

David Collins Leukaemia Foundation of Tasmania Inc.



Annual Report 2012

"Your help is our hope"

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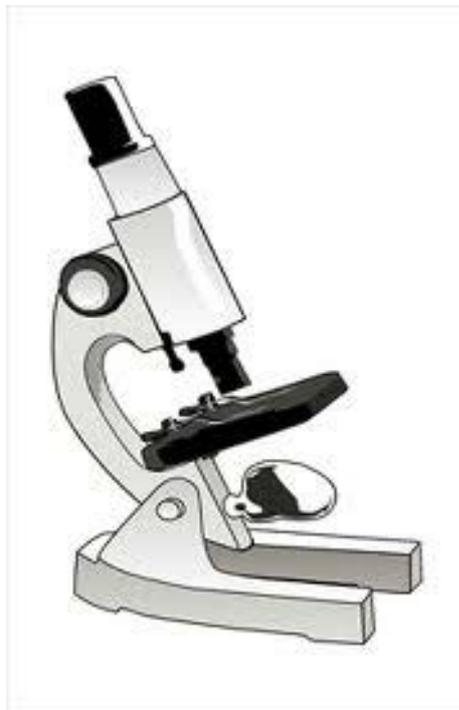
The David Collins Leukaemia Foundation of Tasmania Inc. is a Tasmanian organisation dedicated solely to the care and cure of Tasmanians living with leukaemia, lymphoma and related blood disorders. All money raised stays in Tasmania.

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Published March 2012
Printed by Tadpac +61 6272 5000
ISSN 1838-823X

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2012 Office Bearers

Patron:	The Governor His Excellency The Honourable Peter Underwood AC
President:	Mrs D Tuck
Vice President:	A/Prof G Woods
Secretary:	Mrs A Ogilvie
Treasurer:	Miss S Woods
Executive Officer:	Mr G Petterd
Life Members:	Mrs B Collins, Mr N Deane, Dr M Baikie
Ex Officio:	Mr S Thomson

Committee:

Mr D Asten, Mrs A Piaszczyk, Mr N Deane, Mr I Napier, Dr K Marsden, Mrs A Steele, Ms K Dun

President's Report

I have pleasure in presenting the President's report for the David Collins Leukaemia Foundation of Tasmania for 2012. The year was one of continued achievements of the objectives of the Foundation.

During 2012 the Foundation has continued to:

- Accommodate patients from intrastate at David Collins House - occupied for 256/365 days of the year.
- Fund local research and professional development.
- Provide medical equipment to our hospitals around the state.
- Support Tasmania patients and their families with direct financial assistance for payment of utilities accounts, car registration, wood and food vouchers.
- Complete a joint project with St John's Campus, Calvary Health Care Tasmania to refurbish an area for an extension to the day chemotherapy unit.



Committee members and supporters of the Foundation participated in the official opening of the day unit, along with Calvary Health Care Tasmania Executive members and staff. Members of David Collins' family were also proudly present. The unit was officially opened by Professor Ray Lowenthal and blessed by Archbishop Adrian Doyle. The successful completion of the project was a fine example of cooperation between the Foundation and Calvary to achieve an outcome that will benefit patients for many years.

I would like to acknowledge our Patron the Honourable Peter Underwood who continues to support our aims and objectives. Thank you to the Cancer Council for an ongoing collaboration with research award presentations and the use of the meeting rooms for our regular committee meetings.

The 2012 Button Day total was slightly less than last year - \$19,300, but still a significant amount given the current financial climate. Our regular button sellers and high school student volunteers continue to make an important contribution, not only by collecting money, but by providing a community presence and increasing exposure of our name. Members statewide remain committed to not only Button Day but also to monitoring and collection of counter tins and general donations.

The financial situation of the Foundation remains strong due to our ongoing wise stewardship in decision making with investments and allocation of funds. Bequests from donors and from estates continue to contribute to our income.

Finance Sub-Committee met regularly to monitor our investments, reporting back to the Committee members to ensure that informed decisions were made when planning the direction of the Foundation. I would like to thank Sarah Woods who has undertaken the role of Treasurer for five years. Her work has been outstanding, both in guidance and in the presentation of the financial situation of the Foundation.

I would like to thank all Committee members and commend our Executive Officer, Graeme Petterd for his continued commitment, liaison with other service providers and promotion of the Foundation statewide.

