National Haemophilia
Haemophilia Foundation Australia
www.haemophilia.org.au
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2020 - GET+INVOLVED

CONTENTS

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Editor: Suzanne O'Callaghan

It's not too late to complete the **PROBE (Patient Reported Outcomes Burdens and Experiences)** questionnaire!

The survey is available at https://tinyurl.com/PROBE-Australia.

Or ask HFA or your Foundation for a print copy

HOW WILL PROBE HELP PEOPLE WITH HAEMOPHILIA?

PROBE is a multinational study where Australians can give evidence about living with haemophilia and the impact of different sorts of treatment on their bleeds, pain and quality of life.

HFA will use the data to better understand current issues - and this data is crucial for our treatment advocacy.

You are invited to complete the survey if:

- **you are an adult with haemophilia or carry the gene**
- **or you are an adult and DON'T have a bleeding disorder (as a comparison group)**

Consider being involved to help us with this important study!

ANY QUESTIONS?

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

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

Gavin Finkelstein is President, Haemophilia Foundation Australia

FROM THE PRESIDENT

Gavin Finkelstein

2020 WFH WORLD CONGRESS

The 2020 WFH World Congress will be held in in Kuala Lumpur, Malaysia from 14-17 June.

Australia has a long history of involvement in the Congress and was represented at the very first World Federation of Hemophilia Congress in 1963. The Congress is held in a different country every two years, which is decided through a bidding process. It seems so long ago now that our bid 'a la Olympics' style was successful in Buenos Aires, Argentina in 2010. Australia stood proudly as the co-host with WFH in 2014 when the World Congress was held in Melbourne. It took a solid four years of planning and we were delighted to be involved.

After the Melbourne Congress people told me how that Melbourne meeting had helped them: so many people took time off work and away from their families to join the camaraderie of the global meeting in Melbourne to hear and learn more about living with a bleeding disorder, and to find out about the new treatment pipeline.

It is a great time to go to another Congress – and with the June meeting in our own region there is the benefit of shorter travel times, lower costs and time away.

Importantly, the KL meeting comes at a very important time in the development of treatment and care for haemophilia. Never have we known so many new treatments in development which promise better outcomes for our health. It is important for us to realise some of the trial drugs may not reach the market in the long run because they do not end up being safe and effective, or they will not be practical from a commercial point of view, but we can expect a range of different types of treatments to become available over the next few years. It is important that we take personal responsibility for staying on top of our future treatment options. Congress is a great way to hear about these developments and how they will improve our lives.

CONNECTING TO OUR GLOBAL COMMUNITY

For those of us involved in representing the bleeding disorders community, the Congress puts it all in perspective. We see 'up very close' just what the issues are around the world for people with bleeding disorders and the ways we can step up our efforts to influence care and treatment in Australia and other countries. We can learn from the advocacy experiences of others, and pick up on emerging issues that might later become barriers to treatment access. In Australia in the last few years our community has not had timely access to new treatments and we need to find ways to improve this.

We also look forward to using the Congress opportunity to meet with our Myanmar Twinning partners. Sam Duffield, an HFNSW member, and Leonie Demos, President of HFV, have met with the Myanmar patient group to explore ways HFA and Myanmar can work together to improve treatment and care in Myanmar and to help the patient group there to develop new skills in advocacy and representation. Our joint application to WFH to become formal twinning partners in the WFH Haemophilia Organisation Twinning Program has recently been approved so we can use the opportunity to make forward plans.

THINKING OF ATTENDING?

Congress program details can easily be found on the WFH Congress website - www.wfh.org/congress/

Note that the regular registration period ends 17 April 2020, and after that you will need pay for a late registration. HFA or your local Foundation may be able to assist you with financial support for your registration fee so do think about whether you can attend.

At the time of printing, there is still global concern about coronavirus (COVID19) and you are encouraged to get advice from relevant authorities and your doctor. The Australian government provides details at **Smart Traveller** - www.smartraveller.gov.au/news-and-updates/coronavirus-covid-19 .

WORLD HAEMOPHILIA DAY 2020

GET+INVOLVED 17 April 2020

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.

17 April 2020 is the 30th anniversary of World Haemophilia Day! The longevity of this celebration is proof of the dedication and tight-knit nature of our community.

The theme of World Haemophilia Day in 2020 is **Get+involved.** Whether you are a person with a bleeding disorder, a family member or caregiver, a corporate partner, a volunteer, or a healthcare provider, we want to encourage you to help increase the awareness of inherited bleeding disorders and the need to make access to adequate care possible everywhere in the world.

LIGHT IT UP RED

Landmarks and monuments in Australia and around the world will support World Haemophilia Day by changing their lighting red on 17 April 2020.

Show your support on the night, and post photos on our Facebook page of you and your friends at the landmark. #WHD2020

Keep an eye on our website and Facebook page for a list of locations that will be supporting the day. We have some new and old places, and a location in every state/territory. We would love you to share your photos and pictures on the day.

HFA Website – www.haemophilia.org.au

HFA's Facebook page - www.facebook.com/HaemophiliaFoundationAustralia.


WORLD HEMOPHILIA DAY
2020 | APRIL 17
GET
+IN
VOL
VED
facebook.com/wfhemophilia
Find important educational resources and hear from top experts at
elearning.wfh.org
@wfhemophilia
Comment, tweet, follow and hashtag #WHD2020 to stay social!
WORLD HEMOPHILIA DAY
APRIL 17
Celebrating
30 years
WFH
WORLD FEDERATION OF HEMOPHILIA
FÉDÉRATION MONDIALE DE L'HÉMOPHILIE
FEDERACIÓN MUNDIAL DE HEMOFILIA

JOIN US FOR THE AUSTRALIAN PREMIERE OF *BOMBARDIER BLOOD*!

