



ANNUAL REPORT



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HAEMOPHILIA FOUNDATION AUSTRALIA

21 | 22



Since 1979, Haemophilia Foundation Australia has been working 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 **6,600** people diagnosed with haemophilia, von Willebrand disease (VWD) or other related inherited bleeding disorders.

- Haemophilia/Carry the gene = **3,034**
- VWD = **2,324**
- Rare clotting factor deficiencies/other bleeding disorders = **1,201**

(Australian Bleeding Disorders Registry Report 2020)

What have we achieved in 2021-2022?

Education resources

- **420** print copies distributed ▼27%
- **38,920** PDF downloads ▲3%
- **67,092** information web pages viewed ▼20%
- **6,532** copies of National Haemophilia posted to members

National Haemophilia

- **24,680** online views
- **7792** downloads
- **837** HFA members received regular e-news ▲14%
- **98** Factored In members received regular Youth e-news

haemophilia.org.au

- **154,668** views of HFA web pages ▲12%
- **130,494** website visits
- Highest use is **25-34** age group

factoredin.org.au

- **12,526** website visits ▲14%
- **15,065** page views
- Highest use in **18-24** age group

Social Media

- **3.4K** fans on Facebook ▲15%
- **785** followers on Twitter ▲8%
- **759** followers on Instagram ▲18%
- **52** followers on new LinkedIn page

Representation and advocacy

- Made **5** formal submissions
- Made **6** submissions to government or regulatory bodies
- Participated in **51** advisory body meetings or discussions
- Held **19** rounds of community consultation
- Held **105** 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

International Work

- Participated in international meetings and webinars hosted by the World Federation of Hemophilia (WFH) including World Congress in May 2022.
- Gavin Finkelstein, HFA President served on the WFH Congress Multidisciplinary Program Committee for the 2022 World Congress
- WFH Twinning partnership with Myanmar continued

HFA National Conference

- **265** virtual delegates
- **12** sessions over 2 days
- **823** live views of conference sessions
- **270** post-conference on-demand views

Awareness

- **54** promotional packs sent to individuals, schools childcare and workplaces
- **464** total engagement on across all social media channels during the week
- Bleeding Disorders Awareness Week focussed on awareness and engaged with over **3380** people on Facebook alone
- **44** landmarks in Australia lit up red for World Haemophilia Day

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 to Consumer Affairs Victoria and the Australian Charities and Not for Profits Commission (ACNC).

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 Kim Beazley AC , 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 9 September 2021, 28 October 2021 (including the Annual General Meeting), 9 December 2021, 17 March 2022 and 16 June 2022. 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 Queensland

Adam Lish

Haemophilia Foundation New South Wales

Daniel Credazzi

Haemophilia Foundation Tasmania

David Fagan

Haemophilia Foundation Victoria

Leonie Demos

Haemophilia Foundation Western Australia

Gavin Finkelstein

South Australia

Paul Bonner, Observer

Office Bearers



Gavin Finkelstein - President,

Daniel Credazzi - Vice President,

David Fagan - Treasurer

I-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 from April 2022)

Poppy Sparsi, Administration Manager (Part-time)



Sharon Caris



Natashia Coco



Suzanne O'Callaghan



Poppy Sparsi

President's Report - Gavin Finkelstein



I am pleased to provide my annual report to Council.

HFA has operated in difficult circumstances again this year, as we entered the third year of pandemic conditions. The uncertain times meant we could not confidently plan ahead for face-to-face events, and most of our meetings and gatherings were held virtually, instead. This was not ideal, and we look forward to returning to full and open services. Nevertheless, I am pleased we remained connected with the community and focused on our purpose and mission.

We continued our digital communications work that was aimed at improving the experience of our community members when visiting our websites and communicating with us. We can now provide more timely and creative information and education messages to different parts of our community; and in the way they have told us they prefer to receive information. We have shared many more personal stories and experiences of people in our community. We are grateful to those who so readily share their experiences for the benefit of others who like to hear about and learn from the lived experiences of people like them. Our website is also well used beyond the bleeding disorders community, as it is recognised as a site for high quality evidenced-based education resources by students and others. We are proud of our status as an approved information partner of HealthDirect Australia.

Our digital communications work is never complete; we need to be agile to adapt to new technologies and meet community expectations. Although we make decisions based on sound technical professional advice, the technologies become outdated or obsolete quickly and despite a plan for continuous improvement, we face budget challenges trying to keep up. This work presents a significant and ongoing cost burden for HFA, but our website remains a priority as it our primary communication tool for our connection with our community.

A key part of our work is to provide advice from the viewpoint of people living with a bleeding disorder to governments and other stakeholders. We do this through formal submissions to government inquiries and our regular discussions with governments and blood sector stakeholders about community needs and issues. This year has been no exception, and we have actively participated in reviews and developments in the health and social sector.

We are excited about the new and emerging treatments in phase 3 clinical trials and over the next year we will focus on access and funding. Firstly, we want to ensure everyone in our community has the information they need to make informed decisions about the most suitable treatment for their condition. We will also make sure that government decision makers understand the benefit of the new therapies, including gene therapy for haemophilia, so they are funded and available without delay after they are registered for use in Australia.

HFA will ensure that the day-to-day needs of people living with bleeding disorders are considered and that improved health and quality of life outcomes are at the front and centre of the decision making. The experiences and health outcomes of those who have treated with extended half-life clotting factor therapy, and more recently, non-factor products such as Hemlibra and those who

have used clinical trial treatments or gene therapy will be critical to inform our advocacy. We will also make sure opportunities to improve treatment and care for people living with von Willebrand disease and other rare clotting factor deficiencies are adopted and that models of care and treatment meet their needs.

As we close the year's business, we are negotiating a further grant with the Department of Health and I note that HFA will be in a very difficult financial position without further grants as our peak body grant finishes next year and our grant that enabled HFA to contribute to blood sector policy finished at the end of this current year. Our government grant discussions were interrupted by the conventions and requirements of the Federal election in May, but we are optimistic that our discussions and proposals for future work will be successful once the new government is settled.

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.

REPRESENTATION AND ADVOCACY

A changing world

Much has changed for the bleeding disorders community over the last 12 months. New haemophilia treatments have become available in Australia and have been life-changing for many people in our community. At the same time, the COVID-19 epidemic has continued to impact, opening up opportunities with healthcare and communication in the virtual space, while at the same time imposing restrictions and burdens on individuals and healthcare providers.

The HFA vision is for active, independent and fulfilling lives for people in our bleeding disorders community. Our community is diverse. We represent people with a range of bleeding disorders and of all ages, with varying needs.

What are the needs of our community? How are they changing? To achieve our vision, we need to consult with our diverse community and understand their challenges and aspirations for today and into the future.

Representing our community also involves advocating for improvements and efficiencies into the future. Our experiences with government processes for assessing new treatments along with the personal stories about impact from our community members mean we have much to contribute to discussions about treatment and care. This is particularly important to current government consultation for the National Medicines Review and the review of Health Technology Assessment. As other new therapies for haemophilia and other bleeding disorders come to market, including gene therapy, we will draw on these resources to support our advocacy for access.

Ensuring the patient voice is heard encompasses the entire patient journey. In bleeding disorders, which are genetic and inherited, this can mean screening for the risk of bleeding disorders in future generations as well as living with a bleeding disorder and its complications over a lifetime. The impact on partners and families also needs to be a key consideration.

Best practice treatment and care

New treatment products

Access and equity have been the theme for discussions around innovative new therapies for haemophilia. Clinical trial reports and the observations and reports of people who have participated in some of these trials are moving at a rapid pace globally and our community is excited about the possibilities for better health outcomes and improved quality of life in Australia.

We finished the 2021 Australian Conference looking forward to some of the new treatments already available and others around the corner. The HFA Treatment Policy had been affirmed as we learned how important it is that our community continues to have access to a range of treatment products, including the older treatments that are effective and necessary for some people in our community. We will continue to advocate in support of the national framework established under the National Blood Agreement that means all Australian governments, federal and state/territory, share the cost of our treatments and that these are managed and supplied at no cost to patients by the National Blood Authority. We do not take this system for granted as we know how many of our global bleeding disorders friends do not have the surety of supply and ongoing treatment. As new therapies for bleeding disorders, including gene therapy for haemophilia, come to market we will be advocating to our governments for timely access.

