

## CHRIS BACK ON TRACK AFTER BEATING RARE LYMPHOMA

**Chris Stokes' experience with lymphoma began after Easter 2006 when he had a couple of uncomfortable months. He developed tummy pains, alternated between being constipated and having the trots, and his stomach was "really noisy".**

"It was rumbling and grumbling and I could hear it all night," said the strata manager, 33 of Newport, on Sydney's Northern Beaches.

His doctor thought Chris had Giardia, then stomach ulcers, but the treatment for these conditions didn't help.

Then on May 23 that year, Chris decided something was seriously wrong and when he finished work he took himself to Mona Vale Hospital.

After some tests and a CT scan he was told to stay in hospital where he had a raft of tests over the next week.

"They were heading towards Crohn's disease," Chris explained.

But after a stomach biopsy he was diagnosed with a B-cell type lymphoma, called Burkitt's lymphoma, which is rare.

Chris began four cycles of chemotherapy, his weight dropped from 96kg to 63kg and he spent the best part of the next five months in hospital.

"I was that weak, I had no muscle left and I struggled to walk, to move and to dress myself."

He was in remission after the second cycle of chemo but he got really sick during the last two cycles.

"You try to keep yourself awake because you're scared of dying," said Chris, who at one time didn't sleep for three days when his white blood cell count wasn't coming back.

"And I had the mouth ulcers from hell."

Chris then got a staph infection after his treatment program finished.

He finally went home in September, set about rebuilding himself and returned to work just before Christmas.



*Above: Chris and his dog, Jess, out on the water.*

*Right: Chris Stokes with his partner, Amanda McCreidie.*



The hardest thing, Chris said, was losing four of his close mates from hospital who all had different types of lymphoma.

"For some reason they died and I'm alive," said Chris who is still trying to make sense of this.

"I spent a lot of nights with these guys, you become very close to them."

Chris says he thinks about the disease everyday: "It's always there but life is there to be lived."

"I have as much fun as I can and fit in as much as I can because you never know if you'll be here tomorrow.

"I'm also less stressed and I don't take things as seriously," said Chris who is now getting other aspects of his life back on track, such as his mortgage payments.

**Chris took part in the Leukaemia Foundation's activities for World Lymphoma Awareness Day 2007. He was featured in a documentary in which he shared his experiences with the disease and also helped publicise the event when he was interviewed on radio.**

# COALITION OF COUNTRIES WORLDWIDE WORK TOGETHER TO RAISE AWARENESS

The international Lymphoma Coalition was formed in 2001 by four lymphoma support organisations to raise awareness of lymphoma and support people diagnosed with this cancer.

These were the Deutsche Leukämie-Lymphom Hilfe (Germany), Lymphoma Association UK, Lymphoma Research Foundation (USA) and Lymphoma Foundation of Canada, with assistance from Roche International.

Representatives from the Leukaemia Foundation in Australia have attended each of the Coalition's annual meetings since its inaugural meeting in December 2002 which was attended by members of support organisations from six countries.

The Coalition now has members from 35 countries around the globe including Japan, Bulgaria, Serbia and Argentina which joined last year. In 2008, the Coalition plans to incorporate as a legal entity and recruit more members.

The most recent Annual Lymphoma Coalition meeting was held in Atlanta, USA, in December 2007, in association with the annual American Haematology Society Meeting.

Members provided updates on their *World Lymphoma Awareness Day* activities for 2007 and made plans for the 2008 awareness day campaign.



Representatives of the Lymphoma Coalition's member organisations from around the world in Atlanta.

There were special presentations by two international experts on lymphoma – Dr Joseph Connors from Canada (*Improving our understanding of the causes of lymphoma*) and Dr Chris Hatton from the UK (*New treatments for lymphoma*).

Nancy Lins and Linelle Blais of the American Cancer Society spoke about trends in volunteerism and a series of stimulating discussions about fundraising included corporate sponsorship (Pru Etcheverry, LBFNZ), major gift campaigns (Sue Bliss, LRF, USA) and events (Donna Grogan, LLSA, USA).

