

The Leukaemia & Blood Foundation is committed to improving the quality of life for the estimated

100,000

New Zealanders living with a blood cancer or related condition.

Mission



To help New Zealand patients and families living with blood cancers and conditions while raising awareness and supporting the search for new treatments and cures for these diseases.

\$2,000,000

**Amount to date we have
funded for research.**

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Chairman's Report

The current economic climate has meant that the past year has been a challenging one. Illness and disease take no heed of difficult economic times. If anything, the call on the services offered by the Leukaemia & Blood Foundation (LBF) has increased.

The board is determined that despite the challenging economic environment, the work and the services offered by the LBF should not be reduced in any way. Indeed, the board recognizes the need to continue increasing our capacity to support those that rely on us.

The need for sustainable programmes and initiatives is critical. While there is a need to keep a watchful eye on the coming financial year, our greater concern is to ensure the LBF continues to provide essential services to patients and their families.

We strive to improve our effectiveness and ability to meet the needs of patients and families nationwide. To that end, I am pleased to note that the LBF opened patient support services offices in Christchurch and Wellington to better meet the needs of patients from those regions. In addition, we launched LifeBloodLIVE, a ground-breaking online haematology community for those who live in rural communities and who cannot attend local support groups.

Like any not for profit organization, fundraising is critical to our organization being able to sustain itself. We continue to create unique fundraising events and pursue creative ways in which to market those events. We are focused on gaining national media coverage for our events and awareness campaigns like World Lymphoma Awareness Day and Leukaemia Appeal Week.

Through our robust collection of events we are able to raise much needed funds. We are indebted to all of our supporters and very thankful that the LBF enjoys tremendous support from both the public and corporate sectors in our fundraising endeavours. I continue to be humbled by the generosity displayed to the LBF from many quarters. That generosity has enabled the LBF to capacity build. I look forward to continuing the strides that have been taken in expanding our services.

I wish to acknowledge the contribution made to the work of the LBF by our dedicated staff and volunteers. I also wish to acknowledge the leadership of the executive director and the input of the medical director. Finally, I record my gratitude to the board members for their sage contribution to deliberations.

Arthur Loo,



Chairman



Executive Director's Report

We have had a big year bolstering our patient services and building our capacity to cover these costs.

It has been exciting to see our patient support programmes embed this year allowing us to reach many more patients and families with more services. This has included the introduction of new patient support and education groups around New Zealand and the launch of our eagerly anticipated interactive patient website LifeBloodLIVE. This website is of great benefit and comfort to many patients and survivors and is especially valuable for those living in more remote areas.

We have increased our advocacy work on behalf of patients and families and collaborate with other cancer not-for-profits allowing our voice to be heard at the relevant forums thereby ensuring blood cancers are on the radar of health authorities. Our active participation in international coalitions, such as the Lymphoma Coalition, allows us to exchange information with the leading blood cancer patient organisations worldwide.

We work closely with the Lymphoma Network. Sponsored by the LBF, the Lymphoma Network was established to improve information exchange and knowledge sharing among New Zealand lymphoma specialists. Lymphoma, a little known, but prevalent cancer, is growing in incidence both globally and in New Zealand. This year saw the continuation of our successful

'Know Your Nodes' campaign as well as a number of health professional and patient seminars and events focused on addressing issues for patients living with lymphoma.

We completed our first Winter Workshop series for health professionals. Our speaker from the Central Queensland University spoke on the high impact on patients and families who are forced to relocate to main centres for treatment, often for months at a time. Psychosocial research is an emerging research trend. We have made a commitment to a major research project in this area of relocation. The aim is to ensure that patients and families unmet needs are identified and that we match our services accordingly; this initiative will get underway late 2009.

Whilst this has been a positive year income-wise we know the year to come will be the most challenging yet for our fundraising. We continue to create unique events such as Shave for a Cure, Dining for a Difference, the Golf Marrowthons and the Firefighter Sky Tower Challenge as a way to grow our income.

As the demand on our services increases our income needs to increase markedly to cover our costs. At our current donation and event income level this not sustainable. To that end, we are every appreciative of the generous support we receive and the continued belief in our work by our wonderful corporate partners. A huge thank you to Fidelity Life, Holden, Bell Gully and PricewaterhouseCoopers and a very warm welcome to our fabulous new partner Farmers who have made such a difference to our year.

A heartfelt thank you to our highly dedicated LBF staff, to our trustees for their direction and determined adherence to the vision and mission of LBF, to the many volunteers and supporters who everyday make our work possible. Thank you for your kind support. It is only because of you that we are able to continue our work.

Pru Etcheverry,



Executive Director



Medical Director's Report

The Leukaemia & Blood Foundation's (LBF) committed investment in New Zealand haematology continues to play an influential role in new research development.

The LBF is the only dedicated funder of haematology research and continues to use its resources to sponsor two research groups, the Leukaemia Study Group and the Bone Marrow Transplant Study Group. In addition, the LBF now also sponsors the Lymphoma Network and is a key driver of lymphoma awareness in New Zealand.

