

## REBECCA STEERS A NEW COURSE IN LIFE POST LYMPHOMA

**Rebecca Harris now leads a happier and better quality life than prior to her diagnosis with lymphoma last year.**

These days the musician is careful about her diet, has made major lifestyle changes, and does things she's never done before.

"I used to be a complete workaholic," said Rebecca, describing her "crazy exciting life", split between Australia and Europe, lecturing in cello at the Charles Darwin University, playing in the Darwin Symphony Orchestra, and busking and performing at festivals in Germany with contemporary band, worldfly, among other things.

But Rebecca no longer lives to work. She enjoys organic food, meditates daily, doesn't cut back on sleep, dedicates time to be with her friends and to walk her dog, Buster, and has aimed to remove "anything toxic" from her life.

"I tended to push my body very hard and I attribute much of my illness to that. I'm pretty good at managing being tired," explained Rebecca, who first noticed a lump in her neck in April 2009.

She visited her doctor several times but no tests were carried out as the doctor opted to "wait and see". In July 2009, Rebecca embarked on a five-month intensive music tour, travelling 16,000km around Europe.

"I was getting more and more tired, and skinnier and skinner," said Rebecca, who after returning to Australia, started a new job in January 2010, managing a music school.

During a visit to a physiotherapist, Rebecca was told the lump in her neck was definitely not a cyst, so she had more tests.

"The bloods were super clear, but blood tests don't necessarily indicate non-Hodgkin lymphoma (NHL)," she said.

"Because the lump in my neck looked suspect, it was removed in February and around the same time, I came down with pneumonia which really knocked the stuffing out of me."

The biopsy showed the lump was cancerous. After a raft of tests including PET and CT scans, a bone marrow biopsy and ultrasounds, Rebecca's diagnosis was confirmed. She had follicular, low grade NHL, and this turned her life around.

"Because it is stage one, it is potentially curable, and I'm going to hold on to that hope," she said.

"I shed rivers of tears initially and looked at what I really wanted to do with my life. If I have two years or 20 years, I'm going to make sure they're good years."



*Rebecca Harris – in remission and pursuing the simple things in life*

Before treatment began, Rebecca studied everything she could get her hands on about the properties of the food she ate, as well as the chemicals, colours and additives in products she used, like make-up and shampoo. She threw away hundreds of dollars worth of products made up of potentially carcinogenic ingredients.

She did a course in Buteyko breathing with Victorian instructor, Brian Firth, which helped her dramatically both with breathing and learning to relax.

"I wanted to try and get as well as I could myself. I'm sure it made a difference," said Rebecca, who no longer drinks alcohol and has removed salt and sugar from her diet.

She started radiotherapy in April last year, confident and comforted to be among the first group of patients to go through the new radiotherapy unit in Darwin.

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# LYMPHOMA CO-ORDINATOR WELCOMED

**This year, about 5000 Australians will be diagnosed with lymphoma and the Leukaemia Foundation works hard to ensure its services are known and available to these people. In line with this commitment, the Foundation has welcomed a new national lymphoma co-ordinator, Jane Miles (right), based in Newcastle.**



"This role enables me to focus on my passion to deliver comprehensive information, education and support programs for people with lymphoma, based on best practice principles," said Jane, who leads the Foundation's team of highly trained lymphoma support services co-ordinators.

"Some lymphoma patients may not be aware that the Leukaemia Foundation tailors its range of services to specifically support and care for them," said Jane, a registered nurse with 15 years of experience.

"The Foundation's education, support, practical assistance and research funding covers all the blood cancers and are for people living with lymphoma as well as leukaemia, myeloma and related blood disorders."

## REBECCA STEERS A NEW COURSE IN LIFE

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Rebecca's family and friends were towers of strength and came from Adelaide and Sydney to stay with her during treatment. During these therapy sessions that finished in early May 2010, she listened to music.

"Music is hugely important and incredibly healing for me – it's my religion. A piece of music can calm you and take you away from a bad situation."

She also described the support she got from the Leukaemia Foundation as "phenomenal".

"They'd call each week, and just being able to talk to someone if you needed to was very comforting and valuable. They also assisted me with transport to and from treatment."

Rebecca said she enjoyed the opportunity to give a little something back to the Leukaemia Foundation when she performed Ave Maria on the cello at the Foundation's *Light the Night* event in Darwin.