Join us to celebrate **World Haemophilia Day** on Friday 17 April 2020 with the **Australian Premiere** of *Bombardier Blood* followed by a ride on the Melbourne Wheel as it turns red in support of the day!

Bombardier Blood is a powerful documentary about Colorado-based Mountaineer Chris Bombardier, who has never let haemophilia stop him from climbing some of the world's tallest mountains. In 2017, Chris partnered with filmmaker Patrick James Lynch, who also has haemophilia, to film his journey through Nepal to summit the world's tallest peak, Mount Everest.

Bombardier Blood Australian Premiere Friday 17 April - 6.45pm for 7pm start

Hoyts Docklands, Melbourne

Followed by ride on the Melbourne Wheel

Ticket Price: $28 (adult) and $23 (child) including movie and Melbourne Wheel ride (movie only tickets are also available)

To purchase tickets, visit https://www.trybooking.com/BIPRL

For more information contact HFA 03 9885 7800 or email donate@haemophilia.org.au

The film will also be shown in other states. Check with your local Foundation.

GOING FOR it

The HFA Go For It Grants program provides awards to inspire and support people affected by a bleeding disorder to achieve new personal goals. This might be for a new personal challenge, such as an adventure activity which tests the person's emotional and physical abilities, or an activity that enhances existing skills and interests and creates new opportunities.

Mark received a Go For It Grant in 2019. The Grant enabled him to pursue a strong personal interest in cyber security and to undertake a stimulating course, which provided him with new information and learnings to apply in his work. He spoke to HFA about his experience with the Grant and the personal impact for him.

The HFA Go For It Grants program is sponsored by Pfizer.

The Go For It Grant allowed me to enrol in an online course in Cybersecurity with RMIT University. I had held an interest in this field for the last few years, but hadn't done anything about it. I teach Japanese at a local high school but have always been interested in technology and its applications. I am often the go-to person at work for technical support advice when the I.T. support crew is unavailable.

CYBERSECURITY

The Cybersecurity course is fascinating. There are so many functions these days that involve some level of network communications. Even our televisions, fridges and telephones now are 'smart' and rely on network access. This means that they also are open to receiving information, including corrupted information designed to disrupt or give another person control to information (malware).

My course has taught me to be able to run a risk assessment for my workplace and identify some large vulnerabilities in the network. The risk assessment highlighted a number of areas of concern, but allowed me to focus on one area in particular that would have devastating consequences to our college. I was able to establish some protocols designed to mitigate or avoid the risk and also come up with an incident response plan should a breach of network security occur. I will table this and present it to our college Principal for his consideration.

WHAT I TOOK AWAY

I became interested in studying cybersecurity when I heard my nephew planned to study forensic computing at university. I thought it sounded fascinating and had wished I'd had the opportunity to do the same.

I've been teaching since 1991 and had also done some work helping people learn to use computers and generally troubleshoot and repair issues. My role as a teacher doesn't require me to be particularly skilled in cybersecurity but there seem to be generally a rise in the types and complexity of cybersecurity attacks.

I think that generally speaking cybersecurity is often either ignored or underestimated and that we often overlook some very basic strategies of controlling information and resources yourself. My father-in-law recently was convinced he was talking to a Telstra representative as they had called with his billing information, address and telephone number and persuaded my father in law that he needed this person's assistance to eradicate a virus on his network. He was being swindled and could have lost a significant amount of money had he not been vigilant and sceptical. Human error in clicking on and accepting phishing emails or disclosing personal information is one of the big risks we run in today's internet connected world.

In the future I hope to use what I have learnt from the cybersecurity course to assist the organisation I work for to become more aware of potential breaches in cybersecurity and more vigilant and active in controlling threats.

This was made possible by the Go For It grant. Thank you so much for allowing me to pursue an interest I've held for quite a long time.

Nicoletta Crollini is the Haemophilia Social Worker, Royal Prince Alfred Hospital, Sydney

LONELINESS

Nicoletta Crollini

According to the *Australian Loneliness Report*, loneliness is experienced by 1 in 4 Australians and people under the age of 65 report experiencing higher feelings of loneliness. Even though we might associate loneliness with growing older, an article I read recently explained that loneliness is not just something experienced by the elderly, who in fact report to feel the least lonely in society.

How do we define loneliness? It can be defined as the feeling or perception of being alone and separate from people. In contrast, social isolation is defined as physically being apart from people. Thus, loneliness is unique to every individual. You can physically be alone but not feel lonely, or you can be surrounded by many people and feel lonely.

Research shows loneliness focuses on the quality of relationships we have and not the quantity. A quality relationship is a meaningful connection where the individual feels understood by others.

Some facts about lonely people:

Lonely people report having poorer health, both physically and mentally, than those who feel more connected.

Lonely people have increased levels of depression and anxiety regarding social interactions.

Additionally, higher levels of loneliness are associated with increased levels of social interaction anxiety, reduced social interaction, poor mental wellbeing and a poorer quality of life.

STRATEGIES FOR CONNECTION

So, with all this loneliness doom and gloom, how can one feel less lonely and more connected?

