

Annual Report 2003-2004



Improving care
and treatment for
people with
haemophilia,
von Willebrand disorder
and related bleeding
disorders through
Advocacy, Education
and the promotion of
Research



Haemophilia Foundation Australia

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Annual Report 2003/2004

*Haemophilia Foundation Australia (HFA) represents people and their families with haemophilia, von Willebrand disorder, other related bleeding disorders and for those infected with blood borne viruses which have occurred through the use of blood products necessary for their treatment. We are committed to improving care and services through **advocacy, education** and the promotion of **research**. We support a network of State and Territory Foundations and we are a National Member Organisation of the World Federation of Hemophilia.*

Ethical Standards

Haemophilia Foundation Australia is committed to the highest standards of ethical behaviour in all financial relationships, program development and other activities.

National Patron

The Right Honourable Sir Ninian Stephen, KG, AK, GCMG, GCVO, KBE.

State, Territory and Regional Patrons

AUSTRALIAN CAPITAL TERRITORY

Major General Peter R Phillips, AO, MC.

WESTERN AUSTRALIA

His Excellency Lieutenant General John Sanderson, AC. Governor of Western Australia

NEW SOUTH WALES

Doctor I Roger Vanderfield, OBE.

VICTORIA

Sir James Gobbo, AC.

TASMANIA

Lady Green

SOUTH AUSTRALIA

Doctor Donald Handley, MBBS, FRACP, FRCPA.

QUEENSLAND

Her Excellency Ms Quentin Bryce, AC. Governor of Queensland

Life Governors

Jennifer Ross AO

Maxine Ewart

Barbara Volk OAM

Dawn Thorp

Ted Troedson

Alan Ewart

Fred Wensing

Bruce Fielding

Alison Bellamy

Bevlee Cassell

Mike Barry

Rob Christie

EXECUTIVE BOARD



Back, L-R: Gavin Finkelstein, Peter Mathews,
Robert Lamberth
Front, L-R: Ann Roberts, Joseph Guarnieri

President	Rob Christie, South Australia (until October 2003) Ann Roberts, Victoria (elected October 2003)
Vice President	Ann Roberts, Victoria (until October 2003) Peter Mathews, New South Wales (elected October 2003)
Treasurer	Gavin Finkelstein, Western Australia
Executive Members	Joseph Guarnieri, Australian Capital Territory Robert Lamberth, Queensland (elected October 2003)

COUNCIL MEMBERS

Joe Guarnieri, <i>Australian Capital Territory</i>	Robert Lamberth, <i>Queensland</i>	Ann Roberts, <i>Victoria</i>
Glenn Irwin, <i>Hunter Valley</i>	Rob Christie, <i>South Australia</i>	Gavin Finkelstein, <i>Western Australia</i>
Peter Mathews, <i>New South Wales</i>	Sharyn Wishart, <i>South Australia</i>	Geoff Sue, <i>Western Australia</i>
Kevin Murphy, <i>New South Wales</i>	Nigel Williams, <i>Tasmania</i>	
Michele Albert, <i>Queensland</i>	Neil Boal, <i>Victoria</i>	

STAFF

Sharon Caris, Executive Director
Natashia Coco, Development Manager
Heather Lauder, Executive Secretary
Lyn Gaspero, Secretary (Part-time) until December 2003
Carol McCaskie, Administration/Development Officer
(Part-time) from March 2004
Kevin Lai, Accountant (Part-time)

(Not pictured: Kevin Lai, Lyn Gaspero)



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PRESIDENT'S REPORT ~ Ann Roberts, President



I am pleased to present my first Annual Report as President of Haemophilia Foundation Australia (HFA). It has been a full and productive year which has seen the completion of several projects, a successful national conference, and special challenges which have demonstrated the importance of strong levels of commitment to our objectives and the cooperation of all Haemophilia Foundations around the country.

Rob Christie completed his final term as President in October 2003 and our member Foundations joined me in congratulating him for his excellent leadership through a period of significant change. Rob's hard work and dedication in this role over a four year period and his many years of work with Haemophilia Foundation South Australia was recognised when the award of Life Governor was presented to him at the 2nd Australasian Haemophilia Conference Dinner in October.

We have maintained a high level of support to State/Territory Foundations by providing resources for them to undertake specific local projects. This has meant that groups have been able to specifically tailor activities such as camps and workshops to meet local needs.

Our strong commitment to education was met through the 2nd Australasian Haemophilia Conference held on the Gold Coast in October 2003, at which over 250 people attended to learn more about developments in the treatment and care of haemophilia and related bleeding disorders in Australia and overseas. We were privileged that contributors to the conference program included clinical and policy experts as well as people with bleeding disorders and their families who shared their experiences. Haemophilia Foundation Queensland and the Queensland Haemophilia Centre worked hard to bring us an excellent meeting.

A major focus during the year was to continue our strategy for best practice haemophilia treatment products and to ensure a supply of the safest products for all people with bleeding disorders in Australia. The National Blood Authority was established on 1 July 2003 with the purpose of improving and enhancing the management of the Australian blood banking and plasma product sector at a national level.

We lobbied strongly for the adoption of the recommendations in the Australian Health Ministers' Advisory Council's Blood and Blood Products Committee *Report of the Working Party on the Supply and Use of Factor VIII and Factor IX in Australia* which was tabled in April 2003. The Working Party recommended increased access to recombinant factors whenever clinically indicated, and that a target of 85% for recombinant factors should be achieved by 2004 at the latest. It was recognised that plasma derived clotting factors would be needed by some people with haemophilia for clinical reasons and by those with von Willebrand disorder who require von Willebrand factor containing blood products. HFA argued that where alternatives to plasma derived clotting factors could be used for the treatment of haemophilia these should be provided in view of the mounting safety concerns about the relative risks of plasma derived clotting factors compared to recombinant treatment products.

HFA has worked for a number of years towards the goal of ensuring everyone has access to the best products for their treatment, however we reviewed our strategy in early 2003 when there had been such a delay. The government funding arrangements were being negotiated across jurisdictions and new national purchasing and payment processes were planned to be put into effect after 1 July 2003. HFA had several meetings with Federal and State/Territory Ministers and health officials but still there was no joint agreement for funding to allow this policy reform to occur.

Our members became more and more frustrated that the delays of governments continued to put their health at unnecessary risk. We encouraged our members to communicate their concerns directly to their local Members of Parliament. Members embraced this with great passion and over the first quarter of 2004 HFA received hundreds of letters about this issue from individuals and politicians concerned about

treatment standards and funding. In spite of the National Blood Agreement which identified how the jurisdictions would share the cost of the new policy, we have still not achieved our goal.

