About Haemophilia Foundation Australia

Haemophilia Foundation Australia (HFA) represents people with haemophilia, von Willebrand disorder and other related bleeding disorders and their families. We are committed to improving treatment and care through representation, education and the promotion of research. HFA supports a network of State and Territory Foundations in Australia. As a National Member Organisation of the World Federation of Hemophilia, HFA participates in international efforts to improve access to care and treatment for people with bleeding disorders around the world.

The Foundation was incorporated in 1986 after a history over several years of advocacy and providing support to people with haemophilia and their families.

Funded by government grants and donations from private companies, service organisations and individuals, the Foundation is governed by a Council of Delegates representing State/Territory Member Foundations which set policy and strategic objectives. A small staff team manages the operations of the organisation.

The Foundation is an income tax exempt not for profit organisation. Donations of $2 and over are tax deductible.

MEMBER FOUNDATIONS

HAEMOPHILIA FOUNDATION AUSTRALIAN CAPITAL TERRITORY
Major General Peter R Phillips, AO, MC., Patron

HAEMOPHILIA FOUNDATION NEW SOUTH WALES
Doctor I Roger Vanderfield, OBE., Patron

HAEMOPHILIA FOUNDATION QUEENSLAND
Her Excellency Ms Quentin Bryce, AC. Governor of Queensland, Patron

HAEMOPHILIA FOUNDATION SOUTH AUSTRALIA
Doctor Donald Handley, MBBS, FRACP, FRCPA., Patron

HAEMOPHILIA FOUNDATION TASMANIA
Lady Green, Patron

HAEMOPHILIA FOUNDATION VICTORIA
Sir James Gobbo, AC., Patron

HAEMOPHILIA FOUNDATION WESTERN AUSTRALIA
His Excellency Lieutenant General John Sanderson, AC. Governor of Western Australia, Patron

LIFE GOVERNORS

Jennifer Ross AO	Ted Troedson	Alison Bellamy
Maxine Ewart	Alan Ewart	Bevlee Cassell
Barbara Volk OAM	Fred Wensing	Mike Barry
Dawn Thorp	Bruce Fielding	Rob Christie
EXECUTIVE BOARD

Back, L-R: Gavin Finkelstein, Peter Mathews, Rob Christie
Front, L-R: Robert Lamberth, Sharyn Wishart, Ann Roberts

President
Ann Roberts, Victoria

Vice President
Peter Mathews, New South Wales

Treasurer
Gavin Finkelstein, Western Australia

Executive Members
Joe Guarnieri, Australian Capital Territory (to February 2005)
Robert Lamberth, Queensland
Sharyn Wishart, South Australia (from April 2005)

COUNCIL

Joe Guarnieri (to February 2005) Australian Capital Territory
Christopher Wensing (from March 2005)

Glenn Irwin (to September 2004) Hunter Valley

Peter Mathews New South Wales

Kevin Murphy

Robert Lamberth

Michele Albert (to September 2004) Queensland
Janet Rogers (from September 2004)

Rob Christie South Australia

Sharyn Wishart

Nigel Williams Tasmania

Ann Roberts Victoria

Neil Boal

Gavin Finkelstein

Geoff Sue (to August 2004) Western Australia

David Bell (from August 2004)

STAFF

Back (L-R) Carol McCaskie, Development/Administration Assistant (Part-time), Natasha Coco, Development Manager

Front (L-R) Heather Lauder, Executive Secretary (Part-time), Sharon Caris, Executive Director

Not pictured:
Kevin Lai, Accountant (Part-time)
I am pleased to present my second report to the Haemophilia Foundation Australia (HFA) Council and to the bleeding disorders’ community.

It has been a year of consolidation for HFA. Our ongoing and regular activities around education, advocacy and research have continued in line with our objectives and we have met our obligations to our members.

**Strategic Planning**
We commenced a strategic planning process in October 2004 and work has continued through the year to develop a shared agreement and commitment to strategic directions for the organisation as we move forward.

**Governance**
To ensure that HFA is a transparent, efficient and effective organisation capable of delivering its objectives.

**Financial Sustainability**
To ensure that HFA is financially sustainable with sufficient resources to achieve identified objectives and accountable to its supporters.

**Advocacy**
To ensure best practice treatment standards and quality of life for people with haemophilia, von Willebrand disorder and other rare bleeding disorders, to minimise the risk of adverse complications of treatment and ensure best practice treatment and care for people with blood borne viruses.

**Education and Information**
To promote knowledge and community awareness of haemophilia and related blood disorders and facilitate information, education and knowledge exchange for people with haemophilia and related blood disorders and their carers, health professionals and policy makers.

**International Development**
To contribute to the development of treatment standards and care in the developing world through participation in twinning and other collaborations.

**Research**
To build capacity to support Australian based scientific, medical, and psychosocial research to benefit the bleeding disorders community and their families.

**Youth Development**
To support and encourage leadership and mentoring opportunities for our young people to support them towards independent and fulfilling lives, and respond to the changing needs of our community.

Last year I expressed my great disappointment and frustration that our need for increased access to recombinant treatment products for all people with haemophilia, regardless of age and viral status was still not fulfilled.

This had been a long battle for HFA. The emerging risks of known and unknown pathogens that might come through the blood supply could be avoided for many people if they had access to recombinant alternatives. The potential for vCJD to be transmitted through blood was recognised by authorities worldwide, and there was great anxiety in the international bleeding disorders’ community.
We started the year with a new resolve to press harder to ensure our community had access to adequate supplies of the safest products for their care. The efforts of many were finally rewarded in August 2004 when Federal Health Minister Tony Abbott advised HFA that safer recombinant treatments would be funded for everyone. This is a great achievement for all Australians with haemophilia and it means that from the last half of this year everyone had access to recombinant products regardless of age, and blood borne virus status. Whilst it is expected that most people will switch to recombinant clotting factors the decision to do so must be a decision made by the patient on the basis of sound clinical advice.

