National Haemophilia
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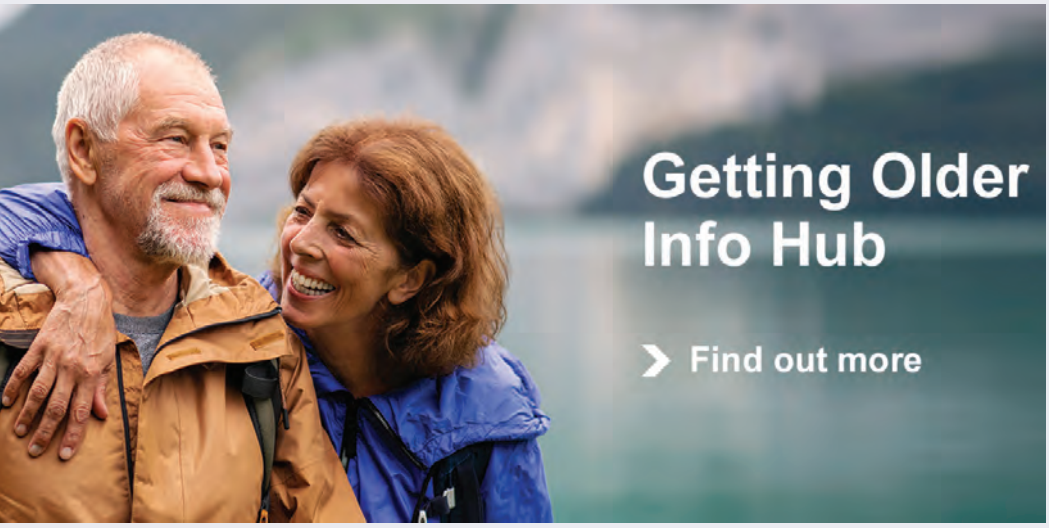
WFH VIRTUAL SUMMIT
June 14-19, 2020

CONNECTING THE GLOBAL BLEEDING DISORDERS COMMUNITY

BRINGING THE COMMUNITY TOGETHER VIRTUALLY

CONTENTS

Haemophilia Foundation Australia
Registered No.: A0012245M
ABN: 89 443 537 189
7 Dene Avenue Malvern East,
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



HFA GETTING OLDER INFO HUB

Check out the new **Getting Older Info Hub** on the HFA website - **www.haemophilia.org.au/getting-older**.

Your go-to zone to find online information on getting older with a bleeding disorder!

Any feedback or ideas on more topics?

Contact Suzanne at HFA on socallaghan@haemophilia.org.au or phone 1800 807 173.

COVID-19 restrictions

During the COVID-19 restrictions HFA staff are working from home, but most services are continuing as usual.

Please note you can contact HFA staff via phone and email as usual. Calls to 03 9885 7800 and 1800 807 173 numbers are being redirected and answered. You can contact HFA staff via hfaust@haemophilia.org.au or visit CONTACT US on the HFA website (**www.haemophilia.org.au/about-us/contact-us**) for our direct contact details.

We thank you for your support and understanding. You can be assured that HFA will continue to support the bleeding disorders community and operate as closely as possible to business as usual.

Gavin Finkelstein is President, Haemophilia Foundation Australia

FROM THE PRESIDENT

Gavin Finkelstein

NEW WFH HAEMOPHILIA GUIDELINES

The new World Federation of Hemophilia (WFH) guidelines for the management of haemophilia were published in August 2020. We have been advised by the Australian Haemophilia Centre Directors' Organisation (AHCDO) that the *Guidelines for the management of haemophilia in Australia* (2016) will also be reviewed following this.

The WFH guidelines include a range of new recommendations following the innovations in treatment and care that have emerged in the last five years or so, such as the use of genetics in diagnosis, new treatment approaches and use of new products. The new guidelines recognise that haemophilia can be managed very differently than before, with a focus on achieving more effective haemostasis (blood clotting) and improved health outcomes.

However, as before, the new WFH guidelines are built on the very important framework for haemophilia care and treatment that includes:

- principles of care
- national coordination and delivery of haemophilia care
- comprehensive haemophilia care
- network of haemophilia treatment centres
- national patient registry
- national or regional procurement of haemophilia therapies

ACCESS TO TREATMENT

This framework has existed in Australia since the National Blood Agreement (2003) when all governments agreed to share the cost of publicly funded treatment products for people with bleeding disorders. It remains our preferred system, but it can be improved. On one hand it has been exciting to see the range of treatment options and new innovations coming globally, but frustrating that in Australia we experience long delays to access them.

HFA started a discussion in 2019 about the potential impact of delays to new and emerging therapies for our community. For example, extended half-life (EHL) clotting factors were first registered in Australia in 2014, and adopted as the standard care in similar health care economies for much longer, yet they only became publicly available to all Australians with haemophilia in July 2020 as a result of the recent government tenders. This is despite a positive recommendation from the Medical Services Advisory Committee (MSAC), which is the relevant government committee to review suitability for government funding for haemophilia treatments. A positive recommendation from MSAC is followed by processes under the National Blood Agreement to make new therapies available. EHLs will make a real difference to the health outcomes for many people with haemophilia A and haemophilia B in our community, and it is a relief they will now be available to everyone.

We came to a consensus with treating health professionals that some new medicines could lead to better health outcomes for patients and reduced costs for governments, but the process for timely evaluation and the issues that should be taken into account needed review. Recently I was pleased when the Federal government announced some health sector reviews of how medicines are assessed for funding. Some of this work will be relevant to bleeding disorders and we will participate.

At the time of writing, people with severe and moderate haemophilia A with and without inhibitors who could benefit from Hemlibra® still do not have access despite a favourable recommendation from MSAC. Hemlibra® is a new treatment option for adults and children with severe and moderate haemophilia A (with and without inhibitors), and many people treated with it report no bleeds at all. It is not HFA's job to recommend specific treatments, but it is our job to advocate for a range of best practice publicly-funded treatment products so our members can decide with their treating doctor which product is best for them.

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WORLD HEPATITIS DAY 2020

We mark World Hepatitis Day globally on 28 July. In 2020 we asked our community to help with the worldwide goal of hepatitis elimination by 2030 by starting a conversation - talking to friends, family or a doctor.

New revolutionary hepatitis C treatments are widely available in Australia. They have very high cure rates. Treatment is simple - tablets not injections, few if any side effects.

WHAT ARE THE ISSUES FOR THE BLEEDING DISORDERS COMMUNITY?

Many Australians with bleeding disorders and hep C have now had treatment and been cured. See their stories on the World Hepatitis Day page on the HFA website - https://tinyurl.com/BD-WHepD2020.

Have you been cured of hep C? How is your liver going? 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.

Some people with bleeding disorders or who carry the gene may not realise they have hep C. You could be at risk if you ever had a blood product before 1993. Is this you or someone you know? Have you ever been tested for hep C? If not, now is the time to talk to your doctor about a hepatitis test - and have treatment to be cured, if you do have hep C!

Thousands of Australians are now living free of hep C, but many have not yet had treatment. Treatment is simple and nearly all are cured – start the conversation.

There is a small number of people with bleeding disorders and hep C whose treatment has not yet been successful. Close liaison between their hepatitis specialists and their Haemophilia Treatment Centre is very important for their care. Research into new and improved hep C treatments continues.

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

FOR MORE INFORMATION

Visit

- www.world.hepatitisday.org.au
- The HFA World Hepatitis Day page - https://tinyurl.com/BD-WHepD2020

From the President (cont.)

We are keen to demonstrate in the upcoming government reviews that new and emerging therapies that are life changing for patients, and will improve their health dramatically, can also be cost effective for governments. The problem is that some of the processes for evaluating these newer products are no longer fit for purpose. I look forward to our contributions to these reviews, and work with stakeholders to make sure the National Blood Agreement continues to ensure the most suitable treatment products for bleeding disorders are available to everyone across the country.

NATIONAL PATIENT REPRESENTATION

In closing, I wanted to mention that we continue to work with individuals from South Australia and the Northern Territory, although we do not have formal membership of the HFA Council. We are pleased we have been able to maintain an observer from South Australia on the Council and that community representatives are well engaged in the Haemophilia Treatment Network committee to ensure the patient voice is heard in South Australia.

BLEEDING DISORDERS AWARENESS WEEK

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

What a different year it is going to be – with COVID-19 restrictions different in each state/territory and the unknown we have decided to develop a virtual campaign. This will involve many fun things that all ages can get involved in.

The theme of the week is ***One Community, Many Faces***. We will showcase our community and highlight the many different bleeding disorders and experiences.

GO RED FOR BLEEDING DISORDERS

Looking for something to do during Bleeding Disorders Awareness Week either face to face or virtual? Host a red-themed event and **Go Red For Bleeding Disorders**! Some quick ideas are:

- Host a red-themed morning tea
- Host a Red Cake Day
- Dress red for a cocktail night
- Host a red themed crafternoon
- Wear red in support of the day

More information and ideas will be on our website.