To find out more about the Lymphoma Coalition visit [www.lymphomacoalition.org](http://www.lymphomacoalition.org)

## NATIONAL BLOOD CANCER REGISTRY

**Blood cancers, including lymphomas, are a significant health concern in Australia and account for 10% of all cancers.**

State cancer registries have collected broad incidence and mortality data but the lack of a central repository to consolidate information on treatment patterns and patient outcomes, to optimise clinical decision-making, has been a gap in the management of blood cancers.

To address this unmet need, the idea of developing a national registry was conceived with the goal of providing complete, accurate data on the management trends and outcomes of Australians with blood cancers and related disorders.

Clinical haematologists and consumer organisation representatives formed a project management group and following a research and consultation phase, the first stakeholder meeting, *Working Towards An Australian Blood Cancer Registry*, was held in Sydney in September 2005.

There was unanimous support for the registry concept by delegates including representatives from consumer organisations, clinicians, researchers, academics, cancer registries government, pathology laboratories, the pharmaceutical industry and software developers.

Since then the Australian Blood Cancer Registry (ABCR) has made inroads into repository development, funding and standards setting and has embarked on various projects such as implementing and piloting data collection via the Lymphoma Wizard Project, communicating the development of the ABCR with key stakeholders while garnering clinical and

financial support to bring the vision of the ABCR to fruition.

In November 2007, the ABCR's third annual stakeholder meeting in Sydney was attended by 43 delegates and received unanimous support for the registry's work to date and a strong commitment from stakeholders to continue supporting future initiatives.

Two projects are planned for 2008. In Western Australia, a state-wide data collection will begin that will initially focus on lymphoma sub-types, then move on to encompass other forms of blood cancer. In South Australia, a 'RESIST' registry will begin collecting data on CML patients who fail to respond to standard treatments and are being treated with second-generation drugs. The aim of these two projects is to demonstrate the effectiveness of both the Lymphoma Wizard as a data collection tool and improved outcomes for patients through better data collection and analysis.

The ABCR is collecting detailed and accurate information on blood cancers. This information will be used to improve the capacity of clinicians, patients, their families, carers and governments to make informed and timely decisions on the management of blood cancers.

The ABCR will provide clinical haematologists and oncologists with accurate and detailed information to improve survival and treatment outcomes and set standards to achieve best practise in clinical care.

Since January 2007, the Leukaemia Foundation has provided its services as Secretariat for the ABCR. To find out more about this project, visit the website, [www.abcr.net.au](http://www.abcr.net.au).

# PHD SCHOLAR'S RESEARCH SHOWS PROMISE AS TREATMENT



Leigh Ellis far right, with researchers at the Peter MacCallum Cancer Centre.

## Research by Leigh Ellis at the Peter MacCallum Cancer Centre in Melbourne is investigating a new form a chemotherapy known as histone deacetylase inhibitors (HDACi).

Leigh was awarded a PhD scholarship by the Leukaemia Foundation in 2005 for research on the use of novel inhibitors as anti-cancer agents.

Lymphoma represents around 55% of new blood cancer cases and HDACi shows great promise in treating lymphoma in both the laboratory and clinic. However little is known about how these drugs actually work against cancer cells.

HDACi have the ability to induce cell cycle arrest,

differentiation and apoptosis (cell death) in a variety of cancers. The main aim of Leigh's research is to better understand the molecular pathways required by HDACi to induce their effects by using a mouse model that resembles human Burkitt's lymphoma.

Leigh has shown that HDACi can kill these lymphomas.

"We have also deleted or over expressed important genes required by these lymphomas that enable survival and/or chemo-resistance and HDACi have been able to kill these lymphomas or inhibit their growth," explained Leigh.

Successful therapy experiments also have been achieved in mice bearing the same lymphomas, significantly extending the life of the mice.

One of the HDACi Leigh is investigating is being used in a phase I clinical trial with patients diagnosed with cutaneous T cell lymphoma (CTCL). Patients on the trial have responded well to HDACi therapy and preliminary data suggests that significant alteration in the expression of certain genes could be the primary reason for the patient's response.

These and future results will enable a better understanding of how HDACi kill tumor cells and will allow the Leukaemia Foundation's national research program to devise new methods of treatment using HDACi as single agents and in combination with other anti-cancer drugs.