I wish to thank all those who participated at various levels of this special challenge. Just as the changes that brought prophylaxis for children and home therapy some years ago, this is a major development and one which means treatment opportunities in Australia are equal to world wide standards for best practice. We must remain aware of new developments, new products, and new threats to the safety and supply of treatment products, including the safety and quality of plasma derivatives for whom recombinant alternatives are not suitable.

We have other challenges. Our community still suffers from the effects of blood borne viruses and we have much to do in the area of hepatitis C particularly. Many people have lived with a long history of hepatitis C and are experiencing more symptoms and difficulties. We are facing new challenges for our members, including decisions about treatment, financial issues and the need for education and support. The financial burden on people undergoing treatment is overwhelming for many. We need to find a solution that will provide individuals and their families with the care, treatment and support they need whilst they undergo treatment and deal with the consequences for their life post treatment, whether or not treatment is successful. We need to pursue this urgently and progress our efforts for recompense to ensure people have the financial resources they need.

HFA and its members continue their work with World Federation of Hemophilia (WFH) and I am pleased the Australian bleeding disorders’ community had strong participation in the International Congress of the World Federation of Hemophilia in Bangkok in October 2004. The contribution of Australians at that meeting – those with bleeding disorders, health professionals, research leaders and policy makers demonstrated the achievements in this country and the high level of goodwill and commitment to excellence. We were pleased to welcome Mark Skinner who was elected President of WFH at the WFH General Assembly and delighted that Rob Christie, immediate past president of HFA, was elected to the WFH Executive Committee as Vice President, Finance.

I am pleased to report that State/Territory Foundations were fully represented at the Council Meeting held in October 2004. The Executive Board met in Melbourne on 3 occasions and had 5 teleconferences during the year. As I finish my term of office, I thank Council and the Executive Board, State/Territory Foundations and HFA staff for their effective collaboration during the year.

Our achievements would not be possible without the support of other health sector stakeholders, health professionals at haemophilia centres around Australia, our volunteers, donors, and valued Sustaining Patrons to whom we are extremely grateful for their support.
I am pleased to report the Foundation had a strong year in which it consolidated plans and established directions for the future. We maintained a steady financial performance and ensured the organisation met its objectives for advocacy, education and research. I have reported several of our key activities for the interest of members and supporters.

**Research**

The Haemophilia Foundation Research Fund has provided for 14 research projects over its eleven year history, representing a total amount of $288,198.70. The multidisciplinary Haemophilia Foundation Research Fund Committee recommends grants each year to the Executive Board. The Committee is comprised of representatives from HFA Council, Australian Haemophilia Centre Directors’ Organisation, the Australian Haemophilia Nurses’ Group, Australian Haemophilia Counsellors’ and Social Workers’ Group, and the Australia and New Zealand Physiotherapy Haemophilia Group. We thank Committee members for their commitment and support throughout the year.

The HFA Board will review the Fund’s objectives and operations with a view to ensuring it is sustainable and responsive to the future needs of the community.

Although an amount of $50,000 was allocated for new research projects for 2004-2005, a change in the timing of the application process will mean the 2005 grant allocations will be finalised in July 2005.

Final payments for grants in the previous year were made to:

- Dr Greg Hodge, Women’s & Children’s Hospital, Adelaide - $7,145 Investigation of the immunomodulatory effects of factor VIII concentrate on leucocyte cytokine receptor expression in vitro, with relevance to immune mechanisms involved with inhibitor formation and tolerance induction

- Dr Stuart Roberts, Gastroenterology Department, The Alfred, Melbourne - $12,752.35 Pharmacogenomics of Interferon Ribavirin treatment in chronic hepatitis C infection

The Fund has limited capacity for growth without specific fundraising campaigns. We were honoured this year to have been selected by the Country Women’s Association of NSW as one of its special causes for fundraising in 2004. HFA was presented with a donation of $30,400 at the Country Women’s Association of NSW AGM in May 2005 attended by Sharon Caris, Executive Director, who told members about the Fund and the work of HFA. Professor Kevin Rickard also attended the AGM and described how research has improved clinical outcomes and contributed to the improvement of care and treatment of children and adults in Australia.

**Health Professionals**

HFA auspices and supports special interest health professionals’ groups to provide leadership and enhance comprehensive haemophilia care around the country. During the year we have maintained our strong commitment to the support and education of health professionals and encouraged collaboration between specialist haemophilia nurses, physiotherapists and counsellors and the bleeding disorders’ community.

The annual meeting of the Australia and New Zealand Physiotherapy Haemophilia Group was held in Melbourne in November 2004 and was attended by physiotherapists from haemophilia centres around Australia. The Australian Haemophilia Nurses’ Group met in Melbourne in November 2004. Two meetings of the Australian Haemophilia Counsellors’ and Social Workers’ Group were held during the year. The first meeting was held in Melbourne in August 2004 and a further meeting was held in Sydney in May 2005.
Members of each of the health professionals’ groups have generously volunteered their time to work with HFA to develop the scientific and psychosocial program for the 13th National Haemophilia Conference in September 2005. The multidisciplinary committee is Chaired by Dr Chris Barnes, Director of the Henry Ekert Haemophilia Treatment Centre at the Royal Children’s Hospital in Melbourne and its membership includes health professionals from haemophilia centres around the country.

