

About myeloma

Myeloma (also known as multiple myeloma or plasma cell myeloma) is a cancer of the blood in which malignant plasma cells are over produced in the bone marrow.

Myeloma is the second most commonly diagnosed blood cancer and around 1200 Australians are newly diagnosed each year.

The risk of developing myeloma increases with age. Almost 80% of all new cases occur in people over the age of 60. Myeloma is uncommon in people under 40 and occurs more frequently in men than in women.

Myeloma is typically diagnosed when the disease is at its most serious.

The cause of the disease remains unknown and the most common symptom is severe bone pain, usually felt in the back or ribs, and malfunctioning kidneys.

There is no cure for myeloma. Treatment aims to induce periods of remission.



Leukaemia Foundation

VISION TO CURE
MISSION TO CARE

1800 620 420
www.leukaemia.org.au

RESEARCH GRANT AIDS CHILDHOOD LEUKAEMIA DISCOVERY

The Leukaemia Foundation helped fund Australian research that could lead to improved treatments for the most common form of childhood leukaemia.

Drs Matthew McCormack and David Curtis from the Rotary Bone Marrow Research Laboratories in Melbourne received almost \$100,000 from the Foundation last year for research into a common type of childhood leukaemia - T-cell acute lymphoblastic leukaemia (T-ALL).

They led a team of scientists at The Royal Melbourne Hospital and University of Melbourne that made the discovery while studying mice prone to developing this form of leukaemia.

Dr McCormack, a leading international expert on childhood leukaemia, said the cellular origins of this form of leukaemia was not well understood.

“Our discovery that these cells are similar to normal stem cells explains why they are capable of surviving for long periods. It also explains why they are remarkably resistant to treatment,” said Dr McCormack.

Children with T-ALL currently receive extended therapy over two to three years in an attempt to stop a relapse. More targeted therapy on the thymus cells could reduce the length and toxicity of treatment and prevent relapse, and this is the focus of this team’s future work.

Leukaemia Foundation National Research Program Manager, Dr Susan O’Brien, said the discovery paved the way for further research which could lead to better treatments for people with this form of leukaemia in the future.

“The Leukaemia Foundation has invested almost \$1.2 million in ALL specific research since 2005, funding the most promising projects as assessed by a panel of leading



Dr Matt McCormack, left, with Dr Kylie Mason and Dr Stephen Ting at the 2010 launch of the Leukaemia Foundation’s national research program in Melbourne in February

Australian scientists and haematologists,” Dr O’Brien said.

On February 15, in Melbourne, the Foundation announced a record \$4 million investment in research funding for 2010 including \$2 million in new grants incorporating the inaugural Leukaemia Foundation Phillip Desbrow Senior Research Fellowship which was awarded to Dr Carl Walkley.

Leukaemia Foundation of Australia CEO, Peter Cox says the Foundation is committed to growing its National Research Program which has seen \$16 million invested since 2005.

“Sadly blood cancer is the second most common cause of cancer death in Australia. Research is the only way to improve blood cancer survival rates,” Peter said.

For more information about the launch of the Leukaemia Foundation’s 2010 research program and new research projects, see pages 6 & 7.

SUPPORT UNDERPINNED IAN'S POSITIVE ATTITUDE

The Leukaemia Foundation's Warragul Support Group has been a great source of friendship, information and morale for Ian Cooper.

Ian, 66, of Drouin, east of Melbourne, was diagnosed with myeloma just before Easter in 2008 and he joined the Leukaemia Foundation's support group later that year. He found out about it from the Foundation's Gippsland support services co-ordinator, Judy Woods who runs this group that meets once a month.

Ian is a regular among the 12 to 15 members, including people with myeloma, leukaemia and lymphoma, and carers, who get together for coffee and cake.

"Some tremendous friendships have developed and the thing I like is we support one another. If someone is low or facing a particular problem, we rally round and boost morale and give emotional support," Ian said.

"And I find just talking about an issue helps.

"My wife and I have been to as many education forums as possible too.

"I've tried to get as much information as possible on myeloma, so I know I am going down the right path as far as medication is concerned, and know what I can do to assist in the process."

Ian said his life had been a roller coaster over the last two years. Half way through 2007, the primary school teacher got a bout of the flu that he just couldn't shake for six months.

"I went to my GP continually and tried to overcome it with medications and had a series of tests."

At the time he was working four days a week, helped a dairy farmer with milking on the weekends and was also physically active - swimming a kilometre every day, as well as bike riding and walking regularly.

"On occasions I got tired but I just put it down to the amount of activity I was doing."

In January 2008, still trying to recover from the flu, Ian had a battery of tests and while the results were clear, his GP referred him to an oncologist.

"I had a bone marrow biopsy and bloods and the like and half way through he said I definitely had myeloma," explained Ian who began chemotherapy the week after Easter.

In August that year he had a stem cell transplant at the Peter MacCallum Cancer Centre in Melbourne.

"It was a grey area as to whether a stem cell transplant would be beneficial. They won't do it at 70 but what assisted me was that I was so fit."

During the transplant, Ian's wife, Pat, continued working.



Pat and Ian Cooper with their grandchildren Hannah, Louise and Jacob, in October 2008

She travelled the 100km to Melbourne to visit him each day and then drove back home so she could go to work again the next day.

