



HAEMOPHILIA FOUNDATION AUSTRALIA



annual report
2016-2017

Haemophilia Foundation **Australia**

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

Our Governance

HFA is incorporated in Victoria. Its members are each of the state/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
- best practice governance
- to be the trusted national representative organisation and recognised community voice on bleeding disorders

Our Funding & Donor Partners

HFA has a national fundraising program. All donations, grants and sponsorships are managed in a spirit of transparency and best practice, and all partnerships must have a meaningful benefit to HFA's mission and goals.

Our donors and funding partners include governments, companies, philanthropic trusts and foundations, service clubs and individuals. Corporate partnerships are underpinned by memorandums of understandings or contracts that confirm obligations, responsibilities and benefits to each party. Government grants with the Australian Government Department of Health are subject to contracts and agreements.

Meet the Organisation

NATIONAL PATRON

The Right Honourable Sir Ninian Stephen, KG, AK, GCMG, GCVO, KBE
(*Sir Ninian passed away 29/10/17 before this publication was printed*)

STATE PATRONS

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

WESTERN AUSTRALIA Her Excellency the Honourable Kerry Sanderson, AO,
Governor of Western Australia

NEW SOUTH WALES Dr Kevin A Rickard, AM, RFD

VICTORIA Dr Alison Street, AO

TASMANIA Lady Green

QUEENSLAND His Excellency The Honourable Mr Paul de Jersey, AC, Governor of Queensland

President: Gavin Finkelstein

Executive Director: Sharon Caris

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		

HFA COUNCIL (2016-2017)

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.

Haemophilia Foundation Australian Capital Territory

Claudio Damiani

Haemophilia Foundation New South Wales

Daniel Credazzi

Haemophilia Foundation Queensland

David Stephenson

Haemophilia Foundation Tasmania

David Fagan

Haemophilia Foundation Victoria

Leonie Demos

Haemophilia Foundation Western Australia

Gavin Finkelstein

South Australia

Paul Bonner, Observer



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

Office Bearers

Gavin Finkelstein - President, Daniel Credazzi - Vice President, David Fagan - Treasurer

EXECUTIVE DIRECTOR AND STAFF

Sharon Caris, Executive Director

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) until January 2017

Jane Turney, Administration Officer – Development (Part-time)

Suzanne O’Callaghan, Policy Research and Education Manager

Hannah Opeskin, Health Promotion Officer (Part-time)



Sharon Caris



Natashia Coco



Carol Joy



Janine Staunton



Jane Turney



Suzanne O’Callaghan



Hannah Opeskin

President's Report Gavin Finkelstein



2017 has been a busy year for us. We have focused on our strategic plan and vision for everyone in our bleeding disorders community to have active, independent and fulfilling lives. This has driven our advocacy for new treatments and educational resource development during the year.

As we reflect on 2016, we remember how very important it has been for the health of many Australians with bleeding disorders who also lived with the hepatitis C virus. Along with other specialist organisations, HFA had been advocating for government funding and urgent access to the new direct acting anti-viral treatments for hepatitis C which had been emerging globally. Without government funding these would not have been affordable. The news that the Australian government was determined to eliminate hepatitis C was welcome, and I am pleased that many individuals in our community are now reporting successful treatment outcomes. There is a small number where treatment has not yet been successful, and we wish those people well with the further new treatment options that may be suitable for them. We also remember those for whom these new treatments came too late and think of their families and loved ones.

HFA has continued to advocate for new treatments for haemophilia. There are several extended half life products registered for use in Australia and we are disappointed that these are still not funded under the National Blood Agreement. The experience of several of our members who have participated in clinical trials and some of their treating clinicians are very positive about the improvements these products have made in their lives. They have reported having fewer infusions, less or no bleeding at all, and improvements which make their own and their family's lives more manageable and predictable. Where it has led to improved school and work attendance, this has had a profound effect on their lives. We strongly support treatments that provide greater opportunities for improved health outcomes. To this end, we held a Parliamentary event in Canberra in May to share information with MPs and their advisors about these new treatment products. I was pleased about the level of engagement and interest in how these new products can improve the lives of people living with haemophilia and hope there will soon be appropriate funding pathways to support access. HFA has made it clear to governments that it will play its part in evaluating the outcomes of these products.

A major achievement early in the year was the redevelopment of new websites for HFA and member Foundations. The scope of this work covered both the national and youth websites as well as each state/territory foundation website. This work means we now provide consistent evidence based education resources and branding, while each Foundation retains control over its communications with local members. This is a major achievement that had been the only

recommendation made following an independent review of HFA in 2011 that we hadn't yet resolved. We were able to address this recommendation because of a special project grant from the Australian Government Department of Health for which we are extremely grateful.

HFA consulted with members to inform the ten policy submissions that were made to the Australian government and government agencies during the year. These submissions were on wide ranging topics which impact our members in different ways including medicines and medical devices, complementary medicines, digital health, and the National Health and Medical Research Council Statement on Ethical Conduct in Human Research.

I acknowledge the relationships HFA has with the Australian government Department of Health and its agencies such as the National Blood Authority for consultation and policy advice and we particularly thank the Department for funding the HFA secretariat and special communications and website projects during the year. I also thank organisations such as the Consumers' Health Forum of Australia (CHF), Australian Federation of AIDS Organisations (AFAO), National Association of People with HIV Australia (NAPWHA), the Australian Red Cross Blood Service and the Australasian Society for HIV, Viral Hepatitis and Sexual Health Medicine (ASHM). We often share policy concerns and dilemmas and work together to share and develop ideas, and promote agreed policy.

HFA values the input of members of 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 to the development of HFA's policy and education resources as well as their commitment to developing, maintaining and enhancing clinical excellence in their disciplines.

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.

Highlights

REPRESENTATION AND ADVOCACY

HFA's vision is 'active, independent and fulfilling lives for people in our bleeding disorders community' – but what does this mean to people with bleeding disorders and their family and partners? And how can HFA best represent the community to achieve this?

Over the last 12 months we have been privileged to hear personal stories of individuals and families as they relate the impact of clinical trials with new longer acting haemophilia treatments on their health and quality of life. We have heard the excitement of community members who have finally been cured of their hepatitis C with the new treatments. At the same time we have been appreciative of the generosity of community members and specialist haemophilia health professionals in communicating with us about the issues where there is also still much work to be done: around the needs of women and girls, the problems of early ageing and disability, concerns around transition to the adult world and the challenges for young people in managing treatment for their bleeding disorder, and the barriers for those who have not yet accessed treatment for their hepatitis C.

This first-hand experience, along with the advice and support of experts, ensures that HFA can target 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.

Working with the community

With a delegate of every member Foundation at each meeting of HFA's governing Council, rather than decision-making by an Executive Board, the Council forum has become recognised as a valuable environment to initiate robust discussion and national activity about ongoing and emerging issues. Delegates are either the state/territory President or a key local leader, whose role is to facilitate the communication between HFA and their Foundation. This has provided an important forum for issues raised at a local level and enabled a swifter response from the Foundations on national initiatives, such as the women and girls project, the youth strategy and the national website project. Our new youth leaders have also begun to step up and take on formal leadership roles in their local community, adding a youth voice to the foundation work on representation.

Hepatitis C

Hepatitis C remains a high priority for HFA.

