

Interested in Clinical Trials?

The decision to enter a clinical trial can be one of the most difficult a cancer patient makes, and it's important to have all the facts.

Unlike standard therapy, in a clinical trial doctors don't know, ahead of time, what the results will be. If they did, there would be no need for the study in the first place. That's why the question of whether to participate in a trial can be difficult.

If you decide to enter a trial, you will be asked to read about its goals and then sign a special consent form. Patients need to be well enough to enter the study, and should discuss all treatments with their doctor before deciding what course to take.

Some trials may take place only at one hospital, while others have many locations, across New Zealand and across the world.

WHAT IS A CLINICAL TRIAL?

A clinical trial is a research study that helps to determine whether a new drug is safe and/or effective. Each study is designed to answer questions and to find better ways to screen, diagnose, prevent, or treat, a disease or condition.

WHY ARE CLINICAL TRIALS NEEDED?

Trials provide the evidence that a treatment works. Some clinical trials help to determine if a new treatment is safe and can improve the health of patients. Other trials compare a new therapy to an existing one to

find out which is better at treating, or preventing, a disease.

WHAT ARE THE BENEFITS OF PARTICIPATING IN A CLINICAL TRIAL?

Participation in a clinical trial gives patients access to cutting-edge, potentially life-saving and life-enhancing treatments, as well as medical care from a team of researchers, doctors, and nurses.

WHAT ARE THE RISKS?

The risks depend on the type of treatment being studied and the health of the patient. For some people, there could be unpleasant, even serious, side effects. Often these side effects are temporary and end when the treatment stops. There are both known, and unknown, risks with any clinical trial. To be sure you understand the known risks before you join any study, talk to your doctor.

HOW DO I FIND OUT IF I'M ELIGIBLE?

Each study's protocol has guidelines stating who can, and cannot, join the clinical trial. These guidelines (eligibility criteria), apply to anyone who wants to sign up for the study. The criteria vary by study and could include your age, gender, medical history, current health status, and the particular type, or stage, of disease you may have. Before

you join the trial, you will be asked to sign an informed consent form. If there is something on the form you do not understand, ask questions. Study doctors and nurses are available to answer your questions and help you understand the risks and benefits of the trial. Then, a doctor or nurse will assess your medical history, perform a physical exam, and perform laboratory tests to determine whether you meet the eligibility criteria.

WHAT HAPPENS AT THE END OF THE TRIAL?

After you complete the study, you may, or may not, be able to continue receiving the drug. Once the trial ends, researchers analyse the data to understand the safety and effectiveness of the treatment. During the funding approval process, some pharmaceutical companies choose to continue to make the drug available through an expanded access program.

Currently, clinical trials are ongoing throughout New Zealand in diffuse large cell lymphoma, as well as newly-diagnosed and relapsed follicular lymphoma. Different hospitals throughout New Zealand offer a range of trials. The best way to find out what may be available for a particular patient is to ask your haematologist or oncologist.

Our Vision to Cure and Mission to Care

The Leukaemia & Blood Foundation (LBF) is New Zealand's leading resource of information specifically for patients and families affected by leukaemia, lymphoma, myeloma and related blood conditions.

We provide emotional support and a range of practical assistance, as well as information for patients, family members

and friends affected by these diseases. The LBF also works to raise public awareness, funds research into cures and better treatments, and represents the needs of patients and their families to the Government, related agencies and other relevant bodies.

The LBF receives no government funding and relies on the generous support of

individuals, companies, trusts and grants, as well as support in kind.

To find out more about the work of the Leukaemia & Blood Foundation, and how you can help, call 0800 15 10 15 or visit www.leukaemia.org.nz.



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

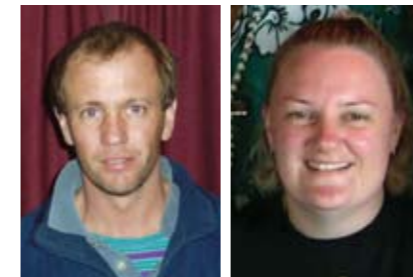


Lymphoma today

Supporting people living with lymphoma

www.leukaemia.org.nz

spring 07



Dwayne Greenwood and his sister Jac.