"After the transplant they said it would be six months before I would be any good and it was," said Ian. "I go to strength and meditation classes and I feel pretty good. But I can only walk one kilometre and swim 200m, and am gradually trying to build that up."

For 12 months from November 2008 Ian was on thalidomide.

"That was part of the follow-up treatment, to help kill the paraprotein in my system, and I'm still on steroids and a stack of other tablets. My paraprotein is creeping up but it's nothing that has rung a bell to say I need more chemo treatment."

Ian went back to work at the beginning of 2009, as a school librarian for three days a week.

"I went back for emotional reasons," said Ian.

"I was going to retire at the end of 2008 but I was forced to stop teaching earlier, due to illness. I decided I'll go on my terms, not because of my health, so now I plan to give teaching away at the end of 2010."

What has been invaluable to Ian is the support of his wife, family and friends at the Leukaemia Foundation.

"They gave me the courage to have a positive attitude and the belief that I'd come out the other side," he said.

GROWING OUR COMMITMENT TO CLL

The Leukaemia Foundation is dedicated to improving support for people in the community who are affected by chronic lymphocytic leukaemia (CLL) – the most common type of leukaemia in Australia.

This year more than 700 Australians will be diagnosed with CLL, a slow growing leukaemia that is usually a disease of older adults. It is rarely diagnosed in people under the age of 40.

A diagnosis of CLL does not always require immediate treatment in around 30% of people and the Foundation's National Support Services Manager, Anthony Steele said people with this form of CLL were often sent home on a 'watch and wait' program.

"But some people have termed it the 'watch and worry' program," Anthony said.

Others have a more aggressive form of CLL and require treatment soon after diagnosis. There is no cure for CLL although much research is underway seeking improved treatments and potential cures.

"Because people with CLL often do not require active treatment, they may not be referred to support networks such as the Leukaemia Foundation to help them when they return home to life after being diagnosed," Anthony said.

Seven years ago, businessman and Leukaemia Foundation board member, Warren Lippiatt, was diagnosed with CLL. He described the impact of CLL on his life and that of his young family recently when he spoke at the launch of the Foundation's research program for 2010 in Melbourne.

Fellow businessman, Jim Selim, who also has CLL, has made a commitment to the Leukaemia Foundation to donate \$1 million to CLL research over three years,

and Roche Pharmaceuticals has contributed \$200,000 to the research program in 2010-11 specifically to support CLL research.

The Leukaemia Foundation will increase its services to people with CLL this year. This includes:

- a record investment of \$591,000 on CLL research, to search for a cure;
- the development of a bi-annual newsletter, *CLL News**, to provide up-to-date information on CLL research, clinical trials, and patient stories; and
- a CLL telephone discussion forum for people from regional and remote Australia, to meet other people with CLL, share insights into living with the disease and learn more about how to live successfully with the disease. Guest speakers are invited to provide expert information and advice to these often under-served regional groups.

If you would like more information about our activities or CLL support, contact Support Services in your state on 1800 620 420.

* *CLL News*, sponsored by Roche and Gensyme, is an addition to the Leukaemia Foundation's range of popular patient newsletters. Current titles are *Lymphoma News*, *Myeloma News*, *Myelodysplasia News* and *Chronic Myeloid Leukaemia News*. These newsletters can be downloaded from: www.leukaemia.org.au.



Warren Lippiatt is living with CLL

MAY 19 IS NATIONAL MYELOMA DAY

The Leukaemia Foundation will hold its inaugural National Myeloma Day on May 19 this year.

This special day will celebrate achievements including early access to the latest myeloma treatments in Australia, help increase awareness by GPs of myeloma and its diagnosis, and promote awareness of this form of blood cancer within the general community.

Myeloma is the second most common blood cancer in Australia, after lymphoma, and accounts for around 15% of all blood cancers. The incidence of myeloma also is growing at the fastest rate of all the blood cancers and around 1500 new cases will be diagnosed this year.

Patient groups and health professionals have recognised that diagnosing myeloma is difficult and can often take many months, due to a limited awareness of the condition and its general unspecific symptoms.

Myeloma usually develops in the elderly and is incurable. Symptoms of the disease are often mistaken for other conditions, potentially delaying correct diagnosis and prompt treatment.

In celebrating National Myeloma Day a *Myeloma Diagnostic*

Tool for GPs will be launched by the Leukaemia Foundation and distributed across Australia.

This support tool, developed specifically for use within the Australian health care system, is based on the Myeloma UK Diagnosis Pathway and inspired by the success of the Leukaemia Foundation's Lymphoma diagnostic tool in 2008.

It is aimed at encouraging GPs to consider myeloma as a diagnosis when generalised symptoms occur, leading to earlier diagnosis of the disease. These people can then be referred to a specialist treatment centre for ongoing care.

In the last 12 months, myeloma patients in Australia were granted earlier access, through the PBS system, to various drugs used to treat myeloma. The Leukaemia Foundation would like to celebrate this with people who are affected by myeloma all around the country in a series of activities. Details will be posted on the Foundation's website: www.leukaemia.org.au.

For more information, or if you would like to hold an event to commemorate National Myeloma Day, contact your local Support Service Co-ordinator on 1800 620 420 or National Myeloma Co-ordinator, Kaye Hose: myeloma@leukaemia.org.au.

