

# Lymphoma today



Leukaemia &  
Blood Foundation  
*Vision to Cure - Mission to Care*

Supporting people  
living with lymphoma

[www.leukaemia.org.nz](http://www.leukaemia.org.nz)

winter 09

## Drawing comfort, finding courage

**As they strolled the Paris backstreets, searching for a cafe, Erin Moss struggled to keep up with her husband Norman.**

**The couple were enjoying a longed-for holiday. “When we reached the cafe I just collapsed in a chair.”**

It was June 2007 and it would take four months, endless tests, scans, procedures, blood tests and several biopsies before Erin would learn she had Hodgkin lymphoma.

The feeling of an ‘obstruction’ in her throat and her swollen neck was diagnosed earlier that year as a side effect of her osteoporosis medicine and later as a serious thyroid problem.

**Erin says: “All this time the swelling was spreading. Each surgeon and specialist I saw had a different name – lump, mass, tumour and lesion – and as it grew it shunted my thyroid and windpipe over to one side. By this stage, if I could have ripped it out with my bare hands I would have done.”**

Norman recalls: “Towards the end I was getting quite angry and desperate.”

Then, on 15 October 2007 the doctors stated that Erin had Hodgkin lymphoma.

She admits: “I didn’t know what to say. I asked the doctor if that was cancer and he said ‘yes’, but it was treatable. After

he hung up I remember feeling numb. Norman just held me and said, ‘we will do this together’. He has been my rock.”

**Within days, Erin learned her disease had reached stage 2B and was classified as “Bulky” and she was receiving chemotherapy at Auckland Hospital. By now, the mass was 15cm by 10cm, had severely enlarged her neck, completely encased the artery and was snaking down her chest.**

Both Erin and Norman are full of praise for the public health system and the dedicated medical team who supported them. Norman says: “The nurses were really caring; they prepared us well and were always there.”

Erin found that keeping a diary and photographic record of her progress was particularly beneficial. She explains: “The photos meant I had a record of how much smaller the growth was becoming, which really helped me mentally. In fact, it started going down after the first treatment!”

**During the six cycles (12 treatments) of chemotherapy over almost seven months, Erin slept most afternoons at her Botany Downs home, “and sometimes in the mornings too. I said to Norman that I didn’t think it was**



Erin and Norman

**possible for a human being to feel so sick.”**

For a few days it looked like Erin was going to keep her hair, but then it started falling out. “I hacked the rest off and ended up looking like Shrek,” Erin recalls. “But once I lost my hair I felt I could look the other daystay patients in the face. It was like a bond.”

Over the course of her treatment, Erin was admitted to hospital several times with fevers.

**Then doctors discovered lumps in both her breasts – luckily the biopsies came back negative – and Erin found herself back in hospital to have a stent inserted in an artery after developing heart problems.**

But one of her darkest periods came when another member of her family was diagnosed with a blood cancer. She remembers: “At first he was doing really well but on the day I found out I was in remission he told me his doctors were running out of treatment options. I felt so guilty. He died two weeks later.”

CONT. ON PG 4

## E-community forum fosters friendship

A ground-breaking online haematology community has proved a valuable lifeline for lymphoma patients and their families.

Since the Leukaemia & Blood Foundation (LBF) launched LifeBloodLIVE in September 2008, patients and families living with blood cancers or conditions have welcomed the opportunity to share their stories, feelings and top tips, or simply connect with people in a similar situation.



Amy Munro, LBF Support Services Manager, explains: "Some of these people may not attend our regular education and support programme sessions because they work, don't live in an area where the programmes are offered, or just don't feel comfortable discussing these issues face-to-face."

"The great thing about the forum is it offers confidentiality and anonymity and people can receive support in their own homes. They can simply visit the community and surf through the range of comments already posted, or register and have their say."

Amy adds: "When you are a patient there is only one set of people who really understand what you are going through, and that's other patients."