One of the cornerstones of our 'vision to cure' has been the dedicated research grants that we have provided for more than 30 years. To date, the LBF has funded \$2,000,000 in research into blood cancers and conditions. In addition, we have funded summer research projects for students, as well as travel grants for scientists, clinicians, nurses and laboratory staff to attend national and international scientific meetings.

The involvement of the LBF in research will ultimately lead to benefits and improved outcomes for New Zealand patients. There are also many indirect benefits, including the education of medical and nursing staff looking after patients with blood disorders, support of the haematology research environment, retention of scientist and clinicians in New Zealand, and the encouragement of young scientists and clinicians to consider a career in haematology and haematology research.

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 and independently review the many grant applications. Haematology is one area of medicine that has witnessed dramatic advances in treatment thanks to research investment.

The challenge for organisations such as ours is to ensure that these new drugs are made available to the patients who will benefit. The LBF has played an increasingly important role in the area of advocacy where we work hard on behalf of patients to secure funded access to the medicines they need. It was over seven years ago that the LBF lobbied on behalf of patients to have access to Glivec, and more recently we have made submissions to Pharmac in support of funding a number of other much-needed new and innovative medicines for leukaemia, lymphoma, myeloma and for thalassaemias.

In addition, the LBF supports the Leukaemia Study Group and the Bone Marrow Transplant Study Group which provide valuable forums for haematologists around the country. The focus is primarily an update on opportunities to participate in clinical trials and at times cover other topics of importance to patients and treatment, such as access to medicines.

In New Zealand, lymphoma patients may be treated by a haematologist or oncologist depending on their location, the lymphoma subtype they have and the stage of the disease. As these specialists rarely meet nationally, knowledge is seldom shared. The Lymphoma Network, sponsored by the LBF, is a national network aimed at improving patient care through collaboration.

The Lymphoma Network is working on the key issues relevant to lymphoma patients and their treatment ensuring that national guidelines and protocols are established and that there is a forum to discuss research in this area. Together the Lymphoma Network with the LBF hopes to be able to have a positive impact on the lives of patients and their families.

The LBF continues to offer patients a range of crucial emotional and practical support which has a role to play in healing and recovery. Health professionals are grateful for the commitment and care our patients receive from the LBF and acknowledge the tremendous effort required to maintain the level of excellence in the services provided.

Dr. Peter Browett



Medical Director



Leukaemia & Blood Foundation Successes

Thanks to your support, we are able to broaden our range of patient services and mark new LBF milestones. Here are just a few of the memorable events we shared.

Patient Support Services

- Opened **2** regional offices in Wellington and Christchurch where our Support Services Coordinators are based.
- Launched LifeBloodLIVE, an online information and support forum for haematology patients, their families and friends.
- Continued **11** existing education and support programmes nationwide.
- Created **4** new education and support programmes in Tauranga, Christchurch, Palmerston North and Wanganui.
- Hosted **2** international speakers: Dr. Pam McGrath, for the inaugural Winter Workshop Tour, educational sessions for health professionals working in haematology. The sessions were held in three locations and attended by 72 people. Brisbane's Brian Amos conducted a workshop series for patients, families and caregivers as well as health professionals in Auckland, Wellington and Christchurch about the psychosocial impact of a haematological malignancy on the patient and family.
- Sponsored cancer survivor Phil Kerslake to speak at the first Northland Haematology/Oncology education and support meeting.
- Provided **845** gifts of financial assistance to **399** patients. These included vouchers for supermarkets, petrol stations and taxis, and help to ensure that patients and families are able to travel to treatment centres and restock the cupboards during what can be a very difficult time financially.

Information

- Produced LifeBlood and Lymphoma Today newsletters for patients and families.
- Launched 3 new patient information booklets on allogeneic stem cell transplants, autologous stem cell transplants and CML to ensure patients and their families have access to the most up to date resources possible.

Research

- Funded research into blood cancers and conditions—\$2 million to date.
- Funded Relocation programme on psychosocial research in collaboration with Central Queensland University.
- Funded summer studentships, research projects for students.
- Funded travel grants for scientists, clinicians, nurses and laboratory staff to attend national and international scientific meetings.
- Sponsorship of Study Groups – BMT and leukaemia and sponsorship of the newly established Lymphoma Network.

Awareness

- Raised awareness through our World Lymphoma Awareness Day campaign and Leukaemia Appeal Week as well as fundraising events by gaining national broadcast, print and online media coverage.

Advocacy

- The LBF Executive Director was appointed to the International Lymphoma Coalition new board of directors.
- Attended the national Cancer Non-Governmental Organisation (CANGO) forum to elevate blood cancer to health authorities and agencies such as the Cancer Control Council, the Ministry of Health and other relevant organisations.
- Advocated on behalf of patients for access to drugs.

Patient Support Services

Each year the Leukaemia & Blood Foundation resolutely seeks new ways to expand our provision of support to patients, their families, whānau and friends, and 2008/2009 proved no exception.

With a mission to care, we are passionate about easing the extraordinary stress people face as they travel the long, and often rocky, road of diagnosis, treatment, and living with their condition and its impact on their lives.

Alongside the assistance we offer to patients, we also provide support to families, carers and friends when a loved one becomes ill.

During this last year, we have continued to build on our existing network of services and proudly introduced a range of new resources and programmes.