HFA consulted widely with member Foundations after the Senate Community Affairs References Committee commenced its Inquiry into Hepatitis C and the Blood Supply in Australia in August 2003. We reviewed our hepatitis C strategy at our October Council meeting and further work on this was undertaken by a sub-committee of the Board. We consulted members through an anonymous questionnaire in October and received over 200 responses from people who were concerned about the impact of hepatitis C upon their lives. This consultation work resulted in a substantial submission to the Senate Committee followed by an oral presentation by HFA representatives to the Committee in Melbourne on 5 April 2004.

HFA called for recompense for people with bleeding disorders who were infected with hepatitis C through their treatment, a review of support services and for government policy to ensure people have access to safer recombinant treatment products urgently. The Committee tabled its report in the Senate on 17 June and made six recommendations, one of which was a recommendation to implement the Factor VIII and Factor IX Working Party recommendations "as a matter of priority". HFA will develop its response to the recommendations in the light of the government response to the recommendations of the Senate Committee.

It was a great disappointment in May 2004 that the government failed to make provision for additional usage of recombinant clotting factors in its Federal Budget. After the Senate Community Affairs References Committee on Hepatitis C and the Blood Supply in Australia recommendation on 17 June 2004, there were now three expert committee reports in Australia, as well as a growing body of international experience being ignored by Australian governments. I again pressed the Federal Health Minister, the Hon Tony Abbott, seeking a funding commitment. By this time most State/Territory governments had indicated to HFA they had set aside their share of the funding required.

We have strongly put the issue of the safety and supply of haemophilia treatment products before State/Territory and Federal governments. In fact we have devoted much time and resources to this because of the urgency and seriousness of the situation. We know that many Members of Parliament and senior government officials are aware of the safety issues, and of our members' concerns, however as a decision has still not been made we will take this unresolved issue into the next year.

My commitment to members that our advocacy for a supply of the safest treatment products for people with haemophilia and von Willebrand disorder will remain strong until we ensure everyone has treatment which equals international best practice standards.

HFA Council and its Executive Board worked hard this year to respond to issues and make policy in a timely and effective manner. It has been important for State/Territory Foundations to work closely with HFA, particularly on the advocacy issues which have required State/Territory and national cooperation. The year has seen HFA increase its capacity for advocacy through its relationships with government departments, Members of Parliament, corporate organisations and other advocacy organisations such as the Australian Hepatitis Council. Our successes grow from the solid relationships we have forged over several years with many stakeholders.

HFA participates actively in a network of international haemophilia organisations through its membership of the World Federation of Hemophilia (WFH) and appreciates WFH's support and assistance throughout the year.

I express my sincere thanks for the work of HFA Council members and the Executive Board, State and Territory Foundations, Sustaining Patrons, supporters, volunteers, staff and the many stakeholders who have made a valuable contribution towards our objectives throughout the year.

OUR HIGHLIGHTS ~ Sharon Caris, Executive Director

OUR YOUNG PEOPLE

We are delighted that the Youth Mentoring and Leadership Program has progressed to the next level. The Youth Program held concurrently with the 2nd Australian Haemophilia Conference gave us an opportunity to identify several young men and women who could become future leaders of the haemophilia community. This group of highly motivated young people now meets as the HFA Youth Committee on a monthly basis via teleconference. The group has considered a range of issues, including how to involve young people in Haemophilia Foundation activities, making plans for leadership and mentoring training, and enhancing their capacity to provide peer support, and developing personal development and communication skills. The Youth Committee has taken responsibility for the Youth Newsletter which is distributed as a supplement to *National Haemophilia* and will work towards a creative program of activities for the 2005 national conference.



Youth Committee
(Standing L-R)

*Robert McCabe (WA), Secretary; Chantel Roberts (VIC), Member;
Gavin Finkelstein (WA), HFA Executive Board Representative;*

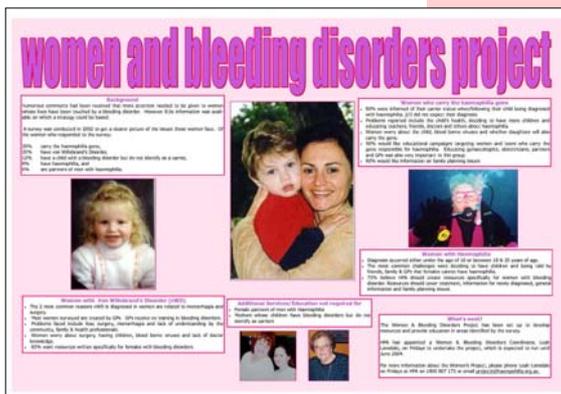
Paul Bonner (SA), Member.

(Seated L-R)

*Anna Sznyter (TAS), Chairperson; Craig Bardsley (QLD), Member;
Natashia Coco, HFA Representative.*

(Not pictured: Rebecca Head (SA), Member)

WOMEN WITH BLEEDING DISORDERS



Leah Lonsdale undertook more work in this important area during the year in her role as part time project officer with HFA. We receive many calls for support from women and girls who have been diagnosed with a bleeding disorder or who require support in their capacity as a carer of a partner or relative who has a bleeding disorder. This further work involved developing education material, exploring opportunities to raise community awareness and connecting women with relevant services for diagnosis, care and treatment and support.

New material has been written and a number of new facts sheets are currently under review for publication on several topics,

including menorrhagia, women with haemophilia, carrier issues and information on von Willebrand disorder for health professionals.

2nd AUSTRALASIAN CONFERENCE

The 2nd Australasian Haemophilia Conference was held from 10 – 12 October, at Legends Hotel, Gold Coast with the theme “Never lose sight of where you are going”.

The conference was officially opened by the Hon Wendy Edmond, Queensland Minister for Health, and Brian O'Mahony, President, World Federation of Hemophilia, presented a valuable overview of haemophilia care around the world. Over the two days of the conference 250 delegates attended sessions on topics which interested individuals with haemophilia, von Willebrand disorder and related bleeding disorders and their families as well as health professionals, government officials and policy makers on the developments in treatment and care, new technologies, ethical issues and health care policy in Australia and internationally.

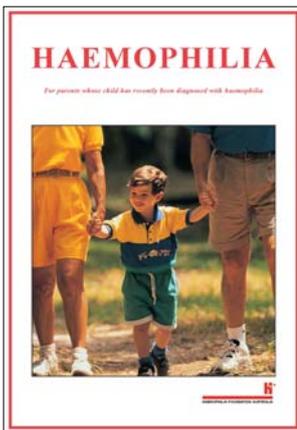


A concurrent youth program was run for 24 young people whose ages ranged from 12 – 29 years. The program enabled them to meet and share experiences and attend education sessions. Highlights of the program included a workshop to address issues for siblings of people with haemophilia or von Willebrand disorder and a session which used illustration and writing as a technique to explore values and feelings. The group also enjoyed a visit to Sea World and during another excursion many were able to experience parasailing for the first time.

