



HAEMOPHILIA FOUNDATION AUSTRALIA

# 2020-2021 ANNUAL REPORT





## Representing the Australian bleeding disorders community.

Inspiring excellence in treatment, care and support through advocacy and representation, raising community awareness, education and promotion of research.

### 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 **6,500** 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 2020-2021?

#### Education resources

- **575** print copies distributed
- More than **29,290** PDF downloads
- **83,599** web pages viewed
- **6,521** copies of *National Haemophilia* posted to members
- More than **35,040** online views or downloads of *National Haemophilia*
- **725** HFA members received regular e-news
- **172,032** views of HFA web pages

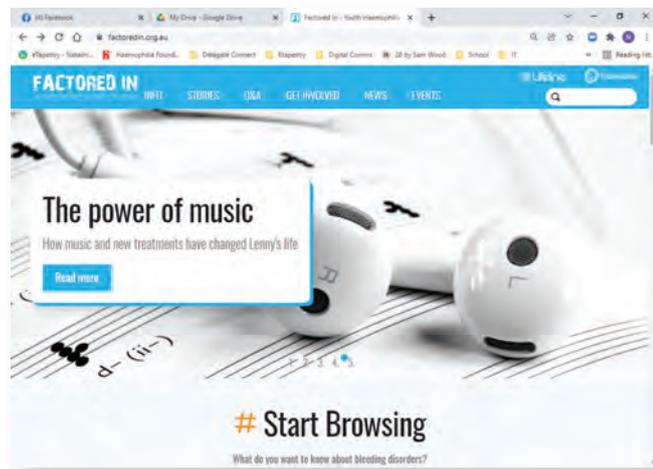
#### Social Media

- **2,960** HFA Facebook 'likes'
- **63%** of HFA Facebook 'likes' are aged **13-44** years
- **730** HFA followers on Twitter
- **645** followers on Instagram



### Factoredin.org.au

- **11,011** website visits
- **16,998** page views
- **53%** of users were female
- **7%** of users were male
- Highest use in **18-24** age group



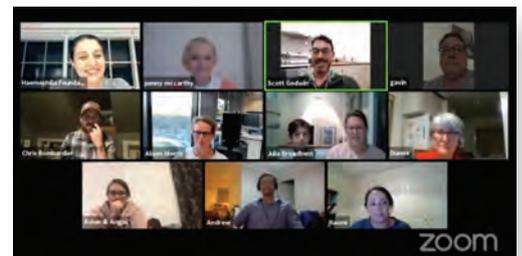
### www.haemophilia.org.au

- A very high ranking in Google searches
- What's the most popular? Our high-quality information about haemophilia and von Willebrand disease, followed by articles in National Haemophilia and our COVID-19 vaccine FAQs
- **54%** of visitors access it with mobile devices such as smartphones and ipads/tablets



### Representation and advocacy

- Consensus Statement, calling for a clear, transparent, end-to-end process to evaluate new therapies
- Made **2** formal submissions
- Made **10** submissions to government or regulatory bodies
- Participated in **27** advisory body meetings or discussions
- Held **31** rounds of community consultation
- Held **113** 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
- Gavin Finkelstein, HFA President is a member of the WFH Congress Multidisciplinary Program Committee for the 2022 World Congress

### Community Awareness

- Over **235** people viewed the online webinars
- **19%** of our facebook audience engaged in our post over the week in some way
- BDAW Campaign focussed on awareness and engaged with over **3200** people
- **22** landmarks 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.

#### ***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 Her Excellency the Honourable Kerry Sanderson, AO, Governor of Western Australia  
NEW SOUTH WALES Dr Kevin A Rickard, AM, RFD  
VICTORIA Dr Alison Street, AO  
TASMANIA Lady Green  
QUEENSLAND His Excellency The Honourable Mr Paul de Jersey, AC, Governor of Queensland

**President:** Gavin Finkelstein

**Executive Director:** Sharon Caris

## LIFE GOVERNORS

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

## HFA COUNCIL

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 18 July 2020, 24 October 2020 (including the Annual General Meeting) and 18 March 2021. All Delegates to the Council act in a voluntary capacity. Each member Foundation was represented at every meeting for the year.

### ***Haemophilia Foundation Australian Capital Territory***

Claudio Damiani

### ***Haemophilia Foundation New South Wales***

Daniel Credazzi

### ***Haemophilia Foundation Victoria***

Leonie Demos

### ***South Australia***

*Paul Bonner, Observers*

### ***Office Bearers***

**Gavin Finkelstein** - President,



**Daniel Credazzi** - Vice President,

**David Fagan** - Treasurer

*I-r David Fagan, Gavin Finkelstein, Daniel Credazzi*

### ***Haemophilia Foundation Queensland***

Adam Lish

### ***Haemophilia Foundation Tasmania***

David Fagan

### ***Haemophilia Foundation Western Australia***

Gavin Finkelstein

## **HFA STAFF**

**Sharon Caris**, Executive Director

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

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

**Poppy Sparsi**, Administration Manager, (Part-time)

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

**Jasmin Lai**, Administration Assistant (Part-time)



*Sharon Caris*



*Natashia Coco*



*Suzanne O'Callaghan*



*Poppy Sparsi*



# President's Report - Gavin Finkelstein



## *Covid 19*

I am pleased to present my 2021 report to Council. We are living and working in extraordinary times. Last year we might not have expected a further year of lockdowns and virtual meetings, but our office in Malvern East has remained closed for another year due to the COVID-19 pandemic, our staff have continued to work from their homes, and HFA has not conducted any face to face activities.

As a national organisation our work usually takes us all over Australia to meet with member foundations, community members, governments and other stakeholders. We have changed the way we do things and we can still be effective with the compromises of virtual communications platforms. We know the power of meeting face to face to share experiences and we look forward to hosting events and meetings, and to reach out to consult with our community and stakeholders as soon as we can. Nevertheless, we have also learned we can do some of our work more effectively using virtual methods and we can look forward to having a flexible approach in the future.

I wish to thank Council, State/Territory Foundations, our staff, each of our stakeholders, and most of all, our community members for bearing with us, and for their perseverance in such difficult circumstances for them and their families personally, and in their work. We know it has not been easy for many people in our community this year, most particularly for our frontline health workers. Many of our Haemophilia Treatment Centre staff have been reallocated to other work, while others have continued to run the services of their HTC via telehealth services and other novel ways of providing healthcare.

We are also mindful that many people in our global community have been significantly affected by the pandemic, with people with bleeding disorders or their loved ones becoming ill with COVID-19 to add to their burden of limited treatment, and we are grateful for the World Federation of Hemophilia efforts to provide support in underserved areas.

Our Twinning partnership with the Myanmar Haemophilia Patient Organisation has been interrupted by COVID-19 and political instability; however, we look forward to our future work together.

## **Treatment & Care for Bleeding Disorders**

A critical goal of our Strategic Plan is to ensure best practice treatment and care for people living with a bleeding disorder. After many years of little change, extended half-life clotting factors are more widely used and we look forward to non factor treatments for haemophilia, and gene therapy. We are hearing the outcomes of clinical trials and look forward to the benefits these new products will bring to improve quality of life and better health outcomes. We anticipate these products will bring us much closer to our vision for active, independent and fulfilling lives.

## **Advocacy**

Last year I reported on the Roundtable we had initiated to seek ways to overcome the delays to funding and access to new products. There has been an unacceptable lag between when products are registered by the Therapeutic Goods Administration as safe and effective and when these products are funded and made available to the people who need them. We developed a Consensus Statement that calls for a clear, transparent single end-to-end process that builds on the National Blood Agreement and takes into account the significant experience of our community in treating and managing haemophilia.

The recommendations from the Consensus Statement were used in advocacy with our stakeholders, including governments and informed HFA's submission to the House of Representatives Committee Inquiry into approval processes for new drugs and novel medical technologies in Australia 2 November 2020 and further discussion with the Committee at a hearing in Melbourne on 23 April 2021.

Our submission emphasised the importance of taking into account the value and benefits to the quality of life and new possibilities and opportunities of a new treatment from a patient's perspective when evaluating cost effectiveness. The patient stories were loud and clear – their health improved, and many had a greater chance of achieving their education, career and social goals. These patient focused outcomes should be a critical component to cost effectiveness evaluations as they complete the picture for government payers.

## **New therapies**

There had been limited access to Extended Half Life (EHL) factor VIII and factor IX until these products were included on the National Product List from 1 July 2020, even though the first of these was registered in Australia in 2014.

