

annual report

2013-2014



HAEMOPHILIA FOUNDATION AUSTRALIA

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Haemophilia Foundation Australia (HFA) represents people with haemophilia, von Willebrand disorder and related inherited bleeding disorders and their families throughout Australia.

Our goal is to improve treatment and care through national representation and advocacy, education and the promotion of research.

Our vision is for people with bleeding disorders to lead active, independent and fulfilling lives.

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.

Our Governance

HFA is an incorporated association in Victoria and its members are each of the State/Territory Haemophilia Foundations around Australia which each nominate delegates to form the Council and Executive Board.

Our Funding

HFA has a national fundraising program. Our partners include governments, corporate organisations, philanthropic trusts and foundations, individuals and service clubs.

Donations over \$2 are tax deductible

Meet the Organisation

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

MEMBER FOUNDATIONS

AUSTRALIAN CAPITAL TERRITORY - Dr Richard G Pembrey, AM, MBBS, MD, FRACP, FRCPA

WESTERN AUSTRALIA - Mr Michael McCusker, AC, CVO, QC, Governor of Western Australia

NEW SOUTH WALES - Dr Kevin A. Rickard, AM, RFD

VICTORIA - The Honourable Alex Chernov, AO, QC, Governor of Victoria

TASMANIA - Lady Green

QUEENSLAND - Her Excellency Ms Penelope Wensley, AO. Governor of Queensland

LIFE GOVERNORS

Jennifer Ross AO

Ted Troedson (dec)

Alison Bellamy

Maxine Ewart

Alan Ewart (dec)

Bevlee Cassell

Barbara Volk OAM

Fred Wensing

Mike Barry

Dawn Thorp

Bruce Fielding

Rob Christie



EXECUTIVE BOARD



(l-r) Dan Credazzi, Maria Wensing, Ann Roberts, Jonathan Spencer, Gavin Finkelstein

President

Gavin Finkelstein, Western Australia

Treasurer

Ann Roberts, Victoria

Vice President

Daniel Credazzi, New South Wales

Executive Members

Jonathan Spencer, Tasmania

Maria Wensing, Australian Capital Territory

COUNCIL MEMBERS

Maria Wensing

Australian Capital Territory

Sarah Hartley and **David Stephenson**

Queensland

Gavin McKay (Until May 2014)

Garry Lynch (from May 2014)

Daniel Credazzi

New South Wales

Jonathan Spencer

Tasmania

Ann Roberts and **Michelle Sullivan**

Victoria

Paul Bonner (*observer*)

South Australia

Gavin Finkelstein and **Shane Meotti**

Western Australia

STAFF

Sharon Caris, Executive Director

Natashia Coco, Development Manager (Part-time)

Carol Joy, Administration Officer, (Part-time) from April 2013

Kevin Lai, Accountant (Part-time)

Joanne Luciani, Administration Assistant (Part-time)

Janine Staunton, Fundraising Officer (Part-time) from January 2013

Suzanne O'Callaghan, Policy Research and Education Manager

Hannah Opeskin, Health Promotion Officer (Part-time) from February 2014

Kristine Robertson, Fundraising Manager (Part-time)

Kate Walton, Youth Project Officer (Part-time)



(L-R) Sharon Caris, Natashia Coco, Joanne Luciani, Janine Staunton, Suzanne O'Callaghan, Kristine Robertson, Kate Walton, Hannah Opeskin, Carol Joy.

PRESIDENT'S REPORT - *Gavin Finkelstein*



It is my pleasure to report on HFA's activities for the 2013-2014 year. It was one of our busiest and most exciting in our history! Critical programs and activities continued and we were able to meet our objectives, but as the year progressed, the WFH 2014 World Congress became a major focus.

Our Congress journey began in August 2009 when HFA wrote to the World Federation of Hemophilia (WFH) to express interest in hosting the 2014 Congress. WFH Congresses are the largest and most important revenue generating meetings for WFH and are greatly relied upon to support WFH's international development programs. 2014 seemed so far away at that time. But, after winning the support of the world wide bleeding disorders community at the WFH General Assembly in Buenos

Aires in 2010 we started working with the very professional and highly skilled WFH team towards the 2014 Congress. It was challenging, but such a wonderful experience and a privilege for our volunteers and staff to have been involved.

We wanted to be sure everyone who attended would have a wonderful Congress experience and enjoy their visit to Australia. We formed committees to encourage attendance and provide support. We also knew this would also be a once in a lifetime opportunity for many Australians affected by bleeding disorders to attend a Congress, so we raised funds to help them attend.

We attracted a team of volunteers and staff at both national and state/territory level and drew on the strong relationships we have built up with over many years with our stakeholders. We were grateful for the support from government officials, volunteer health professionals, and many suppliers that helped in so many different ways. Not only were we relying heavily on volunteer health professionals to help WFH and HFA shape the Congress program but we also had responsibility for setting up treatment rooms at the National Member Organisation Training held at Creswick in country Victoria before the Congress and in Melbourne during the Congress. This was a complex task of managing clotting factor donations, logistics of importation of clotting factor and ensuring we had sufficient medical, nursing and physiotherapy volunteers for the treatment rooms to assist delegates if they had bleeds. We are indebted to the Australian Red Cross Blood Service for storing and packing clotting factor donations which had been imported to Australia ahead of time for use by Congress attendees.

With the support of local Foundations, and Haemophilia Centres around Australia, our delegate boosting campaign met projected targets. We were pleased that over 600 Australians attended the Congress and overall more than 4000 people attended from 128 countries.

Although the financial results of the Congress will not be available from WFH until the end of the 2014 calendar year, we have been advised the Congress budget was well on track to return a profit at the end of the Congress. The funds HFA spent on helping people with registration, travel and accommodation expenses to attend the Congress were largely covered by a specific fundraising drive that had generated education grants and donations received for this purpose. Of course, to deliver a successful Congress, in addition to the Congress budget managed by WFH, the NMO must also donate resources in kind and through its staff and volunteers, and we thought this would be well worth the effort. Our staff and volunteers went well above and beyond the call of duty, and I wish to thank them all for their efforts.

