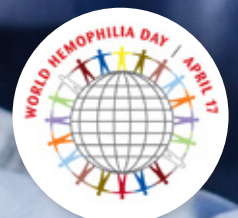


ADAPTING TO CHANGE IN A NEW WORLD



CONTENTS

2	SA news	11	Lenny's story	21	Resilience and adapting to change – career, work and sport
3	From the President	13	Caring for yourself as a carer	26	Youth News – Dealing with life changes
4	2021 Conference	14	VWD update	28	Calendar
6	World Haemophilia Day	16	WFH MSK Congress		
8	Adults adapting to change	18	New HFA videos		
		20	Sport and exercise for girls		

PHOTOS:: Monstera, Vidal Balielo Jr and Karolina Grabowska for Pexels.com

Haemophilia Foundation Australia
Registered No.: A0012245M
ABN: 89 443 537 189
7 Dene Avenue Malvern East,
Victoria, Australia 3145
Postal address:
PO Box 1208, Darling,
Victoria, Australia 3145
Tel: +61 3 9885 7800
Freecall: 1800 807 173
Fax: +61 3 9885 1800
hfaust@haemophilia.org.au
www.haemophilia.org.au
Editor: Suzanne O'Callaghan



NEWS FROM SOUTH AUSTRALIA

Thank you to Christine and Paul for organising the Family Picnic at Bonython Park in Adelaide on May 16. It was great to hear there were some new faces as well as older ones! The children had a lovely time together in the park.

The Haemophilia Treatment Network has organised an Information Evening to be held on 29 June 2021 at the Women's and Children's Hospital to update both adults and families with children on new issues in treatment and care for people living with a bleeding disorder.

A community coffee morning is also being planned for July 2021.

More information to follow. If you want to be kept up-to-date, please email your details to hfaust@haemophilia.org.au. Keep an eye on your inbox and if you are not receiving emails, let us know your email address.

SA BLEEDING DISORDERS COMMUNITY INFORMATION EVENING

Tuesday 29 June 2021

6.00pm - 7.30pm

**Women's and Children's Hospital - Queen
Victoria Lecture Theatre**

Light refreshments served from 5.30pm

Topics Covered

***How Blood Clots & Update on New Treatments -
Dr Yvonne Brennan**

***Hemlibra and Surgery - Dr Ben Saxon**

***Dental Care in Children with Bleeding Disorders -
Dr Ninna Yusson**

***Joint health and physiotherapy - Cameron Cramey**

For more information contact 1800 807 173

hfaust@haemophilia.org.au or book here -

<https://www.trybooking.com/BRSLQ>

Gavin Finkelstein is President, Haemophilia Foundation Australia

FROM THE PRESIDENT

Gavin Finkelstein



COVID-19

Throughout Australia we have experienced lockdowns due to COVID-19 at some time over the last year, and as I write this our staff at HFA and other Victorians have experienced another! Our lives have taken an unexpected turn because of the pandemic, but we see and hear some amazing stories of resilience and strength emerging from the resulting hardship.

We will continue to address the queries we have had from people with bleeding disorders about COVID-19 and having vaccinations and will provide any updated information on the HFA website. You should always discuss your concerns about COVID-19 or the vaccine with your treating doctor.

DIGITAL COMMUNICATIONS

We have been working hard to improve your experience of our websites, e-news and social media platforms and hope you are enjoying some of the new content. If you wish to receive information and updates via email as soon as they are available, you can sign up to the HFA e-news at www.haemophilia.org.au/helpful/sign-up

NEW FACT SHEET

You may have seen our new fact sheet, **Sport and exercise for girls and young women with bleeding disorders**. This was developed to answer questions from a survey of young women and their parents and we hope it will be helpful for young women and girls. Please make sure you let anyone in your family know who might be interested. Read or download it from our youth website - <https://tinyurl.com/FI-sport-girls>.

HEP C

Anecdotally we believe most people with hepatitis C in the bleeding disorders community have had their hep C cured. Many were treated with the new direct acting antiviral (DAA) treatment in recent years which had high cure rates, required tablets rather than injections and had few side effects. This has been life-changing for them.

We are working with the Australian Haemophilia Centre Director's Organisation (AHCDO) to understand the current situation, and to explore how we might reach people who don't know they have hepatitis C and could have treatment. These may be people with mild bleeding disorders who have not required much medical intervention over the years. Sadly, there are some people whose treatment was not successful or the new treatments were too late to help them and they have developed liver disease.

Even if you have cleared hep C, you may need to have your liver health monitored. Ask your hepatitis specialist or GP if you need follow-up for your liver health. For example, if you have cirrhosis and have successful treatment, you will still need ongoing care of your liver. It is easy to overlook these checks, especially if you are feeling well, so I urge you to make a plan with your medical team so you don't overlook this – and spread the message to others.

2021 CONFERENCE



20TH AUSTRALIAN CONFERENCE ON HAEMOPHILIA, VWD & RARE BLEEDING DISORDERS

The **20th Australian Conference on Haemophilia, VWD and Rare Bleeding Disorders** will take place this year from **8-9 October 2021** virtually.

This year we have decided to hold the conference virtually because of the uncertainty of the pandemic but we are very excited to go down this path. Bringing together the different parts of our community with health professionals and stakeholders has always been stimulating and rewarding. We expect our virtual conference will attract more delegates and create innovative learning opportunities and discussion for everyone. We are confident that nothing will be missing - in fact it will be enhanced!

VIRTUAL POSTER DISPLAY

Posters are an integral part of the conference, and we are calling for poster abstracts for our virtual poster display.

We encourage abstracts relevant to clinical practice and care, laboratory science, research, policy, living with bleeding disorders or treatment complications, peer support programs and special projects. This is a great opportunity to share ideas and experiences.

SUBMITTING ABSTRACTS

See www.haemophilia.org.au/conferences for more information and the abstract submission form.

There will be prizes for the Best Abstract and the Best Poster.

Submit your abstract by Friday 30 June 2021.

CONNECTING WITH THE COMMUNITY

Connecting with one another and being able to share experiences is an important part of our conferences. We will be doing things differently because we will not be meeting face-to-face this year, but there will be plenty of great opportunities to connect, share and have fun!

Hosted Social Activities

Look out for the hosted social activities over the two days and join us for the social function on Friday evening.

Remembrance Service

The Remembrance service is an important part of our conference and there will be a chance for all Delegates to participate in a meaningful way.

REGISTRATION

Our aim is to make the Conference available and affordable for all delegates. If the cost and travel has stopped you from attending in the past, this is the chance for you to attend from the convenience of your home or office.

Registration includes:

- Access to all plenary and concurrent program sessions
- Access to all extra activities
- Access to Gold Sponsors' private rooms for health care professionals or for community delegates.
- Hosted opportunities to connect with other delegates

THANK YOU TO OUR SPONSORS

Gold Sponsors

CSL Behring

SANOFI GENZYME



Silver Sponsors

BIOMARIN

Pfizer Haemophilia



- Remembrance Service
- Social function on the Friday evening
- A conference satchel with abstract book and information can be either posted to you or sent digitally.

Registration Fees

Category 1 - \$50 per user access

Person with a bleeding disorder, family and carers
Haemophilia Foundation staff

Category 2 - \$75 per user access

Health professionals, government officials,
pharmaceutical company representatives and other
regular delegates

Register online at -

www.haemophilia.org.au/conference21registration
(online registration required)

FAQs

What do you need to participate successfully?

- Computer with sound card, tablet or smartphone
- WIFI or data, with enough data for a 2-day stream

Do I need to sit in front of a screen for the entire 2 days?

No, there will be breaks, live sessions and pre-recorded sessions.

To get the most out of conference we recommend you attend the live sessions that are of most interest to you so you can ask questions and participate in any conversations.

Will sessions be available for playback on demand afterwards?

All sessions will be recorded. You will be able to access the recordings straight after the session. With your registration you will also be able to access the recordings on demand after the conference.

Will I be able to meet others in the community during the conference? I enjoyed the face-to-face part of past conferences.

Yes, you will have the opportunity to meet others virtually in scheduled social activities. We will have allocated times when this can happen.

Thank you to our sponsors

All delegates will be able to meet our Gold Sponsors in specially dedicated private rooms for health care professionals and community delegates.

How do I stay up-to-date?

Register for our E-news -
www.haemophilia.org.au/Signup
Or visit the Conference page -
www.haemophilia.org.au/conference21

For any enquiries contact:

Natashia Coco
Director of Development and Relationships
ncoco@haemophilia.org.au

WORLD HAEMOPHILIA DAY 2021



It was great to read motivational and inspiring comments on the website.

World Haemophilia Day in 2021 was a great success. This year's theme **Adapting to Change** highlighted that living during a pandemic can pose many challenges, not only for our health, but also for our mental health and wellbeing.

The World Federation of Hemophilia interactive World Haemophilia Day website gave people a space to share how bleeding disorders have affected people and their loved ones. It was great to read motivational and inspiring comments on the website – www.worldhemophiliaday.org

QUIZ

World Haemophilia Day was an opportunity to test our knowledge with a fun quiz.

