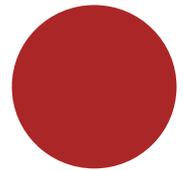
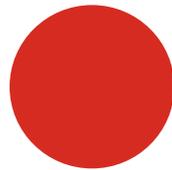
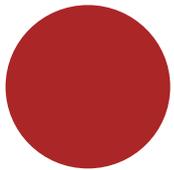


HAEMOPHILIA FOUNDATION AUSTRALIA

*annual report*  
**2015-2016**



# Haemophilia Foundation **Australia**

Haemophilia Foundation Australia (HFA) is the national peak body which represents people with haemophilia, von Willebrand disorder and other rare bleeding disorders and their partners, families and carers throughout Australia.

## **Our Governance**

HFA is incorporated in Victoria. Its members are each of the State and Territory Haemophilia Foundations around Australia. HFA is a National Member Organisation of the World Federation of Hemophilia and participates in international efforts to improve access to care and treatment for people with bleeding disorders around the world.

HFA reports fully to Consumer Affairs Victoria and the Australian Charities and Not For Profit Commission.

### **Our Mission:**

to inspire excellence in treatment, care and support through representation, education and promotion of research

### **Our Vision:**

for people with bleeding disorders to lead active, independent and fulfilling lives

### **Our Goals:**

- effective advocacy
- strategic education and communication
- financial sustainability
- to advance research, care and treatment
- good governance
- to be the trusted national organisation and recognised community expert on inherited bleeding disorders

## **Our Funding & Donor Partners**

HFA has a national fundraising program. Our donors and funding partners include governments, companies, philanthropic trusts and foundations, service clubs and individuals. Corporate partnerships are underpinned by memorandums of understanding and agreements: government grants are subject to contracts; these will be fully reported in Annual Reports and on the HFA website in a spirit of transparency.

# Meet the Organisation

## HFA COUNCIL

HFA Council is established under the Constitution as its main governing committee. The Constitution provides for one Delegate to be elected from each State and Territory Foundation to form the Council. Council meets up to 3 times each year, including for the Annual General Meeting. Council elects office-bearers from its own number. Delegates to Council act in a voluntary capacity. Each member foundation was represented at every meeting for the year.



*I-r, Back: David Stephenson, Gavin Finkelstein  
Front: Daniel Credazzi, Leonie Demos, Claude Damiani (Absent: David Fagan)*

**Gavin Finkelstein (President)** *Delegate for Haemophilia Foundation Western Australia*

**Daniel Credazzi (Vice President)** *Delegate for Haemophilia Foundation New South Wales*

**David Fagan (Treasurer)** *Delegate for Haemophilia Foundation Tasmania*

**Claude Damiani** *Delegate for Haemophilia Foundation Australian Capital Territory*

**David Stephenson** *Delegate for Haemophilia Foundation Queensland*

**Leonie Demos** *Delegate for Haemophilia Foundation Victoria*

**Paul Bonner (ex officio observer)** *South Australia*

## EXECUTIVE DIRECTOR AND STAFF

**Sharon Caris**, Executive Director

**Maura Brookes**, Fundraising Co-ordinator (Part-time) from Aug 2015 – December 2015

**Natashia Coco**, Director of Development (Part-time)

**Carol Joy**, Administration Officer, (Part-time)

**Kevin Lai**, Accountant (Part-time)

**Jasmine Lai**, Accounting Assistant (Part time)

**Janine Staunton**, Fundraising Officer (Part-time)

**Jane Turney**, Administration Officer – Development (Part-time) from February 2016

**Suzanne O’Callaghan**, Policy Research and Education Manager

**Hannah Opeskin**, Health Promotion Officer (Part-time)



*Maura Brookes*



*Sharon Caris*



*Natashia Coco*



*Carol Joy*



*Janine Staunton*



*Jane Turney*



*Suzanne O’Callaghan*



*Hannah Opeskin*

## NATIONAL PATRON

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

## LIFE GOVERNORS

Jennifer Ross AO

Ted Troedson (dec)

Alison Bellamy

Maxine Ewart (dec)

Alan Ewart (dec)

Bevlee Cassell

Barbara Volk OAM

Fred Wensing

Mike Barry

Dawn Thorp

Bruce Fielding

Rob Christie

Ann Roberts

# President's Report, *Gavin Finkelstein*



It gives me great pleasure to present my 2016 report. It has been a productive year, with both staff and Council volunteers actively engaged in developing HFA's new Strategic Plan. We are now working towards the objectives and outcomes we have set. I believe the new governance framework set in place by Council in 2014 has led to improved communication with our member Foundations and more timely decision making throughout the year.

We are a small community with a long history of perseverance and resilience. Our objectives and goals are challenging, but achievable, and should lead us to our vision for people with bleeding disorders to have active, independent and fulfilling lives.

Even though treatment product availability has increased over the years, and prophylaxis has given children and young adults opportunities not expected by earlier generations, we know that living with a bleeding disorder is a lifelong challenge for young families, and throughout the lifespan. We want to be sure everyone is armed with the information they need and has access to the most appropriate health care when they need it.

This year our advocacy focused on seeking government funding for new treatments for people living with hepatitis C acquired from contaminated blood products. Along with several other organisations HFA has advocated strongly for government funding for several new direct acting antiviral medicines and we look forward to more reports of treatment success. Sadly it has been too late for some in our community who have died, while others will continue to live with liver damage. We are working to seek ways to make sure people who do not know about the new treatments are aware and have access to them.

We have entered a new era for haemophilia treatment products and a priority for HFA has been to explore the benefit of extended half life haemophilia products. We have consulted with researchers, clinicians, and some patients with clinical trial experience. These clotting agents and other new therapies in the pipeline will likely change the face of haemophilia treatment. Our objective is to see that Australians with bleeding disorders have the best available treatments for their condition and a pathway to access. We do not shy away from considering the cost and value of treatment products to governments which provide blood products free of charge to us. The upcoming 2016 WFH World Congress may provide more information and answers to some of our questions. Regardless, it is critical that we have a range of treatment products available in Australia, including the extended half life clotting factor products so that patients and their clinicians can develop experience with them, and contribute data to a local body of evidence about the outcomes for patients and their value. Fewer infusions, better vein protection and longer cover will make a significant difference. Current evidence suggests this might come down to evaluation of very personalized treatment regimens on a case by case basis. Given all treatment products are expensive for governments, careful consideration at this level is warranted.

Our strategic education and communication approach lead to several positive outcomes during the year. A priority was to develop and publish new education resources for women and girls and this work will continue next year. We also developed a training program for young men and women to develop leadership and mentoring skills and build their resilience. The 17th National Haemophilia Conference, held on the Gold Coast in Queensland 1-3 October 2015 is an important education meeting for the community and opportunity for the community and their treatment health professionals and policy makers to discuss common issues. Attendance was consistent with previous years, even following the 2014 World Congress in Melbourne in 2014. The national website re-development project in collaboration with State and Territory Foundations is almost completed and we are confident this will result in evidence based education resources for the bleeding disorders community as well as the broader Australian community.

The Foundation retains the confidence of the Australian Department of Health as the national body to represent the bleeding disorders community. While HFA depends on government grants for special projects and to run the secretariat, this does not limit robust discussion about the blood sector and our priority to meet the needs of people living with bleeding disorders and their families. I am pleased our careful and rigorous attention to providing evidence based health information means that we continue to be a valued information partner with the Department.

