Alan Pavisich was diagnosed with lymphoma in July 2005, just 11 months after his baby, Brooke, started treatment for infantile leukaemia. Both father and daughter had very aggressive forms of blood cancer. Despite many setbacks on their treatment journey both are now in remission.

“I just couldn’t believe my little girl was sick,” said Alan when he and his wife, Narelle, found out Brooke had acute lymphoblastic leukaemia in August 2004. At the time Brooke had gone off her food, was lethargic and sported bruises from learning to crawl.

“Narelle is a bit of a worrier,” explained Alan. “So she got on the Internet and said Brooke had some of the symptoms of leukaemia.”

They immediately took their 10-month-old baby to their doctor who said she appeared to be healthy but ordered blood tests, and that afternoon the Pavisichs were told Brooke had cancer. She went straight to the Princess Margaret Hospital in Perth and began chemotherapy that night.

The couple were told that because their child was aged under 12 months, the chances of her beating leukaemia was only 40 per cent. Brooke went on a trial for infantile leukaemia, a treatment program that was aggressive and intensive.

“She was amazing. She always had a smile on her face and didn’t complain nearly as much as I did,” said Alan who was diagnosed with large diffuse B-cell lymphoma just two weeks before Brooke finished her treatment.

He felt sick, had a bad cough and was vomiting but his first blood test was clear. During a subsequent blood test, a lump on his arm became visible when the tourniquet was tightened and in two days it grew from the size of a marble to a golf ball.

“I literally had lumps growing on me overnight,” said Alan who also spent a lot of time in hospital.

His treatment finished with a stem cell transplant in May 2006 and last year the family, which includes Brooke’s brothers, Mark, nine and Matthew, seven, spent their first “normal Christmas” together in three years.
NEW FREE INFORMATION BOOKLET
National: The Leukaemia Foundation partnered with Pfizer Australia recently to launch the latest Pfizer Australia Health Report which focuses on blood cancers. The Pfizer Australia Health Report is produced monthly in collaboration with consumer health organisations and medical experts and provides information and news on a variety of health issues to help Australians live a healthier, happier lifestyle. The printed booklet is available free by phoning 1800 675 229 or by visiting www.healthreport.com.au. The Blood Cancers’ issue features information on leukaemias, lymphomas and myeloma, and highlights the Leukaemia Foundation’s role in supporting patients and families living with these diseases as well as related blood disorders.

IN MEMORY MEDIA TOUCH FOOTY CHALLENGE RAISED $85,000
New South Wales: The 2006 touch footy Harvey Norman Charity Media Challenge was a great success, attracting a crowd from the television, radio and publishing sectors, along with many sporting greats. They competed at Sydney’s Aussie Stadium last November and raised $85,000 for the Leukaemia Foundation. The event was held for the first time in 2005 after Network TEN Sports Programmer, Sam Heard, approached the Foundation to raise funds in memory of his father, Graeme, who passed away from leukaemia, and to help other families in a similar situation. The 2006 challenge marked the 10th anniversary of Graeme’s death which made the event all the more moving.

NEW ACCOMMODATION IN VICTORIA
Victoria: To accommodate the growing demand for patient and carer accommodation in Melbourne, the Leukaemia Foundation has leased two new apartments – at Prahran and North Melbourne. The self-contained apartment at Prahran has two private bedrooms and two bathrooms and is part of a secure complex that is conveniently located directly opposite the Alfred Hospital. At the Max Whiteside apartment complex in North Melbourne, the Foundation has leased a fourth apartment which is self contained and within walking distance of the Royal Children’s and Royal Melbourne hospitals. It is also close to St Vincent’s Hospital and the Peter MacCallum Cancer Centre. In the 2005/06 financial year, the Leukaemia Foundation in Victoria provided more than 2500 nights of accommodation for patients and carers in its apartments and houses in Melbourne, Geelong, Ballarat and Traralgon.

BORDER OFFICE OPENS
New South Wales/Victoria: The Leukaemia Foundation’s new Border office is strategically located at Albury to service the Albury/Wodonga river border area, Riverina in south-west NSW and the Hume area of Victoria. The office was officially opened by the Mayor of Albury City, Cr Amanda Duncan-Strelec, and the Mayor of Greater Hume Shire, Cr Denise Osborne. The Acting Mayor of Wodonga, Cr Rodney Wangman, was present and Amanda Van Werkhoven gave an emotional account of the difficult journey her family faced when her son Jayden, now six, was diagnosed with Burkitt’s lymphoma in September 2006. The family had to relocate to Melbourne for three months while Jayden received intensive treatment and Amanda praised the Foundation for the support the family received at such a distressing time. Jayden is among nearly 100 patients, aged from 14 months to 80 years, who are assisted by Carmel Excell, the Foundation’s support services representative in the area. Carmel has more than 10 years’ experience as a nurse in Perth and Hobart and as a social worker in the Albury-Wodonga region. She is building on the work of the Foundation in the area, previously serviced by periodic day visits to regional patients by metropolitan-based support services staff from Melbourne and Canberra.

CANBERRA RELOCATES TO IMPROVE ACCOMMODATION SERVICE
Australian Capital Territory: In Canberra, the Leukaemia Foundation has relocated to larger premises close to the Canberra Hospital which will greatly improve the accommodation services for patients and families in the ACT. The new complex provides a support centre for the two ACT staff members and a meeting place for the Foundation’s Community Committee.
**JOHN’S BEST EVER CHRISTMAS PRESENT - MabThera**

John Jongeling swears by the drug MabThera which he reckons is the reason he’s in remission today.

