HAEMOPHILIA FOUNDATION AUSTRALIA

ANNUAL REPORT 22|23

Since its establishment in 1979, Haemophilia Foundation Australia has worked to inspire **excellence** in **treatment, care** and **support through representation, education** and **promotion of research. Our vision** is for **people with bleeding disorders** to lead **active, independent** and **fulfilling lives.**

Who do we represent?

- State/Territory Foundations and their members
- Diagnosed and undiagnosed people with a bleeding disorder
- Partners, families, carers of people with a bleeding disorder
- Extended family and friends

In Australia there are more than **7,000** people diagnosed with haemophilia, von Willebrand disease (VWD) or other related inherited bleeding disorders.

- Haemophilia/Carry the gene = **3,130**
- VWD = **2,460**
- Rare clotting factor deficiencies/other bleeding disorders = **1,450**

(Australian Bleeding Disorders Registry Report 2020)

What have we achieved in 2022-2023?

Together with your support, we have produced:

Education resources
HFA education materials about bleeding disorders:

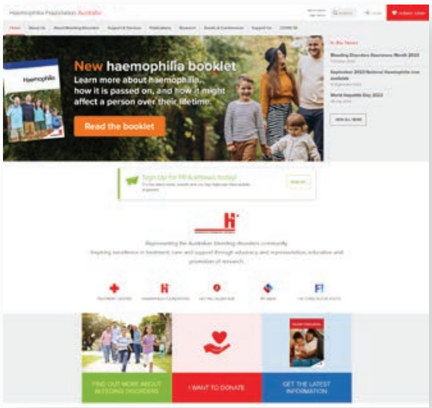
- **512** print copies distributed
- **39,090** PDF downloads
- **55,042** information web pages viewed
- **2** new major education resources
- **14** new website information pages
- **33** updated website information pages
- **8** new personal stories
- **6** new videos
- **18** social media carousels

National Haemophilia

- **6,357** copies of National Haemophilia posted to members
- **4** editions published – September 2022, December 2022, March 2023, June 2023
- **36,283** online views or downloads of National Haemophilia

Websites (haemophilia.org.au & factoredin.org.au)

- **70,463** total users
- **142,587** total pages viewed
- **4.86M** total Google search impresssions



New haemophilia booklet

Learn more about haemophilia, how it is passed on, and how it might affect a person over their lifetime.

Social Media

- **1,601** total posts
- **5,567** total followers
- **207,710** total people reached
- **7.53%** average engagement per post

Email

- **1187** subscribers to HFA news
- **12,348** email opens
- **1360** email clicks

“A friend’s father suggested I have a go at boundary umpiring.

I still felt part of the game, even though I wasn’t playing football, and I trained and was on the grounds and in the rooms afterwards with my mates.”

*- **Chris Gordon,** AFL Grand Final umpire: 2011, 2015, 2018, 2019, 2021 and 2022.*

Image: afua.com.au

Representation and advocacy 2022-2023

- Made **14** formal submissions to government or regulatory bodies
- Made **3** submissions contributing to national consultation
- Participated in **23** advisory body meetings or discussions
- Held **20** rounds of community consultation
- Held **91** rounds of consultation with health professionals, consumer and professional health organisations and other experts
- Auspiced **3** specialist health professional groups in the disciplines of nursing, counselling and physiotherapy

Information Requests

- **61** information requests received via email, phone and social media

International Work

- Attended WFH General Assembly 18 November 2022
- Shauna Adams, ACT, member of the WFH Youth Committee and attended 2022 WFH World Congress and WFH Youth Committee meeting

Awareness
Bleeding Disorders Awareness Month

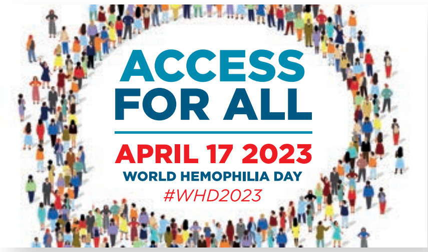
- **59** promotional packs sent to individuals, schools childcare and workplaces
- **4** webinars hosted
- **200** social media posts (avg. 10 per week, per channel)

  Reached **32,192** people

  Saw **1,709** engagements (likes, comments, shares)

World Haemophilia Day

- **51** landmarks lit up red for World Haemophilia Day in Australia
- Shared over **30** social posts across all channels
- Over **1500** views of related content on website



Haemophilia Foundation Australia (HFA) is the national peak body which represents people with haemophilia, von Willebrand disease 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 its activities to the Australian Charities and Not for Profits 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 we only develop partnerships with supporters where there is a meaningful and strong alignment with the mission and goals of the Foundation.

Our donors and funding partners include government, companies, philanthropic trusts and foundations, service clubs and individuals. Government grants and corporate sponsorships are underpinned by memorandums of agreement or contracts that identify the obligations, responsibilities and benefits of the partnership to each party.

Our Organisation

STATE PATRONS

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

WESTERN AUSTRALIA His Excellency the Honourable Chris Dawson APM, 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 *until 1 November 2021*

From 1 November 2021 Her Excellency the Honourable Dr Jeannette Young AC PSM, Governor of Queensland

President: Gavin Finkelstein

Executive Director: Sharon Caris

LIFE GOVERNORS

Jennifer Ross AO
Alan Ewart (dec)
Mike Barry
Ann Roberts
Ted Troedson (dec)
Bevlee Cassell
Dawn Thorp
Alison Bellamy
Barbara Volk OAM
Bruce Fielding
Maxine Ewart (dec)
Fred Wensing
Rob Christie

HFA COUNCIL

The HFA Constitution establishes a Council as its main governing committee. One Delegate is nominated by each State and Territory Foundation to form the Council and Council elects office-bearers from its own number. Virtual Council meetings were held on 20 October 2022 (including the Annual General Meeting), 23 February 2023 and 15 June 2023. All Delegates to the 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 Victoria
Leonie Demos until June 2023
Dan Korn from 15 June 2023

Haemophilia Foundation Queensland
Adam Lish

Haemophilia Foundation Tasmania
David Fagan

Haemophilia Foundation Western Australia
Gavin Finkelstein

South Australia
Paul Bonner, Observer

Office Bearers

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

l-r David Fagan, Gavin Finkelstein, Daniel Credazzi

HFA STAFF

Sharon Caris, Executive Director
Natashia Coco, Development & Relationships Director (Part-time)
Kevin Lai, Accountant (Part-time)
Jasmin Lai, Administration Assistant (Part-time)
Suzanne O'Callaghan, Policy Research and Education Manager (Part-time)
Poppy Sparsi, Administration Manager (Part-time)

Sharon Caris

Natashia Coco

Suzanne O'Callaghan

Poppy Sparsi

President's Report - Gavin Finkelstein

Emerging from the pandemic

Like so many other organisations we hoped the HFA Council would return to a "Covid normal" this year after virtual meetings for more than two years. We hoped to return to full operations with a stronger "in person" presence this year. Our staff moved back to the office in January 2023 for two days each week, while still retaining a degree of flexibility in the way they work, but we have continued with virtual Council meetings due to funding issues. We look forward to seeing everyone at the face-to-face Council meeting after the upcoming national conference in August.

Government Grants

Our government grant situation has not been resolved after more than a year of discussions with Ministers and Department of Health officials and we will face the beginning of the new financial year with uncertainty. We adopted a conservative approach to our work this year, and I am proud of the enthusiasm and commitment of our staff and volunteers in the face of this uncertainty, and the great work that was achieved during the year, nevertheless.

In all discussions HFA has with governments and other stakeholders, there is a recurring theme that HFA is a necessary part of these networks, yet it remains a challenge for HFA to be adequately funded to do this work. There is no other organisation with the capacity to contribute learnings from the lived experiences of people with bleeding disorders and those of their families and carers. Yet, as we face the loss of government grants, there is an expectation that HFA will lead the development of education resources and contribute to government policy from a bleeding disorders community perspective. HFA is well placed to do this as the national peak body for the bleeding disorders community, but we must receive adequate government funding.

Community education and raising awareness

During the year we concentrated on the work we could control and complete. This included a range of new education resources or updated resources required by our community. This work results from deep consultation, including surveys with people living with a bleeding disorder or its complications, and health professionals in their various disciplines who come together with recommendations about best practice and the type of information that should be provided. I thank everyone for their input, and for their voluntary service to HFA.

We updated and added new education material to the Getting Older Hub, and progressed work on the suite of information available to women and girls affected by haemophilia during the year. Further, we increased our social media footprint to provide information messages so that we reach the different parts of our community in accessible ways.

Each year we have a solid calendar for raising awareness, including Rare Diseases Day, World Hepatitis Day, World AIDS Day and World Haemophilia Day. We have made a decision to move Bleeding Disorders Awareness week to a month during October when we will raise awareness of all bleeding disorders.

Treatment and Care

Our advocacy work for best practice treatment and care continued throughout the year. In the climate of new therapies coming to market we are keen to ensure our community members have access to information about their treatment options so they can make informed decisions.

As well as working with community members to identify their needs, and consulting with their treating health professionals, our work involves liaison with the pharmaceutical industry. We seek information about new therapies in clinical trials, and those that may soon be coming to market, to understand what the barriers might be for the various therapies to be brought to Australia. This information can inform our policy advice to governments as well as help HFA understand future treatment opportunities for our community and ensure education and information is available at the right time so people can make well informed treatment decisions.

Our policy is not to promote specific treatments, but our role is to ensure a range of treatment options are evaluated and funded for use in Australia. We can assist with this by sharing the past experiences of our community members and their preferences for treatment and how they would benefit from a different treatment and encourage and support access. I am pleased that clinical trials conducted in Australia, have offered new treatment opportunities to some people in our community.

With new therapies coming to market, including gene therapy, we want to be sure our community members have the information they need to make good treatment decisions. This requires government policy makers to be well educated about the new therapies that are coming to market, how each of these may benefit a person living with a bleeding disorder and a commitment to processes that will support timely access.

We held an education meeting for members of parliament, their advisors and staff at the Parliament House in Canberra on 16 February 2023 to raise awareness and support for haemophilia treatment and care. We appreciate the support of joint chairs of the Parliamentary Friends of Child & Adolescent Health & Mental Health committee, parliamentary members Dr Mike Freelander, Dr David Gillespie and Dr Monique Ryan who hosted our meeting. HFA Vice President Dan Credazzi and his son Jay who lives with severe haemophilia A, generously shared their experience of haemophilia and this was supported by a very elegant presentation by Dr Liane Khoo, Royal Prince Alfred Hospital, Sydney, on the history of treatment and care, as well as the new therapies becoming available. Several members of parliament and their team in attendance reported later how much they valued hearing firsthand from Dan and Jay about their personal experience of haemophilia and how past, current and future treatments were brought to life by Dr Khoo.