During the year the bleeding disorders’ community farewelled Ms Morag McColm, whose work as a counsellor at the Royal Brisbane Hospital spans 14 years. Morag has supported HFA greatly in her role as Chair of the Australian Haemophilia Counsellors’ and Social Workers’ Group over many years, and as an HFA representative at international meetings. Morag worked hard to ensure the psychosocial needs of individuals and their families have been considered in local and national policies and service development.

HFA maintained strong links with the Australian Haemophilia Centre Directors’ Organisation (AHCDO) during the year. AHCDO locates its office at the HFA offices in Glen Iris. HFA and AHCDO consult regularly on policy issues which affect the care and treatment of people with bleeding disorders.

We joined the clinical and patient community to farewell Professor Henry Ekert as he retired from the Royal Children’s Hospital in Melbourne, Professor Kevin Rickard who retired from the Royal Prince Alfred Hospital in Sydney, and Dr Bill McWhirter who left the Royal Children’s Hospital in Brisbane during the year. Each of these clinicians has devoted many years of valuable service to the bleeding disorders’ community.

Each of the special interest groups are valuable stakeholders in the bleeding disorders’ community and HFA encourages their participation in the development of health policy, service development and education through committee representation, consultation and program support. We thank the Chairs of each group for their work throughout the year.

**Damon Courtenay Memorial Endowment Fund**

The Fund was established as a perpetual trust in 1993 by Benita and Bryce Courtenay in memory of their son, Damon, for the benefit of the bleeding disorders’ community. A distribution from the Damon Courtenay Memorial Endowment Fund will be made in the 2005-2006 period.

**Youth Leadership And Mentoring Program**

The HFA Youth Committee continued to grow in strength and numbers. Since convening after the 2003 National Conference in Queensland regular teleconferences have been used to develop a national youth agenda. A youth leadership training weekend held in Melbourne from 16-18 July 2004 was attended by HFA Youth Committee members from Tasmania, Victoria, WA, ACT and NSW. The training focused on leadership and mentoring skills, communication and health issues. Collaboration with State/Territory Foundations to enable these enthusiastic young people to participate as volunteers in their local environment will further consolidate their skills and expertise and give them confidence to move forward. HFA staff and health professionals provided information and support at the training weekend and supported the Committee in its objectives. The Committee now regularly prepares material for the youth supplement in National Haemophilia and reports on activities to the HFA Council. A code of conduct has been developed by the Committee and the Committee is also actively working on a youth stream for the program of the 13th National Haemophilia Conference in September 2005.

![Youth Committee 2004/2005](image)

(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 Szynter (TAS), Chairperson; Craig Bardsley (QLD), Member; Natasha Coco, HFA Representative.
**Education And Information**

**INSPIRE - TAI CHI AND YOGA FOR ADULTS WITH BLEEDING DISORDERS**

Our exciting new education DVD resource was launched by Professor Richard Olley, District Manager of the Royal Brisbane & Women's Hospital on 18 April 2005 in association with World Haemophilia Day which is celebrated on 17 April around the world.

The idea for INSPIRE came from Rebecca Dalzell's work as a haemophilia physiotherapist at the Royal Brisbane & Women's Hospital. Rebecca developed the project with qualified Yoga and Tai Chi instructors and a group of men with bleeding disorders were filmed as they learned the specially tailored techniques in classes at the Royal Brisbane Hospital.

On the DVD Yoga and Tai Chi are each demonstrated as excellent forms of exercise for people with bleeding disorders as they can improve strength, range of movement, endurance, balance, posture and general well being. The movements are shown to be achieved within safe and comfortable limits and are gentle and easy to follow, and can be done at home.

The DVD was a result of collaboration between HFA, the Royal Brisbane & Women's Hospital, Australia & New Zealand Physiotherapy Haemophilia Group and CSL Bioplasma which generously provided the funding for the project.

The DVD is the first of its kind made specifically for the bleeding disorders' community and requests for copies have been received from around Australia and several overseas countries.

**XXVI INTERNATIONAL CONGRESS OF WORLD FEDERATION OF HEMOPHILIA, 17-21 OCTOBER 2004**

The 2004 World Congress held in Bangkok, Thailand was the 26th for WFH and was attended by more than 3,600 people from around the world. Up to date issues about treatment and care, safety and supply of treatment products, new technologies and achievements from around the world were shared by health professionals, people with haemophilia, patient organisations and industry. Australians were well represented as speakers and active participants at the Congress. HFA supported several community members and health professionals to attend the meeting and we are delighted these representatives have brought back new knowledge and information to share with the Australian bleeding disorders’ community.
**Web Site**

The HFA web site is a key tool for education and community awareness and is used increasingly by bleeding disorders’ community members for information and the general community. The number of hits averaged 83,049 per month and more than doubled compared to the previous year. We have achieved significant efficiencies by referring school students to the web site for education material for school projects.

**Support To Members**

HFA works with State/Territory Haemophilia Foundations to ensure activities reflect the needs of their members. HFA staff have regular communication with Foundations through annual visits by the Executive Director, regular communications and mailings to Council Delegates and other processes. HFA provided financial support to State and Territory Foundations to run activities such as camps and workshops and several new project initiatives throughout the year. Funding allocations are made each year on the basis of the needs identified by State/Territory Foundations. Further to this locally based work, HFA works collaboratively with Foundations and other stakeholders to develop submissions and positions to inform opinion for the development of policy and services which affect our community.