Another significant achievement this year was that HFA played an important part in the launch of MyABDR in April by the Assistant Health Minister, Fiona Nash. This app for smartphones and computer web site is for people with bleeding disorders or parents and caregivers to record bleeds and home treatments. In 2011 the HFA Council decided it was important for the community to work with their clinicians to develop a tool to enhance clinical care, and to help measure outcomes of treatments as well as providing an effective way for governments to have access to some of this information so they can make supply plans for sufficient supplies of clotting factor for our community. A priority of this work was to protect the confidentiality and privacy of people using clotting factor. Not only will this tool be useful for people with bleeding disorders and their treating health professionals to understand bleeding patterns, and other aspects of their clinical care, but a secure supply of safe treatment products underpins this best practice care and treatment and having the best information to promote this is critical for government planning and budgets.

During the year HFA worked with the Australian Haemophilia Centre Directors' Organisation (AHCDO), the National Blood Authority (NBA), specialist health professionals groups and haemophilia centre data managers to develop this app. Further work is needed to make it more effective and to iron out some initial bugs, but we appreciate the significant funding the NBA has provided for the development and ongoing maintenance of the app. This of course, means close attention to patient privacy and we are confident that the steps in place provide this assurance.

Our work to update some, and produce new education materials for the bleeding disorders community during the year required representatives of Australia/New Zealand Haemophilia Social Workers' and Counsellors' Group, Australian Haemophilia Nurses' Group, Australian & New Zealand Physiotherapy Haemophilia Group and AHCDO and we are grateful for their commitment and energy to assist. Australian health professionals and community members tell us they prefer education materials developed by HFA for Australians with bleeding disorders and we are continuing to work through the various education resources identified for review and to undertake the consulting work for the new ones we have in development. It is exciting that we will be working to improve our main website and the youth website as well as developing a suite of women's' education resources in upcoming months.

HFA keeps a watching brief on health and other issues that require advocacy for our community, or where issues need to be raised because they are currently not on the agenda of governments and other stakeholders.

During the year HFA continued to take an interest in the implementation of the National Disability Insurance Scheme and how this support people with bleeding disorders. To date there is no direction as to how this might work for them, especially for people with episodic and/or recurring disability.

We provided feedback to the federal Department of Health on the draft National Hepatitis C Strategy and the draft National HIV Strategy and recommended the importance of including people with bleeding disorders who live with hepatitis C and/or HIV for special consideration. We made a submission to the Senate Standing Committees on Community Affairs about the out-of-pocket costs in Australian healthcare system which severely affect people in our community and in some cases prevent them accessing the services required.

Further research and ongoing advocacy is underway to make sure people with bleeding disorders have timely access to the new range of medicines for hepatitis C. Early indications are that these drugs may be very expensive initially; however, we have many people in our community with long term hepatitis C infection who cannot wait for political and funding machinations because of progressed liver disease. These drugs need to be funded and supplied as soon as possible in Australia.

We value our stakeholder relationships and partnerships with other organisations. During the year we pursued common issues and concerns for our community in a broader context. This work involved many organisations in the community and health sectors during the year including collaborations with the Consumers' Health Forum of Australia (CHF), Hepatitis Australia, Australian Federation of AIDS Organisations (AFAO), National Association of People Living With HIV/AIDS (NAPWA), the Australian Red Cross Blood Service and the Australasian Society for HIV Medicine (ASHM).

Our governance review is well underway and I thank all member Foundations for their constructive participation as we develop a new structure for our Council that will make it more responsive and agile and able meet the needs of the community we represent.

HFA values the valuable partnerships it has with other community organisations, our Corporate Partners and other supporters with whom we share common objectives of improving care and treatment to people with bleeding disorders. I wish to thank Council Delegates and State/Territory Presidents, and Committee Members of each of our member Foundations as well as our HFA staff who have worked hard during the year in support of HFA's objectives.

HIGHLIGHTS

REPRESENTATION AND ADVOCACY

Coming to grips with the needs of individuals and gaps in the services and care that is available to them is a key part of HFA's work to represent the bleeding disorders community around Australia. Sometimes this involves finding solutions to policy issues that have prevented or restricted access to health and welfare services. The personal experiences of many very often point to the need for change for others as well.

Over many years HFA has established strong partnerships and collaborations with specialist health professionals, community organisations and representatives of governments. By contributing to inquiries, initiating discussions about issues, proposing solutions and forming informal and formal strategic alliances we can and do influence effective outcomes. What is most important is that the voice of people with bleeding disorders and their families is heard. A frustration in recent years has been that the needs of our community affected by hepatitis C have compounded and we have not been successful in getting the help they need. We are on the cusp of promising new treatments for hepatitis C and will work strongly with our partners to seek treatment access as soon as these medicines are available.

We made several submissions to government and other regulatory or professional bodies on several policy matters including feedback on:

- The National Disability Insurance Scheme criteria and rules
- The draft National Hepatitis C and HIV Strategies

Most importantly we need volunteers and staff who can represent the views and needs of our community or health consumer in general. During 2013-2014 HFA volunteers and staff were invited or nominated to sit on committees and consultation meetings to represent consumer views including:

- Australian Red Cross (now the Blood Service) Advisory Panel on donor deferral based on sexual activity
- Australian Red Cross (now the Blood Service) advisory committee to review donor eligibility criteria relating to injecting drug use (IDU).
- National Blood Authority Technical Evaluation Committee
- Australian Bleeding Disorders Registry Steering Committee
- Medicines Australia Code of Conduct Committee
- Therapeutic Goods Administration Advisory Committee on Biologicals (ACB)
- Hepatitis Australia National Resource Network
- Consumer Health Forum meetings on the Medicare Benefits Schedule and general practice care management plans.

Hepatitis C

Dealing with the impact of hepatitis C on people with bleeding disorders who acquired the virus through their treatment products continues to be a high priority for HFA.

Many people with bleeding disorders acquired hepatitis C from their blood products before 1993, particularly plasma-derived clotting factor concentrates. If they have not yet cleared the virus naturally or through treatment, they have had hepatitis C for more than 20-30 years. For many, advancing liver disease and limited treatment options are a real problem. In 2014 HFA conducted two surveys asking community members about their health care costs and treatment experiences with hepatitis C. It was clear that financial issues are serious barriers to accessing liver health monitoring and treatment. However, treatment that can cure their hepatitis C is urgently needed.