I wish to thank the HFA Council and staff, state/territory foundations, specialist health professionals, our stakeholders, and most of all, our community members for their participation and support during the year.

Gavin Finkelstein

President

REPRESENTATION AND ADVOCACY

The changing landscape

With advances in treatments and changes under COVID, the health and wellbeing landscape for people with bleeding disorders has continued to evolve in the last 12 months.

New and emerging haemophilia treatments have been prominent. Some have become available in Australia and have been life-changing for many people in our community. Gene therapy and other innovative therapies are in advanced clinical trials and some are coming to the global market offering the potential for remarkable improvements to health and quality of life but raising other questions as well.

At the same time, the COVID-19 epidemic has had a lasting impact, with increased access to virtual health and communication, alongside the recognition that in-person care and clinics are also crucial in some circumstances.

HFA represents a diverse community with differing needs: people of all ages with a range of bleeding disorders - haemophilia, von Willebrand disease (VWD) and other bleeding disorders such as rare clotting factor deficiencies and inherited platelet disorders. Understanding their individual needs is crucial to achieving our vision of active, independent and fulfilling lives for all people in our bleeding disorders community. Ongoing consultation with our diverse community is an integral part of our regular activities. Their voices and concerns drive our work in representation and advocacy and there are many forums where we represent their views.

Health Technology Assessment Review

Over the past 12 months we have made several submissions and contributions to the Australian government's review of the government's health technology assessment (HTA) process. HTA is used to assess the quality, safety, efficacy, effectiveness and cost-effectiveness of health technologies, including therapies for bleeding disorders.

Bleeding episodes can be life-threatening, with significant ongoing impacts on health and quality of life, and effective treatment is a priority. We value access to innovative therapies and are committed to playing our part to make sure the right treatment products are available at the right time for everyone in our community and that they are provided as cost effectively for governments as possible. We actively engage in discussions with patients, clinicians, and companies involved in the development of treatments for bleeding disorders, and with governments to understand the barriers and opportunities to encourage manufacturers to bring their innovative therapies to Australia.

Understanding and communicating our community's treatment preferences and priorities is crucial to our advocacy. We recognised the efforts in the HTA Review to elevate the patient voice in access to therapies and contributed to the Conversations for Change consultation to identify specific ways this could be enhanced. We also commented on the Health Technology Assessment Policy and Methods Review and its draft Terms of Reference. Ensuring that treatment is patient-focused involves hearing the patient perspective - valuing the patient voice through qualitative evidence such as personal stories and taking into account outcomes beyond immediate clinical benefits like fewer bleeds or survival.

We also commented on the process to consider new bleeding disorders therapies for funding. In Australia we are fortunate to have a well-established national framework to manage the treatment and care of bleeding disorders and facilitate purchasing of treatment products on behalf of governments. The national blood arrangements to procure and supply blood products are unique and complex, involving multiple bodies, but they are effective in providing access to innovative therapies to all Australians with bleeding disorders and HFA is committed to the national framework that underpins them. We provided suggestions on improving the alignment between the national blood arrangements and the HTA system and where efficiencies and streamlining could take place. However, we also underlined the importance of a robust healthcare environment to deliver and evaluate these highly specialised therapies appropriately and equitably and the value of Australia's national network of specialist Haemophilia Treatment Centres.

Parliamentary event

Dr Liane Khoo, Dan and Jay Credazzi at the Parliamentary event

In February 2023 HFA representatives provided an education event for Federal Members of Parliament to promote awareness of new and emerging haemophilia therapies. This took place under the auspice of the Parliamentary Friends of Children and Adolescent Health, a non-partisan forum co-chaired by Dr Mike Freelander MP, Dr David Gillespie MP and Dr Monique Ryan MP.

Dr Liane Khoo, Director of the Haemophilia Treatment Centre at the Royal Prince Alfred Hospital in Sydney, gave a vibrant presentation on current and emerging haemophilia therapies. We were grateful to Dan Credazzi, HFA Vice President and HFNSW President, and his son Jay who shared their personal experiences as a parent and as a young person with severe haemophilia. Jay described the radical change in his everyday life with a new haemophilia treatment – and his story expressed very clearly the real value of these new treatments to people with haemophilia.

New treatments survey

With new and innovative haemophilia treatments becoming available, what would our community like to see as outcomes from treatment? What would improve their quality of life? During late 2022 and early 2023 we conducted a community survey that asked about preferred haemophilia treatment outcomes now and in the future. Responses were simple and practical. What they wanted from current new therapies was consistent with the clinical benefits reported but it was helpful to hear their wish-list for treatment outcomes in the future and to see that innovations such as a cure, oral treatment and treatment that prevented passing haemophilia on to children were part of their vision for the future.

Gene therapy

The release of the Australian Haemophilia Centre Directors' Organisation (AHCDO) *Gene therapy roadmap* in October 2022 underlined that some gene therapies are nearing commercialisation and that gene therapy is likely to become a viable treatment option in Australia over the coming years. AHCDO's roadmap proposed that patient need be seen as central, with a structured plan for equitable access nationally.

This is a highly specialised area that will rely on the national framework for management of bleeding disorders to work effectively. Patient experiences and their views on preferred treatment outcomes will be fundamental to making decisions about gene therapy. We look forward to working with AHCDO on the health technology assessment processes to evaluate gene therapy for funding, ensuring the HTC infrastructure will support gene therapy and contributing the patient perspective to the elaboration and implementation of the roadmap.

ABDR and MyABDR

The **Australian Bleeding Disorders Registry (ABDR)** system is a key part of the national treatment and health care framework for managing bleeding disorders and integrates a database of people with bleeding disorders in Australia with the system used by Haemophilia Treatment Centres (HTCs) nationally for the clinical management of their patients and for recording treatment product use.

The system includes the **MyABDR** app, which links directly to the ABDR and enables people with bleeding disorders and parents to record home treatments, bleeds and their treatment product inventory. MyABDR is a collaboration between HFA, AHCDO and the National Blood Authority (NBA) on behalf of Australian governments.

The ABDR and MyABDR have a vital role to play in treatment shared decision-making, personalised treatment and other treatment innovations over the patient's lifetime. They enable clinicians and their patients to collaborate on developing and monitoring an individualised treatment plan and to consider their options for new therapies, based on their individual outcomes.

HFA actively promotes the ABDR and MyABDR to the community and we were grateful to the ABDR Data Managers for their June 2023 article in *National Haemophilia* giving an insight into how ABDR data is managed. They outlined how the ABDR enables HTCs to record and monitor their patients' bleeding episodes, treatment product use and relevant interactions with the health system – for example, HTC reviews, hospital visits, surgery, clinical investigations, joint health assessments and other outcomes.

Checking and recording the supply, delivery and usage of these highly specialised treatments is essential to ensure treatment product is available across Australia and to minimise the wastage of precious supplies. The Data Managers described how this involves multiple systems and reminded people with bleeding disorders and parents/caregivers of their important role in recording their data via the **MyABDR** app.

The data produced from the ABDR has become an important evidence base, monitoring current trends in diagnosis and treatment and outcomes after treatment. We value AHCDO's ABDR research project reports and published AHCDO's plain language summaries on congenital fibrinogen disorders and prophylaxis and tolerisation in haemophilia A in *National Haemophilia* this year.

ABDR data has also been made available for HFA education materials and has enabled us to ground our new resources on haemophilia testing in women and girls on current evidence.

Making sure the ABDR and MyABDR continue to be fit for purpose is essential. HFA has regular discussions with community representatives and treating health professionals about improvements to the registry, including with our counterparts in Canada, whose CBDR/MyCBDR system uses the same database software, and who have been exploring enhancements and innovations. HFA is represented in the ABDR Steering Committee, which oversees the ABDR system and its data, and in the ABDR Stakeholder User Group, where we contribute from a patient perspective.

A voice in research

Ensuring people with bleeding disorders have a voice in their treatment and care is a priority for HFA. HFA encourages our community to participate in relevant high-quality research projects. Over the last year we have continued to highlight research study opportunities on the HFA website and through social media and e-news and our community takes a strong interest in this.

A key source of evidence for HFA is the **PROBE (Patient Reported Outcomes Burdens and Experiences) Australia Study**.

PROBE is a validated questionnaire which collects high quality evidence on patient experiences of haemophilia, treatment and quality of life from the patient perspective, using both haemophilia-specific and internationally recognised quality of life scores.

HFA joined the international PROBE Study in 2014 and co-ordinates community responses from Australia for an aggregated international dataset. We contributed to validation for the Australian environment and conducted the first real-world study with the Australian community in 2019-2020. The data was a key source of evidence about quality of life outcomes for the Getting Older report and has since been used by state and territory Foundations in local advocacy.

The PROBE Study is highly respected internationally and will be a valuable tool for comparing outcomes with new and emerging treatments as well as investigating other areas, such as the experience of people with mild haemophilia. It continues to evolve and has trialled innovations such as a mobile app and a longitudinal version. We are preparing for another round of Australian data collection in the second half of 2023 and, after having investigated its feasibility, will include the mobile app alongside the web and print versions as a platform for the questionnaire.

Von Willebrand disease (VWD)

VWD is the most common bleeding disorder worldwide but it is not well recognised and it is thought that many people with VWD are not yet diagnosed. In 2018 HFA joined the World Federation of Hemophilia (WFH) in an international endeavour to create awareness, resources and provide support to improve the lives of those living with VWD.

HFA consults with its VWD consumer focus group regularly to help understand the education needs of our community with VWD. This year they provided, for example, questions about insurance and superannuation to develop a community webinar. We highlight VWD information and personal stories in our regular social media, in our education materials and awareness campaigns such as Bleeding Disorders Awareness Week. VWD will be an integral part of our 2023 conference, with personal stories and a medical update. Our VWD booklet is consistently our most popular resource, with 10,603 downloads in 2022-23.

New international (ASH/ISTH/NHF/WFH) Guidelines on the Diagnosis and Management of VWD were released in 2021 and AHCDO will follow with equivalent national guidelines for VWD management in Australia. We have reported on the international discussions about the new guidelines in National Haemophilia and look forward to working with AHCDO and other health professional groups on the community education and health services outcomes that will result from the Australian guidelines.