HFA will not be able to provide any promotional packs this year due to COVID-19 restrictions but we will have it all downloadable online.

For downloads and information visit www.haemophilia.org.au or contact Natashia on ncoco@haemophilia.org.au or MB 0403 538 109.

Don't forget to follow us on our social media networks for links to virtual events and current up to date information -

EVERYONE HAS A STORY TO TELL

Would you like to share your story for Bleeding Disorders Awareness Week? www.haemophilia.org.au/shareyourstory

Like HFA on Facebook

Like HFA on Instagram

Follow HFA @Haemophilia_au

CONNECTING THE GLOBAL **BLEEDING DISORDERS COMMUNITY**

www.wfh.org/virtual-summit

WFH VIRTUAL SUMMIT June 14-19, 2020

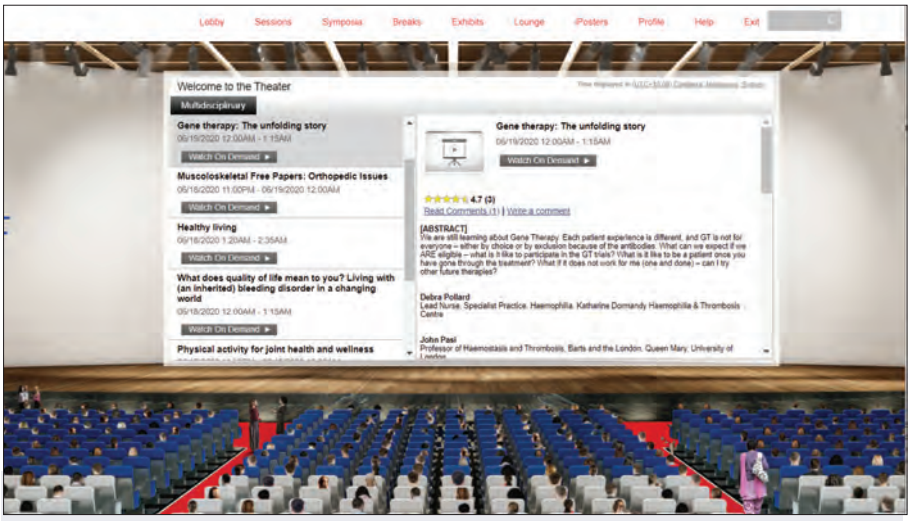
WFH VIRTUAL SUMMIT 2020

In 2020 COVID-19 emerged worldwide and it was no longer safe to hold large face-to-face meetings. The World Federation of Hemophilia (WFH) World Congress that was due to take place in Kuala Lumpur, Malaysia in June 2020 was cancelled. In its place WFH organised its inaugural Virtual Summit.

The **WFH Virtual Summit** was a novel concept of bringing together the global bleeding disorders community virtually – in an online environment, with live webinar sessions and Q&A from delegates who had registered. There was a diverse and stimulating program, with highly relevant topics and discussions such as:

- the impact of COVID-19 on bleeding disorders management and care
- patient experiences of gene therapy
- women 'ageing gracefully'
- what does 'quality of life' meant to you
- VWD and the differences between men and women
- physical activity for joint health and wellness
- treatment products now and in the pipeline
- and many other timely and interesting subjects.

In this issue of *National Haemophilia*, we hear about some of the key sessions from Summit delegates.



HOW TO ACCESS THE VIRTUAL SUMMIT

Many of the sessions have been recorded and are now available to everyone to view on demand free-of-charge. They will remain online until June 2021 – a great opportunity to catch up with all the latest information and debate from the world experts from the comfort of your home!

- Go to https://www.wfh.org/virtual-summit
- Click on WATCH ON DEMAND
- Register
- Then ENTER with your email address
- Select the type of sessions from the top menu
- Then select the session you want to see and click WATCH ON DEMAND
- And settle back for a very interesting session!

COVID-19 AND THE NEW NORMAL

Please liaise with your Haemophilia Treatment Center (HTC) team about the best way for you to communicate with the team during the COVID-19 pandemic as local circumstances may vary.

EMERGING FROM COVID – DEFINING A NEW NORMAL

Moderator: Declan Noone, President, European Haemophilia Consortium

The impact of COVID-19 on the global bleeding disorders community was a key session in the WFH Virtual Summit. Jaime Chase and Nicoletta Crollini give their perspectives on the nursing and psychosocial issues raised.

Emerging from COVID panel discussion

JAIME CHASE

Haematology Clinical Nurse Specialist, John Hunter Children's Hospital, Newcastle NSW

THE CHANGING ENVIRONMENT IN HTCS AND HOSPITALS

Kate Khair, Director of Research, Haemnet

A session that was particularly informative during the summit was ***Emerging from COVID – a new normal***. A number of informative and passionate professionals spoke about how the person with haemophilia may be experiencing healthcare in the pandemic and how their care might change during this challenging time.

It was particularly thought-provoking to hear Kate Khair speak about how healthcare has evolved and will continue to change as the pandemic progresses.

Kate explained that haemophilia care will continue to change and evolve just as COVID-19 changes. Your Haemophilia Treatment Centre (HTC)'s care of you and your haemophilia may have or will change during this time.

The changing face of haemophilia care in the COVID-19 era has been particularly challenging, not only for the person with haemophilia but also for the Haemophilia Treatment Team itself. Teams have been moved perhaps from the HTC to other areas of the hospital and in some cases they may be working from home. Staff may be 'surged' to other areas, which is a term used when staff are required to relieve other staff for short periods due to the hospital's acuity or the intensity of nursing required in particular areas. A great example of this is when staff are 'surged' to help manage queues in COVID testing areas or at screening stations at designated entrances to hospitals.

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The important thing to remember in this ever-changing situation is that the expertise of all the multidisciplinary team is there to help you. Instead of being physically always available, remember they are on the other side of a telephone call to offer their expert advice and recommendations. As the pandemic progresses your clinic appointments will likely move to telehealth. If you have not experienced this as yet, a link is sent to your email address that you utilise to be able to have a virtual clinic with your healthcare professional from your own home. Your HTC may be utilising this option or using a telephone call to review you. If you are having issues with the technical aspects of this option, please talk with your HTC who will be able to offer support and advice.

Kate also discussed what to do in case of a bleed. Your HTC is always there for advice and you may still be asked to present for treatment and review. It may be somewhere different to where you are used to and it may be with different staff. There will be extra precautions taken by staff (such as wearing masks and frequent cleaning) and there may be limits on how many support people you can have with you. Importantly, it was stressed that a bleed needs to be treated and reviewed as necessary. Hospitals are safe places for people to come to and be treated; they should never be feared when treatment is required.

Kate also discussed prophylaxis, and how as restrictions ease or increase in your state or region, you will need to be mindful of your activity levels and discuss with your HTC as required. In regards to surgery, some waitlist or pre-booked elective surgeries may be delayed. Acute surgery will proceed and it is imperative that your surgical team has a treatment plan from your HTC and that you are aware that your follow-up may vary as you move from inpatient to outpatient. Follow-up may be conducted via telehealth rather than face-to-face.

In conclusion, it can be noted that the 'new normal' is an ever-evolving world. Care is delivered differently and as COVID-19 continues, the way that healthcare is delivered may change for the better. There has been a gradual recognition that the new ways of caring for people with haemophilia and their families might be better in the long run. There is less travel, waiting and personal expense noted with this model of care. Your HTC is always there to offer support, expert advice and education to people with haemophilia and their families.

I would encourage everyone to access the Virtual Summit and enjoy the presentations and posters. The educational and supportive content is comprehensive and accessible for all. If you have any questions regarding the presentations, please contact your HTC for further advice. Stay safe and remember to follow health care advice. Your HTC is there when you need them.

NICOLETTA CROLLINI

Haemophilia Social Worker, Royal Prince Alfred Hospital, Sydney

WHAT CAN OUR PATIENTS EXPECT IN A 'NEW NORMAL'

Dr Len Valentino, Chief Executive Officer, National Hemophilia Foundation

The session on COVID-19 was highly informative and useful. It commenced with Dr Len Valentino providing tips on staying safe, with the main point being to stay informed and keep up-to-date with local recommendations. Dr Valentino's advice couldn't be any more relevant at present, considering the varying impacts of COVID-19 throughout Australia.

PTSD, OTHER CHALLENGES AND HELP GETTING TO THE 'NEW NORMAL'

Ed Kuebler, Advocacy and Leadership Programs Manager, Global Blood Disorder Foundation

Following on from Kate Khair, Ed Kuebler discussed the psychosocial implications of COVID-19. Ed noted that people might experience post-traumatic stress disorder (PTSD) as a result of COVID-19, due to high levels of stress experienced during this time as well as the many other ways COVID-19 has impacted individuals. PTSD is the frightening feeling of past experiences of fear, even when one is not in danger. Ed discussed what it would take to 'be ok' and explained this is a state of mind that comes from ourselves through being present and in the moment. He recommended taking a moment for yourself to define what 'being ok' means to you. When exploring your 'ok', consider your past 'ok'. Are you comparing your 'ok' to the 'ok' of people around you? Is your 'ok' the ideal definition of normal? At which point is that an unachievable 'ok'? This exercise will hopefully provide you with clarity about what 'being ok' genuinely means to you.