In August 2010, Rebecca was given remission status. Encouraged to lead as normal a life as possible, she went overseas in September with worldfly for seven weeks, including a spontaneous trip to Dubai to visit a close friend.

December saw her quit her university job of nine years to take time out to pursue "good health, music and the simple things in life". This year she plans to tour and record a second album in Europe with worldfly, but has set some rules.

Jane spent eight years in the haematology/oncology division of the Queen Elizabeth Hospital in Adelaide, working in both the chemotherapy suite and the ward. Her experience includes some palliative care nursing, patient education and advanced care directives.

In late-2009, she joined the Foundation in Adelaide as a support services co-ordinator, providing practical and emotional support to patients and carers living with a blood cancer.

Jane recently moved to Newcastle with her family, and her role as National Lymphoma Co-ordinator involves collating data on advances and new treatments for lymphoma and communicating this information via vehicles including *Lymphoma News*. She will collaborate with consumer representatives, promote lymphoma-related psychosocial research initiatives and advocate on behalf of lymphoma patients, their families and friends.

In 2011, more than 50 education and support programs will be provided to lymphoma patients across Australia, including professional education forums as part of the Foundation's role in commemorating World Lymphoma Awareness Day (15 September).

To support people with lymphoma who live in regional and remote areas, lymphoma telephone discussion forums are regularly held, facilitated by a trained lymphoma nurse. This valuable service enables lymphoma patients to offer advice and support for each other within a safe environment.

**For more information on the Foundation's 2011 national lymphoma program, please email the national lymphoma co-ordinator on [lymphoma@leukaemia.org.au](mailto:lymphoma@leukaemia.org.au) or call your local support services co-ordinator on 1800 620 420.**

"I'll only tour for six weeks at a time, allowing me to recover and return to Australia. Finding a balance between quality of life, time for me and my friends, as well as my work, are high on my list of priorities," said Rebecca.

"I'm looking forward to this new direction."

She also will develop the new classical group, Darwin Chamber Players, do a little teaching, play with the Darwin Symphony Orchestra and take time to play the cello for herself.

"I can't wait for the opportunity to garden, cook and do yoga, as well as renovate furniture (one of my many quirks), not to mention spending time with my family, friends and dog.

"Early last year was the worst time of my life and also the best. These days I try to look at life through new eyes, as if I'm a child – trying not to live in the past or the future, but in the now, aiming to be compassionate and not judgmental. Most importantly, I try really hard not to sweat the small stuff."

## TOP LYMPHOMA TIP

**"Trust your instincts. If you feel like you're not getting answers or appropriate follow-up, seek a second opinion."**

**Rebecca Harris**

# PHD STUDENT MAKES HEADWAY IN SEARCH FOR LYMPHOMA VACCINE

**Leukaemia Foundation PhD student, Kimberley Jones, has made a significant discovery, which could lead to a vaccine for treating Epstein-Barr virus positive lymphoma patients.**

Based at the Queensland Institute of Medical Research (QIMR), Kimberley (right) has been investigating the link between lymphoma development and Epstein-Barr Virus (EBV) – a common virus implicated in up to 150 cases of lymphoma each year in Australia.

Kimberley initially focused her research on post transplant lymphoproliferative disease (PTLD), a complication which can occur following an organ or bone marrow transplant. The disease is generally associated with EBV and high doses of immunosuppressants.

Following a detailed analysis, Kimberley discovered that PTLD patients can generate an immune response to a specific EBV protein that is present in all EBV-positive lymphoma patients.

“We found that PTLD patients are able to generate immune responses to this protein and that minor strain variations influence the size of the response,” said Kimberley.

“Understanding the ability of patients to mount an immune response to this EBV protein and determining methods for inducing a strong response will be critical for vaccine design and treatment strategies.”

Kimberley’s results were published last year in the prestigious international journals, *Blood* and *Leukaemia*



*Lymphoma*, and also were presented at a conference in Washington. Her work was recognised by the Australian Society for Medical Research, with the Health and Medical Research Postgraduate Student Award 2010.

Kimberley has extended her studies to investigate Hodgkin lymphoma (HL) patients’ immunity to EBV proteins expressed within their tumour cells.

A large part of her HL investigation was conducted over four months at leading laboratories in National Institute of Health (NIH) in the United States and at Cardiff University (in the United Kingdom).

