SPRING 2023

THE MISSING FACTOR

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Haemophilia Foundation Victoria acknowledges the support of the Victorian Government.

HFV is committed to Child Safety.
Our Child Safety Statement is available for review on our
website www.hfv.org.au

The Missing Factor is the official publication of the Haemophilia Foundation Victoria (HFV) with four issues annually.

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HFV is funded through the Department of Health and Human Services under Blood Borne Virus Sector due to the historical impact of contaminated blood products on the haemophilia community.

HFV supports our diverse community and our magazine reflect topics that impact our community including bleeding disorders, BBVs, menta health and positive health promotion.

Editor: Yarrow Ruane

PRESIDENT'S REPORT

Hello to everyone in the HFV family!

In my first President's Report, the first thing I should mention is that it is seriously daunting to follow Leonie in this role. She has been a standout leader for us in HFV. I feel like the new coach who has to follow the triple-premiership legend! But we can't very well leave the position open. Someone needs to follow on, and I'm honoured to be chosen.

The next thing I should mention is a little bit about my background. I was born in the US with severe haemophilia B and moved to Melbourne in 2014. I got involved with HFV almost as soon as I came here. I've been on the committee since 2016 and have felt a really strong sense of community and purpose in that work.

In fact over these past ten years, as a new arrival to Australia, my sense of belonging has grown stronger through HFV than through work, study, or any of my hobbies. Part of that comes from the huge impact bleeding disorders have on our lives and the need to connect to other people who understand it. But even more than that, the quality of HFV events gave me a chance to form those lasting bonds.

I look forward to the Men's Retreat as a highlight of my year, and I hope that each of you has some favourite HFV event that you circle on your own calendar. This spring we have lots of get-togethers planned, so let's take the opportunity to keep building that community and fellowship with each other.

In October alone, we have a regional gathering in Shepparton and Seymour, two social dinners in metro Melbourne (Donnybrook and Doncaster), and the lovely walk at Albert Park to cap Bleeding Disorders Awareness Month.

I'm also excited to see what BDAM events you get up to in your own neighbourhood, whether it's baking red velvet cupcakes to share in your office or a presentation your kids give at school.

Finally, looking beyond BDAM 2023, it's vitally important that our committee represents the full range of experiences amongst HFV members. That means we want the committee to be made up of people of people with all types and severities of bleeding disorders, as well as parents and especially of members from all across Victoria.

At the moment I think there is only one committee member who lives outside of metro Melbourne, so if you live in a regional or rural area, I would be grateful if you'd consider joining a committee meeting as a guest this year. It may well spark your interest in joining for next year or some other time down the road.

To set this up please reach out to the HFV staff via email at info@hfv.org.au.

Dan Korn **HFV President**

VALE

Danny Roberts

Danny Roberts, husband of Ann and father to James, Andrew and Chantelle sadly passed away recently.

The Roberts family have been stalwarts of the bleeding disorders community in Victoria for many years, providing leadership to the foundation, and offering comfort and support to individual members and their families. Many who were engaged with the foundation in years gone by will remember Danny fondly.

At camps and other peer support events Danny was always there to support his family, a warm welcoming smile at the ready for everyone he met, always happy for a chat and a good joke. Scary tales and songs around the campfire initiated by Danny were always a highlight of HFV family camps.

When there were raffle tickets to be sold, Danny was first to volunteer, selling an abundance of tickets over the years to help raise much needed funds for the foundation.

Danny will be sadly missed. Our thoughts are with Ann and the Robert's family.

HFV Committee & staff

Report: Julie Boal

Neil and I were fortunate enough to be able to attend the 21st Australian Haemophilia Conference in Melbourne this year. What an incredible achievement it is from everyone involved in making these events a reality. To be able to bring so many stakeholders in Haemophilia care together to learn from one another is truly unique and a huge benefit to our community. When I say "learn from each other", I really mean just that. With every presentation we learn about new therapies or new coping strategies, what's on the horizon and even reflect on the past that has got us to where we are now. But just as importantly, those who are entrusted with our care, the health professionals, the researchers, the support foundations, the drug companies and the government bodies, all get to hear and appreciate first hand our stories and challenges. I hope they take those insights away with them.

I went to many sessions, so what did I learn? Well I learnt that at the moment Gene Therapy may not be the answer for everyone, yet, but big steps are being taken and a lot is being learnt from the trials underway.

I learnt that we have many great options for treatments but we mustn't stop pushing for further advancements. We also have to acknowledge that 85% of the world's Haemophilia patients don't have the same access to treatment.

I learnt that Getting Older is having a

huge impact on PWBD & their loved ones. Problems that we never thought would concern us are suddenly a reality. Heart conditions, failing eye sight, age related cancers, diabetes, and entering aged care homes with the different challenges this presents to someone with a bleeding disorder. From our own experiences of HIV in our lives now for 40 odd years we are discovering the effect of long term infection and the chronic inflammation this has caused, along with the result of extended use of the drugs that have been life saving, but have had an impact on the body. I would love to see HIV Long Term Survivor issues touched on in future conferences.

I learnt that PAIN Is Very Complicated! A message that was echoed by everyone involved in the pain session. There is no single answer to it and everyone's experience of it differs wildly, but there are many strategies that can help and finding one that works for you can be like finding gold.

I think the session I learnt the most from was the one on Rare Bleeding Disorders.

We first heard a wonderful personal story from Chauntelle who is Factor X111 deficient. She told us how she was diagnosed when having her tonsils out & it turned out both her parents were carriers. Her journey has been very eventful. While pregnant and working with her doctors to manage that, she found out she was actually having twins! She had to go on prophylaxis during her pregnancy and had 2 little girls. She has since suffered a stroke and then a seizure which required her having CPR. She now has monthly Factor X111 infusions. I'd like to thank her for sharing her story with us and wish her well for her future.