- **Think positively and do not worry or overthink social interactions**. Try to shift your focus from how you are being perceived to what you are discussing and the person you are talking to.
- **Stop comparing yourself to others and how many friends they have**. Remember, it is about the quality of relationships and not the quantity.
- Change is a normal part of life. **Accepting change or welcoming it** means that you are prepared or can adjust to moments when you lose significant individuals from your life, which is inevitable.
- **Contextualise discomfort, as social interaction anxiety may stop you from socialising**. The feeling of awkwardness does not mean you have done something wrong. Continue to reach out to people, and over time your skills will improve.
- **Preparation can be useful for when the conversation slows down**. You can prepare questions or discussion points for this moment, for example, what movie has the person recently seen, have they travelled or been to a museum lately?
- **Actively listen to the person you are speaking with**. Listen to the person's response when you ask them a question, rather than waiting for your moment to speak. Paraphrase what they have said to you, as this will ensure the person is aware you are genuinely listening to them. Focus on your posture, facial expressions and the words you say. Say their name while speaking to them or anyone else in connection to them, such as their mother's name or pet name. Once again, this highlights that you care and have been paying attention.
- **Take a rest from social media.** This might be a great way to feel instantly connected to people. Social media can be a way of focusing on the quantity of relationships and not quality. Try to create and maintain a healthy offline life. It might be an idea to arrange a meet-up with trusted online friends.
- **Explore unexpected moments of social interaction**, smile at a stranger or make eye contact with people a little more often. Unexpected social interaction can be a way to improve your mood instantly.

- **Help someone out, or ask for help if you need it**. Join in a local community group, volunteer or attend your next local haemophilia event. Helping someone out or sharing an activity with someone is an instant way to feel connected.
- **Reconnect with people from your past.** Most people will welcome this reconnection and feel that you care. It might be an idea to meet at a place that has significance or where you shared fun experiences.
- **Stress management is key.** Figuring out a way to manage your stress, such as deep breathing or mindfulness, can help you through stressful moments.
- **Spending time with pets** can also be a way to reduce or ease feelings of loneliness. If you do not own a pet, arrange to spend time with a neighbour or friend's pet.
- **Chat with your HTC social worker or psychologist** if you are worried or anxious about social interactions as we can help support you and assist in building up your social skills.

Loneliness might not be specific to the haemophilia and rare bleeding disorder community; however, it is something we all experience. Having the knowledge and ability to identify and respond to feelings of loneliness can have positive impacts on our physical and mental health that are instantaneous.

1. REFERENCES

2. Australian Psychological Society; Swinburne University of Technology. Australian loneliness report: A survey exploring the loneliness levels of Australians and the impact on their health and wellbeing. APS; SUT: Melbourne, 2018. <https://psychweek.org.au/wp/wp-content/uploads/2018/11/Psychology-Week-2018-Australian-Loneliness-Report-1.pdf>
3. Lim, M.. The young Australian loneliness survey: Understanding loneliness in adolescence and young adulthood. Victorian Health Promotion Foundation: Melbourne, 2019 <https://www.vichealth.vic.gov.au/-/media/ResourceCentre/PublicationsandResources/Social-connection/The-young-Australian-loneliness-survey-Report.pdf>

Preetha Jayaram is the HFA Getting Older Project Officer

GETTING OLDER PROJECT UPDATE

Preetha Jayaram

GETTING OLDER NEEDS ASSESSMENT

We have reached the final stage of the **Getting Older Needs Assessment**. This is a key part of the HFA Getting Older project. The project aims to identify, understand and respond to the range of needs people with bleeding disorders may have as they grow older, and help find appropriate solutions for them and their partner/family or friends/carers. It reflects HFA's commitment to supporting active, independent and fulfilling lives for people in our bleeding disorders community and you will see this in the types of recommendations and solutions proposed.

The HFA Getting Older needs assessment uses an 'evidence-informed' approach – it recognises that lived experience, expertise relating to clinical practice and evidence from current research each have a role to play in identifying and exploring the full range of issues. We started by scoping out the issues with some initial interviews and other consultation and then extended the project across Australia. We collected data using interviews with community and health professionals, holding community forums, and meeting with other agencies working in related areas. We also collated age-related data from the Patient Reported Outcomes of Burdens and Experiences Study (PROBE) study.

The scoping also identified the need for a wider engagement with the community – beyond those we could interview or who completed the PROBE questionnaire - and so we developed an anonymous community survey to collect national data. This was our way to hear from the wider bleeding disorders community about what is needed and the strategies and services that would help with getting older.

The project also involved establishing a national Consumer Focus Group to develop and test digital solutions for peer support and education. The Focus Group met in November 2019 and has given some valuable and creative ideas and feedback. They will continue to be involved in the development of solutions, such as the Getting Older Information Hub.

The Getting Older Project has had a great response from the bleeding disorders community nationally. To those who gave their time to participate in our Getting Older face-to-face and telephone interviews, forums, the community survey and the PROBE study, and the focus group, I thank you individually for your unfailing support. This is new territory for the bleeding disorders community and your contributions have been invaluable.

We are currently finalising the needs assessment report. Look out for the summary in the June issue of *National Haemophilia.* The full report will be available in print and downloadable from the HFA website.

INFO HUB

As a first step in our digital solutions, we have been working on an online information hub for the HFA website with resources on getting older with a bleeding disorder and peer support options. The information hub will grow and develop over time as we explore the issues raised in the needs assessment. It is currently being designed with the assistance of the HFA Getting Older Focus Group and will be available soon – watch this space!

WHAT'S NEXT?

The Getting Older needs assessment report will include recommendations, including areas to explore further. The aim is to start a discussion both the community and health care providers about where to go next with the recommendations and to look at ways to achieve them. We would value your input and you will have opportunities to provide more comments and suggestions.

My role in the Getting Older Project was a 12-month position and is now drawing to a close. Being involved as the Project Officer in HFA's Getting Older Project has been a unique opportunity in my career history. I thank you individually for sharing your stories with me and giving me a wealth of knowledge and life experiences to take away.

ANY QUESTIONS?

If you have any questions about the Getting Older Project or needs assessment report, please contact Suzanne at HFA

Phone: (03) 9885 7800 Tollfree: 1800 807 713
Email: socallaghan@haemophilia.org.au

This article was published in *The Missing Factor* Spring 2019, the newsletter of Haemophilia Foundation Victoria (www.hfv.org.au), and is adapted with permission.