“Working at NIH and Cardiff I was able to obtain a larger volume of data from our Australian HL samples by using leading edge technologies and learning novel techniques in these world class facilities,” she said.

“It was really exciting to have the chance to work in these labs and my research is in a very good place.

“I’m now analysing the mass of data I generated and if all pans out as I hope it will and the results hold true in HL patients, in the next 18 months we may be at the pre-clinical stage of testing a potential vaccine.

“We’re certainly building the foundations for what possibly could be a new treatment for EBV-positive lymphoma patients.”

Kimberley thanked the Leukaemia Foundation for ongoing funding of her research, and the support of her supervisor, Associate Professor Maher Gandhi.

## PANOBINOSTAT – A PROMISING NEW DRUG

**Hodgkin lymphoma (HL) makes up about 10% of lymphomas in Western countries and mainly affects young adults. Current chemo-radiotherapy regimens cure over 80% of people with HL, but few new treatment options have been developed for several decades. The outcome is challenging for those who are resistant (refractory) to treatment, or relapse after treatment, especially following a stem cell transplant, but several new developing therapies hold promise for these people.**

**Panobinostat - a frontrunner in the development of new drugs for HL - is in a class of novel agents, called histone de-acetylase inhibitors (HDACi).**

Histone de-acetylases are a group of enzymes that modify how genes are expressed, and are thought to facilitate changes in cell reproduction and survival that can lead to cancer.

HDACis are expected to reverse these changes and have been effective in small studies of patients with haematological malignancies, including HL.

Several Australian haematology centres have taken part in clinical trials with panobinostat, gaining valuable clinical experience in using this agent.

Investigators from an international collaboration presented the findings of a pivotal larger (phase II) study of panobinostat in relapsed or refractory HL patients at the 2010 annual meeting of the American Society of Hematology, in December.

Of the 129 patients studied, each had an average of four previous treatments, including an autologous stem cell transplant. They were given panobinostat orally, three times a week during each 21-day cycle, and the result is encouraging for this high-risk group of patients.

There was a partial or complete response in 27% of patients, and 82% showed no progression while on therapy. The most serious side-effect of panobinostat related to bone marrow suppression and was manageable. The median duration of response was at least 6.9 months.

These preliminary results, released in abstract form, must be submitted for rigorous peer review by a panel of expert haematologists, and larger follow-up studies need to confirm and better define the response rates and to detect other side-effects, prior to the panobinostat’s approval for use in Australia.

# TRAVELLING WITH AN EMC: BE INFORMED

**Australians love to travel and increasing numbers of people are being inspired to travel overseas due to the strong Aussie dollar.**

If you have a pre-existing medical condition (known as an EMC within the travel insurance community) such as lymphoma, what are your options when travelling?

Your first consideration is your destination, then the level of medical support that can be provided in relation to your condition.

If you choose to jet off to Peru to walk the Inca Trail with your EMC, then you need to be fully aware that the availability of immediate comprehensive medical support is pretty low, even for those in peak health.

Travelling in the United States for a couple of weeks may sound great, but this is a very expensive destination when it comes to even the most basic medical care. If you can't prove you have insurance or enough funds in your bank account to cover a required procedure, you may be turned down and directed to another hospital, which is not ideal when you are in need of immediate care.

From a medical viewpoint, there are two ways to choose your destination. Ask yourself if the country you are planning to visit has a level of health care that is appropriate for your condition, and what costs are involved if you travel to a country that isn't covered by your travel insurer? When travelling with an EMC, countries including South America, North America, Canada and Africa are considered 'high risk' areas in terms of appropriate care.

Most travellers are unaware that in the following countries, Australian residents are entitled to assistance with the cost of medical treatment under the Reciprocal Health Care Agreement (excluding elective or cosmetic surgery).

→ New Zealand → Finland → United Kingdom  
→ Republic of Ireland → Sweden → Norway  
→ The Netherlands → Italy → Belgium → Malta

These countries each provide care in different ways, so it is best to review the country you are thinking of visiting during the travel planning stages and definitely before you commit to buying airline tickets and accommodation or embark on your travels. This means you have a fall back plan if travel insurance is turned down due to your EMC.

