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annual report **2007**

Chairman's report

The world of the Leukaemia & Blood Foundation is one filled with hope.

This is a world where a brother can become a lifesaver, a suggestion can lead to research success, and a small chilly bin of bone marrow can be worth its weight in gold.

It is a world where all our efforts, from research and education to advocacy and patient support, are underpinned by our vision to cure, mission to care for those with leukaemia and related blood conditions.

This is our 30th year and it is timely to reflect on the journey that has led us here, as well as just a few of the people who have joined us along the way.

HOW IT ALL BEGAN

The organisation, then known as the Blood Foundation, was launched in 1977 with a research focus. In recent years, this has been increasingly matched by the need for patient support and easily accessible information.

In 2001, the LBF's vision expanded to include the funding and running of our Patient Support Services. These are centred on practical assistance, education, information, and advocacy for people living with these diseases.

We are delighted to say we have achieved our aim – to become a fully nationwide, patient-focused, professional service available to any patient and their family.

And we have not under-estimated the size of the need. Every day, 6 New Zealand children and adults are diagnosed with leukaemia or a related blood condition.

THE LEUKAEMIA & BLOOD FOUNDATION TODAY

The Foundation focuses on five key areas:

- Patient Support Services: On-the-ground support for patients, tailored to their needs including financial assistance, counselling and support groups
- Education: Information for patients, family members and health professionals about blood cancers and related conditions
- Advocacy: Representing the needs of patients and their families to government, related agencies and other relevant bodies

- Research: Supporting investigation into leukaemia and related blood conditions, with the help of an independent Medical Advisory and Scientific Committee
- Awareness: Raising public knowledge of these diseases through initiatives such as World Lymphoma Awareness Day

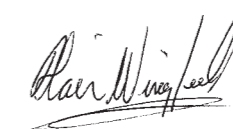
With every initiative, we raise awareness of the LBF's services and, in so doing; we increase the need for them. We now have three Patient Support Services Co-ordinators across the country and are recruiting for a fourth.

With no Government funding, our work is made possible through fundraising activity and the generous support we receive from our corporate partners, donors, and trusts. We know that fundraising is increasingly specialised and complex and we believe the time is now right to create this role.

The need for the LBF is not simply continuing, but increasing, and the Board is aware that it needs to take some steps in response.

In this report you will meet people – and not all of them are patients – whose stories will stir your hearts. A frequent flyer with a precious cargo...a woman who found her miracle...two young boys described by their mother as 'normal, but with extras'...researchers who are looking at improved treatments.

This is the world of the Leukaemia & Blood Foundation.



Blair Wingfield
Chairman



Blair Wingfield is a leukaemia survivor. He was diagnosed at age 39, more than 26 years ago and hasn't needed treatment since 1983. His personal experience gives him a unique view of the disease.

Board members

GREG MOYLE (DEPUTY CHAIRMAN)

With a background in accountancy and law, in 1992, Greg fulfilled a long-cherished goal of establishing his own business – New Zealand Financial Planning. Greg also undertakes a myriad of other charity and community work, including being 2004/2005 President of the Rotary Club of Downtown, Director of Radio Lollipop, Past President of the Mt Albert Grammar Old Boys Association and a member of the school's Board of Trustees.



ARTHUR LOO

Auckland-born Arthur has been in practice as a solicitor since 1977. He is a partner of the Auckland legal firm, Loo & Koo. Arthur is involved with a number of other community organisations and charitable trusts. He is the current Chairman of the Foundation for Alcohol and Drug Education and is a Trustee of the SKYCITY Auckland Community Trust. In addition, he is also the current Chairman of the Auckland Chinese Community Centre Inc. Arthur received the New Zealand Commemorative Medal in 1990 for his contribution to New Zealand.



JOHN WIGGLESWORTH

John is a retired senior partner of chartered accountants firm Porter Wigglesworth and Grayburn. He is a Fellow of the Institute of Chartered Accountants, the Institute of Chartered Secretaries and Administrators, and of the Institute of Directors. His work in the community is far-reaching and includes being a founding Trustee of the LBF.



CHERYL WILLETTS

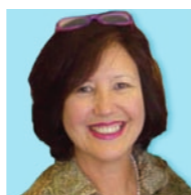
Cheryl was born and bred in Auckland where she has been an active member in the community and last year was presented with a 'Good Citizens Award' by Auckland City. She is a Rotarian with the Auckland East Rotary Club and has been honoured as a



'Paul Harris Fellow' for services to Rotary. Cheryl has been on many committees over the years and helped organise the LBF's first ever 100 Hole Marrowthon, which raised more than \$100,000.

DR HILARY BLACKLOCK

Hilary is Clinical Head of the Haematology Department at Middlemore Hospital, Auckland. She is also a Clinical Haematologist in the Medical Specialists Group of physicians at the Mercy Specialist Centre. Hilary has been published more than 70 times in peer-reviewed journals. She is also Medical Director of the NZ Bone Marrow Donor Registry, and Clinical Associate Professor in the Department of Molecular Medicine at the School of Medicine.



DOUG STRONG

Doug is a retired chartered accountant and orchardist with experience in both commerce and finance and he is currently an adviser in the tourism industry. Doug's involvement with the Leukaemia & Blood Foundation began when one of his children was diagnosed with a blood condition. He started volunteering for the organisation, before becoming a long-serving member on the Board of Trustees. He is also a past Chairman of the Board.



DR PETER BROWETT

Peter is a Consultant Haematologist at Diagnostic Medlab, a Consultant Haematologist at Auckland City Hospital, and a Professor of Pathology and Head of the Department of Molecular Medicine and Pathology at the University of Auckland School of Medicine. His involvement with the Leukaemia & Blood Foundation stems from his clinical interest in the management of patients with haematological malignancies, including blood cell and bone marrow transplantation. Peter has had a long association with the Foundation, acting as Medical Director for many years and, more recently, as a Trustee too.



