

the CARER

www.leukaemia.org.au

About us

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

We invest millions of dollars in the work of Australia's leading researchers to develop better treatments and cures and provide free services to support patients and their families.

We receive no ongoing government funding. We rely on the generosity of the community and corporate sector to further our Vision to Cure and Mission to Care.

27,000 UNITE TO GIVE HOPE



More than 27,000 people came together at Light the Night events around Australia to raise \$1.45 million and make this year's event our most successful yet. Turn to page 5 to read more.

EXCEPTIONAL FAMILY SHOWING EXTRAORDINARY COURAGE

Perhaps the most eager and accurate Xboxer to emerge from the Philippines, Janmikael Matunog and his family are now proud Australian residents with a resilience and courage that inspires all who have the privilege of meeting them.

On 27 July, an 11 year-old Janmikael (Jan) with acute lymphoblastic leukaemia (ALL), received a vital bone marrow transplant that was once thought to be impossible.

Jan and his parents, Joselito and Anna, and sisters Jannina (11) and Mickaella (9), had been living in Darwin when Jan was sent to Adelaide's Women's and Children's Hospital for urgent treatment in October 2010.

Jan had previously been treated for his disease in the Philippines and had recovered well, but he relapsed just a week after he, his mother and sisters relocated to Darwin to join Joselito. The devoted father and husband had been in Australia for three years working as a chef and was in the process of seeking permanent residency.

So soon after their move to Darwin, Anna and Jan found themselves far away in Adelaide – Jan's leukaemia was an acute form requiring immediate treatment – while Joselito stayed behind with his daughters for work.

When it became evident that Jan urgently needed a bone marrow transplant and no family donor was available, his Adelaide medical teams turned to the international bone marrow donor registry seeking a compatible match.

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DECKING THE HALLS TO BRING CHEER

Bridgestone Australia Ltd and the Leukaemia Foundation are bringing a little Christmas cheer to Australians with blood cancer who will be separated from home and loved ones this Christmas.

Many people undergoing vital treatment for blood cancer will spend the festive season in hospital. To help bring a little colour and brightness to people in hospital and those who care for them at this challenging time, we have distributed Christmas trees, complete with brilliant blue and silver decorations, to nine hospitals with dedicated haematology wards and day clinics across the country.

The Leukaemia Foundation is poised and excited about expanding on our Vision to Cure and Mission to Care for Australians with blood cancer in 2012.

All of us at the Leukaemia Foundation wish you and those close to you a very happy and safe festive season.

CELEBRITY SKETCHES TO FETCH FUNDS

A fun new fundraiser, 'Doozie Doodles', aims to turn celebrity "scribbles" into thousands of dollars in support of families living with blood cancer.

International celebrities including John Travolta, Jerry Lewis and Jimmy Barnes are offering up doodles on everything from personal notepaper or music sheets, to napkins from their favourite restaurants, to be auctioned. The creations will raise funds for the Child: Family: Care Program, an initiative delivered by the Leukaemia Foundation and developed by a national coalition of like-minded organisations to support children with blood cancers and their families.

The doodles will each be framed, packaged with a Certificate of Authenticity and listed on our auction website: Post cards and collectors books will also be available. Check out the website for some truly unique Christmas gift ideas – all for a great cause:

www.dooziedoodle.com.

SAVE THE DATE

World's Greatest Shave will be back from 15-17 March 2012. Will you be brave and shave or colour your hair to support Australians with blood cancer?

BIG ACHIEVEMENTS IN ANNUAL REPORT

The Leukaemia Foundation's 2010-2011 annual report is available soon, highlighting many achievements in a year marked by devastating natural disasters, economic uncertainty and subsequent challenges for organisations in the Not-For-Profit sector.

In 2011 we marked an important milestone – the allocation of \$20 million in funding since the formation of our National Research Program in 2005. This achievement was even more significant because it came from the generosity of Australians like you, rather than relying on ongoing government funding.

Other numbers representing some big achievements included:

- **410** new users joined our www.talkbloodcancer.com forum – an average of 34 new members a month.
- **725** families from regional areas were provided with accommodation while they accessed treatment in the major cities.
- **6,500** people attended one or more of our **447** education and support sessions.
- **12,700** unique visitors accessed our booklets and factsheets via our website www.leukaemia.org.au.
- **13,864** nights of free accommodation were provided to patients and carers in our home-away-from-home accommodation units.
- **21,000** trips were made by our dedicated volunteers in our **29** patient transport vehicles.
- **61,000** information and support booklets were distributed through treatment centres and hospitals to patients and carers.
- **800,000** kilometres were travelled by our volunteer drivers in our Holden and Bridgestone sponsored cars to provide courtesy patient transport.
- **3.8 million** dollars was invested by us in vital research to improve treatment and to find cures.

To be notified of when our annual report is available, please email info@leukaemia.org.au.

We thank everyone who generously supported our important work in 2011.