**Stakeholder Relationships**

The Foundation collaborates with other organisations to achieve its objectives. We work closely with other consumer and advocacy organisations and through our membership of government and other committees we can ensure the views of our community are represented. During the year we have consulted with government officials in several areas on blood and policy, treatment product safety, supply and availability, blood borne viruses and other health issues. We have made submissions to several government departments and provided advice to government officials on matters affecting the bleeding disorders’ community. I sincerely thank the many individuals and community organisations and government officials with whom the Foundation works to achieve its objectives for their support during the year.

**Snapshots**

- **Capturing History**

  Haemophilia Foundation Victoria (HFV) is one of the oldest haemophilia support organisations in the world. During 2003 and 2004 HFA contributed funds to enable this history to be written and this year a small amount was provided to launch the book, *Achieving the Extraordinary: Haemophilia Foundation Victoria 1954-2004* at the HFV 50th Anniversary celebrations.
- **Men’s Support**  
Haemophilia Foundation Victoria’s Men’s Support Group regular Men’s Breakfast provides an opportunity for men with bleeding disorders to meet in an informal environment to exchange information, network and benefit from the support of peers who share common concerns and health problems. The group has been running for several years and has become a model for similar support groups in other States. The group was funded partly by HFA (70%) and Haemophilia Foundation Victoria and was able to meet eight times throughout the year.

- **Family Camps**  
Family camps are an effective way for families affected by bleeding disorders to come together, reduce social isolation, share experiences and support each other. A major focus of camps might be to provide respite for parents or for children to learn new skills and develop confidence in a relaxed environment so that they can live more independent lives. They provide a safe environment for children to learn how to treat themselves and for family members to relax in the knowledge that their children with bleeding disorders will be well cared for whilst they are having fun. The experience of attending camps with others with bleeding disorders often leads to families becoming more confident about their children attending school camps and other activities on their own. Some camps are designed for respite for parents and carers. Health professionals and others often attend the camps to support learning and skills development and build and foster relationships between families and their health care providers. HFA contributed funds for family camps run by Haemophilia Foundation New South Wales, Haemophilia Foundation Victoria and Haemophilia Foundation Queensland which were attended by over 250 families and individuals during the year.

- **Support for Women and Carers**  
Peer support groups for female carers of men and boys with bleeding disorders, women who have a bleeding disorder or those who are carriers of the haemophilia gene are important ways for women to share information about their experiences and get support from one another. HFA provided financial support to Haemophilia Foundation Victoria for this group of members in June. HFA funded Haemophilia Foundation Western Australia to run several parents’ meetings and carers’ meetings for its members during the year. The parents’ group enables parents to come together and share their experiences and is particularly helpful for parents with children who are newly diagnosed with bleeding disorders. They are often held at playgrounds or play centres so that children can participate and interact with others. The carers’ group is attended by people who are caring for people with bleeding disorders and other complication such as blood borne viruses and partners who are new to haemophilia.

- **Swimming for Health and Fitness**  
A swimming program for younger members of Haemophilia Foundation South Australia was implemented during the year. Swimming is an excellent form of exercise for people with bleeding disorders as it helps improve muscle and joint strength. Swimming is therefore a good sport choice for children with bleeding disorders and it has the potential for achievement and excellence, and more importantly, it can be fun.
Community Awareness
Raising community awareness is an important focus for Haemophilia Foundation Australia and we achieve this through Haemophilia Awareness Week, public speaking engagements and media campaigns on specific issues.

Haemophilia Awareness Week was combined with Global Feast and World Haemophilia Day which is celebrated in April. State/Territory Foundations joined with HFA and the international haemophilia community to raise awareness and educate the community about the needs of people with bleeding disorders. Community achievements are celebrated and awareness raising events are organised around Australia. HFA Council accepted a recommendation that Haemophilia Awareness Week would be moved to October in future years.

Public Speaking
Members of the bleeding disorders’ community and the Development Manager and/or Executive Director were invited as guest speakers at several service club meetings throughout the year; and participated in live and recorded radio interviews which provided an opportunity to highlight the issues for people living with bleeding disorders.

Fundraising
Our objectives for Fundraising are met through relationships created through mail campaigns, grants from Trusts and Foundations, and our strong connections with many corporate and individual donors.

Appeals
Four appeals were run during the year to coincide with Spring, Christmas, Autumn and Winter (Tax). These appeals were successful and raised over $79,000.

H.link is the main donor newsletter which highlights HFA programs and services and is directed to donors and supporters of our cause. It is mailed quarterly together with our appeals.

HFA is supported by many types of donors including individuals, businesses, service clubs, churches and schools. Donations are directed to education resources and programs and services provided to members of the bleeding disorders’ community.
Trusts and Foundations
HFA relies significantly on Trusts and Foundations and many applications were made throughout the year to State/Territory and national bodies. We appreciate the support of:

- Australian Executor Trustees Limited, Department of Family & Community Service (Volunteer Grant),
- Everglades Fund, Freemason’s Public Charitable Foundation, Goldschlager Family Charity Foundation,

The funds received from these Trusts and Foundations supported programs including family camps in Victoria and New South Wales, Haemophilia Foundation Victoria Men’s Group, a swimming program in South Australia, HFA Youth Mentoring and Leadership Program, Haemophilia Foundation Research Fund and included specific grants for equipment to support the operations of HFA.

Global Feast

We celebrated Global Feast during April. This is a new initiative of the World Federation of Hemophilia to raise funds to improve care and treatment around the world. Haemophilia Foundation Australia joined with haemophilia communities in Ireland, New Zealand, and the UK to jointly raise awareness and develop this new fundraising event.

A highlight for Australia was the HFA Global Feast Lunch with Gabriel Gate, well renowned French chef. Over 60 people enjoyed an afternoon of fine food and drink and listened to Gabriel’s personal “global feast” experiences. A special raffle was run in conjunction with the event and winning tickets were drawn at the lunch. Supporters across the nation, including business and service clubs, also hosted morning and afternoon teas in support of Global Feast.