Executive director's report

At the heart of every LBF fundraiser, every awareness campaign, every hospital visit, lies one desire – to be there for the people that need us.

With a vision to cure and mission to care, the Leukaemia & Blood Foundation is working towards a future free of these diseases. In the meantime our goal is to ensure that no-one has to make that journey alone.

Blood cancers combined are the fourth most common cancer in New Zealand, averaging some 2,200 new cases a year, so that commitment has never been more vital.

We have sought to meet the challenge to grow, and grow quickly. With the recruitment of each of our regional co-ordinators, we have seen patient referrals rise dramatically and our Support Services team now deals with more than 700 requests for support or information each month. We need to find a minimum of \$1,000 a day to fund this service. As we are now seeking a fourth co-ordinator, we expect that \$1,000 to climb, with more patients joining us and new community-based support groups established outside the main centres.

ADVOCACY

Fighting important issues on behalf of patients and families has been a strong focus for us this year. Advocacy takes many forms, from supporting the funding of breakthrough drugs, to being involved in decisions affecting cancer control and services.

The LBF belongs to the Lymphoma Coalition, a global network dedicated to raising awareness of lymphoma. In New Zealand we have worked hard to raise public knowledge of this prevalent, but little known, cancer and have seen a resulting upsurge in enquiries to our organisation.

We also work collaboratively with like-minded cancer organisations in this country. Additionally, membership of groups such as the Access to Medicines Coalition, enables us to ensure patient voices are being heard.

Our greatest resource is, of course, our people. The LBF's work would not be possible without the ongoing dedication of our highly committed staff and an increasing number of

enthusiastic supporters and volunteers. I extend my heartfelt thanks to you all.

The ongoing commitment of our business supporters has elevated our services to a level we could never have achieved alone. We are extremely grateful to Fidelity Life whose sponsorship has transformed our work. Holden generously provides cars to our three Support Services Co-ordinators for patient support. Year after year PricewaterhouseCoopers employees lend their wonderful support – and their heads – to Shave for a Cure® raising vast sums. Additionally, Pascoes the Jewellers donated an incredibly generous gift.

We also owe sincere gratitude to the many trusts and the loyal, individual donors who give so generously each year.

With no government funding, fundraising is a major part of our work. Our focus remains on our long-established iconic fundraiser, Shave for a Cure®, which has its own week in March and which is one of the most important sources of income for the LBF. The 100 Hole Golf Marrowthon is another of our key fundraisers. These high-profile events create greater visibility and engagement within the community.

It is testimony to the Board's confidence and willingness to take informed risks that we have achieved such gains. The Board understands, and is engaged with, the Foundation's vision and they continue to ensure we do all we can to support patients and their families.

Pru Etcheverry
Executive Director



Medical director's report

The Leukaemia & Blood Foundation (LBF) has an important and unique role to play in New Zealand research.

We have long been known for supporting research into blood cancers, but few people realise the LBF is the only New Zealand organisation focusing on non-malignant blood conditions related to clotting and bleeding.

These conditions can be just as impactful as cancer on patients and their families. You only need to read the story of the Raes, which appears later in these pages.

For 30 years we have been funding research for these conditions, providing an important and dedicated source of funds valued by the clinical and scientific community.

There are a number of unique studies underway that were first funded by LBF grants. These include:

- Assessment of the role of genetic risk factor for venous thrombosis
- Analysis of signalling pathways in acute leukaemia cells that in the future may be new targets for therapy
- Molecular studies to explore a possible prenatal origin for some cases of childhood leukaemia
- Detailed molecular mapping of leukaemic cells looking for potential prognostic factors which may guide treatment decisions

In addition, the LBF has funded summer research projects for students, as well as travel grants. The latter enable scientists, clinicians, nurses and laboratory staff to attend national and international scientific meetings where they can discuss their clinical interests and research work, as well as be exposed to the latest developments in the ever-changing world of haematology.

It is vital that we continue to fund research on blood conditions in New Zealand. Not only may that initial support from the LBF lead to a potential breakthrough in the treatment of leukaemia, but involvement in research helps to retain health professionals in New Zealand.

It also improves the standard and quality of care in our units, encourages younger staff and students to question how, and

why, we do things the way we do, and ultimately will result in improved outcomes for our patients.

In supporting research, the LBF is grateful to the members of the Medical and Scientific Committee who bring a wide range of disciplines and expertise to carefully review the many grant applications.

IMPROVED TREATMENTS

There is probably no discipline in medicine, other than haematology, where there have been such dramatic advances in treatment as a direct consequence of research investment. This has led to more efficacious medicines that are improving the survival times and quality of life for patients with blood conditions. These new therapies have moved rapidly from the bench into the clinic, and an important role of the LBF, as an advocate for patients, is to ensure that these new drugs are made available in New Zealand in a timely manner.