We have actively engaged in discussions with patients, clinicians, companies involved in the development of these new treatments, and with governments to understand the barriers and opportunities to encourage manufacturers to bring their innovative therapies to Australia.

HFA contributed the voice of our community to the inquiry which led to *The New Frontier - Delivering better health for all Australians* report published by the Commonwealth of Australia in November 2021. The House of Representatives Standing Committee on Health, Aged Care and Sport had been required to investigate the approval processes for new drugs and novel medical technologies in Australia, with a particular focus on those for the treatment of rare diseases and conditions where there is high and unmet clinical need.

HFA was pleased to see the recommendations about reviewing the health technology assessment processes in Australia, and for the blood sector, and its recommendations to improve alignment between the national blood arrangements and the Health Technology Assessment system. HFA is strongly committed to the national framework that underpins the national blood arrangements and will play its part in this so everyone in our community around Australia has timely access to innovative treatments.



The **Australian Bleeding Disorders Registry (ABDR)** is not only a database of people with bleeding disorders in Australia, but a system used by HTC's nationally for the clinical management of their patients. It is a valuable tool for understanding the characteristics of bleeding disorders and the impacts of clinical interventions such as treatments.

ABDR data provides important evidence for understanding the impact of bleeding disorders. For example, it has been used to explain gender differences in haemophilia severity for recent HFA education resources – and also to highlight the need for more females to connect with an HTC and register with the ABDR. With its capacity to record and report very specific data on treatments and patient outcomes, the ABDR will be crucial to the evaluation of new and emerging therapies for bleeding disorders.

The ABDR system is a key element of the national treatment and health care framework for managing bleeding disorders. The ABDR enables HTC's to document and monitor treatments, bleeding episodes, complications such as haemarthropathy and other outcomes with their patients and to manage carefully the supply, delivery and usage of these highly specialised treatments. People with bleeding disorders and parents/caregivers record their data on home therapy, bleeds and treatment stock via the MyABDR app. MyABDR links directly to the ABDR and is a central communication tool between Haemophilia Treatment Centres (HTC's) and their patients.

The ABDR and MyABDR have a vital role to play in personalised treatment and other treatment innovations. Used in conjunction with pharmacokinetic analysis, they enable clinicians and their patients to collaborate on developing and monitoring an individualised treatment plan, based on the outcomes of the treatment for clotting factor levels and bleeding episodes.

Regular recording with MyABDR is key. MyABDR is a collaboration between HFA, the Australian Haemophilia Centre Directors' Organisation (AHCDO) and the National Blood Authority (NBA) on behalf of Australian governments to support best practice clinical care and treatment of people with bleeding disorders. HFA works with AHCDO and the NBA to promote the system, encouraging people with bleeding disorders to use it to record their treatments and bleeds. AHCDO has reported that treatment recording with MyABDR and adherence to treatment has improved over the last three years. It is also important for monitoring the outcomes of new therapies and was a requirement for access to extended half-life products and emicizumab (Hemlibra®), funded through the National Blood Agreement.

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 is based on the same database software, and who have been exploring enhancements and innovations.

Genetic testing

Technology for genetic testing is evolving rapidly and as a result, there are many questions about the implications for bleeding disorders such as haemophilia, which are genetic and inherited. There are many complexities: testing may indicate a health condition in the parent as well as a child as well as the potential for inheritance and impact on reproductive choices. 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.

To help our community make informed choices, our suite of education resources about haemophilia testing in women and girls is addressing these issues with the advice of genetics and legal experts. There has also been considerable input from affected women and parents as well as Haemophilia Treatment Centres, drawn from both their expert knowledge and experiences. As well as drawing on the latest research and guidelines for females, the resources look at the ethical debate around whether or not to undertake genetic testing in a girl and the issues around disclosure in insurance and employment.

Alongside this work, we have been contributing to the national consultation about reproductive carrier screening. This has involved discussions with genetic testing providers and a submission to government outlining some of the special issues raised in bleeding disorders. Genetic testing technology is likely to develop further. We will continue to monitor the developments and seek policy advice from AHCDO to determine how best to respond.

Getting Older



We continue to address the recommendations in our 2020 **Getting older report**. The report described the needs of a new generation of people with bleeding disorders living into their senior years for the first time. It also provided evidence of those with bleeding disorders who are experiencing 'early ageing'. Many relatively young people with bleeding disorders live with complications that usually come with growing older, including joint and muscle damage, arthritis, pain and mobility problems.

One of the key concerns was about managing to infuse treatments with increasing frailty. Since emicizumab (Hemlibra®), which is injected subcutaneously, has become available for prophylaxis, we have heard many reports from older people with haemophilia A of its great benefits for them, both in reducing bleeds and easier administration.

We are aware that this therapy is not suitable for everyone and will be following up other subcutaneous non-factor therapies as they come to market.

The 2021 Australian Conference provided a valuable forum for community members and HTC multidisciplinary teams to work through the issues and challenges ahead with growing older. Community members had the opportunity to ask international expert Prof Mike Makris about research into new areas, such as bleeding-related arthropathy in people with mild haemophilia and VWD. HTCs are facing the challenge of learning about the issues as their patients present with them. They highlighted the importance of a multidisciplinary approach, educating GPs and other health care providers about preventing bleeding and careful personalised treatment plans; working with aged care homes; connecting patients to local services and advocacy as they grow frailer; collaborating with community physiotherapists.

Transport was also raised by many in the *Getting Older Report*. Opportunities to attend some appointments at the HTC via telehealth under COVID were welcomed and demonstrated that a hybrid system of in-person and telehealth appointments could be helpful.

We continue to develop education materials and links to relevant information on the HFA website Getting Older Hub in collaboration with our community Focus Group and HTC experts. However, resourcing comprehensive care in HTCs to manage the complex issues and challenges ahead will be crucial for achieving better health outcomes as well as developing an efficient system of care.

Ensuring that older people with bleeding disorders can access the support and services they need remains a priority. With a lifetime of disability, pain and mobility problems and in some cases complications such as bloodborne viruses, many are on low incomes. With early ageing, this can be an issue for younger people with bleeding disorders as well. Support to explore government financial safety net options and schemes such as the National Disability Insurance Scheme will assist some older people, but it will also be crucial for HFA to work with the community and other stakeholders to identify and manage service, support and financial gaps.

Hepatitis C and HIV

Many people with bleeding disorders acquired hepatitis C and some also HIV through blood products for their treatment before 1993. Hepatitis C and HIV continue to have a substantial impact on the bleeding disorders community.

Community needs were investigated in the *Getting Older Report*, with recommendations on how to address the range of ongoing clinical, mental health and other psychosocial and financial issues.

HFA Council established a Hepatitis C Sub-Committee to work through priority recommendations. As a first step we requested data from the ABDR to better understand the number affected, treated and cured and current liver health. This was to assist with reaching those who have not yet been tested and treated, particularly those with mild conditions who may not be aware they were at risk of infection and the needs around ongoing liver disease, including cirrhosis and liver cancer. After a considerable review of the data, they advised that the hep C data was too incomplete to be useful to us. We are aware that clinical information on hepatitis C may be contained in other hospital medical records rather than the ABDR or at other health services altogether and may not be shared with the HTC. The AHCDO hepatitis C project report confirmed high treatment and cure rates but could not

provide other meaningful information due to insufficient data. We are exploring other ways to understand the HCV and liver health status of people with bleeding disorders affected by hep C. We also continue to work on strategies to educate people who may have been exposed to hepatitis C many years ago but have not been tested or those who have not had access to newer Direct Acting Antiviral hepatitis C treatments.

We have been working with gastroenterology and hepatitis clinical organisations to clarify current clinical practice and the specific issues for people with bleeding disorders. We are grateful for their assistance in developing health promotion messages targeted at our community.

Our consultation for World Hepatitis Day and World AIDS Day activities in 2021 underlined that support through recognition means a great deal to community members. Their experiences are not forgotten and acknowledgement is a fundamental aspect of Foundation peer support activities as well as in our communications.