Dwayne Greenwood is no stranger to a 70-hour working week so he likes to unwind with a few holes of golf.

That stamina and fairway practice may well prove a winning combination on October 9, when he tees off in the Leukaemia & Blood Foundation's first South Island 100-hole Golf Marrowthon.

In fact, Dwayne's such a keen golfer he played a few rounds back in the summer of 2003/2004 - not long after he'd had a bone marrow transplant.

Dwayne describes himself as "just an average southern bloke". He drives a stock truck all over the South Island, accompanied by his heading dog. He can put in 14-hour days between loading, unloading and driving.

So when, at the age of 29, he found lumps in his neck, he just put them down to another round of glandular fever - he wasn't the sort of guy who went to the doctor. He could play 36 holes of golf in a day...he handled the physical side of the job without a problem.

"I'd have to be dead before I'd take a day off work," he says very matter-of-factly, but with just a touch of humour.

He reckons he'd had the lumps for about 12 months, but finally went to the doctor when his boss said to get them checked out, as they were quite big.

Dwayne tees off for LBF

"I didn't think much about it. I just thought it was stress."

"It" turned out to be follicular non-Hodgkin lymphoma (NHL), a potentially life-threatening cancer.

Dwayne says the diagnosis of NHL was quite frightening, but he always focused on getting fit and getting back to work.

"My friends and workmates knew, but they also knew I was pretty laid back and cruisy about this."

Dwayne then underwent chemotherapy treatment.

"I knew I'd get sicker before I got better, but I just kept hoping the next day would be better," he says.

After diagnosis, Dwayne joined a drug trial. But then, in October 2003, a month after the trial was finished, the lumps started coming back.

Dwayne's doctors decided that due to the severity of his lymphoma, and the fact he was young and fit, they would consider a bone marrow transplant. Both of Dwayne's sisters were tissue-typed and it was 25-year-old Jac who was the match.

"She was quite happy to do anything for her older brother just as long as he got better," says Dwayne, with a great deal of pride in his voice.

In November 2003, Dwayne had intense chemotherapy and radiotherapy to prepare him for the transplant.

Dwayne talks about Jac's bravery, and she talks about the small thing she did to help her brother have a chance. It was more than a small thing, because it was a lifesaver for him.

After 23 days, Christchurch Hospital discharged Dwayne and told him to stay

CONT. ON PG 2



Dwayne and the stock truck he drives across the South Island

Meet the Support Services team

We currently have three Support Services Co-ordinators, all trained nurses, who are available to help patients and families with a whole range of assistance, from an understanding voice on the end of the phone to more practical aid. They are always happy to help with any queries and can be contacted on 0800 15 10 15.



NAENA CHHIMA

I have been working for the Leukaemia & Blood Foundation (LBF) for 17 months. Based in Wellington, I cover the lower and central North Island and Nelson region.

The role has been a great challenge and an exciting change for me as my previous nursing career was hospital-based with 10 years of Oncology and Haematology Nursing experience at the Wellington Blood and Cancer Centre. I was fortunate to be able to practice Healing Touch, Massage Therapy and other Holistic techniques during this period.

My role with LBF has given me the opportunity to offer the community my practical experiences...helping people through these traumatic periods is a passion of mine.



AMY MUNRO

I joined the Leukaemia & Blood Foundation in February 2007 as the Support Services Co-ordinator for Auckland and the upper North Island.

My background is in Haematology and Bone Marrow Transplant Nursing with experience at Auckland City Hospital and, more recently, overseas at University College Hospital in London.

My passion is helping patients and their families in any way I can through what can be one of the most stressful and traumatic periods of their lives. It is a privilege to know that we can make even the smallest difference.



CHRISTINE KERR

I am the South Island Support Services Co-ordinator for the Leukaemia & Blood Foundation. Based in Christchurch, my area covers Canterbury, West Coast, Otago and Southland. I started in this role in March 2007 and I previously worked as a registered nurse in the Haematology Department of Christchurch Hospital, in both the Bone Marrow Transplant Unit and outpatient areas.