It was concerning that we entered the year with no resolution about public funding for emicizumab (Hemlibra®). This non clotting factor therapy was registered in 2018 to reduce or prevent bleeding in people with severe and moderate haemophilia A with and without inhibitors, and there was strong evidence that it improved health and quality of life. It is the first of several other non factor products which may reach the market. HFA had made submissions to the Medical Services Advisory Committee (MSAC) to support approval of emicizumab. We were approached by an increasing number of people who had personal experience with treatment with this product through a clinical trial or compassionate access who were worried it would not be available to them in the long term. HFA and our state/territory haemophilia member foundations used their compelling personal stories in advocacy for funding and we were delighted when the Federal Minister for Health, The Hon. Greg Hunt MP announced on 26 September 2020 that Hemlibra® would be publicly funded under the National Blood Agreement.

## **Ongoing advocacy**

We will continue to work with governments and other stakeholders to make sure our community has access to the treatments and care they need. There is no doubt we will need standard treatment products as well as novel therapies. HFA's job is not to prefer specific treatment products, but rather, our objective is to ensure public funding for a range of treatments that will enable patients and their clinicians to make an informed decision about the treatment of their bleeding disorder. This work first requires consulting with community members about their needs and we will continue to do this. HFA will always seek to advocate for treatment and care that offers the best treatment opportunities for everyone in our community.

We look forward to progressing our contribution to Australian clinical guidelines on von Willebrand disease following the publication of the international guidelines.



## **Getting Older**

We continued to explore the needs of the part of our community who is getting older. This work has included developing a tool for Haemophilia Treatment Centre Directors to work through, to identify their priorities from the Getting Older Reports recommendations. We will also work through these recommendations to identify where community members have fallen through the gaps, and do not receive the services and care they require.

A very important issue raised in the Getting Older Report relates to the ongoing needs of people affected by hepatitis C. The HFA Council has established a Hepatitis C Sub-Committee to help prioritise our priorities. We are also seeking data from the Australian Bleeding Disorders Registry to assist with this. In our education campaign for World Hepatitis Day we focused on post hep C treatment follow-up for those with cirrhosis and encouraging those with mild bleeding disorders who might have been at risk to get tested and treated if HCV PCR positive.

## **Education & Communications**

Our education and communications work has become much more integrated since we embarked on our digital communications project in 2019. Fortunately, this work was well underway and could be accelerated when our work changed due to the pandemic. We worked with a digital communications consultancy for most of this year and plan to recruit an inhouse digital communications specialist to progress this work next year. A significant element of this work involved reviewing and improving our digital infrastructure. This included enhancements at the back end of both the main HFA website [www.haemophilia.org.au](http://www.haemophilia.org.au) and the youth website [www.factoredin.org.au](http://www.factoredin.org.au) and changes to improve user experience and the way our information is provided.

We were pleased to complete several new videos throughout the year, highlighting the different experiences of people who live with a bleeding disorder. Some were webinars, while others were short videos about a range of life experiences and strategies community members used to manage their bleeding disorder. The videos are available on the HFA YouTube channel and on the HFA and Factored In websites.

## **Research**

This year we paid the second of two grant payments of \$10,000 to Dr Nicholas Hunt, ANZAC Research Institute, Concord General Repatriation Hospital for a project called “The transport of CRISPR via nanomedicine to the liver endothelium for the treatment of haemophilia A”. This study will investigate how gene therapy in mice can be performed by delivering new genes and a protein called CRISPR/Cas9 to the liver endothelium. This approach has been proposed as an alternative to other gene therapies which use viruses to deliver gene therapy but where haemophilia A patients may develop immunity to the virus that is used for the gene therapy.

## **Specialist Health Professionals**

We have been very aware that COVID-19 has impacted our specialist health professionals in Haemophilia Treatment Centres very much and we have provided support where we can.

It has not been possible for the Australia/New Zealand Haemophilia Psychosocial Workers' Group, Australian Haemophilia Nurses' Group, nor the Australian & New Zealand Physiotherapy Haemophilia Group to meet face to face during the year, but each group has conducted well attended virtual liaison meetings.

We were pleased to fund eight specialist physiotherapists to virtually attend the WFH Musculoskeletal Congress in May 2021. This was a positive outcome from the pandemic requiring a switch to virtual meetings, as we would generally only be able to fund the attendance of just one physiotherapist to this important meeting.

We appreciate the support from each of the specialist health professionals' groups and the Australian Haemophilia Centre Director's Organisation (AHCDO) for their input to HFA's education resources and communications, in particular for the COVID-19 information on the HFA website and for multidisciplinary input to the *Sport and Exercise for Girls and Young Women with Bleeding Disorders* fact sheet in May 2021.

### **Stakeholder Community**

We value the partnerships we have with health professionals, other community organisations, governments and industry, as each stakeholder as a group or individually helps us to achieve goals and outcomes for our community. In particular, I thank our member Foundations for their contribution to HFA's work. This collaboration is important to our outcomes and the work we do together for our national community.

I wish to thank HFA Council and State/Territory Foundations and the HFA staff for their efforts this year - we have had some great achievements in a very difficult year. Thank you all for your flexibility, hard work and dedication to HFA.



# REPRESENTATION AND ADVOCACY

## Challenges and change

This last year has seen some great changes for the bleeding disorders community. The ongoing COVID-19 epidemic has impacted on the way we live our lives, work, have an education and manage our healthcare, with much of this moving into a virtual space. At the same time new haemophilia treatments became available in Australia and have been life-changing for many people in our community.

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

Achieving our vision involves consulting with our diverse community and understanding what their needs are now and how they are changing. It also requires us to look to the future as well as responding to the challenges of today.

Our advocacy work has highlighted what we have learned from recent experiences of treatment and care to support improvements and efficiencies into the future. This will be important to support the treatment and care developments not only for haemophilia, but for the range of bleeding disorders in our community, and to acknowledge the quality of life issues for people with bleeding disorders and their family and carers across the lifespan.

## Best practice treatment and care

### New treatment products

We have entered an era of innovation in therapy options for Australians with bleeding disorders, which has the potential to deliver significant health outcomes and improve quality of life. With the rapid evolution in gene therapies, clinical trial experience suggests a cure for haemophilia is not far away! Timely access to innovative treatment is a priority for HFA.

This has been a very important year for haemophilia treatment in Australia: we saw broader access to extended half-life clotting factor products in July 2020 followed by an announcement in September 2020 about emicizumab (Hemlibra®), a novel non-factor product, and the decision of all Australian governments to jointly fund it among the suite of products on the National Products List.

We are excited by these new treatment products and others in the pipeline. Access to a new approved therapy has become a reality this year for many, while others have participated in a clinical trial and look forward to a new ongoing treatment option.

Community members with haemophilia have told us about the lifechanging health outcomes from some of these new therapies. Several clinical trials for other non-factor products and gene therapies for haemophilia are also well advanced and show great promise. They offer new opportunities for people with haemophilia, who can expect less or no bleeding at all and a radical improvement in their quality of life and ability to participate in the community.

HFA is committed to the well-established national framework to manage the treatment and care of bleeding disorders and facilitate cost-effective purchasing on behalf of government. After concerns about the very long lag between product registration in Australia as safe and effective

by the Therapeutic Goods Administration and when the products are publicly funded and made available to the people with bleeding disorders who need them, HFA initiated a Roundtable with a small group of specialist doctors and nurses together with HFA community leaders. This resulted in a Consensus Statement, calling for a clear, transparent, end-to-end process to evaluate new therapies, that builds on the National Blood Agreement and takes into account the considerable experience of our community in treating and managing haemophilia and other bleeding disorders.

Our advocacy with stakeholders, including government, drew on the recommendations from the Consensus Statement. There have been a number of Australian government inquiries into the process for evaluating medicines and other novel health technologies over the last 12 months. In late 2020 we made formal submissions to two in particular: the MSAC Guidelines Review and the House of Representatives Committee Inquiry into approval processes for new drugs and novel medical technologies in Australia. We followed this by providing further evidence at a hearing with the Committee in April 2021.

While a significant aspect of our submissions was to encourage a more efficient and transparent process, we also pointed to the critical importance of ensuring the patient voice is central and represented in the evaluation process at every stage - from development of the outcomes that will be measured to the evidence that is used to evaluate the new therapy. Health conditions such as haemophilia are very specialised areas and it is essential to hear from the patients themselves about what they see as an important outcome for their health and quality of life and to support them to provide the evidence of their experiences. This also involves resourcing patient organisations to participate in this work at the level required for government evaluation of new treatments.

