMA

**Brian Hardaker loves flying. He's been doing it as a hobby for 40 years so when he found out he had myeloma, his approach was similar to the time he flew across the Atlantic in a small plane.**

"I decided to treat it like planning and making a flight which you break up into legs," said Brian, 69, a retiree who lives at Mandurah, south of Perth.

"You must set yourself goals and know where you want to end up – for me that was to end up alive."

For Brian, myeloma has been "such an interesting journey".

It started, he says, when he got pneumonia in 2003, again in 2005 and after a third bout in January 2006, his chest specialist ran a range of tests. One result indicated Brian had myeloma. This was confirmed with a bone marrow aspirate and more blood tests but he didn't need any treatment for 12 months.

Then, a week before taking off on a month-long cruise to the UK with his wife, Chris, tests indicated changes to Brian's blood counts and his haematologist preferred that he not go.

But the Hardakers were determined to stick to their plans and two weeks into their trip Brian started getting excruciating pain in his upper back. It would resurface after a couple of days in a different part of his body, but despite the pain he enjoyed the holiday.

Brian still had jet lag when he was admitted to hospital on their return to Australia. That's when he began dealing with 'the little pest,' as he refers to the myeloma, as he would one of his favourite flights - from Mandurah to Kununurra.

"It allowed me to set targets on the information at hand and what I had been given on a weekly basis."

Pain control was the first step, followed by radiology to control the myeloma, thalidomide to kill the myeloma, and then the steps leading up to a stem cell transplant in February/March last year.

## TAKE PART IN THE WORLD'S GREATEST SHAVE 2009

**2009 is the 11th anniversary of one of the nation's biggest and most popular fundraising events - the Leukaemia Foundation's World's Greatest Shave. It runs from March 12 - 14, so join the action and shave your head or colour your hair to raise funds to support the 27 Australians who each week are diagnosed with leukaemia, lymphoma, myeloma or a related blood disorder. Public shave events, where you can have your head shaved, will be held across the country. Check our website to confirm times and venues. You can organise your own event to coincide with a sundowner at work, a weekend BBQ with family and friends, or a**



*Brian Hardaker, seated at the front of the glider*

"It really was a horrible time but I prefer to stay positive. You've got to make the best of every day and I am happy to be alive," said Brian.

"The technology involved is absolutely amazing and if this had happened to me a few years ago, I wouldn't be here now."

Brian said his wife had been a rock of support and his family and friends had been really important, including one who rang him every day no matter where he was in the world.

"And the Leukaemia Foundation has been very good. At my worst times when I was in hospital they gave me a lot of support.

"There were times when I thought I was dying, when I hoped I was dying.... and I was really concerned for Chris.

"They arranged for her to see a counsellor and the next day when she came to see me she was totally changed.

"I will be on medication for the rest of my natural life," said Brian.

He recently received the good news that his pilot's licence medical had been renewed, so he's planning his first major flight in almost two years – to either Exmouth or Broome.



post-game event at your team's clubhouse.

**Will you be brave and shave?  
For more info or to sign up, go to [www.worldsgreatestshave.com](http://www.worldsgreatestshave.com)  
or call 1800 500 088 today.**

# CELEBRATING LIFE IN SYDNEY, CANBERRA AND MELBOURNE

**Inaugural non-denominational Celebration of Life services were held in Melbourne, Sydney and Canberra last November to grieve, remember, honour and reflect on loved ones who lost their battle with blood cancer.**

Nearly 350 people attended the Victorian support services team's first Celebration of Life memorial service in the grounds of Werribee Park Historical Mansion in Melbourne.

The service was led by Mary Klasen, Director of Pastoral Care at the Mercy Hospital for Women in Heidelberg. Her powerful, uplifting and reflective readings complemented the outdoor theme.

Guests brought picnic baskets, rugs, even cricket sets to the day that included several symbolic rituals. They dropped pebbles into the pool of remembrance and were given a tuber tree to take home and plant in memory of their loved one. Music was also an important element on the day and professional singer, Sally Bourne, was described as having the "voice of an angel".

More than 30 families and friends who got together at Hyde Park in Sydney were moved by the beautiful words of palliative care specialist, Dr Frank Brennan and pastoral care worker, Marie Daly.

Celebrant, Carol Flanagan, led the service and a dedication to those who had died from leukaemias, lymphomas, myeloma and related blood disorders, and families and friends remembered their loved ones by placing a stone in a bowl of water that represented the ripple effect of a diagnosis.

