National Haemophilia
Haemophilia Foundation Australia
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LIGHT IT UP RED

#WHD2018

WORLD HAEMOPHILIA DAY

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New Staff Poppy Sparsi

Poppy Sparsi joined the HFA team as the Administration Officer in March 2018.

Poppy comes to the position with over 20 years of experience in administration support roles in a variety of sectors including education, health services and corporate industry.

Since starting at HFA, she has found it rewarding to use the variety of her skills in her new role. 'It's a diverse role in a small but very interesting and busy office,' said Poppy. 'I enjoy interacting with people and working for people, keeping up with technology and just getting the job done.'

After spending 16 years in education at Trinity Grammar School, Poppy took some time off to travel, before securing contract work in a variety of roles including health services and corporate industry.

'Before joining HFA my knowledge of bleeding disorders was very limited,' commented Poppy. 'In my brief time here, I have learned quite a bit more about some of the various disorders, and I'm sure I will continue to learn more.'

Outside of work Poppy enjoys ballroom dancing and is exploring painting and drawing as a new hobby. 'I suggest everyone buy an original now before my works become expensive!' she joked.

Poppy works Monday to Thursday and can be contacted at HFA:

E: psparsi@haemophilia.org.au | **T:** 03 9885 7800

Gavin Finkelstein is President, Haemophilia Foundation Australia

FROM THE PRESIDENT

Gavin Finkelstein

WORLD CONGRESS

We will be reporting on the 2018 WFH World Congress in Glasgow, Scotland in the September edition of *National Haemophilia*. Some of our readers will have attended the 2014 Congress in Melbourne, and will be aware of the broad range of topics covered for people affected by bleeding disorders and their treating healthcare providers at Congresses. The 2018 World Congress program included the latest topics and advances in the management and treatment of people with bleeding disorders. Further, it was the perfect forum to foster collaborations, networks, and relationships to transfer knowledge; to learn, share, and problem-solve through discussions amongst delegates from diverse cultural and contextual settings. Patients and families, WFH national member organizations, health care professionals, scientists, researchers, policy makers, and regulators representing the whole community were all present.

In the meantime I think that many people in the Australian bleeding disorders community will have followed news from the Congress via the WFH website, or perhaps seen some posts on HFA's Facebook page or Twitter feed.

CHALLENGES OF COMMUNICATIONS

These days we have generally come to expect immediate communications and a quick transmission of information. We see this in communications from governments, community organisations and of course, privately, in our personal communications.

For HFA and similar community organisations social media can be challenging, even though it is the preferred way for most people in our community to receive at least some of their information. We need to balance our intention to report events and issues as soon as they arise, with our responsibility to provide accurate and balanced information. Sometimes it might take us a little while to verify information or provide sufficient details and to make sure the wording of our communications conveys the right messages.

Things have changed at HFA. We are very conscious of the need to work with social media as one of our routine channels for communicating information, news and events to our community. This is complex work, and we look carefully at how different messages are conveyed, from the short bites of information on Instagram, the links to more in-depth information on the HFA or other websites or videos on YouTube, and the discussions on Facebook, talking with our community about what we are doing and listening to their feedback. Developing social media strategies to be active in the digital space is a dynamic area for us and we value the expertise our staff bring to this. Kassy Drummond, our Health Promotion Officer, is often found working on the best way to communicate messages via social media, and you may have noticed the colourful visuals and short snappy taglines, along with pathways to more detailed information.

SHARING THE PERSONAL STORY

We also share the experiences of people in our community as real life evidence of what it's like to live with a bleeding disorder. We receive a lot of feedback from our community about how much they learn from each other and support each other– this might be through face-to-face peer support groups on specific issues, and where people come together for family and youth camps and conferences.

We are increasingly sharing the personal stories of people in our community on social media. You might have seen some of the new personal stories we released for World Haemophilia Day in April, including the digital stories on the HFA YouTube channel.