Ed went on to discuss managing losses related to COVID-19. These could be losses of employment, socialising, travel and the many other losses we have all experienced as a result of COVID-19. He recommended reflecting on your experience of loss and drawing upon

your experiences of resilience or your ability to bounce back from challenging situations. Time and compassion are essential when dealing with loss, so be gentle to yourself.

Ed explored the struggles that some might be experiencing in trying to define their 'new normal' as a result of COVID-19. He suggested our 'new' normal should be informed by the relevant COVID-19 information available to us and that it is important to acknowledge the struggle we are experiencing in defining our 'new' normal is more psychological.

He recognised that many people would have very much liked their life before COVID-19, but recommended you unload these feelings and thoughts through the exploration of your new way of life. How does one go about doing this? He suggested writing a list of what you liked before and how they are different now. Don't be afraid to acknowledge those changes or losses and stay in the moment by being present with what is around you. He recommended defining your 'new normal' from a place of positivity: 'you have the power to define this'.

Ed's final comment, which I found to be quite powerful, was to stop resisting and fighting as it will allow you to move forward. Remind yourself, 'it is what it is.' This is a powerful statement of moving forward, accepting your 'new normal', which includes the changes and aids in releasing our internal struggles.

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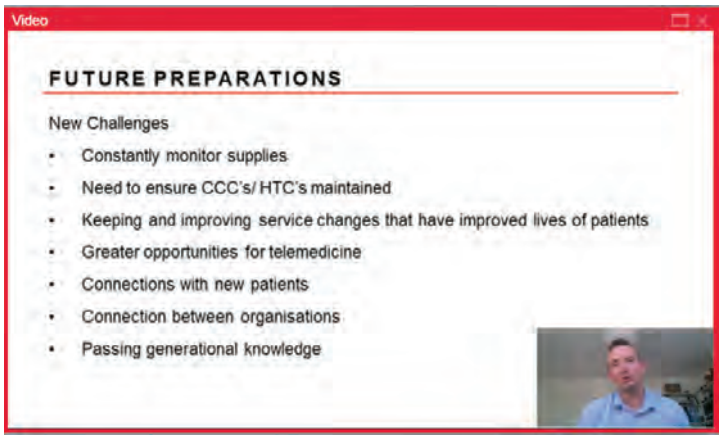
PATIENT CONCERNS AND POSITIVE OUTCOMES

Declan Noone, President, European Haemophilia Consortium



Declan Noone ended the session discussing patient concerns and positive outcomes during COVID-19.

Firstly, Declan explained that technically people with an inherited bleeding disorder are not at an increased risk of contracting COVID-19 than the general population. However, those receiving treatments such as immunosuppressants or steroid treatments as well as individuals who might have other health issues such as pre-existing lung problems are at an increased risk of serious illness from COVID-19.

Declan observed there had been positive outcomes of COVID-19 for haemophilia and rare bleeding disorder treatments: robust treatment supply chains, increased access to home treatments, increased access to treatment home delivery, the rapid roll-out of telehealth medicine, the ability to respond to crisis rapidly, the pharmaceutical industry promptly providing supportive information as well as new methods of engaging with each other, such as the World Federation of Haemophilia Virtual Summit.

Declan ended his discussion by exploring the new challenges ahead and future preparation required. This involves continuous monitoring of supplies to ensure shortages do not occur, and he advised that people with bleeding disorders continue to maintain contact with your HTC and explore the new models of healthcare available such as telehealth.

I found this session to be very helpful and informative. It certainly provided me with clarity and the ability to take a moment to reflect on everything that has occurred as a result of COVID-19. The session left me feeling informed and more than anything provided me with the ability to feel a little more settled, during such an uncertain and unsettling time. I hope you find this summary provides you with these feelings too.

A final reminder, your HTC is here for you, and you can still contact us to talk through any concerns, just like always. Stay safe and take care!

Suzanne O'Callaghan is HFA Policy Research and Education Manager

QUALITY OF LIFE IN A CHANGING WORLD

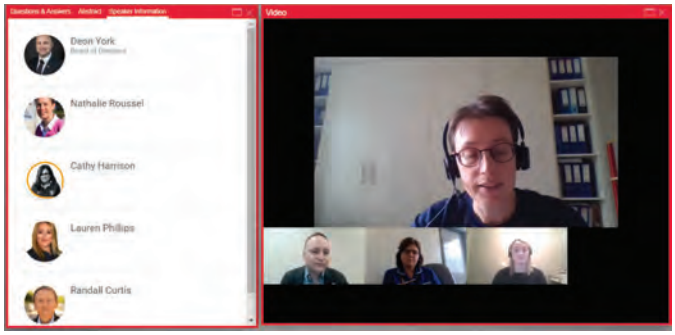
Suzanne O'Callaghan

WHAT DOES QUALITY OF LIFE MEAN TO YOU?

LIVING WITH (AN INHERITED) BLEEDING DISORDER IN A CHANGING WORLD

Moderator: Deon York, Board Member, World Federation of Hemophilia; President of the Haemophilia Foundation of New Zealand

The session on what quality of life means to you at the Virtual Summit took us on an exploration of the challenges and motivations that impact on quality of life, both for the person with a bleeding disorder and the health professionals who care for them. I found it to be an honest, thoughtful and sometimes confronting journey as the presenters gave their individual perspectives on quality of life. The session also took into account the effect of COVID-19 and the complexities of this experience. Cathy Harrison's presentation, for example, highlighted the positive and negative outcomes of this pandemic. Overall it left us with a strong message: what defines each person's quality of life will be individual to them and it is important to ask them and not make assumptions.



MENTAL HEALTH AND HOW IT CORRELATES WITH CHRONIC CONDITIONS

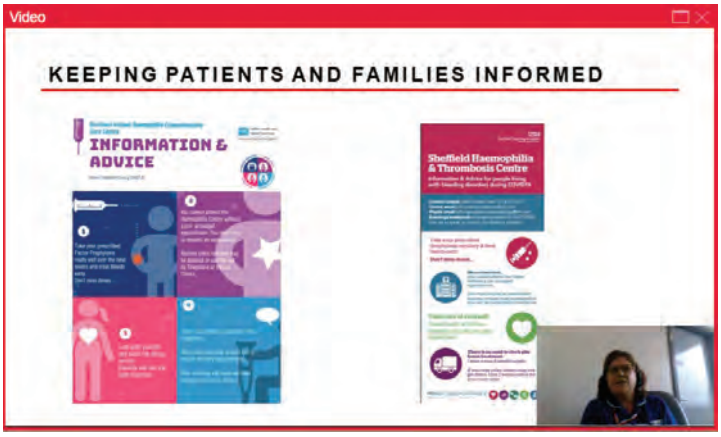
Nathalie Roussel, Assistant Professor, Musculoskeletal Physiotherapy, University of Antwerp

How we think about our health affects how we feel. This seems like a simple statement, but Natalie Roussel explained just how complex this can be in relation to bleeding disorders and quality of life. Using the example of pain, she described how the negative emotions like fear and anxiety can affect a person's experience of pain and will affect their entire day. Current research has underlined that this way of thinking is 'plastic'; that it can be changed into a more positive way of thinking about and experiencing pain.

In haemophilia, joint problems such as target joints will reduce quality of life over a lifetime. Although it might seem counter-intuitive, it has been found that increased physical activity may help to improve pain. Natalie pointed out that overcoming a fear of movement in people with haemophilia would not only decrease their pain but also increase their sense of self-efficacy. Stress management may help them to have better coping strategies. All of these come together to improve quality of life.

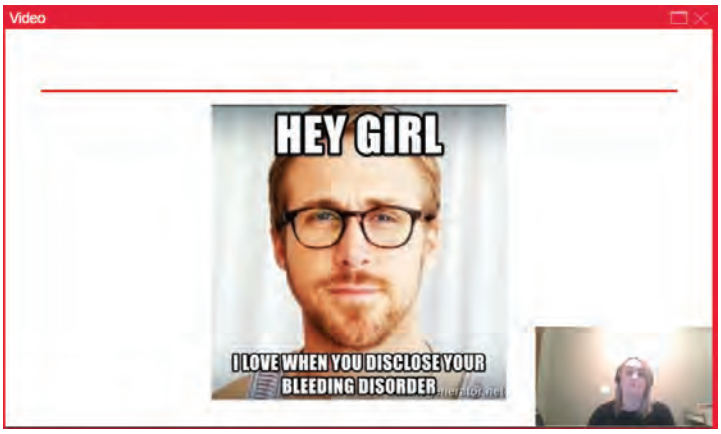
NURSING PERSPECTIVE

Cathy Harrison, Advance Nurse Practitioner, Sheffield Haemostasis & Thrombosis Centre



Cathy Harrison gave an interesting personal view of the COVID-19 crisis from her perspective as a haemophilia nurse. She began by pointing out the effect of COVID-19 on mental health and on those who are more vulnerable in the community. In early surveys in China, although many people did not feel personally at risk from COVID-19, they nevertheless reported generalised feelings of apprehension and horror about COVID-19.