## PATIENTS REJECT CRUCIAL CANCER TESTS

### More than half of Australian adults at high genetic risk of cancer are declining offers for testing, new research has found.

Dr Graeme Suthers, head of the familial cancer unit at the Women's and Children's Hospital Adelaide, said 5000 Australians were diagnosed annually with potentially fatal cancers that could have been prevented or detected earlier through genetic testing and surveillance.

He told the Clinical Oncological Society of Australia's annual scientific meeting in Adelaide last November that 60% of people told by his clinic that they were at risk were declining to be tested or monitored.

"To have a successful familial cancer program, we need engagement by the families themselves," Dr Suthers said. "We also need clinicians that are good at recognising that the person is at high genetic risk."

Dr Suthers' unit had increased from 20% to 40% the proportion of at-risk relatives seeking further information by a policy of writing to them, but that still left a majority

turning their back on potentially life-saving intervention.

It was important to portray genetic testing as an opportunity for prevention, rather than as a negative confirmation of risk, he said.

Source: *Medical Observer*, 23 November 2007, p.1

## NHL AMONG TOP FIVE CANCERS IN AUSTRALIA

More Australians than ever are developing myeloma and non-Hodgkin lymphoma, according to the Australian Institute of Health and Welfare (AIHW).

In recently released statistics, the AIHW listed the two cancers among the top five cancers which had significantly increased in incidence in the 10 years from 1993 to 2003.

Myeloma incidence had increased by 44 per cent and NHL by 36 per cent.

The AIHW also reported that in the 2004-5 financial year, one in 10 hospital admissions in Australia were cancer related, with cancer now the leading cause of premature death in Australia.

For more information visit: [www.aihw.gov.au](http://www.aihw.gov.au)

# ON-LINE SUPPORT FORUM FOR PATIENTS AND FAMILIES



professionals from the Leukaemia Foundation, enables people to share ideas, opinions, helpful and practical advice and personal experiences.

Registration is free and participants can remain anonymous. To participate is easy.

**Talk Blood Cancer\* is a moderated on-line information and support forum for patients and families living with leukaemias, lymphomas, myeloma and related blood disorders.**

Being diagnosed and treated with a blood cancer like lymphoma can be confronting and at times overwhelming. It presents patients and families with many challenges. Being in contact with other people who have experienced or are going through similar, complex feelings associated with the disease is useful.

Talk Blood Cancer is designed to help in understanding and managing the practical and emotional issues that are part of the journey through diagnosis, treatment and recovery.

This safe, supportive, informative environment, moderated by an experienced haematology nurse and allied health

1. Visit [www.talkbloodcancer.com](http://www.talkbloodcancer.com)
2. Click on 'register'
3. Provide a username (for public viewing) and your email address and a password (not public)
4. Take part by posting messages, participating in polls and reading on-line discussions

This service is part of the Foundation's commitment to increasing the delivery and reach of world-class support to patients and families. Talk Blood Cancer is an alternative source of support and information and it is particularly helpful for people who live in regional and rural areas and those who are not able to attend the Foundation's face-to-face support groups.

*\*Talk Blood Cancer was established with financial assistance from the Australian Government through the Cancer Support Groups Program.*

## A LYMPHOMA SURVIVOR'S STORY

**Helen Laurence was 65 when she was diagnosed with follicular lymphoma. In the following account, she describes her experience of diagnosis, treatment and living with non-Hodgkin lymphoma. It reveals Helen's wonderful spirit and the benefits of new treatment strategies in the management of lymphoma.**

*"Two years ago I noticed I was tiring easily and initially I dismissed this as just getting a bit older, but I became more concerned as the fatigue worsened and I experienced nausea and terrible hot sweats.*

*"My local GP was very supportive and persisted in finding the cause. I had lots of blood tests and trips to hospitals for scans, then was referred to a haematologist, Dr Mark Bentley. He diagnosed me with follicular lymphoma. It was actually a relief to know what the problem was.*