Rare bleeding disorders

While individual rare clotting factor deficiencies, inherited platelet disorders and acquired haemophilia can be very rare, it is important that the needs of people who are affected are taken into account and that there is an avenue for them to connect and for their voice to be heard. Because numbers are small, the development of new and highly effective treatments can be slow and there may be no treatment that specifically targets that condition. People with very rare bleeding disorders speak of feeling isolated – not knowing anyone else with the same condition.

We raised awareness about the situation for people with rare bleeding disorders on Rare Disease Day and our social media posts throughout the year have enabled people who are affected to share their experiences and connect with HFA and each other. Following requests from HTCs, this year we have commenced new education resources and consulted with health professional experts and people with rare bleeding disorders to develop them.

We also made a submission to government on a new treatment developed specifically to treat people with acquired haemophilia A.

Women and girls

This last year has seen some significant steps forward in our The Female Factors project. This project aims to help with addressing the delays in diagnosis and appropriate management of females with bleeding disorders that continue to be reported both in Australia and internationally.

One strategy of the project is to provide high quality, evidence-based information that clarifies the clinical pathways for diagnosis, treatment and care and provides women and parents of girls with the tools to negotiate them, including resources they can show to health professionals in the wider community who provide their care. This year we released a simplified version of the Haemophilia testing in women and girls resource. We consulted with AHCDO for their policy relating to the new international guidelines on haemophilia diagnostic categories for females and advice on managing the complexities of genetic testing and factor level testing. We were also grateful to genetics and legal experts for clarifying language, procedures and issues relating to insurance and employment.

Genetic testing

Technology for genetic testing is evolving rapidly. There have been increasing questions about the implications for bleeding disorders such as haemophilia: these health conditions are genetic and hereditary; a parent who is undertaking genetic testing as part of their reproductive decision-making may also have the bleeding disorder but may be unaware of it; and genetic testing in children can be problematic when there are lifetime consequences and having the relevant gene variant may or may not indicate a health condition in the person tested. Diagnosing and managing bleeding disorders is a highly specialised area and appropriate referral is vital.

We responded to the Australian Government consultation on the proposal to expand the newborn bloodspot screening program and noted that it opened a wider discussion with AHCDO, covering complex ethical considerations, questions about testing for the range of bleeding disorders and their differing severities with the available technologies and the relative benefits of undertaking testing of newborns. We are continuing to work through these discussions with AHCDO.

Getting Older


Getting older with a bleeding disorder
Needs assessment report
May 2020

We continue to address the needs of older people with bleeding disorders described in our 2020 Getting older report. While some are part of a new generation of people with bleeding disorders living into their senior years for the first time, others are relatively young and experiencing ‘early ageing’. Both live with complications that include joint and muscle damage, arthritis, pain and mobility problems.

The report highlighted the difficulties in infusing treatments with increasing frailty. New and emerging therapies have potential to overcome some of these issues. For example, we have heard many older people with haemophilia A report that using emicizumab (Hemlibra®) for prophylaxis has had great benefits for them, both in reducing bleeds and easier administration, as it is injected subcutaneously. This therapy is not suitable for everyone and we will be following up other sub-cutaneous non-factor therapies as they come to market.

Transport problems were also raised by many in the Getting Older Report. We were pleased to have the opportunity of the Australian Government consultation on the Reform of the Disability Standards for Accessible Public Transport to provide detailed comment from older people with bleeding disorders and mobility issues.

A key recommendation was to develop a Getting Older Hub on the HFA website to centralise relevant information. We have continued to develop education materials with links to relevant information in collaboration with our community Focus Group and HTC experts and have reworked the look and feel to be more life-affirming and focused on wellbeing, as requested by the community.

However, for our community to live well into their senior years and achieve optimal health outcomes, it will require access to the support and services they need. The Getting Older report identified that significant complications are occurring in older people with mild as well as severe disorders. In order to manage the complex issues and challenges ahead, it will be important to strengthen comprehensive care in HTCs and enable them to develop effective partnerships with other relevant specialities, including general practitioners. This has been an important part of our advocacy around comprehensive care.

Hepatitis C and HIV

Many people with bleeding disorders acquired hepatitis C and some also HIV through blood products for their treatment before 1993. The Getting Older report reviewed the needs of people with bleeding disorders affected by bloodborne viruses and made specific recommendations to address the range of substantial ongoing clinical, mental health and financial issues.

In response, HFA Council established a Hepatitis C Sub-Committee, which has been working through priority recommendations. The Sub-Committee agreed that it was most urgent to deal with clinical needs: ensuring that people with cirrhosis had ongoing liver health monitoring after a hep C cure and reaching men and women with mild bleeding disorders who may not have been aware of their hep C risk and encouraging them to be tested and treated, if required.

AHCDO had confirmed that, while ABDR data indicated high hep C treatment and cure rates, they were not able to access sufficient data on current liver health status for meaningful results.

They noted that a large proportion of people with mild bleeding disorders who could potentially be at risk of hep C have been lost to follow-up and their hep C status remains unknown. We have continued to consult with individual HTCs about their chief concerns relating to hepatitis C and liver health in their patients.

Our discussions and advice from gastroenterology and hepatitis clinical organisations on current clinical practice supported health promotion messages targeted at our community, in particular to address post-cure cirrhosis monitoring. These messages formed part of our 2022 World Hepatitis Day campaign. We continue to use a two pronged approach to reach people with mild disorders who may be at risk of hep C: a social media campaign for the wider community and opportunities to educate general practitioners who may have patients with mild bleeding disorders.

Representation and communication

Engaging our community is vital to consulting with and representing our community. Our digital communications project has used the expertise of a consultant to analyse and identify communications strategies to optimise how we engage with people with bleeding disorders in Australia. With a rapidly evolving digital environment, this has enabled us to make the best use of our various communications platforms for information that our community can trust and to address problems with consultation, such as malicious interference from bots in community surveys.
We are also working on a new website infrastructure that will enable a more agile approach to communication.

COMMUNICATING WITH THE COMMUNITY

EDUCATION AND INFORMATION

Education resources snapshot – in 2022-23

HFA education materials about bleeding disorders

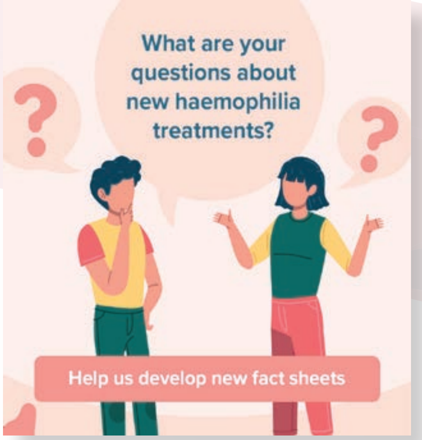
512 print copies distributed

39,090 PDF downloads

55,042 information web pages viewed

We work closely with our community and experts to develop education resources in priority areas. Our resources are relevant to the Australian environment, accurate and evidence-based and focus tested with the community members they are intended for.

New haemophilia treatments



With new haemophilia treatments becoming available in Australia, information to assist people with haemophilia to understand the treatments and make decisions about them has been a priority for HFA.

In January 2023 we conducted a survey to find out what information our community wanted about the new treatments. The survey results will help us to rework the information about new treatments in our key haemophilia resources and also provide the backbone for fact sheets on classes of haemophilia treatment.

We also published several updates from experts for the community:

- A webinar on new haemophilia therapies
- Articles in National Haemophilia exploring what the new therapies are and how they affect health outcomes.

Getting Older Info Hub

Getting Older Hub

Need more information about how to live well when you are getting older and have a bleeding disorder?

We will be adding more information to the Hub and updating it regularly.

Read the HFA Getting Older with a Bleeding Disorder report

What's New

Travel tips
Heading off interstate or overseas? Tips to make your journey a success.

Financial planning and management
Navigating your finances as you grow older.

Zev and Mike and staying active
Enjoying life - watch the video to find out more

The Getting Older Hub is HFA's '*go-to zone to find information on getting older with a bleeding disorder*'. It was a priority recommendation from the HFA Getting Older report. The Hub includes information and links to services for older people, providing pathways and strategies for self-management. There are also guidelines for health and aged care professionals in the community developed by the expert haemophilia health professional groups.

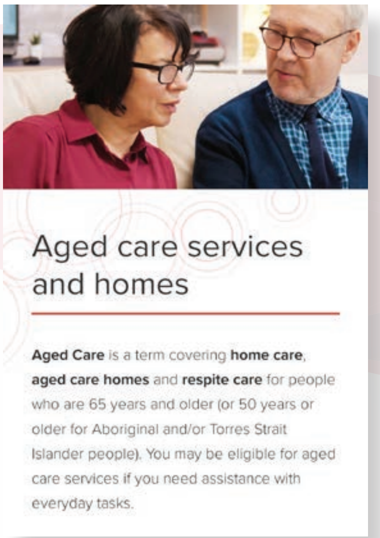
Over the last year we have brought a new look and feel to the Hub, with a more dynamic and life-affirming approach. This was an outcome of our 2021 community evaluation, where suggestions included images of younger people, some more ‘light-hearted’ topics and encouraging people to visit the site regularly and contribute their own stories. The landing page, redeveloped with guidance and feedback from our community focus group, highlights new information and stories and was launched in July 2022.

Gavin's outback camping story

Personal stories are an important way for community members to connect and Gavin’s video on his experiences of outback camping combined helpful and practical tips with an emphasis on enjoying life. This sparked other travel and camping stories and we look forward to publishing them in the coming year.

To highlight living well, new articles also covered:

- Getting back to hobbies and socialising after COVID
- Changing your career path



Aged care services and homes

Aged Care is a term covering **home care**, **aged care homes** and **respite care** for people who are 65 years and older (or 50 years or older for Aboriginal and/or Torres Strait Islander people). You may be eligible for aged care services if you need assistance with everyday tasks.

Navigating Aged Care services continues to be a major issue and a substantial new section on Aged Care services and homes has been added to support community members as they manage their needs and plan their future.

The Hub will continue to grow and evolve as more information is developed or sourced and is guided by consumer and expert health professional reviewers.

Women and girls project

In May 2023 we published ***Haemophilia testing in women and girls: a guide.*** This is a simple approach to complex issues, using infographics and relatable stories to explain what is involved in genetic testing and factor level testing, why some women and girls have bleeding problems or haemophilia and others do not and what your diagnosis means.