Try it out! <https://tinyurl.com/WHDQuiz21>

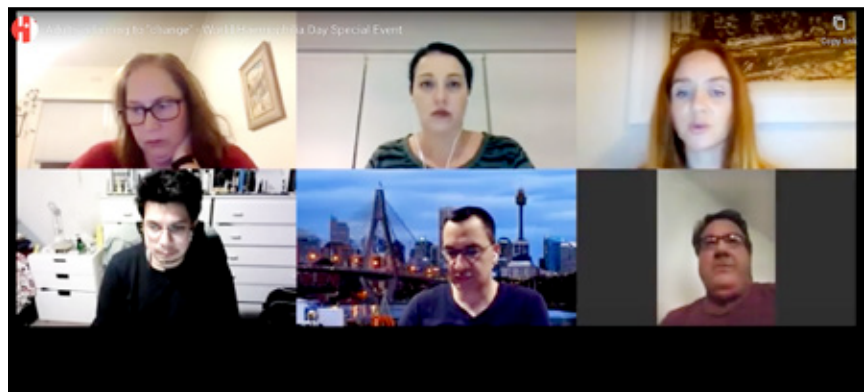
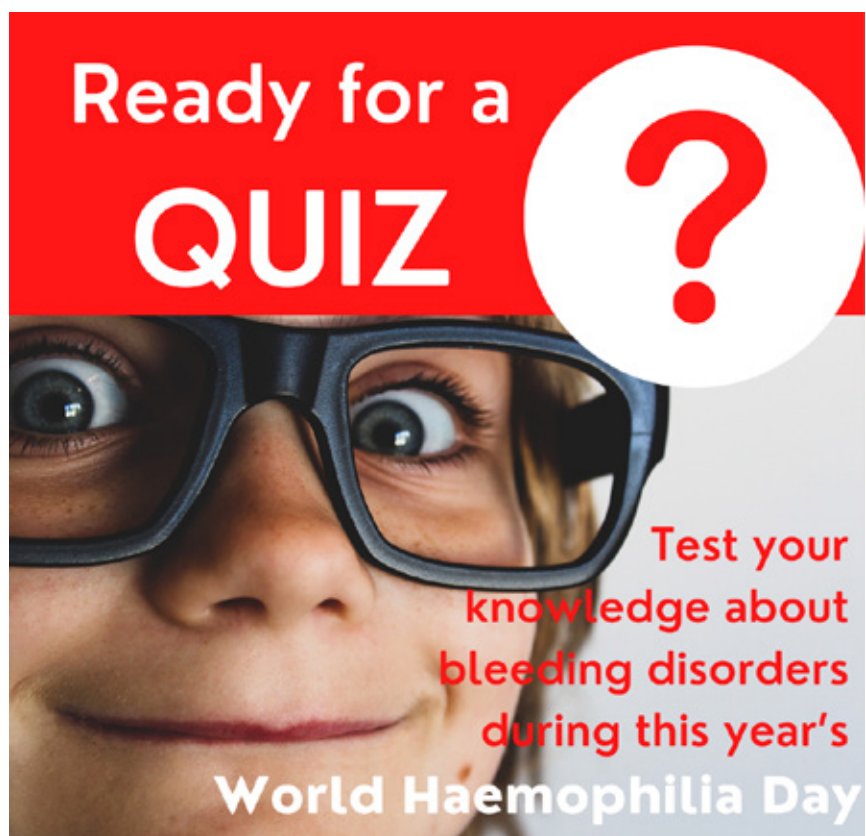
WEBINARS

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

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

You can listen to the recordings here - www.haemophilia.org.au/webinarsWHD21.

Read the reports about the webinars in this issue of *National Haemophilia*.



>>

LIGHT IT UP RED AROUND AUSTRALIA

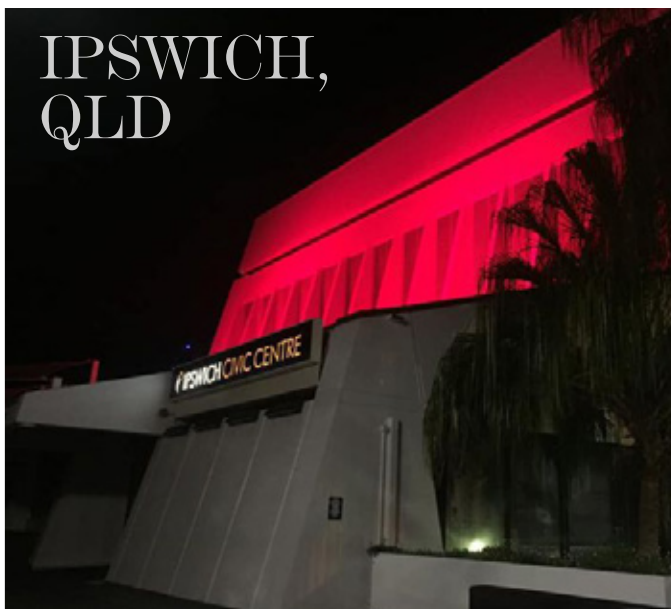


HFA also participated in **Light it Up Red** with landmarks in Western Australia, Queensland and Victoria going red to raise awareness about bleeding disorders.

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



BELL
TOWER,
WA



IPSWICH,
QLD



KANGAROO
POINT, QLD



TOWNSVILLE,
QLD

ADULTS ADAPTING TO CHANGE

HFA Zoom and Facebook Live webinar for World Haemophilia Day, 15 April 2021

Facilitator: Natasha Coco, Haemophilia Foundation Australia

Speakers:

Jane Portnoy, Haemophilia Social Worker, Ronald Sawers Haemophilia Centre, The Alfred, Melbourne

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

Lenny, who has haemophilia

Watch the video of the webinar at -
<https://tinyurl.com/WHdvideo-adults-2021>

This year's theme for World Haemophilia Day is **Adapting to change**. Living through the COVID-19 pandemic has posed many challenges to our health and also to our mental health and wellbeing. Jane Portnoy, Nicoletta Crollini and Lenny came together to speak online about some of the challenges for people with bleeding disorders in Australia and Lenny shared the inspiring story of what change has meant for him in the last year.

How do you have a life that embraces change?

RESILIENCE

Resilience is an important factor in this. Nicoletta explained that resilience is the ability to overcome adversity, bouncing back from difficulties and recovering from the challenges that we experience in our life.

Why is resilience useful in our lives? People who struggle with resilience often experience mental health problems such as depression or anxiety. They may crumble when life's challenges occur and are less likely to seek support. However, resilience is something we can all work to develop over time at any age.

Ways to develop resilience:

- **Link in with support networks** – social networks like friends and family, your local Foundations and HFA, and professionals like haemophilia social workers
- **Seek help** to work through problems
- **Explore how you have worked through problems in the past** and create your own toolkit to manage difficulties
- **Practice self-compassion** – it's OK to make mistakes
- **Practice self-care** – give yourself time to do activities that help you feel relaxed and happy.

**World
Haemophilia
Day 2021**



HFA LIVE ZOOM SESSION
7.30pm EST THURSDAY 15th APRIL
ADULTS: Adapting to 'CHANGE'

TREATMENT CHANGES

How can patients best prepare themselves for treatment changes?

The last 12 months have seen some exciting new treatment options for people with haemophilia in Australia. Jane pointed out that, while it can be really positive, swapping to a new treatment can also be quite scary.

- **Make sure you have the information you need** – through reading articles and stories, talking to your HTC, talking to your peers.
- **Write your questions down and bring them to your HTC** – there are no silly questions, and if you have more questions after your appointment, you can always talk to your HTC again.
- **Does change cause you anxiety?** Try the things that help you to feel calm and get a good night's sleep before you visit the HTC to change your treatment. Avoid the things that don't help – for example, too much alcohol. Let people around you know that you are feeling anxious. Your HTC can help with an individual plan to support you.

EMBRACING CHANGE

Change is an inevitable part of life. How can you build a life that embraces change?

Nicoletta underlined the importance of having a resilience skillset – your armour and backbone – to manage welcome and unwelcome changes in your life. Some other useful strategies:

- Stepping back and looking at the situation, so you can prepare yourself and make informed choices and decisions
- Take some time to reflect
- Acknowledging that you don't always have control over a situation and looking at what you can control
- Self-care is always key.

SEEKING SUPPORT

When should people seek support if they are worried about their mental health?

Basically, the message is to seek help if you are concerned about your mental health, said Jane. Talk to trusted people in your social network or your health professionals, for example, those at your HTC or your general practitioner or other health care settings where you have a relationship.

This can help you find suitable support and sometimes you may be able to talk through your worries and have help with them.

Online mental health support

Some community services also offer online chat and telephone services when you have concerns and feel you would like some support.

Organisation	Telephone	Website
Beyond Blue	1300 22 4636	beyondblue.org.au
Lifeline	13 11 14	lifeline.org.au
MensLine Australia	1300 789 978	mensline.org.au
Headspace	1800 650 890	headspace.org.au
Kids Helpline	1800 55 1800	kidshelpline.com.au

>>

LENNY'S PERSONAL EXPERIENCES

Lenny has grown up with challenges not only from his haemophilia, but also from other disabilities he acquired through trauma at birth – problems that affect his eyesight and mobility, cause a build-up of fluid on his brain and a palsy, and other learning difficulties. His hearing, however, is acute and he has gravitated towards music as something he loves and now as his career.