A voice in research

To achieve our vision of active, independent and fulfilling lives for people in our bleeding disorders community it is critical to ensure they have a voice in their treatment and care. Developing a knowledge base around the patient experience, treatment outcomes and what quality of life means to them is a priority both for HFA and others in Australia and nationally. This involves reliable evidence of their preferences and experiences to contribute to health technology assessment and other evaluation processes for new and emerging therapies and policy development. HFA encourages our community to participate in relevant high-quality research projects. We highlight research study opportunities on the HFA website and through social media and e-news and our community takes a strong interest in this.



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

PROBE is a validated international study which collects high quality evidence on patient experiences of haemophilia, treatment and quality of life, from the patient perspective. The PROBE questionnaire measures health-related quality of life using specific haemophilia-related questions (the PROBE score) and the internationally recognised EQ-5D-5L utility index and EuroQoL visual analog scale (EQ-VAS) of global health.

HFA joined the international PROBE Study in 2014. We contributed to validation for the Australian environment and then conducted the first real-world study with the Australian community with data from 337 Australian participants in 2020. This 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 provides unique information about the quality of life impact of various current treatments and will be a valuable tool for comparing outcomes with new and emerging treatments. The PROBE Study itself continues to evolve and some innovations, including mobile app and longitudinal versions, are currently being trialled internationally. Over the last year we have

consulted with the international study group to consider which of these innovations to integrate into the 2023 round of data collection for the Australian Study.

Von Willebrand disease (VWD)

Von Willebrand disease (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. The World Federation of Hemophilia (WFH) established the VWD Global Call to Action asking its member organisations to take action to create awareness, resources and provide support to improve the lives of those living with VWD. HFA joined WFH in this endeavour in 2018 and represents the Western Pacific Region in the WFH VWD Global Group.

To understand the needs of our community members with VWD, HFA consults regularly with our VWD consumer focus group about information and education needs and community engagement. We are mindful of highlighting VWD information and personal stories in awareness campaigns such as Bleeding Disorders Awareness Week, in social media and in our education materials and events, such as the 2021 Australian Conference. Our VWD booklet is consistently our most popular resource, with 11,496 downloads in 2021-22.

As part of the Call to Action, HFA has made specific commitment to support the development of national VWD clinical guidelines. The international (ASH/ISTH/NHF/WFH) Guidelines on the Diagnosis and Management of VWD were published in 2021. Dr Nathan Connell and Dr Simon McRae, members of the international panel for the VWD guidelines, discussed the new guidelines and their implications VWD for management in Australia at the 2021 Australian Conference. We look forward to working with AHCDO and other health professional groups on the community education and health services outcomes that will result from the new guidelines.

COVID-19

The COVID-19 pandemic has continued to impact on our community and the health services who provide their care. Although working from home, HFA staff have remained connected with our community, taking advantage of our robust digital infrastructure to conduct business as usual as much as possible.

We have supported the COVID-19 vaccine rollout, updating the FAQs on our website to answer common community questions in collaboration with AHCDO and promoting COVID-19 advice provided by HealthDirect. Our FAQs have been a valuable resource for vaccine appointments. As the vaccine rollout gained momentum in states such as Queensland and WA, we have continued to be contacted by less well-connected members of our community with their concerns about COVID-19. This has been an opportunity to reconnect them with their local Haemophilia Treatment Centre.

Over the last year our Haemophilia Treatment Centre staff have remained stretched, dealing with COVID-19 duties in their hospitals or on national committees. We are very grateful for the extra work done they have done in extraordinary circumstances to be available to help their patients and to support our work to communicate with the community.

Representation and communication

A vital aspect of representing our community is communicating well with them. Our digital communications project concentrates on strategies and infrastructure to optimise how we engage with people with bleeding disorders in Australia. We have been working with digital communications experts to analyse and improve engagement with the community on our various communications platforms and to refine all aspects of our communications.

COMMUNICATING WITH THE COMMUNITY

EDUCATION AND INFORMATION

Education resources snapshot – in 2021-22

HFA education materials about bleeding disorders

420 print copies distributed

38,920 PDF downloads

67,092 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.

COVID-19 vaccine FAQs



With the COVID-19 vaccine national rollout continuing during 2021, there were many questions about how to administer the vaccine safely to people with bleeding disorders.

The **HFA COVID-19 vaccine FAQs** were a collaboration with the Australian Haemophilia Centre Directors' Organisation to answer common questions, both from the community and health professionals such as general practitioners. In October 2021 we updated the FAQs, taking into account the new vaccines available and advice from Haemophilia Treatment Centres on common new questions about managing intramuscular injections. We also consulted Treatment Centre patients about their experiences and how best to promote the FAQs.

The **HFA COVID-19 vaccine FAQs** were a collaboration with the Australian Haemophilia Centre Directors' Organisation

The FAQs have been very popular. In 2021-22, there were:

9412 page views

367 PDF downloads

During 2021 COVID-19 and lockdowns had an ongoing impact on our community. It was important to make sure other areas of health were not neglected and we continued to develop and promote our digital education resources to ensure the community had access to information if they were not visiting their Treatment Centre physically.

Getting Older Info Hub



The Getting Older Hub is a recent development on the HFA website, established in June 2020 as the '*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.

Navigating services was a major focus over the last year, with new information on:

- Financial planning and management
- Navigating aged care and disability services
- Travelling under COVID-19.

Personal stories are an important way for community members to connect and Perry's video about living with VWD was a welcome addition for our community with von Willebrand disease.

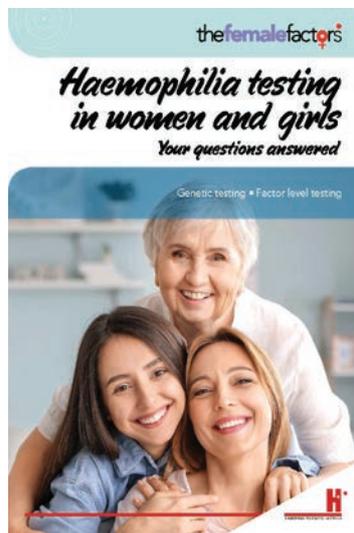
In late 2021 HFA evaluated the Hub with a community survey. It was received very positively, but some commented that it needed a more upbeat look and feel, including images of younger people, some more 'light-hearted' topics and encouraging people to visit the site regularly and contribute their own stories.

'Easy to access and to navigate around the site. It has real people talking about their conditions.'

'It is a collated area with lots of important relevant information for aging haemophiliacs. Instead of trying to find all of the information myself, it is presented there with no digging required.'

This was valuable feedback. We have commenced the work to take a more life-affirming approach with the help of the Hub focus group and we expect to relaunch it in July 2022. 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 2022 we published **Haemophilia testing in women and girls: your questions answered**. This is a comprehensive guide, answering questions about 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 the ins and outs of disclosure to employers and for insurance. The way haemophilia is diagnosed in females has changed recently and the resource includes the new diagnostic categories.

It is a complex area and we worked closely with our women and expert reviewers to make the information more accessible, with infographics, tables and personal stories.

We are currently working on a shorter and simpler version for younger women and parents.

'Congratulations, this is a great result - wonderful.'

'This is a great resource.'



Female Factors survey 2021



In late 2021 we conducted a community survey to evaluate two recent education resources for young women – **Female Factors** and **Sport and exercise for girls and young women with bleeding disorders**.

63% thought they were **very** or **extremely useful**

75% thought the **design and layout** was **very good** or **excellent**

What did they do with them?

50% had **passed these resources on to others** – health professionals, family/friends, colleagues 'to educate them'.

What did we learn?

- We need shorter and longer versions for our diverse readership.
- We need to promote the resources more. While 96% had seen *Female Factors*, only 35% had seen the more recent resource *Sport and exercise for young women*.

'I think the information was great. Not sure if needed improving at this point.'

'Age appropriate, not condescending.'

'We should be proud of these resources and use them as much as possible.'