*"Dr Bentley started me on chemotherapy soon after the diagnosis and I went to the hospital clinic every Thursday for six to eight hours while I was given the treatment. The first few treatments were quite difficult for me as I was nauseous and became restless, agitated and couldn't sleep very well or concentrate on reading. The hardest thing for me was losing my hair, but in time I accepted this and even noticed that I have cute ears that have been hidden by my hairstyle!*

*"A month after finishing treatment, Dr Bentley told me I was in full remission. Several months later, we decided I would have a stem cell harvest. I had to have very strong chemo prior to this, then the actual harvest took two days. It was very involved. While I enjoyed learning about the*

*procedure, I also found it a difficult, emotional time and I was left feeling quite flat. However, now I have a store of harvested cells as my insurance policy if the lymphoma returns.*

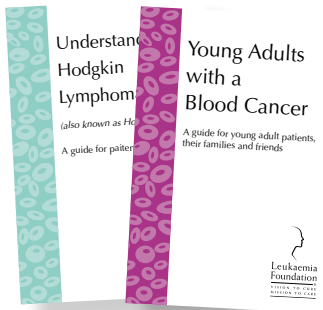
*"I was very tired following the stem cell harvest but over time have regained my strength. Dr Bentley suggested that I continue on MabThera as a maintenance program. It is totally different having just the MabThera without the chemotherapy. I had no nausea and one of the wonderful benefits is that you don't lose your hair but I was lethargic and a little emotional at times. I had always believed that mentally nothing could crush me, but when it's out of your hands there were times when I just had to have a big cry and I think that's a good release and helps the healing process.*

*"Since the completion of my treatment in September, I've felt great. We recently returned from a skiing holiday in Canada in which I totally participated and had loads of energy. It was a fabulously therapeutic time and I was so delighted for my husband, who put his life on hold for me, that we could once again enjoy travelling together. Just 12 months ago, when I had just finished treatment, I was so exhausted I could hardly even walk down the hall. The difference now is incredible.*

*"The results of the treatment are obvious to me and to my husband. I feel very well at the moment and have confidence in my future health. My next maintenance treatment is due soon."*

# NEW INFORMATION BOOKLETS

A new information booklet, *Young Adults with a Blood Cancer*, has been developed by the Leukaemia Foundation to help young Australians, their friends and families understand blood cancers.



It draws extensively on information published in 2007 by the Leukaemia Research Fund (UK).

Leukaemia Foundation support services staff and other health professionals also provided invaluable feedback on its content.

Danielle Tindle, who is employed by the Leukaemia

Foundation as the project officer to research and develop a young adults education and support program, facilitated the production of this booklet. As a young lymphoma survivor herself, Danielle has translated her personal experience into her career focus. Earlier this year, she received a CanTeen scholarship to undertake postgraduate study in the cancer care of adolescents and young adults. This research is instrumental in the development of the Leukaemia Foundation's new young adults program and booklet.

*Young Adults with a Blood Cancer* provides information on diagnosis and treatment, side-effects and the physical, social and psychological impacts of diagnosis and treatment. It also discusses longer-term effects and life after cancer.

## PRACTICAL ISSUES FOR LYMPHOMA PATIENTS

By Kim Hobbs, Social worker, Westmead Hospital, NSW

**People living with lymphoma in rural locations have higher levels of unmet supportive care needs than their urban counterparts. Access to resources and organisations, such as the Leukaemia Foundation, to assist with practical needs will help ease the challenges of coping and adjusting to living with the disease.**

**Income support:** If employed at the time of diagnosis, don't resign immediately. Ask your employer about eligibility for entitlements such as sick leave and long service leave. Determine if medical certification is required and begin this process as soon as practical as it may take some time. Seek advice from a union if leave entitlements or rights are unclear. If unemployed or in casual work when diagnosed, or if paid leave expires during the illness, contact Centrelink (ph 13 27 17, [www.centrelink.gov.au](http://www.centrelink.gov.au)) for advice on potential support, eg Sickness Allowance or Rent Assistance. Meet with a Centrelink social worker to discuss specific situations. Charitable organisations like the Leukaemia Foundation may provide food vouchers and help with household bills. Most areas have cancer patients' assistance organisations and service clubs that may offer financial support.

