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Leukaemia Foundation

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1800 620 420
www.leukaemia.com

Margaret White gets together with members of the lymphoma support group in Adelaide.



WORLD LYMPHOMA AWARENESS DAY

World Lymphoma Awareness Day (WLAD) is an international campaign taking place on 15 September 2005. Coordinated by a coalition of health organisations around the globe, the Leukaemia Foundation is responsible for the promotion of the event throughout Australia.

The day aims to help people recognise lymphoma symptoms, which are difficult to identify as they are often mistaken for less serious conditions such as the flu or fatigue. It is hoped that improved awareness of lymphoma will increase early diagnosis and treatment, thus improving the lives of those affected by lymphoma.

For more information about World Lymphoma Awareness Day visit www.lymphomacoalition.org

What is lymphoma?

Lymphomas are cancers of the lymphatic system. The lymphatic system is part of the body's defence against infection – the immune system. Lymphomas occur when a type of white blood cell - a lymphocyte - becomes cancerous. Over time cancerous lymphocytes crowd out normal lymphocytes and the immune system can no longer function properly.

Lymphoma...the facts.

- Lymphomas are the sixth most common form of cancer in Australia
- The incidence of lymphoma has doubled in the past 20 years, with no known cause
- Lymphomas are seen in all age groups but are more common in people over the age of 50
- There are 35 different sub-types of lymphoma currently recognised by the World Health Organisation
- Non-Hodgkin's lymphoma is a government National Health Priority Area

Margaret's story

To mark WLAD, *Carer* spoke to South Australian Blair Athol resident, Margaret White, about her personal experience of living with lymphoma.

73 year old Margaret had been feeling unwell for a while but was really concerned one morning when she woke up with a large lump on her neck.

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MESSAGE FROM THE CEO....



Welcome to this issue of *Carer* magazine, which highlights the Foundation's work in achieving our Mission and Vision.

Between 8 – 12 August, the Foundation will be holding Leukaemia Week. During this time we will be thanking the many doctors, nurses, GPs, social workers, therapists and other health professionals

across Australia who have continued to support us. Staff at the Foundation are also using the awareness week as an opportunity to inform health professionals, patients and families about the free of charge support services that we provide. You can find out more about Leukaemia Week activities on page six.

I was truly inspired by reading Margaret White's story about living with lymphoma (page one). Her story highlights the need for World Lymphoma Awareness Day (15 September) to raise awareness about this devastating disease. The Foundation is delighted to be leading this event in Australia as part of the Global Lymphoma Coalition.

In addition to support groups, the Foundation offers education programs in metropolitan and regional areas across Australia. During 05/06, as well as workshops to help patients, families and carers cope with the shock of diagnosis, survivorship and grief issues, we will be delivering more than 94 disease-specific sessions. Read more about these programs on page seven.

The Foundation is giving everyone a good excuse for a lunch between 10 -18 September. We invite you to make a difference in a very simple way by hosting a World's Largest Lunch.

Margaret Ryan
Chief Executive Officer

NEWS IN BRIEF

WORLD'S GREATEST SHAVE TO CARE AND CURE

In 2006, World's Greatest Shave will take place from 4-6 May. The national and state Top 20 business clubs for WGS 2005 were announced on 19 July. PricewaterhouseCoopers were again the No.1 business fundraiser, for the second year running. Find out who else made the list by visiting www.worldsgreatestshave.com or look out for it in the next edition of *Carer*.

A big thank you to everyone who took part in 2005. The total has now reached over \$8 million.



PwC staff in Sydney.

THANK YOU TO SUPREME PRINTERS

Supreme Printers in Adelaide have provided a huge amount of support for the Leukaemia Foundation

over the past 12 months. Supreme gives the Foundation a significant discount on printing and design of materials, and the money we save helps us to provide important services to patients and their families. So a big thanks to Steve McNicol and all the staff at Supreme.

THANK YOU TO INVOCARE

In July, Karen Sorensen, Support Services Coordinator Southern NSW & ACT, presented a paper at an international conference in the UK. The conference examined the specialised area of grief and bereavement and Karen's paper was entitled, 'Creative goodbyes – limited only by your imagination, not your talents'. Karen learnt about international best practice in grief issues.

A big thank you to national funeral company, Invocare, for sponsoring Karen's flight to the UK.