Back in July 2002, John, 51, was diagnosed with an aggressive form of non-Hodgkin lymphoma.

The only symptom he had was a lump in his stomach which he thought was a hernia. His wife, Marja, suggested he go to the doctor who organised an X-ray and one-week later he was told he had cancer.

More scans and a needle biopsy at St Vincent’s Hospital in Launceston revealed he had three months to live without treatment, but a week later this prognosis was reduced to two weeks, when he “blew up like a balloon”.

Over a period of two weeks John had more than 16 litres of fluid (dead lymphatic cells) taken from his body.

He was transferred to the Launceston General Hospital for treatment which began with chemotherapy followed by a course of MabThera.

In March 2003, John had a stem cell harvest in case he needs to have a transplant down the track.

Two years after his diagnosis and nine months after he was told he was in remission, he relapsed. At the time, John collapsed with pancreatitis, developed adult diabetes, glaucoma and suffered internal bleeding for which he received 4.5 litres of blood over two days. He was treated for these conditions over the following two months before he could begin another course of treatment with MabThera, on December 22, 2004.

“If I hadn’t had it, I don’t think I’d be here,” said John, who has been in remission now for more than two years.

John works for himself “pottering three mornings a week” manufacturing and installing skylights, but he works much harder as an ambassador for the Leukaemia Foundation. He’s had his head shaved twice launching the **World’s Greatest Shave** in Launceston and for Roche in Melbourne and has spoken at the Foundation’s support groups.

“I live day to day now and I’m having a good time with my wife,” said John.

“Each day is a new beginning and each morning I thank God, as you just never know.”

**About MabThera and lymphoma**

Lymphoma, the most common type of blood cancer, is also the nation’s fifth most common cancer.

Lymphoma is a growing public health issue and the number of Australians diagnosed with non-Hodgkin lymphoma (NHL) is projected to increase by more than 30 per cent between 2002 and 2011.

The antibody therapy, MabThera, used in combination with chemotherapy, more than doubles the time NHL patients spend in remission and allows patients to live longer.

MabThera belongs to a group of medicines known as monoclonal antibodies. These are proteins which specifically recognise and bind to another unique protein called an antigen. MabThera works by binding to an antigen on the surface of certain white blood cells known as B lymphocytes. During the process of binding to the antigen, the abnormal growth of the B lymphocytes is stopped. It is the abnormally growing B lymphocytes that are responsible for certain types of NHL.

MabThera is approved by the Pharmaceutical Benefits Scheme in Australia for the treatment of symptomatic, previously untreated, CD20 positive, stage 3 or 4, follicular, B-cell NHL, in combination with chemotherapy, and for relapsed or refractory follicular or low grade B-cell NHL, and previously untreated, CD 20 positive, diffuse large B-cell NHL in combination with chemotherapy.
Public transport poses a huge risk to patients who are undergoing treatment because they have weakened immune systems and are vulnerable to infections.

Therefore the Leukaemia Foundation’s Patient Transport Program is an important part of its mission to provide personalised care and support to patients.

The program resulted from the generous sponsorship of Bridgestone Tyre Centres, Holden and the Peter Brock Foundation in 1999. Since then, along with the help of additional sponsor, iSOFT, a team of dedicated and trained volunteers has driven patients to and from their medical, outpatient and other specialist appointments.

In the last 12 months, volunteer drivers have:
- travelled 700,000 kilometres
- made 17,598 trips in 31 cars
- provided 4070 patients with transport.

The Foundation’s national support services manager, Brian Amos, said the Patient Transport Program was vital to both patients and carers.

“The service is specifically designed to relieve the pressure faced by patients and families who have a problem getting to treatment, such as a family which does not have a car,” Mr Amos said.

“It also ensures patients arrive at appointments safely and on-time, as well as providing a friendly face to greet patients.

“The Foundation could not provide this important service without the help of generous companies like Bridgestone, Holden and iSOFT and we thank them for their continued support.”

The transport program services major treatment centres in metropolitan and regional areas and in some cases the Foundation also assists with alternative transport for patients in rural areas. While transport is available for all patients who need to get to and from treatment, priority is given to people who:
- are transport disadvantaged
- are continuing with frequent treatments after bone marrow transplants
- have low blood counts
- are undergoing active treatment
- are undergoing supportive therapies eg. blood transfusions
- require admission or day investigations.

Volunteer driver, Tony McMahon, Leukaemia Foundation Victoria and Tasmania general manager, Ian MacDonald, transport and accommodation co-ordinator, Samantha Drosten, and iSOFT MD, Nigel Lutton.

ISOFT & BRIDGESTONE CONTINUE THEIR SUPPORT

Victorian patients and their families are travelling in the comfort of a new patient transport vehicle provided by healthcare software company, iSOFT. The vehicle, unveiled at Melbourne’s Docklands in December, is one of three donated to the Foundation by iSOFT. The others are in Brisbane and Canberra.

iSOFT nominated the Leukaemia Foundation as its preferred charity five years ago.

Staff have shown tremendous support towards the Foundation, volunteering their time and raising sufficient funds to provide patient courtesy transport vehicles which have transported more than 1000 families and travelled more than 349,851 kms. Nigel Lutton, iSOFT managing director for Australia and New Zealand, said the company was committed to helping patients and their families who were living with blood cancers.