HFA has relationships established over many years with community and consumer health organisations and other not for profit organisations that we collaborate with on specific issues raised by our members. The Consumers' Health Forum of Australia (CHF) provides an avenue for us to contribute to policy on chronic illness and medicines access where we do not make our own submissions to government and other organisations. During the year we have consulted with Hepatitis Australia and state/territory hepatitis organisations, Australian Federation of AIDS Organisations (AFAO), National Association of People with HIV Australia (NAPWHA), the Australian Red Cross Blood Service and ASHM (supporting the HIV, viral hepatitis and sexual health workforce).

We are grateful for the contribution and support received from the Australian Haemophilia Centre Directors' Organisation, Australian Haemophilia Nurses' Group, Australian and New Zealand Physiotherapy Haemophilia Group and the Australia/NZ Haemophilia Social Workers' and Counsellors' Group, whose members are health professionals working at Haemophilia Treatment Centres around Australia. They give their professional and personal time to assist HFA with education resource development, and contribute their ideas and recommendations to improve treatment and care for people with bleeding disorders and we are grateful for this. We are also pleased we can support the national physiotherapy, nurses and counsellors groups to enable them to promote excellence in their clinical areas.

I wish to acknowledge those individuals and organisations who take a special interest in HFA by providing support as donors and as sponsors of our programs. I also thank Council Delegates and our member Foundations for their support, and HFA staff who have worked hard during the year in support of our objectives.

# Our Highlights & Achievements

## REPRESENTATION AND ADVOCACY

Working towards our vision of active, independent and fulfilling lives for people in our bleeding disorders community gives a real focus to HFA's work around representation. Crucial to this is making sure the voice and experience of people with bleeding disorders and their families is heard. In 2015-16 there were exciting new developments in haemophilia and hepatitis C treatment. How will they impact on people with bleeding disorders? Gaining an understanding of community members' treatment experience and views, as well as the advice and support of experts, has been key to HFA in targeting our work on representing the community. The reorganised HFA Council structure has been another successful way to connect more directly with our state and territory membership and speak to community issues more quickly and effectively.

### **Understanding the voice of the community**

In 2015 HFA's governing Council put in place the new constitution so that each member Foundation now has one delegate at Council, either the President or a key local leader who facilitates the communication between HFA and their Foundation. Individual Foundations have found the Council forum a valuable environment to initiate robust discussion and national activity about issues arising at the local level. At the same time, there has been a swifter response from the Foundations around ongoing and emerging issues, such as new haemophilia and hepatitis C treatments, the youth strategy, information for women and girls, and the national website project.

### **Hepatitis C**

Hepatitis C has continued to be a high priority for HFA. Many people with bleeding disorders in Australia acquired hepatitis C from their treatment products before 1993, particularly human plasma-derived clotting factor concentrates. Some have cleared the virus naturally or through treatment. However, many others have had hepatitis C for more than 20 years. For them advancing liver disease and limited treatment options have been a real problem.

In 2015 the Pharmaceutical Benefits Advisory Committee (PBAC) had recommended several new direct acting antiviral (DAA) hepatitis C drugs for subsidisation under the Pharmaceutical Benefits Scheme (PBS). These new drugs have revolutionised hepatitis C treatment, with very high cure rates, few if any side-effects, and short treatment courses. HFA had made substantial submissions to the PBAC in support of these treatments, including the comments and personal experiences of community members drawn from HFA surveys, and had corresponded with the Australian Government about the need for access to these treatments without delay.

In September 2015 HFA joined Hepatitis Australia and 25 other organisations in an open letter to the Australian Health Minister about the urgent need for these treatments.

In December 2015 came the very welcome announcement from Australian Minister for Health Sussan Ley that the new treatments would be available on the PBS from 1 March 2016

*“This is fantastic news for people with bleeding disorders and hepatitis C,” said Gavin Finkelstein, President of Haemophilia Foundation Australia. “They have been waiting so long for access to treatment to cure their hepatitis C. Many have seen their liver disease progressing and were despairing. This decision by the Government will change people’s lives and we would like to congratulate Minister Ley for seeing the process through to make these treatments available and affordable to all Australians with hepatitis C.”*

HFA sought advice from haemophilia and hepatitis clinical experts on the best approach to hepatitis C treatment for people with bleeding disorders. This resulted in a national health promotion campaign encouraging people with bleeding disorders and hepatitis C to make an appointment with the specialist clinic to discuss their treatment options. Personal stories have been essential to engaging community members in this campaign. HFA has also been working closely with Haemophilia Centres to understand and address any barriers to treatment uptake among their patients.

With the high cure rates, we are hopeful that hepatitis C can be eliminated in the Australian bleeding disorders community. HFA will be making every effort to ensure affected members are aware of and have access to these new treatments.

### **Best practice treatment and care**

What defines best practice treatment and care? What resources do we need for advocacy around future directions in healthcare? A strong evidence base is essential. HFA is committed to creating this evidence base and making sure that people with bleeding disorders can contribute to it.



**MyABDR** is critical to both managing the treatment and care of people with bleeding disorders, and to creating real world health data. It is a secure app and web site that allows people with bleeding disorders and parents/caregivers to record treatments and bleeds at home and manage their treatment product inventory. It links directly to the **Australian Bleeding Disorders Registry (ABDR)**, which is the system used nationally by Haemophilia Treatment Centres for the clinical care of their patients.

MyABDR was established as a collaboration between HFA, AHCDO and the National Blood Authority (NBA) on behalf of Australian governments to support best practice clinical care and treatment of people with bleeding disorders. Since its release in 2014, it has undergone a number of enhancements, with more still to come. Improvements have been developed in consultation with the

community, through focus groups and other consultation facilitated by HFA. A suite of education materials has also been developed by HFA, along with regular foundation newsletter articles promoting MyABDR and the new developments.

Many Haemophilia Treatment Centres now work closely with their patients on the treatment and bleed information they record on MyABDR and discuss it at their review appointments. However, there is still a proportion of people who treat at home and do not record regularly, even if registered with MyABDR. This data is very important to clinical management and we are investigating ways to promote and increase recording.

Alongside clinical management and helping governments to plan for treatment product purchase and supply, data from the ABDR also has the potential to be a valuable source of research data to improve patient care. The data that people with bleeding disorders contribute via MyABDR could provide much more specific evidence about the impact of individualised treatment regimens and bleeds and their management. HFA's mission is to ensure to world's best practice in relation to treatment and care. This is reliant on the kind of evidence-based data that could be built through MyABDR and we will continue to work with the community, AHCD0 and the NBA to achieve this.

By June 2016 there were 700 registered MyABDR users

### **Treatment Product Access**

The emerging extended half life clotting factor products represent one of the most significant improvements in haemophilia treatment since virally safe products and prophylaxis became standard treatment.

Prophylaxis within the comprehensive care model is the preferred model of care in Australia. Patient and clinician priorities are generally to prevent and/or reduce bleeding episodes by keeping factor activity levels above 1%. The new products however, offer higher activity levels and the half life of factor VIII may be extended by 1.5 times and 2 - 5 times for factor IX.

This offers very different possibilities for care and management - trough levels maintained higher than 1% with no bleeding. Currently, even with prophylaxis some children and adults suffer joint damage, although they are adhering to their treatment plan. Others may struggle with their treatment plan for a number of reasons. A prophylaxis protocol could be tailored to the individual based on bleeding patterns and clotting factor levels as well as taking into account factors such as age, joint health, and physical activity. Trough levels could be kept to a level where there is no damage from bleeding at all.

Extended half life factors were not included in the most recent National Blood Authority tender process, because the first extended half life products had not been registered by the Therapeutic Goods Administration for use in Australia in time for them to be considered for inclusion in the preliminary tendering processes. Nevertheless, we were already aware from early data from phase 3 clinical trials that these products would likely change the face of treatment. Stories from Australian patients who had chosen to participate in global clinical trials were positive and their clinicians were excited about the outcomes.