Managing the stress of COVID-19 for her patients was very important to Cathy. At the beginning of the pandemic in the UK, the HTCs were concerned to make sure services were maintained to people with bleeding disorders and worked together as a team to achieve this. The process was exhausting, especially as the team was slowly separated through redeployment and illness. Even when she herself contracted COVID-19, Cathy continued to work from home to support the HTC team. They realised that it was crucial to keep their patients informed to reduce feelings of



anxiety about their access to services. The HTCs remained open for acute episodes and maintained contact with their patients through telephone, email and videohealth services. They offered support to surgical teams for urgent surgery, even though this was more difficult than usual as they could not see the patient face-to-face.

What will be important for the future? Cathy underlined that it will be essential not to make assumptions about patient preferences and to find out from their patients what has worked well and how they would prefer to receive their services.

PATIENT PERSPECTIVE

Lauren Phillips, Youth Committee Member, Haemophilia Foundation of New Zealand

Lauren is a woman living with moderate/severe type 1 von Willebrand disease (VWD). She took viewers on a quick journey on her life and experience and what is important to her as a patient. She stressed that it was her personal perspective and others will have their own voice and experience.

She was not diagnosed until she was 8 years old in the UK, after years of severe nosebleeds and anaemia. At first her parents were told she might have leukaemia, and after the great fear this caused, they were relieved to find it was actually VWD. For Lauren, this was a lesson that she needed to be well-informed about her health condition and to be able to work closely with her medical team to spare her parents more anxiety about her health. When she and her family emigrated to New Zealand, she was put on home therapy and reflected that access to good quality treatment was very important to quality of life.

When she left home to go to university, she was for the first time in charge of her treatment and treatment plan. At this point in her life she was referred to a gynaecologist and diagnosed with endometriosis. Being treated for her endometriosis made an enormous difference to her menstrual bleeding and pain and changed her beliefs about her potential to be in a relationship and have children. This also highlighted for her that there could be other medical complications with her bleeding disorder.

With her improved quality of life, she felt she had more to offer and joined the Youth Committee at HFNZ. This has meant that she has connected with other people with bleeding disorders internationally and has been a very positive experience for her. A big issue for her has been disclosing her bleeding disorder, particularly to new partners. For her, disclosing was a way to find a partner that would accept her and her bleeding disorder. She is now married and considering starting a family with her husband.

Summing up, Lauren underlined that 'quality of life' means different things to different people and that it is important for clinicians and community members to ask individual people with bleeding disorders what 'quality of life' means to them.

THE AGE DISPARITY ON QUALITY OF LIFE MEASURES

Randall Curtis, Project Manager, Hemophilia Utilization Group Study (HUGS)

Randall Curtis has severe haemophilia and has been involved in research to measure patient experiences for many years. He highlighted what he called the 'disability paradox': that in spite of joint problems and pain over their lifetime, older people with haemophilia often score higher on quality of life measures than people the same age with similar health conditions like osteoarthritis. Researchers believe this is because older people with haemophilia have had arthritis and pain since they were young and have adapted to it. Their frame of reference is other people with haemophilia who are their age. As a result, the types of measures used in assessing health may under-report their problems with activities of daily living. Randall concluded that it will be critical to quality of life research in haemophilia to also use measures that can describe actual everyday functioning and issues such as joint problems and pain and can reflect the impact of changes in care.

Suzanne O'Callaghan is HFA Policy Research and Education Manager

WHAT HAVE WE LEARNED FROM PROBE?

Suzanne O'Callaghan

If you saw the PROBE data about ageing and haemophilia in the HFA Getting Older report, you may have wondered if similar results are found internationally.

Intrigued by the early results from Australia, the international PROBE investigators analysed the PROBE data at a global level and found some strong correlations. Their conclusions? Aging is associated with a steeper decrease in health status and health related quality of life in people with haemophilia than in people who do not have a bleeding disorder. In people with haemophilia, this decrease is large enough to be identified and measured every 10 years from the age of 18 years. The results were published in a poster at the ISTH 2020 Virtual Congress.[1]

PROBE (Patient Reported Outcomes Burdens and Experiences) is a multinational validated study where Australians can give evidence about the impact of living with haemophilia and of different sorts of treatment on their bleeds, pain, activities of daily living and quality of life. There is also a comparison group of people who do not have a bleeding disorder. The PROBE questionnaire includes different sets of questions to measure health-related quality of life: specific haemophilia-related questions (the PROBE score), the EQ-5D-5L utility index, and the EuroQol visual analog scale (EQ-VAS) of global health. Interestingly, the international study also found that the PROBE score is more sensitive than the EQ-5D in measuring the association of ageing on the specific domains (eg, physical, psychological, social) that were measured in both people with haemophilia and people who do not have a bleeding disorder.

HOW CAN YOU BE PART OF PROBE?

As you can see from the Getting Older report, the PROBE study is a very important source of data to help HFA to better understand current issues - and this data will be crucial for our treatment advocacy.

Have you already completed the PROBE questionnaire? If not, please take a moment to consider making your contribution to the data. The more responses we have, the more robust our data will be and the more questions we will be able to answer. At the moment, we still need more people on prophylaxis to complete the survey for solid data on the different types of treatment. But we would be keen to hear from everyone!

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)

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

Or ask HFA or your Foundation for a print copy

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

REFERENCE

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Sumit Parikh is the AHCDO ABDR Senior Research Fellow

UPTAKE OF MYABDR IN AUSTRALIA

Sumit Parikh

With COVID-19 gripping the entire world, the ISTH Congress, the scientific meeting of the International Society for Thrombosis and Haemostasis that takes place each year, was a virtual experience in 2020. The Australian Haemophilia Centre Directors' Organisation (AHCDO) had one poster this year, **Uptake of MyABDR in Australia**, which was very well received, with many positive comments and feedback.

It is well-recognised that care for people with haemophilia has improved much over the last two decades. However, one of the biggest challenges to formally assess the benefit of routine prophylaxis remains the need to regularly monitor adherence and treatment outcomes. The main aim of this project was to review the uptake of MyABDR among haemophilia A patients in Australia: it is imperative to understand how this smartphone and website application is being used to self-record home treatments and bleeds.

Around 30% of haemophilia A patients are registered on MyABDR (including 68% severe and 12% non-severe). Results demonstrated that 75% of MyABDR users are on routine prophylaxis and/or immune tolerisation therapy. To measure approximate 'adherence to prophylaxis', the prescribed treatment regimen was compared against product delivered/supplied. To understand how often patients were recording their treatments in the MyABDR app, or 'adherence to logging', the prescribed treatment regimen was compared against treatments recorded in MyABDR.

It was very encouraging to observe an upward annual trendline of the adherence to logging curve looking at a time period of almost 6 years, as treatment recording has greatly improved in the last 2 years. Parallel comparison of adherence to prophylaxis and adherence to logging highlighted that patients who are consistently adherent to their treatment regimen and recording in MyABDR benefit the most, as can be seen in evidence from the EHL (Extended Half-Life) Interim Program.

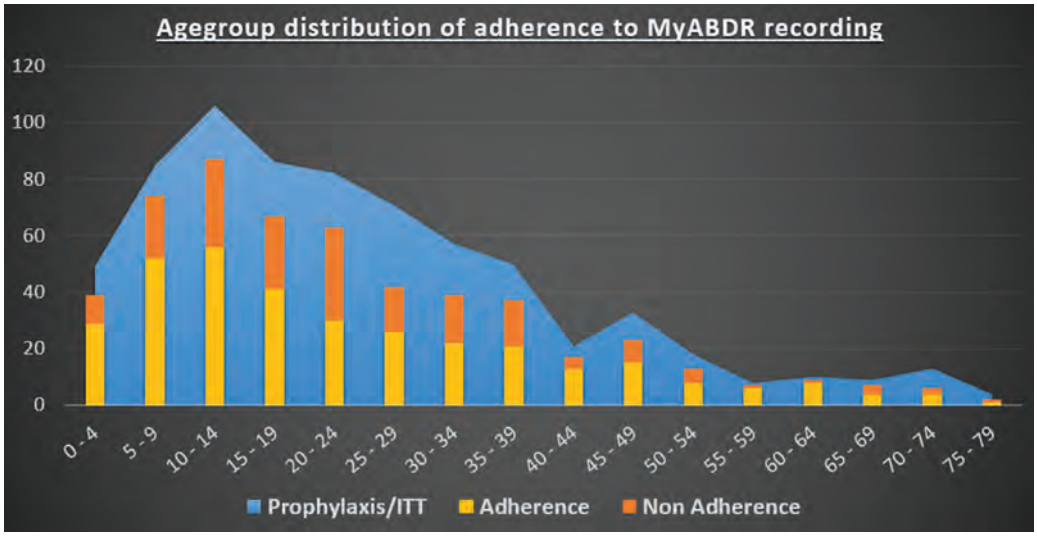
There is a small proportion of patients who persistently do not record in MyABDR. From a community perspective, if we can ascertain any limitations and/or establish reasons why patients do not record, there could be an opportunity to improve the uptake of MyABDR. This would then more accurately reflect the benefits of routine prophylaxis.