BALLGOERS SWING INTO ACTION TO LAUNCH NEWEST PATIENT ACCOMMODATION VILLAGE

A *Swing into Action Ball* celebrated the launch of the Leukaemia Foundation's latest purpose-built patient accommodation project which is due to begin construction in Adelaide mid-year.

Foundation staff and volunteers rolled out the red carpet for SA Minister for Health John Hill and 300 South Australian business and community members at the black tie affair. They were treated to an amazing night of fine food and wines, fabulous prizes and entertainment in the Hilton Adelaide's Grand Ballroom last October.

International cabaret performer, Tom Burlinson, wowed the crowd and performed all the big Sinatra hits, supported by the renowned South Australian Police Band.

A highlight of the night was the first public unveiling of plans for the SA Patient Accommodation Village. An animated 3D fly around of the village design showed architectural impressions of the 14 two and three-bedroom fully furnished apartments, recreation areas, and the new office building for the Leukaemia Foundation of South Australia which will be incorporated into the complex.

Guests also heard from Leukaemia Foundation ambassador and former Miss Universe Australia, Kimberley Busted, who shared her family's personal experience with blood cancer.

The crowd was keen to get involved in the fundraising mood of the night, with guests vying for the opportunity to sing a duet with Tom Burlinson. For \$3000, the exclusive duet was snapped up by Leukaemia Foundation Board Director, Lucio Di Giallonardo, who sang *Come fly with me* wonderfully in tune with Tom. Patrick Coope also generously donated \$1000 to have the first dance of the night with Kimberley Busted.



*Kimberley Busted and winner of the first dance, Patrick Coope
Tom Burlinson and the SA Police Band
Guests enjoying the Swing into Action Ball in Adelaide*

For information about recognition opportunities available at the SA Patient Accommodation Village, please contact the Leukaemia Foundation's SA office on (08) 8273 3555.

COLLABORATING TO CONNECT PEOPLE WITH BLOOD CANCERS

The Leukaemia Foundation has teamed with the Cancer Council to provide a one-to-one support program, called Cancer Connect, that links people affected by blood cancer.

Cancer Connect is an opportunity to listen to concerns, share experiences and support others coping with life after a blood cancer diagnosis. This support is available at all stages of the blood cancer journey – at diagnosis, during treatment and when treatment has been completed.

Talking to someone who has been through a similar experience can be helpful.

The program is for people who would like to make contact with a person who has had a similar blood cancer experience to their own. This includes people recently diagnosed with cancer, cancer survivors, their partners, parents, family members or friends, and those caring for someone with blood cancer.

In the program, trained volunteers who have had a blood cancer can be matched with people who are seeking practical advice and emotional support.

Cancer Connect volunteers have been trained by staff at the Cancer Council and the Leukaemia Foundation to ensure they provide optimal service, and have the knowledge and skills to look after themselves in the process.

The Cancer Connect program for people with blood cancers has been established in Victoria and South Australia, and training begins this year in NSW.

Support is provided over the telephone and the Victorian and South Australian programs are open for people to participate nationally until programs are implemented in the other states.

This is an important pathway for blood cancer survivors to channel their own experience in a positive way and help newly diagnosed people.

To volunteer as a mentor, or to find a support person to assist you, please contact your local Support Service Co-ordinator at the Leukaemia Foundation on 1800 620 420.

FOUNDATION TO BENEFIT FROM CALENDAR GIRLS STAGE SHOW

The Leukaemia Foundation is the charity partner for the upcoming stage production of *Calendar Girls*, with three special charity performances that you can attend.

Calendar Girls is based on the true story of Angela Baker, who lost her 53-year old husband to lymphoma. A group of her extraordinary friends, members of a Yorkshire Women's Institute group in the UK, persuaded one another to pose nude for a charity calendar with a difference, to raise money for blood cancer research.

These 'calendar girls', as they became known, were unaware of the media sensation they were about to unleash. They inspired a feature film in 2003 and a subsequent stage play in London's West End that raises funds for leukaemia research in the UK.

Their story will soon delight Australian audiences when the stage show opens here in April with an all-star Australian cast. There are three charity performances - the final dress rehearsal in each capital city in which the production will run.



Starring in the Australian stage production of *Calendar Girls*, from left, Cornelia Francis, Amanda Muggleton, Rhonda Burchmore, Lorraine Bayly, Rachel Berger, Jean Kittson and Anna Lee

Brisbane: April 7, Queensland Performing Arts Centre

Sydney: April 28, Theatre Royal

Melbourne: June 16, Comedy Theatre

To purchase tickets, visit www.leukaemia.org.au, or call 1800 640 420.

In addition to the charity performances, proceeds from merchandise sold throughout the Australian season will raise funds for the Leukaemia Foundation.

BRINGING SUNSHINE THROUGH MERCHANDISE SALES

The *Calendar Girls* opportunity inspired the Leukaemia Foundation to produce a new range of *Bringing Sunshine* merchandise.

The Foundation has adopted the sunflower as a symbol of hope because John Baker, who inspired *Calendar Girls*, grew sunflowers and gave them to friends and family in the hope that he would have recovered by the time they flowered.