COMMUNICATIONS

HFA communications snapshot - in 2021-22

6,532 copies of National Haemophilia posted to members

More than **32,470** online views or downloads of *National Haemophilia*

837 HFA members received regular e-news

haemophilia.org.au

- **154,668** views of HFA web pages
- **130,494** website visits
- Highest use is **25-34** age group

factoredin.org.au

- **12,526** website visits
- **15,065** page views
- Highest use in **18-24** age group

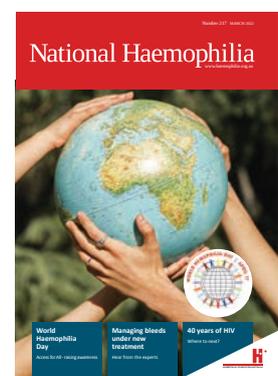
Social Media

- **3.4K** fans on Facebook
- **785** followers on Twitter
- **759** followers on Instagram
- **52** followers on new LinkedIn page

National Haemophilia, HFA's quarterly journal, is the trusted source of the very latest high-quality information and news about bleeding disorders, for both community and health professionals. Australian bleeding disorder experts contribute topical educational articles in plain language and these are complemented by personal stories from people with bleeding disorders. We recognise that our readership has diverse preferences, so it is 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 robust print readership.

The most popular articles from the last year were:

- Understanding disability and aged care services
- A young woman's story of growing up with VWD
- Exercise and resistance training
- News from South Australia was also highly sought after.



In September 2021 we launched the modernised digital and print versions of National Haemophilia. This involved:

- a more contemporary design
- online features to enhance reading on mobile devices, searching articles by topic or keyword, and downloading designed PDFs of individual articles as fact sheets.

With each article available as a web page and a PDF, back issues can be searched with search engines such as Google and are very popular – for example, a 2018 article on looking after your veins had 3,711 pageviews.

Digital Communications Project

HFA continues with our Digital Communications Project. After working with a digital agency we employed a contractor to continue working with us on this project.

www.haemophilia.org.au.



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.

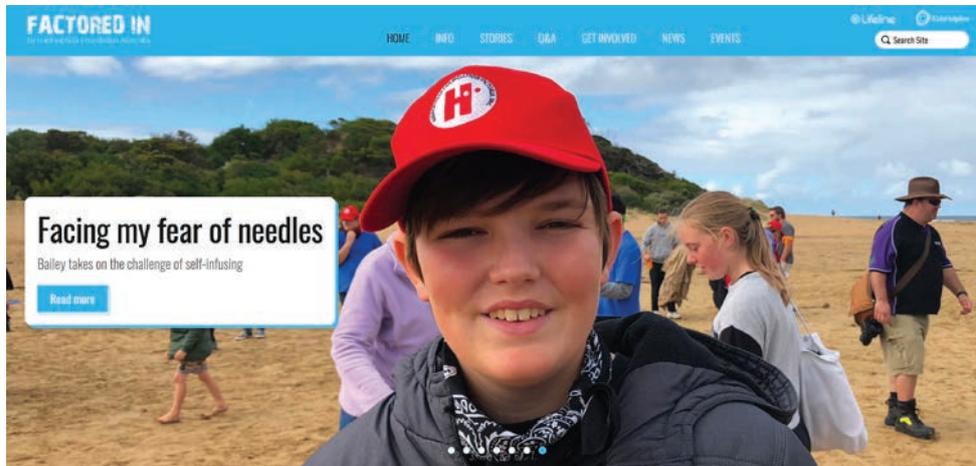
Our site is constantly updated with news updates, high quality information and all publications are available for downloads. The site is the most valued and access source of current evidence based information in Australia. HFA is an accredited information partner with HealthDirect, which provides a national 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.

Our website in 2021-2022

- Has a very high ranking in google searches
- Average of **70** returning visitors per month
- Average of **5582** new visitors per month
- In total we had **154,668** views of HFA web pages
- Our highest users are **25-34** age group
- What is most popular? Information on haemophilia and von Willebrand Disease, COVID19 vaccine FAQ's and articles in **National Haemophilia**

www.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.

Our Factored In website in 2021-2022

- **12,526** website visits
- **15,065** page views
- Our highest users is **18-24** age group
- Over half of our users for Factored In are on a device of some sort – smartphone/mobile or Ipad/Tablet.
- What is most popular? Q & A: What is the difference between haemophilia A and B? What are the differences between child services and adult services? Big bouncy vein problems? And Personal Stories.

Thank you to our young people for sharing their personal stories:

- Getting Stronger: Gavin talks about growing up with haemophilia and what he has learned about developing his strength and resilience.
- Getting the message out: Adam has severe haemophilia A. He explains why he is involved in raising awareness at his school and in his local community.
- Growing up with VWD: Simoni tells her personal story of growing up with the challenges of type 3 (severe) VWD.
- Growing up with haemophilia: Dale grew up with haemophilia A, but he never let it stop him from doing anything.
- How changing treatments has changed Scott's world: Scott shares how changes to his haemophilia treatment have made it possible for him to do more
- Facing my fear of needles: Bailey explains how he dealt with the challenge of infusing his treatment when he had a fear of needles.

Social media

Our diverse community is active on a variety of social media platforms and our presence on Facebook, Instagram, Twitter, You Tube 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 2021-2022

- Continued high quality posts that are eye catching and consistent.
- Consistent in Social Media Posts over the time period. Total 758 Posts over all channels. Most posts on Facebook
- Added feature on Instagram to allow for easier click on links.
- On average all channels increased by 4% fans/followers (ex new LinkedIn page)
- Most engagement posts:
 - VWD and Shauna sharing her personal experience
 - World Haemophilia Day

We continued to run social media campaigns for key dates which have high engagement rates:

- World Haemophilia Day, 17 April 2022
- World Hepatitis Day, 28 July 2021
- International Women's Day, 2 March 2022
- Men's Health Week, 13-19 June 2022
- Bleeding Disorder Awareness Week, 10-16 October 2021

Snapshot

- **3.4K** fans on Facebook
- **785** followers on Twitter
- **759** followers on Instagram
- **52** followers on new LinkedIn page

AWARENESS

Bleeding Disorders Awareness Week 2021

During the week of **10-16 October 2021** we celebrated Bleeding Disorders Awareness Week. The week is an opportunity for the community, Haemophilia Foundations, Haemophilia Treatment Centres, stakeholders and schools to take part in a campaign and activities to raise awareness about haemophilia, von Willebrand disease and related inherited bleeding disorders throughout Australia.

We had many fun activities for all ages, such as the colouring in competition, an online quiz, word find and a virtual Red Classic. It was also great to see some face to face events back and running and Red Cake Day's.

Red Classic

Our national virtual Red Classic event saw people participate in all different ways - ride, scoot, walk even horse riding! Thanks to our participants for some great photos.



Freddie leading his family and grandma riding her horse



Sam and Rocky walking the Red Classic



Steph and family trekking the Red Classic

Red Cake Day



Our Red Cake Day cupcake packs were very popular.

At Jaylin's childcare the cupcake packs were a special highlight, where they baked and ate as a group.

Thank you to everyone who participated in Bleeding Disorders Awareness Week.

Bleeding Disorders Awareness Week in pictures



John Hunter Children's Hospital

Haemophilia Treatment Centre, The Alfred





Bleeding Disorders AWARENESS WEEK

10-16 OCTOBER 2021

WHAT IS A BLEEDING DISORDER?

Haemophilia

- A rare genetic bleeding disorder where the blood doesn't clot properly.
- Caused by an alteration in the gene making clotting factor VIII (8) or IX (9).
- Usually inherited, but 1/3 of people have no previous family history.
- A lifelong condition and can be life-threatening without treatment.
- Treatment can help prevent repeated bleeding into muscles and joints, which causes arthritis and joint problems.
- Most people diagnosed with haemophilia are male.
- Women and men can have the genetic alteration causing haemophilia and pass it on to their children.
- Some females who carry the gene also have bleeding problems; some have haemophilia.

How common?

- In Australia there are more than 6,500 people diagnosed with haemophilia, von Willebrand disease or other related inherited bleeding disorders.

Von Willebrand disease (VWD)

- An inherited bleeding disorder.
- Occurs when people do not have enough of a protein called von Willebrand factor in their blood or it does not work properly.
- Most people with VWD have mild symptoms but some people have a more severe form. With all forms of VWD there can be bleeding problems and some people bleed quite often.
- Many people are not aware they have the disorder and are currently undiagnosed.
- Both men and women can have VWD and pass it on to their children.