In Western Australia the Leukaemia Foundation has renewed its relationship with Bridgestone Tyre Centres which has provided two new vehicles for the Foundation’s Patient Transport Program.

The three-year contract was enthusiastically supported by the 28 Bridgestone Tyre Centre franchisees across WA and the new-look vehicles were delivered to the Foundation in November sporting a colourful decal.

The cars are hard at work and the six regular volunteer drivers are expected to travel an estimated 150,000 kms over three years supporting patients and families. Total hours recorded by the volunteer drivers in WA over the last 12 months is equivalent to a full-time paid employee which is a significant cost saving to the Foundation.

In South Australia, two new patient transit vehicles also provided by Bridgestone Tyre Centres were unveiled at Victor Harbour in November. In the last 12 months, 3759 individual trips were made by trained volunteer drivers who travelled more than 140,000 kms within metropolitan Adelaide.
KRISTAL’S BEST FRIEND HELPS HER THROUGH TREATMENT

When five-year-old Kristal Shawyer had to go to Adelaide for treatment last October she really missed her animals – a cat, two dogs, two rabbits, two guinea pigs, fish and a turtle.

So her mum, Leanne Zabaldano, organised for her dad, Travis, to drive the 500 kms home to Millicent, in the south east of South Australia, to bring back Zarla, Kristal’s German shepherd.

For the next four weeks Zarla lived in the family’s four-wheel drive, parked at the front of the Leukaemia Foundation’s units at Richmond where they are living in a two-bedroom unit.

For health reasons dogs are not permitted to live at the patient and family accommodation complex so the Foundation helped Leanne organise a letter drop, asking if anyone in the nearby streets could help by letting Zarla stay in their backyard.

The neighbours next door to the units came to the rescue so now Zarla has somewhere to live and Kristal can see her every day.

“It’s made a big, big difference,” said Leanne. “Kristal is an only child and she and Zarla are best friends.

“Thank you to the Leukaemia Foundation for their support and accommodation. It’s fantastic. Without that I don’t know where we’d be.

“They also organised for a laptop computer to be donated to Kristal so she can contact her friends in Millicent by webcam. She is learning to write and the schooling program on the laptop is so beneficial.”

KRISTAL’S BEST FRIEND HELPS HER THROUGH TREATMENT

RIDE FOR LIFE - TRIP OF A LIFETIME

Leading Australian adventure travel company, World Expeditions, has developed a new trip in 2007 exclusively for the Leukaemia Foundation and will donate $1000 to the Foundation for each confirmed booking.

The 15-day Ride for Life is a small group journey that is a fantastic chance to see the amazing countries of Vietnam and Cambodia from a completely different perspective.

This is an opportunity to cycle through remote villages of southern Vietnam and into Cambodia, from Ho Chi Minh to Angkor Wat (pictured), visiting the Mekong Delta, Cu Chi Tunnels and other significant landmarks along the way. The trip ends with time to explore the great temple complex of Angkor Wat.

Ride for Life departs from Perth, Sydney, Melbourne or Brisbane on 18 October 2007 and costs $3990* per person.

Please call World Expeditions on 1300 720 000 for a copy of the detailed trip notes, cost inclusions and to book your place.

The maximum group size is 16, so places are limited.

* subject to minimum numbers and twin share occupancy.
When Cathy Ringwood was diagnosed with chronic lymphocytic leukaemia in 1999 she identified a gap in the market — the need for peer support groups for people like her living with chronic leukaemia.

Her enquiries led her to the Leukaemia Foundation in Victoria and as a result the Chronic Leukaemia Support Group was established.

This friendly and supportive group provides the opportunity for people diagnosed with chronic leukaemias, and their carers, to meet and share their experiences. A variety of guest speakers, such as haematologists, a dietitian, exercise physiologist and other health professionals are invited to present to the group on occasions throughout the year.

Cathy attributes the group’s success to the experienced support services staff at the Foundation who moderate each session.

“Peer support is invaluable in normalising the reaction of feelings,” said Cathy.

“It is healthy to share experiences and very healing to see members doing well.”

Cathy also highlighted a misconception that joining a support group meant you were part of the group for life.

“Support groups are there to move freely in and out of as needed,” she said.

“There certainly are periods when people feel more vulnerable and require greater assistance, such as when adjusting to a diagnosis and when they may require some help to make decisions.”

Members of the Chronic Leukaemia Support Group enjoyed their Christmas break-up at the Foundation’s office at Box Hill in Melbourne.

Taking Control at Warragul

Many of the 28 people at the first Taking Control support program for patients and carers at Warragul in Victoria in December travelled for several hours to attend.

They came from throughout the broader Gippsland region to hear several key professionals speak on their field of expertise.

Speakers and their topics included lawyer, John Berrill, from Maurice Blackburn Cashman who covered Legal Issues and Illness; Jo Anne Tamlyn explained What is Chronic Illness Alliance; Gayle Druzovec, oncology dietitian, Food for Life; Peter Armour, Centrelink, Q & A Session, and the Leukaemia Foundation’s Samantha Schembri, Taking Control. The speakers provided practical advice and strategies to assist patients living with blood cancers and as a result it was an empowering day.

Jo joins Tassie Support Services Team

Jo Beams has been appointed by the Leukaemia Foundation as the support services co-ordinator for northern Tasmania. Located at the Foundation’s Launceston office, Jo is a registered nurse with more than 10 years’ experience. She has worked in a range of health care settings in Tasmania, from an acute medical oncology ward to a primary health care setting with community nursing. She also was a palliative care project co-ordinator, establishing a specialised palliative care unit at Calvary Health Care Tasmania.
When Vanessa Dorrington was being treated for leukaemia she often felt guilty about how her illness was affecting her family and friends. She suffered from and was treated for depression, which she described “as worse than the chemotherapy” and Vanessa was rocked when her long-term relationship ended six months after she was released from hospital.