**Treatment costs:** State health departments can offer advice on specific support schemes for travel to urban centres for medical treatment. Your local Medicare office and pharmacist can advise on the 'safety net' threshold to reimburse the cost of pharmaceuticals. Support services may be available for Veterans Affairs cardholders and for indigenous people.

This resource is valuable as young adults have unique psychosocial needs throughout the cancer journey. A diagnosis of cancer impacts young lives at a time which is critical in terms of education, employment, relationship-building and identity formation.

The information booklet, *Understanding Hodgkin Lymphoma (also known as Hodgkin's Disease)* has been revised and updated. The author, Lilian Daly, is a registered nurse with more than 15 years experience in haematology and stem cell transplantation and works part-time as a nurse clinician in haematology/bone marrow transplantation at St Vincent's Hospital in Sydney.

Lilian was helped by people who have experienced Hodgkin lymphoma as a patient or carer, the Leukaemia Foundation support services staff, nursing staff, clinical haematologists and oncologists from across Australia.

Hodgkin lymphoma is a relatively rare disease that accounts for 0.5% of all cancers and 10% of all lymphomas diagnosed. Each year around 400 people in Australia are diagnosed with the disease that occurs more frequently in males than in females.

Copies of these booklets are available from the Leukaemia Foundation. Call 1800 620 420 or download a copy from the Foundation's website: [www.leukaemia.org.au](http://www.leukaemia.org.au). In the top menu, click on **About the diseases**, then click on **Information booklets**, and scroll down to the booklet you require: *Young Adults with a Blood Cancer* or *Understanding Hodgkin Lymphoma*.

**Finances:** Check your documents and policies. Make or update wills and consider making an Enduring Power of Attorney, in case it is required. Seek advice about superannuation and insurance entitlements such as lump sum or disability payments. There is comprehensive coverage of these issues on the Brain Tumour Australia website: [www.bta.org.au](http://www.bta.org.au) or contact the Australian Prudential Governing Authority: [www.apra.gov.au](http://www.apra.gov.au).

**Back to work:** Patients frequently report difficulty in settling back into the workplace. Visit [www.livingcaringworking.com](http://www.livingcaringworking.com) for information on working and living with a life-threatening illness. For people caring for someone with an illness while still working, visit [www.workingcarers.org.au](http://www.workingcarers.org.au).

**Children:** It can be difficult to share news of a diagnosis with children. However, accurate and timely information reduces their fears and increases their ability to cope. It is better for them to hear distressing news from a parent or caregiver, rather than finding out by chance. Plan family time, even when parents are very ill. The Cancer Council of South Australia has a booklet on this topic that can be downloaded from [www.cancersa.org.au](http://www.cancersa.org.au) and more information is available from [www.canteen.org.au](http://www.canteen.org.au) and [www.myparentscancer.com.au](http://www.myparentscancer.com.au).

For help and practical advice: **Cancer Council Helpline (Ph: 13 11 20); Leukaemia Foundation (Ph: 1800 620 420); Centrelink (Ph: 13 27 17)** and your local hospital social worker and Community Health centre.

# TRANSCONTINENTAL CYCLIST IS A LYMPHOMA SURVIVOR

**Lymphoma survivor, Mel Macarthur's goal is to circumnavigate the world by bicycle and on foot.**

He describes this quest as a "pilgrimage" and "an inner journey".

It began in 1998 when Mel, who says he has been in the elite category of fitness all his life, cycled 12,000km from Dublin in Ireland to Jerusalem in Israel.

After cycling through the South Island of New Zealand in 2002 further legs of his global journey were put on hold when he was diagnosed with large diffuse B-cell non-Hodgkin lymphoma in November 2004 at the age of 58.

After the removal of a lymph node and treatment, which he completed in June 2005, Mel, a church minister who lives in the Blue Mountains outside Sydney, is in remission and getting on with what he was doing before.

Eight days after completing the last cycle of his chemo, Mel set out on an 11-day trek through Kakadu.

"It's a very healing place," he said.

"I started out not feeling well, but the scenes were breathtaking and after five days I started picking up and didn't feel bad when I came out.

"I attribute this to keeping my goals firmly in my mind .... it's important not to lose sight of them."