This last year has been both difficult and exciting for him. He was working to complete his Bachelor of Arts degree in music and psychology, but COVID-19 restrictions meant that he had to participate on Zoom and with his sight problems, made his group assignments difficult. When he explained his visual difficulties to his fellow students, they were more understanding and the experience of studying improved for him. He has now completed his course – a great achievement!

Another really positive change for him has been switching to a new haemophilia treatment. Because of his vision impairment, he had always relied on his parents to infuse his treatment and had a 'massive needle phobia'. The new treatment is injected sub-cutaneously, under the skin, and is much less complicated. To Lenny's delight and surprise, he is able to manage his treatment himself, which has meant a whole new independent life and future for him.

Read the full version of Lenny's story in this issue of *National Haemophilia*.

Q & A

Q – Lenny, how were you so resilient that you gave the new treatment a go?

Lenny explained that the first thing he did was find out what a 'sub-cutaneous injection' was. Once he learned that he didn't need to find a vein, but could just inject it into the fatty tissue under his skin on his stomach, he was excited because he realised he could inject his treatment himself. Before he has new experiences, he always feels a sense of panic about what it would be like. When he was shown the actual equipment, he was shocked by how small everything was and realised he would need extra strength glasses. He needed to make sure he was doing it right. He had a couple of supervised self-administered injections with the nurses at the HTC, but for the first couple of times on his own, he asked his Dad to supervise him drawing up the solution to make quite sure he had enough.

Q – How did you get over your feelings of anxiety?

One of the most important things for Lenny was the opportunity to research the new treatment online and then ask the nurses at the HTC more questions about how it worked and how to prepare it.

Q – Suggestions on how to cope with recovering from surgery?

In Lenny's experience, being able to sit up and move around after surgery makes rehabilitation more bearable. He had to spend the majority of his time confined to one room but found things to distract himself and occupy his time – watching educational videos and other shows on TV.

Letting others know how you are going is also important, said Jane. You can talk to the HTC social workers and nurses, letting them know if you are having any problems, and they can work with you on how to manage. It's good to have things to watch and read and people to visit you. You can prepare this in advance – a little kit bag of things you had been meaning to do, the book or video you hadn't got around to yet.

Nicoletta also pointed out that it is good to create a routine – waking up at a certain time, mornings for reading, late mornings talking to a relative or watching a show, etc. Create a little bit of structure for yourself. If you are in hospital for a long time, the loss of routine and boredom can be hard and it is helpful to have strategies to overcome it.

Our thanks to Jane, Nicoletta and Lenny for taking part in the webinar and sharing their expert advice, tips and personal experiences. 🙏



Lenny graduating
Photo: Lenny

OVERCOMING PERSONAL CHALLENGES LENNY'S STORY



At the recent HFA webinar for World Haemophilia Day, Lenny spoke about his personal challenges, what he has done to overcome them and the exciting changes that had occurred for him in the last year.

Photo: Lenny

Lenny has haemophilia A at 2% - technically moderate haemophilia, but he is treated as severe because of other medical complications from trauma at birth. As a result, he also has several other disabling conditions: hydrocephalus, acquired brain injury (ABI) vision loss, mild palsy and some learning difficulties.

Lenny explained how these medical challenges impact on him.

'Hydrocephalus is caused by abnormally high pressure in the brain caused by the build-up of cerebrospinal fluid. Because of this I have a VP [ventriculoperitoneal] shunt which drains the excess spinal fluid from my brain.

'The next challenge I have is a rare form of ABI vision loss known as Parinaud (or Dorsal Midbrain Syndrome). This means I can only see with one eye at a time, and I have no control over when one eye switches off and the other one takes over. As well, both eyes have limited peripheral vision, and very limited up and down gaze. Because of the monocular vision, I have no depth perception and would trip over easily.

'The other challenge is mild palsy which means that one side of my body is weaker than the other, which causes issues with my balance and mobility. All the above have affected in some way my ability to learn in mainstream education.'

MUSIC, STUDY AND TECHNOLOGY

Finding a way around his medical challenges led Lenny in a particular direction with his education and interests.

'In terms of my vision impairment, technology has played a big part in my education and my daily life. I started to become acquainted with the computer since Prep and have learnt to touch type. Learning new software also comes naturally to me. This was a real asset during the lockdown as all my classes were conducted online and we mostly worked in isolation. In addition, I had to learn a new music software on my own to complete my music compositions in my final unit at university.

'Reading music scores was fraught with difficulty due to my vision and coordination issues, however my piano teacher patiently encouraged me to read music notation.

'Because of a fear of repeat shunt revisals surgery, I never felt safe doing sports, so I gravitated towards music. As a child I was fascinated and loved hearing the beautiful melodic sounds created by my aunts and cousins on the piano. With my limited vision, I would learn each part separately, and then learn to coordinate both hands and then ditch the book and play from memory. My short-term memory was severely

impacted by all the neurosurgeries, but my long-term memory is fantastic.

'I was surprised to discover that due to my limited vision, my hearing is very acute, and it is perfect for music. Mum helps me enlarge the pages to A3 and often she has to increase the white space in between the staves.

'As I am not involved in team sports — and classical piano is very much a solitary instrument — I picked up the clarinet — and joined the school band for several years until Year 12 when I had a severe cerebral bleed which hospitalised me for 6 weeks, and as a result I had to give it up.'

Lenny's tertiary studies gave him an opportunity to pursue his interest in music – and to explore some of his own questions about the human mind.

'Recently I completed a Bachelor of Arts with two majors in Music and Psychology. I chose psychology because I was intrigued to discover how my brain works and how people generally learn (even though I passed, I still don't know!) Normally a 3-year course, I completed it on a half-time basis due to my vision impairment. Even though I completed all of my assessments by the deadline, it was a struggle to juggle my time between reading the textbooks, copious amounts of researching, and completing my assignments.'

THE CHALLENGES OF COVID

'During the 2020 lockdown, I struggled with collaborative assignments via Zoom. My study partners thought I was being lazy and uncooperative, but I was actually just slower because it took me so long to find relevant data on the internet. It was a dark moment in my student life, but once I told them about my vision impairment they were more understanding. It improved the whole experience.

A NEW TREATMENT

Having haemophilia has always been a challenging experience for Lenny.

'There was a time when I hated my condition. I couldn't cope with the constant injections, which caused massive needle phobia. Even with all the challenges, I now realise that I can still count my blessings. I have had excellent medical care and support at both my paediatric and adult Haemophilia Treatment Centres.'

Then Lenny was offered the opportunity to change his treatment from a standard factor VIII replacement

therapy to a new type of treatment, which mimics a clotting factor.

'Changing my treatment has definitely been a Godsend.

'When I was first told about the new regimen, I was excited as I only had to do it once a week as opposed to two to three times a week - which I needed for 22 years. Due to my vision impairment, I have always relied on one of my parents to do the injecting either via a port or intravenously. This new treatment is subcutaneous and has meant that I can do my own injections.

'To my surprise, I found that the whole procedure was more straightforward and less complicated compared to the sterile procedure for the port as there are fewer components to organise. Preparation can take place over a smaller area and it takes less time, as there is no need for complex sterile setup. With this treatment you only need to swab the bottle tip as well as the injection site. With intravenous injections, I was always fearful of the needle hitting a nerve. At times the vein would hide/tissue mid-infusion and the whole procedure had to start all over again. That caused a lot of angst for me.

'When I first saw the treatment kit I was so surprised to discover how small the vial and syringe were, and the little amount of product required compared to the normal factor VIII. The only challenge for me was reading the fine measurements which I managed to overcome by purchasing a cheap pair of magnifying glasses from the local chemist.

'I did my first two treatments at the Haemophilia Treatment Centre under the supervision of the haemophilia nurses. Since then, I've been successfully self-infusing at home. As my confidence grows, I find that the transition has been smooth and without too many hassles. Overall, the whole experience has been positive and I think it will allow me more freedom and independence in the future.'

How would Lenny sum up his treatment experience?

'For me, life now feels more in control because I can self-infuse instead of relying on my folks.'

Everybody has different requirements in relation to their treatment. HFA does not make recommendations about specific treatment products, but if you are interested and would like to discuss new treatment options for haemophilia, speak to the team at your Haemophilia Treatment Centre. ■

TAKING CARE OF YOURSELF AS A CARER

Kathryn Body

Do you find yourself irritable, a bit short with people, easily upset, regularly frustrated, sometimes tearful, tired, unable to enjoy life like you used to?

You may be needing to do some deliberate self-care.

I write deliberate or planned self-care because there's rarely time in the day for self-care in the multiple commitments that being a carer brings. Your diary will be full of appointments for those you care for, so add another appointment, one for you.

Look at your week, look at your day.

Decide on a day and time when you will just look after you. This could be really hard at first, but it's worth remembering that information when you were hearing the safety instructions on a plane (remember those days?):

'Adjust your own oxygen mask before assisting others.'

When googling this phrase, I found a website [smartrecovery.org](https://www.smartrecovery.org) that used this analogy too and I quote from them:

'To avoid burnout, managing our self-care is a key responsibility to maintain our happiness, our physical health, and our mental health. It requires consciously planning to include time in our day to attend to our own needs and make that time a priority. If we don't, we eventually won't be able to care for others.'