Clinical trials of the new wave of direct acting antiviral (DAA) hepatitis C drugs have raised hope that a cure may be within reach for nearly all people with hepatitis C. Two of these DAAs, simeprevir and sofosbuvir, are due to be evaluated by the Pharmaceutical Benefits Advisory Committee (PBAC) in July 2014 for subsidisation through the Pharmaceutical Benefits Scheme (PBS). HFA gave feedback to PBAC on these treatments in June 2014 and highlighted the importance of making them available and affordable through the PBS.

Best practice care and treatment for bleeding disorders: Australian Bleeding Disorders Registry (ABDR) and MyABDR

MyABDR was released in February 2014. This exciting innovation is a secure app and web site that allows people with bleeding disorders and parents/caregivers to record treatments and bleeds, manage their treatment product inventory and update their contact details. MyABDR links directly to the Australian Bleeding Disorders Registry (ABDR), which is the system used nationally by Haemophilia Centres for the clinical care of their patients.

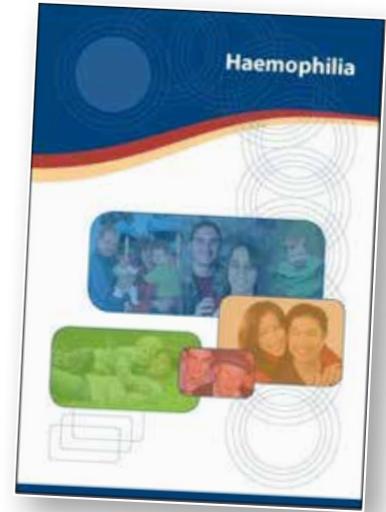
Development of MyABDR is a collaboration between HFA, the Australian Haemophilia Centre Directors' Organisation (AHCDO) and the National Blood Authority (NBA) on behalf of Australian governments. The intention is to support best practice clinical care and treatment of people with bleeding disorders. HFA has taken a lead role in facilitating community consultation, developing patient education materials and promoting MyABDR to the community.

After a whirlwind national tour with the NBA team introducing MyABDR to community members, we have been pleased to see a rapid uptake. 1468 people with bleeding disorders received treatment product in Australia in 2012/13. Within 6 weeks of its release, 145 patients had registered to use MyABDR and were actively recording treatments.

EDUCATION AND INFORMATION

Revised Haemophilia Booklet

HFA's *Haemophilia* booklet is an important introduction to the basics about haemophilia, with explanations about bleeding and haemophilia, levels of severity, diagrams showing inheritance and the latest information about how to manage haemophilia from planning a family through to birth and onwards. Expert health professional and consumer reviewers were very involved in updating the booklet with substantial revisions to the inheritance, carrying the gene and genetic testing sections. The revised booklet was released in July 2013 and has proven to be very popular:



By 30 June 2014:

- 1346 downloads from the HFA web site
- 862 print copies distributed

COMMUNICATING WITH THE COMMUNITY

National Haemophilia, HFA's quarterly journal, has a strong reputation in the community as a source of high quality, relevant and up-to-date educational information and news. Over the last 12 months it has also had a valuable role in promoting the World Congress and showcasing Australian work in bleeding disorders to both a national and international audience. Popular features have included women's personal stories, debates on clinical practice, such as the use of ice in haemophilia, football umpiring and haemophilia, and youth activities. The June 2014 issue was held over for a bumper World Congress issue in July 2014.



The **Haemophilia Foundation Australia web site** is one of HFA's most important communication tools. It is a reliable and respected source of information for the bleeding disorder community, health professionals, stakeholders, the general community and students. It has a large and increasing number of visitors, who generally look at several pages at a time and download many publications. More than 35% of visitors access it with smartphones and ipads/tablets. The World Hemophilia Congress in Australia in May 2014 led a surge in visits to the web site, underlining the increased interest in the world haemophilia community.

HFA is an accredited information partner with HealthInsite, which provides a national online gateway to high quality health information for the Australian community on behalf of governments in Australia.

The **HFA free email newsletter** is a popular way of connecting with bleeding disorder community members and supporters. It gives regular and timely updates about HFA activities and fundraising opportunities, new HFA publications and other news, and provides links to more information on the HFA web site.



Social media

In a new more strategic social media approach, HFA has intensified its presence on **Twitter** as well as **Facebook**. This was particularly valuable for keeping in touch with the community during the World Congress. Throughout the Congress, the Facebook page was updated daily with the latest Congress related news and photos about sessions, activities and competitions - with more than 50 comments, likes or shares on one post. It also received cross-postings from international organisations such as Haemophilia Scotland and the Hemophilia Federation of America. HFA's following on Twitter has increased dramatically, with followers and retweetings from national haemophilia organisations in other countries and international organisations such as the World Hepatitis Alliance.

HFA communications snapshot - over the last year

- 5457 copies of National Haemophilia posted to members
- 1849 copies of National Haemophilia downloaded from web site
- 771 HFA members received regular e-news
- 49,851 visits to view HFA web pages
- 1674 HFA facebook fans/"likes"
- 54% of HFA facebook fans/"likes" in 13-34 age group
- 122 HFA tweets
- 128 followers of HFA on Twitter



YOUTH PROJECT

The World Congress provided a great opportunity to consolidate HFA's work to enable young people affected by bleeding disorders to connect and explore leadership and mentoring roles.

Youth at Congress



Over 30 Australian youth delegates attended a Meet & Greet weekend before Congress. The weekend activities were facilitated by Purple Soup and set along the Yarra River, and included movie making, cupcake

decorating and mock poker tournaments. Many international youth delegates who attended the National Member Organisation (NMO) training prior to Congress joined our Australian youth delegates for the cupcake decorating. Congress proved to be a unique opportunity for young people across Australia and internationally to make new and lasting social connections. It was evident that Congress had sparked a united interest in becoming more involved in the bleeding disorders community.