Deirdre Tuck

President, David Collins Leukaemia Foundation of Tasmania 2012

Thirty Two Years of Achievements 1980 - 2012

For each of the 32 years the Foundation has had significant achievements for each year.

Yearly Achievements

- 1980 Incorporated
- 1981 Presented research grant of \$12,128 and first button day raised \$1,466
- 1982 Research grants totalled \$30,000 and \$5,000 to oncology services
- 1983 Fundraising target of \$80,000 and achieved \$90,348
- 1984 Formation of North West Group
- 1985 Purchased David Collins House
- 1986 Car donated by Mr R Baker raffle raised \$23,000
- 1987 Publication of "Kristy's Book"
- 1988 First statewide Button Day
- 1989 Roger Scott's "Walk for Life" raised \$12,978
- 1990 Progressive fundraising exceeded \$1,000,000
- 1991 Committed \$10,000 to establish Tasmania Bone Marrow Registry
- 1992 Formation of Northern Group based in Launceston
- 1993 Northern Group raised \$5,827
- 1994 Bi-Annual statewide meetings introduced
- 1995 Research grants > \$60,000 plus \$12,000 to Bone Marrow Registry
- 1996 Progressive fundraising exceeded \$1,600,000
- 1997 Established "Special Purpose Investment Fund" of \$502,959
- 1998 \$10,000 in equipment presented to the Royal Hobart Hospital
- 1999 North West Group raised a record of \$9,500 for the year
- 2000 Research grants exceeded \$95,000 and became affiliated with the Cancer Council of Tasmania
- 2001 \$11,500 refurbishment of David Collins' House
- 2002 Tom Goninon walked from Wynyard to Hobart to raise \$23,000 in memory of his grandson
- 2003 Joint DCLF/LFA \$8,000 grant to fund Tasmanian Bone Marrow Transplant Support Group
- 2004 Professional Development Awards for Health Care Workers
- 2005 Appointment of first employee as part time Executive Officer
- 2006 Beverley Collins, Norm Deane and Dr Margaret Baikie - Life Members

- 2007 Comalco at Bell Bay sponsored refurbishment of bathroom at David Collins' House
- 2008 Income from investments and other fundraising totalled \$106,621
- 2009 Purchased equipment valued at \$44,000 for hospitals throughout Tasmania and progressive fundraising exceeded \$3,000,000
- 2010 Reception at Government House to celebrate 30 years and entered partnership with Ponting Foundation
- 2011 Increased "Special Purpose Fund" to \$750,000
State amount of \$22,067 collected on Button Day highest ever
Committed \$80,000 for redevelopment of Oncology Day Centre at St John's Calvary Healthcare to be named "David Collins Suite"
- 2012 \$21,075 for three treatment chairs Outpatients Oncology RHH The Blessing & Opening by Archbishop Doyle AM DD of the David Collins Suite Oncology Day Centre, St John's Calvary Health Care Tasmania

Our Patrons

- 1980 - 1994 Sir Donald Trescowthick
- 1995 - 2004 Dr Margaret Baikie
- 2005 - 2012 The Governors of Tasmania

Statewide Button Days

1981-2012 - \$ \$360,153

Research Grants

1981 - 2012 - \$1,747,135

Professional Development Awards

2004 - 2012 - \$56,320

David Collins House Accommodation

2010	2011	2012
111 days	332 days	256 days

Research Reports



Elizabeth Tegg: Validation of newly identified genes in the pathogenesis of chronic lymphocytic leukaemia

Collection of CLL samples, flow sorting and DNA extraction

Collection of samples has started and the flow sorting protocol is in place. It took several months' work to resolve many technical issues with the flow sorter, but we are now confident that all is functioning well for the patient testing. Recruitment has commenced and is continuing with the support of all the local haematologists and nursing staff in outpatient clinics. I have also arranged an overseas placement with Prof Michael Stratton (of the Wellcome Trust in the UK). Professor Michael Rudolf Stratton, FRS is a British clinical scientist and the third Director of the Wellcome Trust Sanger Institute. He currently heads the Cancer Genome Project and is a leader of the International Cancer Genome Consortium. This will help further expand my genetics skills and is a great opportunity for genetics research in Tasmania in general and I hope to set up a collaboration with his unit. This will greatly help with the analysis of the gene sequencing that I will undertake as part of the CLL project.