To understand more about what this would really mean for our community, HFA invited a group of patients who were currently on, or had been on clinical trials, and some of their doctors and haemophilia nurses to share their stories at a Workshop in February 2016. Also in attendance were representatives of the HFA Council and staff and an official from the National Blood Authority.

The purpose of the workshop was to discuss local and international experience with extended half-life clotting factors and other new treatments in development, primarily to inform HFA's approach to access.

As we expected the number of treatment products of interest to grow beyond those registered in Australia at the time of the workshop, we invited Dr Lianne Khoo, from the Royal Prince Alfred Hospital in Sydney to give a presentation on the range of new treatments on the horizon, and how they work. We wanted to hear more about longer acting clotting factors as well as antibody treatments which act almost like bypassing agents to factor VIII and factor IX. Further, after many years of frustration with gene therapy trial outcomes, in the past two years we have seen promising research data emerge and we wanted to hear more about some of this work.

The personal stories of those who had been participating in several clinical trials were shared. The treatment products had significantly changed their lives. Their experiences are an important part of our advocacy for access.

Although it will take time to build a body of evidence around all the outcomes/indicators required by payers, clinicians and the community, we can already see from the data generated from clinical trials, and the experience of local clinicians and their patients and families, that there are strong arguments for their use.

The anecdotal evidence and patient stories at the workshop were profound. The clinical evidence was compelling.

The Haemophilia Foundation Australia (HFA) Council is now reviewing its Treatment Product policy in the context of extended half-life (EHL) clotting factors and the upcoming new national treatment guidelines being developed by Australian Haemophilia Centre Director's Organisation (AHCDO) and the National Blood Authority (NBA).

A range of improved health and quality of life outcomes have been reported: better control of bleeding; higher trough levels can be achieved if required; better compliance with prophylaxis; fewer infusions leading to better vein protection - which is critical for children and those who are ageing; reduced risk of infection and/or thrombosis from fewer infusions; less pain, suffering and family disruption; reduced loss of work and school time; improved clinician/patient engagement and commitment to recording; and the benefit of a doctor being able to develop a treatment plan specifically for individual patients based on their bleeding patterns. These things can be life-changing for people with haemophilia and their families. We understand the concern of governments about the cost of these products. HFA has urged governments to consider the cost for the new treatments carefully against the benefits. There is now a great opportunity to increase the range of treatment products to include extended half life factors to enable patients and their treating clinicians to make the best possible treatment decisions.

## **PROBE**

In 2015 Haemophilia Foundation Australia joined the PROBE (Patient Reported Outcomes Burdens and Experiences) Study.



PROBE is a multi-national patient-focused research project led by a global team of patient and academic investigators, including Mark Skinner, former WFH President, and Assoc Prof Alfonso Iorio from McMaster University, Canada, who have worked closely with HFA on the Australian arm of the study.

The PROBE study allows people with haemophilia to report their haemophilia severity, treatment history and the impact of haemophilia on their daily life. This data will be used to analyse the perspectives of people with haemophilia on outcomes that affect their own life and care. The research will support efforts to improve treatment and comprehensive care programs in Australia and other countries around the world.

HFA completed phase 1 of the PROBE study in December 2015. This involved testing the methodology and statistics that could be gained from the results by asking 35-50 adults from the Australian bleeding disorders community to complete a print survey. The surveys were analysed by the PROBE research team at McMaster University, Canada. Part of this phase also included testing the ethical process against Australian standards, streamlining data handling procedures and seeking ethics approval via Monash University, Melbourne.

Results demonstrated validity and that the research methodology was robust. The International PROBE team also made some small adjustments to the survey questions based on feedback from Australian participants.

Our thanks to Dr Liz Bishop from the Michael Kirby Centre for Public Health and Human Rights at Monash University for her support of the research into the ethical process.

### **National representation**

Over many years, HFA has established strong partnerships and collaborations with specialist health professionals, community organisations and government representatives. 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.

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

- Future supply arrangements for imported plasma and recombinant products
- The AHCCDO guidelines for management of haemophilia in Australia
- New hepatitis C treatments for listing on the Pharmaceutical Benefits Schedule.

Most importantly we rely on volunteers and staff who can represent the views and needs of our community or the health consumer in general. During 2015-2016 HFA volunteers and staff were invited or nominated to sit on committees and consultation meetings to represent consumer views including:

- Australian Red Cross 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
- Australian Bleeding Disorders Registry User Reference Group
- Medicines Australia Code of Conduct Committee
- Hepatitis Australia World Hepatitis Day Project Reference Group
- Hepatitis Australia National Resource Network
- Australian Commission on Safety & Quality in Healthcare Risk Communication Project Steering Group

## COMMUNICATING WITH THE COMMUNITY

### EDUCATION AND INFORMATION

Education resources snapshot - in 2015-16  
HFA booklets, folders and fact sheets  
3,493 print copies distributed  
More than 20,775 PDF downloads

### Women and Girls' Project

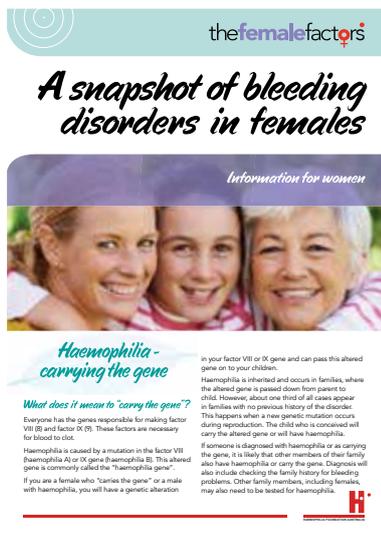
# thefemalefactors

It has been exciting to see the HFA project to develop information and resources specifically for women and girls with bleeding disorders coming together in 2016.

The project has been named **The Female Factors** - a title chosen by the women and girls participating in the project to acknowledge:

- The range of factor gene alterations causing bleeding disorders that affect females in our community
- The many factors females need to deal with to manage their bleeding disorder.

The first of the suite of new resources was published in June 2016: **A snapshot of bleeding disorders in females**. The Snapshot is an introduction in a magazine-style format, with basic information and personal stories and tips about navigating your way through the health care



system. It has been released both online and in print - many women asked for print copies to share with their family and health care providers.

Much of the work around how bleeding disorders affect females is very new. Information for the resources in The Female Factors project is based on the very latest research and developed from the experience and questions of Australian women and girls who have bleeding disorders. Women and teenage girls and their parents have contributed ideas for topics, personal stories and tips, and comments on the drafts. The resources are also being reviewed by expert health professionals to make sure they are accurate, relevant and speak to the needs of Australian women and girls.

For teenage girls and young women living with a bleeding disorder or finding out you carry the gene can be very challenging. HFA consultation highlighted the importance of a separate suite of resources targeted at teenage girls and young women. This information is being developed alongside the adult resources and will be published on the **Factored In** web site and in other formats, if appropriate.

## COMMUNICATIONS



**National Haemophilia**, HFA's quarterly journal, is recognised in the community as a source of high quality, relevant and up-to-date information and news about bleeding disorders. It provides educational articles on a range of topics, including plain language articles from Australian bleeding disorder experts. It is available in the formats preferred by the bleeding disorders community and stakeholders: in print and online as a PDF, as a magazine through ISSUU, and with each article as a web page. Popular features have included conference reports; women's issues; MyABDR updates; hepatitis C news; updates on medical issues, such as impact of joint problems on walking and blood in the urine; family concerns such as sibling rivalry; mindfulness; and youth activities.