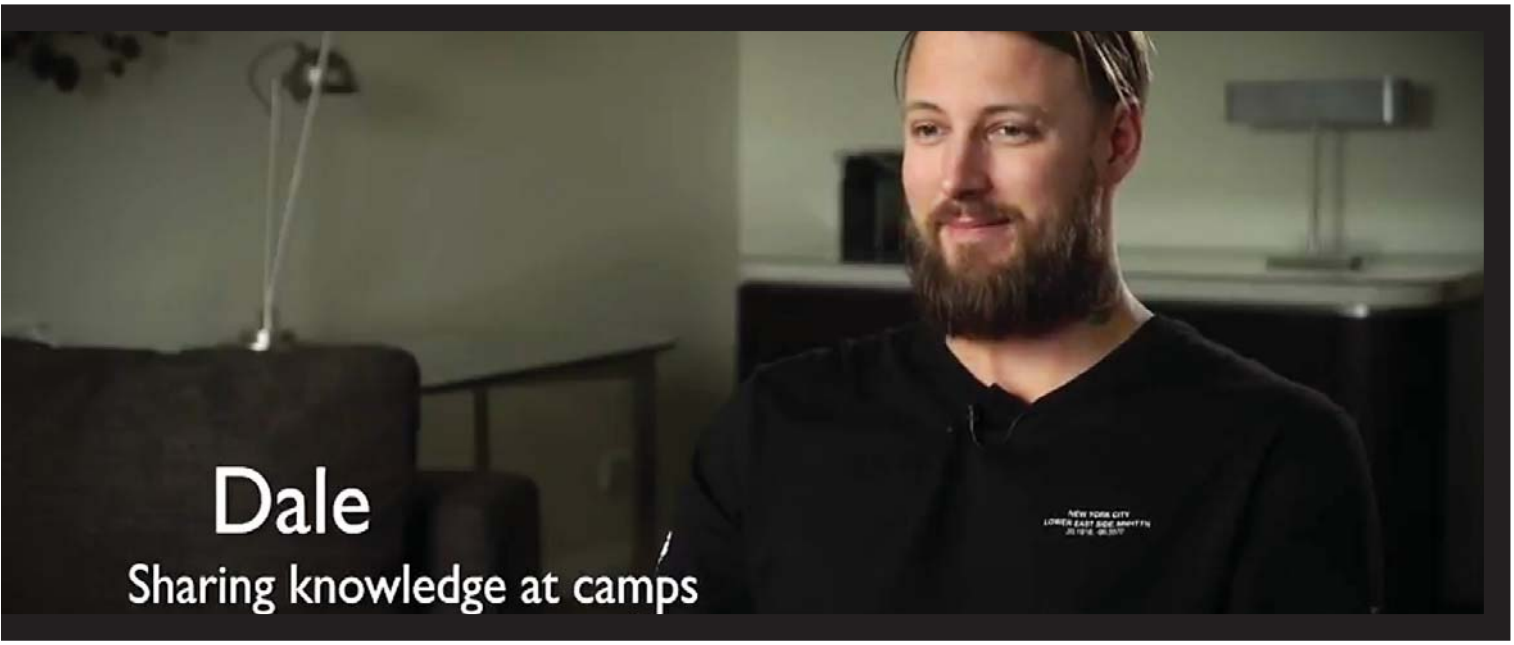
Our digital story project is ongoing and aims to capture a range of the personal experiences of people in our community so these can be shared with others. We are grateful to the people who have generously come forward to share some of their experiences, such as what it feels like when first learning of new diagnosis, or the complications of a bleeding disorder, and the importance of community support and information. If you haven't yet seen these videos, click on the YouTube link under STAY CONNECTED at the base of the HFA website to be directed to the HFA YouTube channel. We will be uploading more of these digital stories on the HFA website over the next few months and will be redeveloping our home page to make these digital stories more prominent – stay tuned!

WORLD
HAEMOPHILIA DAY

Every April 17 World Haemophilia Day is recognised worldwide to increase awareness of haemophilia and other inherited bleeding disorders. This is a critical effort since with increased awareness comes better diagnosis and access to care for the millions who remain without treatment.

World Haemophilia Day was started in 1989 by the World Federation of Hemophilia (WFH) which chose to bring the community together on April 17 in honour of WFH founder Frank Schnabel's birthday.

Dale's digital story on the HFA website



In 2018 the global theme was SHARING KNOWLEDGE MAKES US STRONGER. It was about sharing experiences of bleeding disorders with the world in order to improve awareness and increase access to treatment.

On World Haemophilia Day HFA launched a series of digital and written personal stories of people with bleeding disorders talking about how they have used their experiences to raise awareness in the community.

To view these personal stories visit https://tinyurl.com/WHD-sharing.

LIGHT IT UP RED!

Together with other landmarks from around the world, Australia had landmarks turn red to celebrate World Haemophilia Day.