A cancer diagnosis can be devastating, and living with cancer is stressful for the whole family. As a Support Services Co-ordinator, I enjoy getting to know patients and their families over what can be a long period of treatment, helping them through living with cancer, and back into life.

CONT. FROM PG 1

off work for 100 days. Dwayne's used to being busy all the time, so 100 days of 'nothing' was a challenge, but very important for his health.

After a bone marrow transplant, a patient's immunity is very low. They are prone to infection and need to take special care around food and animals. For Dwayne, carting pigs was out of the question because they're dusty and that dust can contain infectious material.

Back at work, he got what he calls "a wee truck" to drive. Not the big double-decker truck and trailer unit he'd been navigating around the South Island for so long.

He got his big truck back nine months later.

Now 33, and looking back at his illness, he says he didn't really know he was sick with lymphoma.

"You're loading and unloading stock every day. It's hot, it's cold. You sweat. You get tired. I didn't know the tiredness was the illness. You work 14 hours a day and you put it down to the work."

Dwayne is now in remission and down to 12-monthly checks.

And early on the morning of October 9 at Clearwater Resort in Christchurch, Dwayne will tee off and aim for the first of 100 holes placed around lakes and streams, framed by the majestic Southern Alps.

He'll be playing in some great company – people like himself who've come through their illness; those who've lost friends or family, and sporting legends like Robbie Deans and Nathan Astle. And those who want to help fund the Leukaemia & Blood Foundation's Support Services in the South Island.

In his very unassuming way, this average southern bloke is going to do what he does best – get on with his life with a few holes of golf.

To find out more about the Christchurch Golf Marrowthon, visit www.marowthon.org.nz

World Lymphoma Awareness Day

It's been dubbed 'the cancer that no-one knows' and it occurs in a part of the body which remains a mystery to most New Zealanders.

But with the number of people diagnosed with lymphoma each year more than doubling in the last decade...a trend forecast to continue over the coming years¹...it is increasingly important that people learn more about this blood cancer.

To mark World Lymphoma Awareness Day on September 15, the Leukaemia & Blood Foundation (LBF) has launched a new easy and fun way to unravel the mysteries of your lymphatic system.

Simply visit www.knowyournodes.org.nz to take part in a quiz and find out what you know - or more importantly don't know - about one of the body's most vital systems.

Pru Etcheverry, Executive Director of the Leukaemia & Blood Foundation, said: "Lymphoma is now the sixth most common cancer in New Zealand. It has a considerably higher incidence than cervical cancer, yet few people have heard of it.

"New Zealanders really need to know their nodes – both the lymphatic system and the signs and symptoms of lymphoma. If detected early, there is a better chance for quicker diagnosis, treatment and overall survival."

Research conducted by the Leukaemia & Blood Foundation revealed that only 9% of 500 New Zealanders surveyed could name lymphoma as a type of cancer, while less than 1% considered lymphoma as a possible cause of the most common symptoms².

Those common symptoms are often misdiagnosed as flu or

fatigue and include painless swelling in lymph nodes like the neck, armpits or groin; fevers (especially at night); temperature swings; unexplained weight loss; persistent coughing, and enlarged tonsils.

Most people who have complaints like these will not have lymphoma. However, according to the LBF's Medical Director,



Dr Peter Browett, anyone experiencing these symptoms over a period of more than two weeks, should visit a medical professional.

1. Ministry of Health 2002, Cancer in New Zealand. Trends and Predictions: A Summary
2. Research Solutions: Lymphoma Awareness Research August 2005 – data on file

Factfile

- Lymphoma can occur in all ages, but is most common in people 50 years and over
- There are more than 35 types of lymphoma that are categorised under Hodgkin lymphoma and non-Hodgkin lymphoma
- Around 750 people will be diagnosed with lymphoma in

New Zealand this year – around 80 will develop Hodgkin lymphoma and around 670 will develop non-Hodgkin lymphoma

- The Leukaemia & Blood Foundation (LBF) is New Zealand's leading resource of information for patients and families living with lymphoma. You can contact the LBF on 0800 15 10 15 or visit www.leukaemia.org.nz

The latest figures

Latest cancer statistics show lymphoma is still on the rise - right in line with Ministry of Health predictions.