MyABDR is a valuable tool to determine the relationship between treatment, outcomes and patient compliance. The quick snapshot in this poster provided a good overview of MyABDR usage in Australia. We intend to undertake further study to evaluate bleeds recorded on MyABDR to improve our understanding of the outcomes and to investigate whether it helps with reviewing and adjusting a patient's prescribed treatment regimen, if required.

Best wishes to all. Stay safe - and keep recording in MyABDR!

REFERENCE

Parikh S, Curtin J, Carter T, Brown S, Prasad R, Mcrae S, Tran H. Uptake of MyABDR in Australia. [Abstract PB0832] ISTH 2020 Congress. Research and Practice in Thrombosis and Haemostasis. 2020; 4 (Suppl 1). https://abstracts.isth.org/abstract/uptake-of-myabdr-in-australia/



Suzanne O'Callaghan is HFA Policy Research and Education Manager

VWD UPDATE

Suzanne O'Callaghan

INTERNATIONAL VWD CLINICAL GUIDELINES

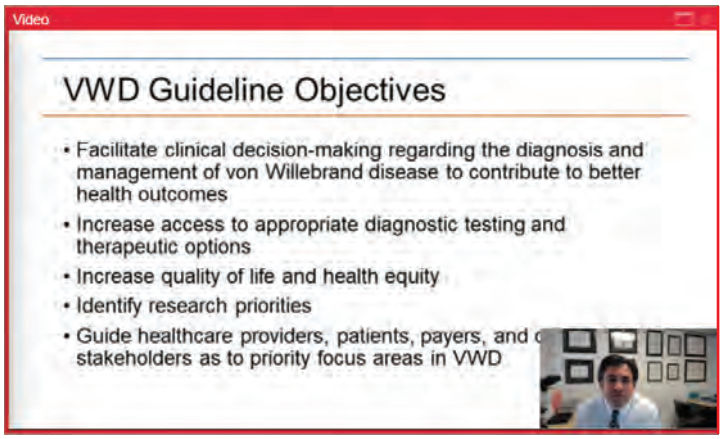
The WFH Virtual Summit provided an update on the **international von Willebrand disease (VWD) clinical practice guidelines** and it was exciting to hear that the guidelines are to be published in December 2020.

The clinical practice guidelines are a collaboration between several organisations: the American Society of Hematology (ASH), the International Society on Thrombosis and Haemostasis (ISTH), the World Federation of Hemophilia (WFH) and the National Hemophilia Foundation (NHF). There are two panels, diagnosis and clinical management, and there are clinical and patient representatives on both panels, including Australian clinicians and patients.

THE PATIENT VOICE

Over the last two years there have been a couple of opportunities for the global VWD community to participate in the development. The most recent was the online survey in April-May 2020 and our thanks to the Australian community members who contributed their feedback. At the update session Dr Nathan Connell, clinical vice chair of the guideline development panels, explained how critical the patient voice had been to the approach and focus of the guidelines. The patient involvement has helped the panels to align the guideline development to the patient journey and what patients value highly, for example:

- A diagnosis that gives access to appropriate management
- Clear diagnostic thresholds to give a definitive diagnosis
- Clinical management that reduces the risk of bleeding, especially the effect of bleeding on quality of life
- Shared patient-doctor decision-making about risks and benefits
- Recognition that values and preferences are likely to vary among individual patients
- The importance of education material for patients and clinicians about long-term prophylaxis for decision-making.



Dr Nathan Connell presenting virtually on the VWD guidelines

NEXT STEPS

This is the first time that international clinical guidelines have been developed for VWD. The comments by stakeholders are currently being reviewed before publication. When the international guidelines are published, the Australian Haemophilia Centre Directors' Organisation (AHCDO) will review them to develop Australian guidelines for a consistent national approach to diagnosis and management. HFA will then use the AHCDO guidelines as the basis for updating our VWD education materials. Watch this space!

GLOBAL VWD CALL TO ACTION

The **WFH Virtual Summit** provided an opportunity to highlight information about VWD in several of the sessions:

- A medical session updating on the latest in VWD diagnosis and treatment
- A multidisciplinary session on the perspectives of people with VWD and the differences between men and women
- The WFH session on the international VWD clinical guidelines
- And multiple sessions about issues for women and girls.

You can access the Virtual Summit sessions on demand at https://www.wfh.org/virtual-summit/

WFH leads a worldwide call to action on VWD, 'to acknowledge the work that needs to be done, to make a commitment to recognizing VWD and other rare bleeding

disorders by taking action to create awareness, resources and provide support to improve the lives of those living with VWD'. Australia joined the call to action in 2018 and HFA is a member of the WFH VWD Global Group, which supports this work.

In a recent article in the WFH magazine *Hemophilia World* (https://tinyurl.com/WFH-VWD2020), WFH described the impact of raising awareness about VWD and improving access to diagnosis and treatment, using South Africa, Nicaragua, Sudan, Bangladesh, Colombia and the Netherlands as examples.

HFA is looking forward to opportunities to raise awareness about VWD during Bleeding Disorders Awareness Week, 11 to 17 October 2020. We will be looking for personal stories about the experience of living with VWD. For more information, check the Bleeding Disorders Awareness Week page on the HFA website - https://tinyurl.com/BDAW2020. Do you have a personal story to tell? Perhaps now is the time to share your story!

HFA also has a VWD Focus Group of men and women with VWD, who give ideas and feedback on HFA's VWD awareness and education activities, generally via email or online survey. If you would be interested in participating in this group, contact Suzanne at HFA on socallaghan@haemophilia.org.au or phone 1800 807 173.

Photo by dlritter, FreeImages

This article is reprinted with permission from *Bloodline*, the magazine of the Haemophilia Foundation of New Zealand (www.hfnz.org.nz), vol. 47 no. 3, December 2019.

Cat Pollard is Advanced Clinician Physiotherapist, Auckland Regional Haemophilia Service

ULTRASOUND JOINT SCANNING IN HAEMOPHILIA

NEW ULTRASOUND SCANNING BRINGS IMPROVEMENTS FOR HAEMOPHILIA CARE

Cat Pollard

The musculoskeletal care of people with bleeding disorders is highly specialised with the ultimate goal of minimising joint arthropathy. The Australia and New Zealand Physiotherapy Haemophilia Group (ANZPHG) are a core group of dedicated haemophilia physiotherapists who aim to provide best evidence care to those living with bleeding disorders. For this edition of *National Haemophilia*, Cat Pollard has kindly shared an article that she wrote for the Haemophilia Foundation of New Zealand (HFNZ) about the integration of ultrasound scanning into haemophilia care. Cat is the Advanced Specialist Physiotherapist for Haemophilia in the Auckland District of New Zealand and a valued member of the ANZPHG.

Alison Morris, Australian co-chair, ANZPHG

We are donning our X-ray vision goggles and looking deeper into joints than ever before. Well, not really, but at a number of Haemophilia Treatment Centres across Australia and New Zealand, the specialised haemophilia physiotherapists have been trained to use ultrasound imaging to more closely monitor joint health.

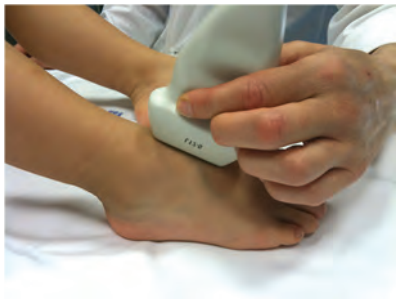
In addition to our normal physical assessment, known as the Haemophilia Joint Health Score, we will be performing an imaging protocol called the Haemophilia Early Arthropathy Detection with Ultrasound (or HEAD-US for short). This means we will be using the ultrasound scanner to look at the elbows, knees and ankles. These are the joints most commonly prone to bleeding episodes. In order to detect and grade any changes to the synovium (which is the layer surrounding the joint which helps produce fluid to keep the joint lubricated); the cartilage (the protective coating covering the bone ends); and the bones.