Thank you to the people who attended the landmarks on the night and shared their photos

1. Darwin Convention Centre
2. Pfizer Headquarters, Sydney
3. Story Bridge, Brisbane
4. Adelaide Oval
5. Bell Tower, Perth

Thank you to all who supported World Haemophilia Day.

WORLD HEMOPHILIA DAY / APRIL 17

MYABDR
WHAT'S COMING UP?

From the National Blood Authority and HFA MyABDR teams

WHAT HAPPENS TO YOUR USER FEEDBACK?

As part the ongoing work to improve MyABDR, HFA and the National Blood Authority regularly seek feedback from MyABDR users about changes they would like to see to the app or website. You may recall, for example, the MyABDR user survey in June-July 2017. These become "change requests".

Change requests can also come from other sources. For example, users can give feedback directly to the MyABDR Support Team or HFA or local Foundations, who then pass them on. Haemophilia Treatment Centres (HTCs) can make recommendations from based on their patients' experiences. There are also change requests from the NBA to deal with bugs, data reporting, security and functionality issues.

These change requests go through a process of assessment and prioritisation with input of representatives from HFA and HTCs, as well technical review by developers and business analysis at the National Blood Authority. HFA also has a MyABDR focus group of users who sometimes provide feedback on specific requests or proposed solutions.

During this process, the proposed changes are reviewed for approval by the Australian Bleeding Disorders Registry Steering Committee. The Committee's membership includes the Australian Haemophilia Centre Directors' Organisation, HFA, the National Blood Authority and a federal and state government representative. It deals with issues such as privacy, ethics, data accuracy and system development.

UPCOMING ENHANCEMENTS

You will be pleased to hear that – with a lot of work behind the scenes to assess the current change requests – more improvements are planned for MyABDR over the next 18 months.

The National Blood Authority has compiled a list of change requests and new functionality/enhancements and will commence a project to update the MyABDR system in latter half of 2018 and 2019.

Stay tuned for more details!

ANY QUESTIONS OR NEED HELP?

Don't forget that the MyABDR Support team is always happy to help you with any problems, and can make a time to get back to you if that suits you.

They are available 24 hrs, 7 days a week

T: 13 000 BLOOD / 13 000 25663
E: support@blood.gov.au.

MYABDR TIPS

Some people are coming back to using MyABDR after being on a clinical trial or starting to use MyABDR for the first time. What tips do regular MyABDR users have for new users? Michael, a MyABDR user from South Australia, had this to offer:

My favourite features are:

- *4-digit pin access code for log in*
- *Easy-to-track stock levels*
- *Simple user interface for recording bleeds*

My tips for new users or people coming back to it are:

- *Get into the habit of bringing your device with you when injecting so it's right there and you don't forget.*
- *Put the app on your device's front screen so it's always in sight. Even subconsciously you will see it and this helps to remind you to use it.*

Suzanne O'Callaghan is HFA Policy Research and Education Manager

THE FEMALE FACTORS SURVEY

Suzanne O'Callaghan

In April 2018 HFA undertook an evaluation survey of our two recent **The Female Factors** booklets, *A snapshot of bleeding disorders in females* and *Finding out you carry the gene*. We wanted to know if we were on track with the booklets we had published and what improvements to make in the future.

The Female Factors is the HFA women and girls project. The project is developing specific information resources for Australian women and girls affected by bleeding disorders to:

- **Increase their understanding of their bleeding disorder**, treatments and strategies to manage it
- **Help them to feel more connected** with each other by sharing personal stories and tips with others in similar situations
- **Develop high quality, evidence-based information** that they can show to other doctors, nurses, dentists, physiotherapists, etc who provide their care.

These resources aim to deal with some of the problems experienced by Australian women with bleeding disorders. HFA's consultation has found that many women have been treated in the community, for example, by a GP rather than a Haemophilia Treatment Centre. However, most doctors have not received training about managing bleeding disorders. As a result many women have had problems with diagnosis and referral, and had bleeding problems with surgery, medical and dental procedures, with menstruation (periods) and after childbirth. Many women also spoke about their difficulties in being 'taken seriously' by health professionals, as some of their non-haemophilia health professionals (eg, general practitioners, surgeons, dentists) didn't know that women can have bleeding disorders. This is similar to the experience of women with bleeding disorders in other developed countries such as Canada.