"I don't think there's anything on this planet that more trumpets life than the sunflower," said John who sadly died before the sunflowers bloomed.

Dave Simms, General Manager of Community Fundraising said the merchandise would be sold throughout the *Calendar Girls* season and through the Foundation's online shop.

"This gives us a good opportunity to assess what sells well and extend the range if the response is positive," Dave said.

"Traditionally we've sold most merchandise through our largest fundraising event *World's Greatest Shave*. With *Bringing Sunshine* we're entering a new era of fundraising as we begin to sell a bigger, brighter range of 'official Leukaemia Foundation' products online.

"With your help, the Foundation can continue to bring sunshine into the lives of patients and their families from their diagnosis, through treatment and beyond," Dave said.

The range includes lapel pins, silk flowers, polo shirts, mugs, umbrellas, aprons and handy handbag hangers and can be ordered on: www.leukaemishop.org.au.



2010 RESEARCH PROGRAM LAUNCHED

The Leukaemia Foundation will invest more than \$4 million in research funding this year. This is \$1 million up on 2009 following generous community support for events such as *World's Greatest Shave*, and corporate and individual donations.

New grants in the National Research Program for 2010, worth more than \$2 million, were announced at the new Hilton Melbourne South Wharf last month. In addition, the Foundation provides a further \$2 million in ongoing funding.

The launch, hosted by radio and television personality, Alan Brough who is also an ambassador for the Foundation in Victoria, was attended by members of the blood cancer research community in Melbourne and Leukaemia Foundation supporters.

The inaugural Leukaemia Foundation Phillip Desbrow Senior Research Fellowship was awarded to Dr Carl Walkley to establish an innovative new program of research at St Vincent's Institute of Medical Research in Melbourne.

The Fellowship, named in honour of the first CEO of the Leukaemia Foundation, Phillip Desbrow, was presented by Jan Desbrow, in memory of her husband who sadly passed away in 2003.

Leukaemia Foundation of Australia CEO, Peter Cox said the Foundation's research program encouraged talented students, medical graduates and researchers to find new treatments and better ways to care for patients and families living with blood cancers.

"Australian's generous support has enabled the Foundation to select the best blood cancer projects nationally and ensure they are well funded," Peter said.

"We're the only national not-for-profit organisation in Australia dedicated to funding research into blood cancers and our commitment to improving the long-term prognosis for patients is unwavering."



Assoc. Professor Paul Ekert, Professor Angel Lopez, Dr Susan O'Brien and Assoc. Professor Andrew Roberts



Dr Andrew Wei, Peter Cox and Sally Young

"We're indebted to all the Australians who take part in fundraising events, such as the *World's Greatest Shave*, to help us fund the best and most innovative blood cancer research in our country."

Find out how you can support our National Research Program with a bequest or donation, call 1800 620 420.



Dr Carl Walkley – recipient of the inaugural Phillip Desbrow Senior Research Fellowship

Dr Carl Walkley, recipient of the Leukaemia Foundation's new and most prestigious award - the Phillip Desbrow Senior Research Fellowship - is from the Stem Cell Regulation laboratory at St Vincent's Institute of Medical Research, Melbourne.

Dr Walkley said it was a great honour to be selected for the award, instigated by the Foundation to provide sustained support for an outstanding young scientist.

"By providing \$200,000 annually for five years, this Fellowship will allow me sufficient time to develop new models and approaches to treatment," said Dr Walkley.

He will investigate the relationships between blood cells and non-blood cells in the bone marrow, to better understand how these interactions contribute to the development of blood diseases.

"I hope my research will make a difference in the lives of patients with leukaemia, lymphoma and other blood diseases such as myeloproliferative disease and myelodysplastic syndrome," he said.

Dr Susan O'Brien, General Manager of the Leukaemia Foundation's National Research Program said the Foundation was extremely impressed by the calibre of Dr Walkley's research proposal, his international research and the publication of his work in the world's most acclaimed scientific journals.

"It is our belief that the research Carl will undertake during the next five years will be recognised internationally and ultimately will make a real difference to the 10,000 or more Australians who are diagnosed with blood cancers each year," Dr O'Brien said.

NEW GRANT RECIPIENTS

LEUKAEMIA FOUNDATION PHILLIP DESBROW SENIOR RESEARCH FELLOWSHIP (\$200,000/yr, 2010 - 2014)

Dr Carl Walkley

St Vincent's Institute of Medical Research, VIC
Cell division, blood stem cells and proliferative diseases

NEW GRANTS IN AID (January – December 2010)

Dr G. Best and Assoc. Professor S. Mulligan

Kolling Institute, NSW (\$100,000)
A novel agent targeting the heat shock protein 90 in chronic lymphocytic leukaemia

Dr H. Cullup

Mater Medical Research Institute, QLD (\$100,000)
Methods to prevent graft versus host disease after transplantation

Assoc. Professor P. Ekert

Murdoch Childrens Research Institute, VIC (\$98,000)
Blocking Hox genes to treat leukaemia

Dr S. Fuller and colleagues

University of Sydney, NSW (\$100,000)
Study of genes that cause chronic lymphocytic leukaemia

Assoc. Professor D. Gill and Assoc. Professor N. McMillan

Princess Alexandra Hospital, QLD (\$100,000)
Novel growth factors in chronic lymphocytic leukaemia