HEALTH PROFESSIONALS' EDUCATION

HFA is strongly committed to the support and education of health professionals who work with people with bleeding disorders. It is important that we have comprehensive care provided through haemophilia centres to meet the needs of the haemophilia community based upon up-to-date sociological, scientific and medical knowledge. HFA supported the annual meetings of the Australia and New Zealand Physiotherapy Haemophilia group, HFA Nurses' Association and the Australian Haemophilia Counsellors' and Social Workers' Group and provided executive support to each of these groups throughout the year. HFA also worked closely with the Australian Haemophilia Centre Directors' Organisation on common issues relating to best practice care and treatment. I sincerely thank the many health professionals who generously assist HFA by reviewing education material and supporting our programs.

EDUCATION AND INFORMATION



During the year we reviewed some of our education material and developed facts sheets with general information on haemophilia and von Willebrand disorder. The education material provided to people who have recently had a child diagnosed with haemophilia, *Meeting Haemophilia for the First Time*, which was first published in 1993, has been reviewed and re-written and the format was re-designed after a consultation process with representatives of Haemophilia Foundations, health professionals and families. The new loose-leaf folder will provide space for local information to be inserted about local haemophilia centre services and support services provided by State/Territory Foundations. The presentation style allows for outdated material to be replaced from time to time to ensure the publication remains relevant to the needs of families with young children with haemophilia.

WEB SITE

The Commonwealth government provided a small grant for HFA to re-develop the web site in 2002. The site was tested and reviewed by many people at the 2nd Australasian Haemophilia Conference in October 2003 and the new site was launched soon after. In March 2004, HealthInsite approved HFA as an information partner.

The site has many features including download publications, facts sheets, annual reports and newsletters, frequently asked questions, a dedicated kids' and youth section, a secure on line donation facility and the capacity to upload news, events and notices. Since going live traffic has increased seven fold. Email newsletters have been developed and readers and supporters can register on line to receive this update. This is a successful feature and over 60 people have registered for this facility.



SUPPORT

HFA supported State and Territory Foundations to run ongoing activities and set up new initiatives for their members throughout the year. For example, in April 2004, a total of 55 people – parents, children with haemophilia and their siblings, made their way to Camp Wilkin at Anglesea for the Haemophilia Foundation Victoria Family Camp.

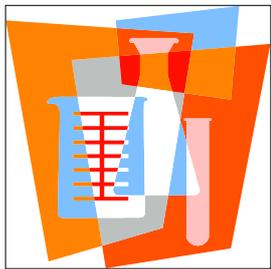
The camp is a unique opportunity for families affected by bleeding disorders to meet and provides opportunities for families to exchange their experiences of living with bleeding disorders and to reinforce and expand peer support networks. The experience of living with a bleeding disorder continues to change for

families. Access to prophylaxis (preventive) treatment at home has enabled families to become more independent in recent years. Although this independence is still only possible with strong relationships with haemophilia centre staff for clinical advice and support, many families do not need to attend hospitals as frequently and do not meet up with each other as families did before them. Camps like this bring families together so that they can share their experiences and learn from each other and gain support. Over the weekend children and teenagers participated in canoeing, archery, flying fox, and a high ropes course. Friday night's camp fire and Saturday's Trivia night added to the fun, "especially the camp fire songs!" There was also an allocated time for "Secret Mums and Dads Business", which gave parents an opportunity for time out and peer support. The success of weekends such as this comes from strong cooperation between haemophilia centres and local Foundations. The informal environment allowed several children to learn how to treat themselves under the guidance and support of haemophilia nurses who generously attended education sessions at the camp. The best motivator for children to take over their own treatment is to follow the example of their peers, and the supportive environment encourages parents who may be anxious about the transition to feel more confident about their children taking responsibility for their own treatment.

The Haemophilia Foundation Victoria Men's Group met eight times during the year in Melbourne. The group provides an opportunity for men with bleeding disorders from around the State to come together in an informal setting to exchange information and gain support from one another.

In November 2003, the annual Haemophilia Foundation New South Wales Family Camp was attended by 138 people at the Sydney Academy of Sport at Narrabeen. The Academy is attractive to children because of the range of sporting activities available. Over the two days children participated in a ropes course, archery, canoeing and the most popular was the indoor heated pool. Santa made a guest appearance and gave each of the children a present and the Clown Show completed an exciting camp.

RESEARCH



Over the ten year history of the Haemophilia Foundation Research Fund, 14 research projects have been funded amounting to \$282,698.70. Although some of these grants are small and serve as part funding for larger projects, they do make a difference and the outcomes of these projects have had a positive impact on the haemophilia community.

In 2003, Dr John Rasko, Centenary Institute, Cancer Medicine & Cell Biology, NSW, was granted an amount of \$11,000 over two years, for his project:

"Towards a cure for haemophilia: development of a preclinical model of gene therapy."

The project involves a multi faceted approach to improving gene transfer rates using a relevant model of gene therapy in baboons. Dr Rasko will analyse the reasons why gene delivery has been relatively inefficient in the past by examining different types of delivery systems and ways in which they may be improved, combining this with clinical research associated with haemophilia.

DAMON COURTENAY MEMORIAL ENDOWMENT FUND

The Damon Courtenay Memorial Endowment Fund was generously established as a perpetual trust in 1993 through the offices of Haemophilia Foundation Australia by Benita and Bryce Courtenay in memory of their son, Damon. When the interest reaches \$10,000 in any year, a distribution is made to individuals or families affected by haemophilia and von Willebrand disorder. A distribution was made in August 2003 and benefited many people through the provision of financial support for items such as mobility aids, equipment and home modifications, education courses, computer equipment and funding to attend haemophilia conferences.

DEVELOPMENT ~ Natasha Coco, Development Manager

COMMUNITY AWARENESS

Haemophilia Awareness Week and World Haemophilia Day

Haemophilia Awareness Week 2004 ran from 11 – 17 April. The theme for the week was 'How aware are you?' which aimed to raise public awareness of haemophilia and von Willebrand disorder and bring attention to the needs of the bleeding disorders' community. World Haemophilia Day was celebrated around the world by National Member Organisations of World Federation of Hemophilia on 17 April.



Publicity packs were sent to State and Territory Foundations and haemophilia treatment centres which contained posters, flyers, business sized information cards, balloons, bookmarks and facts sheets to be used in displays at hospitals, offices, shopping centres and other public places.

During Haemophilia Awareness Week, the issues experienced by people with haemophilia, von Willebrand disorder and related disorders and their families were presented in different ways through newspaper articles and radio segments in South Australia, Victoria and Tasmania.

Public Speaking

Members of the haemophilia community and HFA were invited as guest speakers at several service club meetings throughout the year, and several requests for live and recorded radio interviews provided an opportunity for us to highlight the issues for people living with bleeding disorders.