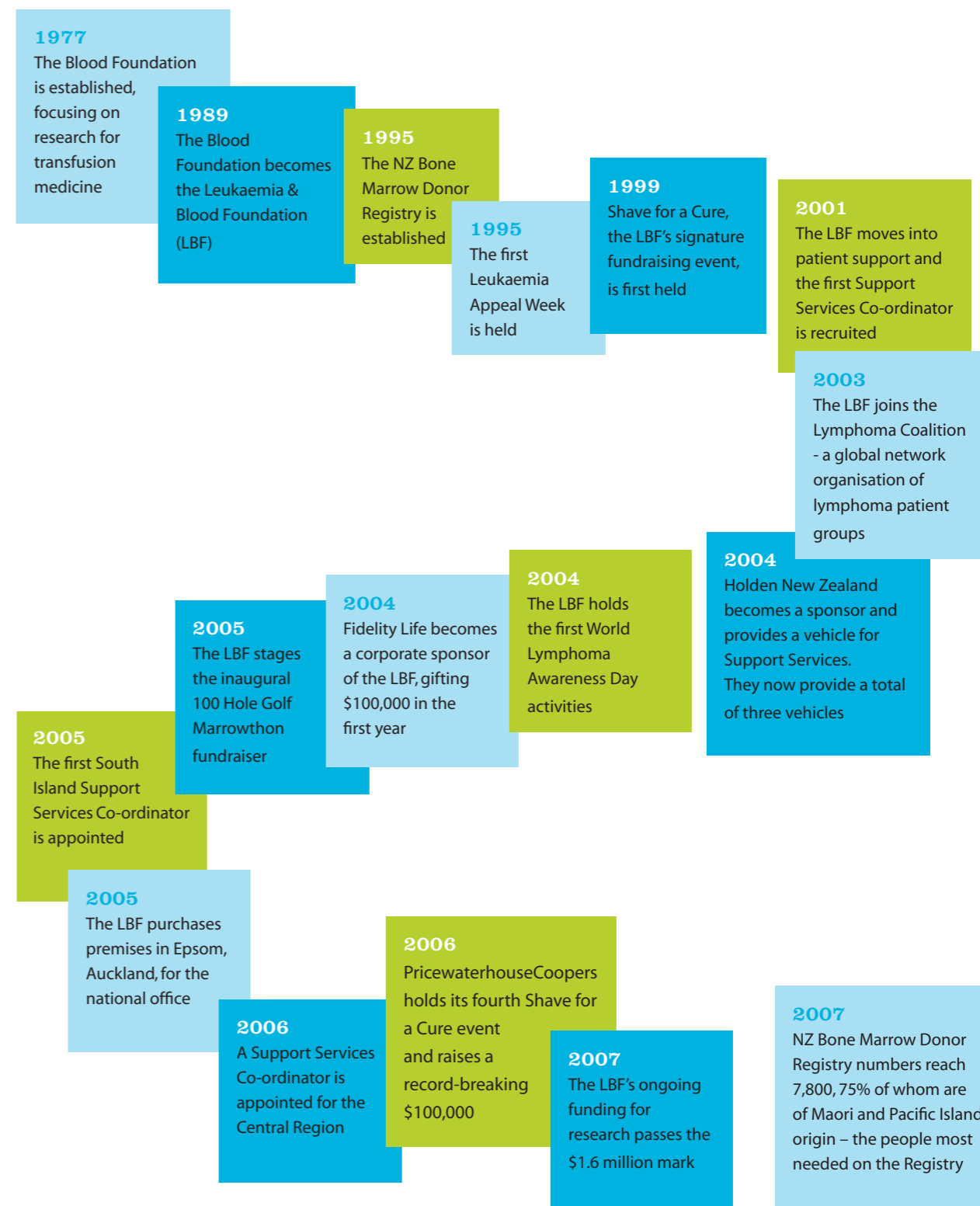
It is also a fact of life that media calls are becoming increasingly common, and while helping a journalist to understand a disease like lymphoma has no immediate benefit to our patients, it is important that the LBF is a credible source of information on blood cancers and conditions.



Dr Peter Browett
Medical Director



Our milestones



It costs
\$1000 a day
to provide our
Patient Support
Services.



We are here to help

The passion and commitment shown by our Support Services team is the cornerstone of the Leukaemia & Blood Foundation's mission to care.

Being diagnosed with leukaemia or a related blood condition can be overwhelming. Patients and their families face extraordinary stress from diagnosis, as well as therapy which may continue for months, or even years. Quite often they have to relocate for specialist care.

We aim to ease some of the burden placed on patients, through a range of personalised and practical free programmes and services. As well as offering assistance to those undergoing treatment, we are also there for families at a time when their world has turned upside down.

For many people, initial diagnosis can prompt a whole host of questions. Having someone to talk to, who understands some of the issues and challenges, is vital. Our Support Services team offers regular telephone, email, or face-to-face contact.

Feedback from patients and families is that they really value our regional, disease-specific support groups. They find reassurance in having a safe environment in which they can share their thoughts and concerns, and many continue attending for several years following diagnosis.

Information and education is an important feature of Support Services. There are currently 10 titles available in our free booklet series, providing a good introduction to some of the main conditions. Further titles are planned.

Our website, www.leukaemia.org.nz is also proving a really valuable information tool for patients, particularly those uncomfortable about openly seeking support. We have added pages dealing with the difficulties of living with the diseases, from how to tell others, through to looking after yourself. And we've included a patient noticeboard, offering a range of relevant articles.

We also have a comprehensive selection of books, CDs, DVDs and videos available for loan in our resource library. These cover specific blood diseases, cancer treatments, care, support and inspirational reading.

GROWING DEMAND

During this financial year we were able to employ a third Support Services Co-ordinator and are now looking to recruit a fourth as the call on the team's services continues to grow.

Our three Support Services Co-ordinators are all registered nurses who have specialised in haematology and bone marrow transplant. They are dedicated to providing top quality psycho-social care to patients and family members throughout New Zealand.

The LBF's ongoing challenge remains raising the \$1,000 a day required to fund their much-needed support.



Our Support Services team:
Amy Munro, Naena Chhima and Christine Kerr.



**Every day,
6 New Zealand
children and
adults are
diagnosed with
blood cancers.**

Kids with extras

“I try hard for them to be normal and they are normal – they just have extras.” Susan Rae

Ethan Rae, three, and brother Oscar, just turned one, are typical boys who love to play.

But for these two a bump or fall can be life-threatening and their parents, Susan and Tony, have just learned that both boys will need bone marrow transplants - believed to be New Zealand's first for siblings.

The pair have Wiskott-Aldrich Syndrome, an immune deficiency syndrome which affects 1 boy in 250,000. Their mum unknowingly passed it on and the chance of each son inheriting it was 50/50 “so bad luck to get two,” says Susan.

DIAGNOSIS

The long wait for a correct diagnosis ended in October 2007. It was slow in coming as neither boy had typical symptoms. When Ethan was three-and-a-half months old Susan noticed a spotty rash on his head. A full blood count showed his platelet count was 26 – normal being 150-400. “He was diagnosed with a different condition that kids usually grow out of so when Oscar was tested at birth and had a count of 33 it was a complete shock,” says Susan.