Back in 2002 they released projected cancer registrations for the coming years, up to 2011¹. They calculated that non-Hodgkin lymphoma, in particular, would be one of the fastest growing cancers.

And that increase is being felt worldwide, with non-Hodgkin increasing in incidence by 80 per cent since the early 1970s².

NZHS statistics for 2005³ reveal 777 people were registered with lymphoma, while in 2000 that figure sat at 600... that's a 30% rise.

The Government predict that by 2011 it will have risen to 1,252¹.

Lymphoma in 15 to 24-year-olds also appears to show an upward trend – in 2003 they comprised 12.5% of cancer registrations in that age group, but by 2005³ that was 17.9%.

Worldwide, there are now one million people living with lymphoma⁴ and nearly 1,000 people are diagnosed with the disease every day⁴.

1. Ministry of Health 2002, Cancer in New Zealand. Trends and Predictions: A Summary
2. World Health Report 2000, World Health Organisation
3. NZHS annual cancer registrations statistics (2005 figures are provisional only)
4. GLOBOCAN 2002: Descriptive Epidemiology Group of the International Agency for Research on Cancer (IARC)

* psychosocial corner



By Phil Kerslake
Lymphoma survivor, author,
speaker and life coach.
www.lifepaths.co.nz
phil@lifepaths.co.nz

S/he who laughs; lasts

People have always known laughter was good medicine. This was never truer than for lymphoma patients because laughter provides a raft of recovery-assisting physical and emotional benefits. 'We don't laugh because we're happy, we are happy because we laugh,' philosopher and psychologist William James once observed.

It also encourages your immune system to function better while providing you with a physical workout. Muscles in your chest, abdomen, shoulders, neck, face and scalp are exercised and other parts of your body become more relaxed - invaluable during the sedentary state you can find yourself in while undergoing treatments.

Cancer has been known to break the funny bones of the most fun-loving of people, but a morose state is not conducive to preserving your hope, resilience or will to live. In chapter 14 of *Life, Happiness ... & Cancer* ('Humour heals') I describe the two ways I applied laughter and humour to my lymphoma recoveries.

Firstly, I developed my own 'humour library'; collecting recordings of my favourite comedies from television and film. Secondly, I made a conscious effort to see the funny side of everyday cancer-related events and occurrences. I even found humour in the shock realisation (while showering one day...) that chemo's alopecia-effects were not confined to my scalp!

I found William James' words to be on the button. I didn't have to feel like laughing to induce laughter and derive the benefits it produced. When I was stressed, depressed or battle weary, watching comedies lifted me.

Phil's formula

While health professionals concentrate on securing the best medical outcome for their patients, all too often the emotional impact of the diagnosis and treatment takes a back seat.

Dealing with the psychosocial aspects of living with cancer is a subject very close to the heart of well-known lymphoma survivor, life coach, speaker and author, Phil Kerslake.

And now Phil, author of *Life, Happiness... & Cancer: Survive with Action and Attitude!*, has agreed to share the wisdom gained from his own experiences in a regular column for *Lymphoma Today* readers.

In each edition, Phil will focus on ways patients and their families can aid the healing process and he begins with the therapeutic benefits of humour. But perhaps even more inspiring is Phil's own story....

"I found my first enlarged lymph nodes (then misdiagnosed as glandular fever) when I was about 15. In 1979, aged 19, I was diagnosed at Auckland Hospital with a low-grade non-Hodgkin lymphoma, with a prognosis that I might live up to ten years.

By my final encounter in 2004, I had contended with six episodes of both non-Hodgkin lymphoma and Hodgkin lymphoma, twice regressing to stage IV. My medical treatments incorporated eight operations, including the removal of my spleen, almost two years of chemotherapy, a high-dose chemotherapy regime with an autologous stem cell transplant, and two courses of radiotherapy.

Managing the emotional challenges of my cancer experiences had been a strong area of interest for me since reading some of the early books on the subject, notably, the 1978 classic *Getting Well Again*, by Carl and Stephanie Simonton and James Creighton.