Factored In



The Factored In website was developed in 2012 with the input of the HFA Youth Working Group as an interactive blog-style, online community for young Australians with bleeding disorders and their siblings, aged 13 to 30. It includes youth-friendly, evidence-based education material and personal stories on topics such as bleeding disorders, employment, travel and sport, which is reviewed by specialist health professionals and members of the HFA Youth Working Group. The Q & A section is very popular, where young people can ask their peers or health professionals questions - subjects have ranged from sport to vein care. They can also comment on content, upload their own personal stories and keep up to date with youth events across Australia.

The WFH Congress was a timely opportunity to review the website with youth delegates. Informal discussions revealed that improvements to the menu and alerting system would be helpful - and that Youth Working Group members were keen to be involved in promotion and sustainability. A youth survey to evaluate Factored In and its useability is planned as a result. HFA is also working on a program to train a team of selected youth leaders as website moderators.

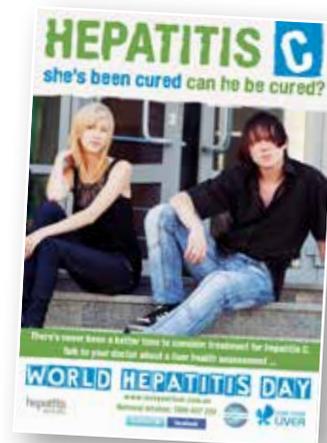
Factored In Snapshot - over the last year

- 81 members (59 male/22 female).
- 1566 website visits
- 4175 page views

PUBLIC AWARENESS

World Hepatitis Day

World Hepatitis Day was marked globally on 28 July 2013. The Australian theme in 2013 was “Learn to love your liver on World Hepatitis Day” and had a focus on maintaining or improving your liver health and seeking treatment. The national campaign aimed to raise awareness of liver health with the general community and present viral hepatitis neutrally as a health condition linked to liver health. The intention is to create a better quality of life for people with viral hepatitis by normalising viral hepatitis and reducing stigma. HFA is a Partner in the World Hepatitis Day Campaign and worked together with Hepatitis Australia and state and territory Foundations to support the campaign with a range of community activities, including promotional postings on Facebook, articles on the HFA web site and in newsletters, shopfront window displays, morning teas with cupcakes and forums on improving your wellbeing.



World AIDS Day 2013

In 2013 the World AIDS Day international theme was “**Getting to zero - zero new HIV infections, zero discrimination, zero AIDS related deaths**”. The national campaign focussed on the role of HIV positive people in strengthening community spirit through their ability to educate others and their resilience. This is particularly true of the bleeding disorders community where people may live with and manage multiple health conditions. With the upcoming World Hemophilia Congress and International AIDS Conference in Melbourne in 2014, World AIDS Day was an opportunity to join with the international bleeding disorders community as well as the local community to show solidarity and raise awareness about HIV.

Haemophilia Awareness Week and Red Cake Day, October 2013



Haemophilia Awareness Week and Red Cake Day were held this year from 13 to 19 October 2013. Haemophilia Foundation Australia and Haemophilia Foundations around the country worked together to raise awareness about inherited bleeding disorders.

There was great interest in the week and we had many supporters to help us fundraise and raise awareness over the week. Red Cake Day was a hit again this year, and proved to be a versatile concept for individuals and organisations along with schools and companies that wanted to do something practical while highlighting the needs of people with bleeding disorders.

Over 100 schools, hospitals, libraries, families and local communities around the country received promotional materials to help them run their own Red Cake Days and Haemophilia Awareness Week activities. They held different types of events, but they all worked together with us to raise awareness about bleeding disorders or host a Red Cake Day. We are grateful for the support and uptake of this exciting event which we hope is becoming a regular feature on everyone's calendar.

Many of our corporate supporters including Baxter, Bayer, Biogen Idec and CSL Behring held a Red Cake Day at their offices and raised awareness of the needs of people with bleeding disorders with their colleagues, many of whom work in other areas of their businesses.

An exciting Red Cake Day event at Federation Square in Melbourne was sponsored by Pfizer. The rainy day did not dampen the enthusiasm of the people who came to see Maria Vella from the Great Australian Bake Off demonstrating her cake decorating skills. We are grateful to the Cupcake Bakery for donating cupcakes which were sold in support of Red Cake Day.



Paint the Town Red, Neerim South & Bendigo Bank Branches, South Gippsland Region



Now in its fifth year, the township of Neerim South in Victoria once again hosted 'Paint the town Red'. The event is organised by Donna Field and a wonderful team at the Neerim District Community Bank®. We are grateful that staff at Bendigo Bank Branches in the South Gippsland Region also displayed posters and promotional items to raise awareness about bleeding disorders and helped to raise funds. *Paint the Town Red* and fundraising from the Neerim District Community Bank® and Bendigo Bank Branches South Gippsland Region raised \$1,980 for Haemophilia Foundation activities.

CAMPS AND WORKSHOPS

Camps, groups and workshops

HFA supports a range of program and services run by the state/territory foundations such as camps, parent carers groups, men's group, women with inherited bleeding disorders group and rural education workshops. These programs and services bring the community together, provide education and peer support. In 2013-2014 HFA supported five programs around Australia.



HFNSW Family Camp, November 2013

The annual Family Camp, in its 14th year, saw 130 people attending over the course of the weekend. New families joined in the fun and activities. Everyone, particularly the kids, really enjoyed the great activities on offer, the giant slide, go karts, archery, canoeing, paddle boarding, swimming, and craft activities.

HFWA Community Weekend, March 2014

75 parents and children joined together at Point Walter Recreation and Function Centre for the biennial weekend. The camp was facilitated by Purple Soup who specialise in adventure therapy for children with special needs. Over the weekend families participated in many outdoor activities and dedicated workshops were held such as family relationships and early diagnosis, fears and coping strategies. Most importantly the weekend was a time to meet new people and see old friends and share experiences.

TREASURER'S REPORT ~ Ann Roberts



I am pleased to report that HFA is in a sound financial position following a very active year.

The financial reports were presented to Cook Jones for audit and signed off by the company. Cook Jones has also provided specific audit reports on our government grants in line with Agreements with the Department of Health and Ageing.

Both income and expenditure has grown over recent years as it has done in 2014 where our total income increased by 20% to \$1,070,922 from \$890,358 in 2013.