*'What do we really need to maintain our physical and mental health? Exercise, good nutrition, alone time, social time, time for creative endeavours, medical care, and support groups are just a few ideas to consider.'*¹

I would like to unpack some of these suggestions with a few ideas that you might find helpful.

1. Exercise - getting outside and going for a walk, doing a bit of gardening, trying online Pilates. Enjoying sunshine, fresh air and movement.



2. Good nutrition - eating regular meals, taking time to prepare food that you enjoy. Trying a new recipe can be fun.

3. Alone time - taking time to not be responsible for anyone just for a short while can be so restorative. Using that time to enjoy book - try an audio book from your local library. It's a great way to get away without leaving the couch.

4. Social time - arranging a regular coffee or lunch with a friend helps us to feel connected. It can be a time to relax, enjoy a good laugh and catch up on others' lives.

5. Taking time for creative endeavours - taking up an old or new hobby. Try dancing, knitting, painting, restoring furniture, listening to music, using your hands in some way.

6. Medical care - taking time to get that appointment for a skin check or annual health check.

7. Join a support group - the Haemophilia Foundation in your state or territory usually has groups where there are others who share similar experiences to yourself as a carer. You can contact the counsellor or social worker attached to your Haemophilia Treatment Centre for general information or referral.

Check the HFA website www.haemophilia.org.au or phone them on 1800 807 173 for contact details of your local Haemophilia Foundation or Haemophilia Treatment Centre.

By taking time for yourself you will improve your individual wellness, mentally and physically, and enjoy all benefits that can help you to thrive. 📖

REFERENCES

1. SMART recovery. Oxygen mask rule for family & friends. <https://www.smartrecovery.org/oxygen-mask-rule-for-family-friends/>. Accessed 19 May 2021.

VWD UPDATE

Suzanne O'Callaghan

The publication of the international clinical diagnosis and management guidelines for von Willebrand disease (VWD) in January 2021^{1,2} was greeted with great excitement around the world.

Australia has been well-represented in the development of the international guidelines, with Dr Simon McRae in the VWD Diagnosis Panel and Susie Couper from HFWA in the VWD Management Panel.

In Australia the international guidelines will be translated for the local environment by the Australian Haemophilia Centre Directors' Organisation (AHCDO) and published as Australian guidelines for consistent diagnosis, treatment and care around the country. We are looking forward to this as an opportunity to raise awareness about VWD nationally, both for health professionals and the wider community.

We have joined with our international colleagues in a global initiative to deal with VWD issues in the community. HFA is a member of the World Federation of Hemophilia (WFH) VWD Global Group, representing the Western Pacific Region. This is a WFH working group comprised of patient organisations, dedicated to addressing the unmet needs and improving the quality of life (QoL) of the VWD community.

SPEAKERS



Nathan Connell, MD,
MPH
U.S.A.



Michelle Lavin, MB
BCh BAO, PhD
Ireland



Nicolas Giraud
France



Baiba Ziemele
Latvia

IMPROVING VWD CARE

In May 2021 WFH held a webinar on the international VWD guidelines for the global community titled **Improving care for people with VWD**. Speakers were Dr Nathan Connell, Vice-Chair of the international VWD guidelines Scoping Group, Dr Michelle Lavin, Chair of the WFH VWD and Rare Bleeding Disorders Committee, and our colleagues from the WFH VWD Global Group, Nicolas Giraud from France and Baiba Ziemele from Latvia.

VWD diagnosis is complex and needs to take place in specialised laboratories and then interpreted by haematologists with expertise in VWD. There has also been concern about the potential for life-threatening bleeding in women with VWD after childbirth (post-partum haemorrhage), particularly in resource-poor countries.

Nathan Connell and Michelle Lavin described some key features in the international guidelines:

- Consistent VWD type 1 levels for diagnosis
- Recommendations about new more sensitive diagnostic tests
- Recommendations for treatment after childbirth with effective but also cheap and easily accessible treatments.

PATIENT QUALITY OF LIFE

Nicolas Giraud and Baiba Ziemele commented on the quality of life issues from the perspective of the patient.

Baiba noted that the use of bleeding assessment tools and the focus on VWD phenotype rather than factor levels means that there is less confusion in diagnosis and treatment is likely to be more effective in managing symptoms. She was excited to see simple and inexpensive treatment recommended for women after childbirth to prevent post-partum haemorrhage – this will prevent so many unnecessary bleeding episodes and deaths for women around the world.

For Nicolas, the treatment approach was a highlight: shared decision-making between doctors and patients and an understanding that it is not one-size-fits-all.

COMMUNITY CONNECTION

The webinar Q&A also provided an opportunity to discuss how to discuss VWD issues with the bleeding disorders community and how to connect with community members who have VWD.

Nicolas suggested that National Member Organisations reach out to their members with VWD:


- Pass on information about the guidelines to them
- Create a space to address their concerns and their situation
- Talk to them personally – listen to them so as to understand their personal issues.

He commented that it can be hard for people with VWD to relate to the bleeding disorders community if the focus is on haemophilia.

We are looking forward to this as an opportunity to raise awareness about VWD nationally, both for health professionals and the wider community.

COVID-19 VACCINE

The session finished with a reminder about the COVID-19 vaccine – that the vaccine is safe and effective for people with VWD, but that they may need to speak to their haematologist or HTC as it is an intramuscular injection.

The HFA COVID-19 vaccine FAQs includes advice for people with VWD, as well as other bleeding disorders - <https://tinyurl.com/BD-vaccine-FAQs> 

REFERENCES

1. Connell NT, Flood VH, Brignardello-Petersen R, et al. ASH ISTH NHF WFH 2021 guidelines on the management of von Willebrand disease. *Blood Advances* 2021; 5(1):301–325. <https://doi.org/10.1182/bloodadvances.2020003264>
2. James PD, Connell NT, Ameer B, et al. ASH ISTH NHF WFH 2021 guidelines on the diagnosis of von Willebrand disease. *Blood Advances* 2021;5(1):280–300. DOI: <https://doi.org/10.1182/bloodadvances.2020003265>

WFH MSK CONGRESS 2021



Bianca Da Silva

This year MSK 2021, the **17th WFH (World Federation of Hemophilia) International Musculoskeletal (MSK) Congress**, was presented in a virtual format. It featured a combination of educational sessions, free paper abstract submission and interactive workshops, focusing on the most current up to date knowledge on musculoskeletal approaches to bleeding disorders from experts all over the world and over 600 participants from 83 countries. There were 2-3 sessions per day over a 5 day period, with diverse start times, allowing attendees to participate in as many sessions as possible!

Topics discussed throughout the Congress included Scoring Systems, Physiotherapy, Surgery: Pre and Post, and Replacement Surgery: Tips and Tricks. The four workshops focused on clinical assessment, ultrasound, manual therapy and clinical cases.

SCORING SYSTEMS

Some of my personal highlights were the presentations about scoring systems and assessment tools.

Scoring Systems explored the frequently used assessment tools for haemophilia patients. This included the haemophilia joint health score, patient's participation and activity scoring systems, x-ray, MRI, ultrasound, 3D motion analysis, and pre- and post-surgical assessments.

The **Haemophilia Joint Health Score (HJHS)** is the most common scoring system used in Australia. This is a validated outcome tool that assesses 9 items (including swelling, muscle wasting, crepitus, movement loss, joint pain and strength) in 6 target joints (elbows, knees and ankles).

Interesting concepts discussed during this session included the current use of ultrasound in the identification of an acute bleed, and the future possibility that a patient with haemophilia could perform this assessment with an ultrasound device in the convenience of their own home via telehealth with their treating Haemophilia Treatment Centre. There were also discussions regarding how in the future

artificial intelligence could interpret results or identify changes by comparing previous images.

Current research indicates that **T2 mapping MRI** is a reliable technique for assessing changes of cartilage fibres over time. This is a type of MRI that is able to identify early changes in cartilage. It does this by detecting disarrangement in water molecules and collagen fibres. This would allow for an earlier and more preventative approach to joint degeneration and arthritis. Further research is required to determine whether T2 mapping can significantly predict cartilage damage prior to conventional MRI.

The authors of one poster had designed a **Patient-Derived Symptom Assessment tool** to determine from the patient's answer to a number of questions whether an acute joint bleed was present. Particular questions were more helpful with identification of a joint bleed, and therefore provided a higher accuracy score. There has been considerable debate about how best to assess an acute joint bleed accurately. This assessment tool requires more investigation prior to being used in the wider community, however it shows great promise, and would be particularly useful for areas where ultrasound is not easily accessed.