I then found out all about acquired Haemophilia A, which I knew absolutely nothing about. As Dr Campbell was presenting I was full of questions. My note pad was filling up. Luckily by the end she had answered virtually all of them. No it is not genetic, it is most common in older people around their 70's, it rarely produces joint bleeds, there is no correlation between Factor V111 levels and severity of bleeds, and the antibodies look very different in the lab. It is usually identified by extreme spontaneous bruising. It can be caused by an underlying malignancy, an autoimmune response or by infection, but in 50% of cases the cause remains unknown. The body just rejects Factor V111. Treatment is usually reserved for life threatening situations or pre surgery (if absolutely required). Treatment can include immune suppression with prednisolone and also Emicizumab with a high dose given up front. Most importantly it's taking extra care with things like blood pressure cuffs and blood tests only being performed by the most experienced people. Also using RICE with the ice being particularly important. Typically remission will occur but there remains a chance of relapse up to 3 years. We heard via video from Jenny who was generous enough to tell us about her experience of acquired Haemophilia A.

Having been around the bleeding disorder world for many years it was very eye opening to hear about these other conditions that by their very rare nature get largely forgotten. It is great to see that someone as passionate as Dr Sally Campbell certainly doesn't forget about them!

Conference highlights

I'll just finish with what is often the most important element of these conferences and that is the connections you make and the friendships you develop. The importance of this cannot be underestimated. It is so nice to be around people who "just know".

Thank you to HFA and particularly HFV for providing the opportunity for us to go. I would encourage everyone to get along to the next one if you possibly can.

Report: Tash Mahoney

Women and girls with bleeding disorders

I attended the "Women and girls with bleeding disorders" session on Friday afternoon, which was about how girls are affected by bleeding disorders.

A major takeaway for me from the session was learning about the relationship

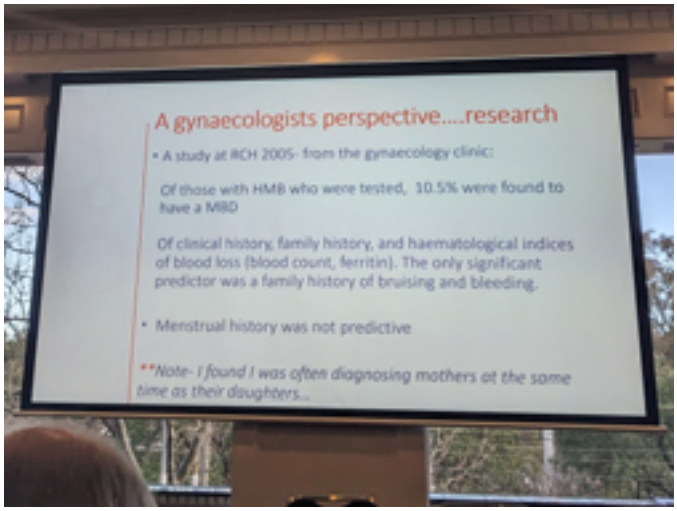


Image: Slide from Prof Sonia Grover, "Women and girls with bleeding disorders"

between endometriosis and bleeding disorders. [Gynaecologist Professor Sonia Grover from the Royal Children's Hospital talked about her research and clinical experience in this area]. The presentation really surprised me.

I would like to say please get girls with low factor in to be seen by RCH. A 10-year battle for [my daughter] Angelina's health now makes sense! Getting help earlier could possibly have helped her avoid the bigger surgeries that she now needs. In some cases, these kinds of [endometriosis] surgeries could be avoided [through early intervention].

Just because we have boys with haemophilia, it's very different seeing it in girls.

Conference highlights

Overall, the conference has had some amazing information, particularly around:

- Current and future treatments
- Girls and bleeding
- Gene therapy

Report: Fiona McDonnell

The impact of new treatments on children and families

I attended the session "The impact of new treatments on children and families". The talk covered:

1. Looking at the pro's and con's of new treatments like Hemlibra
2. The transition from Factor XIII to Hemlibra

The talk highlighted some good general information on new treatments and Hemlibra specifically. One key takeaway was about how treatments can be tailored to peoples' activity levels and around injuries, sports and hobbies. They also discussed the ease of use of Hemlibra (being subcutaneous) and how many people experienced decreased bleeding rates. Finally, the presenters touched on the fact that Hemlibra is only available to some haemophilia A patients in Australia.

A few things surprised me about the session. Firstly, I did not realise that Hemlibra works even for those with inhibitors. Secondly, it was often harder for children to detect their bleeds when on Hemlibra. One overarching issue was that needle fear was a larger problem than anticipated. A sizeable number of primary school aged children at RCH recorded needle distress. Janine Furmedge [Haemophilia Clinical Nurse Consultant at RCH] told us how it breaks her heart that children can have a negative reaction to her, seeing her as "the needle person".

Tips for Hemlibra from the session

1. Children self-administering may give them a sense of control. There is no set age for starting to self-administer – this is a personal choice.
2. Thinner needs may reduce the paid response because of the lower pressure [on the skin].
3. Take Hemlibra out of the fridge at least 30 minutes prior to administering.

Conference highlights

A big highlight was catching up socially and with advances in treatments, given that [my family] missed Hemlibra altogether due to gene therapy. There seems to be less anxiety for parents on Hemlibra. One speaker also said he feels less aches and pains on Hemlibra.

WINTER EVENTS RECAP

Youth Camp

On 23-25 June, we had an awesome weekend out in Glenmore with 17 teenagers and young adults from the HFV community. It was great to see old friends reconnecting from pre-COVID times and a few new faces as well. The fiery archery battle on Saturday will surely go down in HFV history. The Youth Camp Spirit Award for 2023 went to a well-deserving Kenneth Yeung.

Youth Camp 2023 was made possible because a member nominated HFV for a CommBank Staff Foundation Community Grant last year. Huge thanks to our wonderful community for letting us know about opportunities like this when they hear of them!