The success of the new direct acting antiviral (DAA) hepatitis C drugs has made curing hepatitis C in all Australians a real possibility. The Australian Government has joined the World Health Organisation commitment to eliminating hepatitis C by 2030. We believe we can achieve this much earlier in the bleeding disorders community.

Many people with bleeding disorders in Australia acquired hepatitis C from their treatment products before 1993, particularly human plasma-derived clotting factor concentrates. Even before the new treatments became available, some had cleared the virus naturally or through interferon-based treatment. However, many others had been living with hepatitis C for more than 20 years. For them advancing liver disease and limited treatment options had been a serious problem.

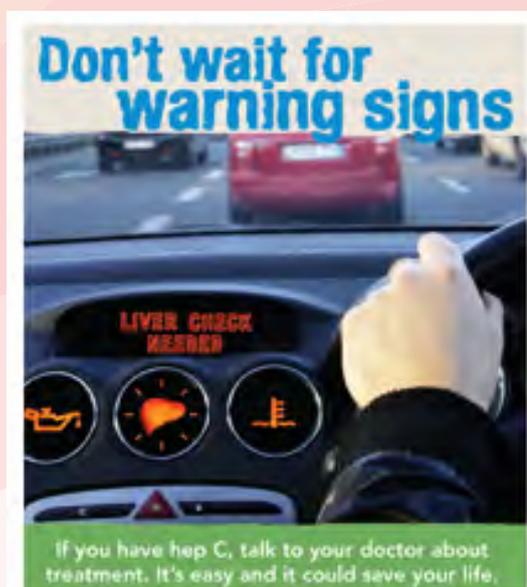
The new DAA drugs have revolutionised hepatitis C treatment, with very high cure rates, few if any side-effects, and short treatment courses. The Australian Government decision to make the new drugs available to all Australians on the PBS from 1 March 2016 has changed the lives of the many people with bleeding disorders and hepatitis C who accessed treatment and have been cured.

I implore people who have not yet had hepatitis C treatment to make an appointment with their health professionals for assessment. I have been fortunate to have cleared the virus following recent treatment with one of the new products and we are hearing many reports of others with bleeding disorders clearing the virus. HFA is taking steps to ensure everyone has relevant information so they can take up treatment if they need it.

Gavin Finkelstein, President, Haemophilia Foundation Australia, December 2016

HFA continues to seek advice from haemophilia and hepatitis clinical experts on the best approach to hepatitis C treatment for people with bleeding disorders. HFA has also been working closely with Haemophilia Centres and Foundations to understand and address any barriers to treatment uptake among their patients. This has resulted in an evolving national health promotion campaign:

- Firstly, encouraging all people with bleeding disorders and hepatitis C to make an appointment with the specialist clinic to discuss their treatment options
- Secondly, reminding people with cirrhosis that they will need ongoing monitoring into the future, even after successful treatment
- Thirdly, looking at strategies to reach people with mild bleeding disorders who are unaware of their hepatitis C status; and to overcome barriers to treatment among those who have not yet pursued treatment for their hepatitis C.



HFA has worked in partnership with Hepatitis Australia on the national hepatitis C treatment campaign, sharing key messages and resources and contributing insights gained from our close consultation with our community living with long-term hepatitis C infection. Over the last 12 months HFA has also made submissions to support new hepatitis C treatments coming before the Pharmaceutical Benefits Advisory Committee (PBAC) that have the potential to provide further treatment options. This includes treatment for the range genotypes, for people who are HIV/HCV co-infected, salvage therapies for the very few who do not have successful treatment with their first round of DAA drugs, or to simplify hepatitis C treatment and make it more accessible to those in rural and regional areas.

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

Best practice treatment and care



A key aspect of the HFA mission is to work towards excellence in treatment and care. To achieve this a strong evidence base on best practice and treatment outcomes is essential. HFA is committed to creating this evidence base and making sure that people with bleeding disorders can contribute to it.

The **MyABDR app and web site** enables 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. Patient usage of MyABDR is critical: it supports people with bleeding disorders and their Haemophilia Treatment Centres to monitor and review their treatment and care together and adjust their treatment plan, if required; and it also creates real world health data to determine the effectiveness of various treatments.

MyABDR was established and then released in 2014 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. There are regular enhancements to the app and website. To understand the user experience and what changes would improve its usability, HFA facilitates consultation with the community. Over the last year this has included:

- MyABDR focus group discussion about proposed quality of life data collection
- Consultation with community and health professionals about proposed security enhancements
- State/territory community feedback at HFA Council meetings
- MyABDR user survey (in collaboration with the NBA) – 94 respondents

HFA regularly promotes MyABDR with foundation newsletter articles on MyABDR features and new developments, with personal testimonials. By April 2017 there were 767 registered MyABDR users. 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 working with AHCD and the NBA to investigate ways to increase recording.

Treatment Product Access

Several new extended half life factor VIII and IX therapies to treat haemophilia A or haemophilia B have been registered in Australia over the past 2-3 years now, but as yet there is no funding pathway to access. The testimonies of the people who have used these treatment products in clinical trials and extended access programs are very positive. Further, impressive trial results promise exciting outcomes for other types of products that we hope will be registered and come to market in the next year, including emicizumab which mimics factor VIII, and is being evaluated for the treatment of haemophilia A with and without inhibitors. This treatment given as a subcutaneous injection once each week to stop bleeding has the potential to change the lives of people with haemophilia A.

Prophylaxis within the comprehensive care model is the preferred model of care in Australia. Currently, even with prophylaxis some children and adults continue to bleed, even when adherent to their treatment plan. Others may struggle with their treatment plan for a number of reasons. Treatment with extended half life clotting factors can be tailored to the individual based on bleeding patterns and clotting factor levels, and taking into account factors such as age, joint health, and levels of physical activity. Trough levels could be kept to a level where there is no damage from bleeding. The new extended half life clotting factor products can achieve higher factor VIII or factor IX activity levels for significantly longer than standard half life products. They offer very different possibilities for care and management. We have reached a time where people with haemophilia can expect no damage from bleeding. This should be a treatment priority.

The immediate and long term outcomes will likely be significant for many people living with a bleeding disorder. Governments need to measure the benefits of these new therapies in terms of the improved outcomes they offer. People living with haemophilia experience significant pain, uncontrolled or breakthrough bleeding which significantly impacts their lives. The consequences of bleeds and chronic arthritis for many can lead to poor mobility, disability, loss of time from work or inability to work at all, time away from school. Parents of children and carers also frequently experience loss of time away from work because they are caring for their relatives, some parents cannot work at all.

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. Many of these outcomes are life-changing for people with haemophilia and their families.

HFA held an event at Parliament House Canberra on 31 May 2017 to raise awareness and support for innovation in haemophilia treatment and patient care and to provide information and perspectives on the impact of haemophilia on individuals and their families and their carers. The event was well attended by Members of Parliament and their advisors and we were able to share with them how policy and decision makers can make a real difference by improving health outcomes, increasing productivity and the quality of life for people with haemophilia and their families by ensuring funded access to the new treatments.

At this meeting presentations from HFA Vice President Danial Credazzi and Chair of the Australian Haemophilia Centre Director's Organisation Dr Simon McRae were able to convey the improved health outcomes and cost benefits of these new treatments. They also had the opportunity to convey to the Assistant Minister for Health, the Hon Dr David Gillespie MP that there was an urgent need for a timely and transparent funding pathway for extended half life therapies and other new medicines like them through the National Blood Authority's (NBA) national framework for haemophilia.