There are many sensitive issues in testing females for haemophilia and this new resource explores gently what to consider with genetic testing, how to tell others about your test results, including family, employers and insurance companies, and support available.

It is an area where much has changed recently and we worked closely with our women and expert reviewers to make the information both evidence-based and accessible.

‘What a great booklet!!’

‘It turned out wonderful. Excellent work to you and the team for another fabulous resource for women!’

Genetic testing and counselling

The steps in genetic testing

1a. Information, discussion and counselling

You will have the opportunity for discussion with a haemophilia specialist and/or genetic counsellor before giving permission to have the test.

1b. Mapping the family tree

They will look at your family tree with you to identify other family members who may have the gene alteration.

2. Giving consent to having the test

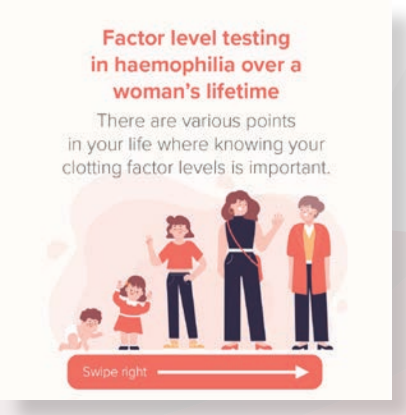
You will be asked to sign a consent form for the genetic test. You can choose not to go ahead with genetic testing or withdraw your consent at any stage before the result is issued by the laboratory.

A genetic test for an obligate carrier is also a paternity test and this needs to be part of the discussion.

If the testing is for your daughter, it may need to be delayed until she is old enough to give informed medical consent herself. You may choose to only have factor level testing in a child.

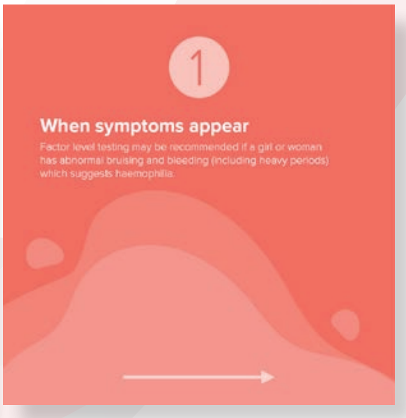
16 Haemophilia testing in women and girls www.haemophilia.org.au

New education resource formats
Social media platforms are an important environment for evidence-based education and many of our community members are active on platforms such as Instagram, particularly younger people. We have taken the opportunity to rework specific topics from our education material as bite-sized resources, targeted at this audience, using formats such as social media carousels. These are very popular and engaging, with community members at times contributing to discussions with their own experiences. We need shorter and longer versions for our diverse readership.



Factor level testing in haemophilia over a woman’s lifetime

There are various points in your life where knowing your clotting factor levels is important.



When symptoms appear

Factor level testing may be recommended if a girl or woman has abnormal bruising and bleeding (including heavy periods) which suggests haemophilia.

COMMUNICATIONS

HFA is a major resource in Australia for providing current, evidence-based information on bleeding disorders. We support all facets of the community, including people with bleeding disorders, their family and friends, and health practitioners. Our content varies from introductory ‘did you know’ facts for people new to bleeding disorders, to detailed explanations of inheritance and treatments such as gene therapy. To best serve and reach the community, we are active on multiple channels including our websites, social media, email, and our quarterly journal, National Haemophilia.

HFA communications snapshot (2022-23)

6,357 copies of National Haemophilia posted to members

36,283 online views or downloads of National Haemophilia

Websites (haemophilia.org.au & factoredin.org.au)

- **70,463** total users
- **142,587** total pages viewed
- **4.86M** total Google search impresssions

Social media

- **1,601** total posts
- **5,567** total followers
- **207,710** total people reached
- **7.53%** average engagement per post

Email

- **1187** subscribers to HFA news
- **12,348** email opens
- **1360** email clicks

National Haemophilia

National Haemophilia**,** HFA’s quarterly journal, is trusted as a source of the latest evidence-based information and news about bleeding disorders, for both community and health professionals. Australian bleeding disorder experts contribute topical educational articles in plain language, alongside personal experiences from people with bleeding disorders. Our readership has diverse preferences, so we make it available in multiple formats - digitally with each article as a web page, as a PDF, as a magazine through ISSUU, and it also has a very robust print readership.

The most popular articles from the last year were:

- New haemophilia therapies/gene therapy
- Starting school with a bleeding disorder
- World Congress report on von Willebrand disease
- ABDR research into congenital fibrinogen disorders.

The new contemporary design and online features to enhance reading on mobile devices have worked well. Pageviews of recent issues have increased by 9% and downloads have increased by 87%.

With each article available as a web page and a PDF, back issues can be searched with search engines such as Google and remain very popular – for example, a 2018 article on looking after your veins had 3,782 pageviews.

HFA Website & Factored In Website

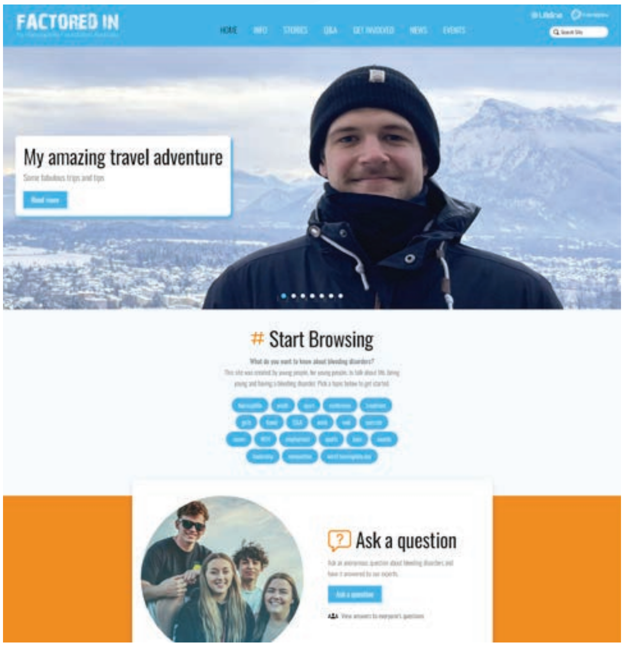
The HFA website is our major communication platform with the bleeding disorders community and other stakeholders, with high quality health information and updates about HFA activities and other news. Our site is constantly updated with news updates, high quality information and all publications are available for downloads.

The site is the most valued and access source of current evidence-based information in Australia. 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.

www.haemophilia.org.au in 2022-2023

- Appeared in **4.86M** Google searches
- Average of **523** returning visitors per month
- Average of **5027** new visitors per month
- In total we had **128,181** web pages viewed
- The majority of our visitors are **Australians aged 18-34**
- The top search queries for our website are **haemophilia, haemophilia pdf, von Willebrand disease, bleeding disorders pdf**
- What is most popular? Information about haemophilia (particularly inheritance and treatment), **von Willebrand disease (VWD)**, including how VWD affects women and girls, the **2023 HFA Conference**, and **gene therapy**.

factoredin.org.au



The Factored In youth website is a key information hub for young people with bleeding disorders. The website provides information for young people about life and being young with a bleeding disorder. It features both personal stories as well as evidence-based information.

www.factoredin.org.au in 2022-2023

- **10,359** website visits
- **14,406** page views
- The majority of site visitors are **aged 18-24**
- **Over half** our users for Factored In are on a device of some sort – smartphone/mobile or iPad/Tablet
- What is most popular? Information about **haemophilia, employment, sex and intimacy,** and **personal stories.**

HFA Social Media

Our diverse community is active on a variety of social media platforms and our presence on Facebook, Instagram, Twitter/X, YouTube and LinkedIn is a valuable and timely way for us to communicate with the bleeding disorders community, supporters and stakeholders.

These platforms are particularly effective for engaging the community with important new information, generating awareness about activities and health promotion messages and encouraging them to click on links to read more. They are also forever changing, and we need to keep up to date on changes.

Social media in 2022-23

- All social media channels saw growth this year, in particular Instagram
- Content featuring community members or promoting community events proved most popular
- Educational snippets, including informational carousels and 'Did you know' infographics were also well received
- Our most engaging posts included:
    - o Congratulating Chris Gordon on his position as boundary umpire at the AFL Grand Final
    - o Talking about sex, intimacy and bleeding disorders
    - o Shauna sharing her personal experience with VWD
    - o Bleeding Disorders Awareness Month
    - o World Haemophilia Day
- **12,526** website visits

We have **5,567** total followers across all of our social media accounts.

- Facebook: **3673**
- Instagram: **932**
- Twitter/X: **867**
- LinkedIn: **85**

We continue to run social media campaigns for key dates throughout the year. This year we changed Bleeding Disorders Awareness Week to last all of October, becoming Bleeding Disorders Awareness Month. This change was appreciated by the community and enabled greater engagement.

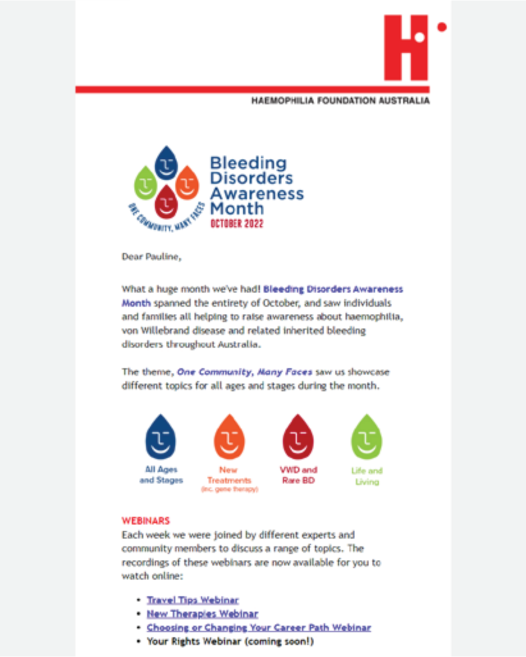
- World Haemophilia Day, 17 April 2023
- World Hepatitis Day, 28 July 2022
- International Men's Day, 19 November 2022
- Men's Health Week, 12-18 June 2023
- International Women's Day, 8 March 2023
- Women's Health Week, 5-11 September 2022
- Bleeding Disorders Awareness Month, October 2022

HFA Email

HFA regularly communicates with our email subscriber list, delivering a monthly newsletter, quarterly National Haemophilia issues, and ad hoc e-letters containing updates and latest news for the bleeding disorders community.