Regional Visit to Geelong

On Sunday 23 July, HFV staff and committee jumped in the car to drive down to Geelong for a visit. We had eight attendees along for afternoon tea on the waterfront, including one young family.

Despite a bit of a gloomy day, it was great to hear about what everyone has been up to over the last year or so.

WINTER EVENTS RECAP

Young Parents Morning

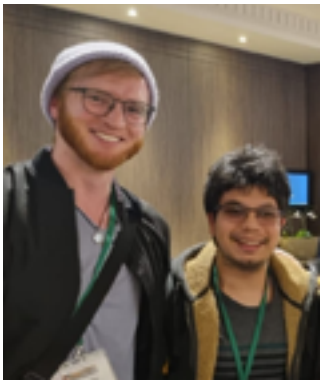
On Saturday 12 August, three lovely families joined HFV staff and committee for a casual morning tea in Doncaster. It can be a strange time for newly diagnosed families to connect with the wider bleeding disorders community, after so many recent treatment changes. However, it has been lovely bringing together different generations to learn from one another.

It is heartening to learn about the experiences of the "new generation" of children with haemophilia. We look forward to continuing to support young families as their little ones grow older and their needs change.

National Bleeding Disorders Conference

The 21st Australian Conference on haemophilia, VWD & rare bleeding disorders was held in Melbourne from 24 to 26 August. HFA pulled together a truly staggering program covering everything from making career choices to pain and rare bleeding disorders. HFV had a great showing, and it was fantastic getting to connect with people from all over Australia (and a few internationals too!).

If you didn't manage to make it this year, recordings of conference sessions will be available soon on the HFA website. We will provide an update on how you can gain access once they go up. In the meantime, check out some conference reports from HFV members on page 5 to 7 of this issue.



Ask Us: Should I Change My Treatment?

By Jane Portnoy

Dear Ask Us,

I have my haemophilia annual review at the hospital in a couple of weeks and am dreading when the doctor asks me again if I want to switch over to the new treatment.

We have discussed this new treatment at a couple of appointments, and I know that there are benefits but I still feel unsure if it will be right for me. It feels safer to just say no.

Sometime I feel silly for not just taking the opportunity and getting on with the new treatment.

Thanks for your help,

From "Uncertain"

Dear Uncertain,

You are not alone. There are lots of people, both with and without bleeding disorders, who need to take their time with these kinds of decisions.

It is okay to spend some time gathering information and then make the change when you feel ready to.

Everyone is different and taking your time will ensure that you feel as comfortable as possible about your treatment.

There are a few questions that it can help to ask...

1 Do you know **why you are hesitant** about this treatment? If so then be honest with yourself, find someone to discuss it with. If you want you can take a **support person** along to your medical appointment to help you feel comfortable to talk about your concerns.

2 There are probably **pros and cons**, have you tried listing them?

3 Is there any outstanding **information that you need to find out**, or questions that you wish to ask that will help you decide?

4 What is your **usual approach** to dealing with any change(s)?

- Are you the type of person who is **cautious of change** or do you usually embrace new opportunities?
- If you are **usually good with change**, why are you not comfortable with this change?
- Have you spoken with **someone independent** about what is going on for you regarding this particular decision? Even if you decide not to change treatments for now, this can help you accept your current position.
- What do you see as the **barriers** to your decision either way?

5 Would it help to **talk to someone** who has made this change already?

6 Would you like the social worker or nurse to **link to someone** who has done a similar change?

7 What do the other people in your **family** think?

8 Have you discussed it with **someone you trust** and whose opinion you value?

Remember that as well as your own personal support people, the team at your local HTC and your fellow HFV members are good support people. We are always happy to talk informally about these types of issues.

If you would like to chat, don't hesitate to call the HTC on 9076 2179 (in business hours) or email the social worker at: j.portnoy@alfred.org.au

Jane Portnoy is a Social Workers at the Ronald Sawers Haemophilia Centre at Alfred Health. This article was written for "The Missing Factor," 2023.

TAKING CARE OF YOUR ABDR DATA

With Julia Ekert, Marina Goruppi, Linda Mason and Deirdre Tuck

Image: Data Manager Julia Ekert at work

Julia Ekert is Haemophilia Data/Product Manager at the Department of Clinical Haematology, The Royal Children's Hospital, Melbourne, Victoria.

Marina Goruppi is Australian Bleeding Disorders Registry (ABDR) Data Manager at Fiona Stanley Hospital and Perth Children's Hospital in Perth, Western Australia.

Linda Mason is Transfusion Scientist/ABDR Data Manager Qld at the Blood Bank/Haemophilia Treatment Centre at the Royal Brisbane and Women's Hospital, Queensland.

Deirdre Tuck is Data Manager/Nurse at The Royal Hobart Hospital, Tasmania.

ABDR Data Managers Julia, Marina, Linda and Deirdre spoke to HFA about their role with Australian Bleeding Disorders Registry (ABDR) data - and had a lot to say about why the ABDR and MyABDR are an important part of the life of the patient with a bleeding disorder.

Recording accurate and consistent information in the Australian Bleeding Disorders Registry is crucial to patient treatment care and Data Managers work as part of Haemophilia Treatment Centre (HTC) teams to ensure this takes place nationwide.

Where would you find a Data Manager? There are Data Managers in every Australian state and territory. Some work full-time, while others work part-time, depending on the number of patients in their HTC. Their workplace varies. Some are based in the clinic, others in the laboratory, some work from more than one hospital, and all can work from home in a hybrid model.

The Data Managers come from a range of backgrounds - nursing, laboratory scientists and administrative streams. Their positions are administered by Australian Haemophilia Centre Directors' Organisation (AHCDO) and supported by the National Blood Authority (NBA).

No matter where they are based, the Data Managers

liaise closely and meet regularly with the Director of the HTC, Haemophilia Clinical Nurses, and other members of the multidisciplinary team.