To ensure access to the treatment and care our community needs to achieve our vision of active, independent and fulfilling lives, we will undertake ongoing advocacy with governments and other stakeholders. HFA's role is to ensure a range of therapies are available that offer the best outcomes for people with bleeding disorders. We will continue to consult with our community about their needs and their perspectives and experiences with treatments and to work towards optimum treatment and care for all people with bleeding disorders in Australia.



## ABDR and MyABDR

The **Australian Bleeding Disorders Registry (ABDR)** is a valuable tool for understanding the characteristics of bleeding disorders and the impacts of clinical interventions such as treatments. The data it supplies has provided evidence, for example, of the new generation of older people with bleeding disorders for the HFA Getting Older report and we are now seeking data on the impacts of hepatitis C on people with bleeding disorders. 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 is used by HTC's nationally for the clinical management of their patients. It enables HTC's to document and monitor treatments, bleeding episodes 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 (HTCs) and their patients.



The ABDR and MyABDR have a vital role to play in personalised treatment and other treatment innovations. They are readily used by clinicians and their patients in conjunction with pharmacokinetic analysis to develop and monitor an individualised treatment plan, based on its outcomes 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 to the community and encourage people with bleeding disorders to use it to record their treatments and bleeds. MyABDR uptake and usage was reported by AHCDO at the ISTH Virtual Congress in July 2020 and noted an encouraging improvement in treatment recording and adherence to treatment in the last two years. Use of MyABDR was a requirement for access to extended half-life products and emicizumab (Hemlibra®), funded through the National Blood Agreement.

To maintain their value, it is important for the ABDR and MyABDR to fit with the current and future treatment needs of people with bleeding disorders and HTC's. 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. The National Blood Authority has work in progress for a gap analysis between the CBDR and the ABDR and we look forward to improvements and opportunities from this.

## Getting Older



The release of our **Getting older with a bleeding disorder needs assessment report** in 2020 sparked important discussions by state and territory Haemophilia Foundations and Haemophilia Treatment Centres about priorities and strategies to implement the recommendations, which continued into this year.

With improvements to treatment and care in recent decades, there is a generation of people with bleeding disorders living into their senior years for the first time. While this is a welcome change, it has its challenges. For this group of older people with bleeding disorders and those who support them and provide their care, this is new territory. They need to manage both the issues of ageing faced by the general population and the impact of ageing on a person with a bleeding disorder, with no prior experience. Nevertheless, with the newer and emerging therapies, there is hope that this generation will also be able to enjoy a better quality of life.

We had valuable guidance from the HFA Getting Older Project Advisory Group on next steps to facilitate discussion with stakeholders about priorities and implementation. The Group included bleeding disorder community members, specialist health professionals from Haemophilia Treatment Centres, along with other experts in peer support for chronic health conditions with complex co-morbidities and researchers in the area of ageing, rehabilitation and independent living who also have experience in haemophilia.

Although there are common issues, each state and territory has its own environment and priorities to consider. With that in mind, we provided Haemophilia Treatment Centres with a discussion tool so that each could work through priorities and strategies arising from the report and its recommendations. In spite of the demands of the COVID-19 epidemic, the Treatment Centre teams took the time to work through the issues and we look forward to consolidating the outcomes from their discussions.

There has also been other progress on implementation. Over the last year some key changes to haemophilia treatment and care have fast-tracked strategies outlined in the Getting Older report. This includes access to new treatments that are longer-acting and/or administered sub-cutaneously and the use of telehealth to manage COVID-19 restrictions. New information for the Getting Older Info Hub on the HFA website has been developed, with contributions on priority topics from expert health professionals and videos from community members on their personal strategies for maintaining independence and resilience.

There are complex issues that remain – integrating care and continuity of care between Haemophilia Treatment Centres and other health care providers such as general practitioners, surgeons or aged care services to manage all of their health conditions; managing complications in older people with mild conditions who have had few bleeds in their lifetime and little contact with a Treatment Centre in the past; managing increasing frailty and memory loss with complex needs; working with aged homes and residential care. Making the person the centre of care will be essential for achieving better health outcomes as well as developing an efficient system of care.



Another important aspect is ensuring that older people with bleeding disorders can access the support and services they need. With a lifetime of disability and in some cases complications such as bloodborne viruses, many are on low incomes. Early ageing is also a problem for some in our community. 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. Exploring 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.

Getting older is a priority area for HFA and we are excited to be embarking on the next stage of our work to achieve our vision of 'active, independent and fulfilling lives' for older people with bleeding disorders.

### **Hepatitis C and HIV**

The Getting Older report highlighted the ongoing needs of people with bleeding disorders and bloodborne viruses. Hepatitis C and HIV continue to have an impact on the bleeding disorders community.

Support through recognition means a great deal to community members and forms a backbone of Foundation activities, including hepatitis C and HIV awareness activities such as World Hepatitis Day and World AIDS Day as well as inclusion in peer support events.

HFA Council has established a Hepatitis C Sub-Committee to work through priority recommendations. As a first step, this has involved requesting data from the Australian Bleeding Disorders Registry to better understand the number affected, treatment uptake and outcomes, current liver health and 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. Anecdotal reports from the community also pointed to communication gaps about the need for post-treatment follow-up for people with cirrhosis, even if cured of hepatitis C. We have been working with gastroenterology and hepatitis clinical organisations to clarify the issues and develop health promotion messages.

### **A voice in research**

Ensuring that people with bleeding disorders have a voice in their treatment and care is critical to good outcomes for their health and quality of life. Developing a knowledge base around the experience and treatment of bleeding disorders has become 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 community members to take part in relevant high-quality research projects. We highlight opportunities to participate in research both on the HFA website and through social media and e-news and our community takes a strong interest in this.



Data from the **PROBE (Patient Reported Outcomes Burdens and Experiences) Australia Study** is a prime example of the value of this evidence.

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 includes different sets of questions to measure health-related quality of life: 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.

Haemophilia Foundation Australia joined the international PROBE Study in 2014, validating and then conducting the first real-world study with the Australian community, and accessed the first round of real-world data from 337 Australian participants in February 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 treatments. The PROBE Study itself continues to evolve and some innovations, including mobile app and longitudinal versions, are currently being trialled internationally. We are monitoring these trials to see whether they will be appropriate and feasible for the Australian Study.

## **VWD**

Although it is the most common bleeding disorder worldwide, von Willebrand disease (VWD) is not well recognised and it is thought that many people with VWD are not yet diagnosed. HFA joined the World Federation of Hemophilia (WFH) VWD Global Call to Action on in May 2018 and represents the Western Pacific Region in the WFH VWD Global Group. Countries who join are asked to take action to create awareness, resources and provide support to improve the lives of those living with VWD.

Responding to the needs of our community members with VWD is a priority. HFA has established a VWD focus group and consults with the group about community education and engagement. Over the last year we have continued to highlight VWD information and personal stories in awareness campaigns such as Bleeding Disorders Awareness Week and in our education materials and events. We have also published articles about the international work on VWD in National Haemophilia.

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 January 2021. AHCDO will develop Australian guidelines from these during 2022. 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**

Our lives have taken a very unexpected turn with the COVID-19 pandemic. This has resulted in extended lockdowns in some states and resulted in great challenges and hardship for parts of our community and the health services who provide their care.

It has been important for HFA to remain connected with our community during this difficult time. HFA staff have been working from home, but our robust digital infrastructure has meant that as much as possible we have been able to continue with business as usual. We have worked with our Haemophilia Treatment Centres and the National Blood Authority to communicate with community members in a timely way and reassure them that Centre services remain available to them, although sometimes via telephone or video call, and that product supply will meet their treatment product needs.



With the commencement of the COVID-19 vaccine rollout, there were many questions from the community. We consulted with Haemophilia Treatment Centre Directors about these queries and in collaboration with AHCDO provided FAQs on our website, which have been updated as more information became available and a valuable resource for vaccine appointments. We have also heard from less well-connected members of our community with their concerns about COVID-19 and this has been an opportunity to put them in touch with their local Treatment Centre.

As the pandemic unfolded, our Haemophilia Treatment Centre staff have been called on to manage COVID-19 in their hospitals or in national committees. We are very grateful for the extra work done they have done in extraordinary circumstances to keep connected and to be available to help their patients.

### **Representation and communication**

To represent our community effectively, it is essential that we communicate well with them and our digital communications project has focused on strategies and infrastructure to optimise how we engage with people with bleeding disorders in Australia. We have looked closely at our various platforms and their target audiences and have been working with digital communications experts to finesse all aspects of our communications. This has also involved new areas for HFA, such as targeted Google Ads to reach the wider community.