Submission of papers to relevant journals

The effect of the cellularity of the bone marrow aspirate sample for cytogenetic cultures. Accepted by The International Journal of Laboratory Haematology.

Report of a duplication of 4q13 and it's association with familial chronic lymphocytic leukemia. Submitted to the American Journal of Human Genetics

Jo Dickinson: Identifying inherited factors underlying familial haematological malignancies

Genetic factors are known to contribute to the risk of developing haematological malignancies, however to date the underlying genetic drivers of disease development remain largely unknown. Our study proposes to identify genes that predispose to the development of familial blood cancers. Knowing the causative genes is not only important in understanding the disease process but also provides a range of benefits in the diagnosis, development of tailored treatments, and identification of new targets for therapy. Studying families with multiple cases of these diseases is a powerful approach used to identify the causative genes. We have recruited a number of large families with multiple cases of blood cancers. Genetic analysis of family members with and without disease has been performed with a view to identifying the genes contributing to these cancers.

A consistently identified risk factor for HMs is family history of disease. Further familial and population based studies have demonstrated that relatives of those diagnosed with a HM are at increased risk of developing other types of blood cancers suggesting that one or a few inherited mutation may predispose to a range of HMs. Whilst genome wide association studies (GWAS) have advanced our understanding of the genetics of these cancers, significant deficits still exist in our understanding of the genes contributing to the development of HMs. Our hypothesis is that the genetic factors, which predispose to HMs, (including leukaemia, lymphoma and myeloma) can be identified through the genetic analysis of large families with increased incidence of these disorders utilising the unique Tasmanian Familial Haematological Malignancies (TFHM) genetic resource. The specific aims of this study are:

Aim 1: Identification of rare HM susceptibility variants located within the genetic susceptibility regions identified by identity-by-descent (IBD) analysis of the TFHMs genetic resource.

Whole genome sequencing for 10 individuals has also been completed. These individuals represent key individuals from three of our most interesting families. Genetic analysis to compare rare genetic changes observed in a number of these individuals has been undertaken. This has proven to be highly complex analysis requiring significant computing resources. In addition the complex computer software available for these analyses is rapidly evolving. Considerable time has been taken in the evaluation of the options available, selection of appropriate software, and then the development of necessary skills in using the software. In conjunction with our biostatistician Dr Jac Charlesworth, we have completed analysis of the genomes with two analysis methodologies VAAST and ANOVA and several genetic variants of interest in these individuals have been identified. Additional analyses are planned to complete this aspect of the project.

Aim 2: Characterisation of the contribution of identified variants to disease through examination of genotype and gene expression correlations in mutation carriers, and functional studies.

From the work completed in Aim 1 to date, we have identified several genetic regions and individual genetic changes for further follow up analysis. We propose to follow these up in the first half of 2013. At present we are verifying the presence of the genetic variants identified by traditional sequencing methods (Sanger sequencing) and then will examine our remaining affected and unaffected controls to ascertain the contribution of the variants to disease in these families.

Most recently there has been a major international effort to identify genes that contribute to the more common HM subtypes using a GWAS approach. The findings of this international research effort has highlighted the fact that multiple and varied genes contribute to HMs in different populations, and further that many genes remain to be discovered. Our proposal is designed to detect the rare variants including structural and repeat expansion variants likely to form a significant component of “missing heritability” that GWAS are not currently designed to detect. Identification of genes contributing to these HMs is also likely to contribute to furthering our understanding of sporadic disease and has significant potential to provide new avenues for diagnosis, assist with tailoring current therapies to genetic sub-types of disease, and to identify new molecular targets for therapies for this group of malignancies. Discoveries of genetic changes associated with HMs have been shown to have a significant impact on the development of new, more effective therapies for HMs with significant improvement in survival and quality of life for sufferers.

Dr. Adele Holloway :	Regulation of the Leukaemia Inhibitory Factor Receptor by RUNX1
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A 'master regulator' called RUNX1 controls growth and development of blood cells. Alterations to this regulator commonly occur in leukaemia. We have found that the regulator controls a factor found on the surface of blood cells called Leukaemia Inhibitory Factor Receptor (LIFR). This project provided an understanding of how LIFR is regulated in blood cells, how its regulation is disrupted in leukaemic cells, and how this is likely to contribute to the development of leukaemia.

