National Haemophilia
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GOING RED FOR BLEEDING DISORDERS AWARENESS WEEK

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HFA GETTING OLDER INFO HUB

WANT TO KNOW MORE ABOUT EXERCISING WITH ARTHRITIS?

Check out the **HEALTH AND WELLBEING** section in the **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
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Gavin Finkelstein is President, Haemophilia Foundation Australia

FROM THE PRESIDENT

Gavin Finkelstein

It has been a very busy three months since the publication of the last edition of *National Haemophilia*. We held our Annual General Meeting and Council meeting virtually on 24 October 2020, where we discussed a number of significant issues, including some major changes taking place at the World Federation of Hemophilia (WFH) and access to new therapies in Australia

WFH NEWS

The COVID-19 pandemic has continued to wreak havoc around the world, and we are deeply conscious of its impact in countries hit hard by the virus and particularly for countries where treatment and care for bleeding disorders was already stretched or unavailable. We are grateful to WFH for providing information and support to National Member Organisations who needed this, and for finding ways for our communities to keep in touch. I attended the 2020 Annual Meeting of the General Assembly of the World Federation of Hemophilia, which was held virtually on 16 October 2020. This meeting would usually have followed the 2020 WFH Congress but was postponed when the Congress had to be cancelled because of the pandemic.

I congratulate Cesar Garrido from the Venezuelan Association for Hemophilia, who has been elected as the WFH President, and sincerely thank Alain Weill for his years of service as President. We look forward to welcoming Cesar to Australia, and to our region, either in person or virtually, as soon as possible.

ACCESS TO NEW THERAPIES

We were pleased the Federal Health Minister, the Hon Greg Hunt MP, announced in September 2020 that Hemlibra® (also known as emicizumab) would be government funded through the National Blood Authority under the national blood arrangements. Hemlibra® is a treatment that can reduce or prevent bleeding in people with severe or moderate haemophilia A with and without inhibitors. Hemlibra® is not a clotting factor and there are specific regulatory requirements for how it may be prescribed. It is only available through specialist clinicians at Haemophilia Treatment Centres and there are special pharmacy and delivery requirements. There may need to be some variations in place for access in different states/territories. Further information is available on the National Blood Authority website: https://www.blood.gov.au/national-supply-arrangements-hemlibra-emicizumab. If you have any questions about your treatment or treatment products, it is recommended that you discuss them with your doctor at your Haemophilia Treatment Centre.

This has been a very important year for haemophilia treatment in Australia: we saw broader access to extended half-life clotting factor products in July followed by announcement about Hemlibra® in September and the decision of all Australian governments to jointly fund them amongst the suite of products on the National Products List. As always, this means people with haemophilia can work together with their treating specialist doctor at their Haemophilia Treatment Centre to choose the most suitable treatment for them.

HFA does not promote specific products, but it is our role to advocate for treatment and care that will offer the best outcomes for people living with a bleeding disorder in our community. This involves consulting with our community members about their healthcare requirements, which helps us make recommendations for improvement. We are excited by these new treatment products and others in the pipeline. Many people have told us about the lifechanging health outcomes from some of these new treatments. They offer new opportunities for people with haemophilia, who can expect less or no bleeding at all and a radical improvement in their quality of life and ability to participate in the community.

Unfortunately, the government assessment and review processes required to determine whether these treatment products will be purchased for Australians with haemophilia have taken several years. We hope these processes can be streamlined to reduce delays.

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It will also be important for the lived experience of patients and their treating doctors to be recognised for the value they can contribute to optimal outcomes for both patients and government payers.

I was pleased HFA had the opportunity to make a submission last month to a Commonwealth government House of Representatives *Committee of Inquiry into the approval processes for new drugs and novel medical technologies in Australia*. Our recommendations for changes to the assessment processes were based on our recent advocacy work. We shared examples of some of the experiences of people and parents of children with haemophilia who have described how dramatically their health and quality of life have improved following treatment with these new therapies.

> 'We shared examples of some of the experiences of people and parents of children with haemophilia who have described how dramatically their health and quality of life have improved following treatment with these new therapies.'

With more new therapies for haemophilia treatment and gene therapy likely to arrive in the next few years, it is an important time to consider new ways to evaluate them for government funding so delays do not continue to occur. HFA is committed to the national framework for treatment and care of bleeding disorders and works with stakeholders to uphold it. It will be a critical aspect of our work with the National Blood Authority, all Australian governments, health care providers and industry to address the assessment processes, while ensuring that the national framework for treatment and care is maintained.

SOUTH AUSTRALIA ACTIVITIES

In closing, I want to acknowledge our South Australian bleeding disorders community. In the absence of a Foundation for South Australia, HFA has been facilitating peer support activities. We had hoped HFA would have had a local activity to bring community members together by now, and we look forward to doing so when COVID-19 precautions allow us to hold community events.

BLEEDING DISORDERS AWARENESS WEEK 2020

Bleeding Disorders
AWARENESS WEEK

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

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

Test your knowledge with the Bleeding Disorders Awareness Week Quiz - https://tinyurl.com/y5tpnzfl

QUIZ

Can you get a perfect score

Approx, how many people globally have been diagnosed with haemophilia?

A 2.5 million
B 2,000
C 210,000
D 85,000

A highlight of the week was a Live Chat Q&A session with Chris Bombardier about his movie ***Bombardier Blood***. Chris shared his experience of climbing Mount Everest. We also had our own Australian rock climbers, the Godwin brothers, tell their story about climbing the rockface *El Capitan* in Yosemite National Park in the USA last year. You can buy and watch the Bombardier Blood movie at https://tinyurl.com/Bombardier-Blood-movie. See the article ***Climbing mountains with severe haemophilia*** in this issue of *National Haemophilia* for a report on the Live Chat session.

The theme was ***One Community, Many Faces*** and we showcased our community and highlighted the many different bleeding disorders and experiences. Short versions of the stories have been included in this issue of *National Haemophilia*. You can read the full stories and watch the videos on the HFA website - https://tinyurl.com/BDAW2020-stories.