The **Haemophilia Foundation Australia web site** is a major communication tool for HFA. It is a reliable and respected source of information for the Australian 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 37% of visitors access it with smartphones and ipads/tablets. The most popular page views and downloads have been information about bleeding disorders, special events, *National Haemophilia* journal and information about treatment services.

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

A goal of HFA Council has been to develop a high quality website infrastructure that is shared by HFA and State and Territory Foundations. This project is due to be completed by the end of August 2016.

The **HFA free email newsletter** is popular among bleeding disorder community members and supporters, with an open rate well above national benchmarks. It is an important way of connecting with HFA about HFA activities and fundraising opportunities, new HFA publications and other news.

## Social media

HFA regular postings on its Facebook page and Twitter are focused on content that is relevant to the Australian bleeding disorders community. Both HFA social media platforms are well-received and have an increasing audience. HFA's growing engagement on these platforms means that they are becoming one of HFA's major means of communication with the general community, and HFA projects such as The Female Factors and events such as Red Cake Day generate substantial community support.

These platforms can be particularly effective for promoting important new information, for example when new hepatitis C treatments became available in March 2016. The HFA Facebook post reached more than 1,700 people, with more than 60 likes, comments and shares.

### HFA communications snapshot – in 2015-16

- 7073** copies of *National Haemophilia* posted to members
- 1222** copies of *National Haemophilia* downloaded from web site
- 705** HFA members received regular e-news
- 55,404** visits to view HFA web pages
- 2102** HFA facebook fans/"likes"
- 58%** of HFA facebook fans/"likes" in **13-34 age group**
- 387** followers of HFA on **Twitter**

Haemophilia Foundation Australia

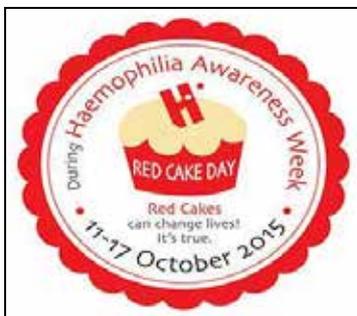


**Haemophilia Foundation Australia**

Published by Sharon Caris [?] · October 6, 2015 ·

Don't forget that Haemophilia Awareness Week is the 11-17 October. Help improve the lives of people with a bleeding disorder and support Red Cake Day during Haemophilia Awareness Week.

Visit <http://www.haemophilia.org.au/redcakeday/> for more info on what you can do to help and how to host a Red Cake Day!



**1,791** People Reached

**117** Likes, Comments & Shares

**90** Likes      **27** On Post      **63** On Shares

**0** Comments      **0** On Post      **0** On Shares

**27** Shares      **25** On Post      **2** On Shares

**61** Post Clicks

**12** Photo Views      **8** Link Clicks      **41** Other Clicks

**NEGATIVE FEEDBACK**

**0** Hide Post      **0** Hide All Posts  
**0** Report as Spam      **0** Unlike Page

## PUBLIC AWARENESS

### World Haemophilia Day



**TREATMENT FOR ALL  
THE VISION OF ALL**  
Globally 1 in 1,000 people has a bleeding disorder.  
Most are not diagnosed and do not receive treatment.

World Haemophilia Day was celebrated in April 17, together with our fellow World Federation of Hemophilia (WFH) National Member Organisations around the world. We supported the WFH goal for Treatment for All.

### Light it up Red!

Together with other landmarks from around the world, AAMI Park in Melbourne, Perth Bell Tower and the Brisbane Storey Bridge turned red on Sunday 17 April to celebrate being united in support. Next year we are hoping all states and territories will be involved.



### Haemophilia Awareness Week and Red Cake Day

Haemophilia Awareness Week and Red Cake Day were held this year from 11 to 17 October 2015. 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.

The Bendigo Bank branches across Australia joined in partnership to raise awareness and funds, and 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.

### PAINT THE TOWN RED

#### Neerim South & Bendigo Bank Branches, South Gippsland Region



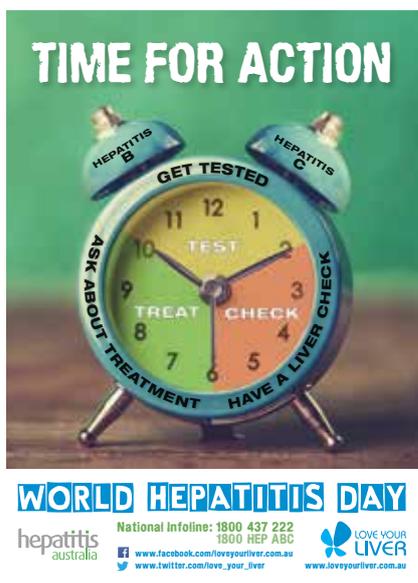
Now in its seventh year, the township of Neerim South in Victoria once again hosted 'Paint the town Red'. The event is organised by Donna Field and a wonderful team at the Neerim District Community Bank®. We are grateful to the staff at Bendigo Bank Branches who also displayed posters and promotional items to raise awareness about bleeding disorders and helped to raise funds.

### SNAPSHOT

- Over **100** Red Cake Day events and awareness activities
- Over **200** Bendigo Bank Branches participated in the week
- The week across the country has raised just under **\$35,000**



## World Hepatitis Day



World Hepatitis Day was marked internationally on 28 July 2015. The Australian theme focused on TIME FOR ACTION. This theme is particularly relevant for people with bleeding disorders and hepatitis C, who have lived with hepatitis C infection for more than 25 years and are at risk of developing advanced liver disease. HFA is a partner in the World Hepatitis Day Campaign and worked together with Hepatitis Australia, state and territory Foundations and haemophilia and hepatitis experts to develop a social media campaign targeted at the bleeding disorders community. The HFA slogan was:

**It's #timeforaction!**

**Know if you were exposed to hepatitis C; get tested; have a liver check; ask about treatment.**

## World AIDS Day 2015

In 2015 the World AIDS Day global campaign continued the theme of **“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.

## 17th Australian New Zealand Conference on Haemophilia and Related Bleeding Disorders



The 17th Australian New Zealand Conference on haemophilia and related bleeding disorders was held in October 2015 at the Gold Coast. Delegates including people with a bleeding disorder, their families and carers, health professional, policy makers, industry representatives and many other stakeholders came together to meet, share information and learn from each other.

Over the 2 days delegates took part in an exciting and information multidisciplinary program, chaired by Dr Simon McRae. Topics included hepatitis C, comprehensive care, von Willebrand disease, inhibitors, youth, genetic counselling and ageing.



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National Blood Authority  
Australia

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**WHAT DID THE DELEGATES SAY?**

*"It had the right amount of information for both myself and my girlfriend that didn't know about haemophilia and now know a little more than before. I thank you for that."*

*"Loved the mix of specialist/carer/personal experience in each session"*

*"It has made me want to work harder in this therapeutic area."*

*"A broad range of topics for both health professionals and families."*

*"Good for networking."*

*"So glad we got to come. It was also a good way for us to touch base with other families in similar situations which doesn't happen a lot for us and we get a lot out of that."*

*"It has given me hope that our boys may have the chance to use a longer acting factor in the future and that this will hopefully see even further improvements in the quality of their lives and our lives as carers."*

*"Broader appreciation of haemophilia from medical and family prospective. Very positive for the future with ongoing improvements in management etc."*

## YOUTH MENTORING AND LEADERSHIP PROGRAM

### [www.factoredin.org.au](http://www.factoredin.org.au)

Factored In is an innovative website for young people with bleeding disorders. It was created with young people to talk about life, being young and having a bleeding disorder. The website contains robust and evidence-based health information relevant to youth and their bleeding disorders, as well as personal stories. Topics include information on sports, treatment, employment, disclosure and travelling.