Media

HFA decided it was necessary to generate media attention to raise public awareness about the seriousness of the issue of access to the safest treatment for people with haemophilia to the general public and to exert pressure on government. HFA obtained the advice of a consultancy firm to develop a media strategy in support of advocacy for best practice treatment products during the year.

9th October 2003
AUSTRALIANS GET SECOND-BEST TREATMENT
Australians living with the blood condition haemophilia are getting the second-best treatment because of government inaction, according to an international expert.
Dr Paul Giangrande, a world authority on haemophilia and Director of the Centre for the United Kingdom, said that treatment because of cost issues had put Australia lagging behind the rest of the world for people with haemophilia. Dr Giangrande said it has long been widely accepted that it means that an urgent financial commitment to genetically engineered products that are available in other countries.
Dr Giangrande, who is also vice president and the Chairman of its Medical Advisory Board of the Australasian Haemophilia Conference, said he understood that Australians living with the condition must be increasingly frustrated from Commonwealth and state health ministers.
"I appeal to Health Ministers and governments to act on the plight of people with haemophilia."
"The delays in implementing a national treatment options available (factor VII) unacceptable."
"Just for one moment I would urge governments who had been forced to settle for second-best treatment have been sat on for too long."
Dr Giangrande said that the UK had opted for safer treatment as soon as possible and that other countries such as USA, Ireland, Canada, Japan and Sweden were doing the same.

27 November 2003
HEALTH MINISTERS MUST ACT ON SAFETY
Haemophilia Foundation Australia (HFA) and State Health Ministers meeting tomorrow will discuss the safety of blood clotting products for people living with haemophilia.
HFA said that the risks associated with blood clotting products needed from the government commitment was needed from the government to ensure that the risks associated with blood clotting products that are not derived from human material and therefore do not transmit blood borne viruses or agents for recipients.
HFA President, Ann Roberts, said that the current practice approach to the treatment options for people with haemophilia could no longer be tolerated.
"We believe the recommendations of the committee are due to be considered again at tomorrow's meeting."

17 June 2004
MEDIA RELEASE
DO WE HAVE TO WAIT FOR ANOTHER DISASTER LIKE HEPATITIS C BEFORE GOVERNMENTS WILL ACT?
Haemophilia Foundation Australia (HFA) today welcomed the findings and recommendations of the Senate Community Affairs Committee Inquiry into Hepatitis C about priority access to safer haemophilia treatments, but was disappointed that there was no financial package of recompense to offset the costs for people who contracted hepatitis C from blood clotting products.
"People with haemophilia who are forced to use plasma derived clotting factors are continuously exposed to ongoing risks of known and unknown blood borne viruses. International experts have already warned authorities about the possibility of West Nile Virus and agents like vCJD slipping through, just as HIV and hepatitis C did. This will be devastating for people with haemophilia. Do we have to wait for another disaster like hepatitis C to occur before governments will act," HFA spokesman Rob Christie, said.

Media releases at other times throughout the year were sent out at critical times to support our advocacy program and resulted in significant radio and/or television coverage in New South Wales, Victoria, Northern Territory, Western Australia, and Queensland on bleeding disorders generally, or the impact of blood borne viruses.

FUNDRAISING

Appeals

Four appeals were run during the year to coincide with Spring, Christmas, Autumn and Winter (Tax). These appeals were successful and raised over \$84,000. *H.link* was re-designed for Spring with a new fresh look. The newsletter is an updated information source about HFA programs and services and is aimed at donors and supporters of our cause.



Trusts and Foundations

Trusts and Foundation applications were made throughout the year to many State/Territory based and national bodies. We appreciate the support of:

Carleton Family Trust, Eirene Lucas Foundation, Everglades Fund, Flora & Frank Leith Charitable Trust, Goldschlager Family Charity Foundation, Greatorex Foundation, Helen Macpherson Smith Trust, JB Were Foundation, Kraus Charitable Foundation, L H Cornell Estate - Tower Trust Limited, L R Cazaly Trust Fund, Lord Mayor's Charitable Fund, Rosenblum Charitable Foundation and William Angliss VIC Charitable Fund.

These Trusts and Foundations supported programs such as family camps in Victoria and New South Wales, Haemophilia Foundation Victoria Men's Group, our HFA Youth Mentoring and Leadership Program, Women with Bleeding Disorders' project, Haemophilia Foundation Research Fund and equipment to support the operations of the organisation.

SPECIAL EVENTS

Be-Tsar Cocktail Party, Sydney 2004

Over 300 people attended the successful Be-Tsar Cocktail Party on Thursday 20th May at Sotheby's, Sydney, organised by the Red Committee. The night was filled with haunting Russian melodies skilfully played by the violinist, Bloody Mary's, borsch shots, and a tasty selection from the blini bar which added to the Russian theme. Simon Storey, supported by Justin Miller, conducted the spirited art auction, and well known Iva Davies ended the night singing "Great Southern Land"!

More than \$100,000 was raised through ticket sales, art auction, donations and the famous Babushkas for Haemophilia Foundation Australia.

Our thanks are extended to the many individuals and corporations who supported the event to make it so successful: Artists ~ Ana Wojak, Angus McDonald, Belinda Black, Charles McKean, Christopher Hodges, David Bromley, Ian Lever, James McGrath, Janet Laurence, John Forrester Clack, John Olsen, Jon Lewis, Lambert Visser, Margaret Woodward, Martin Sharpe, Michael Taylor, Nigel White, Peter Kingston, Rex Dupain, Robert Ryan, Shona Wilson and Tim Gratton.

Sponsors ~ Amanda Buckworth Publicity, Carlton United, Diageo, Double Island-Far North Queensland, Four Seasons Resorts Bali, Harvey World Travel – Circular Quay, Jim's Cellars, Novo Nordisk, Serena Sanderson Catering, Singapore Airlines, Sotheby's Gallery and Taylors Wines.