Leukaemia Foundation

**WORLD'S
GREATEST
SHAVE™**



Scan to watch a special sneak preview of World's Greatest Shave 2012. Get a free QR Reader at your phone app store.



ZUMBA® THE MUSIC BEHIND KARINA'S NEW LIFE

Karina Carrel is a self-declared warrior – and a justifiably proud one. One of her energy sources is her beloved Latino music that she loses herself in as a Zumba® instructor. Another power source is her children, Aaliyah (10), Monique (8) and Jaivan (2½) and husband and partner of 12 years, Paul.

In 2009, the Melbourne mum of three was diagnosed with Hodgkin lymphoma. The eventual diagnosis came after numerous visits to her local medical clinic in search of answers for a persistent cough and, later, debilitating body aches and pains in her chest and upper back. A range of treatments for the pain by several doctors were prescribed, from paracetamol and ibuprofen, to penicillin, to a medication that is also used to treat schizophrenia.

Needing “a fourth opinion”, in desperation Karina booked in to see another doctor and an x-ray was finally ordered.

“The GP called me at 11.30am the next day,” she said. “I knew by the tone in his voice that something was wrong. Cancer was in my mind, but I thought I was just being silly.”

The x-ray had revealed a tumour the size of a tennis ball above Karina’s heart.

A further two months of tests – and an agonizing wait – for Karina and her family followed, before the cause of the tumour could finally be identified.

Karina was officially diagnosed with stage 4 B-cell Hodgkin lymphoma on 19 October 2009.

“They found the tumour had started to spread into my lungs,” said Karina. “It got to a point where I couldn’t breathe. I couldn’t sneeze. I couldn’t swallow food anymore – everything I ate had to be pureed.”

Karina began a chemotherapy regime called ABVD.

“So many questions hit me that day,” she said. “Looking ahead to the finish line, six months seemed like such a long way to go. It felt like an eternity.”

Three months into treatment, Karina discovered a new passion that would fuel her road to recovery while channel surfing late one night.

Initially dismissing the infomercial as “just another fitness fad”, she ordered the Zumba® DVDs.

“As soon as the music started, I was crying,” she said. “I’m Latino. It was our music – our culture. I was so emotional!”

Karina had enjoyed Latin dancing all her life.

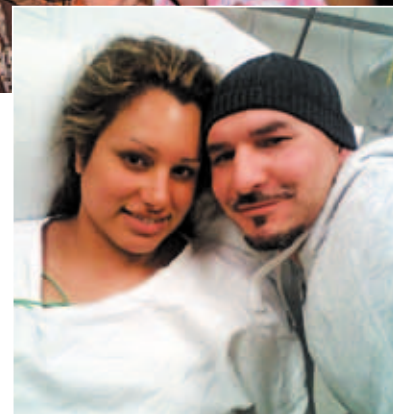
“I would watch two DVDs every day,” she said. “At first I would try to do just one track, but couldn’t. Slowly I built up from doing one track, to two tracks. I would push myself because I dreamed of becoming a Zumba® instructor.”

Almost unbelievably, Karina had her instructor training on the one year anniversary of her first chemotherapy treatment – 23 October 2010. She felt this was a good sign, closing the door of that part of her life and starting a new journey.



Karina and her children, six months before her diagnosis.

Karina grew eager to research how gentle forms of the Latino dancing, in combination with stretching and breathing exercises and meditation, could be of benefit to fellow blood cancer survivors. She discovered that Dance and Movement Therapy (DMT) had been used for many years in rehabilitation centres and medical settings. A name for her concept came easily – Liberation™.



Karina and Paul, in hospital.

Unfortunately, Karina’s ambitions were interrupted in April 2011, when her lymphoma returned.

Foreseeing what lay ahead of her, Karina decided to see a Chinese herbalist, who gave her a combination of herbs

to combat the effects of a second round of chemotherapy.*

“Before I took the herbs I would have dark days, nausea and ulcers in my mouth,” she said. “When I started on the herbs, a lot of that went away. They really helped me.”

In August 2011, Karina’s next PET scan showed she was clear of blood cancer cells, so she returned to her goal of making Liberation™ a reality.

In collaboration with the Leukaemia Foundation in Victoria, Liberation™ was launched recently. Karina’s dream of a one-hour Latin dance class inspired by Zumba Gold® and Dance Therapy to help fellow cancer survivors is now being realised.

“The ultimate goal is for the participant to learn that they are not alone,” said Karina.

**The Leukaemia Foundation strongly encourages anyone with blood cancer who is considering additional therapies, including any herbal preparations, to discuss this first with their doctor to ensure there is no risk of negative interaction with their standard medical treatment.*

“I’m Latino. It was our music – our culture. I was so emotional!”

FAMILY SHOWING EXTRAORDINARY COURAGE

Continued from page 1...

However, further testing was required and because the family were not yet Australian residents with access to Medicare cover, an upfront payment of \$5000 was needed to cover associated costs. Potential donors had been identified, but the additional testing was essential to find the one most compatible.