“I discovered my fiancé had gambled a large portion of our mortgage and our entire savings while I was undergoing chemotherapy and throughout my recovery. I was devastated for a second time within a year.”

These experiences, and the personal knowledge she acquired from going through treatment for acute myeloid leukaemia, means she is richly qualified to provide emotional support for others “who have the horrible weight of this disease on their shoulders”.

As a survivor Vanessa, 41, who lives at The Entrance on the central coast of NSW, is offering to help newly diagnosed and other patients living with blood and bone cancers in the Hunter/Newcastle region.

The primary teacher said she was very fortunate to have a great support network during the four months she was hospitalised after her diagnosis in January 2004.

“You just need to get through it and out the other end,” she explained. “The importance of having a survivor able to listen to the fears and concerns of newly diagnosed patients is paramount. The journey through a terminal illness can be dark, lonely and at times overwhelming.

“I had my parents and my sisters and friends who were there every day. But there are people who don’t have this sort of support and they don’t know what to expect.

“When I got out of hospital, I contacted the Leukaemia Foundation at Newcastle and asked if there was anything I could do on a volunteer basis to help others,” said Vanessa who is training for the volunteer patient support program, Blood Cancer Connect.

“I think it is a really worthwhile cause and I’d like to be there, to check in with them (patients) and to see if they are okay,” she said. “Just chatting to someone who has been there can lighten the load and seeing a survivor of such a hideous disease gives you hope.”

Vanessa believes there was a reason she went through the leukaemia experience.

“It makes you more spiritual and you feel more at peace with who you are. I always believed that I would survive and am grateful that now I have the opportunity to support other patients.”

The Foundation provided Vanessa with counselling, paid for her to have a wig made and supported her parents with information about treatment.

Survivors Take Part in Support Program

_Blood Cancer Connect_ is a support program that trains patient survivors to provide practical and emotional support to newly diagnosed patients with blood cancers.

A pilot program, held in the Illawarra region, was highly successful and last September the Leukaemia Foundation received a grant from The Cancer Council to run the _Blood Cancer Connect_ program in the Hunter/Newcastle region.

Newly diagnosed patients benefit from being able to liaise directly with someone who has already experienced the same disease and/or treatment as them, through hospital visits or by talking via the phone or Internet.

While each person’s experience of treatment is unique, there are common questions and concerns which the Foundation’s volunteers can discuss with patients based on their own personal and practical experience.

The aim of _Blood Cancer Connect_ is to add a new dimension to and enhance the information a patient receives.
 grants in aid 2007

Kavallaris, Gunning and Lock (Children’s Cancer Institute Australia, NSW) $91,750. **Improving the treatment of leukaemia.**

Mollee and McMillan (Queensland Institute of Medical Research, Qld) $100,000. **A new combination therapy for elderly or relapsed acute myeloid leukaemia.**

Hill and MacDonald (Princess Alexandra Hospital, Qld) $100,000. **Understanding how stem cell transplantation cures leukaemia.**

Postdoctoral Fellowships 2007-2009

Nicholas Wong (Murdoch Children’s Research Institute, Vic.) $94,000. **Can the environment cause childhood leukaemia? If so, how and when does this occur?**

Corey Smith (Queensland Institute of Medical Research, Qld) $75,000. **Developing a vaccine strategy to treat EBV-associated Hodgkin’s lymphoma.**

PhD Scholarships 2007-2009

Melanie Sulda (Finders University of South Australia, SA) $40,000. **Novel disease markers and therapeutic targets in B-cell chronic lymphocytic leukaemia.**

Honours Scholarships 2007

Subhobrata Das (Child Health Research Institute, SA) $10,000. **Investigation of Klf5, a potentially new leukaemia-causing gene.**

Matthew Boisseau (Finders University of South Australia, SA) $10,000. **Investigating the reason for resistance of chronic lymphocytic leukaemia to MabThera.**

Dana Ihdayhid (Dominic Di Giacomo Honours Scholar, WA) (Curtain University and Royal Perth Hospital, WA) $10,000. **Mesenchymal stem cells for allogeneic stem cell transplantation.**

Young Investigators Award

Stephanie Su Yin P’ng (Royal Perth Hospital, WA) $10,000. **Assessing the use of Pentoxifylline for treatment of anaemia in myeloma.**

**New treatments in myelodysplastic syndromes’ seminar**

**New Treatments in Myelodysplastic Syndromes (MDS) was the title of the Leukaemia Foundation’s patient education seminar held in Melbourne in November.**

The keynote speaker, Dr Melita Kenealy, haematologist and MDS Clinical Research Fellow at Peter MacCallum Cancer Centre presented an overview of the disease. This included symptoms, best supportive care and the goals of therapy, international research and the translation into clinical trials and new agents in development to treat MDS.

Dr Kenealy is the principal investigator of a new Australian clinical trial to determine the safety and effectiveness of combination therapy with two relatively new drugs, 5-azacytidine (Vidaza) and thalidomide in patients with MDS. The trial began early this year and runs over a two- to four-year period.

“This clinical trial for MDS is the first in nearly 20 years for the Australasian Leukaemia and Lymphoma Group and is a large coordinated effort,” Dr Kenealy said.