To gain access to care, you need your passport and a current Australian Medicare card. For more information visit: [www.medicareaustralia.gov.au](http://www.medicareaustralia.gov.au). (Use the search facility by entering Reciprocal Health Care)

For destinations not covered by the agreement, look into the state of medical care in each country because under the terms of your travel insurance, you may have to personally cover the cost of any treatment you require. For example, Japan doesn't come under the Reciprocal Health Care Agreement but is very medically advanced, so you need to look at the cost of care to ensure you can afford the cost of care there, if required.

Communication is another consideration. Is not having an English-speaking doctor/surgeon cause for concern and would this worry you or your travel partner, should the worst happen? If the answer is 'no', go ahead, but if you have reservations, consider another destination.

Your chosen travel insurance provider will always ask you to submit a Pre-Existing Medical Assessment. Based on that assessment, they will either turn you down, and the fact is - you may be turned down, or they will accept coverage at an additional premium payment. The premium is often based on the number of days away, but can vary between travel insurers. If you are denied travel insurance, you have to ask yourself if you really want to travel.

While travelling is a marvellous experience, you do need to know all the facts first, so you are fully informed when making decisions. For more information and guidance, contact Leisa Burdette, Travel Managers Australia, ph: 0405 100 095 or email: [leisab@travelmanagers.com.au](mailto:leisab@travelmanagers.com.au).

## TEST YOUR KNOWLEDGE IN WEBSITE POLL

**The Leukaemia Foundation's Talk Blood Cancer website provides a safe, supportive place to share what life is like, with others also living with leukaemia, lymphoma, myeloma and related blood disorders.**

**The website ([www.talkbloodcancer.com](http://www.talkbloodcancer.com)) also features regular poll questions such as these, from this month's poll, a selection of which will be included regularly in future issues of *Lymphoma News*:**

**Q: How many people were expected to be diagnosed with a blood cancer in 2010?**

6000  8500  10,000  11,500  14,000

**Q: Leukaemia Foundation volunteers drove the equivalent of how many times around the earth to get people to treatment safely in 2010?**

2 times  5 times  9 times

16 times  21 times

**Q: What cancer leads to the greatest loss of life in Australia?**

Breast  Prostate  Blood  Lung  Skin

**Q: How much money has the Leukaemia Foundation committed to blood cancer research since 2005?**

\$10 million  \$12 million  \$15 million

\$18 million  \$20 million

**For the answers to these questions and more, log on to [www.talkbloodcancer.com](http://www.talkbloodcancer.com)**

## TOP LYMPHOMA TIP

*"The support of people – family and friends – is as important as the doctor side of things. And I always take a friend when I have a check-up, to ask questions and write things down."*

Rebecca Harris

# Q & A: TRAVEL AND LYMPHOMA

Here are some common questions which members of the Leukaemia Foundation's support services team are asked about travelling with lymphoma or another blood cancer. The answers are by Susan Harper, Manager Infection Control & Staff Vaccination, at Peter MacCallum Cancer Centre in Melbourne.

## Q. Are there any precautions I need to take before I go travelling, to reduce the risk of getting an infection?

A. It is important that you discuss your personal travel plans with a health professional, to ensure you have the correct vaccinations for your trip and any booster doses of childhood vaccinations you may need, so:

- make an appointment with your doctor or travel clinic at least six to eight weeks before your departure
- discuss the destination/s you plan to visit
- discuss the medications you should take with you, and
- discuss any vaccinations you should have before you leave.

## Q. What are the safer countries to travel in?

A. It is important to be well informed about the destination you're travelling to, so check the latest travel advice at [smartraveller.gov.au](http://smartraveller.gov.au) to receive email notifications each time the advice for your destination is updated.

## Q. Can a letter detailing my condition from my doctor help if I get an infection and need to go into hospital?

A. It is recommended that if you are travelling and need to take any medications with you, that you:

- discuss with your doctor what medications you will need to take (including antibiotics, in case you get an infection)
- carry a letter from your doctor detailing your medical condition, what the medication is, how much you will be taking, and stating that it is for your own personal use, and

- ensure you leave the medication in its original packaging, so it is clearly labelled with your name and dosage instructions.

It is also advised that you take along a spare pair of glasses and a copy of the prescription, in case of breakage or loss.

## Q. What are important considerations to help lower my risk of infection when travelling?

A. Strict adherence to hand hygiene, washing with soap and water when hands are visibly soiled, after going to the toilet, before eating or preparing food, and using a gel/foam or rub in between.

Before you depart, find out whether the tap water and local food is safe to consume.