The overall objective of this study was to investigate the regulation of LIFR and the factor it works in partnership with, gp130, by RUNX1, specifically:

- a) Determine how RUNX1 contributes to the regulation of these genes, and
- b) Determine how this affects the function of these genes in leukaemic cells.

The research team involved in this project include: Dr Adele Holloway, Dr Liz Tegg, Dr Abeer Qadi (Ph.D Student), Ms Shannon Ray (Research Assistant – part-time), Ms Kathy Buttigieg (Research Assistant – part-time), Ms Rebecca Brown (Honours student).

In this study we found for the first time, that both LIFR and the partner molecule it works with, gp130, are controlled by RUNX1. The LIFR gene has two control switches and we were able to show using a number of molecular and cell biology assays, that both of these switches, as well as the switch that controls the gp130 gene are regulated by RUNX1. Further, we found that only one of the LIFR gene switches is active in haemopoetic cells, and our data suggests that this is because epigenetic factors (ie the structure of the DNA) control the activity of these switches also.

We found that when RUNX1 activity is altered in cells (as occurs frequently in leukaemia) expression of the LIFR and gp130 factors is also altered. Our data shows that the RUNX1-ETO factor that is found in a type of acute myeloid leukaemia represses expression of both LIFR and gp130. We found that activation of LIFR/gp130 inhibits the growth of haemopoietic cells, and therefore the decreased activity of LIFR/gp130 in cells in which RUNX1 is disrupted may confer a growth advantage to the cells.

Publications

Manuscript:

AA Qadi, PC Taberlay, A Young, RN Brown, AC West, JL Dickinson, AF Holloway, 'Characterisation of the LIFR and gp130 genes as RUNX1 targets', *Journal of Cellular Physiology*, manuscript under revision following review.

Thesis:

AA Qadi, Ph.D Thesis 'Regulation of the LIFR and gp130 genes by the RUNX1 Transcription Factor', Ph.D conferred, 20th August 2012.

Professional Development Awards

Each year the Foundation provides Professional Development Awards to young Tasmanian leukemia researchers. There were four awards presented during 2012. (Three reports included.)

The David Balon Professional Development Award

Bridget Walker Clinical Nurse Educator St John's Calvary Health Care and **Catherine Youl** Clinical Nurse and Study Day Organiser Gibson Unit Calvary St John's Campus. \$1854 to conduct Study Day Seminar on blood cancer stem cell collections and transplants for oncology nursing staff at St John's Gibson Ward and other Tasmanian Hospitals.

As a result of the David Balon Professional Development Award for 2012 David Collins Leukaemia Foundation of Tasmania supported a study day addressing "who and what" types of blood cancers receive stem cell collections and transplants. Michelle Salter and Cathy Youl worked to develop the study day venue, theme and organisation of speakers.

The day was divided into lectures in the morning from our guest speakers, Roger Kimber talking on Lymphoma, Anna Johnston on the differing forms of leukaemia and Scott Ragg discussing the role of the scientist and laboratory involvement. They provided detailed power point presentations. Jane Anderson from the LFA discussed her role within the community and the management of referrals for newly diagnosed patients and their families. Roger and Anna took the lecture "back to the basics" and provided the audience with a comprehensive overview of the different blood cancer types and the use autologous and allogeneic transplants.

After lunch we moved into case study mode for the exploration of diffuse large B cell lymphoma. As a presenter I was challenged by the discussion on histology, as this is a lesser skill of mine. However, knowing my strength of facilitation and managing group interaction I was able to ensure good group discussion drawing on the participant's knowledge and skills.

Bridget Walker in her role as educator provided Michele and I support in formulating the day. A total of 25 people attended and the day was very successful. The power point presentations from all the speakers were sent to the study day participants.

Participants reported an excellent day that brought together interesting presenters and participants.

The David Joyce Professional Development Award

Sharon Bush Clinical Nurse Educator, Ward 5 Launceston General Hospital. \$1,500 towards study for Master of Nursing (Cancer /Palliative Care) degree at the Latrobe University.

I would like to take the opportunity to thank the David Collins leukaemia Foundation of Tasmania for awarding me the David Joyce Professional Development Award for 2012 to assist me with the payment for a subject unit in my Masters of Nursing in Cancer/Palliative Care at the La Trobe University in Victoria.