Other Bleeding Disorders

- Other bleeding disorders include rare clotting factor deficiencies and inherited platelet disorders.
- Factor XI deficiency is the most common of the rare bleeding disorders, estimated at 1 in 100,000 people, and is the third most common bleeding disorder to affect women after von Willebrand disease and haemophilia.

1800 807 173
www.haemophilia.org.au





Remy's daycare class had yummy cupcakes

Global VWD Call to Action



Our bleeding disorders community is diverse and HFA has joined the World Federation of Hemophilia Global VWD Call to Action in the global commitment to create awareness, resources and provide support to improve the lives of those living with von Willebrand disease (VWD) and other rare bleeding disorders. Bleeding Disorders Awareness Week in 2021 and Rare Disease Day in 2022 were great opportunities to put this into action. We highlighted the personal stories of community members with VWD and factor X deficiency on our websites and promoted them on our social media platforms. This is an important way for our affected community members to feel connected as well as recognised.

World Hepatitis Day is marked globally on 28 July. In 2021 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 specifically targeted at the bleeding disorders community.

New, simple and effective treatments offer the potential of a cure for nearly all.

Many Australians with bleeding disorders and hepatitis C have now had treatment and been cured, but others may not be aware that they have hepatitis C. For example, men and women with mild bleeding disorders may rarely visit a Haemophilia Treatment Centre and may not have understood their hepatitis C risk or been tested. Our campaign aimed to reach the family and friends of men and women with mild bleeding disorders to pass the message on. There was also an important message for people with bleeding disorders with liver cirrhosis resulting from their hepatitis C - even if they are cured, they remain at risk of liver cancer and need to have ongoing liver health monitoring.

We are grateful to Gavin Finkelstein, HFA President, and 'Mary-Anne' for sharing their personal stories about finding out they had hep C, treatment and cure. These stories were published on our website and in *National Haemophilia* and shared widely across social media networks.



While most have been cured, it is also important to our community for our campaign to acknowledge the small number of people who have not been able to have successful treatment and those who live with advanced liver disease.

World AIDS Day 2021

In 2021 it was 40 years since the first official report of HIV. The World AIDS Day campaign marked the anniversary with the theme **40 years of HIV - where to next?** This is a deeply significant question for the bleeding disorders community. 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 anniversary was a time for thoughtful and poignant reflections on this question. Community members with haemophilia and HIV shared a picture of where they find themselves today and what World AIDS Day means to them. Jenny Ross AO, former HFA Executive Director, and Dr John Rowell, former Director of the Queensland Haemophilia Centre, described the early days of HIV with the tragic loss of life, and then the moments of optimism, with ground-breaking new HIV treatments becoming available in 1996 and advances in haemophilia treatment generally.

HIV remains an important part of our community's history. It drew on its resilience and led to a resolve to respond as a community, taking on advocacy around safer treatment and support, a commitment that is ongoing. The responses of our community members remind us how vital it is to create a supportive, non-judgemental and stigma-free environment for our community members affected by HIV.

We marked 1 December 2021 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. In the March 2022 National Haemophilia we published a special feature reflecting on the World AIDS Day theme - on the history of HIV in the Australian bleeding disorders community and thoughts on how to address it now and in the future.

WORLD HAEMOPHILIA DAY



World Haemophilia Day is celebrated worldwide on 17 April to raise awareness about haemophilia, von Willebrand disease and other inherited bleeding disorders. Light It Up Red is a way of raising awareness about bleeding disorders by lighting up local landmarks red on World Haemophilia Day and sharing photos with the wider community through communication channels such as social media.

The theme was **Access for All** - an important reminder that around 75% of people living with haemophilia worldwide have not yet been diagnosed, let alone have access to treatment and care.

Community stories

"The more people that raise awareness, the more it helps get the message out." - Adam's story.

Why is **Access for All** important to the Australian bleeding disorders community? How can we support the cause of sustainable and equitable access to care and treatment globally? Personal stories are a valuable way of making this real for the wider community.

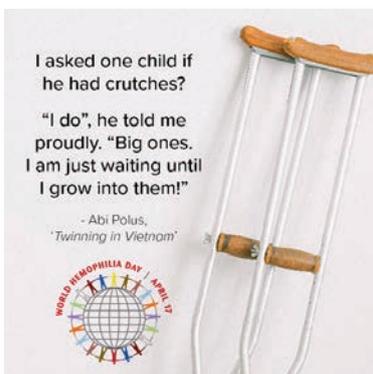
In Australia people with bleeding disorders, mothers, siblings and haemophilia physiotherapists shared their experiences and highlighted the difference access for all can make.



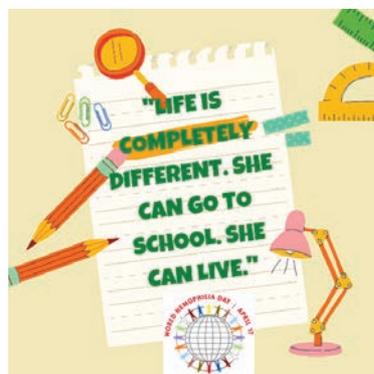
Kanga Adam's story
<https://tinyurl.com/FI-Adam> roo Point, QLD



Angelina's story
<https://tinyurl.com/FI-siblingbros>



Twinning stories
<https://tinyurl.com/Twinning-WHD>



Leah's story
<https://tinyurl.com/Leah-treatment>

Lighting it up Red around Australia

HFA also participated in Light it Up Red with landmarks going red to raise awareness about bleeding disorders.

Thanks everyone for your support and celebrating such a significant day in the community.

ACT



The Rocks for Sick Kids initiative sees thousands of rocks being hand-painted by Michelle each year and donated to children's hospital wards and outpatient clinics around Australia. She discovered that the endless hours spent in Emergency Departments, hospital wards and outpatient clinics pass more quickly when she is mindfully painting a bit of joy onto a rock.



Royal Australian Mint



The Shine Dome, Australian Academy of Science

NSW



The Kidz Factor Zone, The Children's Hospital at Westmead, Sydney

QLD



Townsville



Victoria Bridge, Brisbane

NATIONAL CONFERENCE



The 20th Australian Conference on Haemophilia, VWD and Rare Bleeding Disorders was held 8-9 October 2021. The virtual event was a great success, with over 30 speakers contributing to a range of stimulating and informative sessions. The Conference was available to watch on-demand post conference.

EMBRACING A CHANGING WORLD

We have seen substantial change in both the bleeding disorders community and throughout the world since our last conference. COVID-19 and advances in treatment and care have had an impact on everybody. This year's conference took a special focus on these changes, with our theme, Embracing a changing world.

With topics across a range of areas and current issues, the 2021 Conference catered to everyone in our community. Sessions were presented by local and international expert health professionals, as well as by community member leaders. Sessions also included personal stories from people with bleeding disorders, giving a vibrant picture of real-life experience and the impact of these changes.

Conference Reflections

A FOUNDATION PERSPECTIVE

Haemophilia Foundation Australia President Gavin Finkelstein spoke with HFA about the Conference and its impact from his perspective.

What were your overall impressions of the Conference?

The Conference was a great job in difficult circumstances. It was very important to keep the continuity of conferences taking place, even during the COVID-19 epidemic, when we couldn't meet in person.

There is a lot that is happening in the haemophilia space, with the new treatments, and there also needs to be an increased awareness of the issues for women with bleeding disorders. Everything is changing very rapidly and people in the bleeding disorders community are hungry for the latest information. It was great to have information that is practical and delivered in a way that is very accessible.

What stood out for you?

The whole paradigm of accessing information has changed and we need to make use of the platforms available to us. A lot of us prefer to meet face-to-face for a conference, but when we can't, this digital space can still be very dynamic and bring information to people. The short personal stories were invaluable, and they impact on a lot of people because they sit and watch them and think about what it means for themselves.

What was your take-home message?

We just don't know what's going to happen in the future, so it's important to be flexible and go with the flow.

THE HTC PERSPECTIVE

Haemophilia health professionals reflected on their experience at the conference.