Dr C. Hawkins

La Trobe University, VIC (\$56,256)
Definition of the mechanism by which caspase-2 suppresses lymphomagenesis

Dr K. Mason, Assoc. Professor A. Roberts and Dr D. Huang

Walter and Eliza Hall Institute, VIC (\$100,000)
Promoting cell death to improve treatment of chronic lymphocytic leukaemia

Dr P. Neeson and Assoc. Professor D. Ritchie

Peter MacCallum Cancer Centre, VIC (\$98,000)
A new chronic lymphocytic leukaemia model that aids better understanding of the disease and how to treat it effectively

Assoc. Professor D. Ritchie and Dr P. Neeson

Peter MacCallum Cancer Centre, VIC (\$100,000)
Using the immune system against chronic lymphocytic leukaemia

Dr J. Pimanda

University of New South Wales (\$98,000)
Do leukaemic cells adopt blood stem cell properties to induce leukaemia?

Dr L. Purton and Dr M. Askmyr

St Vincent's Institute, VIC (\$98,000)
Helping blood cell numbers recover after transplantation or chemotherapy

Dr S. Ting and Dr S. Russell

Peter MacCallum Cancer Centre, VIC (\$50,000)
Understanding how blood and leukaemia stem cells function

Dr S. Vuckovic and Dr L. Catley

Mater Medical Research Institute, QLD (\$100,000)
Regulation of human dendritic cell biology by vascular endothelial growth factor

PHD SCHOLARSHIPS

(40,000/yr, January 2010 - December 2012)

Ms S. Charmsaz

Queensland Institute of Medical Research, QLD
EphA proteins may be therapy targets in leukaemia



Alan Brough, back row centre, with new grant recipients who attended the launch

Ms U. Sansom-Daly

University of NSW, NSW
Where to after treatment? A new way to support young people with cancer and their parents

Ms L. Schafrank

Centre for Cancer Biology, SA
Eradication of leukaemic stem cells using therapy combinations in chronic myeloid leukaemia

Ms L. Varghese

Walter and Eliza Hall Institute, VIC
Understanding the molecular mechanisms that regulate blood stem cell activity

Mr D. Watkins

Centre for Cancer Biology, SA
Defining the unique characteristics of CP-chronic myeloid leukaemia patients that respond poorly to imatinib

Mr J. Wong

Westmead Millennium Institute, NSW
Targeting signalling in acute lymphoblastic leukaemia

PHD (CLINICAL) SCHOLARSHIPS

(\$55,000/yr, January 2010 – December 2012)

Dr A. Johnston

John Curtin School of Medical Research, ACT
Identification of genetic changes in aggressive B-cell lymphomas and impact on tumour growth

Dr C. Wallington-Beddoe

Westmead Millennium Institute, NSW
New therapies for acute lymphoblastic leukaemia

HONOURS SCHOLARSHIP

(\$10,000, January to December 2010)

Mr T. Colgan

University of Western Australia, WA
Developing a method to isolate notch-induced cancer cells

NEW INVESTIGATORS GRANT

(\$5000, January to December 2010)

Ms Kaija Strautin

University of Western Australia, WA
Measurement of blood markers to determine cell therapy treatment for graft versus host disease

CANCER AUSTRALIA PDCCRS FUNDING PARTNERSHIP

(\$36,000/yr, February 2010 - January 2013)

Professor John Seymour

Peter MacCallum Cancer Centre, VIC
PET adapted therapy in advanced Hodgkin lymphoma

For more information on all the research projects, visit www.leukaemia.org.au/web/research/fellowships_grantees.php

PATIENT TRANSPORT CENTRALISED IN SYDNEY

On any given weekday around Australia, 31 cars are used by the Leukaemia Foundation to transport patients and carers safely between hospital and home.

This free transport service ensures patients can get to and from their treatment safely and without any increased risk of infection that could potentially result from using public transport.

Nine of the 31 cars are in metropolitan Sydney, making it the Foundation's largest transportation hub.

The Foundation's General Manager NSW/ACT, Stuart Allen, said volunteer drivers in Sydney made 390 trips, carrying patients and carers to and from hospitals, clinics, surgeries and accommodation in July 2008.

"Twelve months later, that figure increased by an astounding 134% to 914 trips, and during 2008/09 our Sydney drivers spent almost 19,000 hours on the road and covered 465,760 kilometres," Stuart said.

"We expect demand for the service to increase this year and the challenge for us is to make sure our fleet can match this demand."

The dramatic increase over the 2008/2009 financial year highlighted the need for new operational arrangements to be introduced regarding transport, accommodation and volunteers in New South Wales and the Australian Capital Territory region.

In November 2009, the first step was taken with the appointment of Alison Landeweer to the St Leonards office in Sydney. Alison, who has customer service experience with the Pharmaceutical Society of Australia, NSW Health



Matt Ridley and Alison Landeweer - based at the St Leonards office

and Centrelink, works with Matt Ridley on transport, accommodation and volunteer tasks.

This co-ordination role has seen transport centralised. One telephone number is now used for all Sydney transport inquiries and all patient transport allocations for the Sydney metropolitan area are managed through the St Leonards office.