Continue to take anti-malarial medications (if prescribed). Avoid being bitten by mosquitoes by wearing light coloured loose-fitting clothing that covers your arms and legs.

Regularly apply an appropriate insect repellent and stay in mosquito-proof accommodation.

If travelling overseas during summer in your destination, remember to apply SPF 30+ sunscreen 20 minutes before you go outdoors and every two hours afterwards, wear a hat that protects your face, head, neck and ears, and seek shade.

Carry bottled water.

Make up a small medical kit, including items such as headache tablets, antacids, antiseptic lotion, cotton wool, bandaids, a crepe bandage, SPF 30+ sunscreen and an appropriate insect repellent.

**For information about safe travel tips, visit:**  
[www.smartraveller.gov.au](http://www.smartraveller.gov.au) and [www.who.int](http://www.who.int)

## TAKING MEDICINES OVERSEAS: KNOW THE RULES

**It is important to be aware of the restrictions on taking or sending Pharmaceutical Benefits Scheme (PBS) medicines overseas. The Australian Government subsidises around 2500 prescription medicines under the PBS. Exporting PBS-subsidised medicines leads to a significant financial loss to both the Australian Government and the community. It is also dangerous for people to take prescription medicine that has not been prescribed for them. The most common illegal export of medicines happens by mail or when people take them in their luggage. People caught illegally exporting medicines face two years imprisonment and/or a \$5000 fine. Therefore it is important to read the following information, to ensure you meet all the legal requirements.**

**PBS-subsidised medicines:** It is illegal to take or send PBS subsidised medicines out of Australia unless it is for your own personal use or someone travelling with you, such as a child. The quantity of PBS medicines you can take is restricted. Before travelling you should contact the embassy of the country you are visiting to ensure the medicine is legal there. You should also carry a letter from your doctor detailing what the medicine is, how much you will be taking and stating that the medicine is for your personal use. You should leave the medicine in its original packaging so Customs can see who dispensed it, for whom it was dispensed and the cost. Customs can detain any medicine it suspects is being illegally exported.

**Non-PBS medicines:** Medicines that have not been subsidised by the PBS can be taken or sent overseas. However, you should still contact the embassy of the country you are travelling to, to ensure the medicine is legal there. You should also carry a letter from your pharmacist stating the medicine has not been subsidised. Some overseas countries will require a letter from your doctor for any prescription medicine. You should leave the medicine in its original packaging, so Customs can see who dispensed it, for whom it was dispensed and the cost.

**Reciprocal health care agreements:** The Australian Government has signed Reciprocal Health Care Agreements with several countries. This means Australian residents are entitled to assistance with the cost of medical treatment in Belgium, New Zealand, the UK, Ireland, Sweden, Netherlands, Finland, Italy, Malta and Norway. (See the website address below for information on individual countries.)

**More information:** Medicare Australia has a 24/7 information line to answer all your queries. They advise getting your information from them earlier rather than later, as a phone call from the airport can be too late.

Travelling with PBS Medicines enquiry line: 1800 500 147

Translating & Interpreting Service: 13 14 50

[www.medicareaustralia.gov.au/public](http://www.medicareaustralia.gov.au/public), then Migrants and travellers > Travelling overseas

# GRAHAM PROJECT-MANAGED HIS LYMPHOMA

**Graham Widger's approach to overcoming lymphoma was to tackle his treatment and recovery as he would a work project.**

He started with an action plan, ensured he was fully informed and proactive, regularly reviewed his progress, developed strong relationships with doctors and medical staff, and sought collaborations when necessary.

"My oncologist was very supportive of the whole process," said Graham, whose approach has achieved an outstanding result – being alive, in remission and with a baby on the way.

The six months prior to his diagnosis on 16 June 2009 saw a lot of change in Graham's life. His first child was born in January, his managerial job for Melbourne toll road operator, CityLink, was highly demanding, and he was training for a 17km fun run.

"I've always been fairly fit and active and I was paying particular attention to my health," said Graham, 31, at the time.

But in March 2009, he noticed that the harder he trained, the less fit he was becoming. He attributed his tiredness to having a newborn, but couldn't account for being short of breath. His doctor suggested he get more sleep, drink more water and take vitamins.

"But I felt there was something underlying," said Graham. He persisted with training, competed in the fun run and described his time as "absolutely terrible".