The last few years in have been challenging for many in the world, virtual conferences and zoom meetings have become the norm rather than the face-to-face meetings and conferences we had been familiar with. Some of the positives of these virtual forums are less/no travel time, being able to watch at suitable times, re-watch sessions and the ability to watch concurrent streams; negatives would be lack of in person networking and opportunities for discussion around the issues presented.

'The HFA conference embraced the changes that have become our healthcare reality in recent times and made the conference even more accessible with most sessions viewable on demand after the event.'

Sue Webzell, Haemophilia Clinical Nurse Specialist, Hollywood Private Hospital

The 20th Australian Conference on Haemophilia, VWD and Rare Bleeding Disorders 2021 was an interactive, informative conference to attend virtually. Even though we could not see in each other in person, the event was thought-provoking and provided great insight into haemophilia, VWD and rare bleeding disorders.

'Some sessions in particular resonated with me, providing further understanding and prompts on what patients, families and health professionals can do to improve the care of people with bleeding disorders.'

Jaime Chase, Haematology Clinical Nurse Specialist, John Hunter Children's Hospital

WHAT DID THE DELEGATES SAY?

'Overall I can't commend HFA enough for the efforts taken in organizing the conference and making it accessible through the wild circumstances we find ourselves in this year.'

'This conference has provided me with a much greater understanding of living with a bleeding disorder as well as appreciate even more the connectedness this community has with everyone involved.'

'The conference has made me reconsider the way that I approach exercise and active living.'

'Increased knowledge but missed the F2F connections.'

'I would have loved face to face from a very selfish point of view, but I appreciate the opportunity that this has given to participants who usually can't travel easily. I think it also facilitated more questions being asked, for example in the sex, sexuality and intimacy session that I think people would have shyed away from.'

'One of the best conferences I have attended. Great variety from all different angles. Thank you!'

INTERNATIONAL AND LOCAL DEVELOPMENT

World Federation of Hemophilia (WFH)

General Assembly

During the year HFA attended several meetings that were conducted virtually by WFH – this included the General Assembly of the World Federation held on 7 May 2022. This meeting is the governance meeting held each year by WFH to report on WFH performance and programs. Gavin Finkelstein, HFA President attended the meeting virtually, and our alternate delegate was Shauna Adams who had been able to attend the Congress in person.

WFH World Congress

WFH held a hybrid Congress 8 -11 May which enabled delegates to attend virtually or in person in Montreal, Canada.

HFA was delighted that Shauna Adams from HFACT attended the Congress in person and the General Assembly that followed as the nominated alternate HFA voting delegate. Shauna had been awarded a Youth Fellowship by WFH to attend the Congress which was to have been held in Kuala Lumpur, Malaysia in 2020, before it was postponed due to the COVID-19 pandemic. Shauna had also been able to carry over a 2020 HFA Go For It Grant made to cover part Congress attendance costs to enable her attendance in Montreal.

HFA was also pleased to take up the opportunity to sponsor several additional delegates to the conference which was only financially possible because they could attend virtually. HFA (virtual) representation included:

- 2 HFA staff
- 9 physiotherapists
- 1 social worker
- 9 nurses

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. HFA makes a distribution approximately every 18 months when sufficient bank interest on the funds has accrued.

Although a funding round did not occur in the current financial year, a call was made for applications to be received by 30 August 2022. Applications will be considered for a range of projects, services and/or care, or an activity aimed at improving the physical and emotional wellbeing and independence of recipient/s such as:

- Training, education and coaching
- Career development
- Personal development
- Conferences and workshops
- Medical appliances and equipment to help people live more independently
- Workshops and peer support activities.

Haemophilia Foundation Research Fund

The Foundation's Haemophilia Foundation Research Fund is made up of income from the donations, fundraising events and bequests received by HFA specifically for research over many years, and a significant bequest of \$1,430,481 from the estate of Maxine Ewart in 2016. This reserve now holds \$2,378,550.

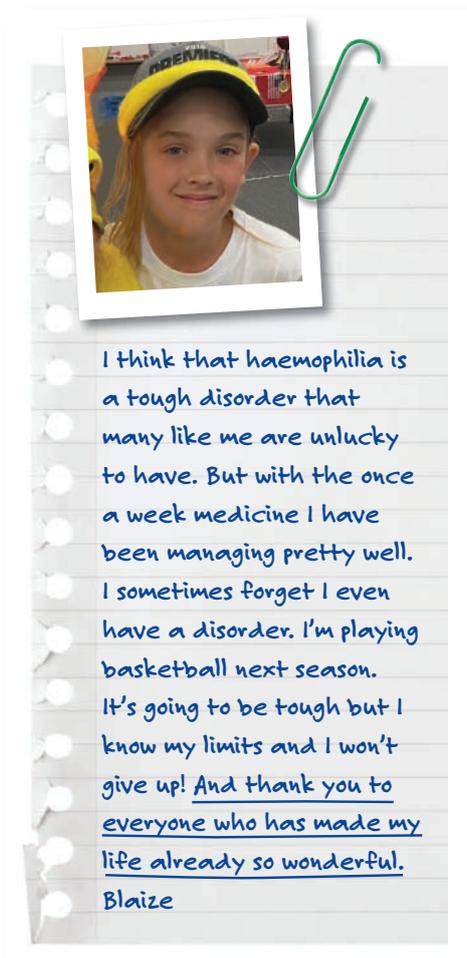
In August 2021, the fund granted \$20,000 to Dr David Rabbolini from the Department of Haematology, University of Sydney for his project Platelet Function Testing using 96-well plate-based aggregometry (OPTIMUL) in Patients with Undiagnosed Bleeding Disorders.

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 continued to support us during the pandemic. Their generosity helps us to continue to provide many of services to assist and support the needs of our members at every age and stage.

Appeals



Direct mail appeals to donors are sent during the year and we thank each individual 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 The William Angliss VIC Charitable Fund this financial year. We also thank the understanding from some of our Trusts that allowed us to carry over grants as we were unable to run the project due to the pandemic.

Treasurer's Report, David Fagan



This year I am reporting a very different result from those of recent years when HFA had strong investment returns and relatively balanced books. Although our financial results have fluctuated in the last 3 years, those strong returns on our investments had allowed for the additional spending needed on critical HFA activities such as the membership and donor database, acquisition, and advocacy for new treatments.

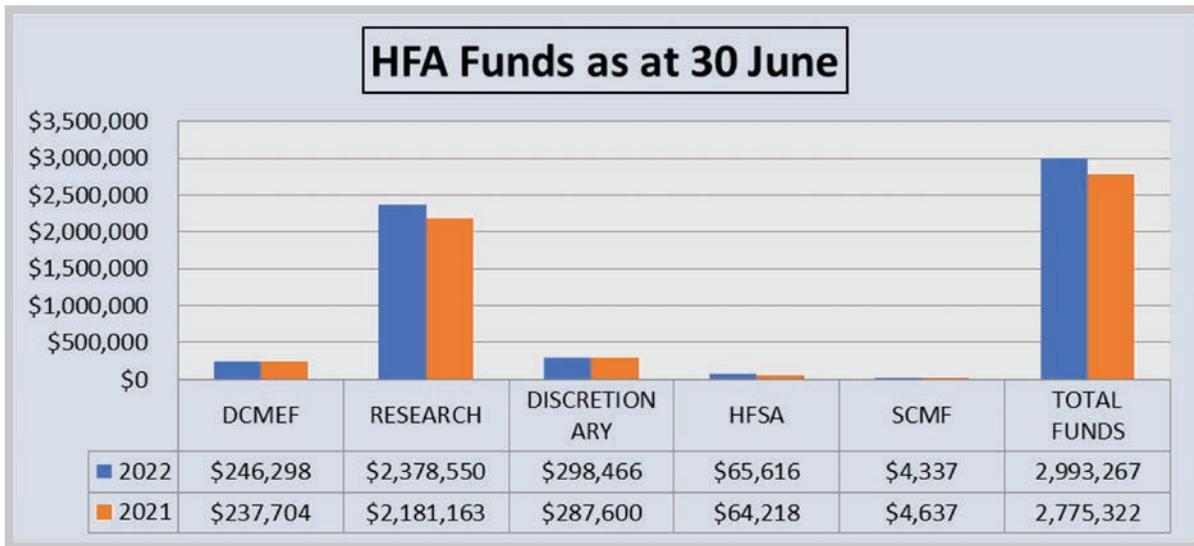
This year however, I am reporting a very different position and I will explain our financial reports in a stepwise manner to reflect our operating income and expenses and the outcomes from our investments for the year.