Robyn Heal and Cara Gannon have VWD Type 1 and are HFV Committee Members

SHARING OUR JOURNEY WITH VWD

Robyn Heal and Cara Gannon

Robyn and Cara are committed to raising awareness about von Willebrand disease (VWD) and helping women and girls with bleeding disorders to connect.

They are participating in the HFA digital stories project, which includes a video series where they talk about their experiences of living with VWD. The first video from this series was released on World Haemophilia Day in 2019. In it Robyn and Cara speak about how important it is to meet other women and young people with bleeding disorders and how valuable they have found Foundation activities such as camps and conferences as an opportunity to connect and make new friends in a relaxed environment.

To watch the video, visit the Digital Stories section on the HFA website - https://tinyurl.com/HFAdigital-connecting

ROBYN'S STORY

I was diagnosed with von Willebrand disease (VWD) Type 1 in my early forties. My brother was going in for surgery and his doctor wanted him to be tested for any issues that might arise. This is when we first found out about VWD. It turns out our mother was the one who has VWD and has passed it down to my brother and me. My father had haemochromatosis and he passed that down to my other brother. I have two daughters and both have VWD as well.

When I was younger I had lots of nose bleeds, very heavy periods and always would bleed from small paper cuts. I have suffered with low iron all my life and have to take iron tablets as well as eat high iron foods.

Raising awareness

I found out about my local foundation, Haemophilia Foundation Victoria (HFV), through the local Haemophilia Treatment Centre. I attended a national conference in Melbourne and became an HFV Committee Member as I feel there's not enough information about VWD and I feel that we don't really get noticed or we get brushed off. I want to raise

awareness about VWD in the wider community and help increase knowledge of VWD among health professionals.

I don't believe many doctors or nurses are informed about VWD or how to treat people with VWD. I've attended hospitals for surgery and the hospital would clear the day of patients as they didn't know if they would have an issue with me. The nurses would google my condition in front of me, so they knew what VWD was. I would hear them talking about how to mix DDAVP (desmopressin) and they had no idea what not to do after having DDAVP.

We may be seen as a low risk group of 'bleeders' (although some people with VWD have severe episodes) but there is not enough awareness and support for our condition. VWD is the most common type of bleeding disorder but we rarely hear about it. Some people with VWD may have few symptoms but there are others like myself and my girls who do have issues that affect our day-to-day lives. I have suffered throughout my life with joint pain and so have my girls. I would love to know if anyone else who has VWD has any issues that they are curious about.

VWD is the most common type of bleeding disorder but we rarely hear about it. **ROBYN**

CARA'S STORY

My name is Cara and I was diagnosed with von Willebrand disease Type 1 at around 12 years old. I was tested for VWD as a result of my uncle's diagnosis, on my mother's side.

My uncle was tested because of a surgery and his doctor wanted to be thorough to ensure there weren't any complications. My mother and sister both have VWD, though they didn't have the same symptoms as me. They were also diagnosed when I was. Looking back, I did have some of the symptoms, mainly nose bleeds, which I have had all through my childhood.

Having VWD has mainly affected the medical side of my life, and luckily hasn't affected my personal life too much. It has been useful to know about, as I've had a surgery where I was able to have a treatment beforehand to control bleeding, as well as treatment in preparation for tattoos. I've found that not a lot of people are informed about VWD and that can be troublesome, like having to explain to some doctors what it is, and how to treat it. There are some great resources that I was given by my HTC that explained what VWD is, as well as some resources from my Foundation that also included other people's stories.

I learnt about HFV, my local Foundation, while attending the national conference for bleeding disorders, where I met part of the HFV committee, and other youth from Victoria, as well as others from across Australia. My mum and I decided to become Foundation members to be a part of a community with others who can help us understand our disorder, and connect with other people with bleeding disorders. I joined the Committee to bring the perspective of a younger generation, which will always be important to help Foundations to appeal to their younger members. Through my local Foundation I would like to connect with more people with VWD. I feel like people with VWD don't get involved as much as they should with their Foundations and it would be a great opportunity to meet people with the same disorder as me, and share our stories with each other.

I hope that there will be more education provided to doctors about VWD, so that a doctor at a hospital doesn't have to be taught about a condition by their patient, and I hope for more awareness and peer support groups, as I was never able to meet any other person witha bleeding disorder until I found my local Foundation. Having VWD has opened up new opportunities for me and it will be exciting to see where those opportunities will lead.

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ABOUT VON WILLEBRAND DISEASE (VWD)

People with VWD (also known as von Willebrand disorder) have a problem with a protein in their blood called von Willebrand factor (VWF) that helps control bleeding. They do not have enough of the protein or it does not work the way it should.

VWD is the most common inherited bleeding disorder worldwide. The altered gene causing VWD is passed on from parent to child. VWD affects males and females equally.

Most people with VWD have few or no symptoms and it causes little disruption to their lives, except when they have a serious injury or need surgery. As a result, many have not yet been diagnosed. Some people with VWD have bleeding episodes more often, and people with the severe form can often have bleeding into muscles and joints with no obvious cause, similar to severe haemophilia. There can be bleeding problems with all forms of VWD.

Common symptoms
Bleeding in VWD usually involves the mucous membranes, the delicate tissues that line body passages such as the nose, mouth, uterus, vagina, stomach and intestines.

Symptoms vary from person to person, even in the same family, and can include:

- nosebleeds, bleeding from the gums
- bruising easily
- bleeding for a long time with minor cuts
- very heavy or long menstrual periods
- excessive bleeding after injury, surgery or dental work, or after childbirth.

Treatment
Several treatments are available, depending on what is appropriate for type of VWD and the individual at the time. This includes synthetic hormones such as desmopressin (DDAVP) and clotting factor concentrate made with von Willebrand factor and factor VIII.