The next step in auditing transport procedures and criteria is underway. The Foundation looks forward to continuing to ensure its courtesy transport program keeps pace with growing demand for this important service.

BEAUTIFUL BARTENDERS GOT U.G.L.Y.



Justine Hall – winner of the UGLY trophy in South Australia

Australia's barmen and barmaids proved they are a good looking bunch with big hearts by raising more than \$330,000 last year through the quirky U.G.L.Y Bartender of the Year fundraiser.

U.G.L.Y. stands for 'understanding, generous, likeable you' and across Australia bartenders held fun events for their patrons to raise funds to support the Leukaemia Foundation's work.

From races to auctions and carwashes to trivia nights, hundreds of bartenders worked hard to win the right to be crowned *U.G.L.Y Bartender of the Year* in their state during 2009.

Congratulations to our winners:

- Justine Hall, St Kilda Beach Hotel (SA)
- Erica Warren-Maurer, Jamberoo Pub (NSW)
- Gail Arnold, Noonamah Tavern (NT)
- Amy Lear, Sale & District Greyhound Racing Club (Vic)
- Callum Kerr, Southerley's Harbour View Bar, Port Denison (WA)
- Marlene Lang, Gin Gin Hotel (Qld).

The event will be held again in November this year.

TRANSPORT TO AND FROM APPOINTMENTS “INVALUABLE”

Prior to his diagnosis with acute myeloid leukaemia in February last year, Scott Macdonald didn't know what leukaemia was and hadn't had anything to do with the Leukaemia Foundation.

Today he describes the Foundation as “the most marvellous bunch of people the planet has ever created” and the patient transport service, which he uses regularly as “invaluable”.

“We couldn't do without it,” said Scott, 53. He's in remission and rebuilding his strength after intensive treatment and a bone marrow transplant in August 2009.

“I'm completely clear of leukaemia but the side-effects of the drugs are huge,” explained Scott.

He is easily exhausted, struggles with tasks such as getting up and dressed and frequently has to rest.

Scott returns to hospital at least once a week for biopsies, blood tests and follow-up appointments.

“It's 50 minutes to St Vincent's Hospital on a good day and parking is nothing short of a nightmare,” explained Scott whose wife, Judy, works as a school teacher.

He still can't drive and he can't catch a train because he is too weak and vulnerable to being exposed to viruses and bacteria which could harm his recovery.

“The cost of a taxi is \$80 one way and we haven't got a cent to our name. After we pay the mortgage and run the house, we break even,” said Scott who gave up work when he was diagnosed.

Scott is driven from his home at Caringbah in southern



Scott and Judy Macdonald with one of the Foundation's patient transport cars

Sydney to and from his medical appointments by one of the Leukaemia Foundation volunteer drivers.

“I always politely ring a week before and they confirm the day before,” he said.

“They are all good drivers and they've always got some good stories. It's the only social contact I get. The people who are driving are all doing it for nothing and many of them have been touched by cancer.

“You don't have to go far to see people worse off than yourself.”

BRIDGESTONE EXTENDS TRANSPORT SUPPORT

Bridgestone Australia Ltd will extend its support of the Leukaemia Foundation's Patient Transport Service with the renewal of sponsorship arrangements in several states and two new vehicles for Victoria.

Soon, 10 of the Leukaemia Foundation's transport service vehicles will be sponsored by Bridgestone Australia Limited and Bridgestone Dealers.

“We are delighted to know that we have the ongoing support of Bridgestone into the future,” said Peter Cox, CEO of the Leukaemia Foundation of Australia.

“Since the relationship began in 1998 their involvement has extended beyond sponsorship to include participating in events like *Light the Night*,” he said.

Bridgestone Australia Limited CEO, Shawn Hara said the relationship with the Leukaemia Foundation works on many levels.

“The relationship lets Bridgestone dealers support their local community and it also helps to build teamwork,” he said.

“We are proud supporters of the Leukaemia Foundation's Vision to Cure and Mission to Care.”

About the patient transport service

- In 2009 more than 400 volunteer drivers delivered this service
- More than 900,000 kilometres were travelled, equivalent to more than 21 laps of the world
- 4492 patients utilised this courtesy service to travel to and from hospital treatment and medical appointments
- In 2010 the Foundation has 31 vehicles, generously provided by Bridgestone Australia and GM Holden.

CELEBRATION SERVICE A STEPPING STONE FOR MARGARET

The Leukaemia Foundation's Celebration of Life service and regular contact from the Foundation has helped Margaret Lance since the death of her husband, Bruce.

Diagnosed with chronic lymphocytic leukaemia (CLL) in January 2006, aged 52, Bruce passed away in March last year following a bone marrow transplant.

"Unfortunately his heart and lungs just couldn't cope with the procedure," explained Margaret.

The couple regularly travelled to Perth over three years as Bruce underwent a range of different treatments. When he was diagnosed the Lances were living in Northam, 100kms north east of Perth, and they drove backwards and forwards for doctor's appointments and chemotherapy.

A year later, Bruce who continued to work as a branch manager in the automotive industry, was transferred to his hometown of Esperance, 700km south of the WA capital.

Several times platelets had to be flown to Esperance which doesn't have a Blood Bank, but when Bruce's white blood cell count crashed on a couple of occasions, he was flown to Perth for treatment.