'I work in a laboratory in an office with no windows but I share it with the HTC Director and it's a very collegial atmosphere in the laboratory.'

'I am in a laboratory as well, in an open office, and I work in the Haematology Department, very much part of the wider haematology team, not just the haemophilia team.'

'I work in an office within the HTC in both the adult and children's HTCs. I see some of the patients at the adult Centre and chat to them while I am doing other things, such as taking blood.'

What is the ABDR?

The Australian Bleeding Disorders Registry (ABDR) is the system used by HTCs around Australia for the clinical care of their patients. It is much more than a simple registry of diagnosis, with data about a patient's bleeds, treatments and the treatment plan, results of tests and other measures, hospital admissions and related clinical interventions such as surgery, and information about treatment outcomes. It also includes details about ordering, supply and use of treatment products for each individual patient.

In these days of home treatment, it is important to know what is going on outside the hospital. Since 2014 people with bleeding disorders or parents/caregivers have been able to use the app MyABDR on their mobile device or their computer to contribute data about their or their child's bleeds and treatment, along with a record of treatment stock they are managing at home.

The ABDR has evolved enormously since it was first established in 1988. Originally it was an Access database funded by Haemophilia Foundation Australia which was updated using spreadsheets provided by each HTC. In 2008, funding was provided by the NBA, and the ABDR became a national and very complex internet-based database. The role of the Data Manager was developed to ensure that accurate ongoing information was recorded nationwide and to co-ordinate the protocols for entering data into the ABDR.

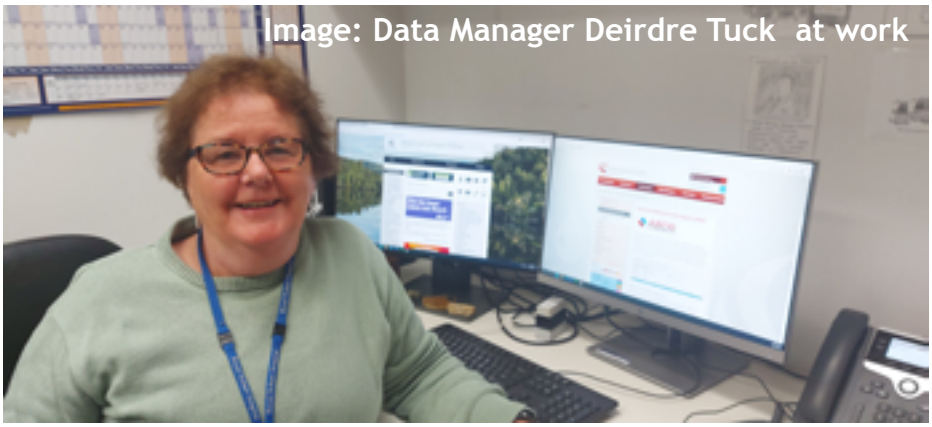


Image: Data Manager Deirdre Tuck at work

Ensuring accurate data

"We are haemophilia detectives."

The goal is to ensure that all the relevant information about each patient enrolled in the ABDR and MyABDR is accurately recorded in a timely manner.

Adding data to the ABDR is a complex task. A Data Manager's work can be like being a detective, proactively investigating and building a record from pieces of information held in different hospital files to be an accurate picture of what has happened for a patient.
Each individual patient's record will follow their treatment and care history over their lifetime and it is important that the data is correct.

It is a legal requirement that each patient provides consent to being on ABDR/MyABDR. When they have consented, the Data Manager completes all sections of information within the ABDR database. This provides a very valuable Patient Summary display in the ABDR for the treating team: a concise snapshot with a comprehensive and current overview of each patient's diagnosis, genetic information, treatment, and health outcomes. This information can be also be discussed or shared with the patient, for example, in a clinical review, in MyABDR or an ABDR patient card.

Then ongoing information needs to be recorded: bleeds, treatment product use, relevant interactions with the health system, laboratory testing, radiology investigations - including inhibitor blood tests and adverse reactions. Hospital attendance such as Haemophilia Clinic Reviews, Emergency Department attendances, hospital admissions and surgical details at HTC or other hospitals are documented.

As hardcopy documentation is being phased out in healthcare around Australia, the use of digital medical records makes the work of the Data Manager easier and less 'detective' work is required. When patients move interstate, permission for access to information is transferred via ABDR so that there is a seamless transition for patient care.

Checking and recording treatment product usage is an important responsibility of Data Managers. Home delivery information, Community Pharmacy dispensing of emicizumab (Hemlibra®) and other products, travel supplies and inpatient usage are all cross-checked and recorded. If you manage your inventory of treatment product at home, imagine monitoring a state-wide treatment product inventory! This careful work is essential to ensure treatment product is available, particularly for patients residing in rural areas, and to minimise wastage of precious supplies. It also enables accurate financial reconciliation for treatment products by the NBA.
Putting this information together and checking it involves paying close attention to the work of the HTC, accessing multiple systems and scrupulous attention to detail.

Image: Data Manager Marina Goruppi at work

'As a Data Manager you have to work out how your system works and how you will get your information because it works differently in every hospital and in every state. You get the data in many and various ways. When there's a clinic on and when there is a surgery you know you will have data to enter.'

'You are part of the team. We are sitting in the office space and we can hear that there is a clinic on, or we attend the clinic, or there are various meetings for example, at my HTC we have a clinical huddle every morning.'

'I can login to the digital medical record to verify details, for example, when people have attended the Emergency Department, or follow up on admissions or discharges. Because I am in Pathology, I have access to all of the information of every product that has been dispensed that month. So at the beginning of a new month, I can go and call up all of the information on product that has been dispensed. And it has the name and the date, and then I can go into the digital medical record and find out why it was dispensed.'