1. SOURCE:
2. Haemophilia Foundation Australia. About bleeding disorders. Melbourne: HFA, 2018.
3. https://www.haemophilia.org.au/publications/bleeding-disorders

Having VWD has mainly affected the medical side of my life, and luckily hasn't affected my personal life too much. It has been useful to know about, as I've had a surgery where I was able to have a treatment beforehand to control bleeding, as well as treatment in preparation for tattoos. **CARA**

Megan Walsh and Penny McCarthy are Clinical Nurse Consultants, Ronald Sawers Haemophilia Centre, Alfred Health, Melbourne

Amy Finlayson is Haemophilia/Haematology Clinical Nurse, Queensland Children's Hospital, Brisbane

TRAVEL TIPS

Megan Walsh, Penny McCarthy and Amy Finlayson

Travel, whether it is for business or pleasure, has become a part of our lives. For people with bleeding disorders planning is essential.

Here are a few tips to help make your travel a success.

INTERSTATE TRAVEL

Haemophilia Treatment Centres

It is a good idea if you intend to travel interstate to let your Haemophilia Treatment Centre (HTC) know you are travelling. It may be helpful for your HTC to advise the HTC in the state or territory where you will be travelling of your presence, just in case you run into problems.

Each HTC has different hours of operation. It is a good idea to check in advance with the HTC in the state or territory where you are travelling so you know when health professionals are available and how to access treatment if you need assistance, or where to attend if the HTC is too far away. Haemophilia and other bleeding disorders are rare and not all hospitals have the expertise or treatment you find in your HTC.

Contact details of HTCs around Australia are on the HFA website:

www.haemophilia.org.au/support-services/treatment-services

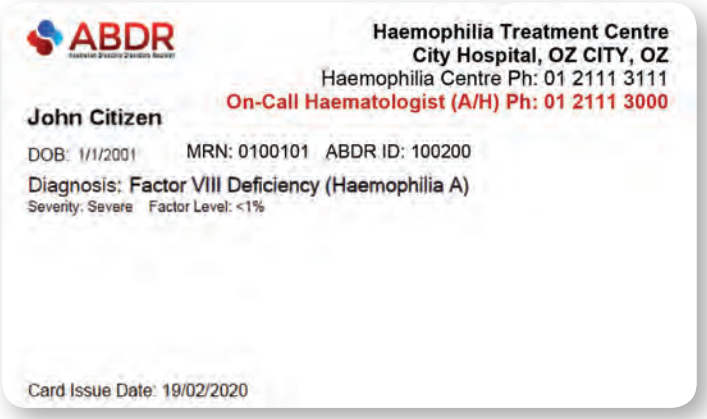
Emergency treatment card

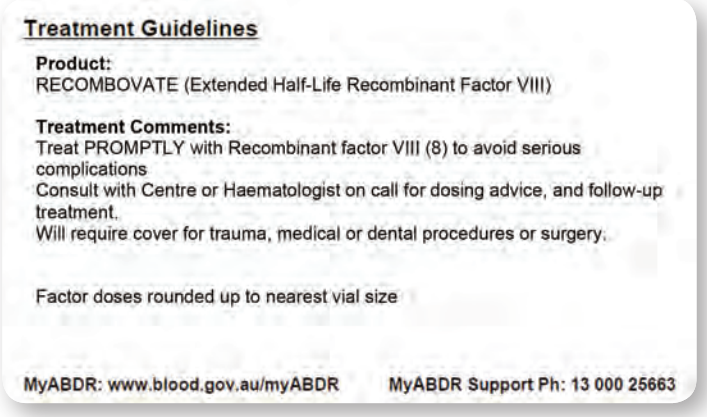
Carry your ABDR patient card as this is enough information to initiate emergency treatment in Australia if needed.

Your ABDR patient card explains your diagnosis, what treatment you should be given and who should be contacted for further advice. If you don't have an ABDR patient card, ask your HTC to request one for you.

If you treat at home

- Take your treatment product with you.
- Carry enough of your treatment product with you for your stay. This is particularly important if you have changed to one of the newer products as some HTCs may not stock the full range of products or carry the full range of vial sizes.





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- If you run out of factor while away, most HTCs would require you to visit the HTC and see a doctor for any product to be issued to you, even if you wanted to top up your prophylaxis stock. This is because factor is a prescribed medication.

- If you have an extended trip planned and your scheduled home delivery date is in that time, you may be able to have your delivery redirected to your holiday accommodation. This does require some advance planning and needs to be discussed with your HTC.

Product transport and storage

If you are flying, ask your HTC to provide a letter stating that the factor and needles and syringes must be carried on board in the cabin section, as the baggage hold in a plane is exposed to extreme temperatures which may affect the factor.

If your child has an implantable port-a-cath device, please ask your HTC to provide a letter stating that factor and port-a-cath consumables must be carried on board in hand luggage. You may not be asked to show the letter but better to be safe than sorry! And there is nothing worse than you arriving in Tasmania and your luggage arriving in Darwin!!

- The factor can be put through the scanner in airport security without harm.

- **For all travel,** carry your product in a cooler bag. Even though most products can be stored at room temperature, it is very easy for them to overheat in hot weather particularly in cars or when camping. Do your best to keep it cool.

- Always ensure you use the remaining product first when you return home.

OVERSEAS TRAVEL

Planning

Planning is essential!

www.Smartraveller.gov.au has all the general information you need, but having a bleeding disorder requires extra planning.

With notice your HTC can provide a travel letter suitable to for customs that will allow you to take factor out of Australia and bring any remaining vials home. You will also require a medical letter from your haematologist in the unlikely event you need medical attention while away.

Travel insurance

No matter how fit and healthy you are, you can't afford to travel overseas without travel insurance.