"We used to stay in a motel and pay the bill ourselves as we were both working. We felt we could pay for a lot of our own expenses so others could use the Foundation's accommodation," Margaret explained.

But for six weeks, early last year when Bruce went to Perth for his transplant, Margaret accepted the Foundation's offer of accommodation close to the hospital.

"I could walk back and forth to the hospital which was my way of therapy," she said.

"The Leukaemia Foundation has been really good to me. They ring me from time to time, just before a major anniversary – three months and six months.



Margaret Lance with her late husband, Bruce

Six months to the day Bruce died, Margaret and family members put together a team and took part in *Light the Night*, raising a couple of thousand dollars.

And last November, Margaret attended the Celebration of Life service in Perth with Bruce's mother, Dot, and his sister, Rhonda, and found it very helpful.

"I would definitely do it again. To me it was another form of closure - another hurdle you have to cross and you see you're not the only person in this situation. You go through a range of emotions and talking to people there you realise it's just normal."

As the first year anniversary approaches since Bruce died Margaret admits she's finding it "a bit tough".

"Our daughter and son, Christie and Kyle, have been a great help and are very supportive but I'm finding it harder now than I did earlier on," explained Margaret who initially went back to work three days a week to keep busy, but recently she resigned.

"I need to sort myself out and deal with a few things around the house and my sister and husband have come down to Esperance for a couple of months to help me out."

SKIN LYMPHOMA SEMINAR TO BE HELD ANNUALLY

An educational seminar for people diagnosed with the rare blood condition, skin lymphoma, and their carers was held in Melbourne last November.

The day-long event, facilitated by the Leukaemia Foundation in collaboration with Peter MacCallum Cancer Centre, provided a forum to hear leading specialists discuss new advances in skin lymphoma.

The innovative program for this rare sub group of lymphoma attracted patients and carers across the state.

The conference, attended by 50 people, began with an informative presentation on advances in treatment and wound management by leading haematologist, Professor Miles Prince, from Peter MacCallum.

A panel discussion followed with input from Professor Prince, Dr McCormack, Dr Ryan and interstate guest

speaker Dr Bryone Kuss, haematologist from Flinders Medical Centre. In the next session, John Berrill, principal lawyer at Maurice Blackburn Lawyers addressed the legal implications of chronic illness and he expertly answered countless questions from patients and carers.

The afternoon session saw patients and carers go to separate rooms to discuss the psychological impact of disease – a strategy that enabled both groups to independently explore and discuss issues experienced as either a patient or primary carer. Jen Daddow, from Carers Victoria and Hamlata Bhana, haematology social worker from Peter MacCallum facilitated the carer discussion.

The conference empowered patients and their carers with information and enabled valuable interaction, discussion and peer support and will continue as an annual collaborative event to support this patient group.

SUPPORTING THE BEREAVED AND CELEBRATING THE LIVES OF LOVED ONES LOST

Providing emotional and practical support to patients, families and their loved ones is an important part of the Leukaemia Foundation's range of free services.

The Foundation's team of Support Service Co-ordinators offer assistance over the phone or face-to-face at home, in hospital or at one of the Foundation's accommodation centres, depending on an individual's needs.

In 2009 this support was extended to include the establishment of a new position, Grief and Bereavement Co-ordinator, and the Foundation intends rolling out this service nationally in the future.

Donita Menon, who has been appointed to this role, works out of the Foundation's Sydney office and her main focus is to talk to the bereaved and help them through their journey of grief.

Last year there were more than 4000 deaths from blood cancer in Australia and the demand for support to the loved ones left behind is great.

"The most common theme seems to be the silent pressure to 'move on'," said Donita.

"Often, families and friends find it difficult to see someone they care about feel sad.

"When someone has died many people appear to be 'strong', however, behind closed doors, the pain of losing someone you love can be a very lonely and agonizing reality.

"Many bereaved people struggle with the genuine belief that

they are 'not coping'. Yet, grief is a normal, natural, powerful and human response to loss," explained Donita.

"Experiencing and expressing grief helps the healing process. It allows us to experience the pain of loss and gradually readjust to life without the person who has died."



Donita Menon - helping the bereaved through their journey of grief

There may be times when bereaved people just need to talk to somebody. Many people find it easier to speak with someone who is not closely related to them, who understands the grief journey, and has time to listen.

Integral to the Leukaemia Foundation's Grief and Bereavement program is Celebration of Life. These services are held in each state once a year. Families and friends are invited to take part, to remember, reflect and honour loved ones who they have lost to leukaemia, lymphoma, myeloma and related blood disorders.

The grief experience can be a very lonely. Time, support and allowing the bereaved to grieve can help them heal and live better with the painful, as well as the happy memories.

The Foundation's Grief and Bereavement Service is free and is offered to all bereaved families, either in person or by phone. If you need grief and bereavement support please call the Leukaemia Foundation on 1800 620 420.

BAE SYSTEMS PARTNERSHIP DELIVERS \$206,000

Australian defence and security company, BAE Systems, donated \$206,000 on behalf of its employees during an 18-month partnership with the Leukaemia Foundation.