A number of these were spearheaded by our new Support Services Manager, Amy Munro, who was appointed during a restructure of the team in September 2007.

We were delighted to appoint a fourth Support Services Coordinator in March 2008 to meet the ever growing call on our services. Our Support Services team are all registered nurses who have specialised in haematology and bone marrow transplant nursing. They are dedicated to providing high quality psychosocial care throughout New Zealand.

With the expansion of the team, we have welcomed the opportunity to increase our education and support programmes and groups. This year we have started groups in Tauranga, Christchurch, Palmerston North and Wanganui which now brings our total number of programmes running nationwide to fifteen.

These regular meetings offer patients and their family members an opportunity to network with other people on the same journey, to explore their feelings and discuss shared experiences in a safe environment.

In these times of technological advancement, we launched New Zealand's first online information and support forum for haematology patients and their families. We had received many enquiries about online support and were thrilled to be able to introduce this forum for New Zealanders. LifeBloodLIVE.org.nz provides users with a safe environment to 'meet' others who share similar experiences. Feedback from users suggests this forum is particularly welcomed by people who may not be able to attend face-to-face meetings or who do not live in areas where these are offered.

Another important source of information for patients is our free booklet series and the last year saw us introducing an update to our Chronic Myeloid Leukaemia booklet and two new booklets about Stem Cell Transplants – the first New Zealand-based resources on this topic.

Ensuring patients and their families receive the support and information they need remains one of our top priorities and we continue to seek ways to improve our services. But with costs already sitting at around \$2,000 a day, our ongoing challenge is to raise the money needed to maintain and grow these important services.



Patient Stories

Living for Today

Sid and Myra

When Sid Hider's multiple myeloma was at its worst, even driving over a speed bump resulted in tears of pain.

Multiple myeloma is a cancer of the plasma cells in the bone marrow. Tumours are formed, thinning the bones, which can lead to lesions and fractures. In fact, in Sid's case it led to two broken ribs after he enjoyed a good laugh at a country music concert and ultimately led to his diagnosis more than seven years ago.

At that stage, Sid was just 53. He says: "When I first heard the diagnosis I felt relieved; at last I could put a label on it. Then afterwards Myra and I looked up 'multiple myeloma' in a medical book and I saw the words 'cancer' and 'no cure'..

"That first week was very traumatic but I quickly realised it was decision time. I looked in the mirror and said, 'I am going to fight it. I'm going to be a survivor."

Myra also found it tough but Sid's first chemotherapy session proved a real turning point for them both. Myra says: "We met a woman who had been living with myeloma for 14 years – she's been our inspiration."

Sid, 61, has also drawn great comfort from the support and education programmes offered by the LBF. Recalling the first meeting he attended, Sid says: "I suddenly felt I was normal! I have received a tremendous amount of support and care from my myeloma mates and over time I have supported others wherever I can."

He adds: "The LBF is a real safe house and has provided invaluable advice and support. The new online forum, LifeBloodLIVE is great; I would really encourage people to use it."

By the time he was diagnosed with multiple myeloma stage 3 IgG Kappa, Sid's skull, neck, shoulders, ribs and spine were affected and several vertebrae had collapsed.

Sid started chemotherapy and was given morphine for the pain. "The chemotherapy made me very emotional. In fact, during those first three months I quickly learned two things - how to say 'no' and how to cry," he recalls.

After a good response to chemotherapy, his consultant recommended a stem cell transplant and Sid's own cells were harvested. The transplant took place at the end of November 2001 and three weeks later Sid returned home, eight kilos lighter and very fatigued. His strength slowly returned as he set himself small physical goals.

He says: "I knew the aim of the treatment was to get me to the plateau stage – you don't go into remission with myeloma."

In May 2002, Sid returned to work part-time, then full-time a couple of months later. He says: "I feel my work has been an important part of my recovery. Myra and I also travel more. It's very important to live in the 'now'; tomorrow's another day."

Sid and Myra's close relationship has proved a great source of strength for the couple.

To learn more about Sid's multiple myeloma experiences and read an extended version of this interview, please visit www.leukaemia.org.nz.



Drawing Comfort, Finding Courage

Erin and Norman

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 in Europe but Erin recalls: "Every single step was a nightmare. 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 and as it grew it shunted my thyroid and windpipe over to one side." Then, on 15 October 2007 the doctors stated that Erin had Hodgkin lymphoma. She admits: "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'."

Within days, Erin learned her disease had reached stage 2B Bulky and she was receiving chemotherapy at Auckland Hospital. 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 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 day stay patients in the face. It was like a bond."

Erin, 47, has been in remission for a year 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."

She has drawn great comfort from the support of the LBF and now exchanges regular messages with other patients on the LBF online forum, LifeBloodLIVE. 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!"



About Blood Cancers

The Blood Cancers

Blood cancers are complex and often people know little of these diseases. We are committed to improving the quality of life for patients and their families living with blood cancers or conditions and aim to demystify these illnesses.

Leukaemia

There are several types of leukaemia. The diseases are categorised into acute or chronic leukaemias, depending on their progression and the specific blood cells involved.