When the Leukaemia Foundation became aware of Jan's situation, we contacted the Little Heroes Foundation and together the two organisations met the cost of the testing recognising the unique situation this family faced.

On 27 July 2011, with their Australian residency finalised and access to Medicare then available, Jan had a life-saving bone marrow (stem cell) transplant at Sydney's Children's Hospital.

The days since Jan's transplant have been hard. Some days are harder than others. However, this incredible family is determined to still find reasons to smile.

In the interview for this story 100 days after his transplant, Jan jokes that he's "turning into a girl" – the stem cells he received were from an American female donor.

Soon after Jan's transplant, Anna said doctors were pleased with his early progress.

"After eight days, his cells started to grow," said Anna. "The doctors said that was good. For others, it can take two weeks. He now has 100% of his cells coming from the donor."

Jan's five weeks in isolation in Sydney were tough on both mother and son.

"It was hard being in one room while Jan was confined," said Anna. "Sometimes we were both very grumpy."

"It's not right to feel jealous, but I found it hard with other families who had others there to support them."

The Leukaemia Foundation activated a wide network of emotional support for the Matunogs, with our teams in Darwin, Adelaide and Sydney maintaining regular contact with each family member. We also initiated extra support, putting the family in touch with local Filipino communities.

Over the days and weeks in Sydney, Anna was especially grateful for the support of Sydney's Filipino community and a special Filipino doctor who provided her with home-cooked Japanese meals.

For Joselito, Jannina and Mickaella, the 11-plus months of separation from their mother and wife, brother and son, have not been easy.

"I get calls from Anna, crying, and it's so stressful too for Anna with the two girls in Darwin," said Joselito. "I tell myself 'don't worry', but sometimes I can't help myself. I try to tell myself to count my blessings."



From left: Joselito, Jannina, Janmikael (in beanbag), Mickaella and Anna Matunog: "Counting our blessings".

Joselito works split shifts in order to be available to get his daughters to and from school. The family doesn't own a car, so he makes use of public transport to ferry the girls wherever they need to go. On most days Joselito rises by 5.30am, then often doesn't finish his second shift until 11pm.

It's an exhausting, but unavoidable, routine.

"Sometimes in the morning I cook some food for the night time," said Joselito. "I just pray. I need a little bit of patience too."

Anna and Jan were relocated to Adelaide on 7 October, where Jan spent five more weeks in isolation in hospital.

At the time of producing this newsletter, a much-needed but temporary family reunion was taking place. Delighted to have his sisters on hand again to play with and make fun of, Jan was sporting an infectious grin that widened with each new Xbox game level he conquered.

Upon returning to Darwin, Joselito's top priority was to find a suitable rental property to accommodate his family in. They currently have a carpeted two-bedroom unit, but they need to find a house with three bedrooms for the reunited family of five. They also need to find somewhere without carpet, which presents health risks for Jan's compromised immune system.

On the day of this interview, Jan was about to celebrate his 12th birthday. He was born on 13 November, 1999. As Anna recalled, her son was the result of an "easy delivery".

Proving that his wild wit can never be subdued, the seemingly oblivious Jan glanced up from his Xbox encounter, and emphasised, with a grin, "a special delivery!" he said.

Touché, Jan! You're so clearly right.



27,000 LIGHT THE NIGHT TO GIVE HOPE



From left: Bridgestone Australia Ltd's Mr Nobu Mieno, Group Chairman and Managing Director; Joanne Denley, Director - Human Resources and Risk Management; and Andrew Moffatt, Senior Executive Director, at *Light the Night*.

Australians have embraced the Leukaemia Foundation's newest and most inspiring fundraising event, turning out in their thousands at this year's *Light the Night* to raise more than \$1.45 million.

More than 27,000 people came together at twilight events around the country to shine lanterns of love, life and hope to help create a brighter future for people with blood cancer.

Now in its fourth year, this year's event was even more special, with beautiful new lanterns for people to shine and take home to keep. Guest performances from Daryl Braithwaite, Kate Ceberano, Leo Sayer and Stan Walker also contributed to making our Sydney, Melbourne, Adelaide and Perth events even more memorable.

The support from regional areas also shone through, with dozens of community *Light the Night* events as well as lantern drives taking place.

"*Light the Night* is spectacular and this year's event has been celebrated as our most successful yet," said Peter Cox, CEO of the Leukaemia Foundation of Australia.

Bridgestone Australia Ltd is a proud supporter of the Leukaemia Foundation, providing our Patient Transport Vehicles. In 2011, the company continued its support and again joined forces with the Foundation as *Light the Night* Principal Partner.

Mr Nobu Mieno, Bridgestone Australia's Group Chairman and Managing Director, said participation in this year's *Light the Night* held extra special meaning.