As we know, even one bleed into a joint can cause subtle changes to the joint as a whole, and more than one bleed can substantially alter the synovium, cartilage and eventually the bone surface itself. When a bleed occurs, the blood that leaked into the joint is removed by the synovium but the process of this irritates and inflames it, causing it to grow. This then makes it easier to pinch the synovium when the joint is moving, triggering another bleed. This leads to a vicious cycle of more frequent bleeds and more damage and changes occurring. Detecting these changes early and taking measures to stop this from happening will help to minimise this cycle and keep the joints as healthy as possible.

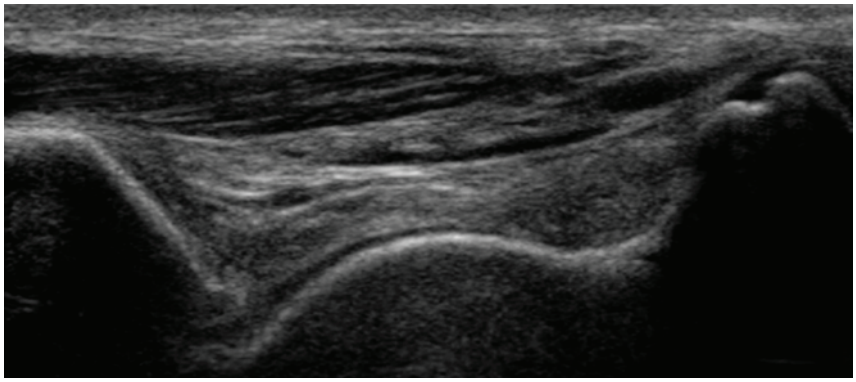
The HEAD-US protocol is being used in other countries as well as Australia and New Zealand with great success. A research study to look at the effectiveness of the HEAD-US protocol demonstrated that it was able to identify a greater proportion of joint abnormalities than physical assessment with the Haemophilia Joint Health score. However, this is not to say that the joint score is no longer useful as it is still able to identify other issues which cannot be detected by imaging alone.

USING HEAD-US WITH JOINT BLEEDS

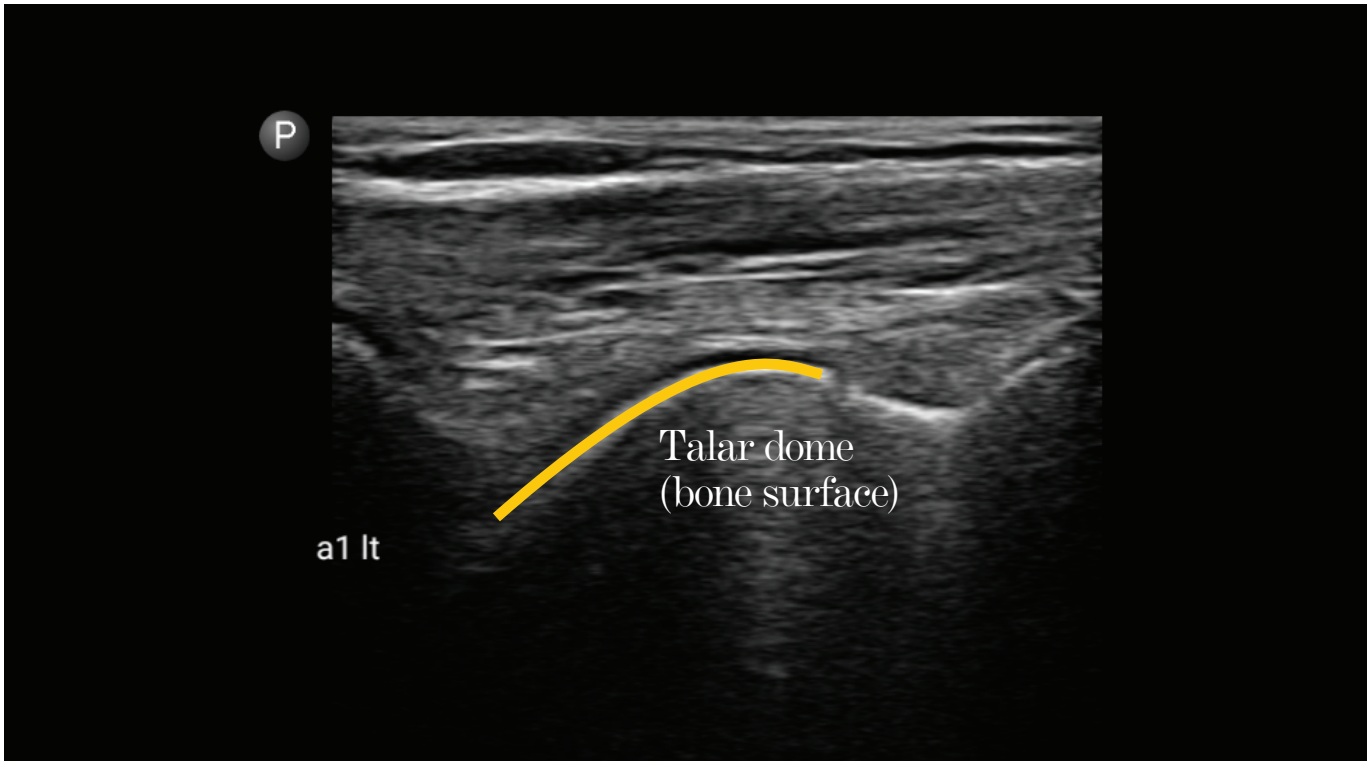
Within the Haemophilia Treatment Centre in Auckland, New Zealand this ultrasound protocol has been invaluable to assist in guiding treatment and identifying issues early. One such case involved a seven-year-old boy with severe haemophilia who had experienced three bleeds in the same ankle over a seven-month period. On physical examination there was only a small amount of swelling to the ankle and a very slight reduction in range of movement compared to the other side. However, when we used the ultrasound to look deeper inside the joint, we were able to identify significant changes to the synovium, cartilage damage and changes to the growth of the bones in his ankle (see images).