It was the ‘Batman’ episode that led Susan to the Leukaemia & Blood Foundation – the only New Zealand organisation supporting people with blood-related conditions. “Ethan hit the bridge of his nose on the bed head and the bruising spread so badly that in the end he looked like he was wearing a Batman mask!

“The LBF welcomed me with open arms. They have been fabulous. I can call if I have bad news or am having a bad day,” says Susan.

Life for the Raes has some strict limits. Ethan goes to Tiny-Y where he can play in a controlled environment. “I’m the anxious Mum at the playground,” says Susan. “I’ve spent the

last two years waiting for someone to come up to me and say ‘what are you doing to that child?’ because the bruises can be so bad.”

Susan and Tony are relieved to finally have a diagnosis. “It’s nice to have a name and an excellent chance at a cure. I couldn’t have spent the rest of my life waiting and worrying every time they have a bump or get sick – it’s given me too many grey hairs!

TRANSPLANTS

“We purposefully didn’t read about transplants until we had a definitive diagnosis and so at the moment we’re a bit overwhelmed by the magnitude of what’s ahead.” Each boy will need to spend 6-8 weeks in hospital, including a week’s chemotherapy, and they will almost certainly never be able to have children. But they have an 87% survival rate at five years post transplant, “and that’s as good a result as you can hope for,” says Susan.

She adds: “We are lucky. We have two beautiful boys, fantastic doctors and amazingly supportive family and friends so, yes, the next year or two will be tough but we are going to be fine.”



Susan Rae with Oscar (left) and Ethan (right).



**Leukaemia
is the most
common
childhood
cancer in
New Zealand.**

“My brother is my miracle”

**“My doctor said it could be a reaction to the infections or it could be leukaemia. I thought, ‘don’t be ridiculous, it won’t be leukaemia.’”
Juli Mercer**

Juli Mercer’s experience with leukaemia started with some infections and a routine iron test.

“My doctor called with the test results on a Sunday afternoon and said there was something wrong with my blood and that it could be a reaction to the infections or it could be leukaemia. I thought, ‘don’t be ridiculous, it won’t be leukaemia.’”

Juli had her first specialist appointment on Monday, a bone marrow biopsy on Tuesday, and a diagnosis of acute myeloid leukaemia (AML) on Wednesday.

On Thursday, she began 10 days of chemotherapy. “The registrar said, ‘with blood like yours, there’s no waiting list.’”

The chemotherapy was followed by two weeks in hospital and then daily visits for transfusions and other treatments. But she didn’t go into remission.

Chemotherapy with a stronger drug did put Juli in remission, but it hit her hard. For 23 hours out of 24 for four days she was hooked up to a drip with one hour off to have a shower. She lived from one anti-nausea treatment to the next.

Once home, she managed to avoid the usual post-treatment infections, but still had daily hospital visits for transfusions, tests and dressings.

“It’s your family and friends who get you through. Their support, and support from people I didn’t even know, people like the LBF,” said Juli.

“The school and church communities organised meal rosters. David’s family and mine were incredible - they took week about turns living in our house for an entire year.”

It also meant David could keep working. “If he stopped work we’d have had no income. We wouldn’t have been able to pay bills or buy food.”

She added: “The LBF helped me get through. They were really good to talk to. The nurses were always so busy, but with the LBF I could say ‘is this normal?’ or ‘today I feel crap’. They were there when I needed them.”

After a third round of chemotherapy, Juli was told she would need a bone marrow transplant. Her only brother Chris had already been tested while here on holiday from the UK.

“My brother and I were a perfect match. He was my miracle.”

Chris flew 27 hours to New Zealand and the stem cells were extracted over six hours. Juli had more chemotherapy to completely kill off her bone marrow. The infusion of new stem cells took only 20 minutes.

LOOKING TO THE FUTURE

Juli’s journey wasn’t over, because she developed graft versus host disease (GVHD). It can happen after a transplant when the new immune system sees the body as foreign and fights against it.

“It can be fatal but in its mild form it can be anti-leukaemic, so having it actually helps me, even though I still take immunosuppressants and steroids and have monthly inhalation therapy to protect my lungs.”

When Juli was diagnosed, her second son, James, was 14 months old.

“Now he’ll be five in December and I think it is so wonderful that I’ve had all that extra time with my kids.”



James and Juli Mercer.

Lymphoma diagnoses are on the rise in 15-24 year olds.



A southern bloke

“I drive a stock truck. You work 14 hours a day, 70 hours a week, you sweat, you get tired. I didn’t know the sweating and tiredness were illness.”
Dwayne Greenwood

Dwayne describes himself as “just an average southern bloke”. He never expected to be diagnosed at the age of 29 with a life-threatening cancer.

With his heading dog and a double-tier truck and trailer, Dwayne moves stock all over the South Island. He had no idea he was sick because the job always made him sweaty and tired. He thought the lumps in his neck were just another dose of glandular fever.

“I’d probably had the lumps for about 12 months, but it was my boss who said to get them checked as they were quite big. I didn’t think much about it, thought it was stress or something.”

Dwayne was diagnosed with non-Hodgkin lymphoma (NHL) and became part of a clinical drug trial. But a month later, Dwayne’s cancer was back and his doctors decided he needed a bone marrow transplant.

“It was quite frightening, but I just wanted to get fit and get back to work. I knew I’d get sicker before I was well...I just kept hoping the next day would be better.”

FINDING A DONOR

Both his sisters were tissue-typed and it was 25-year-old Jac, his younger sister, who was the perfect match. Dwayne says proudly, “She was quite happy to do anything for her older brother just as long as he got better.” Jac says it was a small thing she could do to help her brother have a chance.

After the transplant, Dwayne was told to stay off work for 100 days while his immune system strengthened. A man who drives a stock truck simply can’t go back to work.