# EDUCATION AND INFORMATION

## Education resources snapshot - in 2020-21

### HFA education materials about bleeding disorders

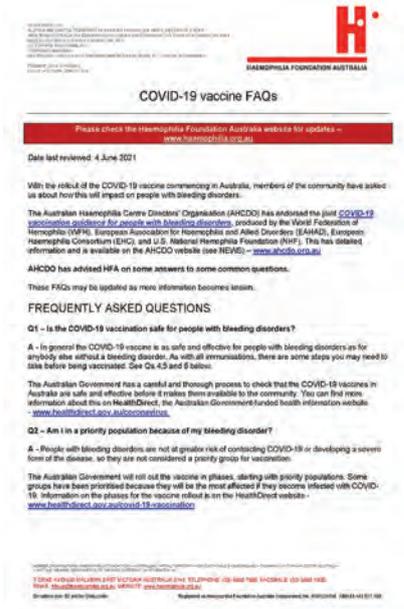
575 print copies distributed

More than 29,290 PDF downloads

83,599 web pages viewed

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

### COVID-19 vaccine FAQs



In February 2021 we published the COVID-19 vaccine FAQs on our website. The FAQs were a collaboration with the Australian Haemophilia Centre Directors' Organisation to answer common community questions that arose when the COVID-19 vaccine rollout began in Australia. Many people with bleeding disorders had questions about whether having a bleeding disorder made them a priority population with COVID-19 and the vaccine's safety for them. They also needed advice on how to have an intramuscular injection safely.

In June 2021 we updated the FAQs. We also provided a PDF version at the request of Haemophilia Treatment Centres, so they could be downloaded and printed for vaccine appointments to make the process smoother for people with bleeding disorders.

The FAQs have been very popular, with 4122 pageviews by the end of June 2021.

*'Great job! The FAQs read really well.'*

With COVID-19 at front of mind for our community and the impact of lockdowns on print resource distribution, it was important to make sure other areas of health were not neglected and we continued to develop and promote our digital education resources.



## Getting Older Info Hub



The Getting Older Info 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.

The most popular articles from the last year were:

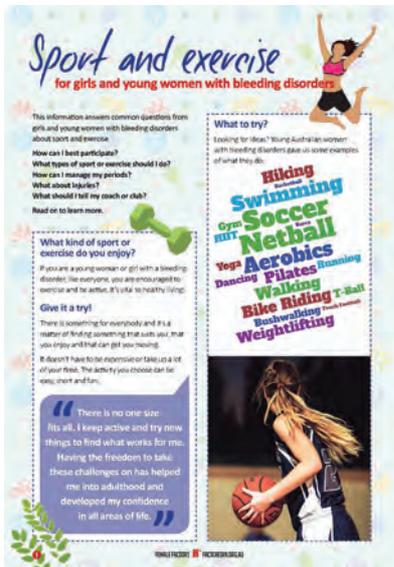
- exercise and arthritis
- bleeding problems
- surgery and dental care
- self-care for carers
- digital stories about staying active and independent and resilience.

There was also new information on financial services, including concession cards, and planning for the future with advance care planning.



The Info 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 2021 we published ***Sport and exercise for girls and young women with bleeding disorders***, which answered the questions of young women and parents about how to play sport and exercise safely, managing periods and rehabilitation after injury.

This was made available in multiple formats:

- Web pages and PDF on Factored In
- PDF download on the HFA website
- Print version for clinics and community events

*'This is an excellent resource.'*

*'Can't wait to give them out.'*



If you are a woman with a bleeding disorder, getting good care in an emergency or if you are having medical or dental procedures can involve some preparation and being able to speak up for yourself. The Women bleed too educational video was released in April 2021 and outlines what to do and how to prepare, illustrated by personal experiences from Australian women with bleeding disorders.

*'Wow, what an amazing piece of work!!'*

*'So clear and calm, the women and info were just wonderful. I loved that the video was not frightening. The written facts in the video hit the right note as well.'*





8 | 9 October 2021

Virtual

# 20<sup>TH</sup> AUSTRALIAN CONFERENCE

ON HAEMOPHILIA, VWD & RARE BLEEDING DISORDERS

**EMBRACING A CHANGING WORLD**

Gold Sponsors

**CSL Behring**



**SANOFI GENZYME**



Silver Sponsors

**B:OMARIN**



**Pfizer Haemophilia**

HFA made a decision in late 2020 to run the 2021 conference virtually. We thank the following sponsors who confirmed their commitment to our conference.

*\*Some sponsorship monies were received in this financial year 2020/2021\**

## COMMUNICATIONS

### Digital communications

HFA worked with a digital communications agency, Ntegrity during the financial year on a project to review and improve our digital communications. Our objective was “to grow HFA’s brand awareness and reach throughout the bleeding disorders community—while building and strengthening relationships with all existing supporters”.



**National Haemophilia**, HFA’s quarterly journal, is well-respected by both community and health professionals for high-quality information and news about bleeding disorders. 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:

- A young woman with factor X deficiency embracing independence
- Reports from the WFH World Congress on COVID-19 and the new normal
- Bleeding Disorders Awareness Week
- News from South Australia was also highly sought after.

With each article available as a web page, 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 6,824 pageviews.



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

The **Haemophilia Foundation Australia website** is our major communications platform. We update it continuously with news updates and new high-quality information and all publications are available for download. For the Australian bleeding disorders community, health professionals, stakeholders, the general community and students, who are regular users, this is a valued and accessible source of current, relevant and evidence-based information.



### Our website in 2020-2021

- A very high ranking in Google searches
- Visitors stay on the site and look at more than 1 page, download publications and watch videos
- What's the most popular? Our high-quality information about haemophilia and von Willebrand disease, followed by articles in *National Haemophilia* and our COVID-19 vaccine FAQs
- 54% of visitors access it with mobile devices such as smartphones and ipads/tablets
- Search engine optimisation has resulted in a sustained overall increase in website usage and referrals through Google searches.

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

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

The **HFA email newsletter** is a popular way of connecting with bleeding disorder community members and supporters about HFA activities and news. It is well-received, with a higher open rate than the Australian benchmark. Over the last year we have integrated our e-news subscribers with our new online membership and now have a cleaner and more robust list to communicate with the community and supporters.

## Social media

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

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.

- Our post about **HFA youth leader Tim's story about weightlifting and haemophilia** had an organic reach of 3,200, with 101 post clicks and 54 reactions, comments and shares
- Our post on **World Haemophilia Day light it up red activities** had an organic reach of 1,100, with 40 post clicks and 104 reactions, comments and shares.

Instagram is the fastest growing social media platform worldwide. It is a way for us to engage more visually with the community, particularly younger people, using images, infographics and links to the HFA and Factored In websites for more information. We have continued to grow our presence on Instagram.

- In 2020-2021 we made **138 Instagram posts** and have **increased our followers by 45%**.



### HFA communications snapshot - in 2020-21

**6,521** copies of *National Haemophilia* posted to members

More than **35,040** online views or downloads of National Haemophilia

**725** HFA members received regular e-news

**172,032** views of HFA web pages

### Social media

**2,960** HFA Facebook 'likes'

**63%** of HFA Facebook 'likes' are aged 13-44 years

**730** HFA followers on Twitter

**645** followers on Instagram



## **www.factoredin.org.au**

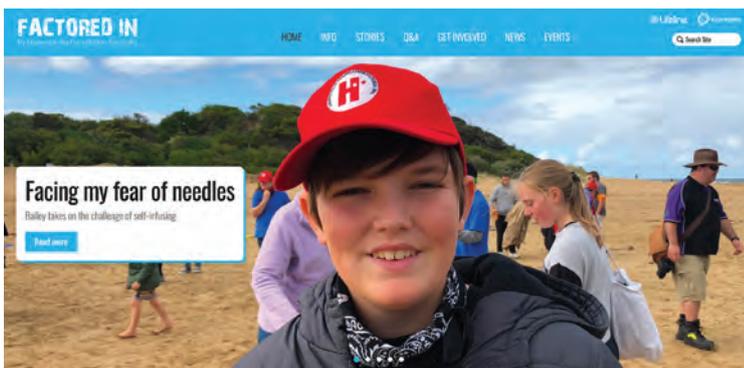
Factored In is the HFA youth website. It was created in 2012 and it had a makeover in 2021. The website provides information for young people about life and being young with a bleeding disorder. The website features personal stories as well as evidence-based information. While the information pages provide a robust backbone for the Factored In website, personal stories are key to engaging young people.

In July 2020, we re-launched the home page for easier navigation and to highlight key areas such as showcasing new stories, browsing by topic area and making the latest content prominent.