You will see from the report that government grants were stable. The amount received by way of government grants in 2014 included a small amount of remaining funds carried over from the Youth Project grant and two thirds of a “once off” grant of funds from the National Blood Authority which has enabled HFA to employ an additional staff member to offset the additional MyABDR work. The remainder has been carried forward to the next year. Our two core government grants were re-negotiated and are currently stable, but without these funds we would not be viable from year to year.

While we report an overall decrease of 8% on our fundraising and donation income line item, this is largely due to a timing issue because two of our Corporate Partners varied their payment timing cycle and our Corporate Partnerships are reported on a cash basis only when received. It is very positive that our general donations from other fundraising activities increased by 13% for the year.

The Conference sponsorship line item under income is consistent with our two year cycle of national conferences. However, while this year there was no conference to report, we have reported the \$145,575 which represents a government disability grant and funds raised from industry specifically to fund delegates to attend the 2014 World Congress. We are extremely grateful to have received these grants as they largely offset the full costs of this unusual but critical expenditure line item.

Our investment income of \$33,257 reflects a decrease of 12% from the previous year. The effective Interest rate for the year was 2.52% compared to 2.95% in 2013. Approximately half of our funds are now managed under Macquarie Management and we hope to improve the return on the funds currently held in Perpetual Trustees for the Damon Courtenay Memorial Endowment Fund during the next year following the Trust review. I note there was no distribution this year from the Trust.

You will note that line item “other income” is significantly higher than the previous year and this reflects reimbursements from WFH for Congress related expenses.

Our Operating Expenses of \$626,304 increased by 4% compared to \$604,979 in 2013. This is reflected in slight increases in salaries and human resources costs, as well as office and fundraising expenses. No CPI increase was paid to staff this year; however at its last meeting the Executive Board made a decision to address this during the next year.

HFA Objectives Expenses increased by 69% over the year, and this led to a net increase of 21% in all expenses over the year to \$1,013,233. This increase is largely related to the Congress.

Our Operating Expenses are significantly higher than our Objectives Expenses and include the cost of all salaries of our staff. We report all human resources expenses as Operating Expenses for consistency rather than allocate administration and personnel costs to our Objectives outputs.

Overall, in summary, there was a net surplus of \$57,689 for the year. Importantly, HFA funds grew by 5% from \$1,150,007 in the previous year to \$1,207,696 by the end of 2014.

I am pleased to report that our bank investments are solid – after accounting adjustments our Research Fund holds \$438,514, the Damon Courtenay Memorial Endowment Fund holds \$233,885, and our discretionary funds (including the funds of \$63,908 we have earmarked for a future HFSA but must be reported as HFA funds) amount to \$691,664.

I wish to thank the HFA team for their work this year which has achieved a strong financial result and for their efforts to make the World Congress a success. We expect to hear officially from WFH about the amount HFA will receive as its 20% share of Congress profit later in the year; however I am pleased to report that we have been advised by WFH that we are likely to receive an amount of around CAD\$500,000. Once the Congress funds are agreed and distributed by WFH I will recommend that HFA undertakes a full investment review.

FINANCIAL REPORTS AND AUDIT REPORT

HAEMOPHILIA FOUNDATION AUSTRALIA INCORPORATED
ABN 89 443 537 189
INCOME STATEMENT
FOR THE YEAR ENDED 30 JUNE 2014

	Note	2014 \$	2013 \$
INCOME			
Commonwealth government grants		338,240	335,010
Other project grants		74,065	83,431
Fundraising and donations		374,643	406,681
Conference sponsorships and income		145,575	-
Interest		33,257	37,686
State member levies		2,852	619
Other income		102,290	26,931
TOTAL INCOME		1,070,922	890,358
LESS : FOUNDATION OPERATING EXPENSES			
<u>Administration</u>			
Advertisement/recruitment		423	1,569
Audit		7,000	7,459
Annual reports		1,076	1,939
Bank fees and other service charges		1,185	764
Council meetings		11,758	12,987
Executive meetings		5,751	14,833
Personnel expenses		482,630	461,505
Professional insurance		5,013	2,878
Liaison and business development		1,215	1,867
Legal fees		630	-
Travel		274	1,015
Provision for long service leave		6,795	8,232
		523,750	515,048
<u>Property</u>			
Depreciation of assets		11,075	10,236
Leasing of photocopier		3,114	2,635
Lighting and heating		5,360	4,864
Insurance		1,246	1,246
Rent		41,460	40,435
Repairs and maintenance		3,799	3,524
Security		2,719	786
		68,773	63,726
<u>Fundraising</u>			
Appeals and production		27,128	21,516
Resource development		6,653	4,689
		33,781	26,205
TOTAL FOUNDATION OPERATING EXPENSES		626,304	604,979
SURPLUS OF INCOME OVER OPERATING EXPENSES		444,618	285,379

The above Income Statement should be read in conjunction with the accompanying notes.

HAEMOPHILIA FOUNDATION AUSTRALIA INCORPORATED
ABN 89 443 537 189
INCOME STATEMENT (CONTINUED)
FOR THE YEAR ENDED 30 JUNE 2014

	<u>Note</u>	<u>2014</u>	<u>2013</u>
		\$	\$
SURPLUS OF INCOME BROUGHT FORWARD		444,618	285,379
LESS : FOUNDATION OBJECTIVES EXPENSES			
<u>Services and Care</u>			
Information technology		17,559	20,399
Executive		7,435	6,053
Financial assistance		500	1,900
Haemophilia conference and education sponsorships		151,644	6,189
WFH and other conferences		5,625	6,731
Health professionals		28,012	29,914
Newsletter		29,363	31,870
Postage		3,381	2,224
Printing and stationery		5,204	3,378
Specific project expenses		85,319	77,772
Sponsorship and funding		-	10,013
Subscriptions		3,519	3,624
Telephone		7,061	7,343
		344,622	207,410
<u>Education</u>			
Brochures and resources		2,465	2,015
Community awareness activities		5,074	5,290
		7,539	7,305
<u>Research</u>			
Research grants allocated		34,400	14,733
Expenses incurred		368	56
		34,768	14,789
TOTAL FOUNDATION OBJECTIVES EXPENSES		386,929	229,504
TOTAL SURPLUS FOR THE YEAR		57,689	55,875
ACCUMULATED FUNDS BROUGHT FORWARD		920,054	870,386
TOTAL AVAILABLE FUNDS		977,743	926,261
TRANSFER (TO) / FROM RESERVE	8	(3,933)	(6,207)
ACCUMULATED FUNDS CARRIED FORWARD	7	973,810	920,054