During the year young people affected by bleeding disorders evaluated the website through a survey and workshop. As a result the website has been redeveloped to make personal stories more prominent and easier to find.

#### **FACTORED IN IMPROVEMENTS:**

- responsive to mobile and tablet devices through a new content management system
- intuitive menu and navigation system
- user-friendly Q & A portal
- easy to locate and use story submission and member portal
- attractive home page which reflects new website content

#### **FACTORED IN LAUNCH**

The 'new' Factored In was launched on May 24 with a competition to showcase the site and encourage new members.

#### **WEBSITE CONTENT**

New website content has been created by the contribution of personal stories by youth, and by Youth Lead Connect participants submitting their reports and personal stories about attending events and activities as leaders or mentors in their respective states. Youth moderators promote Factored In throughout their local community at camps and activities.

The Youth Working Group is also involved in continuous Factored In development by generating ideas for new content and contributing to stories as well as contributing to evaluation of the website functionality.

#### **FACTORED IN SNAPSHOT**

The number of people using the Factored In website has increased exponentially throughout the year, corresponding to the launch of the 'new' website in May 2016.

In 2015-16 there were

- **103** members
- **4,985** website visits
- **13,995** page views



FACTORED IN PROMOTIONAL POSTCARD



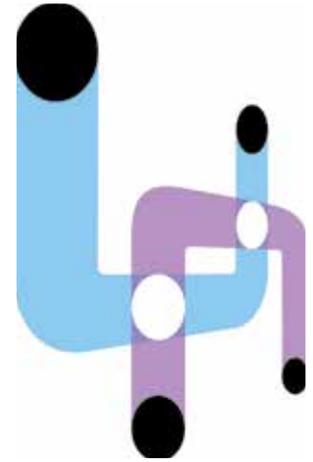
FACTORED IN HOMEPAGE



STORY PIECE

## YOUTH LEAD CONNECT

Youth Lead Connect (YLC) is a new leadership program developed by Haemophilia Foundation Australia (HFA) to build education and life skills for young people with bleeding disorders. YLC benefits both individuals and the bleeding disorders community through the development of real-world leadership and mentoring skills and experience including personal development and making connections. The program promotes engagement in the community through the development of community-based hurdles which must be completed before graduating from the program.



The program began in 2015 with an application process following a pathway similar to a job application. Young people applied to the program with an application form and covering letter, and included an official referee from their local Haemophilia Foundation. Participants accepted to the program received an official acceptance letter from the HFA Executive Director and were required to attend a training weekend hosted in Melbourne.

The training weekend developed skills in leadership and mentoring and identified motivations of the youth to participate in the program. An important part of the program is the hurdles component: after the training weekend youth are required to develop 'hurdles' in consultation with their local Haemophilia Foundation, and to complete their hurdles before graduating from the program.

### Achievements

The following achievements have been accomplished by YLC participants by June 2016:

- a YLC participant had a specific responsibility for planning and overseeing some of the children's activities at a family camp
- a YLC participant has done a talk to youth with haemophilia about umpiring football
- a YLC participant has organised a Women's Brunch
- a YLC participant took on a voluntary role at his local Foundation to practice his organisational skills and this resulted in him being employed in a full time job
- two YLC participants have become committee members in their respective states after attending regular committee meetings
- a YLC participant is helping organize a youth camp in their state

## 5 month evaluation

An evaluation was completed at 5 months, including a survey by participants:

- 75% of participants have completed one or part of their hurdles
- Participants identified:
  - the biggest obstacles to completing YLC hurdles were work, personal, and university commitments
  - the pathway most advantageous to achieving their hurdles was networking and knowing people within their local state. Support from their local foundations was key to achieving the YLC hurdles
  - the YLC program was beneficial to them and their community as it helped engage youth, promote youth involvement and create a pathway to be involved with HFA and locally.



*Youth Lead Connect participants at the weekend workshop*



*Youth Lead Connect participants at the weekend workshop, sharing their personal experiences*

The Youth Lead Connect program for 2016 was supported by an unrestricted education grant from CSL Behring.

## FUNDRAISING

HFA's fundraising program is critical to ensure HFA has sufficient funds for the secretariat and for HFA education programs and peer support activities and to support state and territory based camps and workshops undertaken by our member Foundations.

### Our generous supporters

We are fortunate to have a loyal and committed group of individuals, families, service groups and schools that support our work by making donations throughout the year. Their generosity helps us continue to provide many of services that improve quality of life for people with bleeding disorders.

### Appeals

Direct mail appeals to donors are mailed during the year and we thank each individual who made a donation. The donations raised from these campaigns are used to support programs and services such as family camps, women's resources and local community projects.

### Regular Giving

As haemophilia is a lifelong disorder, support and services are required throughout a person with haemophilia's entire life - from diagnosis, through childhood and youth, to the transition into adulthood and then to older age. Support and assistance is also needed at different times by parents, siblings and other relatives of people with bleeding disorders. Regular donations provide the ongoing support we need to meet the challenges faced by members of our community at each life stage. Thank you to each of the individuals that have committed to give a monthly, quarterly or annual donation towards our work.

**You can save the projects that make a difference in your local community.**

**Western Australia:** Allow people who live far apart to access peer support. The **South West Rural Trip** is a series of dinners to bring people together, share experiences and raise awareness of services available to them.

**South Australia and NT:** Introduce a **Community Gathering** to bring people together socially as well as provide education and share regional treatment and care options.

**Tasmania:** Introduce the **"Engage Tasmania"** project which will increase the level of care and education available to both families and medical specialists.

**Victoria:** **Young Boys Day Out** for children aged 5-8 to meet others their age with haemophilia and families can connect and learn about support and services available.

**Queensland:** **Annual Community Camp** for boys and men with haemophilia focussing on understanding the health system, healthy living, lifestyles and aging with haemophilia.

**New South Wales:** The annual **Family Camp** which provides fun activities to build friendships and peer support as well as education sessions such as self infusion.

**ACT:** Ensuring the **Coastal Camp** is a regular event to bring the community together and help children overcome dependency on parents and manage their own disorder.

**Your donation will help boys like Alessandro and Emiliano connect with others living with haemophilia so they know they are not alone.**

**"When we found out, there were lots of tears. There's no family history and no one had any idea. My Dad didn't even know how to pronounce haemophilia. Everyone thought it was a death sentence".**

**"I took this photo the day after we found out about Kelly's haemophilia... feeling very emotional"**

## RESEARCH

The Haemophilia Foundation Research Fund has distributed \$636,180 for 28 medical, scientific or social research projects since it was established in 1994. HFA has continued to make relatively small annual grants for projects that are judged to make a likely improvement to the lives of people affected by bleeding disorders.

A grant of \$18,182 (+GST) to Dr Seth Masters who is a scientist in the Inflammation Division of the Walter and Eliza Hall Institute of Medical Research was announced in the previous year, however the work was delayed pending ethics approval. We are pleased this research has now gone ahead as it will address the serious issue of progressive joint damage in people with haemophilia that often leads to the need for synovectomy and early joint replacement. The research, Interleukin-1 beta and the inflammasome in haemophilic arthropathy, will address whether the drugs that are used to prevent inflammatory arthropathy in other conditions might also stop disease progression in joint damage in people with haemophilia. This project seeks to validate an entirely new inflammatory pathway that may be involved in haemophilic joint inflammation, for which drugs are available and could be used clinically.