We continue to make updates to the website to ensure that it is user friendly and that young people are finding the information and its useful to their needs.

### **Key Factored In articles 2020-2021**

- *My brothers have haemophilia* – Angelina shares her story of her brothers having haemophilia from a sibling perspective
- *Staying motivated with exercise* – Andrew shares his tips
- *Climbing Mount Everest with haemophilia* – Chris Bombardier tells his inspiring story
- *Rare and embracing independence* – Belinda shares her journey with factor X (10) deficiency.
- *Managing work and career* - young people talk about their experiences with work and choosing a career
- *The power of music* - Lenny tells his compelling personal story about overcoming the complications of haemophilia and how music and new treatments have changed his life
- *Dealing with life changes* - Darren has severe haemophilia and talks about dealing with life changes when you are young and have a bleeding disorder.



#### **Factored In snapshot in 2020-21 there were:**

**11,011** website visits

**16,998** page views

**53%** of users were female

**47%** of users were male

Highest use in **18-24** age group

## AWARENESS

### Global VWD Call to Action



In 2018 HFA joined the World Federation of Hemophilia Global VWD Call to Action and committed to taking action 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 2020 and Rare Disease Day in 2021 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, published them in National Haemophilia and promoted them on our social media platforms. They not only sparked discussion but also enabled affected community members to connect with each other.

### World Hepatitis Day



World Hepatitis Day is marked globally on 28 July. In 2020 the Australian campaign took the theme of *Let's talk hep* to support the worldwide goal of viral hepatitis elimination by 2030 by starting a conversation - talking to friends, family or a doctor.

New, simple and effective treatments offer the potential of a cure for nearly all. HFA believes we can achieve this much earlier in the bleeding disorders community.

HFA is a partner in the national World Hepatitis Day Campaign and worked together with Hepatitis Australia, state and territory Foundations and haemophilia and hepatitis experts to develop a social media campaign specifically targeted at the bleeding disorders community.

Many Australians with bleeding disorders and hepatitis C have now had treatment and been cured, but others are not aware that that they were at risk of hepatitis C infection. This year our campaign aimed to reach the family and friends of men and women with mild bleeding disorders to pass the message on. People with mild disorders may visit a Haemophilia Treatment Centre rarely and may not have understood their hepatitis C risk or been tested. Other messages were for people with bleeding disorders with liver cirrhosis resulting from their hepatitis C, encouraging them to continue to have ongoing liver health monitoring - even if they are cured, they remain at risk of liver cancer. It is also important to acknowledge the small number of people who have not been able to have successful treatment.



## World AIDS Day 2020

In 2020 the World AIDS Day campaign theme was *Now more than ever*. For the bleeding disorders community this is a profoundly meaningful message. We mark World AIDS Day on 1 December across all of our communications platforms as a day to be mindful of the members of our community living with HIV and those who have passed away. 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.

It is important to recognise the ongoing experience of HIV, for affected people with bleeding disorders, their family and friends, the community leaders and the Haemophilia Treatment Centre teams who have cared for them, shared their hardships and still grieve for those who passed away. Our campaign messages give our affected community the opportunity to comment and support each other. Their responses remind us how vital it is to create a supportive, non-judgemental and stigma-free environment for our community members affected by HIV.

## Bleeding Disorders Awareness Week 2020



During the week of 11-17 October 2020 Bleeding Disorders Awareness Week was an opportunity for individuals and families as well as Haemophilia Foundations and other organisations to take part in a campaign and activities to raise awareness about haemophilia, von Willebrand disease and related inherited bleeding disorders throughout Australia.

What a different year it has been! With COVID-19 restrictions different in each state/territory, we moved to a virtual campaign. We had many fun activities for all ages, such as the colouring in competition, an online quiz, Zoom and Facebook Live information sessions and a cupcake baking class.

## Test your knowledge with the Bleeding Disorders Awareness Week Quiz



A highlight of the week was a Live Chat Q&A session with Chris Bombardier about his movie *Bombardier Blood*. Chris shared his experience of climbing Mount Everest. We also had our own Australian rock climbers, the Godwin brothers, tell their story about climbing the rockface El Capitan in Yosemite National Park in the USA last year. We also run two other live webinars on Children and young people and keeping fit and Getting older and exercising.

The theme *One Community, Many Faces*, showcased our community and highlighted the many different bleeding disorders and experiences. Short stories we released and available online and our on socials.

- Mike - older person with haemophilia
- Tim - young person with haemophilia
- Shauna - managing type 3 VWD
- Sharron - A woman with haemophilia, carrier, mother of a son with haemophilia, dad has haemophilia
- Susie - living with type 1 von Willebrand disorder
- Ben - a father's perspective



*Mike*



*Tim*



*Shauna*



*Sharron*



*Susie*



*Ben*





The HFA *Go Red for Bleeding Disorders* campaign enabled people to do a range of activities with their families, friends, workplaces and communities during Bleeding Disorders Awareness Week. It was great to see lots of red cakes and dress in red days. HFA hosted a cupcake baking session to kick off the week.

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



*Giselle ran a great cupcake baking class.  
What great work they all did!*



**Snapshot**  
Over **170** people viewed the online webinars  
**19%** of our facebook audience engaged in our post over the week in some way  
Campaign focussed on awareness and engaged with over **3200** people

## WORLD HAEMOPHILIA DAY



Every year on 17 April World Haemophilia Day is recognised worldwide to increase awareness of haemophilia, von Willebrand disease and other inherited bleeding disorders. This is a critical effort since with increased awareness comes better diagnosis and access to care for the millions who remain without treatment.

This year's theme *Adapting to Change* highlighted that living during a pandemic can pose many challenges, not only for our health, but also for our mental health and wellbeing.

HFA hosted two webinars over the week for World Haemophilia Day:

- Adults adapting to change
- Resilience & adapting to change - career, work and sport (youth issues).

### Light it up red

HFA also participated in *Light it Up Red* with landmarks in Western Australia, Queensland and Victoria going red to raise awareness about bleeding disorders.

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



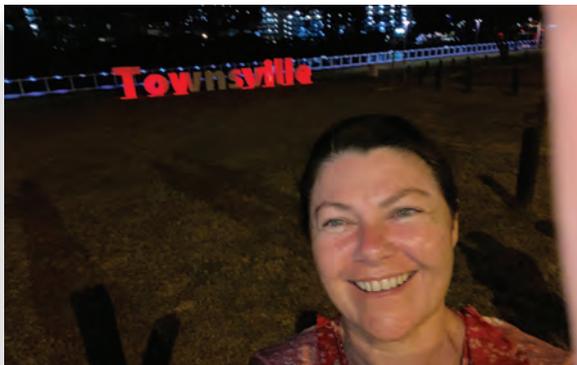
Ipswich, QLD



Kangaroo Point, QLD



Bell Tower, Perth, WA



Townsville, QLD



## 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 \$2,527,381.

In December 2019, the fund granted Dr Nicholas J. Hunt for his project at the University of Sydney which is exploring the transport of CRISPR via nanomedicine to the liver endothelium for the treatment of Haemophilia A. This is part of a broader project which had been expanded to include haemophilia A. We were able to contribute the second part of the HFA grant, in anticipation of necessary materials being transported from the United States so the project could continue later in the calendar year. A second distribution of \$10,000 was paid for this grant in August 2021.



## Fundraising

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

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

### Appeals

Direct mail appeals to donors are sent during the year and we thank each individual who makes 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.

The acquisitions appeal that was planned to be sent in March 2020, was posted in September 2020. We received a great response to the appeal and we thank our new supporters.

**H Living Active and Fulfilling Lives**  
Haemophilia Education Australia

Camps play a crucial part in ensuring children growing up with a bleeding disorder will lead active, fulfilling lives, and help them cope physically and emotionally with their chronic condition.

It is equally important they are given the chance to connect with others who are going through the same things as they are. Not only can it increase their confidence and acceptance of their condition, but the peer support and encouragement they find can be the beginning of lifelong friendships.

The camps are also a great opportunity to try new sporting activities in a safe and supportive environment. For a child with a bleeding disorder this opportunity can be truly life-changing.