It is exciting to gain access to drugs from overseas that previously have not been available in Australia and to be able to use them freely in these trials.

“The future holds promise for new, safer, more effective treatment strategies for people with MDS,” she said.

Through the Leukaemia Foundation’s National Research Program, Dr Kenealy is a recipient of the Max Whiteside Clinical Fellowship.

Many patients supported by the Foundation travelled to the seminar from regional Victoria. The Foundation’s Victorian support services co-ordinator, Tania Cushion, facilitated the seminar.

“Myelodysplasia is a rare disease and it is important patients are provided with information about the latest treatments available,” Tania said.

“The seminar was also a great opportunity for people to connect with others who are going through similar experiences associated with the diagnosis and treatment of myelodysplasia.”

PAGE 8
RESEARCH IS THE KEY TO A CURE

The Leukaemia Foundation’s vision is to find a cure and to make this happen more research is urgently needed.

Innovative research into the causes, diagnosis and treatment of leukaemia, lymphoma, myeloma and related blood disorders is fostered through the Foundation’s National Research Program.

This program supports national research facilities such as the PricewaterhouseCoopers Leukaemia and Lymphoma Tissue Bank, the Leukaemia Foundation Research Laboratory at the Queensland Institute of Medical Research and funds selected clinical trials by the Australasian Leukaemia and Lymphoma Group.

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

For example, Melbourne-based researcher, Associate Professor Ricky Johnstone, is making exciting progress researching the effect of combining specific anti-cancer drug therapies as a treatment for patients with leukaemias and lymphomas. This research is funded through a combined Leukaemia Foundation and Bennelong Foundation (a private philanthropic foundation) project grant.

Applications for the Foundation’s fellowships and scholarships are assessed through a rigorous review process by an independent team of experts in the field called the National Medical Advisory Committee, based on the merit of the proposed research, the achievements of the applicant and the relevance and significance of the proposed work to enhancing our knowledge or treatment of haematological malignancies and improving the way the Foundation cares for patients and their families.

Clinical and postdoctoral fellowships are set at up to $100,000 per annum, PhD scholarships at $40,000 per annum and honours year scholarships at $10,000 per annum.

In 2006, the Foundation received 15 applications for three research project grants; six applications for one postdoctoral fellowship grant; 13 applications for four PhD scholarship grants, and three applications for one honours year scholarship grant. All these applications are for research projects that are highly worthy of support and somehow the Foundation has to find a way to increase current research funding levels.

This is why the Foundation increasingly is looking to its supporters for their assistance through a planned gift, to help fund the cutting edge and innovative research that is so urgently needed to find a cure.

A PLANNED GIFT TO FURTHER RESEARCH

Here are several ways in which the Foundation’s National Research Program can benefit from a supporter’s generosity.

Supporters can make a planned gift to research, either as a one-off gift made now or as an annual gift made in perpetuity (until a cure is found). A growing number of people are choosing to establish a private charitable trust or to set up a prescribed private fund and nominate the organisation(s) they wish to receive their annual gift (in perpetuity).

Another way to make a significant planned gift, perhaps a far greater gift than many people can make during their lifetime, is through a bequest in their will. After making due allowance for loved ones, a bequest for a specific amount or a proportion of the residue of their estate, is one way of leaving a real and lasting legacy to the future.

The Foundation is pleased to provide appropriate recognition for planned gifts.

If you are interested in supporting a research project and wish to discuss it further, or would like to receive more information about funding options (bequest, private trust or fund) please contact Ralph Roath, national manager for planned giving on 03 9949 5815, 0411 544 241 or rroath@leukaemia.org.au.

For further details on the Foundation’s planned giving program visit www.leukaemia.org.au.
Having leukaemia hasn’t been all bad for 12-year-old Timothy Jackson from the small town of Walcha, near Tamworth in NSW.

He’s met lots of famous people including Casey Chambers, actors from Home & Away, the Sydney Swans and the NSW State of Origin side, visited the Aquarium and other Sydney sights and made lots of friends at Randwick Children’s Hospital.

“We were lucky he had the most common form of childhood leukaemia,” said his mum, Sue, about Tim’s diagnosis with acute lymphoblastic leukaemia.

For five weeks Sue had taken Tim back and forth to the doctor because he was off his food and having fevers. Then he had a nose bleed that couldn’t be stopped in Walcha so they went to Emergency at Tamworth Base Hospital. Within half an hour of receiving the blood test results in April 2005, Tim and his mum were on an air ambulance to Sydney.

“He started chemo straight away and Tim and I never saw Walcha again for three months.”

Sue dropped everything including her job as secretary of the local bowls club and after a while Tim’s father Brad, also gave up his job managing a pine mill and moved with Tim’s younger sister, Adrienne, to Sydney so the family could be together.

On one of Tim’s first trips home he was elected vice school captain for 2006. Another time, when he was really unwell, he sat the NSW basic skills test and despite not having been at school for most of the year, he was among the state’s top 10 per cent of students.

“We took a lot of school work with us to Sydney and he went to the hospital school there,” said Sue.

Tim started high school this year and is nearing the end of his two-year treatment program.

“He’s a bit of a hero, he’s handled it so well,” said Sue.

The Leukaemia Foundation helped the Jackson family financially all through 2005.

“They paid a lot of incidental bills like our telephone account and our fuel account in Sydney,” said Sue. “It was just fantastic and they are just really lovely caring people.