Participation in research

HFA encourages community members to contribute to the knowledge base that is developing around the experience and treatment of bleeding disorders. Where there have been opportunities recently for the community to participate and add their voice to local and international research, HFA will highlight high quality research both on the HFA website and through other communications.



One important research project for people with bleeding disorders is the **PROBE (Patient Reported Outcomes Burdens and Experiences) Study**.

HFA joined this multi-national patient-focused research project in 2015. PROBE is 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 2 of the PROBE study in February 2017. This involved testing the reproducibility of the survey results and the stability of the online survey. Australia provided more than 100 survey responses from adults in the Australian bleeding disorders community.

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 will be published on the HFA website when they become available.

Phase 3 will involve a real-world rollout of the survey. The international team is developing an online dashboard that each national haemophilia organisation can use to access their country's results and compare to other world regions. This will be a very valuable independent resource for us to understand the impact of bleeding disorders and treatment on our community and to advocate effectively in the future.

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
- New haemophilia treatments for evaluation by the Medical Services Advisory Committee
- New hepatitis C treatments for listing on the Pharmaceutical Benefits Schedule
- Regulations to support new approval pathways for new medicines and medical devices
- National digital health strategies
- Regulation of complementary therapies
- Revisions to the National Statement on Ethical Conduct in Human Research.

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 2016-2017 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).
- 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
- Hepatitis Australia Hep C Education and Awareness Project Advisory Group

Communicating with the Community

EDUCATION AND INFORMATION

Education resources snapshot - in 2016-17

*HFA booklets and fact sheets
5,097 print copies distributed
More than 9,400 PDF downloads*

Women and Girls' Project



In 2017 the HFA project **The Female Factors** has continued to move ahead.

The project is addressing needs identified in HFA consultation by developing specific information resources for Australian women and girls with bleeding disorders. This is intended to:

- **Increase their understanding of their bleeding disorder**, treatments and strategies to manage it
- **Help them to feel more connected** with each other by sharing personal stories and tips with others in similar situations
- **Develop high quality, evidence-based information** that they can show to other family members and doctors, nurses, etc who provide their care.

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 who are actively involved in the project. The resources are also reviewed by expert health professionals to make sure they are accurate, relevant and speak to the needs of Australian women and girls.

The first resource in the suite was titled A snapshot of bleeding disorders in females, and included information and tips on negotiating the health system. It was distributed through foundation mailouts and used by foundation women's groups to start discussion. Feedback has been very positive.



Haemophilia: finding out you carry the gene was published in April 2017. It explores the responses of Australian women and girls, with personal stories, and covers:

- How to know if you carry the gene
- Common reactions to finding out you carry the gene
- Where to go for information and support.

Importantly, it acknowledges the varied experience of women and girls when they are diagnosed and the very strong impact that diagnosis can have. Women involved in the booklet were keen to share the message that women in this situation are not alone; and told their story and outlined the strategies they used to manage their diagnosis in the hope that it might be of value to other women.

Diagnosis – women's experience

"It wasn't any great surprise – this just became a bit more information to help with decisions."

"When I was diagnosed I felt gutted."

"I found out that I carried the gene when I was 12 weeks pregnant. The stress was enormous as I had to make some important decisions fast."

The booklet was launched by HFA on 11 April 2017 as part of the international World Haemophilia Day **Hear Their Voices** campaign, which aimed to show support for the millions of women and girls affected by bleeding disorders.

Communications

National Haemophilia



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, and personal stories from people with bleeding disorders. 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 congress reports; women's issues; MyABDR updates; hepatitis C news; updates on medical issues, such as prophylaxis and surgery; early ageing; family concerns such as family planning and pregnancy, and preventing fear of needles in children; transition, and youth activities.

Website

The Haemophilia Foundation Australia website is a major communication tool for HFA. It is a respected and reliable source of information for the Australian bleeding disorder community, health professionals, stakeholders, the general community and students. With the launch of the new website in 2016, there has continued to be large numbers of visitors, who generally look at several pages and download many publications. More than 42% of visitors access it with smartphones and ipads/tablets, demonstrating the value of the new website mobile optimisation. 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.

The HFA website is part of a high quality website infrastructure shared by HFA and State and Territory Foundations.

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. 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 World Haemophilia Day generate substantial community support.

These platforms can be particularly effective for promoting important new information, for example the launch of the HFA video on the new hepatitis C treatments in July 2016. The HFA Facebook post reached more than 1,200 people, with more than 30 likes and shares, and supportive comments from community members undertaking the treatment.

HFA communications snapshot - in 2016-17

6,846 copies of *National Haemophilia* posted to members

More than 11,500 copies of *National Haemophilia* viewed online or downloaded

758 HFA members received regular e-news

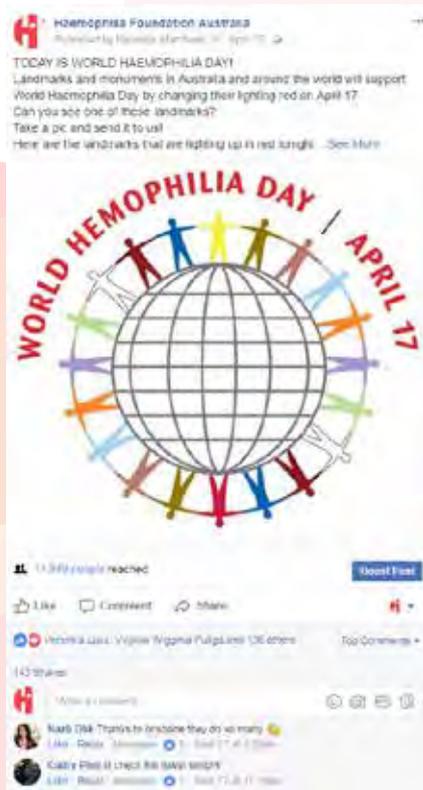
121,098 visits to view HFA web pages

Social media

2,287 HFA Facebook "likes"

72% of HFA Facebook "likes" are aged 18-44 years

491 HFA followers on Twitter



Public Awareness

World Hepatitis Day



World Hepatitis Day was marked globally on 28 July 2016. With the arrival of new and effective treatments and the potential of a cure for all, Australia joined the World Health Organisation in a commitment to eliminate hepatitis C by 2030. HFA believes we can achieve this much earlier in the bleeding disorders community.

HFA is a partner in the national 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.



This year HFA's campaign encouraged all people with bleeding disorders and hepatitis C to pursue treatment with hepatitis C. A cure is particularly important 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.

World AIDS Day 2016

In 2016 the World AIDS Day campaign theme was ***"HIV is still here - and it's on the move"***. For HFA this was a time to reflect on the legacy of Australians in the bleeding disorders community affected by HIV and their commitment to HIV education and determination to overcome stigma and discrimination. One example of this is the Mark Fitzpatrick Trust, set up by the Australian Government to provide special financial assistance to people with medically acquired HIV and their dependents. The Trust was named for a young Tasmanian boy with haemophilia who died of AIDS when he was 10 years old and recognised his mother's work in HIV education. HIV continues to be part of our community's experience. The theme was a reminder of how vital it is to create a supportive and stigma-free environment for our community members affected by HIV.

World Hemophilia Day



In 2017 the theme was HEAR THEIR VOICES.