GO RED FOR
Bleeding Disorders

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

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

The Ronald Sawers Haemophilia Centre in Melbourne all wearing something red

Thank you to MasterChef Lincoln and Avondale Early Learning Centre for the great red cupcakes and sharing about his haemophilia with his mates

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

ONE COMMUNITY, MANY FACES

You can read their full stories and see their videos on the HFA website Bleeding Disorders Awareness Week section - www.haemophilia.org.au/bdaw

In 2020 the theme of Bleeding Disorders Awareness Week was ***One community, many faces.*** In our community there are many different experiences of bleeding disorders. Here, some of our community members share their stories.

TIM – A YOUNG PERSON WITH HAEMOPHILIA

You might not think to put 'haemophilia' and 'weightlifting' in the same sentence, but for Tim, this has been a way to develop his passion for exercise and keeping healthy.

Tim is in his mid-20s and has severe haemophilia A. He has been a full-time paramedic for the past 5 years and describes himself as 'feeling passionately' about physical exercise. He explains that paramedics have one of the highest rates of work-related injuries compared to many other jobs and therefore, staying healthy is very important to him regardless of having haemophilia.

We are so lucky to be part of such a tight knit community and the friendships that we have made along the way.'

SHARRON - A WOMAN WITH HAEMOPHILIA, CARRIER, MOTHER OF A SON WITH HAEMOPHILIA, DAD HAS HAEMOPHILIA

Sharron's father Glenn has haemophilia, so she has always known and lived with haemophilia. When she was a child it was thought that only boys had haemophilia, so it was a surprise to her parents when Sharron was diagnosed with mild haemophilia A.

Growing up, it was a challenge to be accepted as a girl with haemophilia.

'Mum would always go to the school to explain haemophilia to the teachers, but the doctors wouldn't believe I had it as "boys have haemophilia, not girls". I learned at a young age to advocate for myself.'

With a family history behind her, including her own, she has been relieved to see that the experience of growing up with haemophilia has been so much better for her son Ben but proud, too, of how he has dealt with his bleeding disorder.

'Ben's experience growing up was so different to mine, and even more to my dad's era, with better treatment and people are more accepting. Ben wouldn't change having haemophilia as it has made him the person he is and meant he met all the wonderful people. We are so lucky to be part of such a tight knit community and the friendships that we have made along the way.'

BEN – A FATHER'S PERSPECTIVE

Being the father of a small boy with severe haemophilia is full of challenges. For Ben this has involved a big learning curve, but this is a role he has taken on gladly.

'Treating Ryder has not always been easy. We have always made a point of never skipping any of his treatments no matter how hard it was for him to understand or like what was going on. We made him his own factor kits for him to practice giving factor to his teddies (removed the needle from the grippers). We had toys or noisy forms of distractions in the first two years of treating him, and now he is generally comfortable watching one of his favourite shows on TV while we do it. We do also have a small factor treat bag with small inexpensive toys or a new book, puzzles etc - he gets to choose one after his treatment.'

'Boys will be boys, so keeping him cotton-balled was never something we wanted to do. I'm glad that by letting him do certain things, his eye-hand co-ordination, reflexes, agility and spatial awareness are very good, and he avoids some hard knocks that might cause more significant bruising or bleeds.'

'My advice to parents, is to be patient and make sure that you also look after your partner/wife and other family members - they are going through this with you. It's not easy.'

SUSIE – LIVING WITH TYPE 1 VWD

'I have type 1 von Willebrand disease (VWD), which is often explained as a mild condition which does not impact heavily on most people's lives. But everyone's experience is different. Growing up, I was prone to bruising and bled freely. However, my mother maintained that our family were fast healers, so it was OK. I remember hearing, "oh we just bruise, that's what we do".

'However, when my son was diagnosed with type 3 VWD, this led to the testing and diagnosis of both my partner and me. Initially I was shocked, but the more I read about the condition, the more the pieces of the puzzle fell into place. The massive swellings on my legs the size of my fist I got with mosquito bites. The flooding and the massive clots passed with my periods. The time I grazed the back of my foot going downstairs and it bleed for hours, prompting a hospital trip for care. The oozing bleeding after routine dental visits. The countless other times I noticed, Oh, I'm still bleeding, like it's just oozing...'

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SHAUNA – MANAGING TYPE 3 VWD

'As a baby learning to walk, I was progressively becoming covered in bruises with no known reason why. After I fell and cut my lip, the bleeding continued until I was taken to hospital via ambulance where I was diagnosed with type 3 von Willebrand disease. With no known family history of this condition, my parents carefully navigated through my upbringing, figuring things out along the way under the guidance of my haematology team.

'Growing up with von Willebrand's, I've seen a great deal of change to my treatment plans over the years. My symptoms evolve as I age, and I have also experienced changes in my lifestyle that have required a different level of care. Keeping record of my changing symptoms helped establish new care plans, including updating contraceptive methods to manage bleeding, through to moving away from on demand treatment to a prophylactic routine to prevent ongoing joint damage.'

MIKE – AN OLDER PERSON WITH HAEMOPHILIA

Growing up with haemophilia in the 1950s and 1960s was very different to having haemophilia today.

There is a long history of haemophilia in Mike's family. Both his mother and his grandmother carried the gene for haemophilia. Three of his uncles had haemophilia, but this was in the 1930s before effective treatments, and they died in their 20s.

'New treatments today are far better than back in the days when factor treatment first came out. But when I received my first factor treatment, it was a blessing,' said Mike.

The bleeds into his joints left Mike with permanent joint damage in his ankles and elbows.

Mike commented, *'I am aware of my limitations and know what I can and can't do. I know the older you get, things happen, but I like to keep as active as I can. In the future I would like to still be independent and get around. I know not to push myself but to be positive and resilient.'*

My symptoms evolve as I age, and I have also experienced changes in my lifestyle that have required a different level of care

CHILDREN AND YOUNG PEOPLE AND KEEPING FIT

HFA Zoom and Facebook Live webinar for Bleeding Disorders Awareness Week, 13 October 2020

Facilitator: Natashia Coco, Haemophilia Foundation Australia

Speakers:

- *Jo (Johanna) Newsom, Physiotherapist, The Children's Hospital at Westmead, NSW*
- *Robyn Shoemark, Clinical Nurse Consultant, Haematology/Haemophilia, The Children's Hospital at Westmead, NSW*
- *Andrew Selvaggi, who has severe haemophilia with inhibitors*

WHY EXERCISE?

What should young people and children be aiming for with exercise? Jo Newsom noted that the current guidelines recommend that all young people from the age of 5 years up until they are adults should be aiming at around 60 minutes of moderate physical activity daily.