(From left to right:)
Gabriel Gate and 1st prize raffle winner Rae Janes
Sharon Caris, Gabriel Gate, Ann Roberts, A/Prof Alison Street
Gabriel Gate during his speech
It is my pleasure to present the Haemophilia Foundation Australia financial reports for 2005. The overall picture is sound, and HFA has the capacity to move forward to achieve its objectives.

Income from government grants remained stable. Income from fundraising and donations decreased by 28% from $397,451 to $287,825. This is largely accounted for by the nature of, and opportunities for special events held during the year, however it is important to note that general donations and those from trusts and foundations increased marginally from the previous year. HFA took a conservative approach, exercised caution with expenditure, and introduced novel appeals as it maintained a watching brief when it was feared that we may have been adversely affected by international events also requiring support during the year. HFA was not significantly affected by these external factors however, and maintained its strong and loyal general donor base.

Investment income grew by 24% during the year due to an increase in effective interest rate of 4.57% during the year compared to 3.67% in 2004. A feature of HFA’s financial risk management is to ensure surplus funds are mainly invested in short term interest bearing securities.

Member organisation levies increased by $9,850 during the year in line with agreements that State/Territory Foundations will contribute to the cost of funding delegates to attend the World Federation of Hemophilia Congress.

Honorariums received for Executive Director’s participation on special committees and HFA reimbursement for costs associated with office space occupied by Australian Haemophilia Centre Directors’ Organisation has increased by 150% in the period and is reflected as “other income” in the financial statements.

HFA’s Operating Expenses decreased by 7% from $374,171 to $347,286 during the year; and although administration expenses increased marginally, most component costs, including office property expenses, remained steady. The decrease reported in fundraising expenses is associated with reduced costs associated with the Cocktail Party event. Other fundraising expenses remained stable compared to the previous year and this is accounted for by regular appeals and activities with predictable expenses.

HFA’s Objectives Expenses decreased by 36% from $312,925 to $199,442 during the year; however this is consistent with the budget and the special projects that were planned. HFA funded State/Territory Foundations for camps and workshops and other education activities based on the identified needs of each member Foundation. Consultancy around advocacy for best practice treatment products was completed and there was no national conference in the period as there has been in the previous period. Other expenses associated with Objectives (newsletters, health professionals, education and research) remain steady for these recurrent activities. Specific education projects for the year included the Tai Chi/Yoga DVD and further distribution of the education handbook for parents with newly diagnosed children with haemophilia. HFA joined with World Federation of Hemophilia (WFH) in its new fundraising activity, Global Feast, this year, and will consider implications of further collaborative work with WFH in the next period. There was no Damon Courtenay Memorial Endowment Fund (DCMEF) distribution in this year; however there is expected to be a distribution in line with the Trust requirements in 2005-2006.

A funding review was conducted by the Department of Health and Ageing in May 2005. This has led to a further three year Agreement which provides financial stability for some of our operational and objectives expenses. Government grants provide a degree of certainty but these grants must be negotiated periodically in line with HFA objectives.
and achievements and government requirements. HFA therefore needs to be vigilant to ensure it has explored all options so that it is sustainable and accountable to its members, donors and government funding bodies.

HFA has reported a surplus of $68,469 this year, and total Foundation’s Funds of $896,066, an increase of 8% from the previous year. As at 30 June 2005, the Haemophilia Foundation Research Fund and funds held under the DCMEF accounted for approximately 70% of the total Foundation’s Funds.

HFA is in a strong position as it moves forward to 2006. I wish to thank the HFA Council and Board for its support and the work of HFA staff throughout the year.
# FINANCIALS
Haemophilia Foundation Australia Incorporated
Statement of Financial Performance for the Year ended 30 June 2005

<table>
<thead>
<tr>
<th>Note</th>
<th>2005</th>
<th>2004</th>
</tr>
</thead>
<tbody>
<tr>
<td>INCOME</td>
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<tr>
<td>Commonwealth government grants</td>
<td>268,483</td>
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<tr>
<td>Fundraising and donations</td>
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<td>Gross profit/(loss) from sales</td>
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<td>Interest</td>
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<td>State member levies</td>
<td>11,847</td>
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<td>Other income</td>
<td>9,019</td>
<td>3,601</td>
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<tr>
<td>TOTAL INCOME</td>
<td>615,197</td>
<td>705,412</td>
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</table>

| LESS : FOUNDATION OPERATING EXPENSES |        |        |
| Administration                     |        |        |
| Advertisement/recruitment          | -      | 350    |
| Audit                              | 9,750  | 8,250  |
| Annual reports                     | 1,318  | 4,905  |
| Bank charges and service charges   | 1,398  | 2,289  |
| Council meetings                   | 9,189  | 7,531  |
| Executive meetings                 | 13,292 | 16,643 |
| Legal and consultancy fees        | 1,630  | -      |
| Personnel expenses                | 205,060| 197,316|
| Professional insurance            | 3,966  | 4,198  |
| Provision for long service leave  | 6,798  | 3,354  |
| Resource material                  | -      | 543    |
| Staff amenities and training       | 1,604  | 755    |
| Superannuation                     | 17,729 | 16,516 |
| Travel                             | 1,387  | -      |
| Liaison and business development  | 999    | 1,008  |
|                                   | 274,120| 263,658|

| Property                        |        |        |
| Depreciation                    | 8,851  | 8,963  |
| Electricity and gas             | 2,819  | 2,809  |
| Insurance                       | 1,482  | 1,617  |
| Rent                            | 29,169 | 27,152 |
| Repairs and maintenance         | 4,005  | 5,331  |
| Security                        | 364    | 364    |
|                                 | 46,690 | 46,236 |

| Fundraising                     |        |        |
| Appeals and production          | 20,164 | 53,643 |
| Planned giving                  | 1,556  | 529    |
| Resource development and travel | 4,756  | 10,105 |
|                                 | 26,476 | 64,277 |

| TOTAL FOUNDATION OPERATING EXPENSES | 347,286 | 374,171 |
| SURPLUS OF INCOME OVER OPERATING EXPENSES | 267,911 | 331,241 |

The accompanying notes form part of these financial statements.
## Statement of Financial Performance for the Year ended 30 June 2005 (cont...)