STEM CELL TRANSPLANTATION

Bianca Calliss has asked us to make a correction from the last issue of *Carer* regarding her stem cell transplant. Bianca benefited from a stem cell transplant from a matched donor through the Australian Bone Marrow Donor Registry. If you would like to find out more about becoming a bone marrow or stem cell donor, please visit the Registry's website at www.abmdr.org.au where you can find contact details for your state or territory.

FOUNDATION FUNDS CHEMOTHERAPY DRUG RESEARCH

Dr Ricky Johnstone is a 38 year old researcher based at the Peter MacCallum Cancer Centre in Melbourne. Dr Johnstone has received funding from the Leukaemia Foundation to further examine how chemotherapy drugs kill cancer cells and why cancer cells can sometimes overcome these drugs.



After completing his PhD, Dr Johnstone worked at the Harvard Medical School in Boston for three years. He said, "Once I got to Boston I realised how exciting research could be and was keen to return to Australia and set up my own laboratory. I have been at Peter Mac since 2000 and it's a very rewarding environment."

Dr Johnstone is looking at a new class of drug called histone deacetylase inhibitors (HDACi) that kills cancer cells through a process of 'cell suicide'. Dr Johnstone describes the drugs as, "Very exciting. They are remarkably effective on tumour cells, with very little toxicity to normal cells, and have produced great results in the laboratory and early phase clinical trials with patients."

With funding from the Leukaemia Foundation, and help from researchers at the Walter Eliza Hall Institute, Dr Johnstone has used a mouse model that replicates human B-cell lymphoma. In the mouse model, the proteins believed necessary for 'cell suicide' to occur have been either eliminated or over expressed - these conditions also occur in human cancer. The model

can then be used to find out exactly what proteins are necessary for HDACi to effectively kill cancer cells.

This work in the laboratory has led to recent clinical trials in T and B-cell lymphoma patients. Dr Johnstone explains, "It's fantastic that what we have learned from the model can now be translated directly into trialling treatments with patients."

"For example, if the absence or over expression of a particular protein in the model seems to affect responses to a particular HDACi, we will look for this protein in patients' biopsy results. HDACi may then be delivered in combination with another drug to overcome tumour resistance," said Dr Johnstone.

The results of the laboratory work and subsequent clinical trials will lead to more tailored combination therapies for lymphoma patients, and this work is setting a ground breaking precedent for clinical trials with combination therapies.

Dr Johnstone has received funding from a range of organisations to continue his work. "The funding we received from the Leukaemia Foundation was particularly crucial in expanding the mouse model and trialling HDACi in combination with other anti-cancer drugs. The Foundation's support has allowed us to move from the laboratory onto clinical trials involving patients, which in turn will hopefully lead to the development of more effective treatments."

NEW RESEARCH INTO SELF RECOVERY

The Leukaemia Foundation is funding a new research study which will investigate the benefits of exercise for children in remission from leukaemias and cancers for the first time.

The research will be conducted by Kim Laird, Head Physiotherapist of Paediatrics at Princess Margaret Hospital for Children in Perth.

Ms Laird's study hopes to determine if a structured exercise regime will result in increased muscle strength and activity levels in children who have received a bone marrow transplant.

The study will also focus on how cancer treatments such as transplants impact upon a child's overall fitness, including the likelihood of the development of problems such as obesity and fatigue.

The \$10,000 research program is the inaugural project funded by the Leukaemia Foundation in Western Australia's 'New Investigators Research Grants.'

The results of the study will be available in mid 2007.

Physiotherapist Kim Laird and study participant Thomas Corkhill, who was diagnosed with leukaemia in 2001 and finished his treatment 3 months ago.

Photographer: Andrew Ritchie - Guardian Express



EPIC BIKE RIDE TO RAISE FUNDS FOR THE FOUNDATION

Two young men from South Australia are cycling an incredible 16,000km around Australia to raise \$50,000 for the Leukaemia Foundation.

Rob McLean (23) and Evan Jones (18) are undertaking the gruelling trip in memory of Tim Reynolds, a close friend of Rob's who died from leukaemia in 2001, aged just 18.

Soon after completing his HSC, while on holiday in Queensland, Tim was diagnosed with acute lymphoblastic leukaemia. He returned to Adelaide immediately and began 12 months of intensive treatment. After three months of chemotherapy and a brief remission, Tim was admitted to the Royal Adelaide Hospital for a bone marrow transplant. This was unsuccessful and he sadly died at home, surrounded by his friends and family, on 18 January 2001.