"It's been so lovely to watch relationships forming, friendships building, and people sending each other cyber hugs online! And we have seen posts and received emails saying 'hey, thanks for setting this up!'"

The online community, which can be found at [www.LifeBloodLIVE.org.nz](http://www.LifeBloodLIVE.org.nz), is continually evolving, with further enhancements planned in the coming months.

## Top tips for fatigue

Patients often refer to fatigue as the 'invisible' symptom of lymphoma.

At the 2008 World Lymphoma Awareness Day, the topic was put under the microscope at a series of Leukaemia & Blood Foundation (LBF) workshops.

The feedback showed that people experiencing fatigue found comfort in the knowledge that they are not alone.

Amy Munro, LBF Support Services Manager, says: "Fatigue can be caused by chemotherapy and other treatments for lymphoma, or by the lymphoma itself."

"When we were considering topics for the 2008 World Lymphoma Awareness Day, it seemed the natural choice." Unfortunately, fatigue can be one of those symptoms that isn't discussed in detail, and yet it affects the vast majority of patients and is a unique experience for each person.

"It's not only patients who are affected; fatigue has a wider impact on family members and friends as they can often be called upon to take responsibility for day-to-day tasks such as cooking and cleaning."

She adds: "Since the sessions, many participants have told us that the most important thing for them was realising that they are not alone in what they are going through."

"As Support Services staff, we have so many people talking to us about fatigue in their lives that it was really satisfying to help with information and practical advice."

Fatigue is often confused with tiredness, but tiredness is a temporary condition that occurs after physical exertion and goes away after a good night's sleep or nap. Some patients have found that fatigue continues long after treatment has finished and improvement can be slow and lengthy.

Christine Kerr, the LBF's Support Services Coordinator for the Southern Region, confirms: "One patient attending the Christchurch event told me they still get unaccountably tired – and they completed their treatment a year ago."

"Often patients don't get to talk about their fatigue, as it is not a side effect that can be treated. They can feel isolated and that fatigue is something that they should just 'get over'. At the workshop, the opportunity

to talk about it as a real and genuine side effect of cancer and treatment really affirmed people's experiences."

The effects of fatigue can include:

- Having trouble speaking, thinking or making decisions
- Difficulty remembering or concentrating
- Feeling more emotional or short-tempered than usual
- Difficulty sleeping
- Loss of sex drive
- Trouble completing even the simplest of tasks

### TOP FIVE TIPS FOR MANAGING FATIGUE

1. Conserve energy by planning ahead, taking short rest breaks and accepting help.
2. Restore energy by doing things you enjoy, such as listening to music or visiting with family and friends.
3. Build in regular gentle exercise such as walking, swimming or cycling.
4. Improve your sleep patterns by waking up at the same time each day, avoiding coffee and other stimulants, limiting your intake of alcohol and keeping the temperature in the bedroom comfortable.
5. If you can't sleep, keep your mind busy making lists, remembering favourite song lyrics or doing mental relaxation exercises.

The workshops were held in Auckland, Hamilton, Palmerston North and Christchurch. Each featured guest speakers from a variety of backgrounds, including dietitians, physiotherapists, a haematologist and an exercise specialist.

Lisa Speedy, LBF Support Services Coordinator for the Central Region, was delighted when one of the Palmerston North patients told her the workshop had 'made fatigue a reality'. She adds: "I've realised that as health professionals we should be providing ongoing education and support."

For more information on dealing with fatigue, download our handout at [www.lifebloodlive.org.nz/section/news](http://www.lifebloodlive.org.nz/section/news)



## Lymphoma Coalition building global awareness

A change in status for the Lymphoma Coalition will lead to better opportunities to raise awareness about the disease.

The coalition is a global initiative dedicated to increasing understanding of lymphoma and promoting the wellbeing of patients and families. It is the driving force behind World Lymphoma Awareness Day (WLAD), which New Zealand and many other countries support on 15 September each year.