<table>
<thead>
<tr>
<th>Note</th>
<th>2005</th>
<th>2004</th>
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<td>SURPLUS OF INCOME BROUGHT FORWARD</td>
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<td>LESS : FOUNDATION OBJECTIVES EXPENSES</td>
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<tr>
<td>Newsletter</td>
<td>16,998</td>
<td>16,149</td>
</tr>
<tr>
<td>Postage</td>
<td>6,683</td>
<td>10,339</td>
</tr>
<tr>
<td>Printing and stationery</td>
<td>10,127</td>
<td>11,254</td>
</tr>
<tr>
<td>Specific project expenses</td>
<td>49,297</td>
<td>42,164</td>
</tr>
<tr>
<td>Sponsorship and allocations</td>
<td>-</td>
<td>10,000</td>
</tr>
<tr>
<td>Subscriptions</td>
<td>3,717</td>
<td>2,856</td>
</tr>
<tr>
<td>Telephone</td>
<td>7,820</td>
<td>9,976</td>
</tr>
<tr>
<td>Travel</td>
<td>4,175</td>
<td>1,613</td>
</tr>
<tr>
<td>Volunteers’ expenses</td>
<td>139</td>
<td>407</td>
</tr>
<tr>
<td></td>
<td>175,810</td>
<td>288,417</td>
</tr>
<tr>
<td><strong>Education</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Brochures and literature</td>
<td>750</td>
<td>282</td>
</tr>
<tr>
<td>Community education</td>
<td>3,285</td>
<td>1,137</td>
</tr>
<tr>
<td></td>
<td>4,035</td>
<td>1,419</td>
</tr>
<tr>
<td><strong>Research</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Research grants allocated</td>
<td>18,088</td>
<td>23,089</td>
</tr>
<tr>
<td>Research grants incidental costs</td>
<td>1,509</td>
<td>-</td>
</tr>
<tr>
<td></td>
<td>19,597</td>
<td>23,089</td>
</tr>
<tr>
<td>TOTAL FOUNDATION OBJECTIVES EXPENSES</td>
<td>199,442</td>
<td>312,925</td>
</tr>
<tr>
<td>TOTAL SURPLUS / (DEFICIT) FOR THE YEAR</td>
<td>68,469</td>
<td>18,316</td>
</tr>
<tr>
<td>ACCUMULATED FUNDS BROUGHT FORWARD</td>
<td>626,399</td>
<td>606,353</td>
</tr>
<tr>
<td>TOTAL AVAILABLE FUNDS</td>
<td>694,868</td>
<td>624,669</td>
</tr>
<tr>
<td>TRANSFER (TO) / FROM RESERVE</td>
<td>6</td>
<td>(9,211)</td>
</tr>
<tr>
<td>ACCUMULATED FUNDS CARRIED FORWARD</td>
<td>5</td>
<td>685,657</td>
</tr>
</tbody>
</table>

The accompanying notes form part of these financial statements.
# Statement of Financial Position for the Year ended 30 June 2005

<table>
<thead>
<tr>
<th>Note</th>
<th>2005</th>
<th>2004</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>$</td>
<td>$</td>
</tr>
<tr>
<td><strong>CURRENT ASSETS</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cash at call</td>
<td>462,738</td>
<td>367,143</td>
</tr>
<tr>
<td>Cash short term investments</td>
<td>514,246</td>
<td>489,100</td>
</tr>
<tr>
<td>Receivables</td>
<td>35,684</td>
<td>33,812</td>
</tr>
<tr>
<td>Other</td>
<td>15,000</td>
<td>11,148</td>
</tr>
<tr>
<td><strong>Total Current Assets</strong></td>
<td>1,027,668</td>
<td>901,203</td>
</tr>
<tr>
<td><strong>NON CURRENT ASSETS</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Property, plant and equipment</td>
<td>13,501</td>
<td>17,663</td>
</tr>
<tr>
<td><strong>Total Non Current Assets</strong></td>
<td>13,501</td>
<td>17,663</td>
</tr>
<tr>
<td><strong>TOTAL ASSETS</strong></td>
<td>1,041,169</td>
<td>918,866</td>
</tr>
<tr>
<td><strong>CURRENT LIABILITIES</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Accounts payable</td>
<td>84,004</td>
<td>41,383</td>
</tr>
<tr>
<td>Provision for annual leave</td>
<td>29,937</td>
<td>25,522</td>
</tr>
<tr>
<td>Provision for long service leave</td>
<td>17,320</td>
<td>15,840</td>
</tr>
<tr>
<td><strong>Total Current Liabilities</strong></td>
<td>131,261</td>
<td>82,745</td>
</tr>
<tr>
<td><strong>NON CURRENT LIABILITIES</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Provision for long service leave</td>
<td>13,842</td>
<td>8,524</td>
</tr>
<tr>
<td><strong>Total Non Current Liabilities</strong></td>
<td>13,842</td>
<td>8,524</td>
</tr>
<tr>
<td><strong>TOTAL LIABILITIES</strong></td>
<td>145,103</td>
<td>91,269</td>
</tr>
<tr>
<td><strong>NET ASSETS</strong></td>
<td>896,066</td>
<td>827,597</td>
</tr>
<tr>
<td><strong>FOUNDATION’S FUNDS</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Accumulated funds</td>
<td>685,657</td>
<td>626,399</td>
</tr>
<tr>
<td>Reserve</td>
<td>210,409</td>
<td>201,198</td>
</tr>
<tr>
<td><strong>TOTAL FOUNDATION’S FUNDS</strong></td>
<td>896,066</td>
<td>827,597</td>
</tr>
</tbody>
</table>