Red Committee (left–right)

Simon Storey, Edwina Storey, Bronwyn Wannan, John Sheerin, Susan Shier, Fiona MacDonald, Vicki Stait
(Absent: Helane Knespal, Dani Howard)

TREASURER'S REPORT ~ Gavin Finkelstein, Treasurer



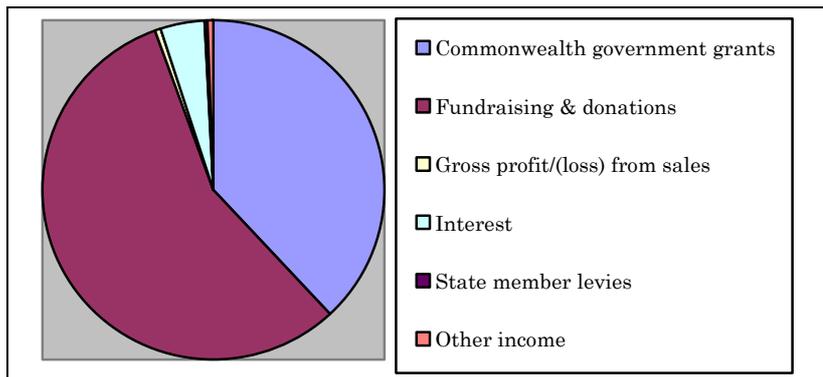
I am pleased to present my report of the HFA financial position and the major movements for the year. Income increased by 16.8% to \$705,412 from the previous year. The Foundation's operating expenses decreased by 2.2% while the expenses for our care and services objectives increased by 112.4%, a net increase of 29.6% for expenses for the year. The surplus for the year is \$18,316, or 75.2% less than last year. Total Foundation's Funds grew by 2.3% from \$809,281 to \$827,597.

a) Income \$705,412 (2003: \$603,980)

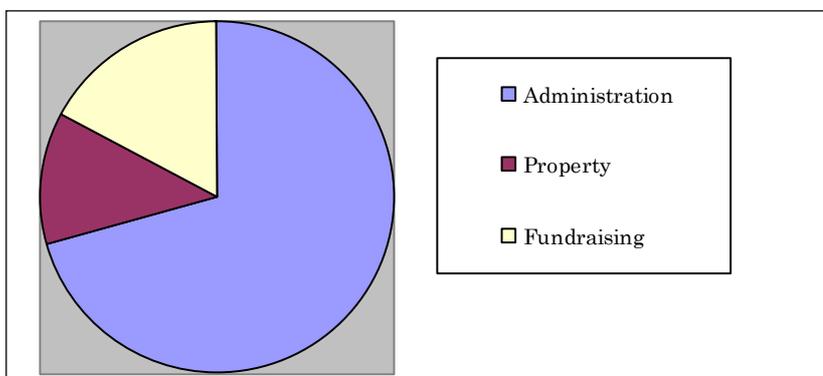
Although income from Commonwealth government grants remained steady, there was an increase of \$95,091 (+ 31%) from fundraising and donations primarily because of the success of the Sydney Cocktail Party and Art Auction. Another significant amount was

raised to specifically support the 2nd Australasian Haemophilia Conference.

Investment income was down marginally by \$2,706 (8.2%) from the previous year. The effective interest rate is 3.67% compared to 2003 when it was 4.51%. HFA's surplus funds are invested mainly in interest bearing securities.



b) Operating Expenses \$374,171 (2003: \$382,757)



Administration expenses increased from \$246,828 to \$263,658 (+ 7%) this year mainly due to an increased number of Executive Board meetings and related activities associated with policy development and advocacy. Human resources expenses increased by 5% due to salary increases and staff changeover costs. Other costs in this category remained steady.

Property expenses related to our rental of the High Street property decreased by \$6,495 (-12%), mainly due to savings achieved from our relocation in 2002 from Malvern. These savings are expected to plateau in future years. Depreciation is higher due to the continued write off of last year's capital expenditure for the installation of a new computer network. (Capital expenditure for this year is \$5,000 compared to \$20,000 in 2003.)

Fundraising expenses of \$64,277 for the year included \$37,000 for the expenses associated with the Sydney Cocktail Party and Art Auction. These expenses are exclusive of administration overheads. Other fundraising expenses only marginally increased during the year.

c) Objectives Expenses \$312,925 (2003: \$147,358)

The considerably increased expenditure for services and care objectives included an amount used for expenses associated with the 2nd Australasian Haemophilia Conference. The year saw an increased expenditure on special projects (\$42,164 compared to \$32,758 in 2003) and included significant outlays for camps (\$11,000), Haemophilia Foundation Victoria history project (\$11,000), the writing and publication of a new education resource for parents with a child who has recently been diagnosed with a bleeding disorder (\$8,000), and the Women's Bleeding Disorders' project (\$8,000).

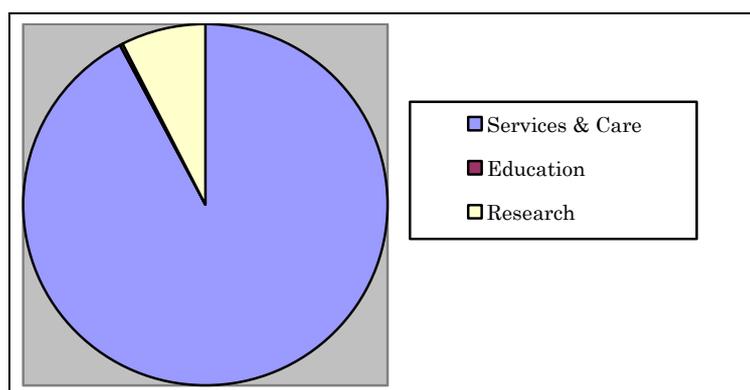
Education of health professionals remained a key activity in line with the specific objectives of the Commonwealth Department of Health and Ageing grant, as did the quarterly newsletter which was supplemented with new tools for communication, education and information dissemination through the redeveloped web site and youth newsletter.

Expenses associated with advocacy and lobbying amounted to \$42,000, some of which was funded by donations. Research expenditure for new and ongoing projects amounted to \$23,089 (\$31,524 in 2003). A distribution of \$10,000 was made in line with the requirements of the Damon Courtenay Memorial Endowment Fund for education grants to individuals.

A new computer system was required and this resulted in 71% higher expenditure compared to the previous year (+\$6,000). This equipment upgrade and enhanced software has resulted in a greater in-house capacity to generate documents and printing, however our more complex technology needs has required HFA to allocate additional resources for off-site IT support.

Funds from HFA reserves were transferred to fund specific projects and the advocacy and lobbying campaign.

I am pleased that HFA is in good shape and has adequate reserves available to undertake designated projects in the next year and to supplement the recurrent operational and objectives expenses.