Studies continue to show that for almost half of all cancer patients; their emotional challenges are as trying as, and at times more trying than, the

physical affects of the cancer and its treatments. Yet, in 2007, they are still essentially disregarded when patient treatment plans are formulated by medical teams; which astounds me.

Managing my emotional state has long enabled me to cope much better with cancer. It has enabled me to remain discernibly more resilient mentally, emotionally, and physically. I am able to control my stress levels and consequently remain focused on the problems at hand. I can communicate more effectively in my own interests, and sustain my hope, faith and will to live, even during times of advanced disease and the heaviest of treatments.



Phil Kerslake received his Rebuilding Lives award in Vienna earlier this year.

To fill the gap in the New Zealand literature on this subject, I wrote my own book *Life, Happiness ... & Cancer: Survive with Action and Attitude* in 2005. Recently winning an international, Roche-sponsored Rebuilding Lives Award has provided me with a grant to embark on writing my second book, which is to focus on rebuilding a life after a cancer encounter.

Today I am in full remission and live in Wellington with my wife of 9 years Gillian and our new son Rhys (born 1 July 2007).



BY DR LEANNE
BERKAHN,
CONSULTANT
HAEMATOLOGIST,
AUCKLAND CITY
HOSPITAL

Recent clinical data demonstrates an improvement in survival for follicular lymphoma patients diagnosed in the 1980s and 1990s that predated the approval of rituximab (MabThera®), the monoclonal anti-CD20 antibody.

Now, more advanced trials compare conventional treatment to new regimens that incorporate rituximab. This type of treatment, termed chemo-immunotherapy, shows survival benefits for patients, but there are many unanswered questions and can these trends be sustained?

Several ongoing studies are investigating these important questions in follicular lymphoma. Many centres in New Zealand participated in the PRIMA study which looked at whether the use of rituximab in the two years following chemotherapy is beneficial to patients with follicular lymphoma. There were 900 patients enrolled in this study worldwide.

Many patients diagnosed with follicular lymphoma do not initially need treatment with chemotherapy as they may not become symptomatic for some time.

While this can be a difficult concept for patients, caregivers and doctors to grasp, it is well backed by randomised studies of early treatment with chemotherapy versus waiting until the patient shows some sign of needing treatment.

Given the relatively benign effects of rituximab compared to chemotherapy, a recent question is whether asymptomatic patients would benefit from rituximab at the time of diagnosis - the aim being to prolong the time before chemotherapy is required. An

Trends in follicular lymphoma and large cell lymphoma

Follicular lymphoma is the second most common type of lymphoma and represents around 24% of all cases.

international randomised study has been designed to answer this question and many New Zealand centres are currently participating.

While most lymphoma cells are exquisitely sensitive to radiotherapy, radiation treatment is not routinely given because the lymphoma is often widespread and the side-effects of the radiation to normal tissues need to be taken into account. Monoclonal antibody therapy (similar to MabThera®) has also been combined with radio-labelled isotopes to create a "drug" called Zevalin, which is a form of radio-immunotherapy.

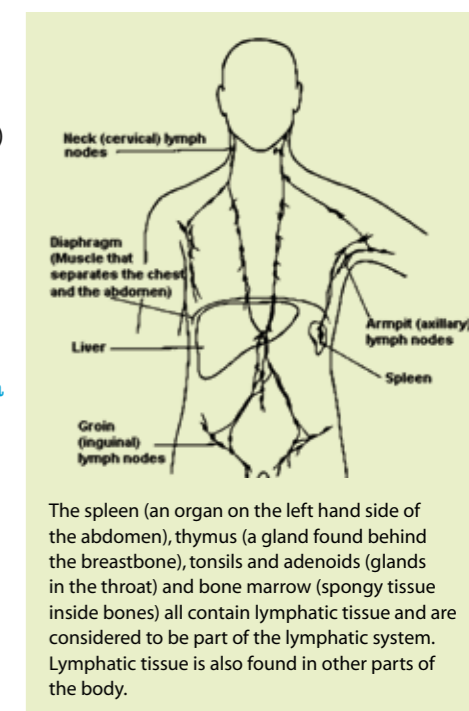
Zevalin can target radiation just to the cells that contain the CD20 antigen... that is, most lymphoma cells. This is a way of delivering radiotherapy without the side-effects we see of radiation to normal tissues.