Some of my personal highlights were the presentations about scoring systems and assessment tools

Diagnosis of Hemophilic Hemarthrosis: Development of a Patient-Derived Symptom Assessment Tool Using Musculoskeletal Ultrasound (MSKUS) for Validation

Srila Gopal¹, Richard FW Barnes¹, Lena Volland¹, David Page², Annette von Drygalski¹

¹Hemophilia and Thrombosis Treatment Center, University of California San Diego, ²Canadian Hemophilia Society



Background

- Patients with hemophilia (PWH) experience painful joint episodes which may or may not be associated with new hemarthrosis
- Point of care (POC) musculoskeletal ultrasound (MSKUS) is a valuable tool for rapidly diagnosing hemarthrosis
- Patient-derived questionnaires describing pain sensations have been suggested for diagnosing hemarthrosis
- We sought to validate a questionnaire developed by an experienced patient group, and compare it against POC-MSKUS to detect hemarthrosis

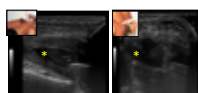
Methods

- We administered a patient-developed questionnaire comprising 20 questions (10 each associated with hemarthrosis and arthritis pain, respectively) to adult PWH experiencing acute painful episodes
- The questionnaire was developed by Mr. Page and derived from an open-text survey, sent to a group of "experienced" individuals with severe hemophilia A or B.
- Patient and providers were blinded to question assignment and the order of the questions was randomly scrambled
- The presence (or absence) of bleeding was confirmed by MSKUS
- We fitted univariate and multivariate generalized estimating equations to identify symptoms associated with hemarthrosis

Results

- Questionnaire administered to 32 patients, presenting with 79 painful joint episodes.
- 23 patients had Hemophilia A and the remaining had Hemophilia B
- Severe Hemophilia (Factor activity <1%): 22 patients
- Median age: 38 years (range 21-74 years)
- POC MSKUS detected hemarthrosis in 36 (46%) episodes

Representative MSKUS images of acute joint bleeding in a patient with hemophilia



Bleeding within joint

Supra-patellar bursa in long and short axis views showing widening of bursa, evidence of mixed echogenic signals, bursal contents that are partially compressible, consistent with clotted blood in the joint

Results

Table 1: Odds ratios (OR) relating pain associated with bleeds vs arthritic pain

Variable	OR	Lower CL	Upper CL
X19: No feeling of sponginess with movement	0.28	0.11	0.75
X5: No significant improvement after factor concentrate	0.29	0.12	0.68
X3: Irregular, non-progressive pain with movement or weight bearing	0.30	0.15	0.64
X16: Pain and discomfort in the absence of warmth or swelling	0.32	0.12	0.81
X2: Pain when flexing the muscle, or if joint, muscle nearest joint	0.35	0.14	0.83
X13: With activity, painless range of motion increases	0.38	0.15	0.95
X18: Moving through range of motion is painful, but feels moveable	0.52	0.18	1.46
X17: Limited, non-progressive swelling	1.01	0.41	2.50
X9: Little pain at rest	1.11	0.44	2.82
X6: Pain at rest	1.11	0.44	2.82
X10: Feeling of fullness in the joint	1.40	0.41	4.77
X11: Progressive swelling	1.47	0.49	4.37
X1: Rapidly increasing pain	1.50	0.59	3.80
X12: Swelling with increasingly painful pulsing sensation leading to joint immobility	1.54	0.36	6.51
X8: Progressive loss range of motion	1.55	0.55	4.36
X4: Pain and only when the muscle or joint is flexed	1.69	0.72	3.95
X20: With activity, range of motion decreases	1.84	0.64	5.30
X15: For non-target joint, recall of an initiating incident	2.18	0.72	6.64
X7: When resting, pain eases by not moving	2.38	0.94	6.02
X14: Like a balloon swelling with water	2.84	0.75	10.77

The potential predictors of hemarthrosis pain vs arthritic pain are ranked in order of increasing odds ratios for a bleed. Red/ highlighted rows indicate questions assigned to hemarthrosis per original questionnaire

Table 2: Predictor tool to ascertain the probability of joint pain to be associated with hemarthrosis

Symptom	'Y' or 'N'	'Y' or 'N'	'Y' or 'N'
X19: No feeling of sponginess with movement.	Y	Y	N
X16: Pain and discomfort in the absence of warmth.	Y	Y	N
X5: No significant improvement after factor concentrate.	Y	N	N
X3: Irregular, non-progressive pain with movement or weight bearing.	Y	N	N
X2: Pain when flexing the muscle.	Y	N	N
Probability of hemarthrosis	6%	61%	93%

Conclusions

Objective diagnosis of hemarthrosis by MSKUS facilitated a prediction tool by informed selection of the most meaningful patient perceived indicators of arthritic versus hemarthrosis pain. The tool requires further validation and will be particularly helpful in situations where MSKUS is not readily available

Funding Source: Health and Resources Service Administration (HRSA) Grant H30MC24045

With new treatments and developments in gene therapy, we are all driving towards the goal of future generations growing up without joint bleeds and joint damage, and without limitations in sport or career choices. This will ultimately change the physiotherapy management of haemophilia, and ongoing screening or scoring systems will need to also adapt to incorporate these changes. This is a very exciting time in the world of haemophilia!

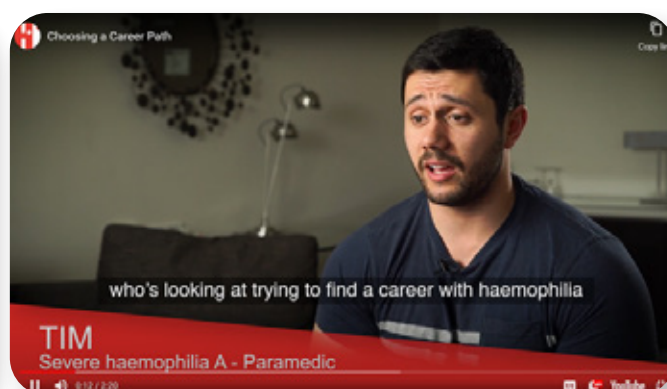
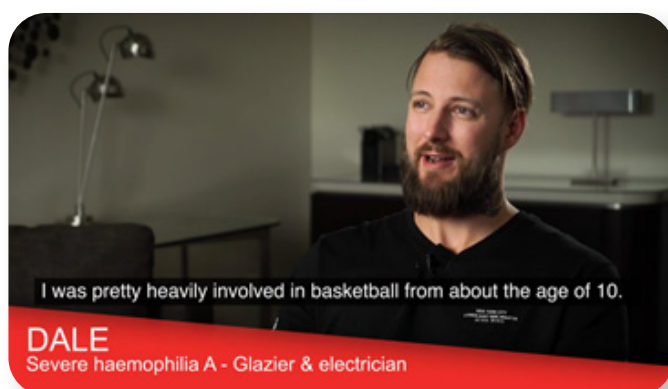
Thank you so much to Haemophilia Foundation Australia for supporting all Australian Haemophilia Treatment Centre Physiotherapists with their registration. It was such an honour to see some of my physiotherapy colleagues presenting at different sessions and sharing their expert knowledge and experience with the world. 🌍

NEW HFA VIDEOS

You may have noticed in your social media and e-news that we have been releasing lots of new videos recently!

This is all part of our digital stories project, where members of our community share their stories and experiences.

You can watch them all on our Haemophilia Foundation Australia YouTube channel - <https://tinyurl.com/HFAYouTube>

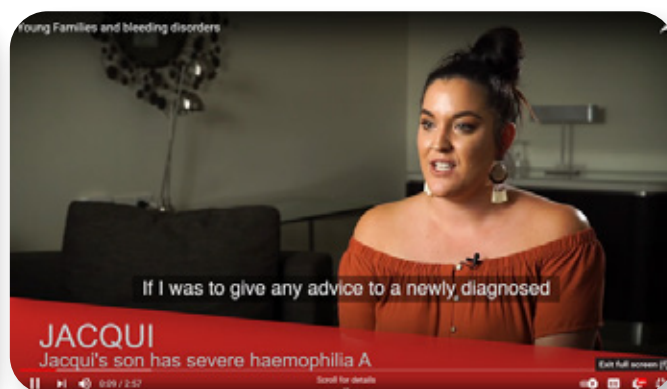


MANAGING WORK

Dale, David, Paul and Tim talk about their experiences of working and employers, managing their haemophilia and overcoming challenges.

CHOOSING A CAREER PATH

With advice from their own experiences, Tim, David and Paul explain how haemophilia doesn't need to hold you back in your career



MY BABY HAS HAEMOPHILIA – MOTHERS TALK

Your baby's diagnosis with haemophilia can be a shock for parents. Kate, Claire, Janelle and Jacqui speak about their diagnosis journey and finding their new 'normal'.

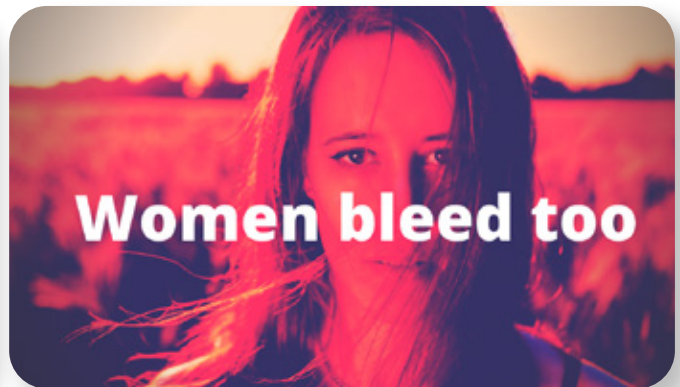
YOUNG FAMILIES AND BLEEDING DISORDERS

Jacqui, Michelle and Janelle reflect on the worries parents have about their young children with bleeding disorders and explore the ways they have overcome their concerns and challenges as a family.