The Leukaemia Foundation has launched an innovative new animated television commercial (TVC) that features some hard-hitting facts and symbolic visuals to illustrate the effects of leukaemias, lymphomas and myeloma.

The 15-second commercial, created at minimal cost to the Foundation by M & C Saatchi in Sydney, uses landmines to illustrate the diseases within an animated ‘bloodstream’.

The TVC was created following the personal experience of M & C Saatchi staff and associates, four of whom have had friends or family members diagnosed with leukaemia in recent years.

Copywriter, Roy Faukner’s nephew died before his 15th birthday from leukaemia. Roy was struck by the random nature of the disease, which like a landmine, is indiscriminate and can occur at any time. He joined forces with art director, Jodie Roach, and senior account manager, Danielle Pandolfo, who also had lost a close friend to leukaemia and the ‘landmine’ concept was born.

Leukaemia Foundation CEO, Adrian Collins, said the Foundation was very pleased with the new commercial.

“It is a great asset to us in helping us to raise awareness of these diseases among the Australian population and reminding people they can help by supporting our vision to find cures,” Mr Collins said.

The campaign was managed by Deborah Kenny who has a cousin living with leukaemia and produced at Film Headquarters in Brisbane by Ian Kenny who lost his father to leukaemia.

Landmine in animated bloodstream in new TVC.

Tim gets top marks despite leukaemia ordeal

Landmine in animated bloodstream in new TVC.

Tim Jackson during treatment.
During his life-saving bone marrow transplant, Danny Widdicombe wrote two songs, *Rock Bottom* and *Isolation*, that feature on the debut album he released last October called *The Transplant Tapes*.

“My whole life has been about music,” said Danny, 31, who was only 19 when diagnosed “by accident” with chronic myeloid leukaemia in 1995.

“I was a party animal and sick all the time,” explained Danny who was living in Melbourne and working in the music industry at the time. “Because my blood counts were crazy, my GP felt something was wrong, so I got caught very early. It (the leukaemia) wouldn’t have been picked up if I had been healthy.”

Danny looked into the treatment options. He took part in a trial for Interferon for two years and when he moved to Sydney in 1997 he went on to “the new wonder drug” Glivec, again on a trial for the next five years.

In 2002 Danny moved back to Brisbane where he had grown up because a matched unrelated donor had been found through the Bone Marrow Donor Registry. Plans were put in place for him to have an allogeneic transplant at the Royal Brisbane Hospital but the donor pulled out and so did seven other potential donors.

“They all came from the USA apparently,” Danny said. “Finally they found another one, so I stopped Glivec for a few months to have a break before the transplant.”

The day before his transplant, in February 2004, doctors discovered his leukaemia had transformed into acute myeloid leukaemia.

“So I was pretty relieved I was having the transplant,” said Danny who was fit, mentally strong and determined to return home as quickly as possible to his wife, Carolyn, who he had met in Sydney, and their children, Oliver, five and India, three.

During the transplant which he described as a spiritual process, Danny repeated a Tibetan mantra every hour: “The more I said it to myself, the more melodies I could create in my head and I’d start going into another world.”

He couldn’t take his guitar into the isolation room so he started writing lyrics about his experience on his computer and listened to lots of music.

“I got really skinny because I couldn’t eat, my muscles disintegrated and I had no hair left, so I escaped into my imagination musically which passed the time better than TV and I also really looked forward to visits from Carolyn and my family.

“On day 20 I was out and free and happy,” said Danny. A year later, on 9 January 2005 they said ‘it’s gone’, the transplant had worked and life is great.”

When he got home songs for his album came flooding out. They were about his entire transplant experience, being in the isolation room, the effects of the drugs and getting back into everyday life. The album is available from www.myspace.com/dannywiddicombe.

The Leukaemia Foundation provided Danny and his family with financial assistance, information and psychological and peer support.

“The toughest time was in 2004 when Carolyn was on maternity leave. We were in dire straits, had a mortgage and were scared of losing the house.”

“Without the Leukaemia Foundation I don’t know how people would survive,” said Danny who now performs at gigs around Brisbane. He played lead guitar with Bernard Fanning last year and regularly sings at Leukaemia Foundation functions.

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Danny Widdicombe, right, with Luke Moller who accompanies him on *The Transplant Tapes*.

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**Isolation**

*This isolation room with windows that frame my view*

I wanna jump outside get back into my life with you

Try and stay positive – it’s not as easy as you’d think

I’m not goin’ down – I’m gonna stay and fight and I’m gonna win

**Isolation**

Haven’t eaten a thing for over a week

My body’s tired – my mind cannot sleep

I’ve pulled out all my hair – I can feel the poison spread

It feels like I’m sinking – but I’ll rise and I’ll get there in the end

**Isolation**

A big black shadow is blowin’ my way

The man in the next room – he died today

But I’ve got my music and I’m in love with my wife

And without my family and friends there’s no way I could have survived.

**Isolation**

**Radiation**

**Isolation**
For environmental scientist, Ian Toleman, it was like the world stopped for eight months when he was diagnosed and treated for Burkitt’s lymphoma in July 2005.

He had experienced cold and flu-like symptoms which he just couldn’t shake off, along with back pain and muscle stiffness. Then he found a lump the size of a grapefruit in his abdominal area and after tests ordered by his local GP, was admitted to the Sir Charles Gardiner Hospital in Perth.

He found himself on a “rapid roller coaster”. After abdominal surgery and chemotherapy, Ian is in remission and on a care and maintenance program, with tests and specialist visits every three months.