"The camps are always a brilliant experience. Getting to meet all these other people with the same problems who know exactly what you are talking about, with all those experiences that other people just don't understand."  
Ben

"This helps to build on their self-esteem and confidence that you can still lead a normal life despite the limitations you have with having a bleeding disorder."  
Dorina, mum of Adam

www.haemophilia.org.au

**CAMPING**

**Staying young at heart and living well: Getting Older education resources**

"I want to live, and I want to age gracefully."  
"I would rather keep doing things that are worthwhile, whatever that may be!"  
Visit the Hub:  
[www.haemophilia.org.au/getting-older](http://www.haemophilia.org.au/getting-older)

**Making life-saving treatments accessible – before it's too late:**

Christopher had a challenging time with his haemophilia and told his mum: "I don't want to have haemophilia anymore". It was heartbreaking. Now look at this happy 8 year old doing normal things.

"Christopher can now ride his bike and scooter without the fear of falling and having a bleed." Brenda

It's said that for every single man or boy diagnosed with haemophilia, as many as eight women – mothers, sisters, daughters, wives – are affected.

**The Female Factors goal is to help Australian women and girls who are affected by bleeding disorders, either directly or through a loved one, and reduce the distress, isolation and anxiety they can experience at all stages of their journey.**

### 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.



## Peer Support Programs

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

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

### HFWA Family Camp, March 2021



**Following is a lovely recap from Bradley's mum...**

*We moved to Perth in 2012 and were invited to our first camp in 2013. I only knew a couple of mums and kids from our weekly hospital visits, so we were anxious a bit of what would happen at these camps. To our astonishment, they were so many families and boys and their siblings, who were just like you and me. I clearly remember getting to know so many people and their stories and it made me feel like this is home. And over the years, these people have become our Haemo family. We have done about 4 camps now, and always looking forward to the next. The first one showed us what these events can do for a newly diagnosed Haemophilia family and the support it brings with them. We had so much fun with the team building and family tasks. But even more so, having the time as adults, to talk about all things Haemophilia, while the kids are taken care off. Every camp includes information sessions for us mums and dads out there and how treatment is getting better and how life for our children has a brighter future. It also gives us adults the support we need in raising our children whilst impacted with Haemophilia. It is a great way for the children to see that they can have normal lives, but also talk about their problems and experiences at those camps, because every single person can relate to them. As much as I try and inform my environment about Bradley's Haemophilia, he can only really talk to other children about haemophilia who are directly impacted. He can do that on these camps and other events put on by the Haemophilia Foundation. And even my daughters, who will one day find out if they are carriers and possibly have a child with Haemophilia themselves, can see through these camps that they would never be alone.*

*To give a brief overview of our last camp: the camp is run by volunteers who are all impacted by Haemophilia one way or another. And a lot of planning and organising goes into these events. Camp started Friday afternoon, but this time around we could only come from Saturday onwards due to work commitments. My kids were a little sad, as we missed the first night, which usually involved a fun activity at night after dinner. We arrived Saturday morning and joined the Haemo family after breakfast. The kids got geared up for kayaking and us parents enjoyed the morning with all other parents / adults. We had our information session followed by a yoga session. The info session was so interesting, as we had new products launched a few months before and another teenage boy was trialling the gene therapy. The insight he was giving us on the trial from his perspective as well as hearing his mum talking about it, was so informative and gives us hope for Bradley one day to be off the needles for good. After lunch we had some family time in our dorms, which gave us a well needed break as it was very hot this day. The volunteers changed the plans a bit, and we could all join the pool for some well needed cooling down, followed by blow up soccer games in the later afternoon. The kids and yes, also adults had a blast bumping each other with the big blow up bubbles and needless to say, the soccer part was somewhat not important anymore. It was good to see everyone laughing and giggling as they ended up playing bowling pins with each other. After dinner, we all get together for some games, dress ups, and on stage contest. It is a fabulous time for the kids to be kids, and the adults to be silly with their children. Quality time right there. Sunday started off with breakfast and we could choose between two activities. My children and I chose the flying fox and had heaps of fun going up and down. We finished camp, with all the members, over lunch discussing what the next camp will bring and what ideas everyone has for the theme. The drive home was spent talking about all the little and big adventures the family had.*

*I always encouraged new families to come along to the camps. It is one thing as a family to live with Haemophilia, but having the support from the Haemophilia Foundation through various event including those camps is priceless.*



## Treasurer's Report, David Fagan



I am pleased to present my 2021 report.

Last year HFA was heavily impacted by the COVID 19 pandemic, and this has continued into 2021. Like many other not for profit organisations we experienced significant revenue loss in critical areas in 2020. However, we remained committed to our long-term objectives including the donor acquisition plan that aims to strengthen HFA's longer term financial situation to fulfil our services and care requirements, and build our advocacy for best practice treatment and care. These additional expenses against reduced income led to a deficit of \$321,315 in 2020, but this was expected and planned for. I am pleased to report this has been turned around significantly.

As we moved into 2021, reduced turnover meant HFA remained eligible for government pandemic financial support and we are grateful this represented 16% of our income to sustain us throughout the year. Our expenses reduced by 33% from \$1,324,979 to \$886,438 this year, partly because we were unable to have face to face events and meetings, and we took great care not to commence work that could be compromised by the pandemic. The HFA office was closed for most of the year, and staff continued to work from their homes for most of the year. Their work switched to our digital communications project work, some of which was brought forward which is a good outcome for our community. Most of this work absorbed the time of staff and the input of digital specialists and this is largely reflected in our administration costs for human resources, and the additional specialist digital services costs that were funded by grant funds. Although the office was unoccupied by staff for most of the year, office expenses did not really reduce, other than some savings on lighting and heating, but these costs were shifted to reimburse staff for their working from home expenses. Our care and services expenses decreased overall by 51%, simply because we were no longer carrying any 2019 conference expenses, and the advocacy consultation was winding up. We met the requirements of approved budgets for each of our two government grants and although we had no face-face meetings we adjusted our business to support virtual meetings for Council and health professionals. Other regular expenses were relatively stable.

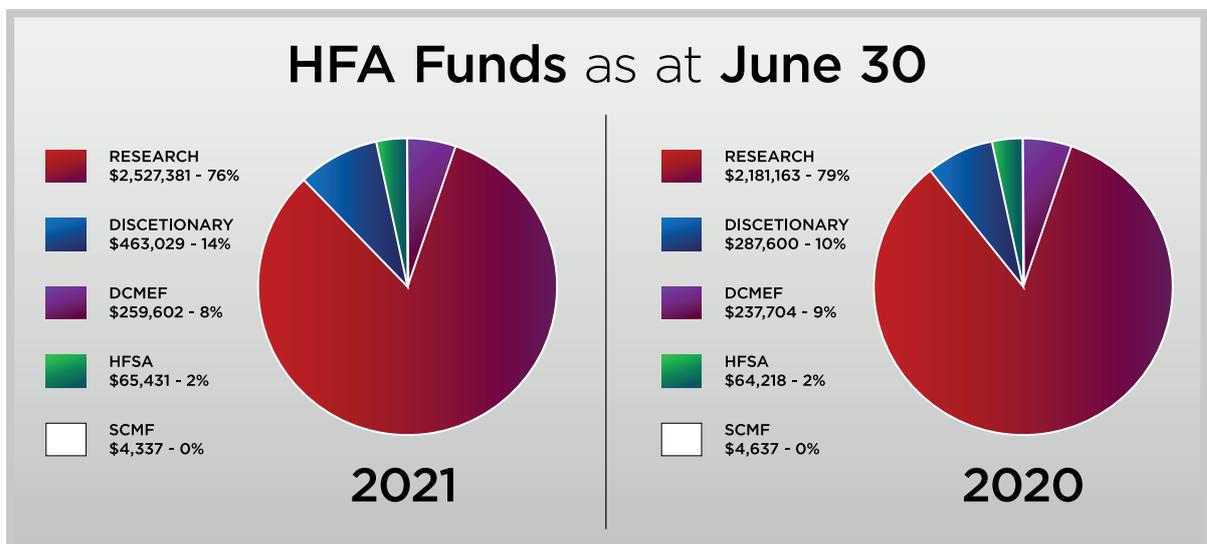
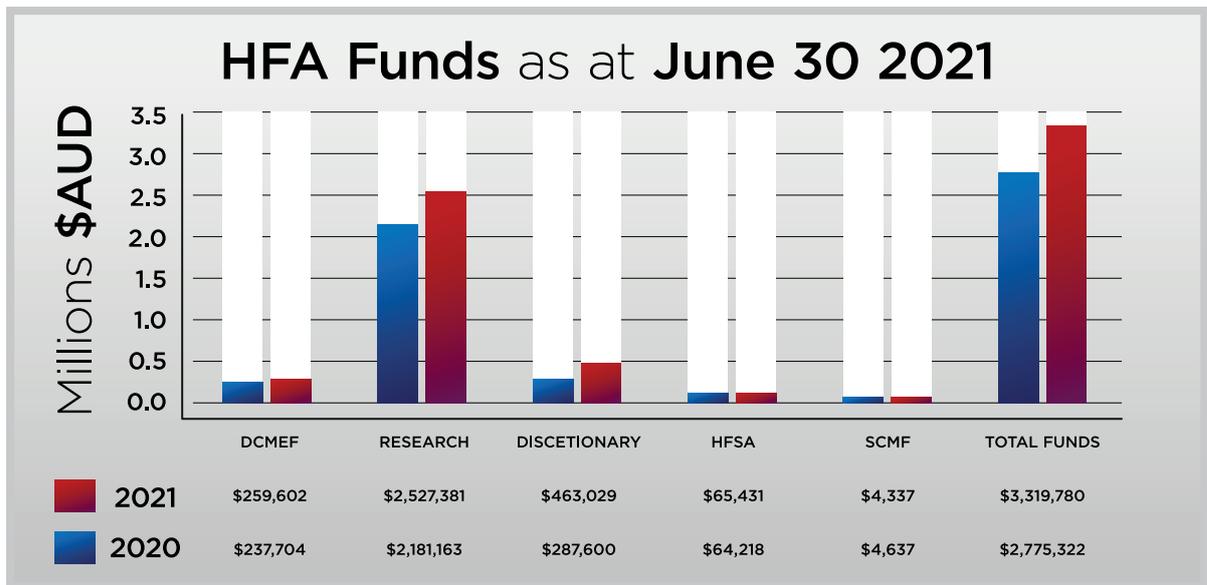
On the income side we had a pleasing outcome. We continued with our acquisition plan and although it has been a difficult year for the economy, our general donation income from existing and new donors remained consistent with the previous year. We plan to build on these relationships with our supporters to strengthen our future donor base. However, we received 41% less in corporate grants and sponsorship this year, largely because we did not have the capacity to undertake novel project initiatives. We look forward to the opportunities of sponsorships for new projects when the pandemic allows us to do so. Fortunately, we have had strong interest in sponsorship for the national conference to be held in October 2021.