"Half way through the run, I knew something was really wrong. I wasn't breathing properly," explained Graham, who visited his doctor often before having a blood test in June. By then his symptoms included blurred vision, migraines, a cough, and night sweats.

"I wasn't considering cancer as a cause – perhaps pneumonia or the flu. But the blood test results came back with ridiculously high inflammatory markers."

After more blood tests and an X-ray, which showed a fist-sized tumour in his chest next to his right lung, Graham was admitted to The Alfred Hospital and put into isolation.

"I'd managed many projects with many consequences, but none of this magnitude. The consequence was daunting – it was my life, my mortality."

Graham had characteristics of both Hodgkin lymphoma and non-Hodgkin lymphoma and was classified as having grey zone lymphoma, which is rare.

His treatment was six rounds of R-CHOP chemotherapy, every 21 days, followed by five weeks of radiotherapy.

"I questioned the frequency of the chemo because of my age and fitness, and it was changed to every 14 days," said Graham who ended up in emergency after the first round.

"I was in a state of shock, felt stripped of any form of control and had to depend on others to make me better," explained Graham.

After leaving hospital, he went to Sorrento for a seaside break with his wife, Melissa, daughter, Sienna, and his dad, before starting the second round of chemo. It was there, while deep in thought about his situation, that he had a "pivotal moment of realisation".

*"I felt like I was in a rubber dingy, in rapids with no oars and the cancer was taking me down a river. I decided it was time to step up."*

Graham Widger



**Graham Widger with Melissa and Sienna**

"I felt like I was in a rubber dingy, in rapids with no oars and the cancer was taking me down a river. I decided it was time to step up. I thought about what I was going to do and called a family meeting.

"After announcing my plan, my father broke down in tears of joy. He clenched his fist and said: 'he's back, my son is back'."

Graham's action plan began by accessing all his medical records under the freedom of information process, to learn about his disease. He received more than 200 pages of medical notes and hundreds of images from two PET scans.

"I needed to know what was happening to me, so I read everything and studied it for myself, so I could make informed decisions."

He met with the hospital dietician and an independent dietician because he wanted to know the science behind what he was told he could and couldn't eat, such as pizza. He also met with a physiotherapist

to find out why he couldn't do certain exercises.

"The gym has always been a release for me, so I wanted to know why I couldn't go to the gym?"

He discovered he could eat pizza, if he made it himself. Also, by eating particular foods that complemented his platelet levels and by avoiding muscle-tearing exercises, he could go to the gym throughout his treatment.

"This gave me a sense of control and I think it was a contributing factor to my remission," said Graham. "Although not everyone is physically able to take this particular approach."

The day after his second round of chemotherapy, Graham walked around the lake in Albert Park with Melissa and Sienna.

"I'd come a long way in only 14 days and psychologically that was a really big step forward," explained Graham. His next goal was to return to the gym "in a managed way".

"With every exercise I felt I was proactively getting this cancer out of my body."

When Graham completed his chemo, there was no evidence of disease, but he decided to proceed with radiotherapy as scheduled, and afterwards, on 11 November 2009, he went to Byron Bay for recovery and family time.

"Remembrance Day took on added meaning for Melissa and me."

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# NEW TREATMENT TARGETS VIRUS

**Brisbane-based haematologist, Dr Colm Keane (right), has found that Epstein-Barr virus (EBV) may play an important role in the development of diffuse large B-cell lymphoma (DLBCL) in older patients.**

In his study funded by the Leukaemia Foundation, Dr Keane made the discovery while looking for prognostic factors or 'biomarkers' to better define DLBCL subtypes (see *Lymphoma News*, December 2009 issue).

Up to 90% of Australians carry EBV, a herpes virus that infects white blood cells and is implicated in several cancers.

Analysing tumour samples from 130 patients with DLBCL, Dr Keane found approximately 10% of these patients carried EBV in their tumour cells. The 10% were all over 50 years of age and most had responded poorly to standard treatment regimens.

"As we age, our immune systems don't cope as well with EBV, which is why it could be contributing to diffuse large B-cell lymphoma. Knowing EBV is associated with poor patient response in older people is especially important," said Dr Keane.

"While the newer treatments such as rituximab have really transformed the outcomes for this cancer – I'd say up to 70% of my patients have been cured – some patients look like they are doing worse, particularly older patients and we don't know why," he said.