Pru Etcheverry, LBF Executive Director, explains: "Previously it was a network, an informal group, but we will soon become a legally registered international charity. The move provides us with a strong platform on which to build new membership and work ever more closely on raising global awareness of lymphoma."

The LBF joined the coalition in 2003 and in 2005 was voted onto the steering committee to help develop a future vision for the organisation. Pru has now been appointed to the new board of directors which will come into being upon incorporation.

The Lymphoma Coalition consists of 41 lymphoma patient organisations from 32 countries, which represent a large cross-section of the world's population.

## A magical tribute

New Zealand label, Polish, has released a memorial tee in honour of founder, Struan Barty, who passed away from lymphoma last year.

Stru and wife Sarah started Polish in 2003 when they identified a niche market of busy mums looking for stylish casual gear. The tees are imported from Los Angeles and printed with Sarah's own designs.

Unfortunately, Stru was diagnosed with an aggressive form of non-Hodgkin lymphoma that claimed his life in July 2008.

Sarah says: "Stru was such a passionate, outgoing person, inspirational in his work. Even in the hospital he was coaching other patients to fight the disease; the nurses loved him."

The Stru Magic tees are available for \$149 with \$5 going to the Leukaemia & Blood Foundation, who supported Stru throughout his treatment.

"These tee-shirts are our way of sharing the Stru magic and keeping his memory alive while, at the same time, helping out this wonderful charity," says Sarah.

Visit [www.leukaemia.org.nz/page/191](http://www.leukaemia.org.nz/page/191) to find out where tee are sold.



L to R: Charles, George, Sarah wearing the 'Stru Magic' tee and Sam.



### LBF REGIONAL OFFICES WELCOME FIRST PATIENTS

In the last edition, we announced new LBF premises were opened in the Central and Southern Regions. Since then, thanks to a generous grant from Southern Trust, we furnished our Christchurch office and held the first patient group meetings there.

Christine Kerr, our Southern Region Support Services Coordinator, has found it invaluable having an office



so close to the hospital and patient accommodation. She has received great feedback from the lymphoma and myeloma groups that have met there. The lymphoma group meets monthly for morning tea. New members are welcome.

Please phone Christine or Lisa in the Central Region on 0800 15 10 15 if you'd like to make an appointment to visit either office.

### NEW SUPPORT PROGRAMMES FOR THE CENTRAL REGION

Palmerston North saw the first meeting of a new haematology patients' group on Saturday, 9 May with lymphoma survivor and author Phil Kerlake as guest speaker. Also a new myeloma patients' group was launched on 6 June. The Wanganui haematology patients' group held their meeting 9 June.

If you are interested in learning more about these groups, please call Lisa Speedy on 04 389 3774 or 0800 15 10 15 (opt 4).

### WINTER WORKSHOP

Internationally recognised health behavioural research leader, Laureate Professor Rob Sanson-Fisher, spoke at a three-day Winter Workshop series (20-22 July) for haematology specialists hosted by the LBF. The workshop focused on helping health care professionals better meet the complex needs of today's haematology patients.

Erin, 47, has been in remission for several months now but is still coming to terms with her diagnosis.

**She says:** “Everyone expects you to pick up where you left off but I’m still processing what happened; it’s so life-changing. I’ve always taken care of my body and logically I know it’s the luck of the draw who gets cancer, but I still feel I have let myself down in some way.”

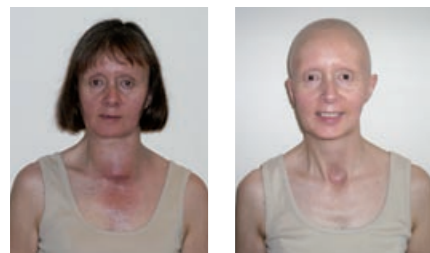
Erin still suffers from ‘chemo brain’ and finds herself struggling with her memory. She jokes: “I write things down, but then I forget where I’ve left the piece of paper!” She is also still battling fatigue.