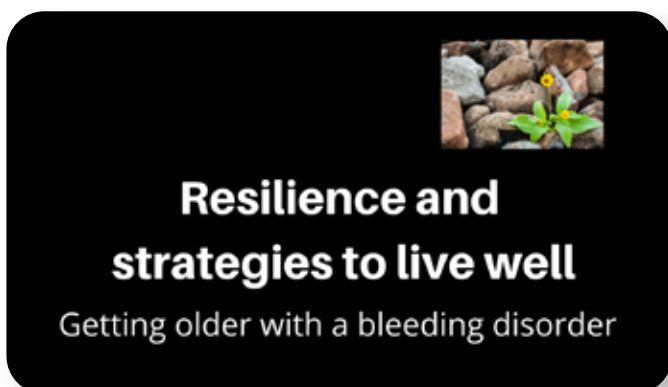
BEING YOUNG WITH A BLEEDING DISORDER

Why are Foundation camps so powerful for young people with bleeding disorders? Sam and Ben explain what it meant for them, with some great footage from the camps as illustration.



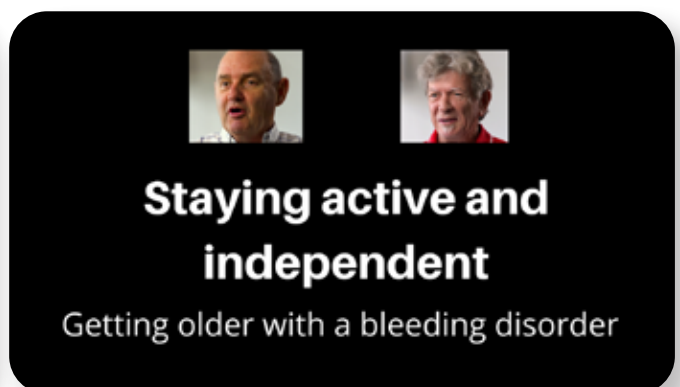
WOMEN BLEED TOO

Sharron, Cheryl, Shauna, Susie and Robyn talk about how women can advocate for themselves in health care settings if they have a bleeding disorder and what they have learned from their own experiences.



RESILIENCE AND STRATEGIES TO LIVE WELL

Zev, Mike and David have severe haemophilia. They talk about their strategies and attitudes to life that keep them optimistic and resilient.



STAYING ACTIVE AND INDEPENDENT

What do you want out of life as you grow older? Zev and Mike have severe haemophilia and don't let their bleeding disorder stop them from enjoying life. They explain their goals for the future and what they do to stay active and maintain their independence.

SPORT AND EXERCISE FOR GIRLS


Accessing the fact sheet

- Read it online or download it from Factored In - <https://tinyurl.com/Fl-sport-girls>
- Ask your HTC for a copy
- Contact HFA to send you copies –
E: hfaust@haemophilia.org.au or
T: 1800 807 173

In May 2021 we released the new fact sheet, **Sport and exercise for girls and young women with bleeding disorders**.

This was developed out of a survey of young women and their parents and answers their questions, such as:

- How can I best participate?
- What types of sport or exercise should I do?
- How can I manage my periods?
- What about injuries?
- What should I tell my coach or club?

Our thanks to all involved in the development: the young women and their parents and the expert health professionals for their comments and advice. 



Sport and exercise

for girls and young women with bleeding disorders

This information answers common questions from girls and young women with bleeding disorders about sport and exercise.

How can I best participate?

- What types of sport or exercise should I do?
- How can I manage my periods?
- What about injuries?
- What should I tell my coach or club?

Read on to learn more.

What kind of sport or exercise do you enjoy?

If you are a young woman or girl with a bleeding disorder, like everyone, you are encouraged to exercise and be active. It's vital to healthy living!

Give it a try!

There is something for everybody and it's a matter of finding something that suits you, that you enjoy and that can get you moving.

It doesn't have to be expensive or take up a lot of your time. The activity you choose can be easy, short and fun.

What to try?

Looking for ideas? Young Australian women with bleeding disorders gave us some examples of what they do:

- Hiking
- Basketball
- Swimming
- Gym
- HIIT
- Soccer
- Netball
- Barre
- Aerobics
- Yoga
- Dancing
- Pilates
- Running
- Walking
- Bike Riding
- Bushwalking
- Weightlifting
- T-Ball
- Touch Football

“ There is no one size fits all. I keep active and try new things to find what works for me. Having the freedom to take these challenges on has helped me into adulthood and developed my confidence in all areas of life. ”

FEMALE FACTORS  [FACTOREDIN.ORG.AU](https://factoredin.org.au)

RESILIENCE AND ADAPTING TO CHANGE - CAREER, WORK AND SPORT



HFA Zoom and Facebook Live webinar for World Haemophilia Day, 22 April 2021

Facilitator: Natasha Coco, Haemophilia Foundation Australia

Speakers:

Penny McCarthy, Clinical Nurse Consultant, Ronald Sowers Haemophilia Centre, The Alfred, Melbourne

Hayley Coulson, Haemophilia Physiotherapist, Queensland Children's Hospital, Brisbane

Nicoletta Collini, Haemophilia Social Worker, Royal Prince Alfred Hospital, Sydney

Darren, who has severe haemophilia

Watch the video of the webinar at -
<https://tinyurl.com/WHDvideo-youth-2021>

Resilience is an important factor in adapting to the many changes that occur during our lives. For young people with bleeding disorders the steps to adulthood involve new responsibilities in many areas of life - tertiary study, working and taking on a career, and managing your treatment, to name just a few. And COVID-19 has made everything more complicated.

In this webinar, speakers explored the challenges for young people, with tips and personal stories.

'It's such an interesting time to be talking about adapting to change,' said Penny McCarthy, haemophilia nurse. 'In the last year I have seen more change in one hit with this COVID epidemic than in all my years of nursing.' She commented that change was part of life at the Haemophilia

Treatment Centre. 'It's a very fluid environment that changes quickly from day to day. A lot of that revolves around the people we look after and making them feel comfortable and addressing their needs – because everyone is different.'

LIFE TRANSITIONS

One of the big transitions in life for young men and women with bleeding disorders is going from a Haemophilia Treatment Centre (HTC) in a paediatric hospital to an HTC in an adult hospital. This occurs during an exciting time in life – when you are leaving school, maybe getting a serious girlfriend or boyfriend, starting a job or uni – but it can be a bit of a shock to the system, commented Penny. The hospital itself looks much less fun and there is a new team to meet, often a larger team than you are used to, because they will be caring for you from when you are 18 until you are elderly. It can be quite daunting – but it is important to remember that the team is there to support you.

Your relationship with the HTC will also change. You are now the adult in charge of your treatment and care and responsible for making decisions, rather than your parents. During your lifetime with haemophilia, your treatments will necessarily change as new treatments become available. Penny described how this works and how education can help you to manage the process.

Ironically, COVID-19 has made some things easier – for example, the HTC now has access to telehealth so you don't always have to come into the hospital for your appointments.

MyABDR, the app for recording treatments and bleeds, is also a great way to communicate with your HTC. It lets your HTC know when you are having bleeds and how you are treating them and gives an opportunity for a discussion



with the HTC team about other strategies to prevent bleeds – and to support you if you are having trouble dealing with new challenges (like a new baby!).

Penny explained that if you have severe haemophilia or are treating at home, you will need to visit the HTC once a year for a review, but otherwise you can usually communicate with the HTC via phone, email or video calls. The HTC is also happy to see you if you are having surgery or dentistry. They are there to help – just call when you need them.

EXERCISE

Hayley Coulson, haemophilia physiotherapist, was the next speaker, and gave a lively presentation illustrated with some drawings she had put together specially for the session.

‘There are many positives with regular exercise,’ said Hayley. ‘Social interaction, emotional changes, reducing stress, improving muscle strength and control, which can support your joints and reduce joint pain, and improving flexibility. It can also prevent long-term issues such as heart disease, obesity, high blood pressure and osteoporosis or weaker bones.’

People with bleeding disorders may be unsure about how to start exercising or what to do, so that exercise doesn’t cause bleeds.

‘This is where seeking advice is important,’ said Hayley. ‘Talk to your HTC or your Foundation or look on reliable websites. You can also talk to other people with bleeding disorders – older people or people your age and get their personal experience.’

INJURIES

What do you need to do if you have an injury?

- Appropriate factor administration if this is part of your treatment plan, as advised by your HTC
- Rest and you can also use ice
- If you have regular joint or muscle bleeds, not walking on the leg is important for recovery
- Monitor the injury carefully. If you can’t walk on the leg, or there is noticeable swelling or limited range of movement in your arm or leg, ask for help – contact your HTC, or the local hospital if you are not close to your HTC, or your regular physio to have a review
- Ignoring the injury and not treating it could impact on your health long-term.

WHAT KINDS OF SPORTS?

Having a review before you start a sport is always helpful, explained Hayley. This will evaluate:

- Your joint motion
- Your muscle strength
- Your flexibility
- Your ligament stability.