You must have travel/medical insurance and the level of cover should include a medical evacuation/repatriation in the case of emergency, particularly if you are travelling to countries where there is limited or no access to haemophilia care. In many countries, even if you are able to get a similar level of care to what you would expect in

Australia, you would be paying full price for all costs for your treatment and care, which could end up being over $100,000 for a single hospital stay.

The Australian government has reciprocal healthcare arrangements with several countries, including the United Kingdom, Republic of Ireland, Slovenia, Malta, Italy, Belgium, Norway, Sweden, Finland, the Netherlands and New Zealand. Australian travellers will be treated free of charge in these countries for emergencies. See **www.medicareaustralia.gov.au** for further information about access to health care in these countries, especially if you have other medical requirements in addition to your bleeding disorder.

Check your travel insurance fine print to make sure that it will cover everything you will need, including your bleeding disorder.

To have cover for haemophilia you must declare it as a pre-existing condition. You may be required to pay an additional premium for this level of cover. If you do not declare your bleeding disorder, your insurance may be deemed void if medical care is required.

It is worth considering having all your documentation letters translated if you are travelling to non-English speaking countries

Cruises

Cruise cover should include medical expenses, as there is no Medicare when you're on a cruise ship. This means you could be facing exorbitantly expensive international medical rates for something as simple as asking the doctor for some anti-nausea medication.

Hospitalisation costs on board can cost as much as $5,000 a day – and all consultations, treatments and medications are charged at private rates. Repatriation costs to get you home from an overseas port can run up to the tens of thousands.

Immunisations

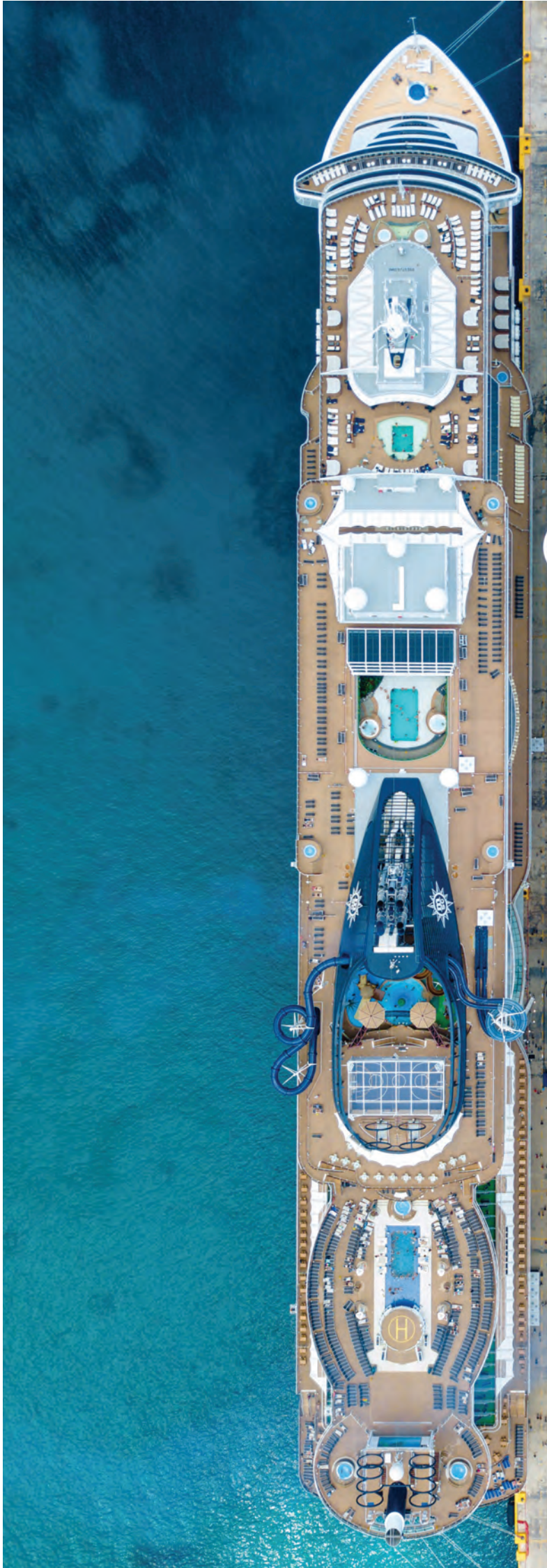
Immunisations are necessary for some destinations and you should check well ahead of time (approx. 8 weeks). Discuss this with your general practitioner (GP) and HTC.

For people who treat at home

Ideally you would carry all the treatment required for the trip with you, but if you are planning to be away for a long time, arrangements can be made to access factor overseas. You will need to plan well ahead for this. Organising this part of your trip will involve a lot of work and it will take at least three months.

All documentation and approvals by the National Blood Authority (NBA) need to be completed and approved before you leave Australia.

The NBA pays for your factor on behalf of Australian governments. The NBA currently has agreed to fund overseas delivery of factor for up to 12 months in a 2-year



rolling period. However, factor can only be supplied overseas in countries where the product is registered and the pharmaceutical company is able to supply it. Each country has different rules and regulations around this so be prepared that there may be costs involved. Costs that you may incur could be doctors' appointments, travel to another country to collect the factor or import taxes. Unlike at home, delivery isn't to your front door!

Product transport and storage

Some airlines have a medical allowance to carry a quantity of medication on board the aircraft, so it is a good idea to ring around to check their requirements, especially if you will be carrying enough vials to last 3 months.