HAEMOPHILIA FOUNDATION AUSTRALIA INCORPORATED
ABN 89 443 537 189
BALANCE SHEET
AS AT 30 JUNE 2014

	Note	2014 \$	2013 \$
CURRENT ASSETS			
Cash and Cash Equivalents	2	413,274	354,679
Investments	3	950,792	923,046
Trade and Other Receivables		6,549	163
Other assets		9,836	-
Total Current Assets		1,380,451	1,277,888
NON CURRENT ASSETS			
Property, plant and equipment	4	10,218	15,363
Total Non Current Assets		10,218	15,363
TOTAL ASSETS		1,390,669	1,293,251
CURRENT LIABILITIES			
Trade and Other Payables	5	7,000	10,582
Short-term Provisions	6	138,946	112,550
Amounts received in advance		34,071	9,109
Total Current Liabilities		180,017	132,241
NON CURRENT LIABILITIES			
Long-term Provisions	6	2,956	11,003
Total Non Current Liabilities		2,956	11,003
TOTAL LIABILITIES		182,973	143,244
NET ASSETS		1,207,696	1,150,007
FOUNDATION'S FUNDS			
Accumulated funds	7	973,810	920,054
Reserve	8	233,886	229,953
TOTAL FOUNDATION'S FUNDS		1,207,696	1,150,007

HAEMOPHILIA FOUNDATION AUSTRALIA INCORPORATED
ABN 89 443 537 189
STATEMENT OF RECOGNISED INCOME AND EXPENDITURE
FOR THE YEAR ENDED 30 JUNE 2014

	Note	Reserve \$	Accumulated Funds \$	Total Equity \$
BALANCE AS AT 1 JULY 2006		203,496	663,092	866,588
Surplus for the year		9,566	111,799	121,365
BALANCE AS AT 30 JUNE 2007		213,062	774,891	987,953
Surplus/(deficit) for the year		248	(36,124)	(35,876)
BALANCE AS AT 30 JUNE 2008		213,310	738,767	952,077
Surplus/(deficit) for the year		(6,288)	(96,162)	(102,450)
BALANCE AS AT 30 JUNE 2009		207,022	642,605	849,627
Surplus/(deficit) for the year		6,578	(30,305)	(23,727)
BALANCE AS AT 30 JUNE 2010		213,600	612,300	825,900
Surplus for the year		831	155,122	155,953
BALANCE AS AT 30 JUNE 2011		214,431	767,422	981,853
Surplus for the year		9,315	102,964	112,279
BALANCE AS AT 30 JUNE 2012		223,746	870,386	1,094,132
Surplus for the year		6,207	49,668	55,875
BALANCE AS AT 30 JUNE 2013		229,953	920,054	1,150,007
Surplus for the year		3,933	53,756	57,689
BALANCE AS AT 30 JUNE 2014	7 & 8	233,886	973,810	1,207,696

HAEMOPHILIA FOUNDATION AUSTRALIA INCORPORATED
ABN 89 443 537 189
CASH FLOW STATEMENT
FOR THE YEAR ENDED 30 JUNE 2014

	Note	2014 \$	2013 \$
CASH FLOWS FROM OPERATING ACTIVITIES			
Interest received		33,257	37,686
Grants received		437,267	305,010
Receipts from constituents		625,360	434,231
Payments to suppliers and employees		(1,003,613)	(771,962)
Net cash flows from operating activities		92,271	4,965
CASH FLOWS FROM INVESTING ACTIVITIES			
Acquisition and disposal of property, plant and equipment		(5,930)	(689)
Net cash flows used in investing activities		(5,930)	(689)
NET INCREASE CASH HELD		86,341	4,276
CASH BALANCE BROUGHT FORWARD		1,277,725	1,273,449
CASH BALANCE CARRIED FORWARD		1,364,066	1,277,725
Cash balance carried forward comprises :-			
Cash and cash equivalents	2	413,274	354,679
Investments	3	950,792	923,046
		<u>1,364,066</u>	<u>1,277,725</u>
Reconciliation of surplus for the year to the net cash flows from operating activities :-			
Total operating surplus for the year		57,689	55,875
Depreciation and amortisation		11,075	10,236
Changes in assets and liabilities			
Increase/(Decrease) in creditors and provisions		39,729	(105,427)
(Increase)/Decrease in receivables and other assets		(16,222)	44,281
Net cash flows from operating activities		92,271	4,965

HAEMOPHILIA FOUNDATION AUSTRALIA INCORPORATED
ABN 89 443 537 189
NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 30 JUNE 2014

NOTE 1 : STATEMENT OF SIGNIFICANT ACCOUNTING POLICIES

This financial report is a special purpose financial report prepared in order to satisfy the financial reporting requirements of the Associations Incorporation Act Victoria. The council has determined that the Association is a prescribed association for reporting purposes.

The financial report has been prepared on an accrual basis on historic costs and does not take into account changing money values, or except where specifically stated, current valuations of non-current assets.

The following significant accounting policies, which are consistent with the previous period unless otherwise stated, have been adopted in the preparation of this financial report.

(a) Income Tax

The Haemophilia Foundation Australia Inc has obtained tax exempt status as a non-profit organisation and is exempt from the payment of Income Tax.

(b) Property, Plant and Equipment (PPE)

Leasehold improvements and office equipment are carried at cost less, where applicable, any accumulated depreciation.

The depreciable amount of all PPE is depreciated over the useful lives of the assets to the association commencing from the time the asset is held ready for use.

Leasehold improvements are amortised over the shorter of either the unexpired period of the lease or the estimated useful lives of the improvements.

(c) Employment Benefits

Provision is made for the association's liability for employee benefits arising from services rendered by employees to balance date. Employee benefits have been measured at the amounts expected to be paid when the liability is settled.