“It was a bit of a wake-up call and I’ve made a few changes in my life,” said the father of two, aged 43, for whom a bike ride at the local park with his son is now a priority.

“I’m enjoying life more, spending more time with the immediate family and friends and not worrying about work as much.

“I consider that I am still recovering,” he explained. “My energy and fitness levels are not back to normal, I have muscle loss and get really tired.”

Ian has returned to full-time work at the Water Corporation which has been very supportive and agreed to him working half the week from home.

“This means I can manage my energy levels and take regular breaks and by the end of the week, I have got the work done.

“I didn’t know about the Leukaemia Foundation until the support services co-ordinator visited me in hospital and explained some of the things they do to help.

“They do a great job fundraising which means they offer the services all free of charge and it certainly makes a difference,” he said.

For Ian this included getting a lift to and from hospital in the Leukaemia Foundation’s patient transit cars.

“One day I was admitted to hospital on the same day because I had a high blood temperature, so they didn’t have to take me home!”

Ian’s children, Wes, 10, and Jordyn, eight, are in the Foundation’s Lucky Bear’s Club which takes them on excursions along with other children whose siblings or parents have been diagnosed with leukaemia, lymphoma or other blood diseases.

The Foundation also organised a discount rate for a family weekend away for the Tolemans at a resort in the Margaret River region after his treatment.

Burkitt’s lymphoma is a form of cancer of the lymphatic system that is relatively rare in western countries. It occurs when a specialized white blood cell called the B-lymphocyte undergoes cancerous changes. The cells begin to grow and multiply out of control and the cancerous cells form tumours. Burkitt’s lymphoma is the most aggressive sub-type of non-Hodgkin lymphoma and the predicted number of new cases in Australia is 12 per year.

The Lucky Bear’s Club program is designed for children with a family member diagnosed with leukaemia, lymphoma, myeloma or a related blood disorder. The program combines workshops incorporating child-centred play therapy with fun day activities which enable participating children to bond with other children living in similar circumstances to their own. In December, 13 children, three carers and support services staff from the Leukaemia Foundation in WA took part in a Lucky Bear’s Club fun day to Perth Zoo. The tickets were generously donated by the zoo through the relationship between the Water Corporation and the Leukaemia Foundation in WA.
Will you ‘be brave and shave’ in 2007?

The Leukaemia Foundation’s World’s Greatest Shave (WGS) is on next month, from March 15-17, to raise much-needed funds for the 30,000 Australians living with leukaemias, lymphomas, myeloma and related blood disorders.

WGS is one of Australia’s largest fundraising events and according to the event’s national manager, Justin Karcher, more than 100,000 people are expected to participate this year.

“It’s great fun and anyone can take part. You can go it alone or get together with friends, workmates or club members to form a group,” Mr Karcher said.

Public shave events will be held right across Australia. This year the event coincides with St Patrick’s Day on Saturday 17th March so people can combine their annual Irish celebrations with fundraising for the Foundation.

Register now at www.worldsgreatestshave.com or call 1800 500 088. You also can visit your local Priceline or Priceline Pharmacy store which are proud supporters of WGS for 2007.

Look out for this year’s creative new advertising campaign for WGS. Produced by de pasquale in Brisbane, it features some curious-looking characters. The commercials feature several personalities, from an eccentric Irishman, to an adorable little girl and someone who looks suspiciously like Arnold Schwarzenegger!

The WGS ad campaign which is currently appearing on Channel Ten in all capital cities and various regional stations aims to grab attention with these quirky, likeable characters.

Makybe Diva owner chops his mullet for $500,000

Tony Santic’s famous mullet got the chop at his Geelong property last November in what is arguably the world’s most expensive haircut.

Last year the well-known South Australian businessman pledged to lose his mullet in exchange for raising $1 million towards a new purpose-built accommodation centre for the Leukaemia Foundation in Adelaide.

This promise was made soon after his great mare, Makybe Diva, won her third consecutive Melbourne Cup.

To raise these funds Tony has called on the South Australian business, racing and local communities which are generously supporting his fundraising effort.

When he reached the halfway mark, $500,000, Tony agreed to have his golden locks trimmed and when he doubles this figure, he’ll shave his head entirely!

In South Australia, the Foundation currently provides units for up to eight families at any one time. The units are fully booked nearly all year and with the incidence of blood cancers on the rise, a new facility is required to meet current and future needs.

The initial $500,000 which Tony raised is a fantastic contribution towards development of the new $4 million centre which when completed will be called The Makybe Diva Village of Courage.

Tony pledged his support for the Foundation when he saw the vital need for free accommodation for rural and regional families who have to relocate to Adelaide for lengthy, potentially life-saving treatment for leukaemias, lymphomas and myeloma.

Around 25 per cent of the 750 children and adults diagnosed with these diseases in South Australia and the Northern Territory live in regional or remote areas.
WORDS FORMED POWERFUL MESSAGES OF HOPE

The Leukaemia Foundation’s 2006 Christmas Appeal featured a personal story from Gina Jeffreys that inspired donors to write a message of hope in addition to giving their financial support. These messages were dedicated to people affected by leukaemias, lymphomas or myeloma, in loving memory of a friend or family member, or as encouragement for doctors and nurses.

Written on specially-designed Christmas decorations the messages were displayed on Christmas trees around the country to inspire and give hope to people touched by these diseases.

The Messages of Hope idea came about through Gina’s touching story of a letter she received 10 years ago from a six-year-old girl with leukaemia who was a member of her fan club.