Photo by Allan Mas from Pexels

This is activity, explained Jo, *'where you are just huffing and puffing a little bit and having a little trouble talking in full sentences'.* This exercise can be broken up during the day and can include incidental activity, like walking up the stairs or walking briskly from the carpark, as well as structured sports time.

The time for physical activity is matched with recommended screentime on devices, video games and TV – no more than 2 hours daily.

Why is exercise good for us? *'It's not just about maintaining fitness and body weight, but about keeping us strong and flexible and agile, helping us maintain our balance and co-ordination so that our risk of falls and injury is reduced,' said Jo. 'And in the case of haemophilia, it's so that our risk of bleeding is reduced because our muscles are more flexible and stronger and better able to protect our joints.'*

Exercise also makes us feel good. *'It releases all sorts of happy endorphins,'* explained Jo.

EXERCISING SAFELY

Jo and Robyn are often asked how to exercise safely with a bleeding disorder. International guidelines talk of 'risk'. *High contact sports* have a high risk of injury and are often not recommended for people with bleeding disorders. *Moderate contact sports* involve bumping, like soccer, or falling and whacking yourself as you fall, like skiing or snow-boarding. *No contact sports* include activities like swimming or golf or orienteering where physical contact is more unlikely.

In reality, young people with bleeding disorders like to play all of these sports and the Haemophilia Treatment Centre team would discuss the implications of any sport you want to play with you. Involvement in sport changes as you grow. In primary school, children will hopefully focus on skills development, such as eye-hand co-ordination or balance and flexibility – throwing, catching, batting, etc. This exposes you to a range of sports and you are in a better place to choose a sport that you like.

Then as you reach your teenage years, you will specialise and choose sports that you are interested in. You are much more likely to continue to play a sport that you enjoy and you may like the sport for various reasons – perhaps because of the friends you make or the competition or the activity itself.

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Photo by Markus Spiske from Pexels

STARTING A NEW SPORT

How to start a new sport? Slowly! said Jo. It takes a little while for your body to adapt to new movements and muscles to recover. Also, starting in a structured environment is important for safety: with the right protective gear for the sport, playing on the right kind of surface, and where there is a referee or umpire to make sure the rules are followed. This might involve joining a club to start a new sport, e.g. soccer or Little Athletics.

Involve your Haemophilia Treatment Centre team when you are starting a new sport. With prophylaxis and new treatments, more options are available to you than in previous generations. Working with your HTC will help to protect you from injury and bleeds. The team will be able to look at your individual situation and see what needs to be modified and if there is any other protective gear or bracing or splinting that might help if you have joint or muscle problems. It might also involve caution with some sports, such as weight training, because bones are soft in young people. But the team are keen to support you to do the sports that you love.

Robyn explained that the HTC will also discuss timing your factor treatment – having your factor before you play, to make sure you are best protected when you are most active. And don't forget about diet and sunshine for healthy bones and muscles!

STARTING A NEW SPORT

Rehabilitation after a bleed is also very important. Recovery will be very individual, but probably slower than you would prefer! Going back to the sport too soon can cause rebleeding into the same injured joint or muscle, which is why your HTC will be cautious about jumping back into play. Robyn highlighted that it is important to treat your bleed when it occurs – and 'treatment' can also involve first aid PRICE (Protection, Rest, Ice, Compression, Elevation) as well as factor.

ANDREW'S STORY

Andrew Selvaggi's personal story has inspired many young people with haemophilia. He joined Jo and Robyn in talking about what he has learned through tackling the challenges of living with haemophilia A and inhibitors. Andrew explained that he had a different experience of treatment and sport when he was a child and teenager to young people with haemophilia today. Now 33 years old, he has been a personal trainer for 8 years and is a senior project manager at a university. His journey to reach this point has been quite extraordinary.

For the first 12 years of his life there was no effective treatment for his inhibitors, and he was wheelchair bound with a long list of bleeding complications. As time progressed, treatments improved and his HTC team supported him to make some fairly radical changes to his life. By the age of 20 he had lost 30 kilograms of weight and had 'got my body and my mind on track'.

'Our bodies are made to move, and the more we move, the better we are,' said Andrew. *'The more sedentary we are, the more sluggish and slow we feel and this has mental impacts. At that time before I lost that weight, I was stuck in a wheelchair. I was bleeding a lot and I was very unhappy and I didn't know why. It was a vicious cycle, purely because the large amount of weight I was carrying put such a strain on my body – and I probably wasn't doing the right rehab.'*

When Andrew lost the weight and started exercising more, his bleeding episodes decreased from two to three per week to two to three per month or two months. He had not been able to develop the muscle mass and strength or skills that other young people develop during childhood – the perception of himself in space and the mind-muscle connection - and is still working on this today, in spite of his relative physical fitness.

Andrew's message to young people with haemophilia: *'Being sedentary isn't something related to haemophilia anymore. Being active is for everyone in the world, including people with haemophilia. With the right treatment plan and the right support and oversight from your HTC team, you can really be active and healthy with haemophilia.'* He gave examples from around the world of people with haemophilia who are pushing the boundaries with sport.

Q & A

The session then moved to a Q & A panel discussion, with questions from the audience.

What is your advice for kids when they don't want to do any exercise?

- Find an activity that you enjoy, and get out and do that
- Consult with the HTC about what activities are safe
- Fitness doesn't need to mean running a marathon - it is about moving around.

How do you deal with a physio who doesn't know anything about haemophilia?

- Haemophilia is quite rare and specialised
- But it relates to core physiotherapy concepts
- Ask your physio to contact your HTC and they can talk to a haemophilia physiotherapist and find out how best to manage haemophilia and bleeds. Sometimes the physiotherapists might decide to share the care arrangements, especially when you live a long way from the HTC.

What can girls do to manage sport if they have heavy periods?

- There are treatments for girls when they have heavy periods
- The HTC will often refer girls to a gynaecologist, who will work out a regime so that they don't have heavy bleeding anymore.

What do I need to tell the coach?

- Tell the coach that you have a bleeding disorder, but also that you have treatment before training or play so that your factor levels are good for exercise
- Let the coach know that if you have a bleed or an injury, you might need an adult to help with first aid or have your parents come to pick you up.

Many thanks to Jo, Robyn and Andrew for putting together such a great session!