For Mel that means cycling around the world, which he dovetails with his treatment every three months, and completing his doctoral program – a dissertation on his pilgrimage.

Now he's planning the next leg of his journey to cross Australia. After cycling from Sydney to Uluru in 2006, he'll cross the Nullabor from Perth to Port Augusta this July.



*Mel Macarthur at the summit of New Priests Pass, Yosemite National Park, last year.*

In August last year, Mel set out across the USA from San Francisco with his son, Andrew, but they had to change plans when they rode into 60+°C temperatures in Death Valley.

Mel intends crossing the South American continent from Santiago in Chile to Buenos Aires in Argentina at the end of 2009, to walk through the Appalachian Mountains in the US, and to do Russia and India "at some point".

"Looking back, no-one wants lymphoma but it's had some benefits such as how I empathise with others and it has greatly tested my character."

*Anyone interested in joining Mel on his cycle across the Nullabor can contact him on 02 4758 6475.*

## INHERITING HAEMATOLOGICAL CANCERS

**Some Australian families may have an underlying genetic predisposition to leukaemia, lymphoma, and other haematological malignancies according to Dr Graeme Suthers from the Adelaide Women's and Children's Hospital.**

Dr Suthers is leading the Australian Familial Haematological Cancer Study (AFHCS) to develop a resource of bio-specimens and data from families for use in genetic research.

The aim of this collaboration between Australian scientists, nurses, doctors and patients is to unravel the mystery surrounding hereditary haematological cancers which may affect up to 200 families in Australia.

"We've collected information as well as samples from several of these families with the aim to gather enough data to find the genes responsible for these hereditary cancers," said Dr Suthers.

"From our preliminary data we believe that, similar to other cancers, five to 25% of haematological malignancies are caused by inherited genes.

"As the genes are also likely to be involved in the more common sporadic occurrences of the diseases, they could form the basis of new pharmaceutical treatments and diagnostics."

While clustering of cancer in families has been recognised for more than 50 years, researchers have only recently had access to

the technology and data necessary to identify the genes involved.

Hereditary genes have been identified for breast and colon cancer but only two genes have been found for haematological malignancies – both of which are involved in relatively rare cases of familial acute lymphoblastic leukaemia (also known as ALL), the most common form of childhood cancer.

Dr Hamish Scott and his team from the Child Health Research Institute at the Walter and Eliza Hall Institute in Melbourne are collaborating with Dr Suthers on the AFHCS.

"The difficulty in identifying genes involved in familial haematological malignancies has been due to the lack of available family data," Dr Scott said.

"Part of the problem has been the relatively small family sizes and the high mortality rate of leukaemia which we are overcoming in this study by recruiting a large number of relatives, both affected and unaffected, and by collecting pathology samples from admitting hospitals."

The AFHCS has collected samples from families with chronic lymphocytic leukaemia, acute myeloid leukaemia, Hodgkin lymphoma and non-Hodgkin lymphoma as well as mixed haematological malignancy families.

*To be involved in this study, please contact Dr Graeme Suthers: [graeme.suthers@cywhs.sa.gov.au](mailto:graeme.suthers@cywhs.sa.gov.au).*

# PATIENTS CAN JOIN WORLDWIDE NHL TRIAL

## The recruitment of patients for a phase clinical 3 trial for people with follicular non-Hodgkin lymphoma (NHL), known as LYM-3001, has reached the half-way mark.

Patients at more than 180 hospital sites across the world will take part and Australian patients are encouraged to discuss the trial with their doctor to assess their suitability in participating.

LYM-3001 is investigating the effect of combination treatment with Velcade® (Bortezomib) and MabThera® (Rituximab) in patients with previously treated follicular NHL, compared to treatment with rituximab alone. The trial is co-sponsored by Johnson & Johnson Pharmaceutical Research & Development and Millennium Pharmaceuticals, Inc.,

To learn more about LYM-3001, or other lymphoma clinical trials, you and your doctor can access a clinical trial search database such as [www.clinicaltrials.gov](http://www.clinicaltrials.gov) or [www.controlled-trials.com](http://www.controlled-trials.com). When searching for LYM-3001, type 'B-NHL Velcade' in the website's search bar and scroll through the listings.