This is not a new treatment and has been studied extensively in Europe and the USA. Zevalin has been approved for use in New Zealand by Medsafe but awaits Pharmac funding approval. Ongoing international studies are looking at the best way of incorporating radio-immunotherapy into treatment for follicular lymphoma, to decide how to best sequence therapies to maximize outcomes.

Another important question is the role of stem cell transplantation in follicular lymphoma.

In autologous stem cell transplantation, which uses a patient's own stem cells, very high doses of chemotherapy are used to eradicate the lymphoma. These doses also affect normal bone marrow to the extent that blood counts are

unlikely to return to a functional level. This is termed myeloablative therapy. The infusion of the patient's own stem cells to rescue the depleted marrow ensures that after an obligatory period of low blood counts, (two weeks), the bone marrow function returns.



Autologous stem cell transplants are given after a patient has responded to conventional doses of chemotherapy and are best used early in the course of the lymphoma such as first or second remission/response.

Allogeneic stem cell transplants use stem cells from a sibling or unrelated donor with the same tissue type as the patient. There is about a one in four chance of a match for each sibling.

CONT. ON PG 6



Lymphoma Coalition

The Leukaemia & Blood Foundation (LBF) is proud to be a member of the Lymphoma Coalition, a non-profit organisation of lymphoma patient groups formed in 2001.

The LBF joined in 2003 and in 2005 was voted onto the steering committee, becoming one of six members helping to develop a future vision for the coalition.

The organisation is a global initiative dedicated to raising awareness of lymphoma and promoting the well-being of people affected by lymphoma worldwide.

It is the driving force behind World Lymphoma Awareness Day (WLAD), which New Zealand, and many other countries around the world, support on September 15 each year (see page 3 for more details on our WLAD activities).

The goals and objectives of the Lymphoma Coalition are simple. It aims to:

- Raise worldwide awareness of lymphoma among the general public, patients, their families and friends, patient support groups, physicians and other healthcare professionals involved in the treatment of lymphoma
- Build partnerships among member groups of the coalition and share best practices worldwide
- Encourage the establishment of new lymphoma patient groups around the world, especially in countries where groups are not already in existence

The Lymphoma Coalition currently consists of 35 lymphoma patient organisations from 29 countries, which represent a large cross-section of the

world's population. The countries include:

- Argentina
- Australia
- Brazil
- Bulgaria
- Canada
- Croatia
- Czech Republic
- France
- Germany
- Hong Kong
- Ireland
- Italy
- Japan
- Latvia
- Lithuania
- Mexico
- Netherlands
- New Zealand
- Poland
- Singapore
- Slovakia
- Slovenia
- Spain
- Sweden
- Switzerland
- United Kingdom
- United States
- Uruguay
- Venezuela

In subsequent editions we will take a look at the aims and activities of some of our international counterparts and keep you updated on what is happening around the globe.

For more information about the Lymphoma Coalition, please visit: www.lymphomacoalition.org

CONT. FROM PG 5

The advantage is the stem cells do not contain any lymphoma and also have functional T lymphocytes that can initiate 'cellular warfare' against the lymphoma cells. This is called the 'graft versus lymphoma' effect and is potentially curative, but, unfortunately, is coupled with graft versus host (GVH) disease, in which donor T cells attack the patient's skin, bowel lining and liver.

The GVH effect makes allogeneic stem cell transplantation a relatively risky procedure that is reserved for younger patients (less than 60-65 years of age).

Large cell lymphoma is the most common form of lymphoma and, unlike follicular lymphoma, is best treated at diagnosis.

The standard treatment is with chemotherapy, often CHOP*, and the addition of rituximab to each cycle, termed R-CHOP, has improved survival in patients with large cell lymphoma. Haematologists are looking at ways of further improving the outcome for these patients.

At some treatment centres, R-CHOP treatment is given over two weeks, instead of three weeks, to speed up the lymphoma cell kill process. This approach requires the use of an injection of G-CSF (granulocyte-colony stimulating factor) under the skin to stimulate normal white cell recovery.