BARTENDERS IN U.G.L.Y. BATTLE

Australia's bartenders have been showing that they're U.G.L.Y. for the Leukaemia Foundation's most quirky fundraising event, *U.G.L.Y. Bartender of the Year*.

During the month of November, hundreds of bartenders across the country were hosting events to have fun and raise money for leukaemia, lymphoma and myeloma research and patient care.

U.G.L.Y. stands for 'Understanding, Generous, Likeable You' and plays on the Australian love of contradiction.

"Bridgestone first started supporting the Leukaemia Foundation in 1986 – so this year we celebrate 25 years of support for this wonderful organisation," he said.

"*Light the Night* is a truly memorable and touching occasion – for that reason we have committed to being the Principal Partner for the next five years. It's a commitment shared and valued by the entire Bridgestone family across the country."

In 2008, Frank Seeley AM, Founder and Chairman of Seeley International, first heard about *Light the Night* being held in South Australia, and was inspired to become its founding sponsor. The following year, Seeley International became the Major National Partner around Australia and, in 2011, the company increased their commitment for this great cause as the Major National Partner for *Light the Night*, out to 2013.

Mr Seeley said that by supporting this inspirational event and getting Seeley International staff involved in supporting the cause, Seeley International was not only helping the Leukaemia Foundation to support those who were coming back from blood cancers, but also strengthening the prospect of making a cure a reality.

"This event is so inspiring and it has become an important source of funds to help combat blood cancers, as well as raising the public's awareness," said Mr Seeley.

Mr Cox paid tribute to everyone who contributed to making *Light the Night* in 2011 our best yet.

"We thank everyone who helped to make this year's *Light the Night* such a success – our generous partners, particularly Bridgestone Australia Ltd and Seeley International, the countless volunteers and each of the 27,000-plus Australians who came together at events around the country," he said.



Seeley International's team of 'angels' sported white winged caps.

It's a fun way to raise serious funds to help people with blood cancer.

The bartender who raises the most funds in each state will be crowned U.G.L.Y. Bartender of the Year and win a trip for two to Phuket. Their venue will win a Hoshizaki Ice Maker valued at \$7,500 thanks to Hoshizaki Lancer.

You can still support your local U.G.L.Y. Bartender at www.uglybartender.org.au.





25 YEARS ON – TIME TO CELEBRATE

This past October, Bruno Rosin and his family celebrated a milestone anniversary – 25 years of their husband and father surviving the disease that once threatened to claim his life.

On 13 October 1986, Bruno had a life-saving bone marrow transplant at St Vincent's Hospital in Sydney.

Bruno was diagnosed with chronic myeloid leukaemia (CML) in 1984 when he was 38 years-old. At the time he was the co-owner of a successful building company, which he had built up after emigrating from Italy as a 17 year-old and teaching himself English.

Bruno's CML diagnosis followed an injury on a building site. The subsequent pain in his chest did not subside and, after seeing several doctors who could not find a problem, he went to the Emergency department at Canberra Hospital. There, a young intern who had recently finished Medical School ordered a full round of blood tests. The young intern was Dr Michael Pidcock – now Director of Haematology at Canberra Hospital and who Bruno continues to see annually – who told him he had CML.

His condition was so advanced that he was immediately put on chemotherapy and it took his medical team three months to stabilise him.

He was then in remission for two years, before his condition worsened again. He was told that he only had one week to live and his only chance of a cure would be through a bone marrow transplant.



Last year Bruno rode his motorbike from Canberra to Cairns.

After Bruno's older brother was found to be a compatible donor, he had his transplant under the supervision of Dr Kerry Atkinson at St Vincent's Hospital, in Sydney. His younger brother donated platelets.

Bruno then spent six weeks in hospital and a further six weeks receiving treatment as an outpatient, before returning to Canberra in December of 1986. He began gradually returning to work from February 1987.

The Rosin family has supported the Leukaemia Foundation at various times since Bruno's transplant, including being involved in organising charity functions on behalf of the Foundation in Canberra. A lifetime on from his illness, Bruno is now retired and is the proud grandfather of 10 grandchildren. At the age of 65 he bought his third motorbike, a scooter, to travel to and from the golf course.

AUSTRALIAN WORKERS A GENEROUS BUNCH

The Leukaemia Foundation has seen a 23% increase in the number of New South Wales-based companies engaged in our Workplace Giving Program in the past year.

The rise in these critical funding relationships is the result of concentrated efforts by our dedicated Business Managers to encourage more employers and employees to support the Foundation's vital work.

Leukaemia Foundation General Manager – NSW/ACT, Christine McMillan, says the Workplace Giving Program is a proactive way for workers to actively engage with the Leukaemia Foundation.

"It's a voluntary scheme where employees can nominate the amount that they would like to donate to the organisation each pay period," she said. "The pre-tax donation is then managed through the payroll system.

"The benefit for us is that the giving process is low on administration and fundraising costs and allows us to channel donation funds to our Mission and Vision initiatives, while forging new giving relationships from a stable and long-term fundraising source."