She has drawn great comfort from the support of the Leukaemia & Blood Foundation (LBF) and now exchanges regular messages with other patients on the LBF online forum, LifeBloodLIVE ([www.lifebloodlive.org.nz](http://www.lifebloodlive.org.nz)). They chat about how they have taken up Sudoku to improve their focus and they share treatment tips and cyber hugs.

Erin says: “It took me a while to find the courage to ring the LBF then I wondered why I hadn’t done it earlier!”

She is also grateful for the “incredible kindness” of family, friends and even strangers. “I never let a day go by now without telling Norman and my family how much I love them.”

**Erin adds:** “Right from the beginning I have tried not to say, why me? Why shouldn’t it be me? I’m no more special than the next person. You have to give yourself permission to be a bit down at times, but, more importantly, permission to be happy and enjoy whatever little things come along.”



Erin pre-treatment and post-treatment

## \*psychosocial corner

By Phil Kerlake  
Lymphoma survivor; author & speaker on navigating cancer  
[www.lifepaths.co.nz](http://www.lifepaths.co.nz)  
[phil@lifepaths.co.nz](mailto:phil@lifepaths.co.nz)



### About being positive...

**When a cancer patient announced at one of my recent public talks, “if one more person tells me to be positive I’ll slug them” – I understood where she was coming from.**

Many patients can recount well-meaning folk imploring them to “just be positive” or suggesting “you’ll be fine – you’re a positive person.”

Those of us who have experienced cancer and its tortuous treatments know a reality that the positive attitude police don’t. Being unceasingly optimistic and positive while facing your mortality in the midst of nausea, fatigue, pain, worries and sadness is an unrealistic and unhealthy expectation.

Dr. Jimmie Holland, MD, a U.S. psychiatrist and psycho-oncology leader coined the term “the tyranny of positive thinking” to describe the approach of those who preach the mind-over-cancer mantra. She has rightfully acknowledged the tremendous pressure and unreasonable expectations it puts on people.

However, this does not mean that optimistic and hopeful outlooks can play no part in realising our recovery aspirations. I wrote in *Life, Happiness... & Cancer*: “Pioneers in mind-body-spirit medicine found, over a number of decades, that cancer patients who have a strong sense of their purpose and will to live tend to live longer than those whose prognosis is seemingly better but who display a greater apathy, depression and an attitude of giving up.”

There are coping and recovery-aiding benefits in acknowledging, exploring

and expressing all the emotions that cancer and its treatments stir. The key is not to languish excessively in states such as depression, despondency, hopelessness or helplessness.

As yet, science provides no clear evidence that doing so will have a predictable effect on the behaviour of your disease one way or the other. But we do know it can result in you not participating meaningfully in problem-solving and decision-making about matters that will impact your life.

And we know that you may be less likely to communicate productively with your medical team and those who care for you, moping passively instead, isolated from the valuable practical and moral support that is there for you. The result of a prolonged negative state can be less resilience and determination to withstand what you often must to cope and prevail through the minefield that is a cancer battle.

For these reasons, I strongly advocate people use whatever activities they find helpful to acknowledge, express and navigate through their negative emotions to a state that is more conducive to proactively working with medicine to fight the cancer. Measures such as relaxation, meditation, support groups, counselling, music, humour and expressive writing are just a few of the many cost-free options available.

## Finding the humour in chemo

**When Richard and Sophie Armitt waved goodbye to family and friends in their native UK, they were excitedly planning a new life in Auckland together.**

Fast forward a year to 2006 and the couple were coming to terms with the news that Richard had non-Hodgkin lymphoma – and it was spreading fast.

Richard recalls: “Looking back, there were very few signs. I had been feeling a bit run down and tired but I wasn’t sleeping brilliantly at the time and was busy hunting for a new job.”

It was the discovery of a lump under his arm during a shower at his Green Bay home that prompted Richard to seek medical help.

**He says:** “I went to see my GP and he was fantastic – I’m convinced he knew what it was straight away. He recommended an ultrasound and as the nurses carried it out I watched the look on their faces suddenly change...”