Statement of Financial Performance for the Year ended 30 June 2004

	Note	2004	2003
		\$	\$
INCOME			
Commonwealth government grants		269,338	257,750
Fundraising and donations		397,451	302,360
Gross profit/(loss) from sales		2,787	293
Interest		30,238	32,944
State member levies		1,997	2,874
Other income		3,601	7,759
TOTAL INCOME		705,412	603,980
LESS: FOUNDATION OPERATING EXPENSES			
Administration			
Advertisement/recruitment		350	1,150
Audit		8,250	7,750
Annual reports		4,905	5,604
Bank charges and service charges		2,289	1,293
Council meetings		7,531	8,755
Executive meetings		16,643	7,572
Legal and consultancy fees		-	4,166
Personnel expenses		197,316	186,954
Professional insurance		4,198	3,643
Provision for long service leave		3,354	1,022
Resource material		543	1,570
Staff amenities and training		755	546
Superannuation		16,516	16,008
Liaison and business development		1,008	795
		263,658	246,828
Property			
Depreciation		8,963	3,899
Electricity and gas		2,809	2,267
Insurance		1,617	1,577
Moving costs		-	10,701
Rent		27,152	29,895
Repairs and maintenance		5,331	3,938
Security		364	454
		46,236	52,731
Fundraising			
Appeals and production		53,643	71,199
Planned giving		529	2,198
Resource development and travel		10,105	9,801
		64,277	83,198
TOTAL FOUNDATION OPERATING EXPENSES		374,171	382,757
SURPLUS OF INCOME OVER OPERATING EXPENSES		331,241	221,223

The accompanying notes form part of these financial statements.

Statement of Financial Performance for the Year ended 30 June 2004 (cont...)

	Note	2004 \$	2003 \$
SURPLUS OF INCOME BROUGHT FORWARD		331,241	221,223
LESS: FOUNDATION OBJECTIVES EXPENSES			
Services and Care			
Awards and presentations		1,632	454
Consultancy		42,634	132
Computer software and supplies		13,782	8,066
Counsellors		6,303	5,460
Executive		10,739	8,120
Financial assistance		2,411	3,409
Haemophilia conference and sponsorships		83,279	-
Other conferences		6,398	3,464
Newsletter		16,149	21,293
Nurses		8,165	3,811
Physiotherapists		8,316	919
Postage		10,339	7,198
Printing and stationery		11,254	6,652
Specific project expenses		42,164	32,758
Sponsorship and allocations		10,000	-
Subscriptions		2,856	4,136
Telephone		9,976	8,254
Travel		1,613	-
Volunteer expenses		407	-
		288,417	114,126
Education			
Brochures and literature		282	963
Community education		1,137	745
		1,419	1,708
Research			
Research grants allocated		23,089	31,524
		23,089	31,524
TOTAL FOUNDATION OBJECTIVES EXPENSES		312,925	147,358
TOTAL SURPLUS/(DEFICIT) FOR THE YEAR		18,316	73,865
ACCUMULATED FUNDS BROUGHT FORWARD		606,353	540,083
TOTAL AVAILABLE FUNDS		624,669	613,948
TRANSFER (TO)/FROM RESERVE	6	1,730	(7,595)
ACCUMULATED FUNDS CARRIED FORWARD	5	626,399	606,353

The accompanying notes form part of these financial statements.

Statement of Financial Position for the Year ended 30 June 2004

	Note	2004 \$	2003 \$
CURRENT ASSETS			
Cash at call		367,143	415,726
Cash short term investments	2	489,100	479,365
Receivables		33,812	39,586
Other		11,148	-
Total Current Assets		901,203	934,677
NON CURRENT ASSETS			
Property, plant and equipment	3	17,663	21,540
Total Non Current Assets		17,663	21,540
TOTAL ASSETS		918,866	956,217
CURRENT LIABILITIES			
Accounts payable	4	41,383	107,643
Provision for annual leave		25,522	18,283
Provision for long service leave		15,840	14,324
Total Current Liabilities		82,745	140,250
NON CURRENT LIABILITIES			
Provision for long service leave		8,524	6,686
Total Non Current Liabilities		8,524	6,686
TOTAL LIABILITIES		91,269	146,936
NET ASSETS		827,597	809,281
FOUNDATION'S FUNDS			
Accumulated funds	5	626,399	606,353
Reserve	6	201,198	202,928
TOTAL FOUNDATION'S FUNDS		827,597	809,281

The accompanying notes form part of these financial statements.

Statement of Cash Flows for the Year ended 30 June 2004

	Note	2004 \$	2003 \$
CASH FLOWS FROM OPERATING ACTIVITIES			
Interest received		30,238	32,944
Grants received		265,623	347,481
Receipts from constituents		405,836	313,286
Payments to suppliers and employees		(735,459)	(533,929)
Net cash flows from operating activities		(33,762)	159,782
CASH FLOWS FROM INVESTING ACTIVITIES			
Acquisition and disposal of property, plant and equipment		(5,086)	(19,668)
Net cash flows used in investing activities		(5,086)	(19,668)
NET INCREASE/(DECREASE) IN CASH HELD		(38,848)	140,114
CASH BALANCE BROUGHT FORWARD		895,091	754,977
CASH BALANCE CARRIED FORWARD		856,243	895,091
Cash balance carried forward comprises:-			
Cash at call		367,143	415,726
Cash short term investments	2	489,100	479,365
		856,243	895,091
Reconciliation of (deficit)/surplus for the year to the net cash flows from operating activities:-			
Total operating (deficit)/surplus for the year		18,316	73,865
Depreciation and amortisation		8,963	3,899
Changes in assets and liabilities			
Increase/(Decrease) in creditors and provisions		(55,667)	94,919
(Increase)/Decrease in receivables and other assets		(5,374)	(12,901)
Net cash flows from operating activities		(33,762)	159,782

The accompanying notes form part of these financial statements.

Notes to the Financial Statements for the Year ended 30 June 2003

NOTE 1: STATEMENT OF SIGNIFICANT ACCOUNTING POLICIES

(a) Basis of the preparation of the accounts

The accounts have been prepared under accrual accounting principles and the convention of historical cost accounting.

The accounting policies adopted are consistent with those of the previous year unless otherwise specified.

(b) Property, plant and equipment

Property, plant and equipment are carried at cost.

Assets are depreciated at rates based on their expected useful economic lives using the straight line method.

The major depreciation periods for Furniture and Office Equipment are 3 to 10 years.

(c) Income Tax

The Foundation has obtained tax exempt status as a non profit organisation under Section 23 (e) of the Income Tax Assessment Act 1939.

(d) Employee benefits

Provision is made for annual leave estimated to be payable to employees on the basis of statutory and contractual requirements.

(e) Comparative amounts

Where necessary, the figures for the previous year have been reclassified to facilitate comparison.

(f) The impact of adopting Australian Equivalents to International Financial Reporting Standards

The Foundation is currently evaluating the key differences in accounting policies, identifying any changes required to the Foundation's financial reporting systems.

The adoption of International Financial Reporting Standards are not expected to have a material impact on the financial reporting of the Foundation.