- Treatment product must be carried on board the plane with you in a cooler bag in the cabin section as the baggage hold in a plane is exposed to extreme temperatures which may affect the factor.
- **The National Blood Authority has stated that no lost or damaged product will be replaced other than in very exceptional circumstances.** Product will not be replaced if it has been lost/damaged in checked luggage or has not been carried and managed with all proper precautions.
- Factor vials and needles and syringes in their original packaging can be put through the scanner in airport security without harm.
- Port-a-cath consumables (dressing packs, sterile gloves, etc) must be carried on board in hand luggage. It would ruin a holiday if they went missing in lost luggage!
- While most factor concentrates can be stored at room temperature, it is very easy for them to overheat in hot weather particularly in cars or backpacks. Do your best to keep it cool or at least room temperature.
- Always ensure you use the remaining product first when you return home.

Aviation security requirements

Aviation security has restrictions, including rules for taking liquids, aerosols and gels.

Medical products and devices are exempt but you must carry appropriate documentation. Be aware that gel or ice packs are not exempt and you may not be able to take these through security. It is essential that you carry letters describing your product, the active ingredients, its presentation and how many vials you are carrying. The letters must state that the product is for your personal use and that the vials must not be opened when they are being checked by security officials. **The product must be carried in its original packaging.** This means you should not unpack the vials from their packaging to save space. You may need to declare the product at some security points and customs, so keep the letters accessible if required.

If you have any medical devices aids or implants, e.g. a metal joint or port-a-cath, you must inform the screening officers prior to screening. It would be worthwhile having this mentioned in your medical letter.

Plasma products

If you are travelling with plasma products produced in Australia (such as plasma-derived factor VIII - Biostate®, or plasma-derived factor IX - MonoFIX®) you will require an export permit to take the product out of the country. Your HTC can arrange this to ensure you have appropriate documents. Please give your HTC plenty of notice!

First Aid

When travelling, always take a bit more factor than you think you will need.

Remember, you will probably be more active than you normally are when travelling, especially as you may be dragging heavy cases, lifting things and putting your bag in the overhead locker. We have reports of people who have been bumped by a taxi, badly bruised by an out-of-control motorbike, walked into a tow ball on safari, tripped and fallen under a rickshaw, and had shoulder bleeds from retrieving heavy cases from the luggage belt. Accidents do happen and you should be well prepared.

Consider taking a first aid kit with you. Here are some items others have found useful:

- Instant ice packs or zip-lock bags for ice packs
- Scarf for a sling
- A simple analgesic such as paracetamol
- A styptic stick or pencil (shaving stick) for small cuts and abrasions
- Fess® nasal spray
- Tranexamic acid tablets for mouth and nose bleeds.

And not to forget Rest Ice Compression Elevation (RICE)! Talk to your HTC about the importance of using RICE while away.

Venous Access

If you are on regular home treatment and are travelling to places with limited access to safe health care, it is a good idea if a partner or your travelling companion learns to access your veins and give your treatment in case of emergency.

If you cannot access your own veins and you are on regular treatment you will have to contact the overseas HTC to investigate whether you can access assistance with your infusions and whether there will be costs for this. Be aware that your travel insurance may not cover this.

Port-a-caths

Families travelling to places with limited access to safe paediatric health care or paediatric emergency care will need to advocate that they access their child's port-a-cath device in the event of an emergency or to give factor treatment in a hospital setting. Please ask your HTC to provide a letter to support this.

If you need assistance to access the port-a-cath and require regular treatment, you will have to contact the HTC overseas to investigate whether you can access assistance with this and whether there will be costs involved. Be aware that your travel insurance may not cover this.

If your child has a temperature of 38 degrees Celsius or above during your trip, you will need to attend the nearest emergency department for a medical assessment as this could be a sign that your child has a port-a-cath infection.

Finding an HTC overseas

For contact details of HTCs around the world, see the **World Federation of Hemophilia (WFH) Global Treatment Centre Directory** at **www.wfh.org**, ask at your HTC or contact HFA on freecall 1800 807 173.

For people who don't normally have treatment at home

Talk to your HTC team about what they would recommend for your individual circumstance.

If you do not usually make up your product, consider learning how to reconstitute it before you leave home! This can be helpful especially in places where the medical staff are unfamiliar with your treatment product.

Keep your documents safe

- Load all letters to your phone or email copies to yourself
- Take photos of your passport, Medicare card, letters and ABDR patient cards

For more information

HTCs in Australia - www.haemophilia.org.au/support-services/treatment-services

HTCs worldwide – WFH Global Treatment Centre Directory – www.wfh.org

International travel advice - www.smartraveller.gov.au

And speak to your Haemophilia Treatment Centre.

And last of all have a great holiday!

Bon voyage!!

CORONAVIRUS

If you have any questions about coronavirus (COVID19) and travel, you are encouraged to get advice from relevant authorities and your doctor. The Australian government provides details at **Smart Traveller** - www.smartraveller.gov.au/news-and-updates/ coronavirus-covid-19 .

Nicola Hamilton and Alana Randall are Paediatric Physiotherapists, The Royal Children's Hospital, Melbourne

NORMAL CHILD DEVELOPMENT

Nicola Hamilton and Alana Randall

Every child requires the opportunity to grow and achieve their developmental milestones. This includes children with haemophilia. Some new parents may not be familiar with what 'normal' looks like, and have some worries about how to appropriately and safely allow opportunities for play and development.

Development is a term used to describe the path that children take as they grow and change from the time they are born, and continues into adolescence and early adulthood.

EARLY YEARS OF DEVELOPMENT

The **early years** are a key time for development. In the first five years of life, your child's brain develops more and faster than at any other time in their life.

Children's developmental progress may b e organised into the following domains:

- Gross motor – such as rolling, crawling and walking
- Fine motor and visual perception – such as grasping and reaching for toys
- Speech, language and communication – such as smiling, babbling and pointing
- Social behaviour and play – such as laughing or anticipating a game of peek-a-boo
- Self-care and independence – such as holding a bottle when feeding or showing shyness with strangers.

All of these developmental areas are linked, and each depends on and influences the others.