I am pleased to advise that I have now completed and achieved my Masters of Nursing in Cancer/Palliative Care and I look forward to passing on my skills to my fellow health care professionals.

The Judy Slevin Professional Development Award

Gillian Sheldon-Collins Bone Marrow Transplant Coordinator, Statewide Bone Marrow Transplant Service. \$1,440 towards visiting Bone Marrow Transplant Units in Melbourne, Geelong and Adelaide.

I am the Statewide Bone Marrow Transplant Coordinator at the Royal Hobart Hospital (RHH). The grant from the DCLFT enabled me to achieve two professional goals. Firstly I was able to visit the two Melbourne facilities where Tasmanians receive Allogeneic (donor) Bone Marrow Transplants. Secondly I was able to see how three different hospitals run their clinics for long term follow up for patients who have had Bone Marrow Transplants.

I was able to spend an entire day at the Royal Melbourne Hospital (RMH). I met several nurses, doctors and health professionals who I had frequently phoned & emailed over the years. It gave me a chance to discuss with them how to improve the flow of communication and documentation between the RHH and the RMH. I also visited the Bone Marrow Donor Institute (BMDI) House where Tasmanians stay while being treated in Melbourne. This is a welcoming & comfortable facility run by volunteers.

I also visited the Peter MacCallum Cancer Institute to speak to them about their system of long term follow up for transplant patients and participated in a clinic. I enjoyed spending time with their patients who were adult survivors of childhood leukaemia. I gained a real insight into the struggles and triumphs of their long term survival.

Geelong Hospital is almost a mirror image of the RHH serving a similar sized decentralised population. The BMT coordinator shared her experiences with me and had some useful tips on conducting long term follow up for patients who return to their homes in small rural communities similar to those in Tasmania.

I am extremely grateful to the DCLFT for enabling me to visit these hospitals and learn from their systems and experiences so that we can adapt them to improve long term follow up for survivors in Tasmania.

Audit Report

Peter Dawson ABN 90 707 520 914

Chartered Accountant
Business Consultant

Independent auditor's report to members of David Collins Leukaemia Foundation Inc

I have audited the special purpose financial report of David Collins Leukaemia Foundation Inc for the year ended 31 December 2012.

Management Committee's Responsibility for the Financial Report

The Management Committee is responsible for preparation and fair presentation of the special purpose financial report and information contained therein. This responsibility includes establishing and maintaining internal controls relevant to preparation and fair presentation of the financial report that is free from material misstatement, whether due to fraud or error; selecting and applying appropriate accounting policies; and making accounting estimates that are reasonable in the circumstances.

Auditor's Responsibility

My responsibility is to express an opinion on the financial report based on my audit. I have conducted my audit in accordance with Australian Auditing Standards to provide reasonable assurance as to whether the accounts are free of material misstatement. My procedures included examination, on a test basis, of evidence supporting amounts and other disclosures in the accounts, and the evaluation of accounting policies and significant accounting estimates. These procedures have been undertaken to form an opinion as to whether, in all material respects, the financial statements are presented fairly in accordance with Australian Accounting Concepts and Standards and other mandatory professional reporting requirements (Urgent Issues Group Consensus Views) (where applicable), and statutory requirements so as to present a view which is consistent with my understanding of the Foundation's financial position and the results of its operations and cash flows.

I believe that the audit evidence I have obtained is sufficient and appropriate to provide a basis for my audit opinion.

Independence

To the best of my knowledge and belief, there has been no contravention of auditor independence and any applicable code of professional conduct in relation to the audit.

Limitation of Scope

As is common for organisations of this type, it is not practicable to establish complete accounting control over cash received from all of its activities. Verification therefore has been limited to the receipt of funds recorded in the Foundation's financial records.

Audit Opinion

In my opinion, the special purpose financial report of David Collins Leukaemia Foundation Inc presents fairly in accordance with applicable Accounting Standards and other mandatory professional reporting requirements in Australia the financial position of the Foundation as at 31 December 2012 and the results of its operations and its cash flows for the year then ended.