NOTE 2: CASH SHORT TERM INVESTMENTS

	2004 \$	2003 \$
Perpetual Trustees	225,412	226,154
ANZ Trustees	96,717	94,163
Commonwealth Bank	166,971	159,048
	<u>489,100</u>	<u>479,365</u>

NOTE 3: PROPERTY, PLANT AND EQUIPMENT

Furniture and office equipment at cost	80,222	75,135
Accumulated depreciation	(62,559)	(53,595)
	<u>17,663</u>	<u>21,540</u>

	2004	2003
	\$	\$
NOTE 4: ACCOUNTS PAYABLE (CURRENT)		
Creditors and accruals	31,636	31,930
Amounts received in advance	9,747	71,998
Unexpended grant	-	3,715
	<u>41,383</u>	<u>107,643</u>

NOTE 5: ACCUMULATED FUNDS

Accumulated funds are set aside for the following purposes:-

- designated projects	61,174	72,865
- research	381,734	393,084
- discretionary reserve	183,491	140,404
	<u>626,399</u>	<u>606,353</u>

During the year there was a net transfer of \$8,400 (2003: \$8,400) from the Discretionary Reserve to Designated Projects to meet the Foundation's objective expenses.

NOTE 6: RESERVE

Damon Courtenay Reserve

- balance at beginning of year	202,928	195,333
- special appeals and interest income	8,270	7,595
- sponsorship and allocations	(10,000)	-
	(1,730)	7,595
- balance at end of year	<u>201,198</u>	<u>202,928</u>

The Damon Courtenay Memorial Endowment Fund was established with funds donated by the family of Damon Courtenay. The funds are to be set aside in a perpetual trust, with income generated being used to finance care, treatment, education and welfare of people with haemophilia and their families, subject to conditions specified by the Courtenay family.

NOTE 7: SEGMENT INFORMATION

The Foundation's objectives are to promote the welfare and education of all people affected by haemophilia and related bleeding disorders and to initiate and encourage research in Australia.

NOTE 8: RELATED PARTY TRANSACTIONS

The members of the Council of Haemophilia Foundation Australia Incorporated during the financial year ended 30 June 2004 were: -

Michele Albert (from November 2003)	Peter Mathews
Angela Bayly (to November 2003)	Kevin Murphy
Neil Boal	Ann Roberts
Rob Christie	Gary Ross (to August 2003)
Gavin Finkelstein	Geoff Sue
Joe Guarnieri	Nigel Williams
Glenn Irwin (from August 2003)	Sharyn Wishart
Robert Lamberth	

No material related party transactions occurred during the financial year.

NOTE 9: FINANCIAL INSTRUMENTS

The terms and conditions of each class of financial asset and liability of the Foundation at the balance date, are as follows:-

Financial Instrument	Note	Accounting Policies	Terms and Conditions
a) Financial Assets - Receivables		Carried at nominal amounts due, less any provision for doubtful debts.	Credit normally on 30 day terms
- Cash at call and cash short term investments	2	Cash short term investments are stated at net realisable value. Interest is recognised in the statement of income and expenditure when earned.	Short term deposits have maturity from one to twelve months. Other investments are at call. Effective interest rate is 3.67% (2003: 4.51%).
b) Financial Liabilities - Creditors and accruals	4	Liabilities are recognised for amounts to be paid in the future for goods and services received and for amounts received for the services to be provided in the future.	Liabilities are normally settled on 30 day terms.

Statement by the Executive

To the best of our knowledge and belief the financial report of Haemophilia Foundation Australia Incorporated, as set out on pages 10 to 16, is drawn up so as to fairly state the results of the Foundation for the year ended 30 June 2004 and the financial position of the Foundation as at that date.



GAVIN FINKELSTEIN
Treasurer



SHARON CARIS
Executive Director

Melbourne – 13 September 2004

INDEPENDENT AUDIT REPORT

To the members of Haemophilia Foundation Australia Incorporated

Scope

The financial report and executive committee's responsibility

The financial report comprises the statement of financial position, statement of financial performance, statement of cash flows, accompanying notes to the financial statements, and the executive committee declaration for Haemophilia Foundation Australia Incorporated (the association), for the year ended 30 June 2004.

The association's executive committee are responsible for preparing a financial report that presents fairly the financial position and performance of the association, and that complies with Accounting Standards in Australia, in accordance with the *Associations Incorporation Act 1981* and the association's constitution. This includes responsibility for the maintenance of adequate accounting records and internal controls that are designed to prevent and detect fraud and error, and for the accounting policies and accounting estimates inherent in the financial report.

Audit approach

We conducted an independent audit of the financial report in order to express an opinion on it to the members of the association. Our audit was conducted in accordance with Australian Auditing Standards in order to provide reasonable assurance as to whether the financial report is free of material misstatement. The nature of an audit is influenced by factors such as the use of professional judgement, selective testing, the inherent limitations of internal control, and the availability of persuasive rather than conclusive evidence. Therefore, an audit cannot guarantee that all material misstatements have been detected.

We performed procedures to assess whether in all material respects the financial report presents fairly, in accordance with the *Associations Incorporation Act 1981*, including compliance with Accounting Standards, other mandatory financial reporting requirements in Australia, and the association's constitution, a view which is consistent with our understanding of the association's financial position, and of its performance as represented by the results of its operations and cash flows.

We formed our audit opinion on the basis of these procedures, which included:

- examining, on a test basis, information to provide evidence supporting the amounts and disclosures in the financial report, and
- assessing the appropriateness of the accounting policies and disclosures used and the reasonableness of significant accounting estimates made by the committee of management.

While we considered the effectiveness of management's internal controls over financial reporting when determining the nature and extent of our procedures, our audit was not designed to provide assurance on internal controls.

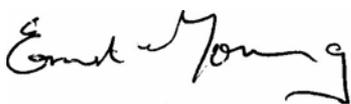
We performed procedures to assess whether the substance of business transactions was accurately reflected in the financial report. These and our other procedures did not include consideration or judgement of the appropriateness or reasonableness of the business plans or strategies adopted by the executive committee of the association.

Independence

We are independent of the association, and have met the independence requirements of Australian professional ethical pronouncements.

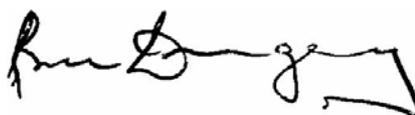
Audit opinion

In our opinion, the financial report of Haemophilia Foundation Australia Incorporated presents fairly, in accordance with the *Associations Incorporation Act 1981*, including compliance with Accounting Standards, other mandatory financial reporting requirements in Australia, and the association's constitution, a view which is consistent with our understanding of the association's financial position as at 30 June 2004, and of its performance as represented by the results of its operations and cash flows for the year then ended.