(d) Provisions

Provisions are recognised when the association has a legal or constructive obligation, as a result of past events, for which it is probable that an outflow of economic benefits will result and that outflow can be reliability measured. Provisions are measured at the best estimate of the amounts required to settle the obligation at reporting date.

(e) Cash and Cash Equivalents

Cash and cash equivalents includes cash on hand, deposits held at call with banks, and short-term highly liquid investments with original maturities of three months or less.

(f) Revenue and Other Income

Revenue from the sale of literature is recognised upon delivery of the goods to customers.

Interest revenue is recognised using the effective interest rate method, which for floating financial assets is the rate inherent in the instrument.

Grant and donation income is recognised when the entity obtains control over the funds which is generally at the time of receipt.

All revenue is stated net of the amount of goods and services tax (GST).

HAEMOPHILIA FOUNDATION AUSTRALIA INCORPORATED
ABN 89 443 537 189
NOTES TO THE FINANCIAL STATEMENTS (continued)
FOR THE YEAR ENDED 30 JUNE 2014

(g) Inventories

Inventories are valued at the lower of cost and net realisable value. Costs are assigned on a first-in first-out basis. Net realisable value is determined on the basis of normal sales patterns.

(h) Leases

Lease of PPE, where substantially all the risks and benefits incidental to the ownership of the asset, but not the legal ownership, are transferred to the association, are classified as finance leases.

Finance Leases are capitalised, recording an asset and a liability equal to the present value of the minimum lease payments, including any guaranteed residual values. Leased assets are amortised on a straight line basis over their estimated useful lives where it is likely that the association will obtain ownership of the asset or over the term of the lease.

Lease payments are allocated between the reduction of the lease liability and the lease interest expense for the period.

(i) Goods and Services Tax (GST)

Revenues, expenses and assets are recognised net of the amount of GST, except where the amount of GST incurred is not recoverable from the Taxation Office. In these circumstances the GST is recognised as part of the cost of acquisition of the asset or as part of an item of the expense. Receivables and payables in the balance sheet are shown inclusive of GST.

(j) Investments

Investments held are originally recognised at cost which includes transactions costs. They are subsequently measured at fair value which is equivalent to their market bid price at reporting date. Movements in fair value are recognised through an equity reserve.

(k) Comparative Figures

When required by Accounting standards comparative figures have been adjusted to conform with changes in presentation for the current year.

NOTE 2 : CASH AND CASH EQUIVALENTS

	2014	2013
	\$	\$
Cash at bank - CBA Office	132,262	80,444
Cash at bank - CBA Main	220,079	210,757
Cash at bank - Bendigo	60,933	63,478
	<u>413,274</u>	<u>354,679</u>

NOTE 3 : INVESTMENTS

Short term Deposits - Perpetual Trustees	272,030	267,468
Short term Deposits - Macquarie's Management	678,762	655,578
	<u>950,792</u>	<u>923,046</u>

HAEMOPHILIA FOUNDATION AUSTRALIA INCORPORATED
ABN 89 443 537 189
NOTES TO THE FINANCIAL STATEMENTS (continued)
FOR THE YEAR ENDED 30 JUNE 2014

	<u>2014</u>	<u>2013</u>
	\$	\$
NOTE 4 : PROPERTY, PLANT AND EQUIPMENT		
Furniture and office equipment - at cost	148,168	142,238
Accumulated depreciation	<u>(137,950)</u>	<u>(126,875)</u>
	<u>10,218</u>	<u>15,363</u>
NOTE 5 : TRADE AND OTHER PAYABLES		
Trade creditors and accruals	<u>7,000</u>	<u>10,582</u>
	<u>7,000</u>	<u>10,582</u>
NOTE 6 : PROVISIONS		
Current		
- Annual leave	83,391	71,837
- Long Service leave	<u>55,555</u>	<u>40,713</u>
	<u>138,946</u>	<u>112,550</u>
Non-Current		
- Long Service leave	<u>2,956</u>	<u>11,003</u>
	<u>2,956</u>	<u>11,003</u>
NOTE 7 : ACCUMULATED FUNDS		
Accumulated funds are set aside for the following purposes: -		
- research	438,515	455,517
- discretionary projects and reserves	<u>535,295</u>	<u>464,537</u>
	<u>973,810</u>	<u>920,054</u>
NOTE 8 : RESERVE		
Damon Courtenay Reserve		
- balance at beginning of year	229,953	223,746
- special appeals and interest income	4,563	6,207
- sponsorships, allocations and costs	<u>(630)</u>	<u>-</u>
	3,933	6,207
- balance at end of year	<u>233,886</u>	<u>229,953</u>

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

HAEMOPHILIA FOUNDATION AUSTRALIA INCORPORATED
ABN 89 443 537 189
NOTES TO THE FINANCIAL STATEMENTS (continued)
FOR THE YEAR ENDED 30 JUNE 2014

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			
(i) Receivables		Carried at nominal amounts due, less any provision for doubtful debts.	Credit normally on 30 days terms.
(ii) 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. Average effective interest rate is 2.52% (2013: 2.95%)
(b) Financial Liabilities			
(i) Creditors and accruals	5	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.

NOTE 10 : RELATED PARTY TRANSACTIONS

The members of the Council of Haemophilia Foundation Australia Incorporated during the financial year ended 30 June 2014 were :-

Dan Credazzi	Gavin Finkelstein
Gavin McCay	Shane Meotti
Ann Roberts	Jonathan Spencer
David Stephenson	Leanne Stephenson (to 21 August 2013)
Michelle Sullivan	Maria Wensing
Sarah Hartley (from 22 August 2013)	

No material related party transactions occurred during the financial year.

NOTE 11 : 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 12 : EVENTS AFTER THE BALANCE SHEET DATE

There have been no events after the balance sheet date that would materially affect the results contained within this report.

HAEMOPHILIA FOUNDATION AUSTRALIA INCORPORATED
ABN 89 443 537 189
STATEMENT BY MEMBERS OF THE COUNCIL

The council has determined that the foundation is not a reporting entity and that this special purpose financial report should be prepared in accordance with the accounting policies outlined in Note 1 to the financial statements.