Everyone is different and this will tell you which sports

might be higher risk for you and your body. Contact sports like boxing and rugby should be avoided where possible and discussed with your doctor. Protective clothing and gear are also important. Hayley suggested looking at the BRuCe Activity Calculator for more information and to assess the risk with particular sports - http://www.brucecalc.net/activity_calculator.php

WORKING

‘It’s important when you are deciding on a job that it works with your bleeding disorder,’ said Hayley. ‘You will be working for quite a long time in your life and having a job that doesn’t place a lot of stress on your body will make a difference.’

The relationship you have with your employer can also help. You may benefit from changing the way you do your work and being able to talk to your employer about this will be important. For example, you may like to investigate changing your role from physical work like packing to less physical work, like customer service. Or you may prefer to develop your strength and fitness to manage your work better.

Hayley commented that there are a range of experts who can help you, from your HTC team to exercise physiologists and others.

MENTAL HEALTH

The third speaker was Nicoletta Crollini, haemophilia social worker, who talked about managing your mental health during the challenges of change and growing to maturity.

‘Life isn’t a perfect journey and we always need to keep a check on our mental health throughout our lives,’ said Nicoletta. ‘For young people there can be so many things that you are working through: study, new jobs, relationships, family, body image, health concerns – and even changing your HTC.’

A helpful first step is to identify the people in your life who are your social supports - you feel comfortable discussing what’s happening in your life with them, you can be honest and feel they won’t judge you. They might be your parents, family, siblings, cousins, your friends and your colleagues.

By talking with your social supports about what’s worrying you, you are helping yourself. You also have the opportunity to get advice and help from people you trust

and love. Sometimes they will also share their concerns and you have the opportunity to help them as well.

The team at the HTC are also there to support and guide you on your journey. Other professionals who can help you are your GP, who can link you to other services, like counselling. Nicoletta highlighted that there are also online mental health support services.

Online mental health support		
Questions or concerns? For support you can talk to:		
Organisation	Telephone	Website
Beyond Blue	1300 22 4636	beyondblue.org.au
Lifeline	13 11 14	lifeline.org.au
Headspace	1800 650 890	headspace.org.au
Kids Helpline	1800 55 1800	kidshelpline.com.au

‘Life isn’t a perfect journey and we always need to keep a check on our mental health throughout our lives,’

TAKING CONTROL

Another way of managing change is to learn more about what is going to happen, for example, by talking to your employer about your new job or to the TAFE about your new course.

Sometimes changes are unforeseen and can be very unsettling. COVID-19 is a great example of a change we weren't expecting. With these kinds of changes, Nicoletta suggested tapping into the things that help us to get up again when we have been knocked over – our resilience, how have we overcome problems in the past. It might be with the help of friends or family or through taking time to think and reflect, or self-care, with the rituals that help you relax, going for walk or watching trashy TV or playing your favourite video game. And once again, your social supports will be important.

DARREN'S STORY

Darren then joined the webinar to give his personal experiences of adapting to change.

Having severe haemophilia hasn't stopped Darren from taking on all the challenges of growing to adulthood – working, travelling overseas, having relationships, managing his own treatment and working closely with his HTC.

His advice to other young people?

He thought it was most important to stay in touch with your HTC and stick to your treatment plan.

'You are 100% in control with whatever you choose to do, within reason. You can live a normal life. Just be cautious. Be very aware of how you live your life.'

You can read Darren's story in this issue of *National Haemophilia – Youth News, Adapting to life's changes*.

Q & A

Tattoos

Q: What about getting tattoos?

Darren has several tattoos but is always careful to choose a safe tattooist. Penny commented that, while HTCs don't condone tattoos, if you are going to get one and you have severe haemophilia, make sure you have it done on the day that you have your prophylaxis.

Parents and boy stuff

Q: How did Darren's parents support him doing all his 'boy things' while he was growing up?

Darren replied that his mother had 'aged very well' considering the rough and tumble when he and his brothers were growing up together! He commented that part of the joys of having boys with haemophilia was that they would do things they weren't supposed to and learn from their own mistakes – for example, kick the footy around and have a swollen foot the next day.

His mother supported him by learning about haemophilia and how to treat him at home, how to ask him appropriate questions, and never wrapped him in cotton wool – always let him try things out, but always with the right safety equipment and an up-to-date treatment plan. If parents hold their children back, it just makes them anxious, Darren explained. They will turn 18 and be too frightened to deal with change.

Starting a conversation with a new employer

Q: How do you start a conversation about having haemophilia with a new employer?

Darren thought there could be a few different ways to talk to a new employer about having haemophilia, depending on the employer and the situation:

- If you are confident about it, you could even mention that you have haemophilia in the interview and explain how it will and won't impact on you and your work
- Darren often says, 'if I didn't tell you, you wouldn't know I have it'
- You may need to go more slowly and give them information and education
- Every employer is different and has different concerns, but many will be thinking about their liability.

When is it too late to treat an injury?

Q: How long waiting is too long? If I can walk but my knee is still swollen and sore after 6 days, should I call you or is it too late?

Hayley responded to this question, saying while it is preferable not to wait, it is important to contact your HTC for support and advice rather than ignore a bleed. Even if the injury isn't in the 'acute' phase, when it will respond better to treatment, there are still things that can be done and you will have follow-up advice and guidance from your physio. This is also an opportunity for education about how to manage bleeds – because when you are doing well on treatment and don't have bleeds very often, you forget what to do.

Darren added that in his experience, haemophilia physiotherapists will continue to work with you and always have new things to try, right through rehabilitation, and no matter how long it takes. And he has learned from experience to seek help early, when the injury is more likely to resolve quickly with treatment.

Changing treatments

Q: Should you contact your HTC to ask about new treatments or wait for them to contact you?

Penny recommended proactively contacting the HTC to express your interest in changing to a new treatment, particularly now that there are several new treatments. The HTCs have had a lot of questions from their patients and have even had to schedule Zoom group information sessions because the numbers interested are so large. If you contact the HTC, they will already know you are interested.

Parents letting go

Q: What advice would you give to parents who are having trouble letting go of their children with a bleeding disorder?

Nicoletta explained that the transition to adult care wasn't black and white and that it is important for parents to feel confident about their child's care, even when they are technically an adult. She suggested taking up opportunities with HTC transition programs to meet the team and see the adult Centre, perhaps attend an appointment or two if everyone is agreeable. It is also important to give young people a good foundation to take responsibility for their own care in their teenage years. Then parents can step away – but also have the relationship with the HTC to touch base if they have concerns, particularly in the first year.

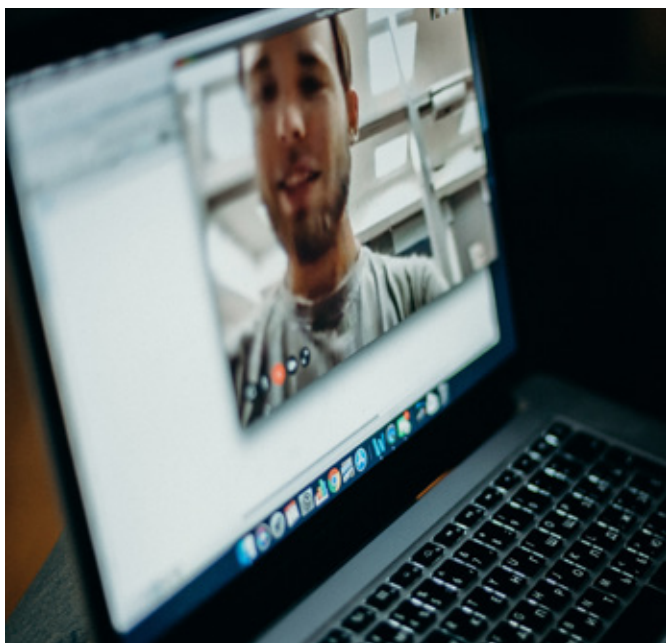
Penny added that the relationship with each person and their family would be individual. She commented that she could understand their concerns as every parent worries, but she thought reaching adulthood and independence with a bleeding disorder was a great milestone and parents should be congratulated for all their hard work in bringing up their child over all the years. Darren suggested rewarding parents – in the first year of transition, take them out to lunch after your review appointment and fill them in on how you are going.

Our thanks to Penny, Hayley, Nicoletta and Darren for taking part in the webinar and sharing their expertise and experience.

MORE INFORMATION

For more information about young people and bleeding disorders, visit the HFA youth website www.factoredin.org.au

If you have any questions about your bleeding disorder or your treatment and care, speak to the team at your Haemophilia Treatment Centre. ■



100% IN CONTROL

“Communication with your HTC is key. They don’t want to be dealing with your mum and dad – they want to deal with you and your partner, the person you choose to be with for the rest of your life.”

Darren joined HFA in a webinar to talk about his personal experiences of dealing with life changes when you are young and have a bleeding disorder.

You can watch Darren in the video of the webinar on the HFA YouTube channel - <https://tinyurl.com/WHdvideo-youth-2021>

Darren is 29 years old and has severe haemophilia.

It may have been a shock to his family when he was diagnosed with haemophilia as a baby, but has it ever stopped him? Definitely not, Darren said.