“She told me she was writing to say goodbye because she had leukaemia and mummy and the doctors had told her it was time to go. She said she would be okay, but she wanted to watch over me to make sure my dreams came true,” said Gina about her little friend who passed away soon after.

This message inspired Gina and her husband, Rod, to write a song, That'll Be Me, in her memory and it is included on Gina’s latest album, Walks of Life.

“Her courage also made me realise that up until that point, my life had always been about my music and myself,” Gina explained.

“So in 1996 I became involved with the Leukaemia Foundation, a wonderful organisation which is totally committed to caring for the 9000 Australian patients who are diagnosed each year with leukaemias, lymphomas, myeloma or related blood disorders, as well as funding research to find cures and better treatments.”

Special thanks to everyone who donated to the Messages of Hope appeal which raised more than $125,000 to help the Foundation continue its vision to cure and mission to care. And special thanks to Gina for sharing her story.

TIGER MOTH FLY IN - AN EYE-catchING FUNDRAISER

A fleet of 10 Tiger Moth planes and a dozen vintage cars and motorbikes featured in the second annual Tiger Moth Fly In, at Edwards Vineyard, Margaret River last November.

Attendees made a gold coin donation to view the display, enjoy a picnic and the carnival atmosphere and that evening the Edwards family hosted an invitation-only sundowner and auction for 180 guests.

The Tiger Moth Fly In was the brainchild of Brian Edwards, who lost his brave battle with chronic myeloid leukaemia in 2003. Tiger Moths were his passion and he was the first man to fly a Tiger Moth solo from the UK to Australia in 1990. His son, Mike Edwards, is the winemaker at the vineyard.

“My father flew from Binbrook airfield in England to Australia, tracing the route of the great Australian aviation pioneers, to honour the memory of his father who was missing in action in World War II and to raise money for charity,” Mike said.

“We held the first Tiger Moth Fly In event in 2005 and we were keen to make the 2006 event even bigger. We had wonderful support from the vintage plane community and the general public and the sundowner was an opportunity for our family, friends and guests to honour the memory of dad whilst raising funds for the Foundation.”

“Our family was delighted with the result of the entire event which raised more than $10,000 for the Leukaemia Foundation and we look forward to making this year’s fly in even more successful.”
HOW WE INVEST IN OUR VISION TO CURE AND MISSION TO CARE

Funds raised by the Leukaemia Foundation provide much needed free patient support services such as accommodation, transport, information and education, emotional support and practical assistance such as financial assistance to patients and families living with leukaemias, lymphomas, myeloma and related blood disorders.

The emotional support may be offered over the telephone, face to face at home, hospital or at the Foundation’s accommodation centres/offices, depending on the geographical and individual needs. Money also goes towards leading research into better treatments and cures.

Here’s an example of where the funds go:

$55:
Pays for one car to transport a patient to and from a treatment centre for one day.

$100:
Provides a patient and their family/carer with a fully furnished self-contained ‘home away from home’ near a treatment centre for one night.

$250:
Provides a patient and their family/carer with a tailored counselling and support program for three months.

$10,000:
Provides an honours year scholarship for research into leukaemias, lymphomas, myeloma and related blood disorders – just one element of the Leukaemia Foundation’s extensive National Research Program.

$40,000:
Provides a PHD scholarship for one year. PHD scholarships usually take three years to complete.

$100,000:
Funds one fellowship for research into better treatments and cures for leukaemias, lymphomas, myeloma and related blood disorders.

Volunteer drivers at a driver training day at Lismore in NSW.

SWIMMERS RAISE FUNDS TO ASSIST PATIENT AND FAMILY

Husband and father of three, Craig Zulian, was diagnosed with a form of acute leukaemia in August 2006.

Confronted with the reality of spending many hours undergoing treatment at Illawarra’s St George Hospital and not being able to work, Craig and his family faced the challenge of maintaining their house mortgage repayments and paying other ongoing bills throughout many months of treatment.

Craig was the 2005 Illawarra Lifesaver of the Year and to help support him and his family during this period, more than 40 swimmers braved still chilly waters to take part in a fundraising event called the Ocean Pool Crawl.

Each participant completed two laps of the seven ocean pools, from Coalcliff to Woonona on the south coast of New South Wales, and raised more than $20,000. Of these funds, 20 per cent was donated to the Leukaemia Foundation.

Craig and his family attended the event to thank everyone for their support, and despite feeling weak from his treatment, he joined in by walking two laps of a pool.

“It was an unbelievable day,” said Craig. “After a couple of months in hospital and going through chemotherapy, a day like that just lifts you up.

“I would like to thank everyone for supporting me through such a difficult time, including the staff at Ward 4 East. I could not have been given a better Christmas present than to be told I am now in remission.”

Craig Zulian with his wife, Sonia, and youngest daughter, Chiahni.
Our support extends across all metropolitan and regional areas

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

From Broome to Ballarat and Darwin to Devonport, the Leukaemia Foundation helps patients and families in every corner of Australia.

Assisted: this means the Leukaemia Foundation provided the patient, their carer and/or family with one or more of the following free services - information, emotional support (by phone, email or visit), referral to specialist services, an education program, practical assistance including financial assistance, transport or accommodation in 2005/2006.

Contact Us
Free Call 1800 620 420 (call will go through to your local office)
Email: info@leukaemia.org.au
Mail: GPO Box 9954 in your capital city
Website: www.leukaemia.org.au

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