'With home deliveries, the companies have an agreement with the NBA to send a monthly report of all the deliveries to the HTCs so that we can see what product was delivered. But at the same time the product orders are checked by the HTC, the company does an inventory with the patient and then the company sends an email with the requested amount to be approved by the HTC, so we can cross-check. With Hemlibra® we now get a monthly report of the community pharmacy delivered product from the company that delivers it - when it's delivered to the pharmacy and when it's picked up by the patient.'

This work is highly skilled and benefits from access to good technology.

'Sometimes you have two or even three systems open at once, which you can do from your desktop. But you also might need to be logged into the hospital system at the same time and interpreting the clinical information from there to add it to the ABDR.'

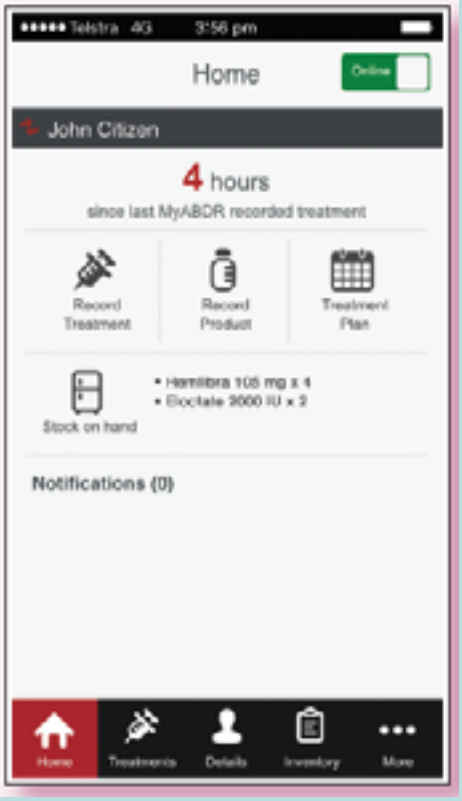
'Two screens make a big difference - sometimes three would be great!'

Privacy and security

Health information systems require very high levels of privacy and security and this has always been at the forefront with the ABDR. The database is managed by the NBA and protected by world best practice security. Moreover, access to the database is restricted and governed by the ABDR Steering Committee. Access to the ABDR by hospital staff is limited to specific health professional roles, such as the HTC team and Data Managers, and must be approved by the HTC Director. Patient privacy is taken very seriously and guarded carefully.

'We can look at hospital data but hospitals can't look at ABDR data. I always lock my ABDR screen when I am not near it, but one of the safeguards is that it closes down if you don't use it for 30 minutes. Also we don't discuss patients using names; we always use their ABDR ID number, including when we are asked to share information.'

Why record on MyABDR?



The contributions patients and parents make in MyABDR are an essential part of

the ABDR patient history. In these days of personalised treatment where people with haemophilia treat at home, the data on when and how much product they used in treatment and details of bleeding episodes play an important role in developing a treatment plan that works best for the individual.

With MyABDR the patient can record quickly on their phone and can keep a record not only of details of treatments but bleeds as well – including the part of the body, so that they can see patterns emerging.

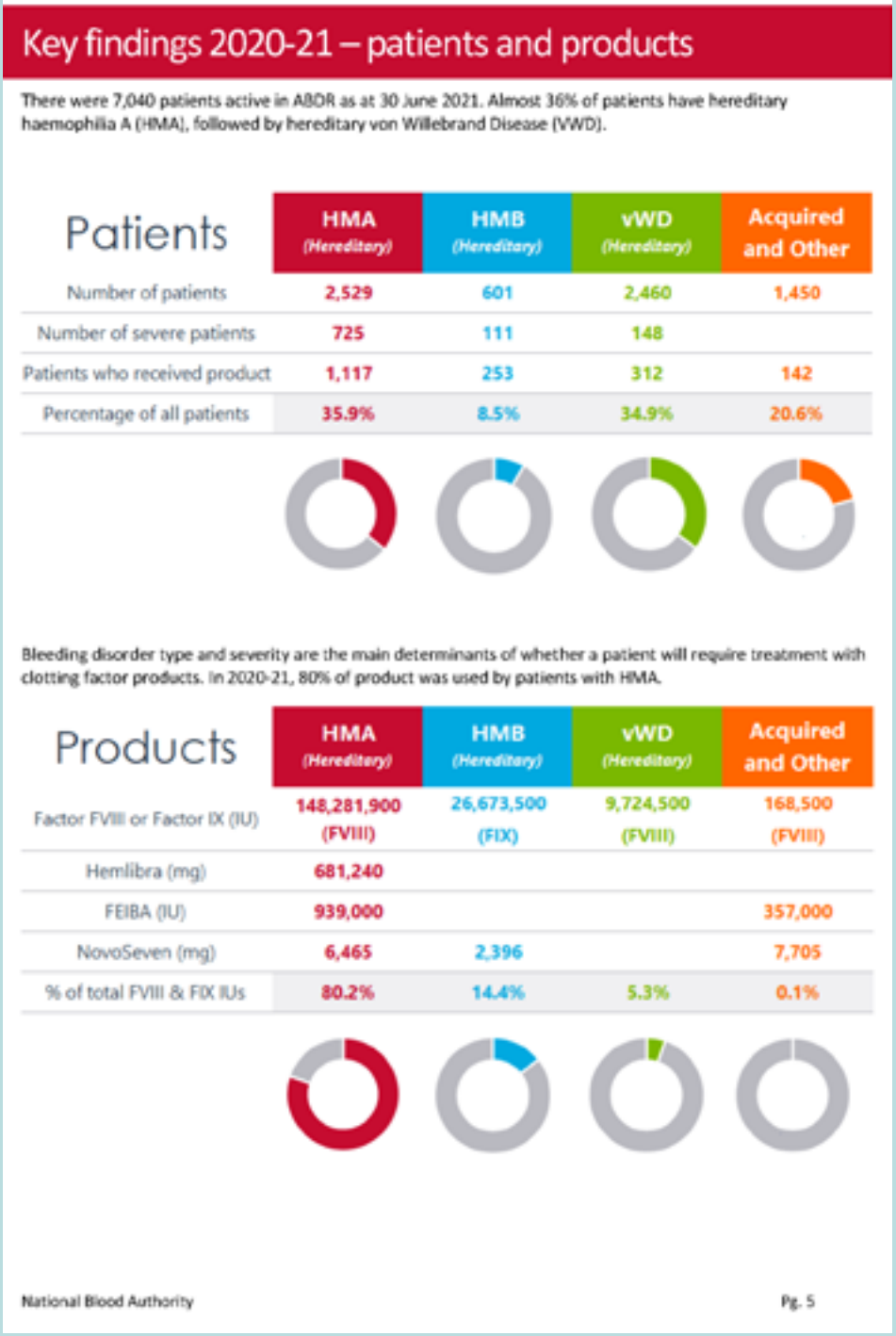
'For patients the ABDR is such a good record of bleeding events and treatments but it needs to show an accurate summary of their progress. When they are reviewed by the doctor, the doctor can look at their record and the ABDR tells a story. And now with new treatments like Hemlibra®, being able to keep a record of the dose and weight are important clinically. It means the individual can get the right dose of the medication.'