Rob said, "If you were unhappy, Tim would find a way to make you happy. He stayed positive through the hardest times and when things got tough he always came up with something to make everyone laugh. Even in his final hours his humour came through – he put his friends before himself."

Rob wanted to do something extraordinary to remember such a great friend, and so 'Loop for Leuk' was born. During the ride, Rob and Evan will average 120kms a day and visit every capital city. The trip will take around 155 days.

The men left Adelaide on 24 April and have travelled through Tasmania, Victoria, New South Wales, Queensland and the Northern Territory. They will be cycling through Western Australia during August and plan to arrive back in Adelaide at the end of September.

Leukaemia Foundation CEO, Margaret Ryan, said, "Rob and Evan are making such a positive impact on people's lives. Not only with the money they are raising but the inspiration they are giving other Australians who can see how dedicated they are to the cause."

For more information about the ride, visit the news section at www.leukaemia.com. To make a donation call 1800 620 420 and let us know that it is for the 'Loop for Leuk' appeal.

Rob and Evan meet Blake at the Leukaemia Foundation's accommodation units in Waverton, Sydney.



Rob and Evan approach the top of '99-bend hill' near Queenstown, Tasmania.

MARGARET'S STORY *Continued from page 1*

In July 2003, after a visit to her GP and a biopsy, Margaret was diagnosed with diffuse large B-cell lymphoma. She was immediately sent to Queen Elizabeth Hospital in Adelaide and had to return every three weeks for chemotherapy.

After 15 months, Margaret went into remission and only needed to visit the hospital every three months. Margaret remembers, "Mentally, going into remission was far worse. In the hospital, I had a support network of doctors, nurses and technicians. They suddenly weren't there anymore. I felt lost and didn't know anyone else who had lymphoma."

Margaret called the Leukaemia Foundation and was told that no support group specifically for lymphoma patients had yet been established in SA. So with the assistance of the Foundation, Margaret established the lymphoma support group in June 2004.

The group provides an environment where people can talk and share their problems, with face to face meetings and telephone support. Margaret says, "Families try to understand but you can never really understand unless you have walked in someone's shoes. Coming to the group is so empowering. You forget your own problems for a while when you are caring for and reaching out to others."

The lymphoma support group meets regularly in the Leukaemia Foundation's office in Adelaide. The Foundation also helps the group with transport to and from meetings, and costs such as printing. Margaret recently received a grant from the government to set up a similar group in the Northern Adelaide suburbs.

"I'm really appreciative of what the Foundation has done. It's very comforting to have the support services staff, Allan and Angela, there to support what we are doing," said Margaret.

GOLF DAY AND DINNER TO REMEMBER GRAHAM

On 14 May in the ACT, the fourth Graham Abell Golf Day and Dinner brought the total raised by this annual event to an incredible \$50,000. The day was a huge success with guests teeing off against the sensational panoramic views of the Brindabella Ranges. The fun continued into the night with great food, wine and fantastic entertainment.

The event is held in memory of Graham, who passed away from leukaemia in 2001 at the age of 27. Graham was a fit and active man who represented the ACT in both cricket and soccer. He enjoyed travelling and spending time with friends and family.

Graham and Janelle Abell were married in February 2000. Janelle recalls, "I remember on our wedding day, he looked so pale and everyone commented that he must be nervous. Nobody knew what poison was taking over his body."

Graham experienced tiredness and headaches on their honeymoon, so Janelle took him to visit the doctor the day after they got back. They were both shocked when a blood test revealed he had leukaemia and needed immediate treatment. After chemotherapy, a period in remission, a relapse and a subsequent bone marrow transplant, Graham was given the devastating news that the transplant had failed.

Janelle said, "Even given this shocking news he stood up and took it on the chin. In the last five months he travelled to Queensland, Sydney and back to

Canberra. He went hot air ballooning, climbed Sydney Harbour Bridge and lived life to the fullest."

Sadly on 25 September 2001 Graham passed away.

After losing Graham, family and friends wanted to do something to help others in his situation and so the fundraising Golf Day and Dinner was born. Janelle and a team of volunteers work hard every year to make the event a huge success. Their efforts are helping the Foundation to improve patients' quality of life and fund research into finding a cure.