We rely heavily on two government grants to fund our national secretariat, to provide advice and to meet our objectives for the bleeding disorders community. Although each of the three year grants finish at the end of next year, we will work with our government partners towards new funding agreements.

I am pleased that we are seeing the benefits from the investment strategy put into effect in 2018. As the year came to an end, income on the funds held in the Haemophilia Foundation Research Fund had more than doubled with the return increasing from \$60,442 to \$142,390. Further, last year we reported a \$95,575 loss on the value of our investments, whereas this year the market is such that I can report an unrealised gain of \$218,362.

The financial outcome this year is that with our investments we had a 37% increase in total income from \$1,003,664 last year to \$1,382,600 this year, against a total expenditure of \$886,438 in 2021 compared to expenditure of \$1,324,979 last year, resulting in a strong surplus of \$496,163 this year. Although we are in a strong position, it is important to note that our discretionary funds remain tight and forward budgets and great care is needed as we plan our expenditure going forward.

Although HFA has faced significant challenges this year, we have been able to manage these effectively, and providing we continue to build up our income from our donation and sponsorship partners and government grants continue we will be well placed to achieve our future objectives. I wish to thank Council and staff for their support during the year.



# Financial Report

**HAEMOPHILIA FOUNDATION AUSTRALIA INCORPORATED**  
**ABN 89 443 537 189**  
**ANNUAL REPORT FOR THE YEAR ENDED 30 JUNE 2021**

Your Council members submit the financial report of Haemophilia Foundation Australia Inc. for the financial year ended 30 June 2021.

## **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 \$496,163 (2020: deficit \$321,315).

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



President

**Gavin Finkelstein**



Treasurer

**David Fagan**

Date : 26 October 2021

**HAEMOPHILIA FOUNDATION AUSTRALIA INCORPORATED**  
**ABN 89 443 537 189**  
**INCOME AND EXPENDITURE STATEMENT FOR THE YEAR ENDED 30 JUNE 2021**

	Note	2021 \$	2020 \$
<b>INCOME</b>			
Government grants		455,000	455,000
Sponsorships, donations and bequests		226,531	352,273
All other revenue		91,884	120,386
Investment income		161,290	83,821
Unrealised gains/(losses)		218,363	(95,575)
Other income		229,533	87,759
<b>TOTAL INCOME</b>		<b><u>1,382,601</u></b>	<b><u>1,003,664</u></b>
<b>EXPENSES</b>			
Administration		361,051	309,259
Leasing of premises and office expenses		84,394	76,701
Fundraising		42,206	96,838
Services and care		388,343	801,010
Education		444	23,602
Research and other grants		10,000	17,569
<b>TOTAL EXPENSES</b>		<b><u>886,438</u></b>	<b><u>1,324,979</u></b>
<b>(DEFICIT)/SURPLUS FOR THE YEAR</b>		<b>496,163</b>	<b>(321,315)</b>
<b>ACCUMULATED FUNDS BROUGHT FORWARD</b>		<b>2,321,217</b>	<b>2,636,619</b>
<b>TOTAL AVAILABLE FUNDS</b>		<b><u>2,817,380</u></b>	<b><u>2,315,304</u></b>
<b>TRANSFER (TO) / FROM RESERVE</b>	<b>8</b>	<b>(21,898)</b>	<b>5,913</b>
<b>ACCUMULATED FUNDS CARRIED FORWARD</b>	<b>7</b>	<b><u>2,795,482</u></b>	<b><u>2,321,217</u></b>

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



**HAEMOPHILIA FOUNDATION AUSTRALIA INCORPORATED**  
**ABN 89 443 537 189**  
**ASSETS AND LIABILITIES STATEMENT AS AT 30 JUNE 2021**

	Note	2021 \$	2020 \$
<b>CURRENT ASSETS</b>			
Cash and Cash Equivalents	2	689,912	506,208
Investments	3	2,629,867	2,269,114
Trade and Other Receivables		4,262	3,978
Other assets		-	-
<b>Total Current Assets</b>		<b><u>3,324,041</u></b>	<b><u>2,779,300</u></b>
<b>NON CURRENT ASSETS</b>			
Property, plant and equipment	4	35,120	45,904
<b>Total Non-Current Assets</b>		<b><u>35,120</u></b>	<b><u>45,904</u></b>
<b>TOTAL ASSETS</b>		<b><u>3,359,161</u></b>	<b><u>2,825,204</u></b>
<b>CURRENT LIABILITIES</b>			
Trade and Other Payables	5	36,478	23,950
Short-term Provisions	6	266,355	241,986
<b>Total Current Liabilities</b>		<b><u>302,833</u></b>	<b><u>265,936</u></b>
<b>NON CURRENT LIABILITIES</b>			
Long-term Provisions	6	1,244	347
<b>Total Non-Current Liabilities</b>		<b><u>1,244</u></b>	<b><u>347</u></b>
<b>TOTAL LIABILITIES</b>		<b><u>304,077</u></b>	<b><u>266,283</u></b>
<b>NET ASSETS</b>		<b><u>3,055,084</u></b>	<b><u>2,558,921</u></b>
<b>FOUNDATION'S FUNDS</b>			
Accumulated funds	7	2,795,482	2,321,217
Reserve	8	259,602	237,704
<b>TOTAL FOUNDATION'S FUNDS</b>		<b><u>3,055,084</u></b>	<b><u>2,558,921</u></b>

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

**HAEMOPHILIA FOUNDATION AUSTRALIA INCORPORATED**  
**ABN 89 443 537 189**  
**CASH FLOW STATEMENT FOR THE YEAR ENDED 30 JUNE 2021**

	Note	2021	2020
		\$	\$
<b>CASH FLOWS FROM OPERATING ACTIVITIES</b>			
Investment income received		21,637	30,441
Grants received		455,000	455,000
Proceeds from sale of investments		-	-
Purchase of investments		-	-
Receipts from constituents		547,948	560,418
Payments to suppliers and employees		(835,992)	(1,341,576)
<b>Net cash flows from operating activities</b>		<b><u>188,593</u></b>	<b><u>(295,717)</u></b>
<b>CASH FLOWS FROM INVESTING ACTIVITIES</b>			
Acquisition and disposal of property, plant and equipment		(2,152)	(2,868)
<b>Net cash flows used in investing activities</b>		<b><u>(2,152)</u></b>	<b><u>(2,868)</u></b>
<b>NET INCREASE CASH HELD</b>		<b>186,441</b>	<b>(298,585)</b>
<b>CASH BALANCE BROUGHT FORWARD</b>		<b>1,001,146</b>	<b>1,299,731</b>
<b>CASH BALANCE CARRIED FORWARD</b>		<b>1,187,587</b>	<b>1,001,146</b>
<b>Cash balance carried forward comprises: -</b>			
Cash and cash equivalents	2	689,912	506,208
Short term deposits	3	497,675	494,938
		1,187,587	1,001,146
<b>Reconciliation of surplus for the year to the net cash flows from operating activities :-</b>			
Total operating surplus for the year		496,163	(321,315)
Depreciation and amortisation		12,936	14,454
Changes in assets and liabilities			
Increase/(Decrease) in creditors and provisions		37,794	(31,163)
(Increase)/Decrease in receivables and other assets		(284)	112
(Increase)/Decrease in investment assets		(358,016)	42,195
<b>Net cash flows from operating activities</b>		<b><u>188,593</u></b>	<b><u>(295,717)</u></b>