Dr Brennan was also at the Celebration of Life service at Aspen Island off Kings Park in Canberra along with



*Samantha Schembri addressing guests at the Celebration of Life in Melbourne, top; Celebration of Life tuber tree, pebbles and program guide, centre; friends and families remember their loved ones at the Sydney Celebration of Life*

celebrant, Gail Everard. Rita Marchant performed two songs from her debut album, *Strong*, and the Maruki Community Orchestra played various classical pieces.

## MOTHER HONoured BY FUNDING LYMPHOMA RESEARCH

**Melbourne University postgraduate student, Lina Happo, was awarded a three-year PhD scholarship by the Leukaemia Foundation to carry out potentially ground-breaking research into lymphoma drug resistance.**

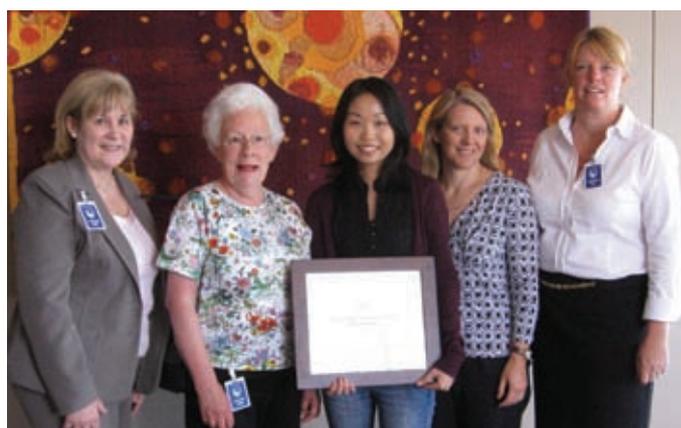
Her scholarship was provided with the generous assistance of Ann Miller.

Ann funded Lina's research project to honour her late mother, Betty Miller, who died from acute myeloid leukaemia in 1967.

Through the PhD scholarship, Lina is able to study the Bcl-2 gene family at the Walter and Eliza Hall Institute for Medical Research. The Bcl-2 gene family plays an important role in controlling the limited lifecycle of healthy cells by inducing survival or death. This research would not have been possible without Ann's kind donation.

"I'm very keen to help out in finding a cure for all types of blood cancers, including leukaemia and lymphoma," Ann said.

Funding a research scholarship is just one of many ways to help the Leukaemia Foundation's Vision to Cure.



*From left: Helen Smith (Fundraising Manager), Ann Miller, Lina Happo, Dr. Clare L Scott (Walter and Eliza Hall Institute of Medical Research) and Stephanie Hechenberger (General Manager Vic/Tas)*

By undertaking research we may be one step closer to finding a cure for blood cancer to which one Australian loses their life every two hours.

To help the Leukaemia Foundation's Vision to Cure by funding a research project or scholarship, please call 1800 620 420 for a confidential discussion.

# LIGHT THE NIGHT RESULTS AND THANKS TO SPONSORS

A new Leukaemia Foundation event, *Light the Night*, held in Queensland, South Australia (pictured) and Western Australia last September, saw thousands of participants come together with glowing balloons of different colours - each with a special meaning.

Gold balloons remembered a loved one, white balloons celebrated being a blood cancer survivor and blue balloons gave hope as a Leukaemia Foundation supporter.

In its inaugural year, *Light the Night* raised \$400,000 from Adelaide, Brisbane, Cairns and Perth, and special recognition and thanks goes to Adelaide's five-star sponsor, Seeley International, and Perth's five-star sponsors, Parmelia Hilton Perth and Box Magazine.



The Foundation plans to host up to 20 *Light the Night* events across Australia in September 2009. For more information call 1800 500 088.

## WHY BERYL IS ONE OF OUR VALUABLE VOLUNTEERS

The Leukaemia Foundation's mission is enriched by the dedicated work of its many volunteers across the nation. They each have their own reasons for helping and Beryl Hackner (pictured), a volunteer at the WA office in Perth, tells us about her experiences in the following interview.

**When did you first offer your time to the Leukaemia Foundation and what was your motivation?**

I was introduced to the wonderful support the Leukaemia Foundation provides during my son Garth's treatment for non-Hodgkin lymphoma. I attended education sessions and carers support groups and really was helped an awful lot through this difficult time. Garth died in 2006 at 35 years of age and through his treatment he had told me that if he became well again he would work for the Foundation. So now I am doing this work for him.

**What type of assistance do you provide through your volunteering?**

When I first signed up as a volunteer I was a driver, taking patients to and from their hospital appointments. It was quite soon after my son's death and I found it quite stressful at times navigating through areas of Perth I wasn't familiar with, knowing I had to get patients to their appointments, etc. So I decided driving wasn't for me, which is when I ventured into other areas. I have provided babysitting for patients, just so they can get out and do day-to-day things more easily. I go into the Perth office and help with mail-outs when needed and I was also a part of *Light the Night* in September which was a truly magical event. I helped run the volunteers tent, signing in everyone and giving them details on where they needed to go, and then once the walk started I



was a track marshal. It was great to be part of such a wonderful event.