Photo: The Canberra Times



Committee members (L to R) Kylie Rodda, Justine Basha, Stephen Gniel, Janelle Abell, Stephen Buct, Michelle Ace, Rachael Barac and Rowena King.

ADDITIONS TO THE NSW SUPPORT SERVICES TEAM

The Leukaemia Foundation was delighted to welcome on board the following new staff during recent months. These new additions to the team will increase the support available to patients in Central and Western Sydney and Central West NSW.

Leonie Snowdon, Sydney Metropolitan Support Services Coordinator, continues to cover Royal North Shore Hospital, St Vincent's Hospital and Northern Sydney.



Danielle McDougall
Western Sydney Support Services Coordinator

Danielle will be increasing the level of support the Foundation is able to provide patients and their families at hospitals in West and South West Sydney. This includes Nepean Hospital, Westmead

Hospital, the Children's Hospital at Westmead, Camden Hospital and Campbelltown Hospital.



Fiona Pearce
Operations Coordinator, Western Sydney

With a background in both cancer nursing and administration, Fiona will be based at Westmead, running the transport program and managing the accommodation complex. Fiona will also be

supporting regional patients and families who need to relocate to Westmead for treatment.



Clare Backhouse
Central Sydney Support Services Coordinator

Clare will be based in Central Sydney and spend time at the Prince of Wales and Sydney Children's Hospitals at Randwick, Royal Prince Alfred Hospital at Camperdown and Concord

Hospital. She will also be covering the Central West NSW region including Dubbo, Bathurst and Orange.

LEUKAEMIA WEEK 8 - 12 AUGUST 2005

During Leukaemia Week the Leukaemia Foundation is organising activities to thank health professionals for their fantastic support over the past year. Leukaemia Week is also an opportunity to let patients, families and health professionals know about the free of charge support we offer, from transport and accommodation to education and emotional support, all free of charge.

What's on?

Here's just a taster of some of the activities taking place during Leukaemia Week. Check out www.leukaemia.com or call 1800 620 420 for more details.

Display stands will be set up in hospitals across the country with a range of posters, leaflets and flyers available to let people know about the Foundation's services. Staff and volunteers will be on hand at some hospitals to give out information and answer questions.

Cards and gifts will be distributed to health professionals to thank them for their support. Leukaemia Foundation Support Services staff will also be getting out and about to meet with health professionals and promote our services.

Free general and disease specific education programs and patient support groups are taking place in some states during Leukaemia Week (visit www.leukaemia.com for times and venues).

- Education sessions for myeloma patients and their carers in Newcastle and Central Coast, NSW.
- Living with chronic illness information evening in Sydney.
- Taking Control two day education program, Coffs Harbour, NSW.
- Acute leukaemias information evening in Perth.
- Multiple myeloma support group in Perth.
- Lucky Bear's Workshop (6-8 year olds) in Perth.
- Carer's support group in Perth.



The Leukaemia Foundation display stand in Prince of Wales Hospital, Sydney, during Leukaemia Week 2004. (L to R) Support Services Coordinator, Leonie Snowden with Clinical Nurse Consultant Kerrie Murphy and patient/volunteer Gladys Lim.

Mission to Care

Services provided	Figures for 2003-2004 financial year*
Furnished accommodation	16 'home away from home' accommodation centres provided 1,201 families with 43,174 nights accommodation
Transport	25 sponsored vehicles transported more than 3,364 families over 758,167 kilometres to and from treatment centres
Education programs	1,691 patients and family members attended face-to-face education programs with trained nurses, doctors, dieticians, counsellors, alternative therapy specialists, survivors and exercise specialists
Patient support groups	101 group activities facilitated
Practical assistance	844 families benefited from practical assistance
Counselling	Approximately 50,000 contacts were made with patients and families by our team of trained cancer nurses and other health professionals. This includes phone support or visits to home and/or hospitals
Volunteers	11,692 hours donated by more than 3,000 volunteers who assisted in supporting patients and families through our national transport program, community fundraising, maintenance of accommodation centres and administrative office support

*taken from Leukaemia Foundation Annual Review 2003-04

SUPPORTING PATIENTS AND FAMILIES ACROSS AUSTRALIA

The Leukaemia Foundation offers a wide range of disease specific and general education programs to help patients and families through the diagnosis, treatment and recovery of leukaemias, lymphomas, myeloma and related blood disorders.