‘I am a fully qualified mechanic and have been working in the heavy diesel industry for more than 10 years now. When I was younger, I worked two jobs.’

TRAVEL

He has travelled widely overseas – all through Vietnam and Thailand, and with his medication.

‘Taking my treatment product overseas had its challenges – it’s massive, but I had the support of my HTC,’ said Darren.

BEING IN CONTROL

‘Communication with your HTC is key. They don’t want to be dealing with your mum and dad – they want to deal with you and your partner, the person you choose to be with for the rest of your life.’

‘You are 100% in control with whatever you choose to do, within reason. I rode a motorbike to work every day along the freeway for about two to three years.

It was not a problem. I snowboarded all through winter as well. It’s about how you support yourself and communicate with your team. Make sure you wear all your safety gear. I snowboarded with my helmet on. When I was a kid, I went water-skiing and Mum and Dad made sure I had my helmet on.’

Who are his biggest supports? Darren counts his girlfriend and parents as key supports in his life. He finds it very important to have positive people in his life – friends and family – who support you to overcome your challenges.

WORKING

Darren gave his tips for managing work.

‘Just be open with your employer – that’s probably the best advice I can give.’ He explained that with haemophilia being so rare, most employers would not understand the impact of haemophilia and may be concerned about you bleeding to death from a paper cut. Educating your workplace is important and dealing with their fears.

TREATMENT AND THE HTC

Darren hasn’t been afraid to take on treatment changes and has taken part in several clinical trials, including extended half-life factors early on. ‘There are some really good things that can come out of it,’ he said.

What was it like for him to transition from the paediatric to the adult HTC?

‘It wasn’t so big and scary for me! I think just be open and be yourself.’

DEALING WITH LIFE CHANGES

QUESTIONS?

Check out Factored In, the HFA youth website, for more info on living life and being young with a bleeding disorder – www.factoredin.org.au

And talk to your team at your Haemophilia Treatment Centre if you have any questions or concerns about managing your bleeding disorder – at work, at home, at play, travelling, in relationships.



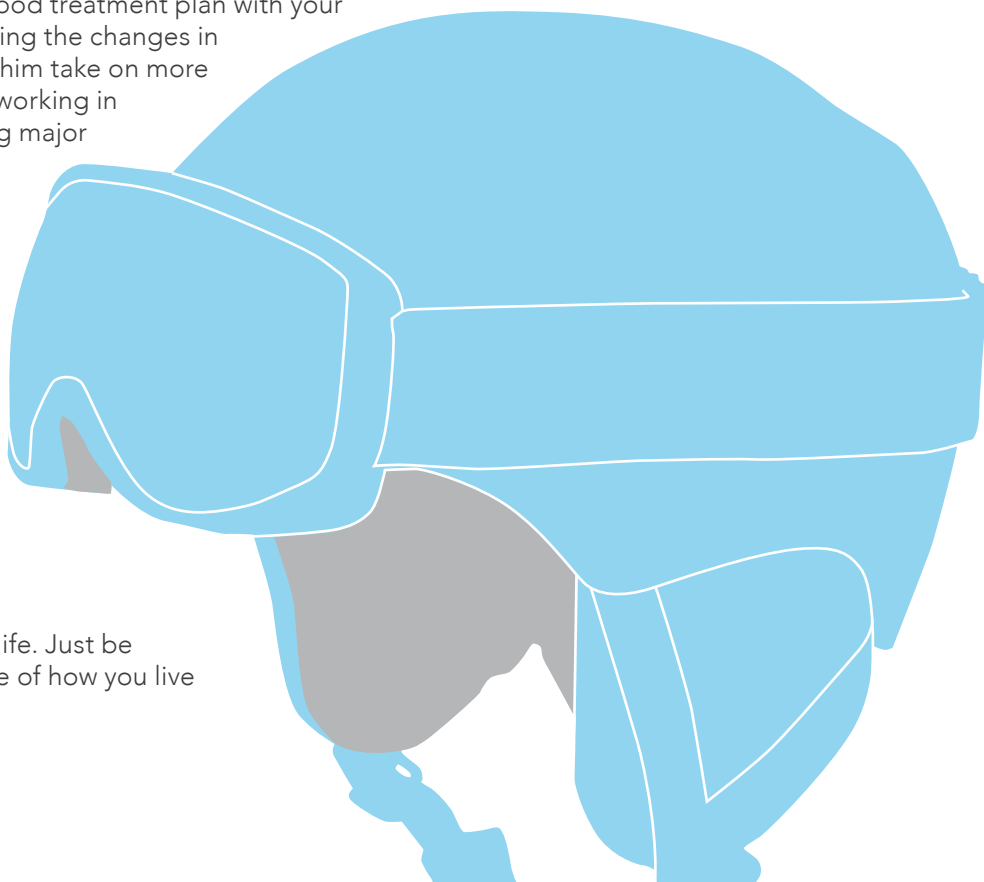
One thing Darren recommended was to put the work into recording treatment and bleeds in the MyABDR app. 'If you can logon to Facebook for an hour a day, you can spend 2 minutes putting your diary into your phone,' he said. It's a simple way to communicate with the HTC – and, according to Darren, a great way to save the HTC nurses from chasing you about your treatment diary!

For Darren, having a good treatment plan with your HTC is key with managing the changes in your life. It has helped him take on more challenging work, like working in remote areas and in big major events.

'Just stick to your treatment plan. You will be at predominantly normal levels, and just don't be silly. If you fall over or have an injury, treat it.'

His message to other young people?

'You can live a normal life. Just be cautious. Be very aware of how you live your life.' H



CALENDAR

WFH Global Summit on women & girls with bleeding disorders

(virtual meeting)

8-10 July 2021

www.wfh.org

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

(virtual meeting)

8-9 October 2021

Tel: 03 9885 7800

Email: ncoco@haemophilia.org.au

www.haemophilia.org.au/conference21

Bleeding Disorders Awareness Week

10 -16 October 2021

Tel: 03 9885 7800

Email: hfaust@haemophilia.org.au

<http://www.haemophilia.org.au/BDaw>

World Haemophilia Day

17 April 2022

www.wfh.org/whd

ACKNOWLEDGEMENTS

Haemophilia Foundation Australia (HFA) acknowledges funding grants received from the Australian Government Department of Health under the Health Peak Advisory Bodies Program and Supporting Access to Blood and Blood Products Program.

We thank the individuals, philanthropic trusts and companies which have made donation to HFA, and the following companies for sponsorship of education programs, conferences or disease awareness programs run by the Foundation for the bleeding disorders community.

HFA acknowledges it has received grants and/or sponsorship from the following pharmaceutical companies for projects in 2020/2021:

BIOMARIN | CSL BEHRING | PFIZER AUSTRALIA

ROCHE | SANOFI GENOZYME

COVID-19 VACCINE FAQs

Do you have questions about the COVID-19 vaccine for people with bleeding disorders?

The Australian Haemophilia Centre Directors' Organisation (AHCDO) has advised HFA on answers to some common questions relating to the vaccine and bleeding disorders.

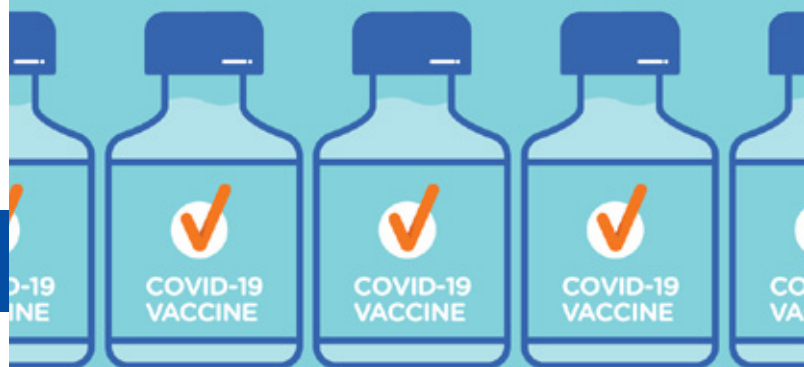
This includes links to the Australian Government information about the vaccine.

Read the **COVID-19 vaccine FAQs** on the HFA website - <https://tinyurl.com/BD-vaccine-FAQs>

The FAQs may be updated as more information becomes known. Please check the HFA website for updates – www.haemophilia.org.au

If you have any questions about your bleeding disorder in relation to the COVID-19 vaccine, contact your Haemophilia Treatment Centre or your treating haematologist.

Australia's COVID-19
Vaccine Roadmap



COVID-19
VACCINATION

NATIONAL HAEMOPHILIA is a publication of Haemophilia Foundation Australia. Every effort is taken to ensure accurate and relevant content, however opinions expressed in NATIONAL HAEMOPHILIA do not necessarily reflect those of the Foundation or the editor, nor is any information intended to take the place of advice from a qualified medical practitioner or health professional.

Haemophilia Foundation Australia does not endorse or assure the products, programs or services featured in NATIONAL HAEMOPHILIA and does not make specific recommendations for any products, programs or services.

We welcome reproduction of articles or quotations from NATIONAL HAEMOPHILIA on the understanding that acknowledgement is made of NATIONAL HAEMOPHILIA as the source. 