Email in 2022-23

- Our email list has grown by **279** contacts (now totalling 1187 subscribers)
- Our emails were opened **12,348** times, and clicked **1360** times
- Average open rate of **41.58%** and clickthrough rate of **4.70%** are almost double the industry benchmarks



Dear Pauline,

What a huge month we've had! **Bleeding Disorders Awareness Month** spanned the entirety of October, and saw individuals and families all helping to raise awareness about haemophilia, von Willebrand disease and related inherited bleeding disorders throughout Australia.

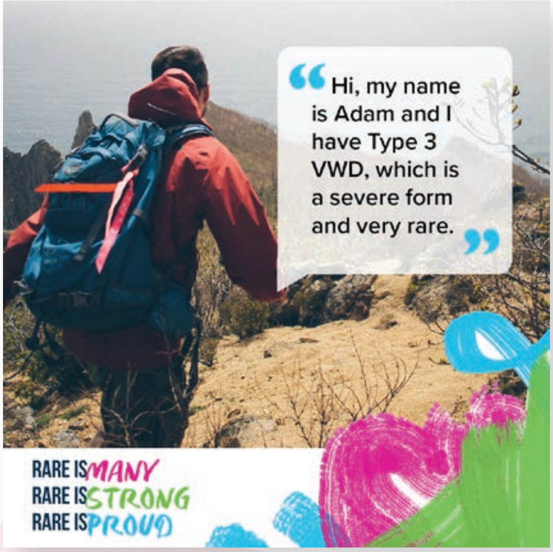
The theme, ***One Community, Many Faces*** saw us showcase different topics for all ages and stages during the month.

WEBINARS
Each week we were joined by different experts and community members to discuss a range of topics. The recordings of these webinars are now available for you to watch online:

- Travel Tips Webinar
- New Therapies Webinar
- Choosing or Changing Your Career Path Webinar
- Your Rights Webinar (coming soon!)

AWARENESS

Rare Disease Day



Our bleeding disorders community is diverse and HFA has joined the World Federation of Hemophilia in the global commitment to create awareness, resources and provide support to improve the lives of those living with von Willebrand disease (VWD), rare clotting factor deficiencies and inherited platelet disorders. Bleeding Disorders Awareness Month in 2022 and Rare Disease Day in 2023 were opportunities to put this into action with information and personal stories on our websites and social media platforms, with some people adding comments with their own personal experiences. This is an important way for our affected community members to feel connected as well as recognised.

World Hepatitis Day

World Hepatitis Day is marked globally on 28 July. In 2022 we joined the international community in the message of Hep can't wait, reminding us that we need to be proactive and act on viral hepatitis.

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.

Our key messages targeted two groups:

- Some men and women with mild bleeding disorders may not be aware they were at risk of hepatitis C or had testing
- Other people with bleeding disorders may have had hepatitis C treatment and been cured – but if they have liver cirrhosis, they remain at risk of liver cancer and need to have ongoing liver health monitoring.

Our campaign aimed to reach the family and friends of men and women with mild bleeding disorders to pass the message on, with a short video highlighting that women are also at risk. We also used postcards with key messages to start discussions in peer support groups.

We are grateful to 'John' and 'Jake' for sharing their personal experience of clearing the virus or being cured and caring for their liver health. These stories were published on our website and in Foundation newsletters and shared widely across social media networks.

While most people have been cured, there remains a small number of people who have not been able to have successful treatment and live with advanced liver disease. It has been important to our community for our campaign to acknowledge their situation.

World AIDS Day

In 2022 the national theme for World AIDS Day was Boldly Positive. HIV remains an important part of our community's history and World AIDS Day is a time for thoughtful and poignant reflections. The HFA Getting Older report documented the devastating impact of HIV epidemic on the bleeding disorders community in Australia, when a substantial number acquired HIV from infected clotting factor treatment products during the 1980s.

The HIV experience drew on the resilience that was already a strong element among people with bleeding disorders and led to a resolve to respond as a community, taking on effective advocacy around safer treatments and providing support. Our community members affected by HIV continue to remind us how vital it is to acknowledge their experience and create a supportive, inclusive and stigma-free environment.

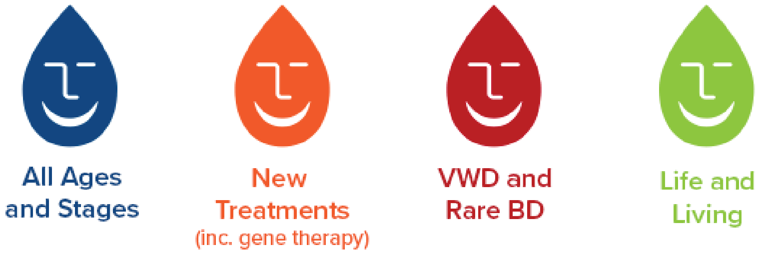
We marked 1 December 2022 across all our communications platforms as a day when we are mindful of the members of our community living with HIV, those who have passed away, and all those who have cared for them, shared their hardships and still grieve for those they have lost. The impact of HIV has been profound. It affected not only the people who acquired HIV and their partner, family and friends, but also the health professionals who have cared for them over their lifetime, and the bleeding disorders community generally.

Bleeding Disorders Awareness Month

For the first time, Bleeding Disorders Awareness was hosted over a month – and what a great month it was.

Bleeding Disorders Awareness Month is an opportunity for individuals and families as well as Haemophilia Foundations and other organisations to take part in a campaign and activities to raise awareness about haemophilia, von Willebrand disease and related inherited bleeding disorders around Australia.

The theme of the month was **One community, many faces.** We showcased different topics for all ages and stages during the month.



WEBINARS

Over the month HFA hosted 4 webinars, covering very topical areas.
The webinars can be viewed at **https://tinyurl.com/BDAM22-webinars**

Travel Tips

New Therapies

Choosing or changing your career path

Your rights: Superannuation and insurance

RED CAKE DAY

Across the country our community hosted Red Cake Days, information stalls, children with a bleeding disorder did show-and-tell to their classmates and Bendigo Bank Gippsland region in Victoria fundraised across their branches.

Alex in her small town of Weipa QLD held seven cupcake days, selling 517 cupcakes in total and raising over $1000. Thank you to St Joseph's Parish School Weipa, C&K Weipa Community Kindergarten, Weipa Town Authority, Weipa Business Equipment and Woolworths Weipa for your assistance.

World Haemophilia Day 2023

Every year on 17 April World Haemophilia Day the bleeding disorders community worldwide comes together to increase awareness of haemophilia, von Willebrand disease and other inherited bleeding disorders.

Joining other countries such as Austria, Canada, Colombia, Egypt, England, Ireland, Japan, Panama, Spain, Taiwan and US, building and landmarks were lit up in red across Australia in support of the day. We had over 60 landmarks across the country lit up red.

The World Federation of Hemophilia, with the support of volunteers from around the world, does remarkable work to improve access to diagnosis, treatment, care, and support for people with bleeding disorders.

CELEBRATING WORLD HAEMOPHILIA DAY

Thank you to everyone who participated in the day.

Performance Personal Training

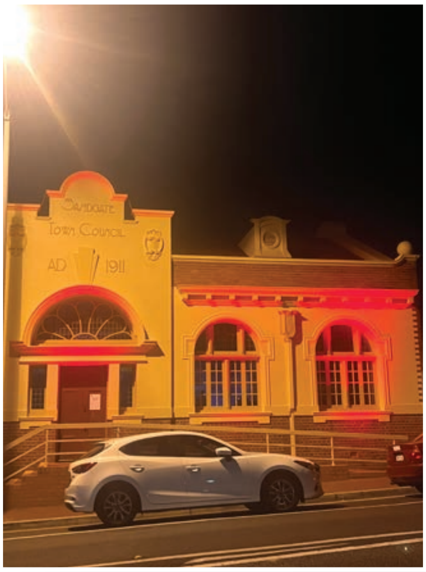
The Haemophilia Treatment Centre team from the Children's Hospital at Westmead

Lighting It Up Red Around Australia

Victoria Bridge and Treasury Casino, Brisbane QLD

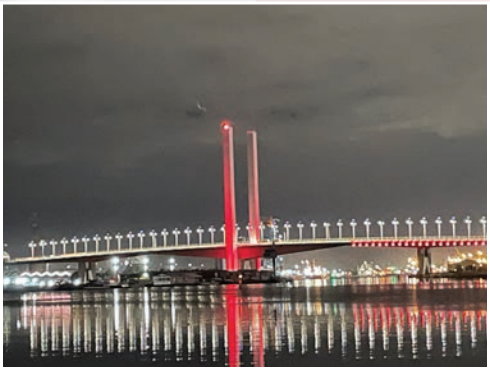
Wrest Point Casino, Hobart TAS

Government House, Brisbane QLD



Sandgate Town Hall, Brisbane QLD

Drum Theatre, Dandenong VIC



Bolte Bridge, Melbourne VIC

Story Bridge, Brisbane QLD

Victoria Bridge, Toowoomba QLD

HAEMOPHILIA FOUNDATION RESEARCH FUND

The Fund was established in 1990 upon the recommendation of the HFA Medical Advisory Panel (now, Australian Haemophilia Centre Directors' Organisation (AHCDO)). Distributions from the Fund have been made since 1994 and is made up of income from the donations, fundraising events and bequests received by HFA specifically for research over many years. Over its 28 years history, the Fund has supported over 35 projects amounting to $678,179.80.

In 2023, a grant of $20,000 was made to Dr Elise Flynn, The Royal Children's Hospital, Melbourne, for a research project on *unexpected procedural distress: an observational study exploring procedural pain and anxiety in patients with haemophilia A receiving subcutaneous emicizumab prophylaxis.*

DEVELOPMENT

World Federation of Hemophilia (WFH)

Participation in WFH activities provides an opportunity for HFA to contribute from its experience to global endeavours to improve access to care and treatment around the world, and to develop and maintain connections with peers in other organisations which share our goals and challenges.

As a National Member Organization (NMO) of the Federation. HFA attended the General Assembly (held virtually) when it was held on 18 November 2022.

We are pleased that Shauna Adams, from HFACT, is a member of the WFH Youth Committee for the period 2022-2024 following her participation in the 2022 WFH World Congress and associated meetings in Montreal.

Damon Courtenay Memorial Endowment Fund (DCMEF)

The Fund was established by Haemophilia Foundation Australia in 1994 with initial financial support from the late Bryce Courtenay and the late Benita Courtenay in memory of their son, Damon. The Fund provides grants to individuals or patient support organisations for the care, treatment, education and welfare of people affected by haemophilia or related bleeding disorders.