MORE INFORMATION

If you would like more information about sport and exercise for young people with bleeding disorders, speak to your Haemophilia Treatment Centre. Contact details of HTCs are on the HFA website - https://tinyurl.com/HTCs-Aus

You can find more information about sport and exercise, along with personal stories, on the HFA Factored In youth website – www.factoredin.org.au

Watch the video of this webinar on the HFA YouTube channel at https://tinyurl.com/YT-haem-fitness

> Being active is for everyone in the world, including people with haemophilia. Our bodies are made to move, and the more we move, the better we are

WFH WOMEN & GIRLS GLOBAL SUMMIT 2020

WFH staged their first ever Global summit on women and girls with inherited bleeding disorders in November 2020. This was a two-day virtual meeting for women with bleeding disorders, patient organisations, healthcare professionals and other supporters from around the world to exchange information and experiences. The Agenda covered diagnosis and management, how women are advocating for better care, and the ways they are getting their voices heard.

The Summit was also an opportunity to launch **WFH's Women and Girls Initiative**. HFA Executive Director, **Sharon Caris**, interviewed key international leaders about what the Initiative will involve. The Initiative is a response to the need for more education and training, both for health professionals and the community. It will focus on diagnosis and comprehensive care for women and girls, integrating women into the work of national member organisations, and supporting outreach, advocacy and wider community awareness.

One of the speakers in the Summit was Australia's **Susie Couper**, who presented on the **international VWD (von Willebrand disease) clinical guidelines and how to use them.**

Look out for Susie's report on her presentation, which will appear in the March 2021 issue of *National Haemophilia,* along with other reports on the Global Summit.

Susie has VWD type 1 and her son has VWD type 3. She was diagnosed as an adult when her son was diagnosed. She is currently on the HFWA Committee and is enthusiastic about the work of her Foundation: 'I am proud that we at HFWA continually challenge ourselves to work towards a better quality of life for people with a bleeding disorder and to provide support for their families. I have a special interest in inclusion, having seen the many benefits of being involved in our peer activities.'

Susie has been one of the patient representatives on the committee to develop the international VWD clinical guidelines and is now a member of the WFH committee for women with inherited bleeding disorders. She is keen to share her experiences: 'to be a member of the WFH committee is a deeply felt privilege. I am learning so very much along the way – let's learn together.'

Our thanks to Susie for her commitment to women, VWD, education and peer support both locally and internationally.

You can watch recordings of the Women and Girls Global Summit sessions at https://na.eventscloud.com/virtualWGBD

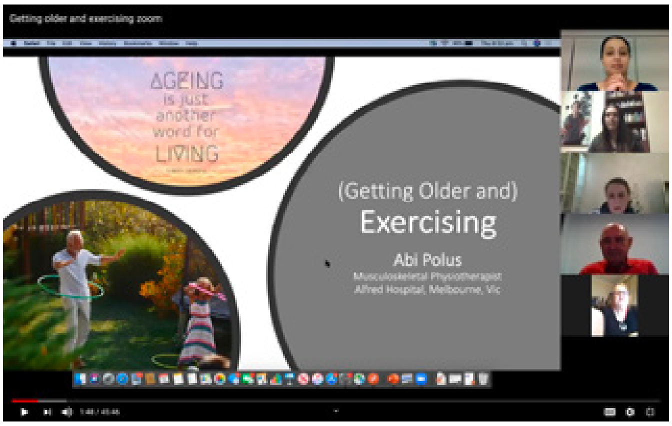
GETTING OLDER AND EXERCISING

HFA Zoom and Facebook Live webinar for Bleeding Disorders Awareness Week, 15 October 2020

Facilitator: Natashia Coco, Haemophilia Foundation Australia

Speakers:

- *Abi Polus, Senior Clinical Physiotherapist – Haemophilia, Ronald Sawers Haemophilia Centre, The Alfred, Melbourne*
- *Megan Walsh, Clinical Nurse Consultant, Ronald Sawers Haemophilia Centre, The Alfred, Melbourne*
- *Zev, who has severe haemophilia.*



'Ageing is just another word for living,' was the way Abi Polus commenced her presentation on exercise, and making the most of life was what this webinar was all about.

Abi described herself as having 'a passion for exercise' and was enthusiastic about the many benefits of exercise for people with bleeding disorders.

IMPROVING MUSCLES AND BONES

She pointed out that after the boom years of bone and muscle cell production in our youth, we naturally enter a steady decline from the age of about 30 years. It is normal to have some change in the cartilage in joints from this age as well. In haemophilia these changes can occur a bit earlier in life, particularly if you are part of the generation who did not have prophylaxis treatment to prevent bleeds and were encouraged not to be active when you were young. Repeated bleeds into joints were also likely to lead to an early onset of arthritis.

However, getting older doesn't mean you need to decrease exercise. Abi explained that the body adapts to the demands put on it. The physical demands of exercise can help to combat the effects ageing has on our muscles, bone and cartilage. Exercise can increase muscle mass, bone stock and lubricate joints. It can maintain the range of movement in your joints and help with balance.

WHAT WORKS FOR YOU

Everybody has a different approach to life and an individual situation with their body. Abi's message - exercise is a way of working with *the body that you have* to have the best chance of achieving *what you want with your life*. It is important to take on exercise that you would like to do, rather than trying to commit to something that you will never enjoy or feel motivated about.

Although people often imagine that they will need to be very fit to have benefits from exercise, Abi pointed out that exercise is very individual – and it may not require a lot of equipment. For one person going up some stairs can involve the same intensity for their body that someone else might experience in a full gym workout.

Abi discussed the barriers to exercise she hears from her patients: time, access to the gym or pool, pain, motivation. She noted that research has shown that exercise in people with haemophilia does not increase pain, it may even decrease it, and has other benefits. Arthritis studies have also shown that exercise and weight management can help to manage the pain related to arthritis.

Her top 4 tips:

- Don't stop the physical activity you are already doing – replace it if you want to make a change
- Move the way you enjoy moving
- Develop good habits
- Don't increase your weight.

A very important message: when you would like to start a new exercise program or have some goals, talk to the physiotherapist at your HTC, and they will help you with a program that will suit your individual needs and physical issues.

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OTHER BENEFITS

Megan Walsh followed Abi's presentation with a discussion about working exercise into your life if you have a bleeding disorder.