“I couldn’t cart because of the dust. Pigs are covered in it and it might have infectious material in it.”

Dwayne is not a man who sits still. As he says, “I’d have to be dead before I’d take a day off.” So taking 100 days off on doctor’s orders was a real challenge.

Back at work, Dwayne was on lighter duties, in “a wee truck”, as he puts it, to make sure he was ok. After nine months he got his big truck and trailer unit back.

GOOD NEWS

He had one relapse that put him back into hospital but he’s now down to 12-monthly checks and has recently been told he’s clear of the disease.

“I’d heard of young people with leukaemia, but I wasn’t aware of lymphoma so the diagnosis came as a shock. I’m pretty laid back about life, so really I just take each day as it comes.”

This year, Dwayne played in the Christchurch 100 Hole Golf Marrowthon to raise money for the LBF. It was 100 holes, which is equal to five-and-a-half rounds. It wasn’t a problem for this keen golfer – in fact, he was feeling so fit he played 102.



Dwayne Greenwood and his truck.

Our Support Services team responds to more than **700 requests** for help each month.



“My husband said, no matter what the doctor says, good or bad news, **we’re in this together.**”

“The Foundation has started a support group in Hamilton. It’s early days, but the

support is invaluable”

“My last CT scan showed I was **IN REMISSION.**

I was a bit cautious about celebrating. I’m still scared it will come back.”

“I try not to take anything **for granted** any more, not even the birds in the trees.”

“Through all this I hope I’m a better person, **more compassionate,** more accepting.”

“But, you know, the sun’s going to

SHINE

tomorrow.”

”

The number of people diagnosed with lymphoma has more than doubled in the last decade.



Demystifying the diseases

Building awareness and understanding of leukaemia and other blood cancers is a vital strand of the LBF's work.

It can mean arranging media interviews with leading health professionals, LBF staff, or the patients and families we are dedicated to supporting.

Or it might involve taking to the streets with our collection tins during Leukaemia Appeal Week in November each year. While this is a valuable fundraiser, it serves a dual purpose, giving us high visibility and reminding the public about our cause and organisation.

Awareness is so important because, with many of these diseases, early detection means there is a better chance for quicker diagnosis, treatment and overall survival.

One of our most important annual awareness activities is World Lymphoma Awareness Day on September 15.

LITTLE-KNOWN DISEASE

Lymphoma is often called 'the cancer that no-one knows' yet the number of people diagnosed each year has more than doubled in the last decade and that trend is forecast to continue. Only some of that increase can be accounted for by a growing and ageing population.

In 2000, there were 600 people registered with lymphoma. The most recent figures, for 2005, show 779 new cases – a rise of 30% (2005 figures are provisional). There are now 1 million people living with lymphoma worldwide.

There are around 35 types of lymphoma – five grouped as Hodgkin lymphoma and 30 as non-Hodgkin lymphoma. Most people in New Zealand are diagnosed with non-Hodgkin and aggressive forms can be fatal in as little as six months.

Lymphoma can occur at any age, but is most common in people aged 50-plus, although there appears to be a rise in the number of 15 to 24-year-olds diagnosed.

The LBF has made lymphoma awareness a priority, providing access to reliable information and offering emotional support through Patient Support Services Co-ordinators.

WORKING TOGETHER

In 2003, the LBF joined the Lymphoma Coalition and held the first World Lymphoma Awareness Day in New Zealand the following year. Then, in 2005, the LBF was appointed to the Coalition's six-member steering committee.

The Coalition is a non-profit network of lymphoma patient groups in 29 countries working to raise awareness of this disease.

A global survey conducted by the Coalition shows over half (55%) of those with lymphoma hadn't heard of the disease before they were diagnosed and nearly half (43%) didn't understand, or only partially understood, what they were told by their doctors at diagnosis. This result is borne out by the LBF's own research. Out of 500 New Zealanders surveyed, only 45 could name lymphoma as a type of cancer.



World Lymphoma Awareness Day is held in countries across the globe on September 15 each year.

The LBF has awarded grants totalling \$1.6 million to fund clinical and scientific research.



Immunology, auditing and the human genome

The Leukaemia & Blood Foundation was first established to fund research and it remains a core activity 30 years later.

We fund clinical and scientific research in haematology and to date we have provided more than \$1.6 million to projects.

The LBF's Medical and Scientific Committee - an independent committee of researchers, health professionals and lay people - oversees these annual grants.

WHAT WE FUND

There are three types of grant available:

1. National Research Grant – for scientific and clinical research in haematology
2. Travel Grants – for health professionals working in haematology to attend national and international meetings
3. Summer Studentships – for university students to carry out projects with a haematological importance

Each of the three projects outlined here is funded by a National Research Grant and supports our policy of funding very specific projects, or parts of projects, we believe have the potential to advance knowledge, diagnosis, prognosis, treatment and recovery.

A small group of researchers, led by Dr Judy McKenzie of the Haematology Research Group at the Christchurch School of Medicine, is looking at the immunology of patients with chronic lymphocytic leukaemia (CLL).

"We know that two membrane molecules called CD40 and CD83 play an important role in immune responses, and our research has shown that soluble forms of these molecules can be detected in blood samples of normal individuals.

"We have established that many leukaemia patients have large amounts of these substances circulating in their plasma, and that in CLL this is a marker of poor survival outcome," says Dr McKenzie.

What Dr McKenzie and her team have been looking for is a source of these molecules for further studies, a search she says they've made good progress on.

They have determined that CLL cells express the genetic code for soluble CD83 and CD40 and that, given appropriate stimuli, the leukaemic cells can be induced to release large amounts of these molecules in cell culture in the laboratory.

"Now we are looking at whether these molecules are actually functional and may be responsible for the breakdown of the immune response in leukaemia," says Dr McKenzie.

The group is currently preparing research papers on their findings for submission to international journals.

HOW WILL THE PATIENT BENEFIT?

While these are experimental findings and inclusion in treatment is a long way off, tests showing elevated levels of CD40 and CD83 in the blood may aid in patient management by determining how CLL patients will respond to various treatment options.