The accompanying notes form part of these financial statements.
Statement of Cash Flows for the Year ended 30 June 2005

<table>
<thead>
<tr>
<th>Note</th>
<th>2005</th>
<th>2004</th>
</tr>
</thead>
<tbody>
<tr>
<td>CASH FLOWS FROM OPERATING ACTIVITIES</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Interest received</td>
<td>37,584</td>
<td>30,238</td>
</tr>
<tr>
<td>Grants received</td>
<td>268,483</td>
<td>265,623</td>
</tr>
<tr>
<td>Receipts from constituents</td>
<td>309,130</td>
<td>405,836</td>
</tr>
<tr>
<td>Payments to suppliers and employees</td>
<td>(489,767)</td>
<td>(735,459)</td>
</tr>
<tr>
<td>Net cash flows from operating activities</td>
<td>125,430</td>
<td>(33,762)</td>
</tr>
<tr>
<td>CASH FLOWS FROM INVESTING ACTIVITIES</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Acquisition and disposal of property, plant and equipment</td>
<td>(4,689)</td>
<td>(5,086)</td>
</tr>
<tr>
<td>Net cash flows used in investing activities</td>
<td>(4,689)</td>
<td>(5,086)</td>
</tr>
<tr>
<td>NET INCREASE/(DECREASE) IN CASH HELD</td>
<td>120,741</td>
<td>(38,848)</td>
</tr>
<tr>
<td>CASH BALANCE BROUGHT FORWARD</td>
<td>856,243</td>
<td>895,091</td>
</tr>
<tr>
<td>CASH BALANCE CARRIED FORWARD</td>
<td>976,984</td>
<td>856,243</td>
</tr>
<tr>
<td>Cash balance carried forward comprises : -</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cash at call</td>
<td>462,738</td>
<td>367,143</td>
</tr>
<tr>
<td>Cash short term investments</td>
<td>514,246</td>
<td>489,100</td>
</tr>
<tr>
<td></td>
<td>976,984</td>
<td>856,243</td>
</tr>
<tr>
<td>Reconciliation of (deficit)/surplus for the year to the net cash flows from operating activities : -</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total operating (deficit)/surplus for the year</td>
<td>68,469</td>
<td>18,316</td>
</tr>
<tr>
<td>Depreciation and amortisation</td>
<td>8,851</td>
<td>8,963</td>
</tr>
<tr>
<td>Changes in assets and liabilities</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Increase/(Decrease) in creditors and provisions</td>
<td>53,834</td>
<td>(55,667)</td>
</tr>
<tr>
<td>(Increase)/Decrease in receivables and other assets</td>
<td>(5,724)</td>
<td>(6,374)</td>
</tr>
<tr>
<td>Net cash flows from operating activities</td>
<td>125,430</td>
<td>(33,762)</td>
</tr>
</tbody>
</table>

The accompanying notes form part of these financial statements.
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.

<table>
<thead>
<tr>
<th></th>
<th>2005</th>
<th>2004</th>
</tr>
</thead>
<tbody>
<tr>
<td>NOTE 2: CASH SHORT TERM INVESTMENTS</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Perpetual Trustees</td>
<td>235,731</td>
<td>225,412</td>
</tr>
<tr>
<td>ANZ Trustees</td>
<td>102,479</td>
<td>96,717</td>
</tr>
<tr>
<td>Commonwealth Bank</td>
<td>176,036</td>
<td>166,971</td>
</tr>
<tr>
<td></td>
<td>514,246</td>
<td>489,100</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>2005</th>
<th>2004</th>
</tr>
</thead>
<tbody>
<tr>
<td>NOTE 3: PROPERTY, PLANT AND EQUIPMENT</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Furniture and office equipment at cost</td>
<td>84,911</td>
<td>80,222</td>
</tr>
<tr>
<td>Accumulated depreciation</td>
<td>(71,410)</td>
<td>(62,559)</td>
</tr>
<tr>
<td></td>
<td>13,501</td>
<td>17,663</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>2005</th>
<th>2004</th>
</tr>
</thead>
<tbody>
<tr>
<td>NOTE 4: ACCOUNTS PAYABLE (CURRENT)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Creditors and accruals</td>
<td>57,857</td>
<td>31,636</td>
</tr>
<tr>
<td>Amounts received in advance</td>
<td>26,147</td>
<td>9,747</td>
</tr>
<tr>
<td></td>
<td>84,004</td>
<td>41,383</td>
</tr>
</tbody>
</table>
NOTE 5: ACCUMULATED FUNDS
Accumulated funds are set aside for the following purposes:
- designated projects
- research
- discretionary reserve

<table>
<thead>
<tr>
<th></th>
<th>2005</th>
<th>2004</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>$</td>
<td>$</td>
</tr>
<tr>
<td>designated</td>
<td>(38,050)</td>
<td>61,174</td>
</tr>
<tr>
<td>research</td>
<td>428,430</td>
<td>381,734</td>
</tr>
<tr>
<td>discretionary</td>
<td>295,277</td>
<td>183,491</td>
</tr>
<tr>
<td></td>
<td>685,657</td>
<td>626,399</td>
</tr>
</tbody>
</table>

During the year there was a net transfer of $8,400 (2004: $8,400) from the Discretionary Reserve to Designated Projects to meet the Foundation’s objective expenses.