She spoke first about the benefits of exercise for older people with bleeding disorders - physically, to keep working and enjoy relationships (for example, playing with grandchildren), and for mental health. With regular exercise, veins are larger and more elastic, muscles are more supportive of joints, bleeds do not occur as often

MONITORING YOUR EXERCISE

Recording treatments and bleeds in the MyABDR app is an important tool for monitoring how things are going with your exercise program in an objective way: are your bleeds decreasing or increasing? Have you started doing something different, eg having some bleeds because you started gardening? You can write some notes in MyABDR to explain this to share with your HTC, as well as to keep your own diary.

This is a good time to work together with the HTC team – the nurses, doctors and physiotherapists – to review how you are exercising and the impact, so that they can suggest other ways to do things or tweak your exercise program or treatment plan if you are having bleeding problems or other issues when you are exercising.
It might be that your exercise program is a little too vigorous for you. Both Megan and Abi underlined that the physiotherapist wouldn't be upset if you said this – they would just revise your exercise program so that it worked for you. And if your HTC doesn't have a dedicated specialist physiotherapist, it is still important to discuss your exercise program with your HTC. They can check questions with expert physiotherapists in other states and talk to the physiotherapist that you see about any bleeding disorder-related issues.

FALLS AND BALANCE

Falls and balance become more problematic as you grow older, along with the likelihood that a fall might result in a fracture. Megan encouraged older people with bleeding disorders to start seeing a physiotherapist to improve balance and strength and perhaps to consider a referral from your HTC to a community falls and balance exercise program.

WORKING WITH YOUR TREATMENT PLAN

Aligning your exercise program with your prophylaxis treatment plan is also important. Megan explained that you would get the most protection from your treatment for vigorous exercise when your factor levels are highest. The effect of a particular treatment on clotting factor levels is individual, i.e., when your clotting factor levels are highest and how long they remain at that level. It will be valuable to work with your HTC team to understand your treatment and factor level patterns and to manage your exercise program around it.

SOME PRACTICAL POINTERS

As you grow older, there are also practical aspects of managing your physical health. Do you have ambulance cover? Do you need help with mobility issues? What services are available? How are things at home – can they be improved, so that you don't trip or can get around more easily? Do you need help with your eyesight? Megan highlighted that the HTC team are happy to help with working through these questions. They can also organise referrals to other health professionals, for example, an occupational therapist, or to services nearer to where you live.

Megan offered an invitation: feeling like your exercise program isn't making a difference? Ask your HTC to show you if anything has improved. You might be surprised at what your physiotherapist has noticed and what changes they can demonstrate to you!

PEER SUPPORT

Keeping in touch with other people with bleeding disorders can be very supportive as you grow older and navigate your way through some of these issues. They will have grown up and lived through their adult life with similar problems and understand what it is like – the good and the bad days.

Growing up with haemophilia before there was effective treatment meant that exercise often resulted in bleeds, hospitalisation and permanent joint damage.

Zev has severe haemophilia and, at 69 years of age, now has what he describes as 'a distinctive walk' as a result of his first 16 years without replacement factor therapy. 'Playing sport, contact sports, running, having an exercise regime, going for a ride was just completely out of the question,' he said.

Now he is on prophylaxis treatment with stable factor levels and appreciates being able to exercise, to the degree that he can. He goes for walks and, although he can't play golf anymore because of elbow problems, he goes in the golf buggy with his mates to enjoy the social interaction. With one fused knee and an above-knee amputation on the other leg, exercise is a little more challenging.

He has worked out that he can use an exercise bike and exercise his arms on the bike as well, which is great for a cardiovascular workout.

Although he doesn't enjoy walking, he pushes himself: he has found an oval with a flat and even turf that he can walk around safely, and can increase the amount that he walks to improve his fitness.

Working with a physiotherapist has meant that he has an exercise program that works for him. Motivating himself to exercise has been part of his challenge. He makes arrangements to attend hydrotherapy with other mates who have haemophilia so that he is less likely to cancel – 'I would feel like I was letting them down.'

Q & A

The session finished with a Q & A panel discussion, with questions from the audience.

Tips for what would motivate people to exercise?

- Doing what you enjoy – dancing, pilates, have a look online and see what you like
- Arrange to meet other people, so that you feel like you have a commitment
- Consider a personal trainer, if you think that would help
- Have reminders to exercise, e.g., on your calendar or fitbit
- Have visual reminders in spaces you use often - leave the dumbbells near a chair you sit on to watch TV, or the exercise band hanging on a door handle you use or walk past
- Keep modifying your goals
- Talk to your HTC physiotherapist and they can help!

What do you do when you have pain with exercise?

- Contact your HTC and they can work out with you if it is pain from a bleed, which needs treatment, or is related to the movements with the exercise
- Warming up and stretching helps.

What can you do when you have a fused knee?

- Use other parts of your body, or use a straight leg
- Try the pool or an exercise bike
- Try not to trip and fall
- Core strength is important
- Talk to your physiotherapist and they can work out an individual exercise program that suits you.

Thanks to Abi, Megan and Zev for an informative and interesting session!

MORE INFORMATION

If you would like more information about an exercise program for you, speak to your Haemophilia Treatment Centre. Contact details of HTCs are on the HFA website - https://tinyurl.com/HTCs-Aus

You can find more information about exercise, along with the full video of this session, under HEALTH AND WELLBEING on the HFA Getting Older Info Hub – www.haemophilia.org.au/getting-older

Getting older doesn't mean you need to decrease exercise. The physical demands of exercise can help to combat the effects ageing has on our muscles, bone and cartilage.

WORLD AIDS DAY 2020

World AIDS Day is marked globally on 1 December.

The theme for World AIDS Day in 2020 is ***Now more than ever***. For the bleeding disorders community this is a profoundly meaningful message.

1 December is a day when we are mindful of the members of our community living with HIV and those with HIV who have passed away.

In the mid-1980s the bleeding disorders community in Australia and internationally was devastated when many people with bleeding disorders acquired HIV through their plasma-derived clotting factor treatment products. HFA's recent *Getting Older* report documented the ongoing impact of this epidemic on our community: the trauma and health challenges for those who were diagnosed with HIV and now live with the consequences, and the grief and sadness experienced by those who lost loved ones and friends to HIV. Often forgotten is the emotional impact on the health professionals at the Haemophilia Treatment Centres too, who had cared for their patients with HIV over their lifetime and knew them so well.