"Based on my preliminary results, I believe it's going to be important for patients over the age of 50 with diffuse large B-cell lymphoma to be routinely screened for EBV in their tumours, so they receive a tailored treatment regimen."

Dr Keane hopes a new immunotherapy treatment will help treat patients who don't respond well to existing therapies.

The head of Dr Colm's laboratory at the Queensland Institute of Medical Research (QIMR), Associate Professor Maher Gandhi, has designed a treatment specifically developed to target EBV-associated cancers.

Patients have travelled to Brisbane from around Australia to receive the immunotherapy treatment that targets EBV-associated cancers, which the Gandhi laboratory is trialling.

For the treatment, patients' white blood cells are isolated and incubated with EBV before being returned to their body – primed to trigger an immune response to the virus.



"I hope this treatment may be of benefit in diffuse large B-cell lymphoma patients in whom EBV is found in their tumour," said Dr Keane.

Other predictors of poor patient treatment responses being investigated by Dr Keane include a low lymphocyte count at the time of diagnosis and the expression of micro-RNA in tumour cells.

He is also involved in studying samples from patients taking part in a phase II clinical trial by the Australasian Leukaemia Lymphoma Group (ALLG).

"Our aim is to develop new management strategies for this aggressive lymphoma, and the unique part of this project is that we're collecting blood samples both before treatment begins and after four treatments," Dr Keane said.

"No one else in the world is collecting this type of data, so it's very exciting. We're really going to be able to investigate what's happening to the immune cells as a result of the treatment."

Dr Keane was awarded a three-year Leukaemia Foundation National Research Program Clinical Fellowship in 2009 and is conducting his research in conjunction with Griffith University and the Queensland Institute of Medical Research.

"I'd really like to thank the Leukaemia Foundation for its support of my research. I wouldn't be able to do it without them to be honest."

Patients wishing to take part in the QIMR immunotherapy trial, or the ALLG trial, should speak to their haematologist.

## GRAHAM PROJECT-MANAGED HIS LYMPHOMA

*Continued from page 6*

Despite having a leave of absence from work for up to 18 months, Graham returned to work within six months of his diagnosis and quickly worked his way to a promotion.

Next Graham and Melissa were "blown away" with news they were expecting their second child, despite being told Graham's life-saving treatment could make him sterile.

"When I got sick, I learnt a lot about myself. I had time to look in the mirror and understand what makes Graham tick. The whole experience taught me at a young age, what is important in life.

"Here I am at 32 with a different view of the world. When I kiss my wife, I don't take that for granted. When I hold my daughter and take her to the park, that's a privilege. It's still early days, but I'm in a good situation at the moment," said Graham, who is half way through writing a book.

"The key message is hope, for people going through a similar experience."

**Graham was visited by a support services co-ordinator from the Leukaemia Foundation, soon after his diagnosis.**

**"He said 'we're here to help' and that was the first reassuring news I'd had.**

**"Just to know they existed, and to have the information they provide, was great.**

**"They're continually challenged for funds to provide services to patients and loved ones and I was always keen to assist," said Graham.**

**Last year he was an ambassador at the Foundation's *Light the Night* event and this year he was involved in *World's Greatest Shave*.**

# EDUCATION AND SUPPORT PROGRAMS

NEW SOUTH WALES		
5 Apr	10-11.30am 11am	Patient and Carers' Coffee Morning, Shortland Wetlands (also 3 May, 7 Jun) Tuesday Chat, Port Macquarie
7 Apr	10.30am-12noon 11am-1pm	Patient Morning Tea, Rural Cancer Care, Orange Young Haematology Information and Support Group, Young (also 2 Jun)
12 Apr	10.30am-12noon 10.30am-12noon	Patient Morning Tea, Palliative Care, Bathurst (also 27 Apr) Tuesday Chat, <i>Your Options in Aged Care</i> , Coffs Harbour (also 10 May, 14 Jun)
14 Apr	10am-12noon 1-3pm 2-3:30pm	Patient Education Morning Tea, Alstonville South Coast Haematology Information and Support Group, Moruya (also 9 Jun) Stress Management/Relaxation, San Remo
28 Apr	10-11.30am	Stress Management/Relaxation, Erina Fair
3 May	10am-11.30am	Patient and Carers' Morning Tea, <i>Interpreting Blood Results</i> , Leukaemia Foundation Hunter office
5 May	10.30am-12noon	Patient Morning Tea, Dietician, Orange
10 May	10.30am-12noon	Tuesday Chat, Patient and Carers' Morning Tea, Coffs Harbour Patient Morning Tea, Bathurst
12 May	2-3.30pm 5.30-7.30pm	Laughter Therapy, San Remo South Coast Haematology Information and Support Group, Bega
25 May	10am 10.30am-12noon	Wednesday Chat, Tamworth Patient Morning Tea, Dietician, Dubbo
26 May	10-11.30am	Laughter Therapy, Erina Fair
30 May	10am-12noon	St George Area Lymphoma Support Group
31 May		Tuesday Chat, Taree
TBA	TBA	NSW Patient Conference, Sydney