An amount of $10,650 was distributed from the Fund during the year, with grants to six people for a range of projects and activities including special education support services, equipment that would facilitate the establishment of a new business and laptops and IT equipment for students.

FUNDRAISING

HFA's fundraising program raises much needed funds for education resources, projects and peer support activities.

We are extremely fortunate to have a committed group of individuals, families, service clubs, schools and businesses that make donations throughout the year to support our work and continue to support us during a pandemic. Their generosity helps us to continue to provide many of services to assist at every age and stage.

Appeals

Direct mail appeals to donors are sent during the year and we thank everyone who has made a donation. The donations raised from these campaigns are used to support programs and services including peer support, family camps, women's resources and local community projects.

Trust and Foundations

We continue to make applications to Trust and Foundations for specific project support. We thank the support of APS Foundation and the William Angliss VIC Charitable Fund in 2022-2023 financial year. We also thank the Marian and EH Flack Trust for enabling us to carry over a grant given in a previous year for this financial year as we had been gnable to run the project due to the pandemic.

PEER SUPPORT PROGRAMS

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, however many have been interrupted due to the pandemic. We were pleased that our member foundations have resumed their camps and workshop programs, and that HFA had been able to support one family camp in NSW.

After two years of cancellations and postponements due to the pandemic, we finally got our Family Camp this year. During the weekend of the 11th-13th of November 2022, our members and families from all over NSW gathered at the Sydney Academy of Sports and Recreation at Narrabeen NSW. For decades our Family Camp was known far and wide across NSW and it was great to be able to get families together again after two years of missing out. It was nice to see old families and meet some new ones. And what a weekend! An opportunity to get away from everyday life to jump into a fully catered, all inclusive two nights and three days of great food, awesome activities, information and knowledge sharing and quality time together. The children and adults enjoyed the activities such as swimming, canoeing, archery, and team challenge games. Kids also had a blast with balloon twisting, face-painting, and the Disco Party with their favourite Claudia! The Trivia night on Saturday was also a highlight for many of the adults. The camp was a great opportunity to catch up with old friends and make new friendships.

Treasurer's Report 2023 - David Fagan

I am pleased to report that HFA has returned a surplus for 2023 after the deficit in 2022 which occurred largely due to low returns in the investment market. However, the surplus this year does not disguise ongoing and serious challenges faced by HFA in relation to government grant income, which is set to decrease significantly.

Income Summary

Our financial performance this year has been solid despite the lower grant income. We received $1,088,350 this year which is 52% increase on $572,833 last year.

Government grant income declined by 12.6% this year, from $455,000 to $397,636 this year, due to a timing issue with one of the grants. However, the grant situation is alarming because one of the two government grants received by HFA for many years will not continue next year. The grant of $195,000 which covered part costs of the HFA secretariat for its peak body responsibilities will stop. Further the other government grant for education and communications has been reduced by half and HFA will receive $130,000 from 1 July for the second half of the calendar year. This in effect represents a 71% reduction in grant income for the 2023-2024 financial year compared to last year and previous years.

Higher income from sources other than grants has masked the loss of grant income and boosted our overall performance. A 70% increase in income from general donations and corporate sponsors, along with a 55% income increase from trusts and bequests compared to the previous year is positive. This does include a timing effect, as income from some of these sources had been lower last year, but we hope we may be returning to pre covid income patterns.

It is important to note that we report conference related income and expenses on a cash basis when it is received. This is reflected in a two-yearly cyclical conference impact. We received $157,000 in conference sponsorship this year; but I note that most conference expenses will be reported in the next financial year.

We have seen an improvement in the returns on our investments, and the unrealised loss of $234,079 last year has turned around and we are reporting an unrealised gain of $167,954 this year.

Expenses Summary

On the expenses side, HFA had a 6.6 % increase on overall expenditure. Most operational expenses remained relatively stable. Website costs of $46,467 this year, compared to $11,841 in the previous year includes a $32,000 investment in a new website to be launched next year. This decision was forced upon us when we were advised that the annual costs for the current website platform provider were to increase from $7,500 to $100,000 per year. A competitive tender process was conducted, and the new arrangements are expected to save costs over time because a significant part of website activity will be managed inhouse. We can continue to offer state/territory foundations a viable option for content for their local websites. The other three significant expenses were for a Parliamentary Event held in Canberra to educate members of parliament on new therapies for haemophilia, a grant to HFNSW for their 2022 family camp which had been held over due to the pandemic, and an allocation of $10, 650 for welfare grants to community members from the Damon Courtenay Memorial Endowment Fund (DCMEF). with total expenses of $948,792 compared to $886,967 in the previous year.

This has resulted in a $139,558 surplus compared to a $314,134 loss last year.

Foundation Funds

I am pleased that as market conditions have started to improve post Covid-19. Our equity investments have increased by 11.5% from $1.97million to $2.20million for the year. However, our cash and short-term balances have decreased by 2.5% for the year from $1,019,769 to $994,000. Nevertheless, overall, cash and investment assets have increased by $200, 000 to $3.2million. Total net liabilities increase by 3.5% to $350,000. The Foundation's Funds currently sit at $2.9million, which is an increase of 5% from $2.7million last year.

Operations and Government challenges

Although our investments are doing well, the loss of $180,000 in grant income of over the last two years has meant we have depleted our discretionary reserves. With the final payment of the remaining government grant to be paid on 1 July 2023, and no further grants scheduled to be received HFA will need to realise cash from investments held for the purposes of research to manage cash flow requirements to cover operational costs until grant negotiations are resolved.

Due to changed working arrangements post Covid -19 and as a potential cost cutting measure, HFA has taken steps to surrender its lease on its office rental property in East Malvern. This has been unsuccessful, possibly because the lease which was signed pre- Covid-19 is likely priced over market expectations and is unattractive to new tenants. The lease finishes in January 2025, and it is unlikely we will identify a tenant to take over the lease in that time.

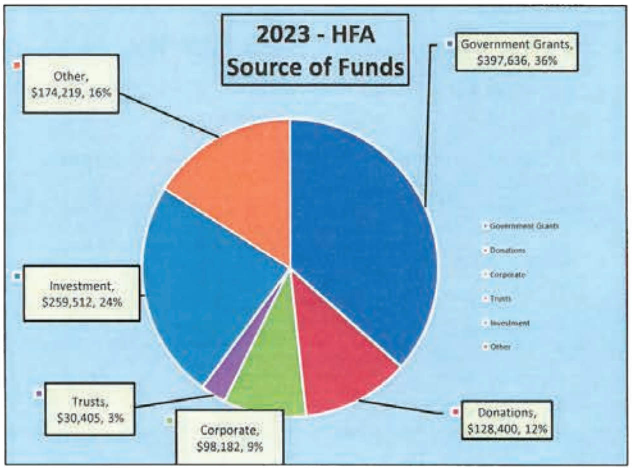
HFA has always been aware of its strong reliance on government grants. Grants represented 35% of all income this year, and up to 40% of HFA income has been attributed to grants in other years. This has been an historical feature of our operations – we are a truly not for profit organisation, with simple objectives and purpose. We represent our community, and when we have the financial capacity to do so we can undertake specific projects. We do most of our work through a small staff team with the expertise to undertake policy development, education, fundraising and development, and communications. Without this inhouse expertise we would be forced to purchase services at commercial rates which would be cost prohibitive.

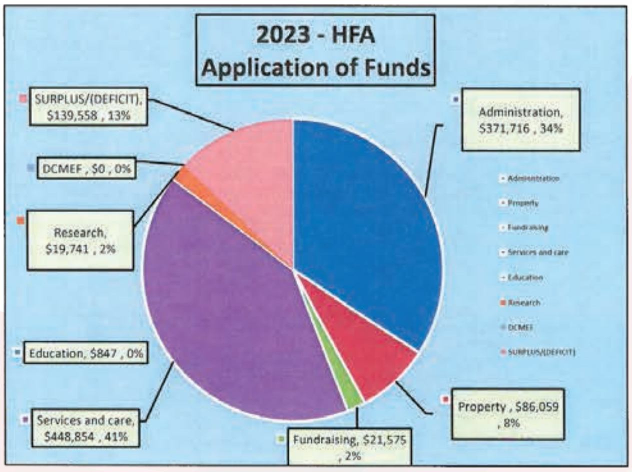
Potential for future operating model

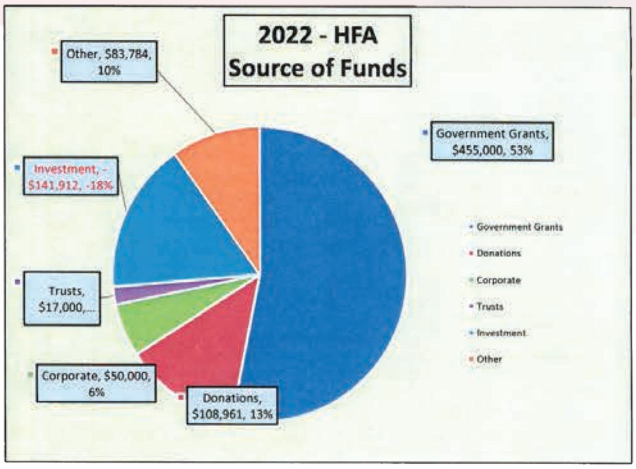
Our model of operating is modest, and we do not want to lose the expertise we have built up because it is our strength. Nevertheless, we are faced with the hard truth that we have limited income generating options without government grants. In recent years we have taken steps to reduce our reliance on government grants. We invested in a donor acquisition plan, and this is consolidating new donors who have joined our cause, but this in no way will enable HFA to move away from the need to receive government or other external grants as well. At this time, HFA has no capacity to make up the difference and HFA will become unviable when reserves are exhausted. HFA has been in discussions with the Department of Health at many levels over the last 2 years about the ongoing need for government grants to enable HFA to operate effectively as a peak body, and provide services to our community, and we are working hard to have the level or previous grants reinstated, in the least, but there is no assurance of this yet. We are pleased there is some recognition that a significant part of HFA's work is to contribute to government health policy and the provision of health education for the Australian community and that historically this has been provided under the government grants for many years.