The *Getting Older* report recognised the very positive contributions people with bleeding disorders and HIV have made to our community: the inspiring optimism and generosity of individuals with HIV, in spite of all their experiences, speaking out and providing leadership and a way forward into the future.

Some of the people with HIV who participated in the *Getting Older* consultation also highlighted other issues that need addressing, including discrimination by health professionals in the wider health sector, based on an unfounded fear of transmission. This can result in barriers to testing and treatment and access to services.

'There needs to be a concerted education campaign for health professionals to educate them about the low risks of HIV infection when the patient is well suppressed.'

TAKING ACTION

On World AIDS Day we are encouraged to educate ourselves and others about HIV.

In Australia HIV infection is now usually well-managed with treatment. However, the *Getting Older* report reminded us how important it is to acknowledge the experiences of our community members with HIV and the impact these experiences have had on them. We also need to recognise the impact on those who love them and care for them: their partners, family, friends and carers.

Hearing their stories and learning about the impact of HIV on them in the past and now is an important part of acknowledgement in our community. Foundations are also conscious of making sure there is always a supportive environment at community events.

Wearing a red ribbon on World AIDS Day can help to raise awareness and reduce discrimination by demonstrating solidarity with people with HIV.

World AIDS Day challenges us to take action – and by this action to ensure that people living with HIV can participate fully in the life of the community, feeling supported and free from judgement, stigma and discrimination.

For more information about World AIDS Day in Australia, visit www.worldaidsday.org.au.

CLIMBING MOUNTAINS WITH SEVERE HAEMOPHILIA

BOMBARDIER BLOOD DOCUMENTARY LIVE CHAT
WITH SPECIAL GUEST
CHRIS BOMBARDIER
FRIDAY 16 OCTOBER 8.30PM EST

BOMBARDIER BLOOD DOCUMENTARY LIVE CHAT

HFA Zoom and Facebook Live webinar for Bleeding Disorders Awareness Week, 16 October 2020

Facilitator: Natashia Coco, Haemophilia Foundation Australia

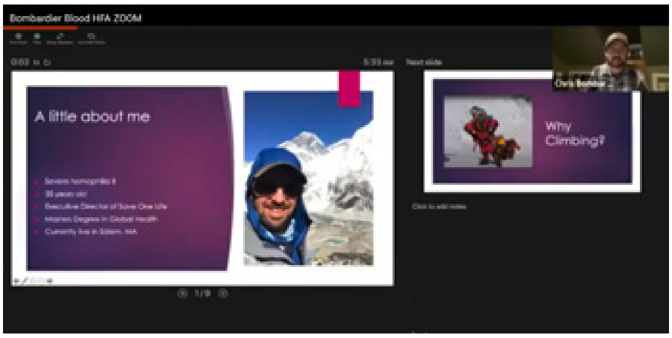
Speakers:

- *Chris Bombardier, a mountain climber with severe haemophilia*
- *Andrew and Scott Godwin, Australian brothers, rock climbers with severe haemophilia*
- *Penny McCarthy, Clinical Nurse Consultant, Ronald Sawers Haemophilia Centre, The Alfred, Melbourne*
- *Alison Morris, Senior Musculoskeletal Physiotherapist, Perth Children's Hospital*

CLIMBING MOUNT EVEREST

In October 2020 US mountain climber Chris Bombardier joined a panel of Australian rock climbers with haemophilia and HTC health professionals in a live chat with the Australian bleeding disorders community about taking on extreme sport with severe haemophilia.

Climbing Mount Everest is an exceptional achievement for anyone, but for Chris Bombardier it also involved overcoming the challenges of having severe haemophilia B. In 2017 Chris partnered with film-maker Patrick James Lynch, who also has haemophilia, to document his journey through Nepal to the top of Mount Everest in a film titled ***Bombardier Blood***. This journey was the culmination of a lifetime of struggle to deal with his haemophilia and to achieve his goal of climbing the Seven Summits, the highest mountains of each of the seven continents. Along the way he was confronted by the limited access to haemophilia diagnosis and treatment in resource-poor countries like Nepal and the extraordinary efforts made by people with haemophilia and their families to manage their condition and their resulting disability and pain. The contrast with his haemophilia experience affected Chris profoundly. He is now the Executive Director of the Save One Life foundation (www.saveonelife.net), which provides direct financial assistance and medical treatment to people with bleeding disorders in developing countries, particularly children and youth.



WHY CLIMBING?

Chris explained that he was a very active child and had played baseball throughout his young life. After college he was searching for something active to do and started mountain climbing with his uncle in Colorado. This involved considerable self-awareness: the safety of all climbers in the team depended on Chris being able to manage himself and his haemophilia, be prepared and to be clear to others beforehand when a situation would be too much for him.

There were also tricky aspects specifically related to treatment: how to carry his factor and keep it at the right temperature during the long trek to the mountain summit, how to infuse in the intense cold and teaching his walking companions about how to infuse him in an emergency.

Chris undertook the Everest summit while the international bleeding disorders community watched from afar. He made a point of taking a small flag signed by the local Nepalese haemophilia community to the top so that they could be with him in spirit and was very appreciative of the international support – with messages from as far afield as Tasmania.

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GROWING UP WITH HAEMOPHILIA

Reflecting on why he decided to start mountain climbing, Chris offered some very honest reflections about growing up with the challenges of haemophilia. When he was young, he had on demand therapy for bleeds as they occurred rather than prophylaxis treatment to prevent bleeds. He described the difficulties at school: the teasing about being on crutches, worrying about injuries at the playground and having to go to the emergency room, and feeling so different for such a long period of his life.

'It wasn't until after college when I got to meet with the haemophilia community that I realised that I had a story going on in my head all the time that I wasn't good enough. I thought I was the only one facing those struggles. For me, meeting the bleeding disorders community and having that connection was a very powerful experience – to accept my bleeding disorder. To realise, yes, I have this thing that is different and a challenge for me, but there are other people who are going through it too, who can support me and who understand – who don't think I am defective or wrong. I think this gave me the confidence to try these climbs and become an advocate for my community.'

CONNECTING TO OTHERS

Chris explained that he would have loved to be involved with haemophilia community camps earlier in his life.