Government grant income of \$455,000 was consistent with the previous year and reflects the two funding Agreements HFA had in place with the Commonwealth government to run the HFA secretariat, provide blood sector policy advice and develop and distribute education on bleeding disorders. However, sponsorship, donations and bequests declined by 22% from \$226,531 in the previous year to \$175,961. As it was a conference year, and most conference income is received in the year before the conference, we experienced the expected two yearly, "conference effect" of a 21% reduction with conference income reducing from \$92,000 in the previous year to \$72,000. Last year we had also received over \$200,000 from the Victorian and Commonwealth governments by way of pandemic support payments, which was not available to us in this current period of reporting. Each of these contributed to the significant 29% reduction in this year's operating income of \$714,745 compared to \$1,002,948 in the year before.

HFA funds are held under the categories of Haemophilia Foundation Research Fund, Damon Courtenay Memorial Endowment Fund and the remainder as discretionary reserves.

Our investments are held in shares and cash in Vanguard and Schroders investment products as well as term and cash deposits with banks in line with our financial plan.

We adopted a relatively conservative approach with our 2017 investment plan in the expectation that some years would be better than others. Investment income for these funds consists of the total interest, dividends and distributions received and the changes in the capital value of investments. In the years since we set up this plan of management the returns have been positive, however this year we have experienced negative returns due to market conditions just as other organisations, companies and superannuation funds have done, due to the global economic circumstances. Unfortunately, these market conditions have caused our investment income to decline significantly this year. Nevertheless, I assure Council that all investments have been maintained, none have been traded, and their value is higher than when they were first invested, but this year we see the impact of negative returns reflected as an unrealised loss in our accounts.



While the funds held for Research earned \$151,327 income last year, this year we received \$84,833, a reduction of 43%. Our smaller Damon Courtenay Fund had returned \$8,425 last year but there was a 16% reduction in earnings with \$7,111 received this year and the interest on our discretionary funds, which are mainly held in bank deposits, fell by 86% from \$1,538 to \$223. Overall, our income from interest, dividends and distributions reduced by 43% from \$161,290 to \$92,167.

Last year we reported a \$204,891 gain (unrealised) on the Vanguard investment and a \$13,472 gain on the Schroders investment, resulting in an overall unrealised gain of \$218,363. But this year the value of these investments has dropped and instead of a positive return we report an unrealised loss of \$213,664 on the Vanguard investment and \$20,415 on the value of the Schroders investment, a total loss of \$234,079 on investments for this year. Our total investment income is made up of \$92,167 of actual income received, and the unrealised loss of \$234,079 which results in an overall \$141,912 loss on investments compared to a \$379,653 gain in 2021.

Our total operating income of \$714,745 less the \$141,912 loss on investments for the year is \$572,833 compared to a total income of \$1,382,601 last year.

On the expense side we have done relatively well, and I congratulate our staff for working hard to keep our operational costs at a similar level of \$886,967 compared to \$886,438 in the previous year. They were not able to run face to face events and meetings but focused on the work they could do in line with our Objectives and ensured positive outcomes for our members. We were fortunate to be able to continue our efforts to strengthen our digital communications.

Much of our outputs are generated by our staff and absorbed in staff and office costs, and I will continue to work with HFA staff to seek savings, particularly in relation to our office expenses as the pandemic has changed the way we use our rented office space, and there may be opportunities from this.

Taking the above into account we have returned a \$314,134 loss this year compared to the surplus of \$496,163 last year.

Going forward we have some challenges. As I have indicated we have been impacted by the market conditions affecting our investments. Council will recall we sought independent financial advice after we received the Ewart Bequest for the Research fund, and for our existing discretionary funds. We were keen to attract better returns instead of our previous approach of simply holding relatively lower interest-bearing cash deposits with banks. We adopted the recommendations in 2017 and have continued to hold our investments in a portfolio of shares and cash. We will continue a watching brief and seek further advice when necessary. In the meantime, we can expect ups and downs, but look forward to strengthening returns. We have benefited from the earlier years of solid returns, with this being the first year we have reported a loss on our books. The material impact of this is that we have reduced our discretionary savings, acquired mainly through our share of the WFH Congress profit.

But we also have come to the end of a financial year with considerable uncertainty about our government grants. Our national peak body grant that partially funds the HFA secretariat is not available to us after 30 June 2023. Our other government grant which supports HFA's capacity to provide advice to the national blood sector and part costs of education and digital communications to the bleeding disorders community finished on 30 June and the timing of the Federal election in May slowed down funding negotiations with the Department of Health. We enter the financial year with this unresolved, but we remain optimistic this will be resolved when the new health ministry is settled.

Even with government grants, HFA is unable to generate sufficient discretionary income necessary for the costs of the education, advocacy and policy work required to represent the Australian bleeding disorders community it undertakes without using discretionary funds which have now diminished to low levels. Uncertainty around government grants and fluctuating sponsorship and donation levels places HFA in uncertain territory.

Looking forward, even if we can reduce or contain costs, and seek savings in some of our operational expenses such as by reviewing our office space requirements for example, we may face ongoing financial issues due to the ongoing uncertainty with government grants. We also face the potential loss of investment income if the economic climate continues to deteriorate. In the short term I do not recommend a change in our long-term investment approach, but we should continue to review this, and seek advice as necessary. However, I do believe it will be necessary to use some of our accrued investment income to support administration costs and discretionary spending which will of course, impact the bottom line in the future.

Financial Report

HAEMOPHILIA FOUNDATION AUSTRALIA INCORPORATED
ABN 89 443 537 189
ANNUAL REPORT FOR THE YEAR ENDED 30 JUNE 2022

Your Council members submit the financial report of Haemophilia Foundation Australia Inc. for the financial year ended 30 June 2022.

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	Leonie Demos
Haemophilia Foundation WA	Gavin Finkelstein

Principal Activities

The principal activities of Haemophilia Foundation Australia during the financial year are to support people with bleeding disorders and their families through representation, education and the promotion of research. No significant change in the nature of these activities occurred during the year.

Operating Result

The surplus for the financial year amounted to \$314,134 (2021: surplus \$496,163).

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



President

Gavin Finkelstein



Treasurer

David Fagan

Date: 17 October 2022

HAEMOPHILIA FOUNDATION AUSTRALIA INCORPORATED

ABN 89 443 537 189

INCOME AND EXPENDITURE STATEMENT FOR THE YEAR ENDED 30 JUNE 2022

	Note	2022 \$	2021 \$
INCOME			
Government grants		455,000	455,000
Sponsorships, donations and bequests		175,961	226,531
All other revenue		72,149	91,884
Investment income		92,167	161,290
Unrealised gains/(losses)		(234,079)	218,363
Other income		11,635	229,533
TOTAL INCOME		<u>572,833</u>	<u>1,382,601</u>
EXPENSES			
Administration		365,710	361,051
Leasing of premises and office expenses		81,883	84,394
Fundraising		27,905	42,206
Services and care		390,959	388,343
Education		510	444
Research and other grants		20,000	10,000
TOTAL EXPENSES		<u>886,967</u>	<u>886,438</u>
(DEFICIT)/SURPLUS FOR THE YEAR		(314,134)	496,163
ACCUMULATED FUNDS BROUGHT FORWARD		2,795,482	2,321,217
TOTAL AVAILABLE FUNDS		<u>2,481,348</u>	<u>2,817,380</u>
TRANSFER (TO) / FROM RESERVE	8	13,304	(21,898)
ACCUMULATED FUNDS CARRIED FORWARD	7	<u>2,494,652</u>	<u>2,795,482</u>