The Foundation was chosen as the focus of the 2008-09 Charity Challenge campaign by a staff vote. Throughout the partnership, BAE Systems staff took part in fundraising activities and hands-on volunteering and BAE Systems' global business made a financial contribution in response to employee fundraising efforts.

"BAE Systems' employees made a significant contribution to our Vision to Cure and Mission to Care during this partnership," said Leukaemia Foundation of Australia's Chief Executive, Peter Cox.

"We thank the employees and management for their generous financial support, as well as their enthusiastic participation in corporate volunteering, such as being track marshals at *Light the Night*.

"Blood cancer is the second most common cause of cancer death in Australia. Proceeds from this partnership with BAE Systems will help to create a brighter future by funding research, and providing practical care to people living with leukaemias, lymphomas, myeloma and related blood disorders today," Peter said.



Wayne Achurch presents the BAE Systems donation cheque to Peter Cox

The campaign's success was attributed to the support of BAE Systems employees and Director of Human Resources, Wayne Achurch, said he was proud to present the cheque on behalf of all employees of BAE Systems Australia.

"The campaign has harnessed the values of our company and reflects the generosity of our employees and the extraordinary efforts of the Charity Challenge team.

"A big thank you to every employee who participated in our partnership with the Leukaemia Foundation and made this donation possible," said Wayne.

NEWS IN BRIEF

2008-09 ANNUAL REPORT AVAILABLE

The Leukaemia Foundation of Australia's 2008-09 Annual Report, covering a year of both excitement and challenges, is now available. A new strategic plan implemented during the 2009 financial year reflected an absolute commitment to *Our Vision to Cure and Mission to Care*, but with a focus on broadening our fundraising base. Our flagship event, the *World's Greatest Shave*, coincided with the tragic bushfires that affected much of Victoria, and while our income was slightly below that of the previous year, the event was more profitable overall due to efficiencies created by new technologies. Organisational development was another feature of the year as the Foundation welcomed its first General Manager for Human Resources to the team, Peter Watson, leading to standardisation of practices across states and increased management support. A training program for all our people is currently under development. The Foundation continued to develop collaborative relationships with synergistic organisations including our first agreement to work with Cancer Australia on research into lymphoma. In a year of challenging economic times, we performed well and thank the Board, management, staff, volunteers and our many supporters for their passion and contribution to our work. To all those who turn to us today and who may need to do so in the future, the Foundation continues to strive for excellence as we walk with you from diagnosis, through treatment and beyond. For an electronic copy of the annual report and financial statements contact us by email: info@leukaemia.org.au or download a copy from our website: www.leukaemia.org.au.



FUNDS RAISED AT SHIP NAMING CELEBRATION

The Governor-General of the Commonwealth of Australia, Her Excellency Ms Quentin Bryce AC, Patron of the Leukaemia Foundation of Australia, selected us as one of two charity beneficiaries from the launch of a new luxury cruise ship. She officially named P&O Cruises' latest superliner in a spectacular ceremony at Circular Quay in Sydney last December. As 'godmother' of Pacific Jewel, her Excellency asked for proceeds from the naming event to be donated to the Governor-General's nominated charities, the Leukaemia Foundation of Australia and Special Olympics Australia. More than \$48,000 was raised at the traditional ship naming celebration,



which saw the Governor-General break a bottle of champagne on the ship's hull (pictured). This was the highlight of the evening of free entertainment, enjoyed by thousands of Sydneysiders, which included live performances by Australian Idol winners, Stan Walker and Wes Carr, and fireworks. Ann Sherry, CEO of Carnival Australia, which operates P&O Cruises, said the cruise line was deeply honoured the Governor-General had accepted its invitation to name its latest ship. "The naming of a ship is a practice that dates back centuries to a time when ships provided the only link between continents, with the naming conducted by a female - usually a member of royalty or a prominent citizen," Ann said. "In keeping with this tradition, we were thrilled that the Governor-General agreed to fulfill this important role and that we were able to donate the proceeds from the evening to the Leukaemia Foundation."

TEDDY BEARS PICNIC AT CANBERRA'S FLORIADE

The Leukaemia Foundation held a *Teddy Bears Picnic* during Floriade in Canberra last October. The fun-filled day for the whole family included a gentle exercise and stretching class for children, live music, and games with the Gecko Gang. The highlight of the day was the raffle to win Lucky Bear - a giant teddy bear, which was drawn by Senator Gary Humphries (pictured).



STRONG SUPPORT FOR WORLD'S GREATEST SHAVE

A record number of people are expected to shave or colour their hair this month to raise funds through the *World's Greatest Shave*. Not only does this fundraiser generate almost half of the income the Leukaemia Foundation requires each year, it is one of our most successful avenues to highlight the impact of leukaemias, lymphomas, myeloma and related blood disorders in Australia, through the media. An addition to the campaign this year was development of a dedicated *World's Greatest Shave* Facebook page. At last count, there were more than 12,000 fans and many active fans who shared their experience, ideas and encouragement. There have also been posts by people who have utilised our services, thanking everyone for supporting them, by supporting the Leukaemia Foundation. Many of these are also members of the Leukaemia Foundation Facebook page. We look forward to bringing you the highlights and final results of the campaign in our next issue of *The Carer* when all the money is in. In the meantime, you can follow our progress at www.worldsgreatestshave.com.



CONTACT US

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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.