'I didn't really know anyone with haemophilia growing up until after college. It would have been great to have been able to talk to people who understood what bleeds were like and the frustration you feel sometimes when you want be physically active and do something but your body is just not keeping up. I didn't have anyone to talk to about that and it was really hard. I felt very lonely. I struggled with depression for a long time.

'I had a lot of negative perceptions of haemophilia and I didn't really accept my bleeding disorder before I got connected with other people. I hated having haemophilia, I really resented having it. I didn't talk about it with other people, I didn't share, because I didn't want them to judge me and think differently of me. Even with my baseball team at high school and college: I would tell them I had haemophilia, but really downplay it and say, it's no big deal, I just have to do this thing every once in a while.

'Now that I am connected with the community, I have realised it is something I shouldn't be ashamed of. Having it is not within my control – I was just born with it – but it has helped me to realise how to overcome challenges and be more resilient. People with bleeding disorders are pretty resilient people – pretty stubborn too! It has taught me empathy and compassion for other people and that is something I am proud of now.'

Andrew and Scott's victory photo after climbing El Cap

WORKING WITH THE HTC

For Chris, understanding the value of working with his HTC on his treatment plan has come to him later in life, after he came to terms with having haemophilia.

'When I was younger there were times when I didn't listen to my HTC about taking my prophylactic treatment and that always ended up in not a good place. Even in college, when I was supposed to take my prophylaxis before baseball games, I didn't want to do it. I didn't want to have to stop and infuse and feel different. And so I didn't do it, many times, and I ended up with some of the worst bleeds I have ever had because I didn't follow their guidance. Now we work together on my physical activities and they help me figure it out.'

Sharing what he has learned from his climbing experience has been a way for Chris to connect to the worldwide bleeding disorders community and hopefully help others to meet their personal challenges.

ROCK CLIMBING CHALLENGE

Two Australian brothers have also shared their climbing challenge experience to raise awareness about haemophilia and promote the message that 'haemophilia doesn't have to be a barrier to achieving something hard' and that you might be capable of more than you think.

Scott and Andrew Godwin have severe haemophilia A and started rock climbing about 10 years ago. Scott had a dream of climbing El Capitan – an iconic vertical climb in Yosemite National Park – and persuaded his brother to take this on. They undertook about 6 months of training and achieved the difficult climb in 2019. They had a couple of attempts – they had to abandon the first attempt when Scott had a bleed – and completed the climb on their second attempt.

Andrew and Scott climbing El Capitan Photos: Andrew and Scott Godwin

Q&A

How to motivate young people to exercise?

- Finding something you enjoy
- Young people with haemophilia can be scared to try sports – we need to change the language in haemophilia to encourage them to participate.

Who was involved in training for Chris’s climb?

- The whole Haemophilia Treatment Centre team!
- The physiotherapist was very involved in training and preparation - and rehabilitation after a serious mountain biking injury before the climb
- Chris had arranged medical and travel insurance
- Chris was on extended half-life factor treatment for Everest, which meant he didn’t have to vary his treatment schedule much, but he made sure he had a treatment before he took climbs ‘where rocks might fall on me’
- He still finds it difficult infusing into a vein, especially when he misses the vein.

‘The Treatment Centre staff were amazing,’ said Chris. *‘I don’t know that they were super-excited by my idea, but they knew I was going to do it anyway, so they would rather be part of that discussion rather than try to fight it.’*

- Ali and Penny underlined that HTCs wanted their patients to be active and the aim would be to work out a treatment plan to protect you as much as possible.

How do you manage mountain climbing with joint problems?

- Scott commented that he found walking downhill difficult with ankle arthropathy, and that is why he preferred rock climbing
- Chris has had more muscle bleeds than joint bleeds – he is not sure why - so his ankles are fine but walking downhill with a heavy pack is hard on his knees.

A comment from a parent attending the Live Chat summed it up: ‘

A massive thank you for showing that you can do anything if you have haemophilia with the right treatment. Two boys with severe haemophilia A here, one who struggled with inhibitors for years, and we live by the motto of not letting their haemophilia define them, provided their treatment is done.’

Our thanks to Chris, Andrew and Scott for sharing their stories so generously, and to Ali and Penny for their support.

MORE INFORMATION

If you would like more information about sport and exercise for you or your child, speak to your Haemophilia Treatment Centre. Contact details of HTCs are on the HFA website - https://tinyurl.com/HTCs-Aus

You can also find more information about sport and exercise, along with personal stories, on the HFA Factored In youth website – www.factoredin.org.au

WATCH THE VIDEO OR READ MORE!

- Watch the full video of this Live Chat session on the HFA YouTube channel at https://tinyurl.com/YT-B-Blood
- You can buy and watch the Bombardier Blood movie at https://tinyurl.com/Bombardier-Blood-movie
- Read and watch Andrew and Scott’s story of training for and climbing El Capitan

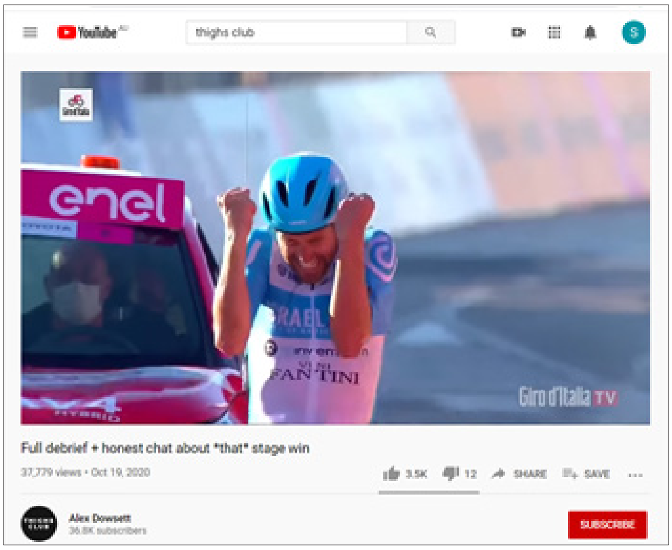
  The training – https://tinyurl.com/FI-rock-climb

  Mission accomplished! - https://tinyurl.com/NH-mission-accomplished

> This journey was the culmination of a lifetime of struggle to deal with his haemophilia and to achieve his goal of climbing the Seven Summits

ALEX DOWSETT CYCLING WIN

Bleeding Disorders Awareness Week was a time for exciting and extraordinary events - and one of these was the news about Alex Dowsett's amazing victory in Stage 8 of the Giro D'Italia cycling race.