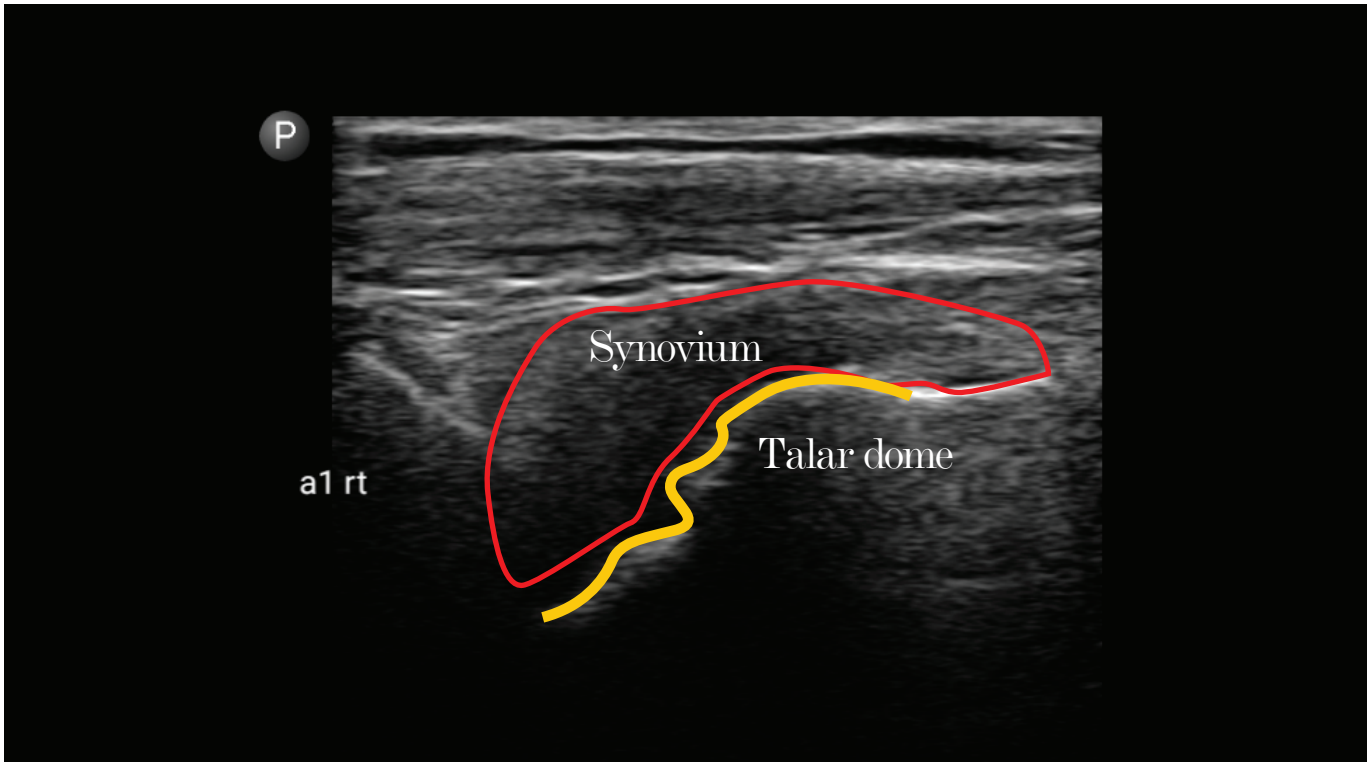


Scanning plane



Normal Anatomy seen in this plane





Images of the ankles for Case study patient 1

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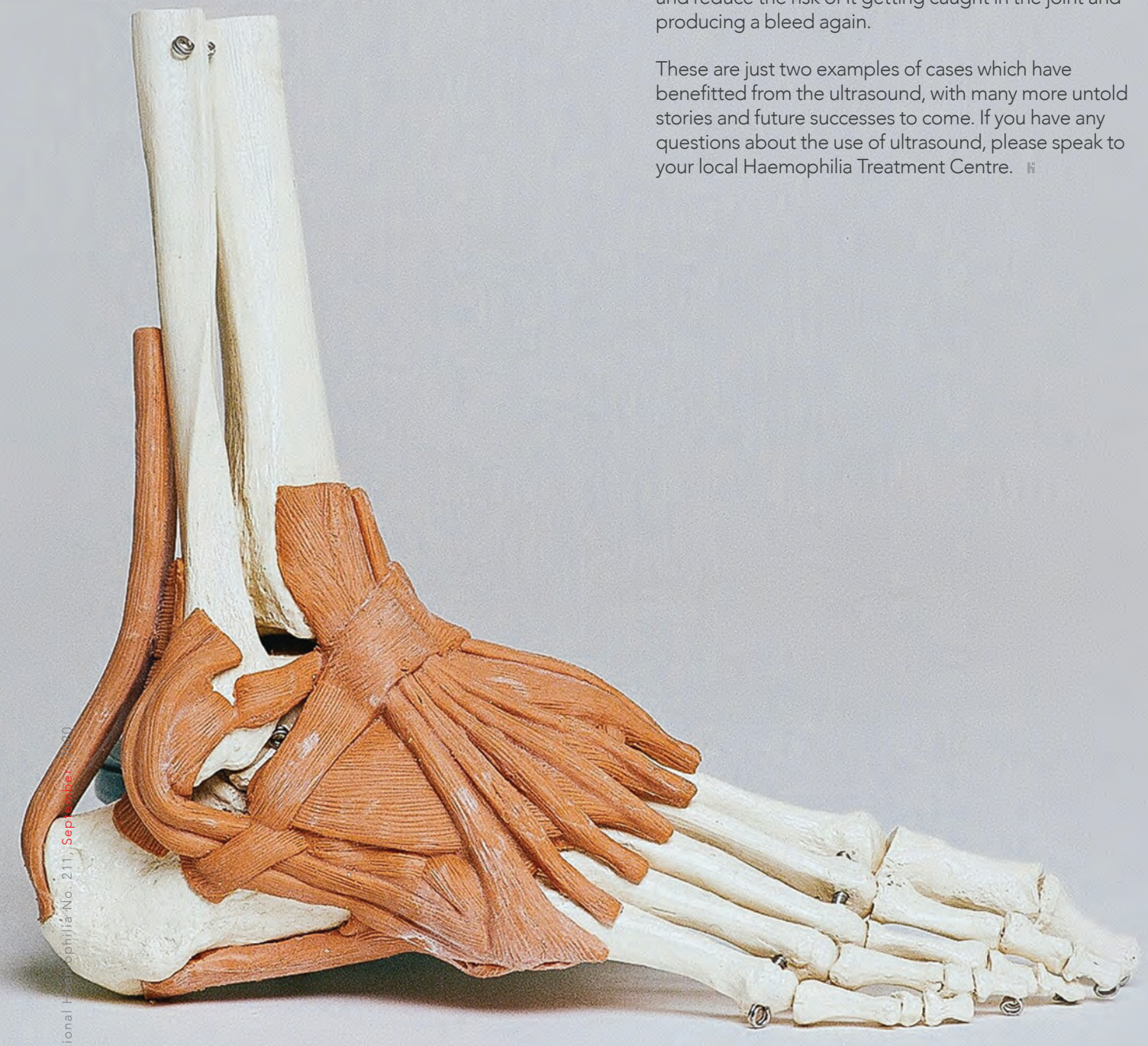
It was clear we needed to get better control over the bleeding episodes in his ankle. As a result, we increased his clotting factor prophylaxis dosage and provided more education to the patient and his family on how to recognise bleeding episodes. His blood was checked to monitor his response to the clotting factor replacement therapy and he was advised to reduce his activity levels for a while to allow the synovium time to settle and reduce the chance of further bleeding.

In another case, a 23-year-old male was also found to have issues with his ankles. In this instance he had not experienced any recognised bleeding episodes in his ankles for over seven years, although he had experienced frequent ankle bleeds as a child. On physical examination his ankles appeared to be slightly more swollen than observed at his last assessment (one year earlier) and there was a small reduction in his ankle movement compared to previous measures taken. Again using the ultrasound scanner and following the HEAD-US scanning protocol it was possible to identify changes to the synovium, cartilage and bone in keeping with a chronic synovitis (the synovium had become enlarged and he was experiencing repeated small bleeding episodes within the joint). In order to manage this more optimally we again made changes to his clotting factor dosing and regime. He was also educated on how to recognise and manage bleeding episodes and was advised on the benefits of weight loss for reducing joint loading. In addition, he was referred for a corticosteroid injection into the ankle. Corticosteroid is a strong anti-inflammatory agent which when injected into the joint can help to settle inflammation of the synovium, allowing it to shrink and reduce the risk of it getting caught in the joint and producing a bleed again.

These are just two examples of cases which have benefitted from the ultrasound, with many more untold stories and future successes to come. If you have any questions about the use of ultrasound, please speak to your local Haemophilia Treatment Centre.



Jane Portnoy is an Accredited Mental Health Social Worker and Family Therapist at the Ronald Sawers Haemophilia Centre, Alfred Health, Melbourne and in private practice at The Alma Road Family Therapy Centre in Melbourne

SIBLINGS AND HAEMOPHILIA

Jane Portnoy

When you have a bleeding disorder, your siblings might be even more important than usual.

We all know that siblings can have a love/hate relationship and people with bleeding disorders are not immune from this. However, the contributions of brothers and sisters can be positive on so many levels. At the same time, siblings can also suffer and are at higher risk for mental health problems than the general population. This is why it is important to look after your siblings. There are many ways for you to support them.

Sometimes you can feel like your siblings are a little annoying or caught up in their own lives. The upside of siblings is they are often there to help you get through the difficult times, small and large. They might provide a distraction during a venepuncture (infusion), or when you are in pain. They might keep you company while you are waiting for your medical appointment, or when you are stuck at home in a COVID lockdown. You have a readymade friend - of course, you won't always see eye to eye, and sometimes you really have to work at it.

The upside of siblings is they are often there to help you get through the difficult times, small and large.

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Siblings understand when others can't. They have insight into your relationship with your parents and are in position to be your strongest ally.

In families where someone has a bleeding disorder, brothers and sisters are regularly recognised as being a strong positive force. They see what you have to go through. They can usually be relied on to be honest, sometimes brutally honest. This works well when you need a reality check, or some advice. They can also be good company and provide a distraction when you need one.

We know that it helps your mental health to have a sibling, but did you know that they can have a difficult time being in a family with a child with a chronic illness. It's important to take care of them as much as they take care of you. This might involve including your brother or sister in what's going on, talking to them and help them understand what you are going through. Making time for your sibling shows them that they are important and you also give them a chance to talk through things that they need to discuss.

You can also watch out for them and identify when they might be having a hard time. Not sure how to go about it? Talk to the other people who help you. The same support system that you have can help you work out who is the best person to help them.

WHO ELSE CAN SUPPORT YOU?

- The **social workers and psychologists at Haemophilia Treatment Centres (HTCs)** are always available to support you and your siblings
- **Your local GP**
- **Headspace** - www.headspace.org.au
- **Little Dreamers, for young carers** - www.littledreamers.org.au (young carers are young people who provide unpaid support to a loved one who has a disability, illness or addiction.) Little Dreamers run a wonderful range of programs, including online support and holiday programs.

FURTHER READING

Scott, Gillian. ***5 tips to help siblings of kids with bleeding disorders: parents can help brothers and sisters cope with a range of emotions.***
https://hemaware.org/life/5-tips-help-siblings-kids-bleeding-disorders

In this article in *Hemaware*, the bleeding disorders magazine of the National Hemophilia Foundation in the USA, Gillian Scott gives tips to help siblings of kids with bleeding disorders.

She suggests

- communicate,
- educate,
- include,
- make time for everyone, and
- find resources.