These programs take place across metropolitan and regional Australia and include presentations from oncology nurses, dieticians, counsellors, psychotherapists and social workers. Sessions deal with the wide range of physical challenges and often complex emotional issues that patients and families may face.

In addition, the Foundation offers programs which allow patients and families to get together with people in the same situation, to share experiences and provide support and encouragement.



Workshop helps patients 'take the next step'.

Taking the next step

Eighty three people attended a workshop in Melbourne during May, which provided patients and their carers with support and advice on taking the next step following treatment.

The Foundation's eminent psychologist, John Boyle, spoke about the impact of finishing treatment and dealing with survival. Dr David Ritchie, from the Late Effects Clinic at the Peter McCallum Cancer Centre, spoke to patients about what long-term side effects of chemotherapy and other treatment they could expect. All attendees were touched by the story of Joel Nathan, chronic leukaemia survivor turned author. Joel is the author of *What to do when they say "it's cancer"* a practical guide for cancer survivors.

Minter Ellison Lawyers generously hosted the workshop for the second year in a row. These important workshops provide an avenue for patients who have completed their treatment to gain support and information related to the ongoing issues associated with their disease.

The Lucky Bear Club Children's Program

Unfortunately, one of the major side effects of a parent or family member being diagnosed with, or undergoing treatment for, a serious illness is the significant change that occurs in the family environment. This change often has a great psychological, behavioural and physical impact on a child's ability to cope.

To help children affected by these traumatic events, the Leukaemia Foundation in Western Australia runs half-day and full-day activities and workshops for children in the 3-5 year, 6-9 year and 10-12 year old age ranges who have a parent or family member with a blood or bone marrow cancer.

These workshops are professionally facilitated by play therapists, health professionals and counsellors, and offer the children the opportunity to express themselves in a safe and creative environment.



Lucky Bear Club – getting children together.

Blood Cancer Connect

The Blood Cancer Connect

program runs in NSW and was developed by the Leukaemia Foundation with the Cancer Council, to provide patients with support and encouragement through their care and recovery.

The program provides one-to-one support from survivors who are trained to support anyone diagnosed with a blood cancer. As survivors they understand the emotional and physical challenges that newly diagnosed patients are facing.

Greg Thurling was diagnosed with chronic myeloid leukaemia in May 2001. He received a successful bone marrow transplant in October 2001 and was one of the first volunteers to complete Blood Cancer Connect training.

"All the mentors have been through a very tough time and have come out the other side. This program lets people know that they are not on their own and there is someone to talk to," said Greg.

Support groups in SA

Support services staff in SA have been developing patient support groups over the past year. Last year the SA office was approached by an enthusiastic patient with lymphoma who had a real passion to start a lymphoma support group (page 1). With the assistance of the Leukaemia Foundation, the support group has been running for the last 12 months.

Meetings are also an opportunity to find out more about the disease. This year has seen the introduction of invited guest speakers including a haematologist, social worker and dietician. There is also a social element to the group, with a very successful Christmas get together held last December in a local hotel.

In addition, a Leukaemia Coffee Morning has been running in SA since April. The groups have been so successful they will be splitting into two after September. One group will be for chronic leukaemia and the other for acute leukaemia patients.

KEEPING FAMILIES TOGETHER

The Leukaemia Foundation in WA is now leasing its first family accommodation unit in the Perth suburb of Bassendean.

The Leukaemia Foundation currently leases one bedroom units in Inglewood and Coolbellup but this is the first unit capable of housing families in Perth.

The family unit is currently a 'home away from home' for a 17 year old boy, his parents and two sisters, who all live in the far north of Western Australia, whilst he undergoes treatment for lymphoma.

Prior to the family moving in, community volunteers from stockbroking firm Goldman Sachs JBWere spent a weekend cleaning, painting, paving and gardening at the unit to make the home as comfortable as possible for the teenage patient and his family.

Kris Laurie, Leukaemia Foundation Regional Manager WA, said that patients from regional Western Australia who are diagnosed with leukaemia or a related blood cancer are forced to relocate to Perth to receive their vital medical treatment.



Ron Bennett, Senior Portfolio Manager at Goldman Sachs JBWere, 'brushes up' on his decorating skills with son Nicholas.

"This type of financial and personal support from corporates and donors will enable the Foundation to be able to continue to provide these essential services," said Mrs Laurie.

"Patients typically begin treatment within 24 hours of diagnosis, often requiring them to uproot and relocate close to treatment centres for weeks, months or even years. Many families find themselves in financially crippling circumstances

whilst coping with the shock and emotional turmoil associated with the diagnosis.