Within days he was in front of a specialist experiencing a “painful” bone marrow biopsy, and around two weeks later Richard received his diagnosis, non-Hodgkin lymphoma stage 4.

Richard says: “It was very aggressive. During the first scan they saw some activity in my chest area; by the end of those two weeks it looked like I had half an apple sticking out of my chest. Then, between the scan and my first treatment, a 5cms growth appeared on my liver.

**“I was diagnosed in the August and I think that if I hadn’t visited a doctor, I might not have seen Christmas.”**

Richard had surgery to remove the lump under his arm, followed by eight rounds of R-CHOP chemotherapy. He recalls: “The medical team were fantastic and luckily my body stood up to the treatment really well. It’s the tiredness I remember, and the blisters that covered my feet. My nail beds became really tender and it’s not until something like that happens that you realise how often you bash your fingers!

“When I look back at photos, I was bright yellow with tiny little eyes and sleeping half the day, but at the time I wasn’t aware of all that, I was just trying to focus on getting better.”

Richard continued to work three days a week throughout his treatment, “It gave me some semblance of a routine.” Then, as his treatment came to an end, he received a phone call for an interview. He says: “It felt exciting but also quite dangerous. During treatment you become quite institutionalised, then, suddenly, you are on your own.”

Richard started the new job in logistics with a North Shore firm at the beginning of 2007 and has now been in remission for more than two years.

When he was diagnosed, both Sophie and Richard received plenty of support from their new Kiwi friends and their families overseas, and Richard visited his local bookshop, seeking helpful guides.

**The 39-year-old says:** I couldn’t find anything that gave me the advice and practical help I wanted. I was left thinking, where’s the fun? So I decided to write my own book.”



Earlier this year, Richard published *Taking Chemo on the Chin* – simple advice from the other side of treatment, a ‘helpful, honest and humorous look’ at cancer treatment. He says: “It’s helped me to move on.”

**Copies of *Taking Chemo on the Chin* are available for loan from the LBF Support Services resource library or can be purchased at [www.koru-cottage.com](http://www.koru-cottage.com).**



Pictured above: Richard (left) and wife, Sophie, (right) with actress Alison Quigan at the launch of Richard’s book. Alison’s Shortland Street character, Yvonne Jeffries, was recently diagnosed with cancer.

## Little known blood cancer increasing in incidence



**World Lymphoma Awareness Day (WLAD) is a global event recognized every year on September 15. This year, the Leukaemia & Blood Foundation, in collaboration with the International Lymphoma Coalition, are aiming to increase awareness about this blood cancer.**

Few New Zealanders have heard of lymphoma although it is the sixth most common cancer in the country affecting close to 800 people every year.

Lymphoma is increasing in incidence in New Zealand; this is in line with increases seen globally. In New Zealand, lymphoma, a cancer of the immune system, has an incidence rate four times higher than cervical cancer and kills more people than melanoma.

Only two percent of New Zealanders know to act on the symptoms of this potentially fatal cancer. The symptoms of lymphoma are often mistaken for other illnesses. The LBF can help patients and families affected by lymphoma receive information and support.

**For more information about WLAD and about lymphoma, go to [www.leukaemia.org.nz](http://www.leukaemia.org.nz).**



# Lymphoma Coalition

The Leukaemia & Blood Foundation is a proud member of the Lymphoma Coalition, a global alliance of 30 countries representing the interests of people living with lymphoma.



IN THIS EDITION WE TALK TO KAREN VAN RASSEL, EXECUTIVE DIRECTOR OF THE LYMPHOMA FOUNDATION CANADA (LFC)

## WHEN WAS YOUR ORGANISATION ESTABLISHED?

Lymphoma Foundation Canada (LFC) has its roots in two distinct, regional organisations founded by non-Hodgkin lymphoma patients in 1998. They both realised there was a need for support and research into lymphoma and the two organisations merged in 2000.