Ernst & Young

Melbourne, 28 September, 2004



R. Bruce Dungey

Partner

ACKNOWLEDGEMENTS

We are appreciative of the generous support of our Sustaining Patrons:

BioScience Division of Baxter Healthcare
 Bayer Healthcare – Biological Products Division
 CSL Bioplasma
 Wyeth

Haemophilia Foundation Australia sincerely thanks all individuals, organisations, service clubs, trusts and foundations for their support for education, care and service through the year:

INDIVIDUALS (Over \$150.00)

Mr Robert O Albert
 Mr David Allom
 Mrs Lorna Aplin
 Mr Paul Bedbrook
 Mr Leo Belcher
 Mr William D Bowness
 Ms Trish Britten
 Ms Jennifer Byrne
 Dr C Caton
 Ms Vicki Childs
 Mrs Mary Coles
 Mr Jeffrey Conen
 Lady Judy Court AM, MBE
 Mrs M L Croker
 Mr & Mrs D Cunningham
 Dr Philippa H Currie
 Mrs Sue Davidson
 Mr K R Eisner
 Mr E Fiani
 Dr J E Fildes OAM
 Mr Ian & Mrs Margaret Freer
 Mr Leslie E Gabriel
 Mr Geoffrey & Mrs Carol Gray
 Mr Antony Green
 Mr Bill & Mrs Betty Hansen
 Mrs N Hartley
 Mr Ian Hicks
 Mr K D Hill
 Mr Boyd C Holdenson
 Mr R J Howatson
 Dr H D Irish
 Mr B & Mrs V Ivory
 Mr & Mrs R V & S P Izzard
 Mrs Rae Janes
 Dr A C King
 Mrs Elizabeth Kirby
 Mr A L & Mrs L A Lane
 Ms Rosalind Lehane
 Ms Ann Lewis
 Mr N & Mrs C Meers
 Dr Robert Morton
 Professor M J Osborne
 Ms H Penfold
 Dr S & Mrs J Pilbrow
 Mr D W Rogers
 Mrs Jennifer Ross AO
 Mr J F Short
 Mrs M Stern
 Mr Simon & Mrs Edwina Storey
 Mrs Dawn Thorp
 Mrs Carolyn Tollemache
 Mr Simon Trinh

Mr E & Mrs G Troedson
 Mrs C R Truscott
 Sir Bruce & Lady Watson
 Mr F & Mrs M Wensing
 Major General R P Woollard AO
 The Hon Sir John Young AC KCMG

SERVICE CLUBS

Cabravale Ex-Active Club
 CWA of NSW - Lawson
 Inner Wheel Club of Gosford North
 International Association of Lions Clubs District 201N3
 Lioness Club of Woollongong Heights
 Lions Club of Adamstown
 Lions Club of Albury
 Lions Club of Armidale
 Lions Club of Arthurs Vale
 Lions Club of Avalon
 Lions Club of Bellingen
 Lions Club of Bingara
 Lions Club of Bonalbo-Upper
 Lions Club of Bondi
 Lions Club of Box Hill
 Lions Club of Bundarra
 Lions Club of Canberra Woden
 Lions Club of Canowindra
 Lions Club of Churchill & District
 Lions Club of City of Lismore
 Lions Club of Condobolin
 Lions Club of Coonamble
 Lions Club of Crookwell
 Lions Club of Darlington Point
 Lions Club of Daylesford/Hepburn Springs
 Lions Club of Engadine
 Lions Club of Figtree
 Lions Club of Frenchs Forest
 Lions Club of Goulburn City
 Lions Club of Grenfell
 Lions Club of Huntly Epsom
 Lions Club of King Island
 Lions Club of Lambton/New Lambton
 Lions Club of Lavington
 Lions Club of Maldon
 Lions Club of Mooroopna
 Lions Club of Moree
 Lions Club of Moss Vale
 Lions Club of Mount Martha
 Lions Club of Murrurundi
 Lions Club of Nambucca Heads
 Lions Club of Newcastle

Lions Club of Oaklands & District
 Lions Club of Raymond Terrace
 Lions Club of Robertson
 Lions Club of St Marys
 Lions Club of Stockton
 Lions Club of Strathmore
 Lions Club of Swansea
 Lions Club of Tamworth
 Lions Club of Tea Gardens
 Lions Club of Tooraweenah
 Lions Club of Torquay
 Lions Club of Toukley
 Lions Club of Walla Walla
 Lions Club of Wandong/Wallan
 Lions Club of Warners Bay
 Lions Club of Warrandyte
 Lions Club of Wentworth Falls
 Lions Club of West Wyalong
 Lions Club of Woonona
 Rotary Club of Albury West
 Rotary Club of Boggabri
 Rotary Club of Chester Hill
 Rotary Club of Grafton Midday
 Rotary Club of Morisset
 Rotary Club of Murrurundi
 Rotary Club of Sorrento
 Rotary Club of Temora
 Rotary Club of Traralgon

BUSINESSES

Abgal Pty Ltd
 Adtrans Automotive Group
 Atalina Nominees Pty Ltd
 Australian Hotels Limited
 Australian Productivity Council
 Baenziger Nominees Pty Ltd
 BMS Mitre 10
 BR Printing Pty Ltd
 Breville Pty Ltd
 Charles Parsons & Co Pty Ltd
 Charlesworth Nuts Pty Ltd
 Cowley Hearne Lawyers
 Crows Nest Bed & Breakfast
 Devro Pty Ltd
 Donnelley Constructions Pty Ltd
 Doug Hall Enterprises Pty Ltd
 Eaststyle Australia Pty Ltd
 Ernst & Young
 Fantech Pty Ltd
 Fax Doctor Pty Ltd
 Frank L Burns
 Golding Contractors Pty Ltd
 H Stevens Pty Ltd

Hannover Life Re of Australasia
 Hella Australia Pty Ltd
 Hollingsworth Greaves Medical
 Ian Boettcher Motors
 Integrated Memory Systems
 International Skin & Hides
 J J Richards & Sons Pty Ltd
 JB Were Foundation
 John Swire & Sons Pty Ltd
 Kailis Consolidated Pty Ltd
 Laing Real Estate
 Madill Motors Pty Ltd
 Matthews Constructions Pty Ltd
 Nissan Motor Co (Aust) Pty Ltd
 North Sydney Executive Centre
 Object Oriented Pty Ltd
 O'Briens, Solicitors
 Omnitex Industries Pty Ltd
 Perfecta Produce
 Pieter van Gent Winery
 Starr Partners
 Tasmanian Seafoods Pty Ltd
 Technology One
 Textile Clothing & Footwear
 Union, New South Wales Branch
 Total Hire & Sales Pty Ltd

TRUSTS & FOUNDATIONS

Carleton Family Trust
 Eirene Lucas Foundation
 Everglades Fund
 Flora & Frank Leith Charitable Trust
 Goldschlager Family Charity Foundation
 Greatorex Foundation
 Helen Macpherson Smith Trust
 JB Were Foundation
 Kraus Charitable Foundation
 L H Cornell Estate - Tower Trust
 L R Cazaly Trust Fund
 Lord Mayor's Charitable Fund
 Rosenblum Charitable Foundation
 William Angliss VIC Charitable Fund