"The Leukaemia Foundation has acquired this unit in order to keep families from regional areas of WA together during a very tough time, both physically and emotionally," said Mrs Laurie.

RAY WHITE HOME SALES BENEFIT LEUKAEMIA FOUNDATION

Home sales in Western Australia's Great Southern Region have resulted in a \$25,000 donation to the Leukaemia Foundation.

Ray White in Albany donated \$100 to the Foundation for every home listing sold between 1 January and 31 March this year and the result exceeded all expectations.

Rino Daniele, Principal of Ray White Albany, said that the large donation was a result of both a booming real estate market and the generosity of the Albany community when they realised a percentage of their home sale would support children and adults living with leukaemias, lymphomas, myeloma and related blood disorders.

Mr Daniele said that he and his Co-Principal, Graham Walker, along with many other Ray White Albany staff also had their heads shaved recently for the Foundation's World's Greatest Shave.

"We chose to support this cause because the Foundation is focused on the care and support of patients from our local community. The Foundation provides patients with accommodation, transport and counselling free of charge while they receive life-saving medical treatment in Perth," said Mr Daniele.

In the past two years alone, the Foundation has supported over 30 patients from Western Australia's Great Southern Region through their transport, accommodation, education and counselling programs.



Ray White Albany Principals Graham Walker and Rino Daniele with the Leukaemia Foundation's Dean Starbuck.

VICTORIAN VOLUNTEERS GIVEN A ZOO OF A DAY!

Up to 100 Victorian volunteers were recognised for their ongoing commitment to the Leukaemia Foundation with a day at Werribee Open Range Zoo in May.

To coincide with National Volunteer Week, this fun event aimed to highlight the important services that volunteers help the Foundation to carry out.

"The tireless support and dedication of our volunteers makes a real difference to the lives of patients and families. For example, our patient transport program is manned entirely by trained volunteers," said Regional Manager Victoria/Tasmania, Chris Browne.

"During treatment, a major concern for patients is the severe weakening of their immune systems. This leaves them susceptible to infections and makes public transport a dangerous option. Volunteer drivers provide a friendly face and someone to talk to during a difficult time, as well as a safer way of getting to and from regular treatment appointments.

"The Werribee Open Range Zoo day was our way of saying thanks."

Tony McMahon has been a volunteer with the Leukaemia Foundation since a close friend's son died from leukaemia four years ago.

"I get so much out of volunteering for the Foundation because I know I'm helping people who through no fault of their own are sick," said Tony.

"I drive the patient transport cars, which I love because I'm able to relax patients on their way to treatment. I see them smiling when they come out, knowing they don't have to go back for treatment for another week, and I feel that I'm making a difference."

National Volunteer Week is an annual week in May dedicated to recognising the vital contribution that volunteers make to not-for-profit organisations.

If you are interested in finding out about volunteering for the Leukaemia Foundation please call 1800 620 420.



Vic volunteers celebrate National Volunteer Week with a snag.

PATIENT SURVIVORSHIP WORKSHOPS MADE A REALITY BY HELEN MACPHERSON SMITH TRUST

The Helen Macpherson Smith Trust recently granted \$25,000 to the Leukaemia Foundation for a series of Patient Survivorship Workshops to take place across Victoria in 2005-2006. These workshops provide an avenue for patients who have completed their treatment to gain support and information related to the ongoing issues associated with their disease, including financial stability, psychosocial issues and coping strategies.

Without private donations, such as the grant from Helen Macpherson Smith Trust, the Foundation would not be able to continue its range of support services for patients and their families.

Thank you to the Helen Macpherson Smith Trust for their support.

NEW FOUNDATION OFFICE OPENS IN THE NT

On 23 June, His Honour Mr Ted Egan AO, the Administrator of the Northern Territory, officially cut the ribbon to open the new Leukaemia Foundation office at Casi House in Darwin.

After seven months of preparation, planning and wondering if it would actually ever happen the exciting moment took place in front of invited guests and dignitaries.

Margaret Ryan, Leukaemia Foundation CEO, Allan Hayward, Acting Manager Support Services SA/NT and Pam Gable, Acting Regional Manager SA/NT all flew in for the event. Teresa Hyatt, who started work as Support Services Coordinator with the Foundation in the NT the following week, attended her first official function. Simmone Jarvis, Community Partnerships Manager NT, joined in the celebrations.