## WHAT IS YOUR VISION AND MISSION?

- To provide education and support for individuals with lymphoma and their support network
- To fund medical research to find a cure for lymphatic cancer
- To advocate for the best treatment and care of lymphoma patients
- To promote further research and new treatments in lymphoma and to promote rapid access to new developments
- To be "THE" lymphoma support provider for education and educational materials so that anyone in the lymphoma community can refer a patient to LFC without one concern

## PLEASE OUTLINE THE SERVICES YOU PROVIDE FOR PATIENTS AND THEIR FAMILIES.

Research is our highest priority and each year we establish two, two-year research fellowships. These efforts contribute to building a knowledge base of how to treat lymphoma effectively, as well as to finding a cure.

We provide information to patients on latest treatments and research through our website and toll free patient line; organise patient education sessions and

seminars and provide community-based resources to help people understand, cope and manage their cancer.

## HOW MANY PEOPLE ARE DIAGNOSED WITH LYMPHOMA EACH YEAR IN CANADA?

8,000 newly diagnosed patients each year and an estimated 50,000 are living with it.

## ARE THOSE FIGURES TYPICAL OR HAVE YOU WITNESSED A CHANGE OVER THE LAST FEW YEARS?

These numbers have been on a slow and steady climb over the past 30 years.

## HOW WOULD YOU RATE CANADA'S PROVISION OF HEALTH SERVICES AND DRUGS FOR LYMPHOMA PATIENTS COMPARED TO OVERSEAS?

Canada ranks twelfth in the world when it comes to access to therapies; very low for such a developed country. We have PET scanners available but due to limited government funding they are used very sparingly. Funding of therapies is a big problem in Canada in the cancer community, especially novel targeted therapies as the government has not yet realised the value versus the cost.

## HOW LONG HAVE YOU BEEN A MEMBER OF THE LYMPHOMA COALITION?

LFC is a founding member of the Lymphoma Coalition and it has been a pleasure to work with such fantastic organisations who are working so hard on behalf of lymphoma patients worldwide.

## DO YOU BELIEVE COALITION MEMBERSHIP HAS IMPROVED THE SERVICES YOUR ORGANISATION OFFERS?

Oh, absolutely. Through sharing

best practice with other lymphoma groups around the world we are able to synergise on literature, marketing ideas and bring global awareness to lymphoma. And we stay in touch on the latest therapies available so we can advocate if they are not available in our own countries.

## RAISING AWARENESS OF LYMPHOMA IS A CHALLENGE. WHAT DO YOU THINK HAS BEEN YOUR MOST EFFECTIVE CAMPAIGN?

Know Your Nodes. It allowed the lymphoma message to carry across all areas; government, the general public, GPs and all those involved in lymphoma care.

## HOW WILL YOU BE MARKING WORLD LYMPHOMA AWARENESS DAY THIS 15 SEPTEMBER?

We would like to see how our friend on YouTube makes out when he finally understands about his nodes (go to [www.youtube.com](http://www.youtube.com) and search on 'LBFNZ' to see the Know Your Nodes video). We will engage the government to help them understand the issues involved with lymphoma, and our volunteers and lymphoma community will take to the streets again. Two other important groups we will address are the media – especially around the young adult statistics – and GPs, in the hope they will become more aware of lymphoma and diagnose earlier.



# Network offers brighter future for patients

Lymphoma consultants have joined forces to establish a national network aimed at improving patient care.



Dr Samar Issa

In New Zealand, lymphoma patients may be treated by a haematologist, medical oncologist or radiation oncologist, depending on their location, the lymphoma subtype they have and the stage of the disease. As the three groups of specialists rarely meet nationally, knowledge is seldom shared.

The new Lymphoma Network, which is sponsored by the Leukaemia & Blood Foundation (LBF), aims to change that, leading to a new era of collaboration.

Dr. Samar Issa, Consultant Haematologist and Clinical Head of the Lymphoma Service at Middlemore Hospital, Auckland, has led efforts to establish the network and has been appointed Chair.