Some companies also match employee contributions.

Australian publishing house, **CCH**, is one of our newest workplace giving partners. Its CEO, Russell Evans, is an active volunteer and board member of other cancer-based organisations.

Of the company's 300 staff, 18% signed up for donations through payroll deductions on the day the Leukaemia Foundation Workplace Giving Program was launched there.

One of Australia's largest creative advertising agencies, **BMF**, is another new workplace partner, also providing pro bono support and holding fundraising events in the office.

NRMA Motoring Services adds volunteer transport drivers from their road service team and holding workplace fundraisers to their workplace giving support. The NRMA's staff will also take part in *World's Greatest Shave* in 2012.

To find out more about our Workplace Giving Program in NSW/ACT please contact Janet Hall on 02 9902 2227 or jhall@leukaemia.org.au, or call 1800 620 420 to speak to someone in your state.



MATESHIP OVERCOMING ADVERSITY IN ADELAIDE

Men and mateship go hand in hand. Proving that this age-old institution can stand up to the toughest of life's challenges, a new support group for men whose lives have been disrupted by blood cancer is filling an important niche in Adelaide.

The inspiration for the Paul Hunter Men's Group was its namesake and founding member, Paul Hunter, who was renowned for his positive attitude and his passion for supporting others like him with blood cancer.

"Paul had a positive attitude which helped other patients," said Andrew Read, Leukaemia Foundation Support Services Coordinator in Adelaide. "Patients don't normally go to visit other patients in hospital – but Paul did. He knew what was important and would listen and offer help to others. He made a positive difference."

The Paul Hunter Men's Group meets monthly at the Foundation's Findon premises, with guest speakers and education sessions to help members live better with their illnesses. Mid-monthly social activities are also held.

Whether they're swapping anecdotes on the impact of their diseases on work and family life around a barbecue, or brainstorming ideas about how new technologies can help to bridge the communication gap with mates in isolation in hospital, group members view their time together as an invaluable social outlet.

Neil Matthews, who was diagnosed with chronic lymphocytic leukaemia (CLL) two and a half years ago, said it was therapeutic to get together with people who "understand exactly where you're at".



Brothers in arms: Members of the Paul Hunter Men's Group are walking the blood cancer journey together.

He said the group was enabling the formation of valuable new friendships, at a time when there was a risk of other relationships falling by the wayside. For many people undergoing treatment for blood cancer, their weakened immune system means limiting contact with others because of their heightened susceptibility to infection. In some cases, once strong friendships are eroded by the unavoidable strain.

"Obviously life changes very quickly when you get sick," said Neil. "You can lose a lot of friends."

"It is liberating to be able to join in with a group of people that understand where you are at and can accept you as you are. I really appreciate the opportunity to both reassure others and also gain reassurance that we are not alone in our experiences resulting from our health challenges."

For more information on the Paul Hunter Men's Group, please contact Andrew Read on 08 8273 3530 or at aread@leukaemia.org.au.

FOUNDATION OPENS NEW NT OFFICE

Excitement is sky high among our Darwin team following the opening of our new Northern Territory office.

Guests including Darwin Lord Mayor, Graeme Sawyer, and Mayor of Palmerston, Robert MacLeod, joined about 40 other guests and our staff in celebrating the opening of the new premises and the move from our former site.



The Winnellie office is located opposite the historic and original Darwin Airport entry gates, providing a spectacular view of the constant flow of military and commercial aircraft.

The Foundation shares a building with the Winnellie Medical Centre, which has fast become a special neighbour. The wife of the centre's resident GP, Dr Alfred Tonga, is currently undergoing treatment for lymphoma and has stayed at a Leukaemia Foundation unit in Adelaide. This accommodation is provided free of charge to regional families needing to relocate to a major city during treatment. Recently at Darwin's *Light the Night*, Dr Tonga's daughter, Rere, was a top fundraiser and gathered a team of more than 30 walkers for the event.

At the new office's official opening, everyone reportedly had a fantastic night and particularly enjoyed the delicious food donated by another favourite neighbour, the Transit Lounge Café.

The Foundation's Shelley Ryan (left) and Alex Mansfield wave from the balcony of the new office.



UNBREAKABLE FRIENDSHIP THE INSPIRATION BEHIND FUNDRAISER



Belinda (centre), with Laura (left) and Nicole, has raised almost \$6000 for the Leukaemia Foundation in honour of her friend, Em.

When Belinda Sudano's best friend was diagnosed with leukaemia, the friendship through "thick and thin" that the girls had shared for years became even stronger.

From telling travel stories, socializing and enjoying long conversations about their interests in fitness, art, design and fashion, the two women enjoyed all the usual activities that two 20-somethings should.

"She was the kind of friend where all you could be doing was sitting on the couch, watching TV, or having fish and chips in the park, and you would still walk away feeling like you had the best afternoon," Belinda said.