Rendell W. RIDGE



(for Peter DAWSON)
23 February 2013

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Email peter@dawsonlienert.com
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Financial Report

Key Results in 2012:

- A net loss of \$75,000 was incurred by the Foundation. This loss includes \$189,000 paid out to Tasmanian's for research and patient care, which reflect the Foundation's core objectives.
- The \$189,000 for research and patient care includes three Research Grants, four Professional Development Awards and \$120,000 for Capital donations. Capital donations include \$85,000 to Calvary, \$5,000 to Cancer Council and \$28,000 to the Department of Health and Human Services for treatment chairs.
- \$105,000 was the adjusted profit when including only ordinary operating expenses of \$54,000.
- Patient accommodation revenue almost tripled in 2012 with over \$13,000 received from one customer.
- There was a drop in general donations, memorial donations and bequests compared with 2011.
- The Foundation recorded a fall in fundraising revenue because there was no annual dinner in 2012.

The David Collins Leukaemia Foundation of Tasmania made significant contributions in 2012. The overall net loss is an indication of the beneficial work the Foundation did during the year. \$189,000 was provided to fund patient care, research grants and large capital equipment and building donations to two of Tasmania's key hospitals.

Operational expenditure of \$54,000, for day-to-day costs of running the Foundation, increased 15% from 2011. This small increase is primarily explained by a change in the salary and wage agreement for Health workers.

David Collins Leukaemia Foundation Inc
Income Statement for year ended 31 December 2012

	2012	2011
Income		
Accrued Interest	27,250	8,802
Bequests	7,000	41,161
Button Day	19,360	22,067
Donations	15,168	45,090
Fundraising	0	7,614
Gain/(- Loss) on Securities	579	-4,825
Interest General Purpose	11,869	15,488
Interest Special Purpose	24,702	33,447
Investment Returns & Dividends	25,301	41,407
Memberships	232	98
Patient Accom Services DCH	26,626	9,116
Ponting Foundation donation	18,800	150,000
Tin Collections	1,639	1,172
Total Income	178,526	370,637
Expenses		
Audit	600	0
Capital Donations (Bequests)	119,721	0
Depreciation	1,524	1,524
Electricity	2,066	2,217
Finance Brokerage	2,499	2,136
Fundraising	1,905	4,595
Insurance	2,690	2,627
Lawnmowing	1,120	821
Office Supplies	1,404	0
Patient Care	4,194	809
Ponting Foundation Payment	10,000	150,000
Printing	1,195	1,167
Professional Development Awards	5,801	3,328
Rates	1,574	1,687
Repairs, Maintenance	891	2,294
Research Grants	59,362	56,000
Salaries	24,546	16,383
Subscriptions	432	1,336
Sundry Expenses	2,543	7,456
Superannuation	1,860	1,474
Telephone	4,560	4,519
Travel & Entertainment	2,860	1,581
Total Expenses	253,346	261,955
Net Profit (- loss) for year	-74,820	108,682

David Collins Leukaemia Foundation
Balance Sheet as at 31 December 2012

	2012	2011
Assets		
Current Assets		
Cheque Account	13,867	4,839
Suncorp Investments	426,743	399,746
Acuity	70,452	179,529
Accounts Receivable	2,530	0
GST Refund Due From ATO	1,684	0
Prepayments	960	967
Accruals	27,250	8,802
Share Investments	0	15,854
General Purpose Investment	151,812	151,812
Special Purpose Investment	750,000	750,000
Total Current Assets	1,445,298	1,511,549
Non-Current Assets		
Building	235,000	235,000
Furniture, Fixtures	15,244	15,244
Deduct Accumulated Depreciation	-13,235	-11,710
Total Non-Current Assets	237,010	238,534
Total Assets	1,682,307	1,750,083
Liabilities		
Superannuation Payable	1,076	713
Trade Creditors	8,415	0
GST Payable to ATO	0	1,733
Total Liabilities	9,490	2,445
Net Assets	1,672,817	1,747,637
Equity		
Asset Revaluation Reserve	177,853	177,853
Retained Earnings	1,569,784	1,461,102
Current Year Earnings	-74,820	108,682
Total Equity	1,672,817	1,747,637

The Foundation
expresses its

SINCERE APPRECIATION

**To all Donors of money,
effort and time during the year.**

Donations of \$2 or more are TAX DEDUCTIBLE

For further information please contact:
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Website: <http://www.leukaemia-tasmania.com.au>