Dr. Issa explains: "When it comes to research and treatment development, lymphoma is one of the fastest growing fields in the world. The incidence of lymphoma continues to rise worldwide, new targeted therapies have been introduced, older patients are being treated more aggressively and patients are living longer.

"For all these reasons there is great need for collaboration and support. I hope that by working together we will improve the outcome of the treatment of lymphoma in this country."

The response from colleagues in the medical world has been extremely positive and the network has now held its second meeting in Auckland.

Dr. Issa has identified a range of issues she would like the group to pursue including:

- National guidelines for the treatment of lymphoma
- Guidelines regarding referral for bone marrow transplantation, radiotherapy and new innovations in imaging like positron emitting tomography (PET) scan
- More support for patients and families
- Lobbying to introduce and fund new targeted therapies
- Greater involvement of New Zealand patients in clinical trials

She is also keen for the network to share knowledge with international groups.

Another important topic is the psychosocial effects of lymphoma, which can range from financial troubles to stress, depression and fatigue.

Dr. Issa says: "The management of patients with lymphoma requires a multi disciplinary approach with input from physicians, nurses and organisations like the LBF. This will enable us to address the issues related to the possible complications of chemo and radiotherapies, including fertility, and secondary cancers."

Dr. Issa also sees the network playing a role in advocacy. "It might involve lobbying to ensure patients have access to new drugs. Together we will be able to create some impact.

"Our aim is also to enrol patients in clinical trials. It is through these local, national and international trials, that patients can access new drugs and be closely monitored."

Another of the group's ambitions is to start a national database to preserve information on patients and treatments.

Dr. Issa explains: "We will be able to follow newly diagnosed patients and record important data, e.g. how many patients achieve remission, why do people relapse, are there geographical patterns?"

"The great thing about being sponsored by the LBF is that not only do we have access to the LBF's knowledge and experience, but they are an independent and unbiased source of funding and support."

During 2009, the network is hoping to establish a website with a public section and a restricted area for clinicians.

Dr. Issa says: "It will allow treatment groups to share information, pose questions about difficult cases and offer us the opportunity to support each other – it can be challenging dealing with such serious illness."

She adds: "Our aim is to provide patients with excellent treatment through collaboration and utilising the best scientific evidence. The network is a step in the right direction."

# Buck shares lymphoma lessons

Rugby legend, Buck Shelford, is well aware just how little we know about the blood cancer lymphoma – his diagnosis in May 2007 was the first time he had heard of the disease.

So the former All Black was happy to throw his weight behind the Leukaemia & Blood Foundation's ongoing campaign to raise public awareness.



Recalling his own experience, Buck says: "I visited my GP after being irritated by a persistently watering eye. I was given some eye drops and saw no improvement so I went to see an optometrist who found a cyst. They performed a small operation and the biopsy showed lymphoma, which I had never heard of."

Lymphoma is the sixth most common cancer in the country, affecting about 800 people every year. A cancer of the immune system, it has an incidence rate four times higher than cervical cancer and kills more people than melanoma. Certain types of lymphoma can prove fatal in as little as six months.

But lymphoma can be difficult to diagnose as it presents in many different ways. The most common symptoms are swelling in the neck, underarm region or groin, unexplained weight loss and tiredness.

Buck encourages people to be vigilant. "If you notice something is wrong, do something about it and get it checked out as early detection can make a big difference."

To increase public knowledge about lymphoma, the LBF takes part in World Lymphoma Awareness Day (WLAD) on 15th September each year. Part of the activities included a fun online quiz to help people learn more about the disease – [www.knowyournodes.org.nz](http://www.knowyournodes.org.nz).

# Clinical Trials

The LBF supports participation of patients with lymphoma in clinical trials. It has been shown that involvement in clinical trials improves quality of care for patients and may allow them access to cutting edge, potentially life-saving and life-enhancing treatments.