"She was a great friend and one of the most kind-hearted people I have ever known. She always knew how to boost you up, and you never doubted where you stood with Em because she made you feel so loved, wanted and valued."

As a tribute to Em, who sadly passed away in April 2011, Belinda was inspired to organise a special event to raise awareness of the impact of blood cancers.

At the time of going to print, Belinda was on track to raise almost \$6000 from her event in Melbourne.

"I like to do at least one fundraiser per year, but for different cases," Belinda said. "For this year's event there was no question or doubt about who I would be raising money for. It's been a long process but organising this event has been one of the ways I still feel connected to Em.

"This is something I would like to try and organise every year or every 18 months, to try and raise awareness of this class of cancers.

"Em was full of life, so had so much zest – she worked hard, and played hard. It's a real tragedy that her experience was cut so short."

RAISING LYMPHOMA AWARENESS THROUGH ZUMBA®

Melbourne's Federation Square came alive to the sound of music recently with a Zumba®thon™ to help raise the profile of World Lymphoma Awareness Day (September 15).

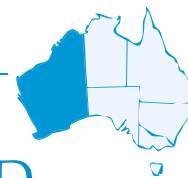
Leading the Zumba® class in front of more than 500 participants was instructor and lymphoma survivor, Karina Carrel (see story page 3), along with 12 fellow instructors.

Lymphomas are the most common form of blood cancer in Australia, and of these, almost 90% will be non-Hodgkin lymphoma. Lymphomas are seen in all age groups but are most common in people aged 50+.



Federation Square was the location for a Zumba®thon™, led by Karina Carrel (lying down).

Lymphoma is the fifth most common cancer in Australia. The peak age for diagnosis of Hodgkin lymphoma is between 15 and 30 years.



FOUNDATION BENEFITS FROM NEW WA AWARD

The Leukaemia Foundation will benefit from a share in a \$100,000 donation from a business recently awarded Western Australia's inaugural Award for Giving.

Western Australian Governor, Malcolm McCusker, presented the award – and a cheque for \$100,000 to be distributed among the business' charities of choice – to David Flanagan, Managing Director of Atlas Iron, before a function for key business leaders at Government House.

In a recent interview with *The West Australian*, Governor McCusker urged West Australians to do more for charity and called on big businesses to use at least one per cent of pre-tax profits for philanthropy.

He also hoped to see every small to medium-sized business “adopt a charity” and display their support. Individuals should also consider how they could give something back.

Mr Flanagan plans to share the \$100,000 between the Leukaemia Foundation and youth help group, Youth Focus.

Mr Flanagan is a member of the Leukaemia Foundation in WA's Business Advisory Council. The Council aims to maximise opportunities for partnerships and networking in the business community, provide opportunities for advocacy for blood cancer patients, and to work towards establishing a dedicated patient accommodation complex in Perth.

MIKE CONQUERING KILIMANJARO

Perth's Mike Thorman rarely shies away from a challenge. On many occasions over the years, he has been able to depend on his two wheels, two legs and plenty of stamina to power him through dozens of state cycling competitions.

This November, Mike put his physical and mental abilities to the ultimate test to help raise money to support Australians with blood cancer by participating in the inaugural Leukaemia Foundation Kilimanjaro Challenge.

Made possible in partnership with Inspired Adventures, the incredible adventure took place over 11 days in late November.

“A while ago, a close friend of mine was diagnosed with blood cancer,” said Mike. “It made me realise that this could happen to anyone, anytime, no matter how physically fit they are.

Continued on page 12...



From left: Youth Focus Chief, Jenny Allen, Atlas Iron's David Flanagan, West Australian Governor Malcolm McCusker and Leukaemia Foundation General Manager (WA) Carolyn Turner. Photo appears with thanks to The West Australian.

“To acknowledge Mr Flanagan's personal and professional connections to regional Western Australia, the Foundation will allocate this funding towards patient accommodation for regional patients required to relocate to Perth – often for extended periods of time,” said Carolyn Turner, Leukaemia Foundation General Manager (Western Australia).

“Building strong support from the corporate sector is vital in allowing us to further our Mission and Vision initiatives from a stable and long-term fundraising source.”

SUPPORT NETWORK EXPANDS IN WA

People living with blood cancer and blood disorders in the Peel region of Western Australia will now have the chance to meet and talk about their experiences with others who are on a similar life journey.

The first Leukaemia Foundation support group for Mandurah was held recently at Cicerello's, which overlooks the Peel inlet. The area is home to many local wild bottlenose dolphins and created a serene location for the 12 people who attended.

While support groups and education sessions have previously been held in Perth and Bunbury, this group is the Foundation's first in the Peel region. Received positively by all who took part in the first meeting, the support groups are now being held monthly.

For more information on the Mandurah group, please call 1800 620 420 or go to www.leukaemia.org.au.