On World Haemophilia Day let's come together to show our support for the millions of women and girls affected by bleeding disorders.

World Hemophilia Day was celebrated in April 17, together with our fellow World Federation of Hemophilia (WFH) National Member Organisations around the world.

Landmarks and monuments in Australia and around the world will supported World Haemophilia Day by "lighting it up red".

Landmarks and monuments that turned red in Australia were:

Victoria: AAMI Stadium **ACT:** Telstra Tower **NSW:** Sydney Cricket Ground

South Australia: Adelaide Oval, Riverbank lighting **Queensland:** Story Bridge, Suncorp Stadium

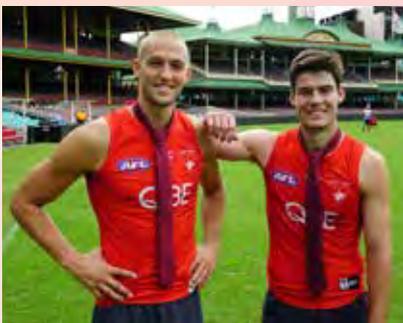
Northern Territory: Darwin Convention Centre

Western Australia: Council House, Trafalgar Bridge, Perth Bell Tower

Tasmania: Kennedy Lane (Hobart), Railway Roundabout, Hobart Elizabeth Mall (Hobart).

Red Tie Challenge

Many businesses and people wore a Red Tie in support of World Hemophilia Day.



Haemophilia Awareness Week and Red Cake Day

Haemophilia Awareness Week and Red Cake Day were held this year from 9 to 15 October 2016. 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 over 80 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 eighth 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 80 Red Cake Day events and awareness activities
- Over 120 Bendigo Bank Branches participated in the week
- The week across the country has raised just under \$15,000



Youth Program

WWW.FACTOREDIN.ORG.AU

Factored In is an innovative website for young Australians with bleeding disorders. It was created by young people to talk about their lives, being young and having a bleeding disorder. Information on the website is specific to young people and bleeding disorders. It is evidence-based, but also features personal stories from youth leaders in the community. Topics include sport, treatment, employment, disclosure, and travelling.

Website content

While the information pages provide a robust backbone to the Factored In website, personal stories are an important way of engaging young people and providing peer support. New personal stories are submitted regularly by Youth Lead Connect participants and other young people in the bleeding disorders community. News items also keep young people up-to-date with upcoming events, such as youth activities, the Youth Lead Connect training and Haemophilia Awareness Week.

Examples of personal stories 2016-17

- Travelling to the World Hemophilia Congress in Florida and being part of the Australian delegation
- Giving talks to young people about being an AFL umpire
- Experiences with self-infusing
- Work-life balance and managing your treatment
- Organising a Red Cake Day event at school.

There is regular consultation with the HFA Youth Working Group about the content and functionality of the website. As part of their Leadership Achievement Goals, Youth Lead Connect participants also promote Factored In at local Haemophilia Foundation events and camps.

Factored In snapshot

In 2016-17 there were:

- 120 members
- 5,670 website visits
- 10,785 page views
- Most popular pages: information about haemophilia, travel; Q & A on sport, vein care; personal stories about the World Congress, camps, girls with bleeding disorders

YOUTH LEADERSHIP AND MENTORING

Youth Lead Connect

By June 2017 9 Youth Lead Connect participants had graduated from the 2016 program, based on their contributions to their local and national youth community. The Youth Lead Connect program continued in 2017 with a new group of youth leadership trainees.

The program was similar to the previous year, with an initial training weekend to develop skills in leadership and mentoring. In their applications the participants identified their existing experience and skills and those they wanted to improve, and the program content was revised to reflect this.

The training weekend was very successful. Participants were highly motivated and keen to connect with each other, as well as learn about themselves and understand what leadership means to them individually. An important change in this year's program of the program was changing the term 'hurdles' to Leadership Achievement Goals. These goals were identified by the youth leaders in consultation with their state Foundation.

Two youth leaders from the 2016 program attended the training weekend as mentors to encourage and guide youth participants on their journey to build their leadership and mentoring capacity.

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

Leadership Achievements by June 2017

- A participant organised and planned a Women's Brunch
- Two participants promoted Factored In at a local family camp
- A participant gave a formal presentation to youth with haemophilia about being a football umpire
- Two participants have become committee members in their respective states after attending regular committee meetings
- Participants in a number of states are planning local youth events
- Participants have written personal stories about their community activities and published them on Factored In.



Youth participants at the training weekend 2017

Research Fund

The Haemophilia Foundation Research Fund has allocated and distributed more than \$650,000 for medical, scientific or social research projects in Australia over the past 23 years. Our Research Committee has always been keen to encourage innovative projects and some of these have undoubtedly led to improvement in the lives of people living with a bleeding disorder or the complications of bleeding disorders. Others may not have been successful in the long run, but have nevertheless tested theories and potentially led to new thinking about the care and treatment.

The purpose of the Fund is to create capacity for local research, and for this, we need strong financial management of the Fund in the first place, followed by strong selection processes for the research projects to be funded. The Ewart bequest in 2015 has given the Fund a boost beyond our dreams. The Ewarts were involved in the establishment of the Fund twenty five years ago and had a strong vision for the future. They knew its value to the bleeding disorders community. We look forward to further contributions to the Fund from others who share the Ewart's vision.

HFA has spent time this year seeking investment advice to ensure the Fund can support research needs moving forward.

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 remains ongoing. His work in collaboration with Dr Anne Powell, Consultant Rheumatologist at The Alfred Hospital and Dr Ian Wicks, Consultant Rheumatologist, Royal Melbourne Hospital is promising for people with bleeding disorders living with chronic arthritis.

Dr Masters says:

Progressive joint damage is one of the main clinical manifestations of Haemophilia A and B. Joint bleeds and subsequent damage most commonly affect the lower extremities accounting for approximately 80% of bleeds. Despite the increase in primary prophylaxis, joint bleeds and damage can continue to occur often needing invasive treatments such as cortisone injections, Yttrium synovectomy and early joint replacements. Disease modifying drugs that can prevent inflammation such as in rheumatoid arthritis may be able to stop this progression, and allow patients with haemophilia to maintain a normal healthy lifestyle without joint complications later in life.

We initiated a project to evaluate certain types of inflammation in joint fluid from patients with haemophilia. We hope to find evidence that a new inflammatory pathway we are researching is present in these joints. We currently don't fully understand how damage occurs following joint bleeds however this pathway may be responsible as it responds to cell stress and blood cells are under significant stress when they end up in a joint. Excitingly, we are working on an oral drug targeting this novel inflammatory pathway, that is selective, cheap and may be able to prevent joint inflammation and damage following bleeds due to haemophilia.

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. We are grateful for each of the individuals that have committed to give a monthly, quarterly or annual donation towards our work.

"I urge you to get behind us – please make a gift today so we can support these vital peer support programs."

Sharon Caris, HFA Executive Director

Men's Groups are critically important as they provide a forum to get together with peers and share experiences. Participants feel that some of their challenges of living with a bleeding disorder are only really understood by others like them. When they are together they share solutions and develop support networks so that they can contact one another later.