- Acute lymphoblastic leukaemia (ALL)
- Chronic lymphocytic leukaemia (CLL)
- Acute myeloid leukaemia (AML)
- Chronic myeloid leukaemia (CML)

One of the key factors contributing to leukaemia is the over-production of immature blood cells, which gather in the bone marrow and chase out their healthy counterparts. As the disease progresses, these leukaemia cells accumulate in the bone marrow, crowding out normal white and red blood cells and platelets. The abnormal cells are eventually released into the circulating blood and carried throughout the body. This means the remaining red blood cells cannot transport as much oxygen to the body's tissues and organs, the normal white blood cells cannot fight infection effectively, while the platelets cannot control bleeding effectively.

Acute leukaemias can progress extremely quickly and often require intensive treatment with chemotherapy within hours of diagnosis. This treatment may last for months or even years and can also include radiation therapy or stem cell transplant. Chronic leukaemias present quite differently and can take years to evolve. Some patients living with chronic leukaemia may not require treatment for some time and can live with their disease for many years without adverse effect. New therapies available for some forms of chronic leukaemia have revolutionised treatment for these patients and can mean that the disease is controlled by taking tablets daily.

Lymphoma

Lymphomas are cancers that affect the lymphatic system and arise when developing lymphocytes (a type of white blood cell) undergo a malignant change and multiply in an uncontrolled way.

Increasing numbers of abnormal lymphocytes, called lymphoma cells, accumulate and form collections of cancer cells (tumours) in lymph nodes (also known as glands) and other parts of the body. Over time, lymphoma cells replace normal lymphocytes, weakening the immune system's ability to fight infection.

There are many different types of lymphoma, which are classified as:

- Hodgkin lymphoma (also known as Hodgkin's disease)
- Non-Hodgkin lymphomas (or B-cell or T-cell lymphomas)

Treatment for lymphoma can vary depending on the sub-type, location and stage of the disease. Treatment can involve chemotherapy, surgery, radiation therapy, or stem cell transplants; however some patients may have a slow-growing (indolent) lymphoma which may not require treatment for some months or years.

Myeloma

Myeloma (also known as multiple myeloma) occurs when there is an uncontrolled growth of abnormal plasma cells in the bone marrow. Unlike leukaemia, where cancerous cells are found in the blood, the malignant plasma cells in myeloma do not usually leave the bone marrow.

A frequent symptom of myeloma is bone pain. People living with myeloma often experience back pain, aggravated by movement. Pain can also occur in other sites such as the upper arms or legs. The pain is due to the growth of the tumour within the marrow and is accompanied by a progressive destruction of the affected bones. This leads to holes in the bones (lytic lesions) or generalised weakness (osteoporosis) of the bone, or both.

Myeloma, when not associated with bone destruction, generalised disease may develop and progress without obvious symptoms. In this case, normal bone marrow cells are replaced by abnormal plasma cells and the marrow ceases to function properly.

Research

Research funding is a part of the LBF's core services and is a high priority. The LBF supports the highest quality research in New Zealand.

Research plays a critical role in building a greater understanding of blood cancers and conditions. Research can also help to bridge the information gap of those involved in health service delivery and policy development.

Ultimately, the benefit will be to the patients and families we support as research and findings can lead to improved treatment to patients and increased survival rates.

We have provided \$2.0 million worth of funding to research to date.

Examples of our research funding include annual research grants, travel grants, summer studentships, sponsorship of Study Groups – BMT and leukaemia and sponsorship of the Lymphoma Network.

Recent research funding include:

- Project Title: Is Cyclophosphamide Activation Compromised in Multiple Myeloma; Dr. Nuala Helsby and Professor Peter Browett; amount: \$34,612.00
- Project Title: Antithrombin summer studentship project, Wellington

Samara Bretherton, Thaneshwary Sooriyakumar, Julia Phillips

Wellington Hospital Haematology Department and Otago Medical School

LBF funded the summer studentship project in 2007/8, an audit of the management of congenital antithrombin deficiency in Wellington over 50 years.

This uncommon condition is associated with a high risk of venous thromboembolism (VTE). The audit identified 20 patients with congenital antithrombin deficiency diagnosed in Wellington between 1980 and 2008. The majority (70%) had suffered at least 1 VTE. Most (69%) of VTE were associated with an identifiable risk factor and 60% occurred in women.

The research team presented the data on the management of antithrombin deficiency and pregnancy orally at the HAA meeting in Perth October 2008 and the data on antithrombin deficiency and surgery was presented as a poster at the International Society of Thrombosis and Haemostasis meeting in Boston, USA in 2009, the latter being placed in the top third of abstracts accepted for poster presentation. The research team is hopeful that they will be able to submit the work as a paper.

The LBF also sponsors three key blood cancer medical groups each year including:

- New Zealand Bone Marrow Transplant Group
- New Zealand Leukaemia Study Group
- The Lymphoma Network

The need for continued support for high quality health research for blood cancers and conditions continues.

About Us

Information

We provide vital information to patients, families, health professionals and the community to improve understanding about blood cancers and conditions. We offer treatment information and support to those living with blood cancers and conditions including disease-specific booklets and a lending library of written and audio-visual materials.