>>

For these women, feelings of isolation are common.[1,2]

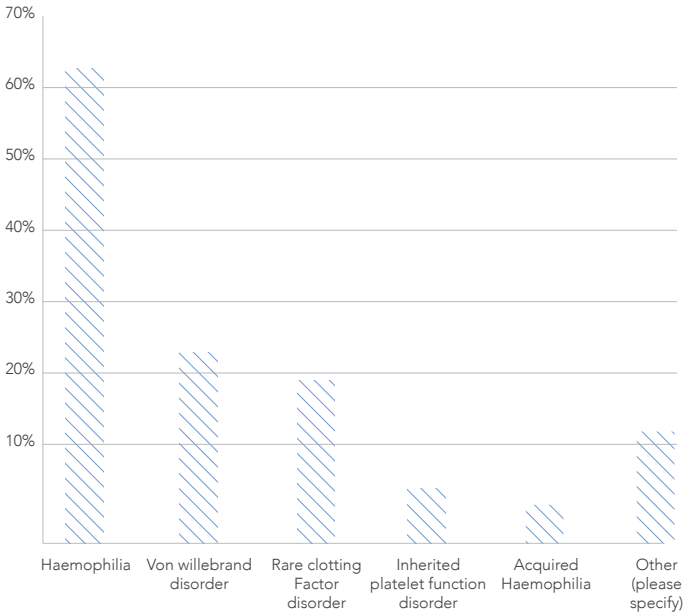
WHO COMPLETED THE SURVEY?

37 people completed the survey.
29 female, **8** male

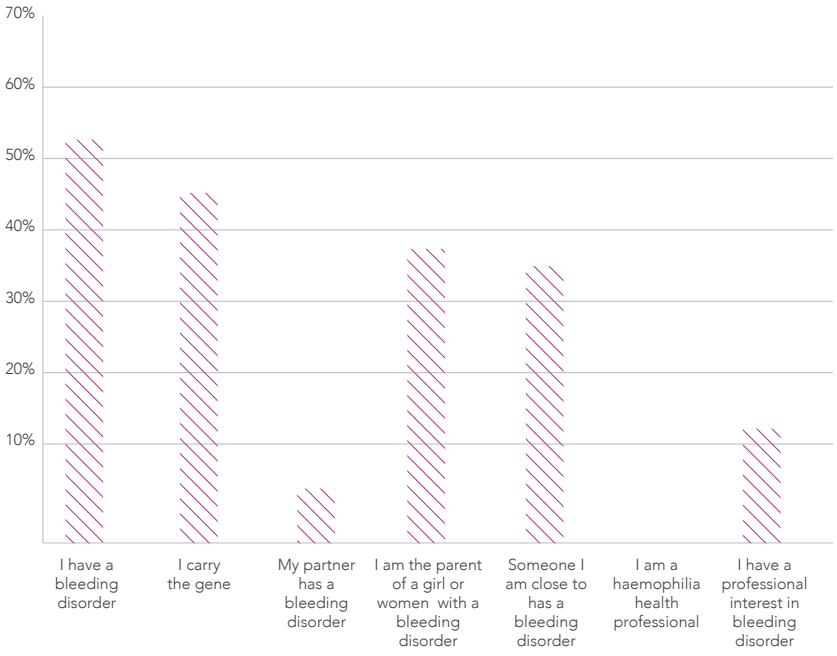
They were from all states and territories except Northern Territory and Tasmania (3 did not disclose where they lived).

72% were **31-54** years of age

BLEEDING DISORDER THAT APPLIES TO YOUR SITUATION



PLEASE TICK ALL STATEMENTS THAT APPLY TO YOUR SITUATION



- introduction to bleeding disorders in females
- working with HTCs and other health care practitioners

- common reactions to diagnosis
- where to go for support

WHAT DID THEY THINK OF THE BOOKLETS

86% had seen the **Snapshot of bleeding disorders in females**
66% had seen **Finding out you carry the gene**

48% had seen the **print** version
66% had seen the **online** version

85% thought they were **very or extremely useful**
72% thought the **design and layout** was **very good or excellent**

What did they like?

- Informative, easy to read
- First information they had seen written for females
- Good reference tool to share with others

Suggestions for improvement

- More detailed information
- More information on VWD, rare clotting factor deficiencies
- Simple summaries for low literacy

'Great layout. Easy to peruse.'

'People can refer to them again - conversations can be forgotten or misunderstood. When sharing information with others who are new to clotting factor issues they feel safe and comfortable and can find answers but also questions to ask health professionals.'

'My daughter was happy there was something that was just for females.'