Full debrief + honest chat about *that* stage win

37,779 views • Oct 19, 2020

Alex Dowsett
36.8K subscribers

Alex is an elite cyclist from the United Kingdom with severe haemophilia A. You may remember him from his trips to Australia to compete in the Tour Down Under in South Australia and the Cadel Evans Great Ocean Road cycling races. This year he has been cycling professionally with the team Israel Start-Up Nation. After an injury knocked him out of the Tour de France in July, he made a great return for the prestigious Giro D'Italia race in October 2020 – and went on to an astounding solo win of Stage 8, way ahead of the pack. It had been a hard year for Alex, and with uncertainty about his employment for next year and a baby on the way in January 2021, Alex said it was just the break he needed.

INTERNATIONAL HAEMOPHILIA AMBASSADOR

Alex is well-known as an ambassador for the haemophilia internationally. He is not afraid to talk about his haemophilia or how he manages his treatment and his cycling career. In 2012 he appeared on the UK television program Embarrassing bodies (Series 5, Episode 3). He is a leading part of the Little Bleeders team, a UK charity that raises awareness about haemophilia and encourages young people with haemophilia to be active and participate in sport. Alex also has a YouTube channel, Thighs Club, where he shares his cycling experiences and tips, along with updates on his haemophilia story and young people with haemophilia who have inspired him.

GROWING UP WITH HAEMOPHILIA

On the Little Bleeders website, both Alex and his parents give their versions of his story – from a traumatic diagnosis as a baby with no family history, growing up with prophylaxis treatment and regular stints on crutches, swimming to improve his strength as a boy and then discovering his love for cycling when he joined his dad and some family friends on a mountain biking trip.

From there he went on to be selected for the Great Britain Cycling Talent Development Squad and pursued a professional career in cycling. This brings its own complications if you have severe haemophilia.

EDUCATING THE TEAM

In Alex's video for World Haemophilia Day 2020, he explained how important it was to educate his own cycling team about haemophilia. Alex could self-infuse his treatment from the age of 9. With his Haemophilia Treatment Centre, he developed a personalised treatment plan, where in everyday life and during training he infuses every second day, but infuses daily when he is racing. He also has a plan to control bleeding with injuries and extra factor is carried in the team car during a race. Joining the new team, he needed to brief not only the team directors and doctors, but also his fellow cyclists. With the Union Cycliste Internationale 'no needle policy' after the performance enhancement drug scandals of previous years, it was quite a shock for one of his new team mates to walk in on him at the training camp while he was injecting his treatment into a vein. Alex had to provide some quick education about haemophilia and that he has a special exemption from the 'no needle policy' to infuse himself with factor VIII during the cycling competitions.

Alex with local SA community members and HTC and HFA staff in 2012 Photo:HFA

INSPIRING THE AUSTRALIA COMMUNITY

Alex has also been a great friend to the Australian bleeding disorders community and keen to share the message that young people with haemophilia 'have such bright prospects'. After his first ride in the Tour Down Under in 2012, Alex met with the local haemophilia community in South Australia and inspired the HTC team at the Royal Adelaide Hospital to set up Team. Factor for the Challenge Tour. In 2019 and 2020 he took time out from his busy racing schedule in Victoria to meet up and have a chat with the Donaldson family from Torquay, particularly with their son Will, who has severe haemophilia and is a keen surfer. Alex and Will discussed the challenges they faced and about driving forward with sport to the best of your ability. Karen, Will's mother, commented that it had been 'pretty special' to have such a meaningful conversation.

Alex's World Haemophilia Day 2020 video features an interview with Will towards the end.

Find out more about Alex's story at:

Alex's story - Little Bleeders -
http://www.littlebleeders.com/alexs-story

World Haemophilia Day 2020 - Alex Dowsett Thighs Club YouTube Channel -
https://www.youtube.com/watch?v=M0Hl3RUOp0Q

Competing in the sport you love (Alex's visit to Australia) – National Haemophilia, March 2019 –
https://tinyurl.com/NH-AD-cyclingstory

Will and Alex in 2019 Photo: Karen Donaldson

CALENDAR

World Haemophilia Day
17th April 2021
www.wfh.org/whd

Bleeding Disorders Awareness Week
10-16 October 2021
Tel: 03 9885 7800
Fax: 03 9885 1800
Email: hfaust@haemophilia.org.au
Web: www.haemophilia .org.au

ACKNOWLEDGEMENTS

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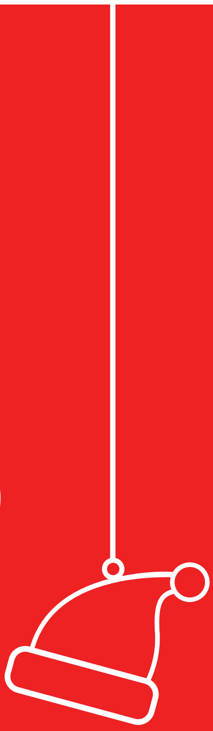
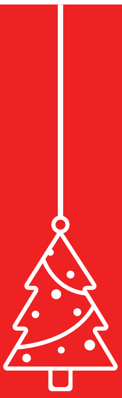
We thank the individuals, philanthropic trusts and companies which have made donations to HFA, and the following companies for sponsorship of education programs, conferences or disease awareness programs run by the Foundation for the bleeding disorders community:

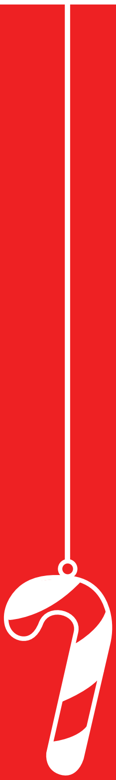
HFA acknowledges it has received grants and/or sponsorship from the following pharmaceutical companies for projects in 2020:

BIOMARIN | CSL BEHRING | PFIZER AUSTRALIA

ROCHE | SANOFI GENOZYME







SEASON'S GREETINGS

The HFA Council and Staff wish you a happy and safe festive season.

Thank you for your support during 2020 and we look forward to working with you again in 2021.

The HFA office will close on **Thursday 24 December 2020** and reopen on **Monday 11 January 2021.** During that time if you have any queries or need to contact HFA, call 0398857800. Messages during that time will be monitored.