Dr Judy McKenzie.

Immunology, auditing and the human genome

Equally important is research outside the laboratory. Haematologist Dr Julia Phillips from the School of Medicine & Health Sciences, University of Otago at Wellington, wanted to audit 20 years of statistics covering patients with multiple myeloma (MM).

"We wanted to find out whether MM is increasing, whether treatment is effective and if "real life" experience matched results reported in clinical trials, which often exclude patients in the poorest health," says Dr Phillips.

A summer studentship proposal was agreed and the LBF funded the 10-week project, which was carried out by medical student Samara Bretherton.

The study confirmed similarities between MM in Wellington and other demographic studies.

"For example, the male:female ratio was similar and we found that while the number of patients diagnosed with MM had approximately doubled between 1986 and 2006, the survival rate has increased with time.

"The project also showed that patients having autologous peripheral blood stem cell transplants – in other words, their own stem cells – and those who received treatment with Thalidomide, survived much longer."

From these findings, Samara was able to confirm that the survival of patients with MM in Wellington has improved over the past 20 years.

Samara was awarded 1st prize for the best summer student project 2006/2007 and her study was presented at the XIth International Myeloma Workshop and IVth International Workshop on Waldenstrom's Macroglobulinaemia in 2007. The findings will also be submitted for publication in a peer-reviewed journal.

HOW WILL THE PATIENT BENEFIT?

Aside from identifying effective treatments, Samara's project provides a database for future research projects and will aid service planning for multiple myeloma treatment in Wellington.



Samara Bretherton



with short, fine, hair Did you know... 'Leukaemia' is a Greek word which translates as 'white blood' Did you know... Platelets are blood cells

Immunology, auditing and the human genome

Research is also about exploring the DNA make-up of cells at a molecular level.

Chronic lymphocytic leukaemia (CLL) is the most common adult leukaemia in western countries. However, its cause is still poorly understood, there are no proven cures and it has a highly variable clinical course where some patients die within a few months of diagnosis, while others do not. In treatment terms, we need to know which patients will need intensive treatment early and which can be spared unnecessary treatment.

Associate Professor Christine Morris is the present leader of the Cancer Genetics Research Group at the Christchurch School of Medicine. Together with PhD student So Young Moon, and Clinical Haematologist Dr Peter Ganly, she is researching genetic changes in CLL cells. These changes are important for diagnosis and can also tell us a great deal about how the leukaemia will respond to different types of treatment.

Her team have established, and are now applying, a powerful new technique called Array Comparative Genomic Hybridisation (Array CGH) that allows them to look at the DNA of CLL cells in great detail.

This is expensive, time-consuming research and, in addition to experimental bench work, involves use of specialised computer software and constant reference to the large repositories of human genetic information accessible freely online.

The changes So Young Moon has identified are tiny and detailed analysis is needed to distinguish them among the 30,000 or more genes that make up the human genome. The team's research so far has revealed a number of genetic changes that have not been identified previously.

These changes may, in future, contribute towards improving individual patient management. However, they must first be shown to be true, and with the LBF's funding it will now be possible to validate some of the findings.

HOW WILL THE PATIENT BENEFIT?

The more we know about leukaemia genetics, the more accurate we can be with diagnosis, prognosis, treatment

options, the development of new drugs and monitoring treatment results.

RESEARCH GRANTS

Some of the Foundation's other recent grants include:

Dr Sheryl Gough, Cancer Genetics Research Group, Christchurch School of Medicine

Novel breakpoints & leukaemia genes, and their clinical prevalence

Dr Peter Browett, University of Auckland

The effect of imatinib mesylate (Gilevec TM) on bone metabolism in vitro and in vivo

Dr Paul Harper, Auckland

Protein Z dependent protease inhibitor (ZPI) mutations in thrombosis patients

Dr Peter Browett, University of Auckland

Inhibition of the phosphoinositide 3-kinase pathway in acute myeloid leukaemia

Dr Ian Morison and Dr Elizabeth Ledgerwood, University of Otago, Dunedin

A study of New Zealand familial thrombocytopenia

Dr Sheryl Gough, Dr Tracy Hale, Dr Peter Ganly, Associate Professor Christine Morris, University of Otago, Christchurch School of Medicine and Health Sciences

Characterisation of genes newly implicated in acute lymphoblastic leukaemia



Associate Professor Christine Morris

that form blood clots to stop bleeding Did you know... Thalassemia is a non-cancerous disease of the red blood cells that results in patients



Blood cancers combined are the 4th most common cancer in New Zealand.

New Zealand bone marrow donor registry (NZBMDR)

Like a scene from a movie, two couriers meet in Hong Kong for the briefest of time. The courier from Germany is carrying two small chilly bins. One is labelled Human Stem Cells for Transplant. Do not X-ray. Do not Delay. Inside the chilly bin, in dry ice, is a small container of liquid – about a cupful. A second chilly bin has a back-up supply of dry ice.

After the transfer NZBMDR staff member, Raewyn Fisher, flies home to New Zealand with the chilly bins at her feet. Simultaneously, in New Zealand, a medical team finishes the last of the conditioning process that prepares the patient for transplant. Over the previous week, the patient has had chemotherapy to kill any residual marrow disease and destroy the immune system so the transplanted stem cells can engraft. Only a short time after arrival at the airport, the new stem cells are infused.

The match could have come from one of the 7,800 people on the New Zealand Registry, but this time the donor was one of more than 11 million volunteers on worldwide registries – the majority of which are of European ancestry.

SEEKING A MATCH

Only one in three New Zealanders needing a transplant will find a match in this country, either via a sibling, another family member, or through the registry. For the others, the NZBMDR staff will need to search the international registries.

“It’s a very efficient Internet search engine – enter your patient’s criteria and you get a list of likely donors. If there’s a match, we work with the donor organisation and the hospital here to co-ordinate the donation and the transplant,” says Raewyn.