Several patient education materials have been developed to help patients understand their options and these have been translated into French, German, Polish, Portuguese and Spanish. The translated materials are available by contacting the trial managers or patient groups in all countries where the LYM-3001 is taking place.

### MORE ABOUT THE LYM-3001 TRIAL

LYM-3001 is open to men and women, aged 18 years or older, who have been diagnosed with follicular B-cell NHL; FL (Grades 1 and 2), who have previously tried one or more other

therapies. If a patient has already tried rituximab, he/she must have responded positively to the drug, and disease must not have progressed for at least six months after the first dose. Patients who have already taken Velcade to treat NHL are not eligible for this study. Patients should talk to their physicians to see if Velcade might be a treatment option for them.

The study is designed to tell researchers whether combination therapy with bortezomib and rituximab is more effective in treating follicular B-cell NHL than rituximab alone.

In the short-term, depending on the treatment given, the number of cancer cells and tumours in a patient's body may be reduced. As a result, patients may feel better than before starting the trial, delaying the need to start the next round of therapy. Long-term benefits may be that patients may live longer.

With any trial, there are known and unknown risks. Before joining the trial, a study nurse or other health care provider will advise each patient about the known risks. Patients should understand all known risks before joining the trial.

There are no guarantees with any trial and it is possible for patients not to benefit from the treatments in this study. This point should be considered carefully before joining a clinical trial. Patients may leave the trial at any time for any reason, and study doctors will advise on the best way to leave the study.

Researchers will do their best to co-ordinate regularly scheduled medical appointments with hospital visits required for the study, as patients enrolled in the study will still need to see their doctor for general medical care.

## INTERNATIONAL EXPERT SHARES KNOWLEDGE ON BIOLOGICAL THERAPIES



*Dr Czuczman at ESA Village patient and family accommodation centre in Brisbane.*

**International speaker, Dr Myron Czuczman, spoke about current and future lymphoma treatment options to a group of lymphoma patients and their families at the Leukaemia Foundation's ESA Village in Brisbane last October.**

Dr Czuczman is a leader in the field of the biological therapy of lymphoma and related cancers. He was in Australia to attend the

combined Annual Scientific Meeting of the Haematology Society of Australia and New Zealand, the Australian and New Zealand Society of Blood Transfusion, and the Australasian Society of Thrombosis and Haemostasis, held on the Gold Coast from October 14 - 17.

Dr Czuczman joined the staff of Roswell Park Cancer Institute, USA, in 1992, as attending physician, Department of Medicine, and was appointed Head of the Lymphoma/Myeloma Service in 1998. He became a member of the Tumour Immunology Program in 2002 where he heads a Lymphoma Translational Research

Laboratory in the Department of Immunology.

He also is an Associate Professor of Medicine at the University at Buffalo School of Medicine and Biomedical Sciences.

His research interests focus on monoclonal antibodies, either alone or in combination with other agents in the treatment of lymphoma, evaluating novel target-specific molecules active against lymphoma in the clinic and laboratory, and studying the mechanisms-of-action and resistance pathways involving monoclonal antibodies currently used in lymphoma therapy.

Dr Czuczman's clinical research contributed to approval by the U.S. Food and Drug Administration of the first monoclonal therapy rituximab (MabThera) for non-Hodgkin lymphoma in 1997.

The Leukaemia Foundation's support services director for Queensland, Barbara Hartigan, said it was a privilege to have such a high calibre speaker as Dr Czuczman to share his experience and knowledge firsthand with patients and families.

"Patient education is an important part of the Foundation's mission to care, so we seize any opportunity to have speakers from all around the world to present information on the latest research and treatment options for those living with lymphoma and associated diseases," Barbara said.

Dr Czuczman's trip to Australia was sponsored by Roche Products.

# WORLD LYMPHOMA AWARENESS DAY HELD IN 35 COUNTRIES

Despite lymphoma being Australia's fastest growing and fifth most prevalent cancer for men and women, four out of five Australians don't know what lymphoma is.

They also aren't aware of the symptoms and that the first sign of lymphoma is usually a painless swelling in the neck, under the arm, or in the groin.