## BEQUEST FOR RESEARCH FUND

Alan and Maxine Ewart had been hard working volunteers for both Haemophilia Foundation South Australia and HFA over many years. They were deeply committed to improving care and treatment and helping families understand more about living with haemophilia. Alan had haemophilia and had worked at the University of Adelaide as a technical officer. Alan had been on the HFA Council and attended many meetings and conferences with Maxine, including World Federation of Hemophilia Congresses, to learn more, and to keep up to date with the latest developments. They were on the very first committee to consider the establishment of an HFA research fund and worked hard to raise the capital required. Alan died in 2013 and Maxine later in 2014. After Maxine's death HFA was contacted by their family to inform us that Maxine had made a very generous bequest for the purposes of research. This very generous gift has strengthened our capacity to operate the Fund well into the future. We will undertake a review to ensure our research policy benefits the bleeding disorders community in the best ways – just as the Ewarts would have wanted us to. HFA was delighted to welcome relatives of the Ewarts to the 17th Australian & New Zealand Conference on Bleeding Disorders on the Gold Coast in October 2015 when this generous bequest was announced.

## AWARDS

### LIFE GOVERNORSHIP

Ann Roberts was honoured with a HFA Life Governorship. Ann has been a long term volunteer to HFA and her own foundation HFV. She was given the Life Governorship for her dedicated leadership to the Haemophilia Foundation Australia Council in each of the roles of President, Vice President and Treasurer over many years and long term commitment to HFA's goals and objectives.

### JENNIFER ROSS AWARD

The HFA Jennifer Ross Award recognises outstanding or significant contribution towards the work of Haemophilia Foundations and/or Haemophilia Centres - beyond the normal expectation of the person's professional role or for special service to people with bleeding disorders and their families. In October 2015, the following people received this award:

Sharon Hawkins in recognition of her service as a Counsellor to the bleeding disorders community in Western Australia, leadership as chair of the Australia/New Zealand Haemophilia Counsellors Group and contribution to HFA services and education programs over many years and her contribution to the global community by representing HFA as co chair of the WFH 2014 World Congress Psychosocial Program Committee

Maureen Spilsbury in recognition of her service as a Counsellor to the bleeding disorders community in Queensland and leadership as chair of the Australia/New Zealand Haemophilia Counsellors Group and contribution to HFA services and education programs over many years

Leonie Mudge in recognition of her service as a Counsellor to the bleeding disorders community in Victoria and NSW and leadership as chair of the Australia/New Zealand Haemophilia Counsellors Group and contribution to HFA services and education programs over many years

Clare Reeves in recognition of her service as a Counsellor to the bleeding disorders community in ACT and active participation in the Australia/New Zealand Haemophilia Counsellors Group and contribution to HFA services and education programs over many years

### HFA VOLUNTEER AWARD

Ron Lees was awarded the Volunteer Award for his dedicated voluntary service to the ACT bleeding community over many years



Jennifer Ross, Ann Roberts,  
Gavin Finkelstein



Jennifer Ross, Clare Reeves,  
Gavin Finkelstein



Jennifer Ross, Leonie Mudge,  
Gavin Finkelstein



Jennifer Ross, Maureen Spilsbury,  
Gavin Finkelstein



Jennifer Ross, Ron Lees,  
Gavin Finkelstein

## Go For It Grants



The Go For It Grants make new opportunities for people affected by haemophilia, von Willebrand disorder and other rare inherited bleeding disorders of all ages. The grant program is sponsored by Pfizer Australia.

This year grants were awarded to three recipients:

- travel costs associated with golfing scholarship to USA university - \$3000
- attendance at 2016 WFH World Congress in Orlando July 2016 -\$5000
- recording equipment for videos to support early performance career - \$2000



### Jayden's golf story

An avid golfer, Jayden began playing when he was 13 years old and has been awarded a sports scholarship for his golf to study at West Virginia University Institute of Technology and play for the college golf team.

*"I started playing in 2010, in competitions and it just progressed from there. I just really enjoyed it and stuck at it, then just lowered my handicap down..."*

Jayden explains that he plays competition once a week and practices most weeknights. He also reveals that he's been fortunate that his haemophilia hasn't impacted on his golf.

*"My haemophilia hasn't affected me in a way that I couldn't keep playing. Yeah I've been very lucky that my haemophilia hasn't caused any troubles at all".*

*"Take every opportunity and get everything organised as quickly as possible and as efficiently as you can. Yeah just try and make it happen - if you're suffering with a blood condition - it doesn't mean that you can't do the things you want to do."*

## 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 2015-2016 HFA supported 8 programs around Australia.

#### **HFWA Family Camp, March 2016**

51 adults and children attended the 2016 family camp at Point Walter Conference & Recreation Centre. Activities over the weekend included Amazing Race, Kite making, Car box making, water games and a talent show.

*"We were all amazed how great the kids & youth interacted with each other. Caring, supportive and with a "nothing holds us back" attitude"*



#### **HFV Family Camp, April 2016**

81 adults and children attend the annual family camp at Forest Edge CYC, Neerim South. The weekend was facilitated by Purple Soup and had activities such as high ropes, secret men's and women's business, mindfulness and finished with the a great trivia night.

*"We had an amazing time on our first camp. It has opened up a whole new world of support and changed our future"*



# Treasurer's Report, *David Fagan*



I am pleased that in 2016 we have built on the momentum of 2015 and that I can report a positive outcome for the year.

While total income increased by 5% from \$1,874,153 to \$1,974,607, our expenses also increased by 36% from \$920,140 to \$1,255,011. Overall, this led to a net surplus of \$719,596 for the year. Our total funds increased by 33% from \$2,161,709 to \$2,881,305 in 2016. The extraordinary increase in net assets is attributed to the further funds received from two bequests during the year, including the Ewart bequest to the Haemophilia Foundation Research Fund.

HFA relies on government grants for secretariat expenses and for projects related to the care and treatment of people with bleeding disorders. Approximately 25% of HFA's income came from government grants this year. The processes for Department of Health grant applications changed last year and led to some uncertainty. HFA made a strong argument for funding under the Commonwealth Department of Health Peak & Advisory Bodies Program and was pleased to receive a grant for the HFA secretariat for the next 3 years while the existing Blood and Organ Services Program grant continued for a further year. This also included an additional one off grant for HFA to undertake a national website re-development. We seek to be self sustaining, however the reality is that these government grants cover administration and secretariat costs which cannot be funded by other fundraising activities, and without them HFA would not be able to operate.

Fundraising from general donors, however, fell by 6% this year and general sponsorships fell by 19%. Our Executive Director and the fundraising team are working hard to identify strategies to address this, particularly in the areas of donor acquisition and retention, increased income from trusts, sponsorship and major gifts. The Ewart bequest represents a wonderful new opportunity for HFA to redevelop the Research Fund, however we also need to find innovative ways to increase general income to meet our operational expenses moving forward.

As reported, our expenditure rose by 33% this year. Approximately 46% of all expenses incurred were for our administration costs which is to be expected and relatively stable from year to year. The HFA secretariat necessarily relies on a team of professional and administration staff as well as Council and other volunteers who work together to implement our objectives. We continue to employ a mix of full and part time staff so that we have an in-house team with varied skills and expertise and this model serves us well. We had no significant unexpected administration costs, and the expenses for our office relocation have now been absorbed.

However, our expenses for care and services almost doubled compared to the previous year. This includes regular expenses including the annual meetings of specialist health professionals groups, communications and education resources, and any camps and workshops run nationally or

where HFA funds have been distributed to State/Territory Foundations. These are usually regular and relatively stable amounts. This year HFA held a Longer Acting Factors Workshop and youth training weekend. This line item also includes the effect of the biennial Australian & New Zealand Haemophilia Conference and any new programs or projects undertaken by HFA.