'Patients are a member of the HTC team in their home treatment. Haemophilia treatment is more of a home treatment than it ever was. In order to understand what's going on at home and whether people are having their doses as per their treatment plan, it's really important that the patients do their part and fill out their MyABDR records - so we know what's going on at home.'

'It can also show how effective treatments are. For example, one of our adult patients was constantly treating himself because he was always bleeding. He's in the third year of a new treatment now and since he's had the new treatment, he has not attended hospital. And that's very clear in the ABDR because his dosages and no admissions are all there.'

'People sometimes think we

Image: A sample of data reported in the ABDR Annual Report



Key findings 2020-21 – patients and products

There were 7,040 patients active in ABDR as at 30 June 2021. Almost 36% of patients have hereditary haemophilia A (HMA), followed by hereditary von Willebrand Disease (VWD).

Patients	HMA (Hereditary)	HMB (Hereditary)	vWD (Hereditary)	Acquired and Other
Number of patients	2,529	601	2,460	1,450
Number of severe patients	725	111	148	
Patients who received product	1,117	253	312	142
Percentage of all patients	35.9%	8.5%	34.9%	20.6%

Bleeding disorder type and severity are the main determinants of whether a patient will require treatment with clotting factor products. In 2020-21, 80% of product was used by patients with HMA.

Products	HMA (Hereditary)	HMB (Hereditary)	vWD (Hereditary)	Acquired and Other
Factor FVIII or Factor IX (IU)	148,281,900 (FVIII)	26,673,500 (FIX)	9,724,500 (FVIII)	168,500 (FVIII)
Hemlibra (mg)	681,240			
FEIBA (IU)	939,000			357,000
NovoSeven (mg)	6,465	2,396		7,705
% of total FVIII & FIX IUs	80.2%	14.4%	5.3%	0.1%

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are "nagging" them about it, but it's more that we want to give them the right medication, with the right treatments and the right doses. Some have now gone from treating three times a week to once a week, once a fortnight, once a month. If a patient records what they are actually doing, it really does make a big difference, especially to the nursing staff who are trying to track all the medication and work out when their next prescription is due and how things are going with the treatment.'

Data for research and planning

The comprehensive information entered by the Data Managers enables deidentified data to be extracted from the ABDR to support research projects coordinated by AHCDO and the Annual ABDR Report, which can be seen on the NBA website. It can answer many specific questions, from how many patients have a fibrinogen disorder to what impact emicizumab/Hemlibra® has had on the factor levels of individuals with haemophilia. Research reports from the ABDR have been presented at national and international conferences and prepared for publication in peer reviewed journals.

This can provide important evidence to understand the impact of new treatments and compare them to existing treatments – what have been the outcomes for people's quality of life, their bleeding episodes and their hospitalisations? How is this impacting on their joints?

Data from the ABDR is also central to the work of the NBA in forecasting future treatment product requirements and budgeting, essential to the ongoing supply and availability of these treatment products to Australians.

Data managers belong to the national ABDR Data Managers Group. Group members meet regularly via teleconferences and once each year meet in person (online during COVID) for study days that also coincide with HFA conference dates. Data Managers are represented on several national committees – the Research Committee, Treatment Advisory Committee and the ABDR Stakeholders Group. It is because of these opportunities that collaborative relationships have developed between the Data Managers Group, the NBA and AHCDO Members and staff, leading to a level of camaraderie that ensures the best outcomes for all.

'I work in a very cohesive environment with the HTC Director and the haemophilia nurse and the scientists. It's a pleasure to come to work with the group and all the latest developments are shared amongst us and we celebrate the improved quality of life of the patient.'

The Data Managers Group would like to dedicate this article to Debra Belleli (dec.), our beloved and dedicated colleague, who worked as a Data Manager at The Alfred hospital in Melbourne for many years. RIP 2022.

This article is reprinted with permission from National Haemophilia, the journal of Haemophilia Foundation Australia, issue No 222 June 2023.

PROBE Australia Study

The 2023 round of the PROBE Australia Study has now commenced!

What is PROBE?

What is the impact of haemophilia on Australians? What has changed since new treatments became available? What about people with mild haemophilia and women?

HFA has joined with the international **PROBE (Patient Reported Outcomes Burdens and Experiences)** study team (**www.probestudy.org**) in a multi-national and well-respected research study to provide strong and credible data about this for our advocacy. The study compares the answers of people with haemophilia and who carry the gene to other people in their community who do not have a bleeding disorder.

You may have done the PROBE survey in 2019. This is a new round of the survey.

The 2023 round will compare results now to 2019, which was before new treatments were widely available in Australia.

How can you help?

You are invited to complete the questionnaire if you are **an adult (18 years+) who lives in Australia** and:

- have haemophilia or carry the gene

OR

- do NOT have a bleeding disorder.