To meet the needs of our patients and families the LBF has several information sharing tools including:

Print

Publications: The LBF produces *LifeBlood* and *Lymphoma Today* newsletters. *Lymphoma Today* is a disease-specific newsletter that focuses primarily on lymphoma. These newsletters offer patient stories, medical information, such as updates on clinical trials, news on our support services and information on our events and fundraising initiatives.

Patient booklets: The LBF produces disease-specific patient booklets that are free to the public. There are currently 11 titles in the booklet series with three new titles planned for the coming year. The booklets provide comprehensive information about the diseases themselves as well as the treatments that are offered for these patients.

Brochures: The LBF produces brochures that offer a snapshot of our patient support services and offerings.

Resource library: We have comprehensive libraries at our offices that offer books and DVDs providing support, information and inspiration about living with blood cancers and conditions.

In person

Our patient support groups and workshops: The Support Services Team coordinate support and education groups and host an online forum for New Zealand patients and their families living with blood cancers and conditions.

Health Professionals meetings and workshops: The Support Services Team coordinate a Winter Workshop series for health care professionals working in haematology and oncology to support health care professionals and to foster information exchange in the haematology community, as well as giving regular presentations to health professionals working in the major treatment centres.

Web-based

LBF website: The LBF website is full of information on patient and family support, grants and research, news and media and a calendar of our events and fundraising initiatives.

LifeBloodLIVE: This is an online information and support forum for haematology patients and their families. LifeBloodLIVE.org.nz provides users with a safe environment to share similar experiences. The forum is moderated daily by a member of the Support Services Team.

Awareness

We work to increase public knowledge about blood cancers and conditions through initiatives such as World Lymphoma Awareness Day. Building community awareness and knowledge increases public support and involvement.

World Lymphoma Awareness Day

World Lymphoma Awareness Day (WLAD) is a global event observed every year on September 15. The LBF has been involved in WLAD for six years. LBF, in collaboration with the International Lymphoma Coalition, aim to increase awareness about this little known 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 also the most common cancer in young people ages 15-24. Certain types of lymphoma can kill in as little as six months.

Lymphoma is increasing in incidence in New Zealand; this is in line with increases seen globally. Lymphoma, a cancer of the immune system, has an incidence rate more than 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 such as flu, glandular fever or other viruses. It is essential the disease is recognised early because, if treated appropriately, some types of lymphoma can be cured.

The LBF promoted the Know Your Nodes quiz as a fun way to increase awareness and knowledge about this cancer. The LBF also created posters, tools and other materials to raise lymphoma awareness in New Zealand.

Leukaemia Appeal Week

Our annual Leukaemia Appeal Week fundraiser in November, Lunch for Leukaemia, saw the launch of our newly appointed national ambassador, Hilary Barry. Joined by Alison Mau and top local business people, Hilary hosted Lunch for Leukaemia at the Villa Maria Estate Winery where guests showed their support for people living with leukaemia and heard first hand of the experiences of living with the condition.

Advocacy

The LBF represents the needs of patients and their families to the government, health agencies, drug companies and other relevant bodies.

The LBF has a strong history of advocating on behalf of patients and their families. We advocate on behalf of patients with employers, insurers, hospitals and others as required. We advocate for patients in relation to their diagnosis, treatment, medicines and issues that directly affect a patient's life and chance for survival.

The LBF collaborates with other cancer Non-Governmental Organisations (NGOs), coalitions and supporters to ensure that patients have a voice and access to medicines and treatments.

This collaboration helps to ensure that our collective voices are heard at the relevant forums. We work to ensure that health authorities acknowledge and address issues related to blood cancers and conditions.

We Work in New Zealand

We work closely with the Lymphoma Network. Sponsored by the LBF, the Lymphoma Network was established to improve information exchange and knowledge sharing among New Zealand lymphoma specialists, including haematologists, medical and radiation oncologists.

In addition, we work with the Access to Medicine Coalition to improve access to highly effective and innovative medicines on behalf of patients.

We work actively with a coalition of like-minded New Zealand cancer organisations called the Cancer Non-Governmental Organisation (CANGO) to ensure that patients have a voice with the Cancer Control Council, the Ministry of Health and other relevant organisations.

And finally, we are represented at the Northern Cancer Network forum ensuring the patient voice is heard at the DHB level.

We Work Globally

Our active participation in international coalitions, such as the Lymphoma Coalition, allows us to exchange information with the leading blood cancer patient organisations worldwide.

The Lymphoma Coalition is a global initiative dedicated to increasing understanding of lymphoma and promoting the best practice treatment for patients and families. It consists of 41 lymphoma patient organisations from 32 countries, which represent a large cross-section of the world's population.

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. The LBF executive director was appointed to the new board of directors which will come into being upon incorporation.

As a Lymphoma Coalition member, the LBF is able to work more comprehensively on raising global awareness of lymphoma.

Affiliations

- Lymphoma Network
- Access to Medicines Coalition
- CANGO
- Northern Cancer Network Forum
- Cancer Control Council
- New Zealand Blood Service
- New Zealand Bone Marrow Donor Registry
- Lymphoma Coalition (International)
- CML Advocates Network (International)
- Leukaemia Foundation Australia (LFA)

Fundraising

Fundraising

Fundraising events have become the backbone of our income and one which we are incredibly grateful for and reliant on.