The new office gives the Foundation a real presence in the NT. It also means that the Foundation can plough money back into the local community, who have been so generous in supporting the Foundation since the first office opened in the NT two years ago.

Guests enjoyed a variety of finger food and a glass of wine whilst Mr Ted Egan sang a song he recorded some years ago about a young child who sadly lost his fight with leukaemia. The young boy had a dream to be a rodeo rider, just like his dad, and the song is titled 'Ride on Little Cowboy'.



His Honour Mr Ted Egan AO, the Administrator of the Northern Territory, officially opens the new office.

REGIONAL TRIPS A SUCCESS FOR SA

During June and July, Pam Gable and Tracey Clegg, Community Partnerships Manager in South Australia, embarked on a series of regional trips throughout the state.

The aim of these visits was to let people know about the Foundation's upcoming fundraising event, World's Largest Lunch 2005. It was also an opportunity to say 'thank you' to current and past supporters of the Leukaemia Foundation.

Appointments were made in advance with Friends of the Foundation groups, local councils, golf clubs, hotels, cafes and restaurants, past patients and industries within each region.

Pam and Tracey were interviewed on the local radio networks about World's Largest Lunch, the Leukaemia Foundation and the services that the Foundation provides for patients and families. They visited local hospitals, community health centres and local support groups to restock their information booklets and update them on the Leukaemia Foundation's activities.

Visits were also made to World's Greatest Shave participants to say a personal thank you for their continued support.

"One of the wonderful memories I take away from these trips is how well the Foundation is received in regional areas," says Pam.

"The way that local South Australians embrace the work of the Foundation and our fundraising events is fantastic. People living in regional areas really understand how hard it must be to relocate to the city when you are diagnosed with a leukaemia, lymphoma, myeloma or related blood disorder."

Regional trips are made twice a year and cover most of South Australia including the South East, Riverland, Eyre Peninsula, Yorke Peninsula, Barossa Valley and the Fleurieu Peninsula.

Shannon Warnest of the Willalooka Tavern talks Lunch with Pam Gable.



A DAY IN THE LIFE

Support Services Projects Coordinator, Leanne Crnek, works part time for the Leukaemia Foundation in NSW. Leanne is responsible for planning, developing and coordinating education and support programs for patients and families throughout NSW and the ACT.

Leanne was previously the Nurse Unit Manager of the haematology unit at Prince of Wales Hospital. She resigned in June 2003 to spend time with her young family and says that the flexible working conditions at the Foundation now allow her to pursue, "a passion and love for haematology and helping patients and families, while looking after two small children".

The free education programs consist of disease specific information evenings, such as living with chronic illness, lymphomas, leukaemias, and myeloma. Another program, Taking Control, is designed to help patients and their families cope with the physical, emotional and financial upheaval that occurs with a leukaemia diagnosis. Professional presentations from exercise physiologists, psychotherapists and dieticians are warmly received by patients and families. Art therapy sessions and humour workshops are also offered as part of the Taking Control program.

Leanne organises venues, catering, facilitators, mail outs, flyers, handouts and information packs to ensure everything goes smoothly on the day. She coordinates events in Sydney and is expanding the series to regional areas. Taking Control weekends have already taken place in Canberra, Newcastle, Wollongong and the Central Coast and will be expanding to Coffs Harbour and Port Macquarie during the next six months.

Leanne says it is very rewarding to meet patients and families who are benefiting from the Leukaemia Foundation's services, "It's great to see the change that comes over people during the program. I met one gentleman in week two of Taking Control who was very anxious, teary and distressed. He was looking for answers and nervous about asking his doctor too many questions.

"To see the relaxed smile on his face on the final weekend as he was playing tennis with his wife, using a fly swatter and a heart shaped balloon, was very satisfying. During the program, people realise they can gain some control over their situation and really come alive in the humour workshop!"

The rollout of more disease specific workshops is planned for the coming months as well as sessions for health professionals on topics such as grief and loss and self care. Leanne says, "My days are really busy and I give 200 percent while I am here. I need to be organised and manage my time effectively – my previous role and personal experience with social functions have provided a lot of practice! I feel very proud to be part of such a worthwhile organisation, providing a quality service and knowing that we are making a difference."



Leanne with Dr Peter Spitzer (aka Dr Fruit Loop), Chairman, Medical Director of The Humour Foundation.