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 2022

	Note	2022 \$	2021 \$
CURRENT ASSETS			
Cash and Cash Equivalents	2	520,537	689,912
Investments	3	2,472,730	2,629,867
Trade and Other Receivables		3,397	4,262
Other assets		50,000	-
Total Current Assets		<u>3,046,664</u>	<u>3,324,041</u>
NON CURRENT ASSETS			
Property, plant and equipment	4	22,915	35,120
Total Non-Current Assets		<u>22,915</u>	<u>35,120</u>
TOTAL ASSETS		<u>3,069,579</u>	<u>3,359,161</u>
CURRENT LIABILITIES			
Trade and Other Payables	5	27,992	36,478
Short-term Provisions	6	298,365	266,355
Total Current Liabilities		<u>326,357</u>	<u>302,833</u>
NON CURRENT LIABILITIES			
Long-term Provisions	6	2,272	1,244
Total Non-Current Liabilities		<u>2,272</u>	<u>1,244</u>
TOTAL LIABILITIES		<u>328,629</u>	<u>304,077</u>
NET ASSETS		<u>2,740,950</u>	<u>3,055,084</u>
FOUNDATION'S FUNDS			
Accumulated funds	7	2,494,652	2,795,482
Reserve	8	246,298	259,602
TOTAL FOUNDATION'S FUNDS		<u>2,740,950</u>	<u>3,055,084</u>

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

HAEMOPHILIA FOUNDATION AUSTRALIA INCORPORATED
ABN 89 443 537 189
CASH FLOW STATEMENT FOR THE YEAR ENDED 30 JUNE 2022

	Note	2022	2021
		\$	\$
CASH FLOWS FROM OPERATING ACTIVITIES			
Investment income received		16,782	21,637
Grants received		455,000	455,000
Proceeds from sale of investments		-	-
Purchase of investments		-	-
Receipts from constituents		259,745	547,948
Payments to suppliers and employees		(899,345)	(835,992)
Net cash flows from operating activities		(167,818)	188,593
CASH FLOWS FROM INVESTING ACTIVITIES			
Acquisition and disposal of property, plant and equipment		-	(2,152)
Net cash flows used in investing activities		-	(2,152)
NET INCREASE CASH HELD		(167,818)	186,441
CASH BALANCE BROUGHT FORWARD		1,187,587	1,001,146
CASH BALANCE CARRIED FORWARD		1,019,769	1,187,587
Cash balance carried forward comprises: -			
Cash and cash equivalents	2	520,537	689,912
Short term deposits	3	499,232	497,675
		1,019,769	1,187,587
Reconciliation of surplus for the year to the net cash flows from operating activities: -			
Total operating surplus for the year		(314,134)	496,163
Depreciation and amortisation		12,205	12,936
Changes in assets and liabilities			
Increase/(Decrease) in creditors and provisions		24,552	37,794
(Increase)/Decrease in receivables and other assets		(49,135)	(284)
(Increase)/Decrease in investment assets		158,694	(358,016)
Net cash flows from operating activities		(167,818)	188,593

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 2022

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

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

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

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

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

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

HAEMOPHILIA FOUNDATION AUSTRALIA INCORPORATED

ABN 89 443 537 189

NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 30 JUNE 2022 (cont...)

(g) Leases

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

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

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

(h) Goods and Services Tax (GST)

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

(i) Investments

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

(j) Comparative Figures

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

	2022	2021
	\$	\$
NOTE 2: CASH AND CASH EQUIVALENTS		
Cash at bank	<u>520,537</u>	<u>689,912</u>
NOTE 3: INVESTMENTS		
Short term deposits	499,232	497,675
Investment securities, at fair value	1,973,498	2,132,192
	<u>2,472,730</u>	<u>2,629,867</u>
NOTE 4: PROPERTY, PLANT AND EQUIPMENT		
Furniture and office equipment - at cost	268,122	268,122
Accumulated depreciation	(245,207)	(233,002)
	<u>22,915</u>	<u>35,120</u>

HAEMOPHILIA FOUNDATION AUSTRALIA INCORPORATED

ABN 89 443 537 189

NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 30 JUNE 2022 (cont...)

NOTE 5: TRADE AND OTHER PAYABLES	2022	2021
	\$	\$
Trade creditors and accruals	27,992	36,478
	<u>27,992</u>	<u>36,478</u>

NOTE 6: PROVISIONS

Current

- Annual leave	174,749	159,546
- Long Service leave	123,616	106,809
	<u>298,365</u>	<u>266,355</u>

Non-Current

- Long Service leave	2,272	1,244
	<u>2,272</u>	<u>1,244</u>

NOTE 7: ACCUMULATED FUNDS

Accumulated funds are set aside for the following purposes: -

- research	2,378,550	2,527,381
- discretionary projects and reserves	116,102	268,101
	<u>2,494,652</u>	<u>2,795,482</u>

NOTE 8: RESERVE

Damon Courtenay Reserve

- balance at beginning of year	259,602	237,704
- special appeals and interest income	(13,304)	21,898
- sponsorships, allocations and costs	-	-
	<u>(13,304)</u>	<u>21,898</u>
- balance at end of year	<u>246,298</u>	<u>259,602</u>

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

HAEMOPHILIA FOUNDATION AUSTRALIA INCORPORATED

ABN 89 443 537 189

NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 30 JUNE 2022 (cont...)

NOTE 9: SUBSEQUENT EVENTS

No matter or circumstance has arisen since 30 June 2022 that has significantly affected, or may significantly affect the association's operations, the results of those operations, or the association's state of affairs in future financial years, other than as follows:

The effects of general global events including COVID-19, disrupt the association and the ability to continue the programs as planned. Whilst these disruptions have begun to ease, the impact on the Association future operations are difficult to predict, however, heightened levels of volatility are expected.

The Responsible Persons have concluded that this uncertainty will not affect the ability of the Association to continue as a going concern for the twelve months from the date of this report.

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.

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 2022 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 2022

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 2022 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 2022

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



SHAUN EVANS
Partner

Dated: 18 October 2022

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
Graham Bartlett
Dulcie Battaglène
Paul Bedbrook
C Benham
Neal Blewett
Dr M G Brooke
Margaret Brown
Diana Cerini
Frederick Chaney
Janet Clohessy
Ron Coleman
J H Cooper
Vicky Cullen
Herbert Domgjoni
Barbara Douglas
Elizabeth Dyer
John Eastment
Ross & Robyn Edwards
Wendy R Farley
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Mr Brenton Taylor & Mrs Donna
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Andrew Michael
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Hilary Penfold
Jennifer Ross AO
Timothy Ross
Steve Russell
Stephen & Denise Ryan
Alison May Smith
Jennifer Talbot
Trang Tat
Dawn Thorp AO
Michael & Alison Wilson

Service Clubs over \$250

Lions Club of Adamstown Inc
Lions Club of Armidale
Lions Club of Battunga Country
The Lions Club of Burleigh Heads
Lions Club of Corryong
The Lions Club of Cranbourne
Lions Club of Gin Gin
Lions Club of Gympie
Lions Club of Kiewa-Tangambalanga
Lions Club of Launceston Windmill Hill
Lions Club of Lismore Inc
Lions Club of Moree
The Lions Club of Nambucca Heads
Apex Club of Oberon
Lions Club of Perth Tasmania
Lions Club of Port Augusta Inc.
Lions Club of Tallygaroopna
The Lions Club of Taylors Lakes
The Lions Club of Torrens Valley
Lions Club of Torquay Inc.
Lions Club of Wynyard
Lions Club of Yankalilla & District

Corporate Donations over \$200

Big Rig Records
Bridgestar
Eastbeth Services Pty Ltd
J J Richards & Sons Pty Ltd

Trusts & Foundations

APS Foundation	\$2,000
The William Angliss VIC Charitable Fund	\$2,000
The Marian & EH Flack Trust	\$10,000

Bequests

Estate of Neil Henry Sturgess

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

CSL Behring Australia	\$22,000
Education Grant	
Pfizer Australia	\$20,000
Education Grant	

Funding received from the Australian Government

Haemophilia Foundation Australia is appreciative of grants received under the Australian Government Health Peak & Advisory Bodies Program and the Department of Health program to fund Supporting Access to Blood and Blood Products.



HAEMOPHILIA FOUNDATION AUSTRALIA

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

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