Development does not progress at the same rate in all children – there is a broad variation in 'typical' ages of achieving milestones or new skills. Most children however, follow a similar pattern or sequence of development.

Developmental milestones are used to monitor infants and children's progress with their development. Health professionals, such as your GP and maternal child health nurse, will review your child's developmental milestones when you attend for check-ups.

If you have concerns regarding your child's development be sure to discuss this with your health care professional, including your Haemophilia Care Team.

PLAY

In the early years, your child's main way of learning and developing is through **play**.

You can help to facilitate your child's development by the variety of positions you put them in, the way you engage and talk to them and the toys you give them to play with.

When they are a baby it is beneficial to place them in different positions, including on a mat and on their tummy. Tummy time should always be when babies are awake and alert and never when they are asleep as per the SIDS (Sudden Infant Death Syndrome) guidelines. Experiencing a variety of positions will help them develop their movement skills.

WHAT ABOUT HAEMOPHILIA?

As a parent of a child with **haemophilia**, it is normal to feel anxious when handling your child as a baby or to be concerned as they become more mobile.

It is important for your child's holistic development to provide them opportunities to move around and explore their world freely, as any other child would.

Letting your child to move freely and experience falls safely also helps to develop their balance and movement and coordination skills which will assist with joint protection as they grow.

The great thing about babies and children is that they are very robust. Did you know that toddlers will fall over 300 times whilst learning to walk!

The following are some practical changes that you may find helpful, but be aware they will not prevent all bruises or bleeds:

- Babies will explore toys by putting them in their mouth. You may choose to avoid toys with hard or sharp edges.
- When children are learning to crawl and walk, you may put padding around sharp corners of furniture or install softer floor surfaces such as carpet.
- Some parents find it helpful to dress the toddler with extra padding when they are first crawling and standing to help with falls. This may include using 2 nappies for extra padding on their bottom or pants with pads on the knees.

ANY QUESTIONS?

If you have concerns regarding your child's development you can discuss these with your general practitioner (GP), Maternal and Child Health Nurse and of course your Haemophilia Care Team.

For additional resources on child development see:

- Raising Children website
  https://raisingchildren.net.au
- Better Health Channel
  https://www.betterhealth.vic.gov.au
- Red Nose
  https://rednose.org.au/section/safe-sleeping

YOUTH NEWS

AT THE RECENT NATIONAL CONFERENCE IN SYDNEY, SOME YOUTH DELEGATES TOOK TIME OUT TO SHARE THEIR EXPERIENCES FOR THE HFA DIGITAL STORIES PROJECT.

THIS MIGHT JUST BE ME HERE

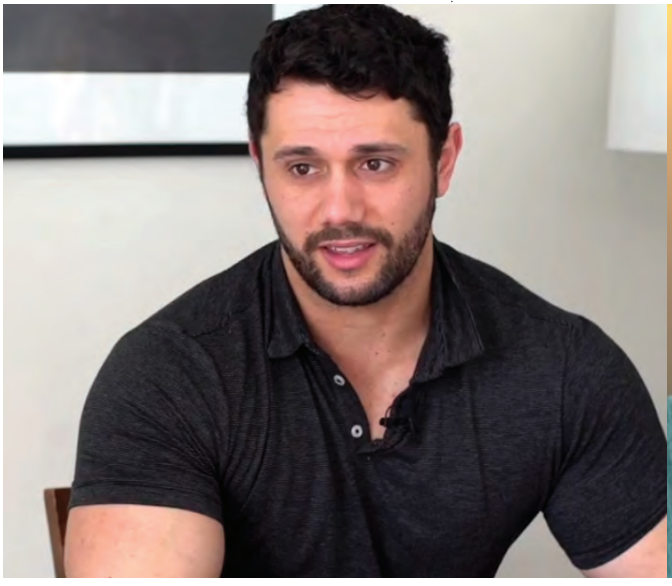
When he started primary school, Tim slowly became aware that other kids didn't have haemophilia – or a port for their treatment. He talks about finding out that he was different, and getting involved in family camps, where there were a whole lot of people who ARE living with the same thing.

Tim

NO, THAT'S NOT RIGHT

At swimming lessons, Sam was told to take off his MedicAlert bracelet. He describes what he learned when he took on the challenge of saying no and having to explain why.

Sam



DIGITAL STORIES

MY BLEEDING DISORDER ISN'T GOING TO HOLD ME BACK

As she grew older, Shauna started to realise that her body needed time to recover after a serious bleed – and that she just needed to be kind to herself. But with a good treatment plan and help from her doctors, this isn't going to hold her back from doing what she wants.

Shauna

WHAT'S GOING ON?

There was no history of haemophilia in Lexie's family, so when she started having major bruising as a baby, her parents didn't know what was going on. Lexie describes her adventures at school and has some advice for other young people with bleeding disorders.

Lexie

GROWING UP WITH A BLEEDING DISORDER

Tim, Sam, Shauna, Lexie and Hamish share stories from their childhood of being diagnosed, bruises and needles as children, going to camp and meeting other kids with bleeding disorders – playing (and sometimes avoiding!) sport and adventure activities, making friends and having fun. Their message to other young people with bleeding disorders: this hasn't stopped me from doing anything I wanted to do.

Watch Videos Here

Check out the videos on Factored In (www.factoredin.org.au) and on the Haemophilia Foundation Australia YouTube channel.

CALENDAR

World Haemophilia Day
17 April 2020
www.wfh.org/whd

WFH World Congress
Kuala Lumpur, Malaysia
14-17 June 2020
www.wfh.org

Bleeding Disorders Awareness Week
11-17 October 2020
Tel: 03 9885 7800
Fax: 03 9885 1800
Email: hfaust@haemophilia.org.au
www.haemophilia.org.au

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