VICTORIA		
6 Apr	10am-12noon	Lymphoma Information and Support Forum, Preston
7 Apr	10-11.30am	Bone Marrow Transplant Information and Support Forum, Preston
8 Apr	10-11.30am	Mornington Peninsula Blood Cancer Information and Support Forum
13 Apr	10.30am-12noon	Leukaemia Foundation Yoga Program, Preston (also 18 May)
19 Apr	10.30am-12noon	Shepparton Blood Cancer Information and Support Forum
28 Apr	10am-12noon	Horsham Blood Cancer Information and Support Forum
26 May	6-8pm	South East Melbourne Blood Cancer Information and Support Forum

WESTERN AUSTRALIA		
18 Apr	1.30-3pm	Patient Support Group, North Perth (also 20 Jun; 18 Jul; 15 Aug; 19 Sep; 17 Oct; 12 Dec)
28 Apr	11am	Lymphoma Education Program: <i>Eating Well</i> , Subiaco
1 Jun		WA Patient Conference, Perth

SOUTH AUSTRALIA		
14 Apr	10.30am	Southern Metro Coffee Group, Reynella (also 12 May; 9 Jun)
19 Apr	10.30am	North East Metro Coffee Group, Salisbury East (also 17 May; 21 Jun)
29 Apr	10.30am	Strathalbyn Coffee Group, Café Ruffino's, Strathalbyn (also 19 May; 16 Jun)
27 May	10.30am	Carers' Coffee Group, Royal Adelaide
4 Jun		SA Patient Conference, Adelaide
27 Jun	10am	The Queen Elizabeth Hospital Carers' Coffee Group, Adelaide

AUSTRALIAN CAPITAL TERRITORY		
12 Apr	10am-12 noon	Canberra Haematology Information and Support Group, Narrabundah (also 10 May, 7 Jun)
20 Apr	11am-1pm	Nutrition Seminar and Practical Demonstration, Canberra
20 Apr	11am-1pm	Nutrition Seminar and Practical Demonstration, CIT Reid Campus, Canberra
29 April	2-3pm	Celebration of Life, Canberra
6 May	9.30am-3pm	Patient and Carer's Day, Relaxation, Dickson Community Centre, Canberra
16 Jun	6-8pm	Seminar: <i>Stem Cell Transplants</i> , Canberra

TASMANIA		
5 Apr	11am-1pm	Hobart Blood Cancer Taking Control Seminar, <i>The Role of the Social Worker</i>
13 Apr	11am-12noon	Hobart Lymphoma Information and Support Forum
19 Apr	11am-1pm	Launceston Blood Cancer Information and Support Forum (also 17 May)

NORTHERN TERRITORY		
1 Apr	10-11.30am	Blood Cancer Support Group morning tea, Darwin (also 6 May)

## NATIONAL TELEPHONE FORUMS

Lymphoma and transplant telephone forums are held regularly for patients in regional and remote areas, and for metropolitan patients who have difficulty accessing the Leukaemia Foundation's regular education activities. To find out more and to register, contact your local support services co-ordinator on 1800 620 420.

**To register for all education and support programs, contact:**

**LEUKAEMIA FOUNDATION SUPPORT SERVICES**  
PH: 1800 620 420 (FREECALL)

**For more information: visit [www.leukaemia.org.au](http://www.leukaemia.org.au) (education and support programs section)**

## OUR VISION TO CURE AND MISSION TO CARE

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's free services include emotional support, accommodation, transportation 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.

*Roche proudly supports the Leukaemia Foundation in its educational activities through an unrestricted education grant.*

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

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 you, phone 1800 620 420 or visit [www.leukaemia.org.au](http://www.leukaemia.org.au)