In relation to the Conference, it is best considered over a two year period. We have reported most sponsorship income in 2015 when it was received, while most conference expenses were reported in the current year when they were incurred.

A special project for the year representing almost 30% of our care and services expenditure was for the national website re-development project undertaken in collaboration with State/Territory Foundations. Fortunately the full costs of this project have been covered by the special government grant provided by the Department of Health for which I add my thanks and appreciation. Most of these expenses were paid from the grant in the current period.

Interest income in 2015 increased from \$38,499 by 31% to \$50,577 this year, with an effective interest rate for the year of 2.19% compared to 2.09% in the previous year. Currently HFA holds funds spread over 4 providers, with 49% held under Macquarie management and a further 32% held in equity securities.

Our ongoing challenge moving forward is to identify reliable and new sources of income to strengthen our capacity to meet the operating costs of the Foundation and respond to new directions as required.

The increase in HFA capital from the Ewart Bequest and the financial success of the 2014 World Congress over the last two years has provided a strong capital base for HFA. We are now taking steps towards an appropriate investment strategy that will strengthen HFA's financial position in the longer term. This important work is underway.

# Financial Report

**HAEMOPHILIA FOUNDATION AUSTRALIA INCORPORATED**  
**ABN 89 443 537 189**  
**COUNCIL REPORT FOR THE YEAR ENDED 30 JUNE 2016**

Your council members submit the financial report of Haemophilia Foundation Australia Inc for the financial year ended 30 June 2016.

## **Council Members**

The names of council members throughout the year and at the date of this report are :-

Haemophilia Foundation ACT	Claude Damiani (appointed October 2015) Maria Wensing (resigned October 2015)
Haemophilia Foundation NSW	Dan Credazzi
Haemophilia Foundation QLD	David Stephenson
Haemophilia Foundation TAS	David Fagan
Haemophilia Foundation VIC	Leonie Demos (appointed October 2015) Ann Roberts (resigned October 2015)
Haemophilia Foundation WA	Gavin Finkelstein

## **Principal Activities**

The principal activities of Haemophilia Foundation Australia during the financial year are to support people with bleeding disorders and their families through representation, education and the promotion of research.

No significant change in the nature of these activities occurred during the year.

## **Operating Result**

The surplus for the financial year amounted to \$719,596 (2015: \$954,013).

Signed in accordance with a resolution of the members of the council.



President

**Gavin Finkelstein**



Treasurer

**David Fagan**

Date: 03 October 2016

**HAEMOPHILIA FOUNDATION AUSTRALIA INCORPORATED**  
**ABN 89 443 537 189**  
**INCOME AND EXPENDITURE STATEMENT FOR THE YEAR ENDED 30 JUNE 2016**

	Note	2016 \$	2015 \$
<b>INCOME</b>			
Government grants		494,945	346,415
Other project grants		-	34,071
Sponsorships, donations and bequests		1,344,733	776,853
All other revenue		96,688	662,880
Interest income		50,577	38,499
Dividend income		15,589	-
Unrealised gains/(losses)		(42,983)	-
Other income		15,058	15,435
<b>TOTAL INCOME</b>		<b>1,974,607</b>	<b>1,874,153</b>
<b>EXPENSES</b>			
Administration		577,552	570,090
Leasing of premises and office expenses		74,799	76,325
Fundraising		46,220	26,381
Services and Care		524,980	234,339
Education		13,278	8,357
Research		18,182	4,648
<b>TOTAL EXPENSES</b>		<b>1,255,011</b>	<b>920,140</b>
<b>SURPLUS FOR THE YEAR</b>		<b>719,596</b>	<b>954,013</b>
<b>ACCUMULATED FUNDS BROUGHT FORWARD</b>		<b>1,923,516</b>	<b>973,810</b>
<b>TOTAL AVAILABLE FUNDS</b>		<b>2,643,112</b>	<b>1,927,823</b>
<b>TRANSFER (TO) / FROM RESERVE</b>	8	<b>(3,036)</b>	<b>(4,307)</b>
<b>ACCUMULATED FUNDS CARRIED FORWARD</b>	7	<b>2,640,076</b>	<b>1,923,516</b>

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

**HAEMOPHILIA FOUNDATION AUSTRALIA INCORPORATED**  
**ABN 89 443 537 189**  
**ASSETS AND LIABILITIES STATEMENT AS AT 30 JUNE 2016**

	Note	2016 \$	2015 \$
<b>CURRENT ASSETS</b>			
Cash and Cash Equivalents	2	275,543	317,160
Investments	3	2,706,287	1,984,654
Trade and Other Receivables		-	7,258
Other assets		6,177	9,836
<b>TOTAL CURRENT ASSETS</b>		<b>2,988,007</b>	<b>2,318,908</b>
<b>NON CURRENT ASSETS</b>			
Property, plant and equipment	4	85,465	94,594
Total Non Current Assets		85,465	94,594
<b>TOTAL ASSETS</b>		<b>3,073,472</b>	<b>2,413,502</b>
<b>CURRENT LIABILITIES</b>			
Trade and Other Payables	5	17,310	8,654
Short-term Provisions	6	169,494	150,146
Grants received in advance		-	90,000
<b>TOTAL CURRENT LIABILITIES</b>		<b>186,804</b>	<b>248,800</b>
<b>NON CURRENT LIABILITIES</b>			
Long-term Provisions	6	5,363	2,993
Total Non Current Liabilities		5,363	2,993
<b>TOTAL LIABILITIES</b>		<b>192,167</b>	<b>251,793</b>
<b>NET ASSETS</b>		<b>2,881,305</b>	<b>2,161,709</b>
<b>FOUNDATION'S FUNDS</b>			
Accumulated funds			
	7	2,640,076	1,923,516
Reserve	8	241,229	238,193
<b>TOTAL FOUNDATION'S FUNDS</b>		<b>2,881,305</b>	<b>2,161,709</b>

*The above Assets and Liabilities Statement should be read in conjunction with the accompanying notes.*

**HAEMOPHILIA FOUNDATION AUSTRALIA INCORPORATED**  
**ABN 89 443 537 189**  
**CASH FLOW STATEMENT FOR THE YEAR ENDED 30 JUNE 2016**

	Note	2016 \$	2015 \$
<b>CASH FLOWS FROM OPERATING ACTIVITIES</b>			
		50,577	38,499
Dividend received		15,589	-
Grants received		404,945	436,415
Receipts from constituents		711,186	1,455,168
Payments to suppliers and employees		(1,198,747)	(896,072)
<b>Net cash flows from operating activities</b>		<b>(16,450)</b>	<b>1,034,010</b>
<b>CASH FLOWS FROM INVESTING ACTIVITIES</b>			
Acquisition and disposal of property, plant and equipment		(5,844)	(96,262)
<b>Net cash flows used in investing activities</b>		<b>(5,844)</b>	<b>(96,262)</b>
<b>NET INCREASE CASH HELD</b>		<b>(22,294)</b>	<b>937,748</b>
<b>CASH BALANCE BROUGHT FORWARD</b>		<b>2,301,814</b>	<b>1,364,066</b>
<b>CASH BALANCE CARRIED FORWARD</b>		<b>2,279,520</b>	<b>2,301,814</b>
<b>Cash balance carried forward comprises : -</b>			
Cash and cash equivalents	2	275,543	317,160
Short term deposits	3	2,003,977	1,984,654
		<b>2,279,520</b>	<b>2,301,814</b>
<b>Reconciliation of surplus for the year to the net cash flows from operating activities : -</b>			
Total operating surplus for the year		719,596	954,013
Depreciation and amortisation		14,973	11,886
Changes in assets and liabilities			
Increase/(Decrease) in creditors and provisions		(59,626)	68,820
(Increase)/Decrease in receivables and other assets		(691,393)	(709)
<b>Net cash flows from operating activities</b>		<b>(16,450)</b>	<b>1,034,010</b>

*The above Cash Flow Statement should be read in conjunction with the accompanying notes.*

**HAEMOPHILIA FOUNDATION AUSTRALIA INCORPORATED**  
**ABN 89 443 537 189**  
**NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 30 JUNE 2016**

**NOTE 1: STATEMENT OF SIGNIFICANT ACCOUNTING POLICIES**

The financial statements are special purpose financial statements prepared in order to satisfy the financial reporting requirements of the Associations Incorporation Reform Act 2012. The council has determined that the association is not a reporting entity.