CALLS FOR BETTER TRANSPARENCY WELCOMED

The Leukaemia Foundation welcomes the Gillard Government's plans to improve transparency within the Not-for-Profit sector, saying an Australian Charities and Not-for-Profits Commission will better inform the general public and further regulate the industry.

Media reports recently focussed on the cost of fundraising for Australian charities and the need for a common approach to transparent reporting within the sector.

"The Leukaemia Foundation is committed to transparent reporting and we welcome Federal Government plans to improve information and consistency across the Not-for-Profit sector," said Peter Cox, CEO of the Leukaemia Foundation of Australia.

"The greatest need is for standardisation of reporting rules, particularly around the definitions of 'cost'. Lack of uniformity currently makes comparisons between charities meaningless, and disadvantages those who readily disclose performance results," he said.

The Leukaemia Foundation says the Australian Charities and Not-for-Profits Commission will also need to determine overall value of the organisation to the community, including employees and volunteers.

GIFTS TO CELEBRATE AND HONOUR

Can't find that perfect gift for your special someone? Why not make an In-Celebration gift and help the Leukaemia Foundation to support the thousands of people across Australia living with leukaemias, lymphomas, myeloma and related blood disorders.

Many occasions can be celebrated this way – a milestone birthday; the birth of a child; an anniversary; a wedding; a graduation; a baptism; retirement; just to name a few. Ask your friends and family to make an 'In-Celebration' donation to the Leukaemia Foundation in lieu of gifts.

Geelong's Jenny Stewarts and David Dundon will be offering guests the In-Celebration opportunity at their wedding in March. The gesture will be a way of ensuring David's daughter, who passed away from leukaemia in 1991, is part of their special day.

"We don't need wedding gifts," said Jenny. "We're in our 50s and don't need help with paying for the honeymoon.

"People always want to give something, so we wanted to do something worthwhile."

We also have a Memorial Giving Program, 'Not Forgotten', which is a special way to honour a loved one's memory.

For both Celebration Giving and Memorial Giving, all donations are acknowledged and receipted. Families are also sent acknowledgement reports of all gifts made.

For further information, please call 1800 620 420 or email info@leukaemia.org.au.

"While cost of fundraising is important, it is not the sole measure of a good charity," said Mr Cox.

"The Commission will need to account for differences between organisational structures, and consider value relative to the scale of the need, the number of organisations servicing it, and the quality of services the organisation delivers."

The Leukaemia Foundation of Australia remains focussed on the responsible use of resources including donor funds, and transparent reporting to its stakeholders.

"Our current focus on developing our bequest and giving programs will continue to increase cost efficiency over time. Compared to many charities, event fundraising represents a high proportion of our overall income, so broadening our fundraising program makes sense.

"Being transparent with our stakeholders is also important and each year, we enter the PwC Transparency Awards to expose our reporting to rigorous external review.

"Last year, the Leukaemia Foundation of Australia ranked in the Top 10 Charities in our category and it's something we want to achieve again this year."

'Tis the season to give hope



This festive season, help us create a brighter future for people facing the challenges of blood cancer and blood disorders.

In 2012, at least 11,500 Australians will be diagnosed with leukaemia, lymphoma or myeloma — or one person every 46 minutes.

\$27 can provide emotional support to help overcome the shock of diagnosis.

\$40 can support the lab costs for a PhD research student for one day.

\$58 can keep one of our patient vehicles on the road for one day.

\$160 can give a regional family in a city for treatment a place to call home for 2 nights.

\$400 can fund a major blood cancer research project for one day.

Please make your Christmas gift of hope at www.leukaemia.org.au or call us on 1800 620 420.

FOUNDATION AIDS MDS & AML BREAKTHROUGH

A breakthrough by Adelaide blood cancer researchers has highlighted the importance of funding provided by organisations like the Leukaemia Foundation.

Researchers from the Centre for Cancer Biology at SA Pathology led an international collaboration in identifying the inherited gene defects which predisposes some people to develop myelodysplastic syndrome (MDS) and acute myeloid leukaemia (AML).

The gene is considered the blood cancer equivalent of a colon, breast or ovarian cancer gene.

The research has received valuable funding from the Leukaemia Foundation, the National Health and Medical Research Council (NHMRC) of Australia, the Cancer Council of South Australia and the University of Adelaide.

Anna Williamson, General Manager Research and Advocacy at the Leukaemia Foundation, says this breakthrough highlights the importance of finding money for research.

“This breakthrough is good news for people with MDS and AML and we are proud to have been able to financially contribute to this work,” she said.

“This is what it’s all about. The ambiguous symptoms of some blood cancers means that most patients are not diagnosed until it is a medical emergency. Identifying predisposition will save lives.

“The Leukaemia Foundation has committed more than \$20million to research since 2005 to improve survival of patients with blood cancer - including \$4.3 million



The Leukaemia Foundation has committed more than \$20 million to research since 2005.

for 59 projects in 2011. It is good to see the fruits of this investment in the quality of research being supported in the field of blood cancer.”