"Peer support groups are absolutely crucial, they provide an opportunity for us to get together monthly and catch up, we all understand each other's problems and exchange information and ideas." Paul



Women's Support groups are a great way to get support from each other and to learn from one another. It makes such a difference when they have others to talk to about treatment and care. For many it is a relief to have others who know just what it is like to be a carer, and how busy and stressful life can be particularly when the person they care for is very unwell. Women who carry the haemophilia gene or live with von Willebrand disorder often feel isolated and alone and having the chance to meet with others is helpful. Mothers of children with a bleeding disorder often tell us how hard it is to juggle all their priorities and take care of others in the family as well.

"While family and friends can be supportive, no one else can really understand what it's like to have a bleeding disorder like other people who have bleeding disorders." Jane

Outreach visits to people with bleeding disorders who live in rural and regional areas help to reduce their isolation and provide important information about their treatment and care. These visits often provide the only time for people to engage with others so they can share their experiences and it also helps us to establish local and regional peer support networks.

"Living in regional Tasmania, it's great to meet others in our area and make connections, not only for us parents, but for the kids as well" Jacinta



Camps and Workshops For Peer Support

Camps, groups and workshops

HFA supports a range of program and services run by the state/territory foundations such as camps, and groups run specifically for parents and carers, men, women with bleeding disorders group and rural education workshops. These programs and services serve to bring people with common needs together, and to provide education and peer support. In 2016-2017 HFA supported three family camps around Australia.

HFNSW Camp, November 2016

The HFNSW Family Camp is held each year. It provides the opportunity for people with bleeding disorders, their families and carers to meet and share experiences with other families from around NSW. The Camp runs over three days and two nights at The Sydney Academy of Sport and Recreation (SASR), Narrabeen. Activities at the camp are planned to meet the needs of the whole family and the program includes information/educational sessions, such as a self-infusion workshop which is facilitated by health professionals from the Haemophilia Treatment Centres in Sydney. Twenty nine families attended and participated in activities designed to offer fun as well as provide learning opportunities, build resilience and confidence including bubble soccer, rock climbing, swimming and canoeing.

"The people & mix of activities and fantastic and we really love the location & the activities are good"

"Great for my son to have 1 on 1 time with his haemophilia nurse"



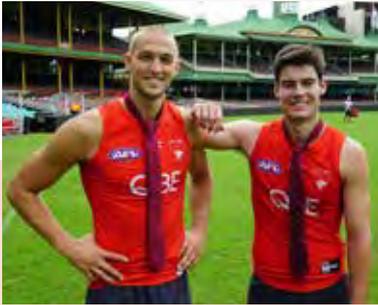
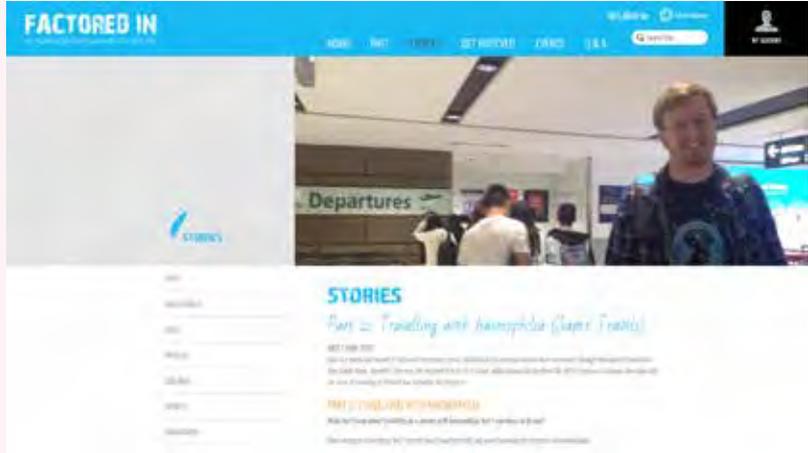
HFV Family Camp, April 2017

Twenty families attended the annual family camp at Anglesea at Camp Willkin Baptist camp from 28 - 30 April 2017. The weekend was facilitated by adventure therapy company, Purple Soup and included activities such as high ropes, secret men's and women's business, mindfulness and an interactive trivia night.

Bailey's personal success at the camp was a highlight for him and everyone in attendance. Bailey wanted to tackle the high ropes course, but 'froze' along the way. With the support and encouragement of the people around him, he successfully backtracked to the start - this experience gave Bailey a great sense of accomplishment because he had the courage and strength to do as well as he could possibly do, and further, it taught those who supported him, the value of persevering in the face of challenge.



Our Year in Pictures



Treasurer's Report



I am pleased to report that we have met our financial obligations, continued to work towards our objectives under our strategic plan, and made plans to consolidate and strengthen investments to meet our longer term needs this year.

As previously reported, our income in the past two years had been significantly higher due to the share of the 2014 WFH World Congress profit with the World Federation of Hemophilia (WFH) and the Ewart bequest. The two preceding years have been exceptional in financial terms for HFA, and the increased funds have required careful planning for the future.

The Ewart Bequest for the Haemophilia Foundation Research Fund has given HFA the capacity to grow its funds held for research, and although there are no plans to change

our approach to research in the short term, we expect the increased funds will lead to new research opportunities in the future. During this year we commenced a stepwise process to seek independent advice for our investments and to scope our financial needs going forward. We are considering an investment plan that will protect our financial assets while providing for growth, and expect to finalise this early in the next financial year.

You will see from our financial report this year, that our regular income and expenditure line items are relatively consistent with the previous year, excluding the impact of the Ewart bequest. Our donation income has increased, and our corporate sponsorship was strong enough that we could meet our regular commitments and new initiatives.

Table 1



Table 2

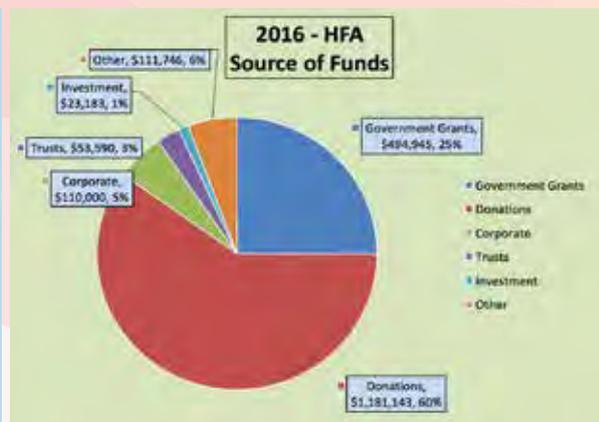


Table 1 shows that our government grants this year have reverted to a similar level to previous years. In the last financial year we had received additional government funds for the redevelopment of all Foundation websites. Pleasingly, this large project was completed in the current reporting period on budget, and to the satisfaction of all.

We rely heavily on the capacity of our staff to work through our identified priorities, and this year some staff changes and newly arising advocacy issues meant that the order of some of our work plans was changed and the completion of some education resources was delayed. This work will be reflected in care and services expenditure next year.