How to do the survey

The questionnaire is available:

- **Web version** at myprobe.org

- Or download the **myPROBE app** from Apple Store or Google Play (Android)

- Or ask **your local Foundation** or **HFA** for a **print survey pack**

Choose **Country-Australia** and **Language-English** and **CONTINUE**. The web and app surveys automatically save answers as you go so you can come back later.

What happens to your data?

The survey is voluntary. All responses are anonymous and confidential. They are combined for statistical data and will not identify individuals. You may have seen the 2019 data in the HFA Getting Older report.

More Information

For more information about the PROBE Australia study, visit www.haemophilia.org.au/research

Or contact Suzanne at HFA:
E: socallaghan@haemophilia.org.au
T: 1800 807 173

PROBE
Patient Reported Outcomes Burdens and Experiences Study

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Navigating the different Aged Care services can be confusing.

In the new HFA Getting Older Hub section on **Aged Care services and homes**, we walk through types of services and care, special issues for people with bleeding disorders and link you to more information.

Find out more at: https://tinyurl.com/GOH-Aged-care

World Hepatitis Day

28 July 2023

World Hepatitis Day is marked globally on 28 July. This is part of a worldwide campaign to see an end to viral hepatitis. In 2023 the theme is **hep can't wait**, reminding us that hepatitis C remains an important issue for our community and that acting now is vital.

In Australia many people with bleeding disorders acquired hepatitis C from their plasma-derived clotting factor treatment products or other blood products before 1993. Several safety measures were introduced by 1993 and the risk of bloodborne viruses from plasma-derived clotting factor products in Australia is now considered to be extremely low. But many people in our community live on with the consequences of those early infections.

As a Partner in the national World Hepatitis Day Campaign, HFA works with Hepatitis Australia and the state and territory Haemophilia Foundations on the annual Australian awareness campaign and is committed to making a difference on hepatitis C in Australia.

Taking action

Current hep C treatments are radically different to the early interferon treatments. They are now a once-daily tablet, with few if any side-effects and very high cure rates. Many Australians with bleeding disorders and hepatitis C have now had treatment and been cured – but some need ongoing care for their liver health.

Were you cured? Has your liver recovered?

It's a temptation to put your liver health out of your mind once you are cured. But if you don't know what your liver test results were when you were cured, don't wait to find out. Take the time to **contact your hepatitis doctor or your GP and ask them.**

Remember

If you had cirrhosis or extensive scarring before being treated and cured of hep C, you will still need to have a liver ultrasound scan every 6 months long-term.

Sadly, some people with bleeding disorders and hep C have very advanced liver disease caused by long term infection. Close liaison between hepatitis or liver specialists and Haemophilia Treatment Centres is very important for care and treatment. Research into management of advanced liver disease is ongoing.

5 ways to keep your liver healthy

A healthy liver is important to us all. Your liver has a lot of different jobs to do to keep your body working well.

These are some tips from our hepatitis

specialists to keep your liver in good shape.

1. **Have a balanced diet**
2. **Stay active and maintain a healthy weight**
3. **Avoid or minimise alcohol intake**
4. **Take care of your mental health and wellbeing**
5. **Ask your doctor if you need liver health monitoring.**

Personal stories

We are grateful to Alex and Jake for sharing their experiences with hep C – being cured and caring for their liver health. Read their stories on the HFA website at www.haemophilia.org.au/world-hep-day

Who is at risk?

For some women and men with mild haemophilia and VWD, who perhaps only had one or two treatments in their lifetime, it has been a surprise to find out they were exposed to hepatitis C.

If you ever had a blood product before 1993, including blood transfusions and plasma-derived clotting factor concentrates, **you could be at risk of hepatitis C.**

You may have been wondering about testing and not got around to it yet. But now is the time to talk to your doctor about a hep C test - and have treatment to be cured, if you do have hep C! Hep C tests are simple blood tests.

For more information

- www.world.hepatitisday.org.au
- The HFA World Hepatitis Day page – www.haemophilia.org.au/world-hep-day

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Notices & Information

BLEEDING DISORDERS AWARENESS MONTH

Each October, our community celebrates Bleeding Disorders Awareness Month through events, fundraisers and fun activities for all ages.

This is a great chance for our wider networks (friends, family, colleagues and neighbours) to learn about bleeding disorders.

The calendar insert in this issue gives a full list of the BDAM events we have planned. There's something for everyone and we would love to have you along.

The annual BDAM walk around Albert Park Lake falls on Saturday 28 October. We ask that you bring along someone from your wider network, so they can learn about our wonderful community first hand.

Bookings can be done via phone to the HFV office, or online here:

https://www.trybooking.com/CLPYN

WOULD YOU LIKE TO JOIN OUR COMMITTEE?

Have ideas about how HFV should be run? Want to help advocate for other people?

We are accepting expressions of interest (EOI) now for 2023/2024 Committee of Management (COM) positions.

Requirements:

- Lived experience with a bleeding disorder (personally or through family/friends)
- Availability to attend 6-8 evening Zoom meetings per year, typically on Tue/Wed
- Motivated to assist in decision-making, including around sensitive topics

We welcome EOI from a diversity of ages, lived experiences, and perspectives.

Please email your EOI to:
info@hfv.org.au

MEMBERSHIP RENEWAL REMINDER

The 2023/24 financial year is now well under way. Thank you to those who have already renewed their HFV memberships.

If you have not renewed yet, we request that you please do so as soon as possible. Please contact the HFV office if you require a form.