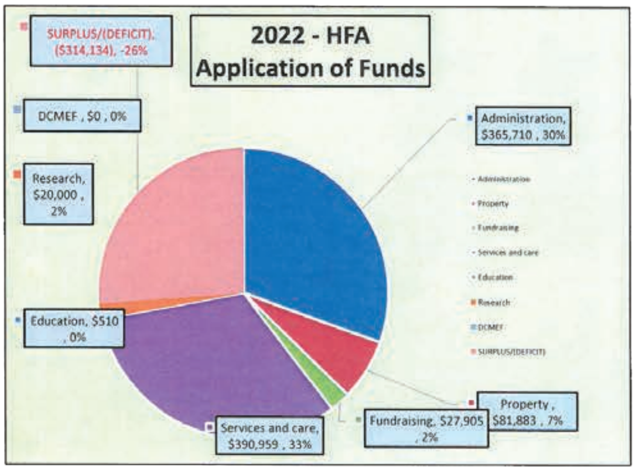
At the AGM last year, I presented a plan to establish an HFA Finance Subcommittee. We have established the terms of reference for this committee and as soon as we are clear about the outcome of the government grant negotiations, I will convene this committee to review our investments and set a plan to take us forward.

I wish to thank the HFA staff for their cautious approach to spending this year. They have managed to balance the requirement for us to complete necessary work towards our objectives so that our community is well served, with little flexibility due to our loss of grant income and further reductions expected.


2023 - HFA
Source of Funds
Government Grants, $397,636, 36%
Other, $174,219, 16%
Investment, $259,512, 24%
Trusts, $30,405, 3%
Corporate, $98,182, 9%
Donations, $128,400, 12%
Government Grants
Donations
Corporate
Trusts
Investment
Other


2023 - HFA
Application of Funds
SURPLUS/(DEFICIT), $139,558 , 13%
DCMEF , $0 , 0%
Research, $19,741 , 2%
Education, $847 , 0%
Services and care, $448,854 , 41%
Fundraising, $21,575 , 2%
Property , $86,059 , 8%
Administration, $371,716 , 34%
Administration
Property
Fundraising
Services and care
Education
Research
DCMEF
SURPLUS/(DEFICIT)


2022 - HFA
Source of Funds
Other, $83,784, 10%
Investment, -$141,912, -18%
Trusts, $17,000,...
Corporate, $50,000, 6%
Donations, $108,961, 13%
Government Grants, $455,000, 53%
Government Grants
Donations
Corporate
Trusts
Investment
Other


2022 - HFA
Application of Funds
SURPLUS/(DEFICIT), ($314,134), -26%
DCMEF , $0 , 0%
Research, $20,000 , 2%
Education, $510 , 0%
Services and care, $390,959 , 33%
Fundraising, $27,905 , 2%
Property , $81,883 , 7%
Administration, $365,710 , 30%
Administration
Property
Fundraising
Services and care
Education
Research
DCMEF
SURPLUS/(DEFICIT)

Financial Report

HAEMOPHILIA FOUNDATION AUSTRALIA INCORPORATED
ABN 89 443 537 189
ANNUAL REPORT FOR THE YEAR ENDED 30 JUNE 2023

Your Council members submit the financial report of Haemophilia Foundation Australia Inc. for the financial year ended 30 June 2023.

Council Members

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

Haemophilia Foundation ACT	Claudio Damiani
Haemophilia Foundation NSW	Daniel Credazzi
Haemophilia Foundation QLD	Adam Lish
Haemophilia Foundation TAS	David Fagan
Haemophilia Foundation VIC	Dan Korn
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 $139,558 (2022: deficit $314,134).

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

President
Gavin Finkelstein

Treasurer
David Fagan

Date: 17 October 2023

HAEMOPHILIA FOUNDATION AUSTRALIA INCORPORATED
ABN 89 443 537 189
INCOME AND EXPENDITURE STATEMENT FOR THE YEAR ENDED 30 JUNE 2023

	Note	2023 $	2022 $
INCOME			
Government grants		397,636	455,000
Sponsorships, donations and bequests		256,983	175,961
All other revenue		159,902	72,149
Investment income		91,557	92,167
Unrealised gains/(losses)		167,955	**(234,079)**
Other income		14,317	11,635
TOTAL INCOME		**1,088,350**	**572,833**
EXPENSES			
Administration		371,716	365,710
Leasing of premises and office expenses		86,059	81,883
Fundraising		21,575	27,905
Services and care		448,854	390,959
Education		847	510
Research and other grants		19,741	20,000
TOTAL EXPENSES		**948,792**	**886,967**
(DEFICIT)/SURPLUS FOR THE YEAR		139,558	**(314,134)**
ACCUMULATED FUNDS BROUGHT FORWARD		**2,494,652**	**2,795,482**
TOTAL AVAILABLE FUNDS		**2,634,210**	**2,481,348**
TRANSFER (TO) / FROM RESERVE	**8**	**(1,116)**	13,304
ACCUMULATED FUNDS CARRIED FORWARD	**7**	**2,633,094**	**2,494,652**

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 2023

	Note	2023 $	2022 $
CURRENT ASSETS			
Cash and Cash Equivalents	2	490,554	520,537
Investments	3	2,704,313	2,472,730
Trade and Other Receivables		5,158	3,397
Other assets		-	50,000
Total Current Assets		**3,200,025**	**3,046,664**
NON CURRENT ASSETS			
Property, plant and equipment	4	14,514	22,915
Total Non-Current Assets		**14,514**	**22,915**
TOTAL ASSETS		**3,214,539**	**3,069,579**
CURRENT LIABILITIES			
Trade and Other Payables	5	29,364	27,992
Short-term Provisions	6	301,443	298,365
Total Current Liabilities		**330,807**	**326,357**
NON CURRENT LIABILITIES			
Long-term Provisions	6	3,224	2,272
Total Non-Current Liabilities		**3,224**	**2,272**
TOTAL LIABILITIES		**334,031**	**328,629**
NET ASSETS		**2,880,508**	**2,740,950**
FOUNDATION'S FUNDS			
Accumulated funds	7	2,633,094	2,494,652
Reserve	8	247,414	246,298
TOTAL FOUNDATION'S FUNDS		**2,880,508**	**2,740,950**

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

HAEMOPHILIA FOUNDATION AUSTRALIA INCORPORATED

ABN 89 443 537 189

STATEMENT OF CHANGES IN EQUITY FOR THE YEAR ENDED 30 JUNE 2023

	Note	Reserves Retained $	Retained Earnings $	Total $
Balance at 30 June 2021		259,602	2,795,482	**3,055,084**
Profit (Loss) attributable to members of the company	8	-	**(314,134)**	**(314,134)**
Transfer (to) / from reserve		**(13,304)**	13,304	-
Balance at 30 June 2022		**246,298**	**2,494,652**	**2,740,950**
Profit (Loss) attributable to members of the company	8	-	139,558	139,558
Transfer (to) / from reserve		1,116	**(1,116)**	-
Balance at 30 June 2023		**247,414**	**2,633,094**	**2,880,508**

The above statement of changes in equity 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 2023

	Note	2023 $	2022 $
CASH FLOWS FROM OPERATING ACTIVITIES			
Investment income received		32,280	16,782
Grants received		397,636	455,000
Proceeds from sale of investments		-	-
Purchase of investments		-	-
Receipts from constituents		431,202	259,745
Payments to suppliers and employees		**(884,630)**	**(899,345)**
Net cash flows from operating activities		**(23,512)**	**(167,818)**
CASH FLOWS FROM INVESTING ACTIVITIES			
Acquisition and disposal of property, plant and equipment		**(2,120)**	-
Net cash flows used in investing activities		**(2,120)**	**-**
NET INCREASE CASH HELD		**(25,632)**	**(167,818)**
CASH BALANCE BROUGHT FORWARD		**1,019,769**	**1,187,587**
CASH BALANCE CARRIED FORWARD		**994,137**	**1,019,769**
Cash balance carried forward comprises: -			
Cash and cash equivalents	2	490,554	520,537
Short term deposits	3	503,583	499,232
		994,137	**1,019,769**
Reconciliation of surplus for the year to the net cash flows from operating activities : -			
Total operating surplus for the year		139,558	**(314,134)**
Depreciation and amortisation		10,521	12,205
Changes in assets and liabilities			
Increase/(Decrease) in creditors and provisions		5,402	24,552
(Increase)/Decrease in receivables and other assets		48,239	**(49,135)**
(Increase)/Decrease in investment assets		**(227,232)**	158,694
Net cash flows from operating activities	9	**(23,512)**	**(167,818)**

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 2023

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

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

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

The depreciable amount of all property, plant and equipment 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 twelve months or less.

(f) Revenue and Other Income

When the entity receives grants, donations or bequests, it assesses whether there is an enforceable contract which has sufficiently specific performance obligations in accordance with AASB 15. Where the contract is not enforceable or does not have sufficiently specific performance obligations, the Entity:

- recognises the asset in accordance with the recognition requirements of other applicable accounting standards (AASB 9 etc.)
- recognises related amounts such as revenue, leases, provisions, contracts etc;
- recognises income immediately in profit or loss as the difference between the initial carrying amount of the asset and the related amount."

If a contract liability is recognised as a related amount above, the Association recognises income in profit or loss when or as it satisfies its obligations under the contract.

Revenue from donations is measured at the fair value of the consideration received and is recognised upon the receipt of cash or of control of an asset other than cash. Interest revenue is recognised as it accrues using the effective interest rate method, which for floating rate financial assets is the rate inherent in the instrument.

(g) 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.

(h) Financial Instruments

Financial assets and financial liabilities are recognised when the association becomes a party to the contractual provisions to the instrument. For financial assets, this is equivalent to the date the association commits itself to either purchase or sell the asset. Financial instruments are initially measured at fair value plus transaction costs except where the instrument is classified 'at fair value through profit or loss' in which case the transaction costs are expensed to the profit and loss immediately.

(i) Comparative Figures

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

(j) New Accounting Standards and Interpretations

The entity has adopted all new accounting pronouncements which have become effective this year. None of these standards have had a material impact on the financial statements of the entity.

The AASB has issued a number of new and amended Accounting Standards and Interpretations which are mandatorily applicable for future reporting periods. The Members have decided not to early adopt any of the new and amended pronouncements. The Members have assessed the effect these new and amended pronouncements will have on the Association and have determined that none will materially impact the Association's financial statements."

(k) Critical Accounting Estimates and Judgements

The Members evaluate estimates and judgements incorporated into the financial statements based on historical knowledge and best available current information. Estimates assume a reasonable expectation of future events and are based on current trends and economic data, obtained both externally and within the Association.

Key estimates

(l) Impairment – general

The Association assesses impairment at the end of each reporting period by evaluating the conditions and events specific to the Association that may be indicative of impairment triggers. Recoverable amounts of relevant assets are reassessed using value-in-use calculations which incorporate various key assumptions.