Table 3

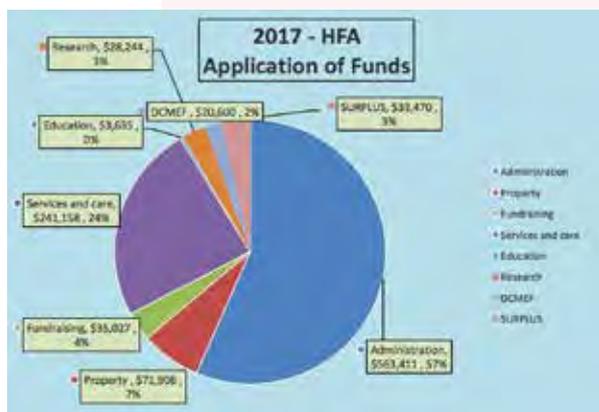


Table 4

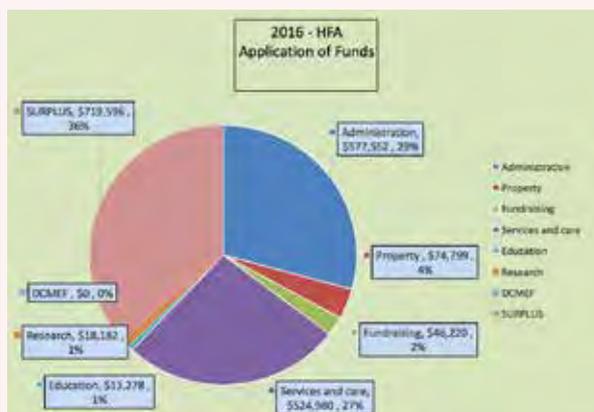


Table 3 shows our expenditure for care and services was spread over several activities, including family camps, youth leadership training, vision and leadership and Damon Courtenay Fund grants, and the haemophilia awareness campaign at Parliament House, Canberra in May this year. Other expenses remained steady and comparable with the year before. Our administration expenses were a little lower than the previous year, partly because we did not replace staff immediately they left the organisation. I am pleased to report that we are starting to see the benefit of a more efficient office layout since the relocation, with our office expenses reduced by 4% overall, and a 38% reduction in the cost of lighting and heating and 16% reduction in office repairs and maintenance, more specifically.

In summary with a total income of \$997,450 and total expenses of \$963,981, we have returned a surplus of \$33,469 for the year.

We would generally aim for a surplus or deficit of around \$10,000 in usual circumstances. We expect to revert to a more typical annual financial cycle moving forward, where income and expenditure is relatively balanced, with variances attributable to the cycle of national conferences every two years and where our expenditure for our care and services activities is carefully managed against our income.

There are several financial matters which will impact HFA going forward. As previously mentioned we continue to be reliant on government grants and donations for our objectives. Donations are variable by their nature, and to an extent relate to the economic climate and experience of charities in general, and of course, our fundraising strategies. We are working hard on the latter and scoping the benefits of an acquisition program. Our government grants have remained stable. It is a strength that we are recognised by the federal government funding as a national peak body, however I note that our government grants cover only 36% of the cost of operating the national secretariat. Our effectiveness depends on the strength of the secretariat and we rely on our staff

to do the necessary work for the secretariat activities as well as our core areas of education, policy development and fundraising. We have managed our human resources costs by holding salaries at previous levels and not filling staff vacancies as soon as they occurred this year, but this can only be a short term objective as this places stress in other areas of our business and potentially could have a negative impact on outcomes. We will address our financial allocation for human resources as a matter of priority to ensure we adequately fund our human resource needs.

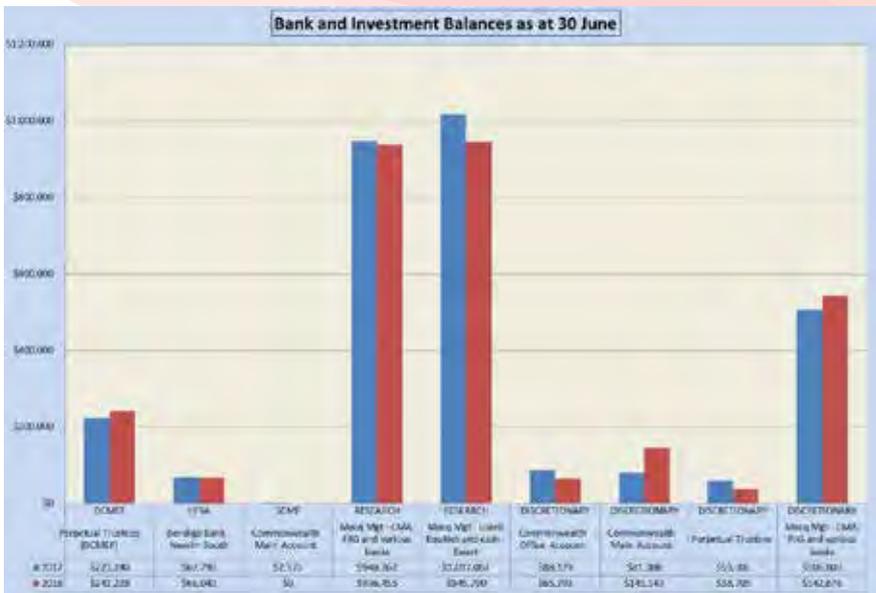
In summary, I now want to brief you about the impact of the last two extraordinary years. You can see from Table 5 that at the end of the financial year HFA had funds of \$2.994m – of this, approximately 25% represents discretionary funds and 65% is for research, the remainder is the Damon Courtenay Fund, and the smallest funds are those held by HFA for the South Australian bleeding disorders community and the Stuart Cousins Memorial Fund for HFT.

Table 5



Table 6 shows how our investments have been distributed in recent years. Currently, all research funds and most of HFA's discretionary funds remain under Macquarie management. Our day to day banking continues to be done with the Commonwealth Bank.

Table 6



Financial Report

HAEMOPHILIA FOUNDATION AUSTRALIA INCORPORATED
ABN 89 443 537 189
COUNCIL REPORT FOR THE YEAR ENDED 30 JUNE 2017

Your council members submit the financial report of Haemophilia Foundation Australia Inc for the financial year ended 30 June 2017.

Council Members

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

Haemophilia Foundation ACT	Claude Damiani
Haemophilia Foundation NSW	Dan Credazzi
Haemophilia Foundation QLD	David Stephenson
Haemophilia Foundation TAS	David Fagan
Haemophilia Foundation VIC	Leonie Demos
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 \$33,470 (2016: \$719,596).

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



President

Gavin Finkelstein



Treasurer

David Fagan

Date: 22 September 2017

HAEMOPHILIA FOUNDATION AUSTRALIA INCORPORATED
ABN 89 443 537 189
INCOME AND EXPENDITURE STATEMENT FOR THE YEAR ENDED 30 JUNE 2017

	Note	2017 \$	2016 \$
INCOME			
Government grants		367,747	494,945
Sponsorships, donations and bequests		343,250	1,344,733
All other revenue		151,565	96,688
Interest income		42,493	50,577
Dividend income		40,821	15,589
Unrealised gains/(losses)		41,295	(42,983)
Other income		10,280	15,058
TOTAL INCOME		997,451	1,974,607
EXPENSES			
Administration		563,411	577,552
Leasing of premises and office expenses		71,906	74,799
Fundraising		35,027	46,220
Services and care		241,158	524,980
Education		3,635	13,278
Research and other grants		48,844	18,182
TOTAL EXPENSES		963,981	1,255,011
TOTAL EXPENSES		963,981	1,255,011
SURPLUS FOR THE YEAR		33,470	719,596
ACCUMULATED FUNDS BROUGHT FORWARD		2,640,076	1,923,516
TOTAL AVAILABLE FUNDS		2,673,546	2,643,112
TRANSFER (TO) / FROM RESERVE	8	17,989	(3,036)
ACCUMULATED FUNDS CARRIED FORWARD	7	2,691,535	2,640,076