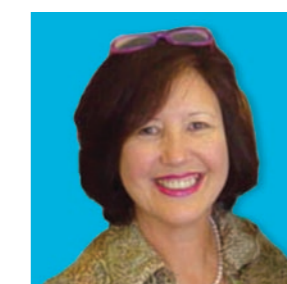
Non-European blood donors aged 18-40 are being recruited as marrow stem cell donors in NZ, and there’s a preference for males under 25, but there are exceptions.

“We have a woman in her 50s who’s had several pregnancies and is the only donor in the world to match a particular patient. She has been asked to donate, even though the risk of rejection is higher because of pregnancy-related antibodies that exist in her system,” says Raewyn.

Only one in a thousand people on the New Zealand registry will ever be asked to donate because the match must be exact. Ethnicity can make this even more difficult, and mixed ethnicity is another challenge, as a donor must be found that closely matches both the recipient’s maternal and paternal heritage.

WHO WE NEED

The registry has increased the number of Maori and Pacific Island donors, but other ethnic groups, such as Chinese, Indonesian and Middle Eastern people, are seriously under-represented. Indians are the hardest to match world-wide because India has no registry of its own. Locating donors for these groups is our next biggest need.



LBF Trustee, Hilary Blacklock, is the Medical Director of the NZBMDR

Financials

for the year ended 31 March 2007

	Notes	2007 \$	2006 \$
Statement of financial performance			
Operating revenue	2	1,168,367	1,386,354
Operating expenses	3	697,576	677,401
Operating Surplus		470,791	708,953
Outcomes	4	438,712	322,407
Net Surplus		<u>32,079</u>	<u>386,546</u>
Statement of financial position			
Equity		1,153,276	1,121,197
Represented By:			
Current assets	5	524,762	529,981
Non current assets:			
Investments	6	73,391	254,504
Fixed Assets	7	1,835,961	1,799,091
		1,909,352	2,053,595
TOTAL ASSETS		<u>2,434,114</u>	<u>2,583,576</u>
Current liabilities		164,465	327,911
Non current liabilities	8	1,116,373	1,134,468
Total liabilities		<u>1,280,838</u>	<u>1,462,379</u>
Net assets		<u>1,153,276</u>	<u>1,121,197</u>

Notes to the Financial Statements

1. Statement of account policies

REPORTING ENTITY

Leukaemia & Blood Foundation of New Zealand is a Charitable Trust under the Charitable Trusts Act 1957. These Financial Statements have been prepared excluding the two divisions of Leukaemia & Blood Foundation: Cord Blood Bank and The New Zealand Bone Marrow Donor Registry. In addition, Leukaemia & Blood Foundation Financial Statements have been prepared including all the divisions.

BUSINESS AND BACKGROUND

The Foundation is a Charitable Trust set up to promote and assist research into the diagnosis, prevention and treatment of diseases such as leukaemia and disorders associated with blood. It also provides information and practical support to patients and their families.

MEASUREMENT BASE

The accounting principles recognised as appropriate for the measurement and reporting of Financial Performance and Financial Position on an historical cost basis have been followed by the entity, except for long term investments which are recorded at market value.

FIXED ASSETS AND DEPRECIATION

Fixed Assets are depreciated on a diminishing value basis to reflect the anticipated usage and obsolescence of the asset.

The depreciation rates in use are:

Computer Equipment & Accessories	33% - 48%
Office Equipment	12% - 60%
Building	4%

ACCOUNTS RECEIVABLE

Accounts Receivables are stated at expected realisable value.

GOODS & SERVICES TAX

These financial statements have been prepared on a GST exclusive basis.

DONATIONS AND GRANTS

Donations and grants are recognised as revenue at the point when the organisation formally acknowledges the donations or grant. Where there are conditions attached the revenue is recognised unless, in the opinion of the committee, the conditions cannot be fulfilled.

CHANGES IN ACCOUNTING POLICIES

There have been no changes in the accounting policies.

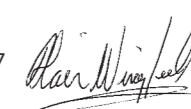
All policies have been applied on bases consistent with those used in previous years.

Financials

for the year ended 31 March 2007

	Notes	2007 \$	2006 \$
2. Operating revenue			
Operating revenue comprises:			
Bequests		46,621	-
Donations & Grants Received		722,824	975,482
Event Fundraising		320,254	273,222
Interest & Investment Income		26,122	46,732
Other Income		52,546	90,918
Total operating revenue		<u>1,168,367</u>	<u>1,386,354</u>
3. Operating expenses			
Administration		416,185	413,028
Audit Fees & Legal Fees		8,422	8,073
Bank Fees and interest on loan		95,999	47,077
Depreciation		71,838	40,634
Marketing & Consultancy		87,458	81,804
Investment Monitoring Fees		517	913
Rental of Premises		-	85,871
Boarding house expenses		17,157	-
Total operating expenses		<u>697,576</u>	<u>677,401</u>
4. Outcomes			
Grants Paid		82,756	75,942
Unexpended Grant Returned		-	(20,423)
Patient Support		355,956	266,888
Total Outcomes		<u>438,712</u>	<u>322,407</u>
5. Current assets			
Cash at Bank		368,839	390,041
Accounts Receivable		155,923	139,940
		<u>524,762</u>	<u>529,981</u>
6. Investments			
The Leukaemia & Blood Foundation invested from its term deposits \$200,000 into a managed portfolio on 1 September 2000. In September 2006, we withdrew \$180,000 to purchase 6 Claude Road, Epsom as our office. As at 31 March 2007, the balances are as follows:			
Opening Balance of Investment		69,799	228,817
Capital Withdrawals		-	(180,000)
Investment Income		1,851	24,919
Monitoring Fees		(518)	(913)
Capital Gain(Loss) on Investment		2,259	(\$3,024)
		<u>73,391</u>	<u>69,799</u>
7. Fixed assets			
	2007 DV Rate	Cost	Acc Depn
Computer Equipment	33% - 48%	178,149	138,564
Office Equipment	12% - 60%	115,364	41,313
Building	4%	878,173	50,848
Land	0%	895,000	-
		<u>2,066,686</u>	<u>230,725</u>
	2006 DV Rate		
Computer Equipment	33% - 48%	154,778	117,146
Office Equipment	12% - 60%	58,200	24,741
Building	4%	850,000	17,000
Land	0%	895,000	-
		<u>1,957,978</u>	<u>158,887</u>
8. Non current liabilities			
The Leukaemia & Blood Foundation has two bank loans with BNZ that mature on 21/09/2030. Account 3015, \$645,792, Interest Rate of 7.55%. Account 3016, \$488,988, Interest Rate of 7.40%. They are secured by a registered first mortgage over the company premises at 6 Claude Rd, Epsom.			