The financial report has been prepared on an accrual basis and are based on historic costs and do 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 these financial statements.

**(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.

Dividend income and any reclaim thereto is recognised when the entity obtains control over the funds which is generally at the time of receipt.

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 FOR THE YEAR ENDED 30 JUNE 2016**

**(g) 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.

**(h) 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.

**(i) 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.

**(j) Comparative Figures**

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

	<b>2016</b>	<b>2015</b>
<b>NOTE 2: CASH AND CASH EQUIVALENTS</b>	<b>\$</b>	<b>\$</b>
Cash at bank	275,543	317,160
<b>NOTE 3: INVESTMENTS</b>		
Short term deposits	2,003,977	1,984,654
Equity securities, at fair value	702,310	-
	<b>2,706,287</b>	<b>1,984,654</b>

**HAEMOPHILIA FOUNDATION AUSTRALIA INCORPORATED**

**ABN 89 443 537 189**

**NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE YEAR ENDED 30 JUNE 2016**

	<b>2016</b>	<b>2015</b>
	<b>\$</b>	<b>\$</b>
<b>NOTE 4: PROPERTY, PLANT AND EQUIPMENT</b>		
Furniture and office equipment - at cost	250,275	244,431
Accumulated depreciation	(164,810)	(149,837)
	<b>85,465</b>	<b>94,594</b>
<b>NOTE 5: TRADE AND OTHER PAYABLES</b>		
Trade creditors and accruals	17,310	8,654
	<b>17,310</b>	<b>8,654</b>
<b>NOTE 6: PROVISIONS</b>		
Current		
- Annual leave	100,617	87,853
- Long Service leave	68,877	62,293
	<b>169,494</b>	<b>150,146</b>
Non-Current		
- Long Service leave	5,363	2,993
	<b>5,363</b>	<b>2,993</b>
<b>NOTE 7: ACCUMULATED FUNDS</b>		
Accumulated funds are set aside for the following purposes:		
- research	1,882,244	900,948
- discretionary projects and reserves	757,832	1,022,568
	<b>2,640,076</b>	<b>1,923,516</b>
<b>NOTE 8: RESERVE</b>		
Damon Courtenay Reserve		
- balance at beginning of year	238,193	233,886
- special appeals and interest income	3,036	4,307
- sponsorships, allocations and costs	-	-
	3,036	4,307
- balance at end of year	<b>241,229</b>	<b>238,193</b>

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.

**NOTE 9: 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**

ANNUAL STATEMENTS GIVE TRUE AND FAIR VIEW OF FINANCIAL POSITION AND  
PERFORMANCE OF HAEMOPHILIA FOUNDATION AUSTRALIA INCORPORATED

We, G Finkelstein and D Fagan, being members of the council of Haemophilia Foundation Australia Inc, certify that:-

the statements attached to this certificate give a true and fair view of the financial position and performance of Haemophilia Foundation Australia Inc. during and at the end of the financial year of the association ending 30 June 2016.



President

**Gavin Finkelstein**



Treasurer

**David Fagan**

Date: 03 October 2016

HAEMOPHILIA FOUNDATION AUSTRALIA INC

INDEPENDENT AUDITOR'S REPORT TO THE MEMBERS OF  
HAEMOPHILIA FOUNDATION AUSTRALIA INC



**M V ANDERSON & CO**  
Chartered Accountants

[www.mvanderson.com.au](http://www.mvanderson.com.au)

#### Report on the Financial Report

We have audited the accompanying financial report, being a special purpose financial report, of Haemophilia Foundation Australia Inc., which comprises the assets and liabilities statement as at 30 June 2016, the income and expenditure statement and the cash flow statement for the year then ended, notes comprising a summary of significant accounting policies and other explanatory information, and the certification by members of the committee on the annual statements giving a true and fair view of the financial position and performance of the association.

#### Council's Responsibility for the Financial Report

The council of Haemophilia Foundation Australia Inc is responsible for the preparation and fair presentation of the financial report, and has determined that the basis of preparation described in Note 1 is appropriate to meet the requirements of the Associations Incorporation Reform Act 2012 and is appropriate to meet the needs of the members. The council's responsibility also includes such internal control as the council determines is necessary to enable the preparation and fair presentation of a financial report that is free from material misstatement, whether due to fraud or error.

#### Auditor's Responsibility

Our responsibility is to express an opinion on the financial report based on our audit. We have conducted our audit in accordance with Australian Auditing Standards. Those 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 association'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 association'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.

#### Opinion

In our opinion, the financial report gives a true and fair view of the financial position of Haemophilia Foundation Australia Inc as at 30 June 2016 and its financial performance for the year then ended in accordance with the accounting policies described in Note 1 to the financial statements, and the requirements of the Associations Incorporation Reform Act 2012.

#### Basis of Accounting and Restriction on Distribution

Without modifying our opinion, we draw attention to Note 1 to the financial statements, which describes the basis of accounting. The financial report has been prepared to assist Haemophilia Foundation Australia Inc to meet the requirements of the Associations Incorporation Reform Act 2012. As a result, the financial report may not be suitable for another purpose.

*M V Anderson & Co*

**M V ANDERSON & CO.**  
Chartered Accountants  
Level 5, North Tower, 485 La Trobe Street  
Melbourne Vic 3000

*Graeme S. Day*

**GRAEME S. DAY**  
Partner

Dated: 4 October, 2016

*Culture  
Commitment  
Confidence*

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# Acknowledgments

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

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The Greatorex Foundation  
The Marian & EH Flack Trust  
The William Angliss VIC  
Charitable Fund

## Independent Special Events

Mrs Karen Grove  
- Entertainment Books  
Skye Football Club  
Team Factor 2016

## Donations Received

**in Memory of:**  
Mr Charles Bayl  
Mrs Alexis Gerritsen

## Bequests:

Estate of Valerie Dawn Bowen  
Estate of Maxine Billie Ewart

## Bequests received from the Estates of:

The estate of Maxine Ewart

## Corporate Donors over \$250

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Happy Valley Clinic  
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Tasmanian Seafoods Pty Ltd

## Corporate Partners

*These partnerships include sponsorship for education and awards programs developed and run by the Foundation*

- Biogen Idec
- CSL Behring (Australia) Pty Ltd
- Novo Nordisk Pharmaceuticals
- Pfizer Australia

## 17th Australian & New Zealand Haemophilia Conference

### Sponsorship

Final payments received from:  
AbbVie  
Novo Nordisk

Thank you to our Conference Sponsors:

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- AbbVie
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## Government Grants

HFA gratefully acknowledges the program grants received from the Australian Government Department of Health and Department of Social Services.

**Haemophilia Awareness Week & Red Cake Day**

Haemophilia Foundation Australia would like to acknowledge the generous contribution from the following supporters during Haemophilia Awareness Week and Red Cake Day.

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Inspiring **excellence** in **treatment, care**  
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**education** and **promotion of research.**

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