More than 4000 Australians are diagnosed with lymphoma each year. That is equal to 11 people every day, yet awareness of this disease and its symptoms is shockingly low.

Raising awareness of the incidence of lymphoma, which has doubled in the last 20 years in Australia, and of its symptoms, was the aim of World Lymphoma Awareness Day (WLAD).

This event was held in 35 countries around the world on September 15 last year. The focus in 2007 was on raising awareness in the general community of the symptoms of lymphoma. The increased incidence of lymphoma is a trend that has occurred in most western world countries.

In Australia, the Leukaemia Foundation and the Lymphoma Support and Research Association joined forces and held a national media campaign to help people recognise the symptoms. These include:

- a painless lump in the neck, under the arm or in the groin
- unexplained fever



Members of Team Lymph Node took part in a fun run for WLAD in Adelaide last September.

- sweating, particularly at night
- itchy skin
- weight loss
- tiredness and lack of energy.

WLAD received coverage in print and electronic media and was estimated to have reached more than a million Australians.

World Lymphoma Awareness Day is held on September 15 every year and in 2008 the aim is to raise awareness about the symptoms and treatment of lymphoma with GPs so the disease is diagnosed more quickly and patients are referred to a specialist as soon as possible.

## LIGHT THE NIGHT ON 17 SEPTEMBER

**Light the Night™ is a new fundraising event that will be held by the Leukaemia Foundation in Adelaide, Brisbane and Perth on 17 September.**

In the USA, *Light the Night™* is an inspiring community event that gives everyone the opportunity to get involved in building awareness of blood cancers and raising funds to find cures.

Now Australians can also pay tribute and bring hope to patients and families living with leukaemias, lymphomas, myeloma and other related blood disorders by taking part in the first *Light the Night™*.

Walkers carry illuminated balloons which creates a sea of twinkling lights - each a beacon of hope. Supporters carry the Leukaemia Foundation's blue balloons, patients carry white, and those remembering a loved one carry a gold balloon in their memory.

Before the walk, guest speakers including survivors, leading researchers and ambassadors will share their inspirational stories. The evening will include opportunities to learn about the work of the Foundation which aims to 'light the night' in all major centres in Australia by 2010. To take part, visit [www.lightthenight.org.au](http://www.lightthenight.org.au) or call 1800 500 088.

### EDUCATION AND SUPPORT PROGRAM ACTIVITIES

Lymphoma Seminar	April 2	Launceston
Lymphoma Support Meeting	April 2 / May 7 / June 4	Melbourne
Q & A session: Lymphoma	April 22	Adelaide
Young Adults Seminar	May 15	Sydney
Lymphoma Education Program	September 11	Perth
World Lymphoma Awareness Day	September 15	all states

**For more information and a complete list of education and support programs for lymphoma patients and families in your state, visit the education and support programs section on [www.leukaemia.org.au](http://www.leukaemia.org.au).**

### LEUKAEMIA FOUNDATION SUPPORT SERVICES

**Ph: 1800 620 420 (Freecall)**

#### New South Wales /

**Australian Capital Territory** Chris Page/Fiona Pearce Ph: 02 9902 2222

**Queensland** Barbara Hartigan Ph: 07 3840 3840

#### South Australia /

**Northern Territory** Steve Marshall Ph: 08 8273 3515

**Victoria / Tasmania** Samantha Schembri Ph: 03 9949 5824

**Western Australia** Sandy McKiernan Ph: 08 6241 1020

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.

The Foundation provides emotional support, accommodation, transport and practical assistance for patients and their families. It also funds research into cures and better treatments for leukaemias, lymphomas, myeloma and related blood disorders.

The Foundation receives no direct ongoing government funding and relies on the continuous support of individuals and corporate partners to provide its services and to fund its research programs.

To find out more about the work of the Leukaemia Foundation and how we can help, phone 1800 620 420 or visit [www.leukaemia.org.au](http://www.leukaemia.org.au)



**Roche proudly supports the Leukaemia Foundation in its educational activities.**

*Disclaimer: No person should rely on the contents of this publication without first obtaining advice from their treating specialist.*