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 2017

	Note	2017 \$	2016 \$
CURRENT ASSETS			
Cash and Cash Equivalents	2	238,499	275,543
Investments	3	2,756,110	2,706,287
Trade and Other Receivables		42,500	-
Other assets		16,891	6,177
Total Current Assets		3,054,000	2,988,007
NON CURRENT ASSETS			
Property, plant and equipment	4	74,427	85,465
Total Non Current Assets		74,427	85,465
TOTAL ASSETS		3,128,427	3,073,472
CURRENT LIABILITIES			
Trade and Other Payables	5	32,909	17,310
Short-term Provisions	6	174,060	169,494
Total Current Liabilities		206,969	186,804
NON CURRENT LIABILITIES			
Long-term Provisions	6	6,683	5,363
Total Non Current Liabilities		6,683	5,363
TOTAL LIABILITIES		213,652	192,167
NET ASSETS		2,914,775	2,881,305
FOUNDATION'S FUNDS			
Accumulated funds	7	2,691,535	2,640,076
Reserve	8	223,240	241,229
TOTAL FOUNDATION'S FUNDS		2,914,775	2,881,305

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 2017

	Note	2017	2016
		\$	\$
CASH FLOWS FROM OPERATING ACTIVITIES			
Interest received		42,493	50,577
Dividend received		40,821	15,589
Grants received		367,747	404,945
Receipts from constituents		505,094	711,186
Payments to suppliers and employees		(981,989)	(1,198,747)
Net cash flows from operating activities		(25,834)	(16,450)
CASH FLOWS FROM INVESTING ACTIVITIES			
Acquisition and disposal of property, plant and equipment		(2,683)	(5,844)
Net cash flows used in investing activities		(2,683)	(5,844)
NET INCREASE CASH HELD		(28,517)	(22,294)
CASH BALANCE BROUGHT FORWARD		2,279,520	2,301,814
CASH BALANCE CARRIED FORWARD		2,251,003	2,279,520
Cash balance carried forward comprises : -			
Cash and cash equivalents	2	238,499	275,543
Short term deposits	3	2,012,504	2,003,977
		2,251,003	2,279,520
Reconciliation of surplus for the year to the net cash flows from operating activities : -			
Total operating surplus for the year		33,470	719,596
Depreciation and amortisation		13,721	14,973
Changes in assets and liabilities			
Increase/(Decrease) in creditors and provisions		21,485	(59,626)
(Increase)/Decrease in receivables and other assets		(94,510)	(691,393)
Net cash flows from operating activities		(25,834)	(16,450)

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 2017

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 (continued) FOR THE YEAR ENDED 30 JUNE 2017

(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.

	2017	2016
NOTE 2: CASH AND CASH EQUIVALENTS	\$	\$
Cash at bank	275,543	
NOTE 3: INVESTMENTS	2017	2016
Short term deposits	2,012,504	2,003,977
Equity securities, at fair value	743,606	702,310
	2,756,110	2,706,287
NOTE 4: PROPERTY, PLANT AND EQUIPMENT	2017	2016
Furniture and office equipment - at cost	252,958	250,275
Accumulated depreciation	(178,531)	(164,810)
	74,427	85,465
NOTE 5: TRADE AND OTHER PAYABLES	2017	2016
Trade creditors and accruals	32,909	17,310
	32,909	17,310

HAEMOPHILIA FOUNDATION AUSTRALIA INCORPORATED

ABN 89 443 537 189

NOTES TO THE FINANCIAL STATEMENTS (continued) FOR THE YEAR ENDED 30 JUNE 2017

NOTE 6: PROVISIONS	2017	2016
Current		
- Annual leave	100,170	100,617
- Long Service leave	73,890	68,877
	174,060	169,494
Non-Current		
- Long Service leave	6,683	5,363
	6,683	5,363
 NOTE 7: ACCUMULATED FUNDS	 2017	 2016
Accumulated funds are set aside for the following purposes: -		
- research	1,965,329	1,882,244
- discretionary projects and reserves	726,206	757,832
	2,691,535	2,640,076
 NOTE 8: RESERVE	 2017	 2016
Damon Courtenay Reserve		
- balance at beginning of year	241,229	238,193
- special appeals and interest income	2,611	3,036
- sponsorships, allocations and costs	(20,600)	-
	(17,989)	3,036
- balance at end of year	223,240	241,229

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 2017.



President

Gavin Finkelstein



Treasurer

David Fagan

Date: 22 September 2017

HAEMOPHILIA FOUNDATION AUSTRALIA INC
(ABN 89 443 537 189)

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



M V ANDERSON & CO
Chartered Accountants
www.mvanderson.com.au

Report on the Audit of the Financial Report

Opinion

We have audited the financial report of Haemophilia Foundation Australia Inc, which comprises the assets and liabilities statement as at 30 June 2017, the income and expenditure statement and the cash flow statement for the year then ended, and notes to the financial statements, including a summary of significant accounting policies, 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.

In our opinion, the accompanying financial report gives a true and fair view of the financial position of Haemophilia Foundation Australia Inc. as at 30 June 2017 and of 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 for Opinion

We conducted our audit in accordance with Australian Auditing Standards. Our responsibilities under those standards are further described in the *Auditor's Responsibilities for the Audit of the Financial Report* section of our report. We are independent of the association in accordance with the ethical requirements of the Accounting Professional and Ethical Standards Board's APES 110: *Code of Ethics for Professional Accountants* (the Code) that are relevant to our audit of the financial report in Australia. We have also fulfilled our other ethical responsibilities in accordance with the Code.

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

Emphasis of Matter - Basis of Accounting

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. Our opinion is not modified in respect of this matter.

Responsibilities of the Committee for the Financial Report

The committee of Haemophilia Foundation Australia Inc. is responsible for the preparation and fair presentation of the financial report in accordance with the financial reporting requirements of the Associations Incorporation Reform Act 2012 and for such internal control as the committee 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.

In preparing the financial report, the committee is responsible for assessing the association's ability to continue as a going concern, disclosing, as applicable, matters relating to going concern and using the going concern basis of accounting unless the committee either intends to liquidate the association or to cease operations, or has no realistic alternative but to do so.

9

Culture
Commitment
Confidence

■ Melbourne
Level 5 North Tower
485 La Trobe Street
Melbourne, Vic 3000
Australia
T. +61 3 9642 8000
F. +61 3 9642 8222
E. info@mvanderson.com.au

■ Mount Waverley
Suite 6, 318-322 Stephenson Rd
PO Box 633
Mount Waverley, Vic 3149
Australia
T. +61 3 9807 7200
F. +61 3 9807 0200
E. email@mvanderson.com.au

Liability limited by a scheme approved under Professional Standards Legislation

gmn
international
Chartered Accountants
Member of the Gannett Group

HAEMOPHILIA FOUNDATION AUSTRALIA INC
(ABN 89 443 537 189)

Auditor's Responsibilities for the Audit of the Financial Report

Our objectives are to obtain reasonable assurance about whether the financial report as a whole is free from material misstatement, whether due to fraud or error, and to issue an auditor's report that includes our opinion. Reasonable assurance is a high level of assurance, but is not a guarantee that an audit conducted in accordance with Australian Auditing Standards will always detect a material misstatement when it exists. Misstatements can arise from fraud or error and are considered material if, individually or in the aggregate, they could reasonably be expected to influence the economic decisions of users taken on the basis of this financial report.