2008 saw an incredible boost to our work with many wonderful and exciting special events and fundraising initiatives taking place.

Shave for a Cure

All across the country New Zealanders embraced our Shave 08 campaign, bravely sacrificing their locks in support of the thousands living with blood cancers and conditions. More than 1,400 kiwis took up the challenge raising over \$630,000 – a truly incredible result!

Golf Marrowthon

A field of close to 40 golfers, including former Black Cap cricketer Rob Hart and New Zealand Women's Golf top amateur player Penny Smith from Rotorua, made the grade at Tirau Golf Marrowthon in March.

It was the first LBF Golf Marrowthon to be held in a rural area and would not have been possible without the amazing support of the Rotary Club of Matamata and their hardworking members. Players raised an outstanding \$60,000 in sponsorship, with Fidelity Life CEO, Milton Jennings singlehandedly raising more than \$21,500 of that total.

Firefighters Sky Tower Challenge

In May, 230 brave firefighters (58 brigades) from around New Zealand competed in the Firefighter Sky Tower Challenge, racing up the 47 flights - or 1,029 steps wearing full firefighting kit and breathing apparatus weighing up to 22kg. The gut-busting event raised a record \$94,000 in support of the LBF.

Farmers Santa Parades

In December, LBF staff, volunteers and patients were out in force, with many dressed as clowns, collecting to bustling crowds at the iconic Farmers Santa Parades in Auckland and Hamilton which raised a very merry \$8,100. Both parades were awash with colour, excitement and families eager to enjoy the festivities and sunshine.

SKYCITY Dining for a Difference

We are delighted to be organising the third SKYCITY Dining for a Difference. The award winning event is the brainchild of New Zealand and international celebrity chef Peter Gordon of SKYCITY's dine by Peter Gordon and The Providores Restaurant in London.

The event was initiated in London as a way for Peter Gordon to honour his sister Tracey who survived acute myeloid leukaemia. Inspired to help other patients with leukaemia, Peter orchestrated a London event titled, Who's Cooking Dinner? which has raised over £3 million for the Leukaemia Unit at Hammersmith Hospital in London.

Working with SKYCITY and the Leukaemia & Blood Foundation, Peter created a New Zealand version of the event. First held in June 2007, the event saw the hugely successful launch of Every Day Counts, offering supporters the opportunity to buy and name a special date on the LBF's calendar for \$1,000. So far, over 100 days have been snapped up.

Held for the second time in April 2009, the event showcased the culinary expertise of thirteen top international chefs who commandeered the kitchens of SKYCITY to help raise an incredible \$160,000.

The gourmet stars included Al Brown of Logan Brown in Wellington, Geoff Scott of Vinnies Restaurant in Auckland, and international names such as Elizabeth Faulkner from Orson in San Francisco, Jereme Leung of Jereme Leung Creative Concepts in Shanghai and Christine Manfield of Universal in Sydney.

Other Events

The year also held many poignant events, with the Richard Haden Memorial Golf Day and the Tessa Hunt Memorial Cycle to name a few. Friends and family came out to honour these two brave individuals who lost their battles with leukaemia and raise much need funds to support patients and their families and to put towards vital research.

Once again, our wonderful partners provide huge support, from Farmers running an 'Add A Gold Coin Donation' in store and raising an incredible \$226,000, to Holden dedicating proceeds from the Holden V8 Supercars Drivers Breakfast, to PwC and Bell Gully battling out with the clippers in the 'Battle of the Buildings' shave event and raising over \$120,000.

We are enormously grateful to everyone who organised, participated in or donated to an event for us. Without you we would not be able to continue our vital supporting patients, their families and whānau.

New Zealand Bone Marrow Donor Registry

Sometimes for blood cancers the only potentially curative treatment is a bone marrow or cord blood transplant from a genetically matched donor.

The best match for a patient is a close family member, however, only one in three patients in New Zealand has a fully matched family member. That is, 70 percent of patients do not have a match.

When there is no match, the next step is to search for an unrelated donor. Patients depend on the New Zealand Bone Marrow Donor Registry (NZBMDR) to help them find an unrelated donor.

The LBF plays a vital role in this service by operating and administering the NZBMDR. There are now more than 8,000 people on the NZ Registry who are willing to donate their bone marrow or stem cells to other patients in New Zealand.

There are another 13.5 million on the worldwide registries, but the majority of these are European. The NZBMDR is part of a global network of registries of people who have volunteered to donate stem cells if they are found to match a patient who needs a bone marrow transplant.

For a successful transplant, the tissue type of a donor needs to match that of a patient very closely. Special testing determines whether a patient and a donor are a good match - the closer the match, the better the result.

Because tissue types are inherited, patients are more likely to match someone from their own race or ethnicity. Adding more donors from diverse racial and ethnic backgrounds to the Registry increases the likelihood that all New Zealand patients will find the match they need.

New Zealand has the highest population in the world of Polynesian people who had very little chance of finding a donor before the NZBMDR was established. The policy of the Ministry of Health and the NZBMDR is to focus on recruiting Maori and Pacific Islanders (and people from other ethnic minorities and/or of mixed racial ancestry) as volunteer bone marrow donors.