These tips are spot on, and the article is a good short read.

Incledon E, Williams L, Hazell T, Heard T, Flowers A, Hiscock H. **A review of factors associated with mental health in siblings of children with chronic illness**. Journal of Child Health Care. 2015; 19(2): 182-194. doi:10.1177/1367493513503584

This is an interesting review of 17 studies and includes one study done at the Royal Children's Hospital in Melbourne. They found that the research demonstrates that sibling mental health is improved with information, professional support and attendance at camps, and perceived parent and peer support. .

FACTORED IN

WWW.FACTOREDIN.ORG.AU

NEW FACTORED IN

Factored In is an HFA website that was launched in 2012 for young people to blog and comment.

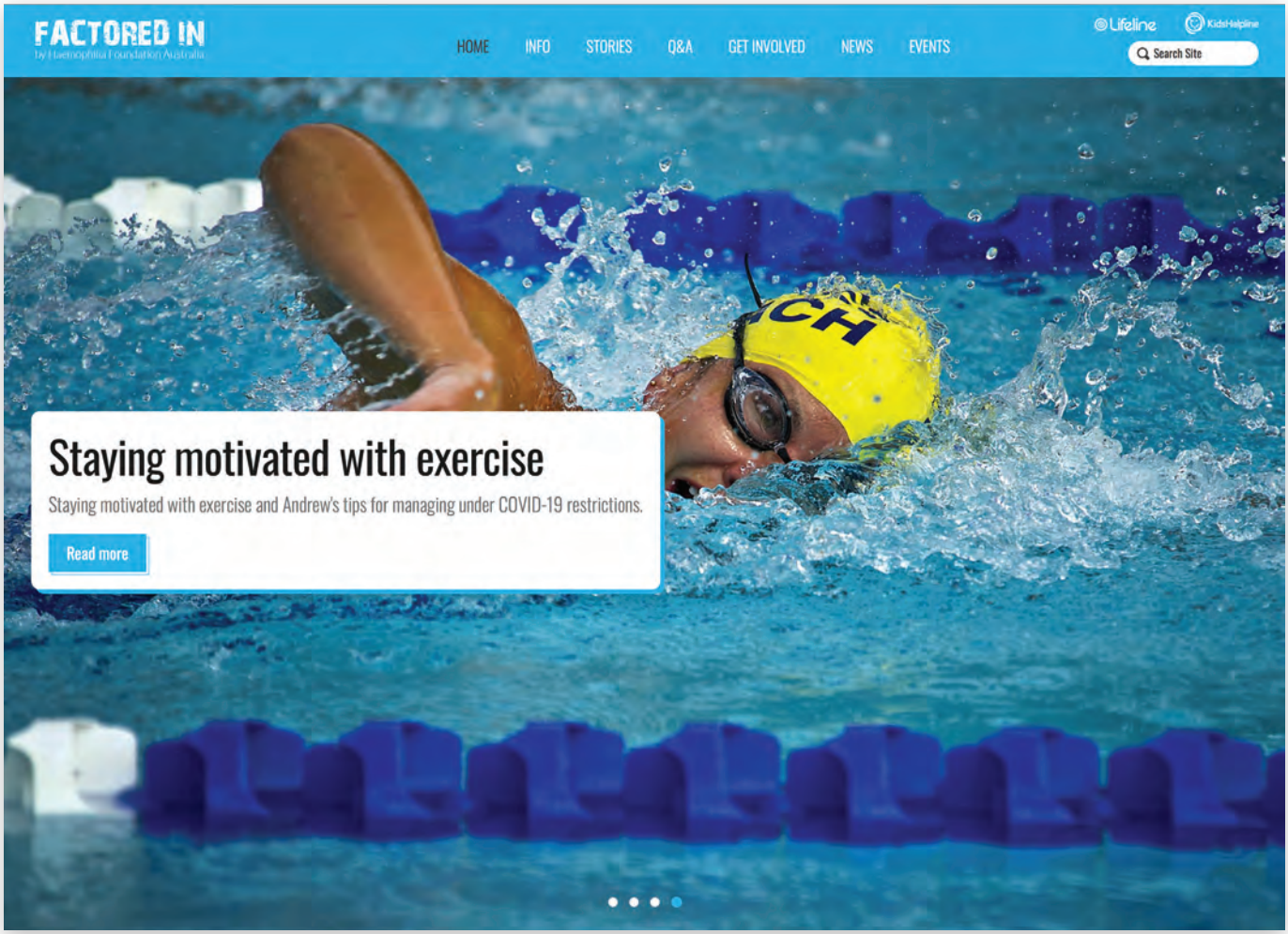
Fast forward to 2020 and, following community consultation with our young people, we have made some changes and given the site a refresh. The site is still for young people aged 13 to 30 with a bleeding disorder or a sibling or partner but it has been refocused as a key information hub.

Key highlights of the site are:

- **Ask a Question** – ask us anything and we will have it answered by an expert.
- **#Start browsing** tool on the home page – if you have a topic you want to read about, simply click on the tag. There are many more topics within the site
- Read **personal stories** covering many topics.

Whether you would like to share your story about your journey or something that is important to you – we would love to hear from you. For more info, email factoredin@haemophilia.org.au

Check out the new Factored In at www.factoredin.org.au.



YOUTH NEWS

What's it like to be the sibling of someone with a bleeding disorder? Angelina shares her story of the highs, the lows, and some tips for other siblings.

I'm Angelina, I'm 16 years old and currently in Year 11… And I have two brothers with severe haemophilia.

I always knew 'the boys' (my brothers) had haemophilia. Nikolas was four years old when he was diagnosed and then when Ryan was born, he was tested straight away. I remember seeing my brother with bruises and to our family, there was nothing abnormal about it. We would just say 'he's bruising again'. After Ryan was born, haemophilia was just part of our life.

HAVING A BROTHER (OR TWO!) WITH HAEMOPHILIA MEANS…

Spending a lot of time in and out of hospital. I often had to stay with family members while my mum was with the boys looking after them and because of this, I think I grew up very quickly. I was always worried about whether the boys were OK and I was always explaining to the other kids at school why the boys were on crutches or in a wheelchair.

I HAVE LEARNT…

I have learnt that my mum is super strong. She always puts the boys and their health first. As a kid I was so used to not getting any attention that sometimes I would even pretend I was sick or hurt when I wasn't, so mum would give me some attention! I don't know how she handles us all!

I WANT OTHER SIBLINGS TO KNOW THAT…

You are not alone - we all share the same experience. Like you, when I was growing up, I never got all the attention. My parents were often away looking after the boys. We missed out on planning family outings or had to cancel family holidays because the boys had a bleed, couldn't walk or weren't well. While it did (and still does) make me a bit upset, it's almost normal for us now. Although it can be disheartening and I can sometimes feel a bit selfish that we can't go on trips.

At times I have felt that I was left out and on my own, and no one else understood what I was going through. But I've been going to family camps since I was four years old and it has been great to meet other siblings. I have loved growing up with other kids. I recommend that everyone attend the family camps because you will meet people who have gone through and experienced the same thing as us, plus it's always a fun weekend!

Make sure you talk to people at the family camps, because they 'get it', whereas people from school often don't 'get it'. At these family camps, I always feel supported and it's great to share stories with others like us. Now as a youth leader, I am able to help younger people going through the same thing I went through when I was a kid.

In 2020, mum was in hospital with Ryan and Nikolas was awarded the 2020 Haemophilia Foundation Victoria Camp Spirit Award. I saw him that weekend and he had grown so much. He stepped out of his comfort zone, and was kind, helpful and mature. We supported each other which was very touching. It made me realise how lucky I am to have them in my life.

GOT QUESTIONS ABOUT BEING A SIBLING?

- Check out Jane Portnoy's article about siblings in this issue of *National Haemophilia*
- Visit the Siblings Australia website - siblingsaustralia.org.au.

MY BROTHERS HAVE HAEMOPHILIA

WHAT'S YOUR STORY?

Do you have a story to share about being a sibling?

Or about living with a bleeding disorder?

We'd love to hear from you!

Go to Share Your Story on Factored In for more info - www.factoredin.org.au/stories/share-your-story

1. Angelina with the younger kids at camp
2. Nikolas at camp
3. Angelina and her brothers

I'VE BEEN GOING TO FAMILY CAMPS SINCE I WAS FOUR YEARS OLD AND IT HAS BEEN GREAT TO MEET OTHER SIBLINGS.

CALENDAR

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

World Haemophilia Day
17 April 2021
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 donations 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:

BIOMARIN | CSL BEHRING | NOVO NORDISK |

PFIZER | ROCHE | SANOFI | TAKEDA

HFA Instagram

You may be familiar with HFA's Facebook page and Twitter feed, but did you know HFA is also on Instagram?

Check it out at

www.instagram.com/haemophiliafoundationaustralia

A great way to keep up with what's happening in the bleeding disorders community.