As part of an audit in accordance with Australian Auditing Standards, we exercise professional judgement and maintain professional scepticism throughout the audit. We also:

- Identify and assess the risks of material misstatement of the financial report, whether due to fraud or error, design and perform audit procedures responsive to those risks, and obtain audit evidence that is sufficient and appropriate to provide a basis for our opinion. The risk of not detecting a material misstatement resulting from fraud is higher than for one resulting from error, as fraud may involve collusion, forgery, intentional omissions, misrepresentations, or the override of internal control.
- Obtain an understanding of internal control relevant to the audit 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.
- Evaluate the appropriateness of accounting policies used and the reasonableness of accounting estimates and related disclosures made by the committee.
- Conclude on the appropriateness of the committee's use of the going concern basis of accounting and, based on the audit evidence obtained, whether a material uncertainty exists related to events or conditions that may cast significant doubt on the association's ability to continue as a going concern. If we conclude that a material uncertainty exists, we are required to draw attention in our auditor's report to the related disclosures in the financial report or, if such disclosures are inadequate, to modify our opinion. Our conclusions are based on the audit evidence obtained up to the date of our auditor's report. However, future events or conditions may cause the association to cease to continue as a going concern.
- Evaluate the overall presentation, structure and content of the financial report, including the disclosures, and whether the financial report represents the underlying transactions and events in a manner that achieves fair presentation.

We communicate with the committee regarding, among other matters, the planned scope and timing of the audit and significant audit findings, including any significant deficiencies in internal control that we identify during our audit.

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: 23 September, 2017

Acknowledgments

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

Individual Donors over \$250

Dr M J Baikie
 Mr Brian Baker
 Mr M & Mrs S Barry
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 Mr Philip & Mrs Carol Blake
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Service Clubs over \$250

Ashmore Lions Club
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 Bendigo Lions Club
 Birregurra & District Lions Club
 Devonport City Lions Club
 Forest Lake Lions Club Inc.
 Hannan's Goldfields Lions Club (Inc)
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 Lions Club International District
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 Lions Club of Speed
 Lions Club of The Entrance
 Lions Club of Tintinara
 Lions Club of Ulverstone
 Lions Club of West Pennant Hills - Cherrybrook
 Lions Club of Wynyard

Morayfield & District Lions Club (Inc).
 Ocean Reed Lions Club Inc.
 Rotary Club of Blackwater
 Rotary Club of Korumburra
 The Bright Lions Club Inc.
 The Lions Club of Jervis Bay (Inc)

Corporate Donors over \$250

Brierley Investments Ltd
 Eastbeth Services Pty Ltd
 Happy Valley Clinic
 HWI Electrical
 JJ Richards & Sons Pty Ltd
 Sprayflo Pty Ltd

Trusts & Foundations

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

Independent Special Events

Mrs Karen Grove - SA Entertainment Book Sales
 Pfizer Australia - Miles for Haemophilia Bike ride
 Team Factor 2017
 Hamilton Public School Decorate a Christmas Tree Fundraiser
 St Joseph's College Geelong 'Brand It' Fundraiser
 Willoughby Girls High School 'Multicultural Day' Fundraiser

Donations Received in Memory of:

Mrs Lorna Aplin
 Mr Paul Dankert
 Mr Ian Vanderfield

Bequests:

Estate of the Late Joan Snell

Government Grants

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

Stuart Cousins Memorial Fund

We are grateful for donations received for this special purpose fund.

Corporate Partners

We acknowledge grants or donations received for education and community support programs developed and directed by HFA for its members. The following grants or donations were received by HFA during the year:

Bioverativ Disease Awareness Program (\$15,000)
 CSL Behring (Australia) Pty Ltd HFA Digital Stories Project (\$20,000)
 Novo Nordisk Pharmaceuticals Patient Support & Education grant (\$16,500)
 Pfizer Australia Disease Awareness Program (\$16,500)
 Pfizer Australia Education resource for newly diagnosed parents (\$50,000)

Youth Lead Connect

CSL Behring (Australia) Pty Ltd Unrestricted educational grant (\$38 500)

Go For It Grants

Pfizer Australia Awards were given to five recipients by HFA (\$12,100)

18th Australian & New Zealand Conference on Haemophilia & Rare Bleeding Disorders October 2017

Gold Sponsors (\$33,000)
 • Bioverativ
 • CSL Behring (Australia) Pty Ltd
 • Pfizer Australia
 • Shire (rec'd in 2017-2018)

Silver Sponsor (\$27,500)
 • Roche

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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235 Ryrie Street Branch
Albury Branch
Anglesea Community Bank
Ararat Branch
Avoca Community Bank
Ballarat Business Centre
Ballarat West Branch
Balnarring Branch
Bannockburn Branch
Bayswater Branch (Vic)
Beechworth Branch
Belgrave Branch
Benalla Branch
Bendigo Business Banking
Bendigo Central Branch
Berwick Branch
Blackwood Branch
Bright Branch
Brighton Branch
Broadmeadows Branch
Bunyip & District Community Bank Branch
Canberra Branch
Carrum Downs Branch
Cheltenham Branch
Clifford Gardens
Cobram Branch
Cohuna Branch
Coleraine Branch
Collie Branch
Coves Community Bank
Creswick Branch
Dee Why Branch
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Docklands Financial Planning
Dromana Community Bank
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North Adelaide Branch
Nubeena & Tasman Branch
Pakenham Branch
Pall Mall Branch
Paradise Point Community Bank
Parkdale Community Bank
Pinjarra Branch
Portarlington Community Bank
Ringwood Branch
Ringwood East Community Bank

Robe Branch
Rosny Park Branch Tasmania
Rowville Community Bank
Sale Branch
Salisbury Branch
Sorell & District Community Bank
SSC Gippsland
Strathmore Branch
Swan Hill Branch
Sydney CBD Branch
Templestowe Branch
Traralgon Branch
Trentham
Tumby Bay & District Branch
Ulverstone Branch
Upper Comera Branch
Upwey Branch
Wallan Branch

Other

Adam Zulawnik and Nao Ikoma
Amanda Palm and Family
Bailey Wallis Family
Bendigo and Adelaide Bank
Brent Dawkins
Calvary Mater Newcastle
Charles Gabriel and staff at Morgans
Cheryl Sutton
CSL Behring (Australia) Pty Ltd
CWA - Neerim South
Damiani Family
Donna Field
Elle Belle Recruitment
Eudunda Family Heritage Gallery and Helpers & Dot Bonner
Fletcher Family
Gambrill family
Hayley Lee
Horkings family
Hunter River High School
Jodie James and Staff
Jon Pitt
McCann family
Maria Heilbrunn
Melanie Snowden
Moama Preschool
Neerim District Community Bank
Neerim District Secondary College
Neerim South Primary School
Nikki Edwards

Novo Nordisk Pharmaceuticals
Philip Hutton
Pippi Wood
St Dominic Savio Child Care Centre & Kindergarten

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

Registered as
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Reg No: A0012245M ABN: 89 443 537 189



HAEMOPHILIA FOUNDATION AUSTRALIA

7 Dene Ave, Malvern East VIC 3145
P: 03 9885 7800 F: 03 9885 1800
E: hfaust@haemophilia.org.au
W: www.haemophilia.org.au