HAEMOPHILIA FOUNDATION VICTORIA INC

13 Keith Street
Hampton East VIC 3188
Phone: 03 9555 7595
Mon - Thurs 8.30am - 4.30pm
info@hfv.org.au **www.hfv.org.au**

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EXECUTIVE ASSISTANT
Andrea McColl andrea@hfv.org.au
COMMUNICATIONS COORDINATOR
Yarrow Ruane yarrow@hfv.org.au

COMMITTEE OF MANAGEMENT:

PRESIDENT Leonie Demos
VICE PRESIDENT Dan Korn
TREASURER Bernard Paes
EXECUTIVE MEMBER Donna Field

GENERAL COMMITTEE:
Ben Inglis
Chris Phong
Zev Fishman

VICTORIAN HAEMOPHILIA TREATMENT CENTRES

Henry Ekert Haemophilia Treatment Centre

Royal Children's Hospital, Flemington Road, Parkville
P. (03) 9345 5099 E. he.htc@rch.org.au

Dr Chris Barnes | Director Henry Ekert HTC
Janine Furmedge | Clinical Nurse Consultant
Erin Krake | Clinical Nurse Consultant
Julia Ekert | Administrator/Data Manager
Nicola Hamilton | Physiotherapist

Ronald Sawers Haemophilia Treatment Centre

The Alfred, 1st Floor, William Buckland Centre
Commercial Road, Melbourne 3004
P. (03) 9076 2178 E. (03) haemophilia@alfred.org.au

Professor Huyen Tran | Director of RSHC
Penny McCarthy | Clinical Nurse Consultant
Megan Walsh | Clinical Nurse Consultant
Kara Cordiner | Haemophilia Nurse Consultant
Susan Findlay | Secretary
Alex Coombs | Haemophilia Social Worker
Jane Portnoy | Hepatitis C & Haemophilia Social Worker
Abi Polus | Physiotherapist
Frankie Mullen | Physiotherapist
Catherine Haley | Physiotherapist
Diana Harte | Psychologist
Debra Belleli | Data Manager

Membership Annual Fees:

$33.00 Standard family membership
$16.50 Concession / Allied (Youth Free)
$55.00 Organisational member
* No joining fee for new members joining at the Standard Family Membership rate.

Ambulance Subscription Subsidy:

To ensure all people with haemophilia have ambulance cover, the Foundation will subsidise Ambulance Subscription Fees to the value of half the family fee.
(Members who have Health Care Cards which also cover their dependants, are automatically entitled to free Ambulance transport for themselves and their families.)

To obtain an Ambulance Subsidy:

Forward subscription receipt (or a copy) to the HFV Office with your contact details. Subsidies will be paid on a reimbursement basis.

MedicAlerts

MedicAlerts: A subsidy of 50% of the first purchase price of any MedicAlert, (with the subsidy payment being up to $30 in value and not including the annual fee) is now available. To obtain a subsidy, forward a cover letter and receipt to the HFV Office.

Live Well Funding:

All current financial members can apply for Live Well Funding for any item or activity which the applicant anticipates will contribute to a positive health outcome. Priority may be given to funding applications for items or activities related to the management of bleeding disorders and associated health conditions.

Care and Counselling:

This is available through your treatment centre.

Magazine:

MEN'S GROUP

Our current group meet for their Annual Men's Retreat - a much needed weekend away that included massages, relaxation and meditation. In 2022, 11 members attended the retreat, including a Tasmanian! Many promised to return after making powerful connections with their peers. There are also opportunities to meet for brunch and lunch during the year.

WOMEN'S GROUP

The group meets once a year over lunch and each alternate year get to enjoy an event with a twist. They have previously learnt circus skills, African drumming, attended relaxing massages, high tea on the Yarra and lunch on the Tram Restaurant. If you have an idea for a ladies day, let us know! We are always looking to try new things.

YOUTH GROUP & BLUE SHIRTS

After a successful reunion at 2022 community camp (with lots of new leaders coming on board) the Blue Shirts will be meeting up in September 2022 for an Amazing Race through the Melbourne CBD. HFV have lots of leadership opportunities available for young people looking to have fun and challenge themselves.

GRANDPARENTS GROUP

WE ARE CURRENTLY LOOKING FOR A NEW CONVENOR FOR THIS GROUP. IF YOU ARE INTERESTED PLEASE CONTACT THE HFV OFFICE.

KIDS EVENTS

We have opportunities for kids to connect throughout the year. Recently, several families met for an indoor climbing day. Check out our events schedule for upcoming kid-friendly activities.

Bleeding Disorders Awareness Month

OCTOBER 2023

WORKING TOGETHER

Find out more!

WHAT IS A BLEEDING DISORDER?

Haemophilia

- A rare genetic bleeding disorder where the blood doesn't clot properly
- Caused by an alteration in the gene making clotting factor VIII (8) or IX (9)
- Usually inherited, but 1/3 of people have no previous family history
- A lifelong condition and can be life-threatening without treatment
- Treatment can help prevent repeated bleeding into muscles and joints, which causes arthritis and joint problems
- Most people diagnosed with haemophilia are male
- Women and men can have the genetic alteration causing haemophilia and pass it on to their children
- 20-30% of females who carry the gene alteration have bleeding problems and may have haemophilia, usually mild.

von Willebrand disease (VWD)

- A hereditary bleeding disorder
- Occurs when people do not have enough of a protein called von Willebrand factor in their blood or it does not work properly
- Bleeding problems can vary a lot between people with VWD. Some people experience little or no disruption to their lives unless they have serious injuries or surgery, and others bleed quite often. There can be bleeding problems with all types of VWD.
- Many people are not aware they have the disorder and are currently undiagnosed
- Both men and women can have VWD and pass it on to their children.

Other bleeding disorders

- Other bleeding disorders include rare clotting factor deficiencies and inherited platelet disorders
- Factor XI (11) deficiency is the most common of the rare bleeding disorders, estimated at 1 in 100,000 people, and is the third most common bleeding disorder to affect women after von Willebrand disease and haemophilia.

How common?

In Australia there are more than 7,000 people diagnosed with haemophilia, von Willebrand disease or other hereditary bleeding disorders.

1800 807 173

www.haemophilia.org.au

HAEMOPHILIA FOUNDATION AUSTRALIA