60 SECONDS WITH..... KITTY MANSON



What first motivated you to volunteer for the Leukaemia Foundation?

When the Leukaemia Foundation first started in Western Australia, I saw an advertisement in the paper calling for volunteers. I was only working part time then so I thought I'd try my hand at volunteering. I have been here for

over ten years and I'm still enjoying myself!

What do you enjoy most about volunteering?
I enjoy the variety of jobs I get to help with around the office and the opportunity to meet new people.

What book are you reading at the moment?
Kate Hannigan's Girl by Catherine Cookson.

What is your favourite movie?
Gone with the Wind.

What is your favourite food?
A lamb roast.

Aside from volunteering, what do you enjoy doing in your spare time?
Playing bowls at the North Perth Bowling Club with my friend and fellow LF volunteer Connie Montgomery.

Who would you most like to sit next to on a long haul flight and what would you ask them?
Dr Fiona Wood - 2005 Australian of the Year and the Director of Royal Perth Hospital's Burns Unit. I'd ask her about the new burns treatments she developed to treat the seriously burned Bali bombing victims. She's very inspiring.

FRED AND THE FOUNDATION

If you were to ask who were the people who have made the Leukaemia Foundation what it is today, Fred Bylett's name would certainly be among the first mentioned.

Fred Bylett (OAM) is the Leukaemia Foundation's longest serving board member, having served on the executive committee in Queensland since the Foundation's inception in 1975. Fred's commitment to the Leukaemia Foundation has been unfaltering ever since. He held the position of president until 1980 and since then has held the position of vice president.

His association with the Foundation began through his involvement with the Holland Park Lions Club, which he helped form in 1969.



Fred and Joyce Bylett.

In 1975 Brisbane's only haematologist at the time, Dr Trevor Olsen, came to speak to the club about the terrible lack of medical equipment, hospital facilities and understanding of a disease called leukaemia. Several club members, including Fred, decided to throw their weight behind this cause and they formed the Lions Leukaemia Foundation, now known as the Leukaemia Foundation.

In September 2003, Fred was awarded an Order of Australia Medal for his dedicated service to the Leukaemia Foundation and Lions Club. In 1992 he was awarded life membership of the Leukaemia Foundation.

Particularly in the early days, Fred's involvement with the Foundation was very 'hands on'. When Hollydene, the first patient accommodation was purchased, Fred and Joyce were involved in the extensive renovations. They also took part in huge numbers of fundraising events.

"It's just tremendous that patients now have such hope, and their chances of survival are so much better than they were 30 years ago," Fred said.

"The other day at an event, a little girl came up to me and said I've had leukaemia and I've been in remission for two years".

Fred replied, "You little beauty, you've just made my day."

WORLD'S LARGEST LUNCH 2005

It's a good excuse for a lunch! Get together for lunch with friends, family or workmates between 10 – 18 September to raise money for patients and families living with leukaemias, lymphomas, myeloma and related blood disorders.

You can hold any kind of lunch.....

A catch-up with the girls, a Friday lunch at the office, a BBQ while watching the footy – anything goes!

It's an easy recipe!

- Select the day and time between 10 – 18 September 2005
- Decide what type of lunch you're going to hold and where it's going to be
- Invite your guests (we'll give you everything you need)
- Ask everyone to make a donation during your lunch
- Think of some fun ways to raise even more money such as a raffle, game or selling World's Largest Lunch souvenirs
- Clubs, pubs and businesses can raise extra funds by covering a wall with mini lunch mascots. Just ask your patrons to donate \$2, write their name on a

mascot and pin it on a wall.

It's an easy way to show your support and it looks great. Call 1800 620 420 for a supply of mascots.

Why is lunch so important?

Having lunch is something we usually take for granted, as we grab a quick bite during our busy day or spend a leisurely lunch on a Sunday with friends and family.

However, if you are being treated for leukaemias, lymphomas or myeloma it's not that simple.

Your immune system is often so low that you need to carefully monitor your diet and you may not be able to mix with anyone in case of infection. As a result, you can miss out on the simple pleasure of having lunch with friends, family, and work colleagues.

By having lunch together, you and your friends will help people who may not be able to enjoy such a simple pleasure.

Register now at www.worldslargestlunch.com or call 1800 620 420 to receive your host kit with everything you need including a lunch box for collecting donations.