In the opinion of the council the financial report as set out on pages 2 to 9:

- 1) presents a true and fair view of the financial position of Haemophilia Foundation Australia Inc. as at 30 June 2014 and its performance for the year ended on that date.

- 2) at the date of this statement, there are reasonable grounds to believe that Haemophilia Foundation Australia Inc. will be able to pay its debts as and when they fall due.

This statement is made in accordance with a resolution of the Council and is signed for and on behalf of the Council by:

PRESIDENT.....


Gavin Finkelstein

TREASURER.....


Ann Roberts

Date : 2 October 2014

INDEPENDENT AUDIT REPORT

To The Members of Haemophilia Foundation Australia Incorporated

Report on the Financial Report

We have audited the accompanying financial report, being a special purpose financial report, of Haemophilia Foundation Australia Incorporated which comprises the balance sheet as at 30 June 2014 and the income statement, statement of recognised income and expenditure and cash flow statement for the year ended on that date, a summary of significant accounting policies and other explanatory notes and the statement by members of the committee.

Executive Committee's Responsibility for the Financial Report

The Executive Committee of the association is responsible for the preparation and fair presentation of the financial report in accordance with Australian Accounting Standards (including the Australian Accounting Interpretations) and the Associations Incorporation Reform Act 2012 (Vic). This responsibility includes establishing and maintaining internal control relevant to the preparation and fair presentation of the financial report that is free from material misstatement, whether due to fraud or error; selecting and applying appropriate accounting policies; and making accounting estimates that are reasonable in the circumstances.

Auditor's Responsibility

Our responsibility is to express an opinion on the financial report based on our audit. We conducted our audit in accordance with Australian Auditing Standards. These Auditing Standards require that we comply with relevant ethical requirements relating to audit engagements and plan and perform the audit to obtain reasonable assurance whether the financial report is free from material misstatement.

An audit involves performing procedures to obtain audit evidence about the amounts and disclosures in the financial report. The procedures selected depend on the auditor's judgment, including the assessment of the risks of material misstatement of the financial report, whether due to fraud or error. In making those risk assessments, the auditor considers internal control relevant to the entity's preparation and fair presentation of the financial report in order to design audit procedures that are appropriate in the circumstances, but not for the purpose of expressing an opinion on the effectiveness of the entity's internal control. An audit also includes evaluating the appropriateness of accounting policies used and the reasonableness of accounting estimates made by the committee, as well as evaluating the overall presentation of the financial report.

We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our audit opinion.

Independence

In conducting our audit, we have complied with the independence requirements of Australian professional ethical pronouncements.

Auditor Opinion

In our opinion:

The financial report of Haemophilia Foundation Australia Incorporated, is in accordance with the Association Incorporation Act including:

- i. giving a true and fair view of the Association's financial position as at 30 June 2014 and of their performance for the year ended on that date; and
- ii. complying with Australian Accounting Standards (including the Australian Accounting Interpretations) and the Associations Incorporation Reform Act 2012 (Vic).

Cook Jones & Co.
Chartered Accountant



David Wynne Jones AM. FCA.
Principal
Camberwell
Date: 6 October 2014

ACKNOWLEDGMENTS

We acknowledge and thank all supporters and donors for their generous support to HFA programs and education activities throughout the year:

Individual Donors over \$250

Warwick Anderson
Lorna Aplin
M J Baikie
Hester Barton
Paul Bedbrook
Lisa Belde
Tania Berechree
Esfandiar Boghraty
Peter & Karen Boyd
Trish Britten
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Yvette Timmins
John Toohey
Vasil Tulevski
Malcolm Vivian
Fred & Maria Wensing
Russell Williamson

Service Clubs over \$250

Lions Club of Blacktown City
Lions Club of Auburn Lidcombe
Lions Club of Austinmer/Thirroul
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Lions Club of Goulburn City
Lions Club of Canberra Woden
Rotary Club of Griffith
Lions Club of Coonamble
Lions Club of Werribee
Lions Club of Croydon
Lioness Club of Dromana
Lions Club of Torquay
Lions Club of Haddon and District
Lions Club of Bendigo
Lions Club of Lorne
Lioness Club of Ballan
Lions Club of Speed
Lions Club of Merbein
Lions Club of Tallygaroopna
Rotary Club of Korumburra
Lioness Club of Golden Valley Keperra
Lions Club of Brisbane Ekibin
Lions Club of Stanthorpe
Lions Club of Kingaroy

Rotary Club of Rockhampton West
Lions Club of Richmond
Lions Club of Victor Harbor & Port Elliot
Lions Club of Tintinara
Lions Club of Port Augusta
Lioness Club of Broome
Lions Club of West Tamar
Lions Club of Wynyard

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The Greatorex Foundation
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William Angliss Charitable Fund

Donations Received in Memory of:

Flora Falls
Ken Mathews
Di Turner
Barnaby Ward
Bob Williams

Bequests received from the Estates of:

The Estate of Frances Dwight

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Dean Harris
Debbie Coulter
Haematology Warriors
Karen Grove
Timothy Ross
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& Red Cake Day**

Michelle Adamson
Debi Atherton
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Royal Darwin Hospital Pathology
St Arnaud Primary School No 1646
Sydney Children's Hospital
Telstra Consumer & Country Wide
The Children's Hospital
WAW Credit Union

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CSL Behring Australia \$40,000
Bayer Australia \$50,000
Novo Nordisk \$40,000

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Baxter Healthcare \$25,000
CSL Behring Australia \$9,090

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Competition Sponsorship**

Octapharma Australia \$5,500

*HFA gratefully acknowledges the
program grants received from the
Department of Health and Ageing.*

Improving treatment and care through
representation and **advocacy, education**
and the **promotion of research** for people
with inherited bleeding disorders

Registered as
Haemophilia Foundation Australia Incorporated
Reg No: A0012245M ABN: 89 443 537 189



HAEMOPHILIA FOUNDATION AUSTRALIA

1624 High St, Glen Iris Vic 3146
P: 03 9885 7800 F: 03 9885 1800
E: hfaust@haemophilia.org.au
W: www.haemophilia.org.au