**You obviously give a lot to the Foundation through your volunteering. Do you think you get anything back?**

Yes definitely. Through my association with the Foundation I have met so many lovely people. From patients to carers and the staff themselves, it is very rewarding for me to be part of the team. I believe if you are going to volunteer your time you really should enjoy it – life is too short. I can honestly say that I really love the volunteer work that I do and look forward to a long association with the Foundation.

## NEWS IN BRIEF

### REGIONAL OFFICE OPENS AT ORANGE IN CENTRAL WEST NSW

In New South Wales, the Foundation's Support Services Co-ordinator for Central West, Helen Snodgrass, has generated enough support by the local community and business to open an office in



The new office in Orange is in the centre of town

Orange. Helen supports patients, families and carers in the Central West through the Bathurst, Dubbo and Orange cancer centres and those who have further treatment in Sydney. Increased awareness of the Foundation in the area resulted in JBM Accounting Pty Ltd providing office space to the Foundation in the centre of Orange for an annual rent of \$1. The space provides room for a Support Services Co-ordinator, volunteers and includes a presentation area. The Foundation's regional office was fitted out using \$4500 raised by Margaret Green through a community fundraising event and a grant of nearly \$10,000 from the Raymond E Purves Foundation which is known for assisting projects that help regional and rural areas.

### MELBOURNE CUP LUNCH AT PARMELIA HILTON PERTH



Fabulous fascinators topped off racing attire worn by guests at a sumptuous three-course Melbourne Cup luncheon at the Globe Wine Bar and Restaurant which raised \$925 for the Leukaemia Foundation. It was the first joint venture between the Leukaemia Foundation in WA and the Parmelia Hilton Perth since the Foundation's national partnership with Hilton Hotels was formed last year. The Foundation's Business Development Manager, Lynne Anderson, and Marketing Manager, Margot Vearing, from the WA office, ran a silent auction of items including designer dresses by Perth label, Joveeba and scenic helicopter flights over Perth and judged the best hat competition. Thanks to Flourish Magazine, Your Skin and Beauty day spa and jewellery designer Josephine Stone for raffle prizes, and to the Parmelia Hiltons' General Manager, Ruth Harrison, Marketing Manager, Julia Clark and staff.

**CORRECTION:** In the photo caption on page 12 of the Spring 2008 issue of The Carer, SA World Lymphoma Awareness Day Ambassador, Ms Vickie Chapman MP was incorrectly identified as Wendy Chapman MP.

## BLOOD CANCER RESEARCH IN THE NEWS

### Australian recognised as

**ASH scholar:** Australian haematologist, Charles Mullighan, received the Joanne Levy Memorial Award for outstanding achievement as the American Society of Hematology (ASH) scholar with the highest scoring abstract for the ASH annual



ASH scholar, Dr Charles Mullighan

meeting, in San Francisco last December. Dr Mullighan received his undergraduate medical, and specialist, training in haematology and haematopathology in Adelaide, and studied immunogenetics at Oxford in the UK. A former post-doctoral fellow in the lab of Dr James Downing at St Jude Children's Research Hospital, Memphis, U.S., Dr Mullighan is now Assistant Member at the hospital. His research interest is the genomic analysis of acute leukaemia.

**New leukaemia genes detected:** A research team led by Richard Wilson of Washington University in St Louis, USA, has discovered eight new cancer genes linked to acute myeloid leukaemia. The genes were isolated using an advanced gene-scanning technology.

**Myeloma cells 'addicted' to master protein:** Despite the complex array of genetic changes driving myeloma, the malignant plasma cells appear to be 'addicted to the protein IRF4. A research team led by Dr Louis Staudt from the National Institutes of Health in Maryland, U.S., found that inhibiting the production of the protein led to the death of myeloma cells in 10 different models of the disease. The discovery opens the way for the potential development of a new treatment.

**New drugs for lymphoma:** Two new drugs have been approved by the U.S. Food and Drug Administration for treating lymphoma. Bendamustine hydrochloride (Treanda®, Cephalon, Inc.) has been approved for the treatment of patients with indolent B-cell non-Hodgkin lymphoma that progressed during or within six months of treatment with rituximab or a rituximab-containing regimen. Enileukin diftiox (Ontak®, Eisai Medical Research) was approved for the treatment of persistent or recurrent CD-25 positive cutaneous T-cell lymphoma.

### 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 leukaemias, lymphomas, myeloma and related blood disorders.