The following are trials in lymphoma either currently recruiting or still underway in New Zealand.

## Hospitals

ACH: Auckland City Hospital	NSH: North Shore Hospital
CHCH: Christchurch Hospital	MMH: Middlemore Hospital
PNth: Palmerston North Hospital	Waikato Hospital

## Chronic Lymphocytic Leukaemia

### OFICIR Trial

Initial treatment of patients over 65 years with chemotherapy and rituximab. Enables participants access to rituximab which is not currently funded. Available at ACH, CHCH and NSH.

### LUCID

This is a randomised study for patients with relapsed chronic lymphocytic leukaemia (CLL). Patients receive chemotherapy, rituximab or chemotherapy plus rituximab and a new antibody therapy. Available at ACH and CHCH.

## Diffuse Large Cell Lymphoma

### The Main study – a trial of R-CHOP versus R-CHOP plus Avastin

This is a trial for patients with large cell lymphoma to be randomised to the standard arm which is R-CHOP chemotherapy or R-CHOP with the addition of Avastin. This agent is designed to impair the blood supply to these rapidly growing lymphomas. The experimental agent Avastin is generally well tolerated but patients who have had recent severe bleeding or high blood pressure are excluded. Available at ACH, NSH and CHCH.

### Pillar 2 Study

This is a randomized trial of RAD001 (everolimus, a novel mTOR inhibitor) versus observation only (standard of care) as maintenance therapy in patients with high risk diffuse large B cell lymphoma post initial immunochemotherapy with R-CHOP (to open shortly). Available at ACH.

## Hodgkin Lymphoma

### HD4

This is a randomised trial of chemotherapy regimens – BEACOPP or ABVD in stage III and IV Hodgkin lymphoma. Available at ACH and Waikato.

### LBH589 study in relapsed / refractory Hodgkin lymphoma

This is a study of a novel histone deacetylase inhibitor, LBH589 (panobinostat) in patients with relapsed or refractory Hodgkin lymphoma following previous high dose therapy and autologous stem cell transplantation. Available at ACH.

## Low Grade Lymphoma

### Stage I-II low grade follicular lymphoma

This is a randomised multicentre trial of involved field radiotherapy versus involved field radiotherapy plus chemotherapy in combination with rituximab (MabThera®) for stage I-II low grade follicular lymphoma. Available at ACH and Waikato.

### Cephalon 3064

Bendamustine + rituximab vs RCVP or RCHOP as initial therapy in advanced mantle cell or follicular lymphoma. The bendamustine treatment is potentially easier for patients to receive than the standard chemotherapy. Available at ACH, MMH, NSH, CHCH and PNth.

### Biogen 114-NH-301 Study

This is a randomised, double-blind study of the drug (Galiximab, a monoclonal antibody) in combination with rituximab vs. rituximab monotherapy for the treatment of patients with relapsed or refractory follicular non-Hodgkin's lymphoma. Available at Otago/Southland and Waikato.

The following trials are currently closed to recruitment: APO/TRAIL, PRIMA Study, Watch & Wait.

For more information on these or other clinical trials please speak to your specialist.

## Our vision to cure – mission to care

The Leukaemia & Blood Foundation (LBF) is New Zealand's leading resource dedicated to supporting patients and their families living with leukaemia, lymphoma, myeloma and related blood cancers and conditions.

The LBF is committed to improving the quality of life for patients and their families living with these blood cancers and conditions by:

- providing personalised patient support services,
- funding research into cures,

- sharing information,
- helping build awareness and
- championing advocacy on behalf of patients and their families.

The LBF receives no government funding and relies entirely on the generous support of individuals, companies, trusts and grants, events and fundraisers as well as support in kind.

No person should rely solely on the contents of this publication without first obtaining advice from their treatment specialist.

To find out more about the Leukaemia & Blood Foundation, and how you can help, call 0800 15 10 15 or visit [www.leukaemia.org.nz](http://www.leukaemia.org.nz).