The aim of this policy is to increase the chances of finding a donor for Maori and Pacific Island patients with serious bone marrow diseases...to the same level as for Europeans... and it is gradually working.

Raewyn Fisher (Executive Officer of the NZBMDR) and her team are also working towards enrolling people with Asian backgrounds – particularly from the Indian subcontinent – India only established a registry this year so has very few available donors for their huge population.

NZBMDR is developing a website, with the help of the LBF, to help raise awareness of this critical need. The LBF is committed to helping as many patients as possible of all ethnic groups to achieve the best outcomes for patients with serious blood conditions.

Contact the NZBMDR on:
0800 800 256 (0800 800 BLOOD)
or visit www.leukaemia.org.nz/page/115
to find out more.

Financials

FOR THE YEAR ENDED 31 MARCH 2009	Notes	2009 \$	2008 \$
Statement of Financial Performance			
Operating revenue	2	2,223,465	1,431,415
Operating expenses	3	1,292,951	898,143
Operating Surplus		930,514	533,272
Outcomes	4	825,465	480,032
NET SURPLUS		105,049	53,240
Statement of Financial Position			
EQUITY		1,311,565	1,206,516
Represented By:			
Current assets	5	568,409	526,896
Non current assets:			
Investments	6	62,490	70,275
Fixed Assets	7	1,968,255	1,946,227
TOTAL ASSETS		2,599,154	2,543,398
Current liabilities		207,765	236,906
Non current liabilities	8	1,079,824	1,099,976
Total liabilities		1,287,589	1,336,882
NET ASSETS		1,311,565	1,206,516

Notes to Financial Statements

1. Statement of account policies

Reporting Entity

The Leukaemia & Blood Foundation of New Zealand (LBF) is a Charitable Trust under the Charitable Trusts Act 1957. These Financial Statements have been prepared excluding the two divisions of the Leukaemia & Blood Foundation: Cord Blood Bank and the New Zealand Bone Marrow Donor Registry. In addition, the Leukaemia & Blood Foundation Financial Statements have been prepared including all the divisions. The trust is a reporting entity in accordance with the Financial Reporting Act 1993.

Business and Background

The foundation is a charitable trust, registered with the Charities Commission. It promotes and assists research into the diagnosis, prevention and treatment of diseases such as leukaemia, lymphoma, myeloma and related blood conditions. The foundation provides information, education, patient and family support services advocates for patients and families, and runs disease awareness programmes.

Measurement Base

The accounting principles recognised as appropriate for the measurement and reporting of Financial Performance and Financial Position

on a 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 Receivable 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.

FOR THE YEAR ENDED 31 MARCH 2009	2009 \$	2008 \$
2. Operating revenue		
Operating revenue comprises:		
Bequests	195,337	5,970
Donations & Grants Received	761,716	650,632
Event Fundraising	1,170,032	689,492
Interest & Investment Income	38,194	32,286
Boarding House Income	55,531	50,274
Other Income	2,655	2,761
TOTAL OPERATING REVENUE	2,223,465	1,431,415
3. Operating expenses		
Operating expenses comprise:		
Administration	712,688	551,405
Audit Fees	5,683	5,000
Bank Fees and interest on loan	107,794	98,216
Depreciation	121,765	90,771
Marketing & Consultancy	306,397	124,114
Investment Monitoring Fees	488	535
Capital Loss on Investment	7,297	3,775
Lease/ Rent	555	270
Boarding house expenses	24,587	20,648
Legal Fees	5,697	3,409
TOTAL OPERATING EXPENSES	1,292,951	898,143
4. Outcomes		
Outcomes comprise:		
Grants Paid	93,413	64,325
Patient Support	732,052	415,707
TOTAL OUTCOMES	825,465	480,032
5. Current assets		
Cash at Bank	518,949	421,627
Accounts Receivable	49,460	105,269
TOTAL CURRENT ASSETS	568,409	526,896
6. Investments		
As at 31 March 2009, the balance of the investments are as follows:		
Opening Balance of Investment	70,275	73,391
Investment Income	-	1,193
Monitoring Fees	(488)	(534)
Capital Loss on Investment	(7,297)	(3,775)
TOTAL INVESTMENTS	62,490	70,275

7. Fixed assets

FOR THE YEAR ENDED 31 MARCH 2009	DV Rate	Cost	Acc Depn	CBV	Depn
2009					
Computer Equipment	33% - 48%	397,126	(246,780)	150,346	(68,087)
Office Equipment	12% - 60%	182,418	(76,549)	105,869	(19,635)
Building	4%	936,955	(119,915)	817,040	(34,043)
Land	0%	895,000	-	895,000	-
TOTAL FIXED ASSETS		2,411,499	(443,244)	1,968,255	(121,765)
2008					
Computer Equipment	33% - 48%	271,417	(175,619)	95,798	(35,658)
Office Equipment	12% - 60%	164,333	(59,999)	104,334	(20,102)
Building	4%	936,955	(85,860)	851,095	(35,011)
Land	0%	895,000	-	895,000	-
TOTAL FIXED ASSETS		2,267,705	(321,478)	1,946,227	(90,771)

8. Non current liabilities

The Leukaemia & Blood Foundation has two bank loans with BNZ that mature on 21/09/2030.