This year, around 11,500 Australians are expected to develop leukaemias, lymphomas or myeloma. And while as many as 40,000 people live with one of these forms of blood cancer today, blood cancer is the second biggest cause of cancer death in the country. Clearly the ongoing need for research is vital.

Details of the Leukaemia Foundation’s multi-million dollar national research program can be found at www.leukaemia.org.au.

TAKE A LOOK AT OUR NEW YEAR’S RESOLUTIONS

At a time of year when many people are contemplating their goals and dreams for the year ahead, the Leukaemia Foundation is readying itself for a number of new initiatives to expand on our free support services for Australians living with blood cancer.

Our ambitions for 2012 include:

- **Introducing** two new newsletters for people with acute lymphoblastic leukaemia (ALL) and acute myeloid leukaemia (AML), to take our range of disease-specific newsletters to a total number of seven. These newsletters provide information about the diseases, latest research, education and support, as well as stories of hope.
- **Upgrading** our website to make it easier for people to find support they need. Our new website is set to go live in the first quarter of 2012 and will feature a range of exciting new functions to improve the on-line experience for the people we support and those who support us.



This is one of two new newsletters that we are adding to our suite of resources in 2012.

- **Increasing** our focus on supporting young families after a child is diagnosed with blood cancer, with the extension of our Child: Family: Care Program pilot program to New South Wales. The program began in South Australia and the Northern Territory with funding from The Little Heroes Foundation and is specifically designed to help families navigate their way through the uncertain time of diagnosis and beyond.
- **Launching** a new internal database for our staff and volunteers. Investing in this system will enable us to implement and manage organisational functions, data records and internal communication through one central source, creating efficiencies by standardising our administration processes.

To keep up to date with our exciting plans for 2012, please visit www.leukaemia.org.au or call your local office on 1800 620 420.

COME TWEET WITH US!

FOLLOW US ON
twitter

The Leukaemia Foundation has launched a twitter account to further encourage interaction between the people we support and those who support us.

Our twitter presence adds another layer to our growing

community of online support – there are already more than 24,000 fans on the Foundation's facebook pages!

Join us in improving the lives of people with blood cancer by following us on twitter at **@LeukaemiaAus**.

MIKE CONQUERING KILIMANJARO

Continued from page 9...

"This was one of the drivers that encouraged me to sign up to face the challenge of climbing Africa's highest mountain to raise funds to support Australians with blood cancer."

The outcome for Mike's good friend, who was diagnosed with lymphoma, has been a positive one.

Each participant in the Kilimanjaro Challenge is raising a minimum of \$10,000, with a portion of this total covering expenses and the remainder going to the Leukaemia Foundation.

After being encouraged to sign up by a friend who was also taking part but has since had to opt out due to injury, Mike mentioned his plans to his workplace colleagues at WA's Water Corporation. He said the support that followed was "amazing".



Mike Thorman is exchanging his usual two wheels for two feet by taking on Mount Kilimanjaro for the Leukaemia Foundation.

"I mentioned the huge task of fundraising to a colleague of mine," said Mike. "She came back to me a day later and said she'd like to organise a fashion show. After three months of planning, the evening raised over \$4000!"

Mike said that others he approached for support were also eager to help, either through donations and other assistance, or by providing products for auction.

Also a professional photographer, Mike planned to capture his Kilimanjaro adventure through his camera lens and record the experience in a journal. Excerpts from Mike's journal and a selection of photos will feature in the next edition of *The Carer*.

"I'm also looking forward to meeting other people on the trip and seeing the African culture to appreciate how much we have in Australia," Mike said.

COLOURFUL CAMPAIGN FOR A GOOD CAUSE

Some paint the town red. But one Victorian community each September turns their town of Moe mauve – all in the name of raising funds for the Leukaemia Foundation.

The 'Make Moe Mauve' campaign was the brainchild of local resident, Jann King, who came up with the idea after participating in *World's Greatest Shave* in 2008 in support of a friend with blood cancer.

"I saw what good work the Leukaemia Foundation does and I just wanted to help," Jann said.

This year, 180 local businesses made Moe mauve by decorating their shop fronts, as well as raising money. Local radio and television stations also jumped on board, helping to boost the overall tally to more than \$6000.



Jann King (far right) and her team of helpers for Make Moe Mauve.

Since the first year when just 30 businesses took part, the colourful campaign has gained momentum – so much so that plans are now afoot for spin-off events in nearby towns.

"Within five years, we're looking to have other towns involved to build a 'regional rainbow'," Jann said.

The Carer welcomes feedback from our readers.

If you have a comment on a particular article or a suggestion for a story, please email stories@leukaemia.org.au or call 1800 620 420.

Leukaemia Foundation
Freecall: 1800 620 420
Email: info@leukaemia.org.au
Mail: GPO Box 9954 in your capital city
Web site: www.leukaemia.org.au



**Leukaemia
Foundation**
VISION TO CURE
MISSION TO CARE