Despite the use of R-CHOP, about 40% of patients have a recurrence or relapse of their lymphoma. In this case, the lymphoma can often still be successfully treated with an autologous stem cell transplant.

Whether the use of maintenance rituximab can reduce the risk of relapse post chemotherapy is also being examined in patients with large cell lymphoma in an international trial.

CHOP = Cyclophosphamide, Adriamycin (Doxorubicin/Hydroxydoxorubicin) Vincristine (Oncovin), and Prednisone

Access to medicines

The Leukaemia & Blood Foundation strongly supports the concept that all patients should receive the medication they need to achieve the best health outcome.

And that view is shared by the Access to Medicines Coalition, a grouping of non-Government, disease-specific organisations advocating increased access to medicines in New Zealand.

As a member of the Coalition, the Leukaemia & Blood Foundation believes the government has a responsibility to all New Zealanders to operate a pharmaceutical funding system that has health outcomes as its primary priority.

The current significant delays we see with drug funding, and lack of access to drugs, are at odds with the Cancer Control Strategy which states it promotes "timely and appropriate access to new medicines".

Unfortunately, under New Zealand's current pharmaceutical funding system,

low investment in important medicines and delays in approval and funding mean our provision is only on a par with developing countries like the Czech Republic and Poland. This revealing fact emerged in May this year in a report published in the Annals of Oncology by the Karolinska Institute¹ (an internationally respected organisation).

These funding delays and decisions not to fund certain important cancer medicines can significantly impact the course of patients' illnesses.

One such medicine is rituximab, MabThera® which is used in the treatment of non-Hodgkin lymphoma (NHL). This medicine has revolutionised the way NHL is treated. An application to PHARMAC for the use of MabThera® as a first line treatment for patients



Access to Medicines Coalition

with indolent non-Hodgkin lymphoma (NHL) was submitted almost a year ago. Despite recommendations for review by PHARMAC's cancer treatment specialist subcommittee (CaTSOP), it remains unevaluated and therefore unfunded².

This drug has dramatically altered the course of NHL by delaying disease progression and increasing survival rates. In other developed countries, including UK, Canada and Australia, this drug is already standard treatment.

Delays such as this do affect disease outcome for New Zealand patients and keep us out of step with funding decisions made worldwide.

1. Ann Oncol; 1; 18 (Suppl 3)
2. PHARMAC, PTAC minutes February 2007

Few signs for uni student

It was when Suzanne Wein's grandmother gave her a big hug that the 28-year-old from Auckland realised something was not quite right.

I thought, "Gosh, my grandmother's chin is really bony," said Suzanne. Then she realised the hug had pushed a chunky necklace she was wearing against a lump on her neck.

Suzanne had just finished her job as a neurological physiotherapist the day before, and was due to start studying a PhD at university on the Monday. She visited her GP and when he ordered a blood test and needle biopsy, Suzanne began to suspect something was going on.

"I don't recall any names, such as lymphoma, being used; just that I had an enlarged lymph node. I knew about them from my health professional background and once I'd put the swelling together

with some other symptoms – night sweats, pain in my hip and back – I knew what it was.

"I was about the fittest I'd been since school. No weight loss, good appetite. Everything else was ok. Nothing else made it apparent that I was that sick."

A CT scan revealed she had Hodgkin lymphoma stage 3, everywhere – neck, armpit, near the heart, spleen. She started treatment in April 2006 with chemotherapy via an IV infusion every two weeks for four to six months. Throughout that period she still attended university.

After four cycles, she had another CT scan and it was positive – the nodes had shrunk. In October 2006 she was

told she was in remission. But then in December 2006, a CT scan confirmed it had come back showing enlarged nodes in her abdomen.

A stem cell transplant followed in April this year. "When I came home, I slept and rested and bit by bit I added things back to my life. I stopped uni but I'm planning on going back in September," Suzanne said.

"I do what I can each day, what I can manage. I've started back at the gym and I can now go out to dinner."

She added, "I had good support and information. The doctors and my GP were amazing. They gave me information without overdosing me."

"I saw an LBF flyer on a wall – a luncheon about lymphoma."

"I could talk to people in the same situation and realised I was not alone. There are people out there who care about those with lymphoma."