On behalf of the Trustees. B Wingfield - Chairman Signed this 20th day of July 2007



Audit report

Excluding Cord Blood Bank and New Zealand Bone Marrow Donor Registry Divisions



We have audited the financial report on pages 5 to 10. The financial report provides information about the past financial performance of the Division and its financial position as at 20 July 2007. This information is stated in accordance with the accounting policies set out on page 7.

TRUSTEES' RESPONSIBILITIES

The Trustees are responsible for the preparation of a financial report which fairly reflects the financial position of the entity as at 31 March 2007 and the results of operations for the year ended on that date.

AUDITOR'S RESPONSIBILITIES

It is our responsibility to express an independent opinion on the financial report presented by the Trustees and report our opinion to you.

BASIS OF OPINION

An audit includes examining, on a test basis, evidence relevant to the amounts and disclosures in the financial report. It also includes assessing:

- the significant estimates and judgments made by the Trustees in the preparation of the financial report; and
- whether the accounting policies are appropriate to the Division's circumstances, consistently applied and adequately disclosed.

We conducted our audit in accordance with New Zealand Auditing Standards except that our work was limited as explained below. We planned and performed our audit so as to obtain all the information and explanations which we considered necessary in order to provide us with sufficient evidence to obtain reasonable assurance that the financial report is free from material misstatements, whether caused by fraud or error. In forming our opinion we also evaluated the overall adequacy of the presentation of information in the financial report.

Other than in our capacity as auditor we have no relationship with or interests in the Division.

QUALIFIED OPINION

Control over the revenues from donations and event fundraising prior to being recorded is limited, and there are no practical audit procedures to determine the effect of this limited control.

In this respect alone we have not obtained all the information and explanations that we have required.

In our opinion, except for adjustments that might have been found to be necessary had we been able to obtain sufficient evidence concerning donation and event fundraising, the financial report on pages 5 to 10 fairly reflects the results of operations for the year ended on that date.

In our opinion the financial report on pages 5 to 10 fairly reflects the financial position of the Leukaemia & Blood Foundation of New Zealand (excluding Cord Blood Bank and New Zealand Bone Marrow Donor Registry Divisions) as at 31 March 2007.

Our audit report was completed on 20 July 2007 and our qualified opinion is expressed as at that date.

Chartered Accountants
Auckland



The relationships with our business partners are vital to the LBF and, more importantly, the patients and families we are committed to supporting. A huge thank you to:

Fidelity Life
THE NEW ZEALAND LIFE COMPANY

PRICEWATERHOUSECOOPERS PwC
Foundation



HOLDEN

We would like to say a special thank you to the following groups, whose generosity has been particularly invaluable to our work:

- Ara Lodge 348 I C Charitable Trust
- ASB Charitable Trust
- Bell Gully
- Guardian Trust
- Lion Foundation
- Lochiel Print
- Pascoes
- SKYCITY
- Textile Recycling Centre Ltd

Our support for people whose lives have been touched by these diseases would not be possible without the kindness of so many individuals, businesses and organisations – a number of whom remain anonymous. Below are listed just a few of those whose kindness we wish to recognise:

- Burnett Trust
- Chenery Memorial Trust
- Clyde Graham Charitable Trust
- J R Lewis Charitable Trust
- J R McKenzie Trust
- June Gray
- Lady Joyce Fisher Charitable Trust
- Matamata Leukaemia Research Trust
- Maurice Paykel Charitable Trust
- Michael Hill Jeweller
- Novartis New Zealand Ltd
- Picot Charitable Trust
- Pub Charity
- Regency Duty Free
- R G Bell Trust
- Roche Products
- Scottwood Trust
- Sir Ernest Davis Endowment Trust
- South Auckland Charitable Trust
- Southern Trust
- Ted and Mollie Carr Endowment Trust

Directory

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Email: lbf@leukaemia.org.nz

SHAVE FOR A CURE

www.shaveforacure.co.nz

EVERY DAY COUNTS

www.everydaycounts.org.nz

KNOW YOUR NODES

www.knowyournodes.org.nz

GOLF MARROWTHON

www.marrowthon.org.nz

MEDICAL AND SCIENTIFIC ADVISORY COMMITTEE

Dr Ian Morison (Chairman) – Research Haematologist

Dr Bart Baker (Acting Chairman) – Haematologist, Mid Central Health

Pru Etcheverry (Secretary) – Executive Director of LBF

Dr Julia Phillips – Haematologist, Capital and Coast District Health Board

Dr Judy McKenzie – Head of Haematology Research Group in Christchurch and Honorary Fellow in the Department of Pathology at the University of Otago in Christchurch

Dr Kathy Crosier – Deputy Head of Molecular Medicine at the University of Auckland; Haematologist, Auckland District Health Board

Dr Humphrey Pullon – Haematologist, Waikato District Health Board

Blair Wingfield – Chairman of LBF Board of Trustees

SUPPORT SERVICES STAFF

Amy Munro – Support Services Team Leader (Auckland and Upper North Island)

Naena Chhima – Support Services Co-ordinator (Wellington and Lower North Island)

Christine Kerr – Support Services Co-ordinator (South Island)

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LBF National office