	2023 $	2022 $
NOTE 2: CASH AND CASH EQUIVALENTS		
Cash at bank	**490,554**	**520,537**
NOTE 3: INVESTMENTS		
Short term deposits	503,583	499,232
Investment securities, at fair value	2,200,730	1,973,498
	2,704,313	**2,472,730**
NOTE 4: PROPERTY, PLANT AND EQUIPMENT		
Furniture and office equipment - at cost	270,242	268,122
Accumulated depreciation	**(255,728)**	**(245,207)**
	14,514	**22,915**

HAEMOPHILIA FOUNDATION AUSTRALIA INCORPORATED
ABN 89 443 537 189
NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 30 JUNE 2023 (cont...)

NOTE 5: TRADE AND OTHER PAYABLES	**2023**	**2022**
	$	**$**
Trade creditors and accruals	29,364	27,992
	29,364	**27,992**

NOTE 6: PROVISIONS		
Current		
- Annual leave	180,197	174,749
- Long Service leave	121,246	123,616
	301,443	**298,365**
Non-Current		
- Long Service leave	3,224	2,272
	3,224	**2,272**

NOTE 7: ACCUMULATED FUNDS		
Accumulated funds are set aside for the following purposes: -		
- research	2,615,816	2,378,550
- discretionary projects and reserves	17,278	116,102
	2,633,094	**2,494,652**

NOTE 8: RESERVE		
Damon Courtenay Reserve		
- balance at beginning of year	246,298	259,602
- special appeals and interest income	11,766	**(13,304)**
- sponsorships, allocations and costs	**(10,650)**	-
	1,116	**(13,304)**
- balance at end of year	**247,414**	**246,298**

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: CASH FLOW INFORMATION

Reconciliation of Cash Flow from Operating Activities with Net Profit from Ordinary Activities after Income Tax

Net Profit / (Loss) after Income Tax	139,558	**(314,134)**
Non-Cash Flows in Net Profit:		
Depreciation	10,521	12,205
Changes in Assets and Liabilities:		
Increase/(Decrease) in creditors and provisions	5,402	24,552
(Increase)/Decrease in receivables and other assets	48,239	**(49,135)**
(Increase)/Decrease in investment assets	**(227,232)**	158,694
Cash Flow Provided by Operating Activities	**(23,512)**	**(167,818)**

NOTE 10: ECONOMIC DEPENDENCE

The Association is dependent upon the ongoing receipt of grants from the Federal Department of Health, to ensure the continuance of its programs.

NOTE 11: CONTINGENT LIABILITIES AND COMMITMENTS

As at 30 June 2023, the entity had no contingent liabilities or commitments (2022: None).

NOTE 12: EVENTS AFTER THE REPORTING PERIOD

No matters or circumstances have arisen since the end of the financial year which significantly affected or may significantly affect the operations of the Association.

NOTE 13: KEY MANAGEMENT PERSONNEL DISCLOSURES

The members of the Committee are the Key Management Personnel of the entity.
No compensation was made to the officers or other members of key management personnel of the incorporated association during the year.

NOTE 14: RELATED PARTY TRANSACTIONS

Transactions with related parties
No material amounts were paid to or received from related parties during the year.

Receivable from and payable to related parties
There were no trade receivables from or trade payables to related parties at the current and previous reporting date.

Loans to/from related parties
There were no loans to or from related parties at 30 June 2023.

NOTE 15: ENTITY DETAILS

Haemophilia Foundation Australia Incorporated is domiciled in Australia.
The registered office is 7 Dene Ave, Malvern East VIC 3145.

HAEMOPHILIA FOUNDATION AUSTRALIA INCORPORATED
ABN 89 443 537 189

RESPONSIBLE PERSONS DECLARATION

We, Gavin Finkelstein and David Fagan, being the Responsible Persons of the Council of Haemophilia Foundation Australia Inc, declare that in our opinion :-

the financial statements and notes satisfy the requirements of the Australian Charities and Not-for-profits Commission Act 2012, and give a true and fair view of the financial position of the registered entity as at 30 June 2023 and of its performance for the year ended on that date; and

there are reasonable grounds to believe that the registered entity is able to pay all of its debts, as and when they become due and payable.

Signed in accordance with subsection 60.15(2) of the Australian Charities and Not-for-profit Commission Regulation 2013.

President

Gavin Finkelstein

Treasurer

David Fagan

Date: 17 October 2023

YOUR FUTURE
OUR BUSINESS

MVA Bennett

HAEMOPHILIA FOUNDATION AUSTRALIA INC
(ABN 89 443 537 189)

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

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 2023, 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 2023 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 *Australian Charities and Not-for-profits Commission 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 *Australian Charities and Not-for-profits Commission 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 *Australian Charities and Not-for-profits Commission 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.

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.

MVA Bennett

MVA BENNETT
Chartered Accountants.
Level 5, North Tower,
485 La Trobe Street
Melbourne Vic 3000

SHAUN EVANS
Partner

Dated: 18 October 2023

YOUR FUTURE
OUR BUSINESS

MVA Bennett

HAEMOPHILIA FOUNDATION AUSTRALIA INC
(ABN 89 443 537 189)

AUDITOR'S INDEPENDENCE DECLARATION SECTION 60-40 OF THE AUSTRALIAN CHARITIES AND NOT-FOR-PROFITS COMMISSION ACT 2012

I declare that, to the best of my knowledge and belief, during the year ended 30 June 2023 there have been no contraventions of:

(i) the auditor independence requirements as set out in the *Australian Charities and Not-for-profits Commission Act 2012* in relation to the audit; and

(ii) any applicable code of professional conduct in relation to the audit.

MVA Bennett

MVA BENNETT
Chartered Accountants.
Level 5, North Tower,
485 La Trobe Street
Melbourne Vic 3000

SHAUN EVANS
Partner

Dated: 17 October 2023

MVA Bennett Assurance Pty Ltd
incorporating JTP Assurance
ABN 13 488 640 554

Liability limited by a scheme approved under Professionals Standards Legislation

Melbourne
Level 5 North Tower
485 La Trobe Street
Melbourne, Vic 3000
T. +61 9642 8000
E. info@mvabennett.com.au

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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.

Individual Donors over $150

Ross Barker
Jennifer Barry
Paul Bedbrook
C Benham
Neal Blewett
Margaret Brown
Dr M G Brooke
Frederick Chaney
Janet Clohessy
Ron Coleman
J H Cooper
Barbara Douglas
John Eastment
Michael Edgeloe
Ramy Elmandrawy
Sean Evershed
Dr Geoff B Feben
Bruce Fielding
Esther Finkelstein
Rob Fitzherbert
Libby Gilchrist
John Griffith
Mark Haran
Pam Harrison
Paul Irvine
David John
BD Kelly
Rajvee Khakhar
Vanita Khakhar
Dr AC King
T Kirby
Leonie & David Koadlow
Malcolm Laing
J B Lancaster
Ron & Jenny Lees
Kevin Lindgren
Vicki Macdermid
D Malouf
Katrina Mcdowall
Brenton Taylor & Donna McFadyen-Taylor
Gilbert Micallef
Michael Rohan Nicholls
Steven Ovington
Patricia Pak-Poy
Hilary Penfold
Cheryl Piantedosi
Jian Wei Qiao
Rosemary Richards
Donald Richardson
Jennifer Ross AO
Swan Family Foundation
Ashley & Jenny Seeto
Alison May Smith
Jennifer Talbot
Trang Tat
Kaylene Taylor
Dawn Thorp AO
Vasil Tulevski

Service Clubs over $250

Lions Club of Adamstown Inc
Rotary Club of Armidale Central
Lions Club of Battunga Country
The Lions Club of Burleigh Heads
Lions Club of Eildon
Lions Club of Gilbert Valley
Lions Club of Gympie
Lions Club of Huntly Epsom
Lions Club of Laidley
Lions Club of Lara
Lions Club of Lismore Inc
Lions Club of Merbein
Lions Club of Moree
The Lions Club of Nambucca Heads
Rotary Club of Northern Yorke Peninsula
Lions Club of Oak Flats
Lions Club of Port Augusta Inc.
Lions Club of Portland
Lions Club of Tailem Bend Inc
Lions Club of Tallygaroopna
Lions Club of Torquay Inc.
The Lions Club of Whyalla Mount Laura
Lions Club of Wynyard
St Luke's Anglican Parish of Mosman Park

Corporate Donations over $200
J J Richards & Sons Pty Ltd
Bridgestar

Bleeding Disorders Awareness Month
Bendigo Bank BDAM Activities
Alex & Darren Coleman

Bequests
Estate of Graeme Alan Krieg

Independent Special Events
Adam Buckle 50th Birthday
Performance Personal Training World Haemophilia Day fundraiser
Heather Lauder 70th Birthday
Entertainment Books
Dexus Flower Auction

In Memory Donations
In Memory of Bill Atkinson
In Memory of Simon McMenamin
In Memory of Mario Martini
In Memory of Gerry Poulton
In Memory of Brett Williams

Trust and Foundations
The William Angliss VIC Charitable Fund
The Greatorex Fund

Corporate Grants & Sponsorship

Haemophilia Foundation Australia seeks grants and sponsorship for disease awareness activities, education projects and other special projects from charities and companies, including some pharmaceutical companies where there is a shared objective to improve the lives of people with bleeding disorders. All corporate grants and sponsorship arrangements must be compliant with Australian government regulatory requirements and HFA policy and subject to agreements which set out the terms, conditions and obligations of each party. HFA does not endorse any pharmaceutical product or treatment.

Education Grants & Sponsorship

Sanofi Education and Advocacy Grant	$50,000
BioMarin Pharmaceutical Government relations project	$33,000
Pfizer Australia Educational Grant	$20,000
Roche Educational Grant	$22,000
CSL Behring Educational Grant	$33,000

Sponsorship of 21st Australian Conference on haemophilia, VWD & rare bleeding disorders to be held in August 2023

Part sponsorship funds received during current year

BioMarin Pharmaceutical	$16,500
Novo Nordisk	$30,000
Pfizer	$30,000
Roche	$4,000
Sanofi	$40,000

Funding received from the Australian Government

Haemophilia Foundation Australia acknowledges grants received under the Australian Government Health Peak & Advisory Bodies Program and the Department of Health for Supporting Access to Blood and Blood Products

HAEMOPHILIA FOUNDATION AUSTRALIA

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

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

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