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



**HAEMOPHILIA FOUNDATION AUSTRALIA INCORPORATED**

**ABN 89 443 537 189**

**NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 30 JUNE 2021**

**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 2021 (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.

	<b>2021</b>	<b>2020</b>
<b>NOTE 2: CASH AND CASH EQUIVALENTS</b>	<b>\$</b>	<b>\$</b>
Cash at bank	<u><b>689,912</b></u>	<u><b>506,208</b></u>
 <b>NOTE 3: INVESTMENTS</b>		
Short term deposits	497,675	494,938
Investment securities, at fair value	2,132,192	1,774,176
	<u><b>2,629,867</b></u>	<u><b>2,269,114</b></u>
 <b>NOTE 4: PROPERTY, PLANT AND EQUIPMENT</b>		
Furniture and office equipment - at cost	268,122	265,970
Accumulated depreciation	(233,002)	(220,066)
	<u><b>35,120</b></u>	<u><b>45,904</b></u>



**HAEMOPHILIA FOUNDATION AUSTRALIA INCORPORATED**

**ABN 89 443 537 189**

**NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 30 JUNE 2021 (cont...)**

<b>NOTE 5: TRADE AND OTHER PAYABLES</b>	<b>2021</b>	<b>2020</b>
Trade creditors and accruals	36,478	23,950
	<b><u>36,478</u></b>	<b><u>23,950</u></b>

**NOTE 6: PROVISIONS**

Current		
- Annual leave	159,546	143,658
- Long Service leave	106,809	98,328
	<b><u>266,355</u></b>	<b><u>241,986</u></b>
Non-Current		
- Long Service leave	1,244	347
	<b><u>1,244</u></b>	<b><u>347</u></b>

**NOTE 7: ACCUMULATED FUNDS**

**Accumulated funds are set aside for the following purposes: -**

- research	2,527,381	2,181,163
- discretionary projects and reserves	268,101	140,054
	<b><u>2,795,482</u></b>	<b><u>2,321,217</u></b>

**NOTE 8: RESERVE**

**Damon Courtenay Reserve**

- balance at beginning of year	237,704	243,617
- special appeals and interest income	21,898	1,622
- sponsorships, allocations and costs	-	(7,535)
	21,898	(5,913)
- balance at end of year	<b><u>259,602</u></b>	<b><u>237,704</u></b>

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

**HAEMOPHILIA FOUNDATION AUSTRALIA INCORPORATED**

**ABN 89 443 537 189**

**NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 30 JUNE 2021 (cont...)**

**NOTE 9: SUBSEQUENT EVENTS**

No matter or circumstance has arisen since 30 June 2021 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 COVID-19 and resulting restrictions on the movement of people can result in difficulties for businesses to generate consistent income and deliver projects and core operations. The effects on the future of certain aspects of the Association's future operations are difficult to predict however it is likely that the association will continue to see some volatility of income and expenses in the current year.



**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 :-

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; and

the financial statements and notes satisfy the requirements of the Australian Charities and Not-for-profits Commission Act 2012.

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: 26 October 2021

**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: 26 October 2021



**HAEMOPHILIA FOUNDATION AUSTRALIA INC**  
(ABN 89 443 537 189)

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

### Report on the Audit of the Financial Report

#### Opinion

We have audited the financial report of Haemophilia Foundation Australia Inc. which comprises the assets and liabilities statement as at 30 June 2021, the income and expenditure statement and the cash flow statement for the year then ended, and notes to the financial statements, including a summary of significant accounting policies, and the certification by members of the committee on the annual statements giving a true and fair view of the financial position and performance of the association.

In our opinion, the accompanying financial report gives a true and fair view of the financial position of Haemophilia Foundation Australia Inc. as at 30 June 2021 and of its financial performance for the year then ended in accordance with the accounting policies described in Note 1 to the financial statements, and the requirements of the *Australian Charities and Not-for-profits Commission Act 2012*.

#### Basis for Opinion

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

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

#### Emphasis of Matter - Basis of Accounting

We draw attention to Note 1 to the financial statements, which describes the basis of accounting. The financial report has been prepared to assist Haemophilia Foundation Australia Inc. to meet the requirements of the *Australian Charities and Not-for-profits Commission Act 2012*. As a result, the financial report may not be suitable for another purpose. Our opinion is not modified in respect of this matter.

#### Responsibilities of the Committee for the Financial Report

The committee of Haemophilia Foundation Australia Inc. is responsible for the preparation and fair presentation of the financial report in accordance with the financial reporting requirements of the *Australian Charities and Not-for-profits Commission Act 2012* and for such internal control as the committee determines is necessary to enable the preparation and fair presentation of a financial report that is free from material misstatement, whether due to fraud or error.

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

# Acknowledgments

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

## Individual Donors over \$250

Mike & Selma Barry  
Jennifer Barry  
Dulcie Battaglione  
Paul Bedbrook  
C Benham  
Neal Blewett  
Ron Brierley  
Dr MG Brooke  
Margaret Brown  
Diana Cerini  
Ron Coleman  
J H Cooper  
Immaculada & Vincenzina Criniti  
Herbert Domgjoni  
Barbara Douglas  
Elizabeth Dyer  
John Eastment  
Michael Edgeloe  
Wendy R Farley  
Bruce Fielding  
Esther Finkelstein  
Rob Fitzherbert  
Dr E S Fraser  
Fred Frohlich  
Eric Gale  
Libby Gilchrist  
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Pam Harrison  
David John  
AC King  
Leonie & David Koadlow  
Mr Liang Kui & Ms Yucen Yan  
Nicole Lacey  
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Ron & Jenny Lees  
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Mr Brenton Taylor & Mrs Donna  
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Timothy Ross  
Stephen & Denise Ryan  
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Carolyn Simmonds  
A Slotegraaf  
Jonathan Spencer  
Mr G Spencer  
Jennifer Talbot  
Trang Tat  
Dawn Thorp AO  
Michael & Alison Wilson

## Service Clubs over \$250

Rotary Club of Armidale Central  
Lions Club of Battunga Country  
The Lions Club of Burleigh Heads  
Lions Club of Emu Park  
Lions Club of Gympie  
Lions Club of Glenroy  
Lions Club of George Town  
Lions Club of Gin Gin  
Lions Club of Haddon and District  
Rotary Club of Korumburra  
Lions Club of Lismore Inc  
Lions Club of Launceston Windmill Hill  
The Lions Club of Lennox Head  
Monaro High School Leo Club  
Lions Club of Lara  
Lions Club of Oak Flats  
Lions Club of Port Phillip  
Lions Club of Runaway Bay  
Lioness Club of Redcliffe Central  
Lions Club of Terang & District  
Lions Club of Tintinara  
Lions Club of Victor Harbor & Port Elliot  
Lions Club of Wynyard  
The Lions Club of Yankalilla & District



### Corporate Donations over \$200

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

### Trusts & Foundations

APS Foundation \$2,000  
The William Angliss VIC Charitable Fund \$2,000

### Independent Special Events

Luiza Monserrat Simon fundraiser  
Entertainment Books SA  
PayPay Australia  
Monaro High School Leo Club

### 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

BioMarin Pharmaceutical Australia \$27,500 Education Grant  
  
Pfizer Australia \$22,000 Education Grant  
  
Sanofi Genzyme \$68,200 Education grant

### 20th Australian Conference on Haemophilia, VWD and Rare Bleeding Disorders Sponsorship

Monies received 20/21 Financial year

BioMarin Pharmaceutical Australia	\$16,500
CSL Behring (Australia) Pty Ltd	\$20,900
Pfizer Australia	\$16,500
Roche Products	\$20,900
Sanofi Genzyme	\$20,900
Takeda	\$20,900

### 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.



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

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