Account 3015, \$627,039, Interest Rate of 8.89%. (2008, \$636,339 at 8.89%).

Account 3016, \$472,275, Interest Rate of 7.40%. (2008, \$480,940 at 7.40%).

They are secured by a registered first mortgage over the company premises at 6 Claude Rd, Epsom.

On behalf of the Trustees.



A Loo - Chairman

Audit Report

Audit Report to the readers of the Leukaemia & Blood Foundation of New Zealand. (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 31 March 2009. 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 Division as at 31 March 2009 and the results of operations for the year ended on that date.

Author'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 judgements 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 concluded 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 explanation which we considered necessary in order to provide us with sufficient evidence to obtain reasonable 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.

Our firm carries out no other assignments for the Division. The firm has not other interests in the Division.

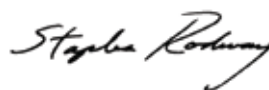
Qualified Opinion

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 donations and event fundraising, the financial report on pages 5 to 10 fairly reflects the financial position of the Leukaemia and Blood Foundation of New Zealand (excluding Cord Blood Bank and New Zealand Bone Marrow Donor Registry Divisions) as at 31 March 2009.

Our audit report was completed on 23 July 2009 and our qualified opinion is expressed as at that date.



Chartered Accountants
Auckland

Our Supporters

Our Supporters

The relationships with our businesses are vital to the Leukaemia & Blood Foundation (LBF). The LBF is indebted to its sponsors, donors, supporters and volunteers whose donations of time and money make it possible for us to continue our services to patients and their families living with leukaemia, lymphoma, myeloma and related blood conditions. We sincerely thank you for your continued support.

Sponsor Partners	Bell Gully Farmers Fidelity Life Holden New Zealand PricewaterhouseCoopers Textile Recycling Centre Ltd.
Event Partners	Air New Zealand Auckland Airport SKYCITY
Other Partners	Bunnings Hubbards Lion Nathan Lochiel Print Pascoes Regency Duty Free Rotary
Creative Partners	Huffer Ogilvy Orange Productions
The Community	Patients and families Donors Health professionals New Zealand schools and universities
Trusts	Ara Lodge 348 I C Charitable Trust McLachlan Charitable Trust Picot Charitable Trust Matamata Leukaemia Research Trust L R Vercoe Charitable Trust Infinity Foundation United Way Sir Ernest Davis Endowment Trust Ted & Mollie Carr Endowment Trust SKYCITY Auckland Community Trust Southern Trust

Directory

Directory

Leukaemia & Blood Foundation

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Auckland 1023, New Zealand

PO Box 99182, Newmarket
Auckland 1149, New Zealand

T: 09 638 3556

F: 09 638 3557

E: info@leukaemia.org.nz

Freephone: 0800 15 10 15

Websites and social media

LBF website: www.leukaemia.org.nz

LifeBloodLIVE: www.lifebloodlive.org.nz

Shave for a cure: www.shaveforacure.co.nz

Know Your Nodes: www.knowyournodes.org.nz

Golf Marrowthon: www.marrowthon.org.nz

You Tube Channel: www.youtube.com/user/LBFNZ

Facebook: www.facebook.com/lbfnz

Twitter: <http://twitter.com/LBFNZ>

Blog: <http://lbfnz.blogspot.com>

Medical and Scientific Advisory Committee

Dr. Bart Baker, Chairman– Haematologist, Mid Central Health

Pru Etcheverry, Secretary– Executive Director of Leukaemia & Blood Foundation

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

Dr. Liam Fernyhough – Haematologist, Canterbury District Health Board

Trustees

Arthur Loo, Chairman

Greg Moyle, Deputy Chair

Peter Browett, Medical Director

Hilary Blacklock, Medical Director NZBMDR

Rachel Lerner

Arthur Pitcher

Doug Strong

Tony Wilding

Cheryl Willetts

Blair Wingfield

Support Services Staff

Amy Munro – Support Services Manager

Debbie Moore – Support Services Coordinator, Northern Region, Auckland & Northland

Lisa Speedy – Support Services Coordinator, Central Region

Christine Kerr – Support Services Coordinator, Southern Region

Sharon Verrall – Assistant Support Services Coordinator

New Zealand Bone Marrow Donor Registry

PO Box 74336, Market Rd, Auckland 1543

Toll free: 0800 800 256 (0800 800 BLOOD)

Tel: 64 9 523 5756

Fax: 09 523 5757

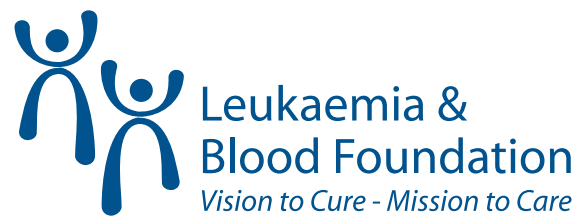
Email: nzbmdr@nzblood.co.nz

750

The number of interactions the Support Services Team has with patients, families and health professionals, including emails, phone calls and visits, per month.

70

**The number of patient
support and education
sessions around the country**



Leukaemia &
Blood Foundation
Vision to Cure - Mission to Care