NOTE 6: RESERVE

<table>
<thead>
<tr>
<th></th>
<th>2005</th>
<th>2004</th>
</tr>
</thead>
<tbody>
<tr>
<td>balance at beginning of year</td>
<td>201,198</td>
<td>202,928</td>
</tr>
<tr>
<td>special appeals and interest</td>
<td>9,211</td>
<td>8,270</td>
</tr>
<tr>
<td>sponsorships and allocations</td>
<td>(10,000)</td>
<td>(1,730)</td>
</tr>
<tr>
<td>balance at end of year</td>
<td>210,409</td>
<td>201,198</td>
</tr>
</tbody>
</table>

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 2005 were:
- Michele Albert (to September 2004)
- David Bell (from August 2004)
- Neil Boal
- Rob Christie
- Gavin Finkelstein
- Joe Guarnieri (to February 2005)
- Glenn Irwin (to September 2004)
- Robert Lamberth
- Peter Mathews
- Kevin Murphy
- Ann Roberts
- Janet Rogers (from September 2004)
- Geoff Sue (to August 2004)
- Christopher Wensing (from March 2005)
- Nigel Williams
- Sharyn Wishart

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:

<table>
<thead>
<tr>
<th>Financial Instrument</th>
<th>Note</th>
<th>Accounting Policies</th>
<th>Terms and Conditions</th>
</tr>
</thead>
<tbody>
<tr>
<td>a) Financial Assets</td>
<td></td>
<td>Carried at nominal amounts due, less any provision for doubtful debts.</td>
<td>Credit normally on 30 day terms</td>
</tr>
<tr>
<td>- Receivables</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Cash at call and cash short term investments</td>
<td>2</td>
<td>Cash short term investments are stated at net realisable value.</td>
<td>Short term deposits have maturity from one to twelve months. Other investments are at call. Effective interest rate is 4.57% (2004: 3.67%).</td>
</tr>
<tr>
<td>b) Financial Liabilities</td>
<td></td>
<td>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.</td>
<td>Liabilities are normally settled on 30 day terms.</td>
</tr>
<tr>
<td>- Creditors and accruals</td>
<td>4</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

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 15 to 21, is drawn up so as to fairly state the results of the Foundation for the year ended 30 June 2005 and the financial position of the Foundation as at that date.

GAVIN FINKELSTEIN
Treasurer

SHARON CARIS
Executive Director

Melbourne – 30 September 2005
INDEPENDENT AUDIT REPORT
Ernst and Young

To the members of Haemophilia Foundation Australia Incorporated

Scope
The financial report and executive committee's responsibility

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 2005, and of its performance as represented by the results of its operations and cash flows for the year then ended.

Ernst & Young

R. Bruce Dungey
Partner

Melbourne 30 September 2005
ACKNOWLEDGEMENTS

We appreciate the generous support of our Sustaining Patrons:

**Baxter Healthcare - BioScience Division**

**CSL Bioplasma**

**Wyeth**

Special Partnerships: CWA of NSW and STOPMA Golf

Haemophilia Foundation Australia sincerely thanks all individuals, businesses, service clubs, trusts and foundations for their support to our programs and education resources throughout the year:

**Individuals (Over $150)**

Mr David Cowan
Mrs Lorna Aplin
Ms Monica Barry
Mr Mather Barton
Mr Paul Bedbrook
Mr & Mrs S Bennett
Mrs Freda C Bishop
Mr William D Bowens
Miss Trish Britten
Dr F Carrangis
Dr C Caton
Ms Vicki Childs
Mrs Mary Coles
Mr & Mrs C F Coughlin
Mrs M L Croker
Dr Phillip H Currie
Mrs Sue Davidson
Mr F Fair
Mr & Mrs F Halford
Mr & Mrs Margaret Freer
Mrs M Gomez
Mr Geoffrey & Mrs Carol Gray
Mrs Susan Haning
Mr Ian Hicks
Mr Boyd C Holdenson
Dr H O Irish
Mrs Renea Jones
Mr A & Mrs L A Lane
Mr Sydney I Lever
Mr K Lichtgen
Mr D Maisel
Mr & Mrs M McKenny
Mr Howard Menak
Dr Robert Morton
Mr M Alani
Ms Jennifer O'Halloran
Professor M J Osborne
Ms Jennifer O'Halloran
Mr & Mrs B McKenny
Mr Sydney F Lever
Miss Wendy Hurse
Mr Boyd C Holdenson
Mr Ian Cherry
Mrs Susan Haining
Mr Geoffrey & Mrs Carol Gray
Mrs M Gomez
Mr Geoffrey & Mrs Carol Gray
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Dr H O Irish
Mrs Renea Jones
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Mr Ian Cherry
Mrs Susan Haining
Mr Geoffrey & Mrs Carol Gray
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Mr Ian Hicks
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Mr Ian Cherry
Mrs Susan Haining
Mr Geoffrey & Mrs Carol Gray
Mrs M Gomez
Mr Geoffrey & Mrs Carol Gray
Mrs Susan Haning
Mr Ian Hicks
Mr Boyd C Holdenson
Improving treatment and care through representation and advocacy, education, and the promotion of research for haemophilia, von Willebrand disorder and related bleeding disorders.