"A lady found it in my work waiting room and was so thrilled to have something concrete about herself."

"Thank you for producing a quality resource for women and their families to use."

WHAT DID THEY DO WITH THE BOOKLETS?

68% passed booklets on to **other family members**
18% showed booklets to **their health professionals**

Why?

'Was good showing my family.'

'To educate carriers in the family who are considering starting a family who hadn't been informed about their considerations or connected to an HTC yet.'

'So that we are not alone and that we suffer as well.'

'Acknowledging that these symptoms are real and do affect the person's life is very helpful. It is also helpful if they are able to talk about them to their doctors and to get some help with their symptoms.'

What was the impact for them?

'The desire to educate more family members/well wishers/school educators.'

'Spurred me on to find out more info from the doctors re children and starting a family.'

'More info and evidence of what I say is not rubbish.'

'I have sought to talk with some others who I know have bleeding disorders to ask their advice.'

'As a male, a broader understanding.'

WHAT'S NEXT

HFA has nearly completed two of the next resources for The Female Factors project:

- Telling others (family, friends, work, insurance, travel)
- Female factors – a booklet for teenage girls and young women.

We are using the feedback to develop the content and layout:

- More information on VWD, rare clotting factor deficiencies, inherited platelet disorders
- Boxes with summary information
- More information on key issues for women and girls with bleeding disorders.

Other resources in the pipeline:

- Diagnosis
- Symptoms, care and treatment
- Family planning, pregnancy and birth.

And we are always looking for women, teenage girls and parents of girls who are interested in contributing to the content with ideas or personal stories or reviewing drafts of the resources.

If you would like to be involved, contact:

Women's resources – Suzanne at HFA
E: socallaghan@haemophilia.org.au
T: 1800 807 173

Teenage girls/young women – Kassy at HFA
E: kdrummond@haemophilia.org.au
T: 1800 807 173

REFERENCES

1. Haemophilia Foundation Australia. Women and bleeding disorders project report. Unpublished report, Melbourne, 2002.

2. Renault, NK, Howell, RE, Robinson, S, et al. Qualitative assessment of the emotional and behavioural responses of haemophilia A carriers to negative experiences in their medical care. Haemophilia 2011;17:237-245.

Cheryl Ellis is Vice-President, Haemophilia Foundation Western Australia and has mild haemophilia A

WOMEN AND P

Cheryl Ellis

PEER SUPPORT FOR WOMEN IN A LOCAL CONTEXT

How are local Foundations exploring peer support for women and what can we learn from their experiences?

The importance of peer support for women affected by bleeding disorders was a key finding in HFA's consultation for **The Female Factors** Project. Often feeling isolated and as though they are the only ones with their experiences, women have found connecting and sharing stories to be immensely valuable and empowering.

The local Foundation activities to connect and support women are a concrete way of making a difference for women. HFA is also including personal stories from Australian women with the evidence-based information in all **The Female Factors** education materials.

This report from Haemophilia Foundation Western Australia (HFWA) is the second in a series about local peer support for women from Australian State and Territory Foundations.

A LITTLE BIT ABOUT ME

I remember very clearly being told by a junior registrar that our beautiful nine-month-old son had haemophilia. He, my husband and I were in a post-operative ward at the children's hospital, surrounded by other family members. This all came about because my son had an unexplained swollen knee. He had just started crawling, and his knee blew up like a balloon one day. Off we had rushed to the GP, who sent us straight to the Emergency Department at the children's hospital, as he thought it was a possible joint infection. After the orthopaedic surgeon washed out his knee (there was a blood clot in the knee, but no infection) the surgical wound kept bleeding. Blood tests revealed that our son had severe haemophilia A.

I look back now and see most of that time as a blur. We had no previous family history, but I knew what the registrar was telling me since I'm a registered nurse. Hearing the words, "Your son has a severe bleeding disorder" felt like a nightmare that I couldn't wake up from, for a long time. Eighteen months later, we had another son who also has severe haemophilia A. Having seventeen and sixteen-year-old sons who **both** have bleeding disorders somehow made it easier, since they are treated the same.

Once we emerged through the ups and downs of bleeds, clinic appointments, infusaports (small devices surgically placed under the skin on their chest to infuse clotting factor treatment), high temperatures, inhibitors, learning to intravenously cannulate and more, my thoughts turned to the consequences for myself. I was genetically tested and found to be a carrier of the haemophilia A gene, but also I have factor VIII levels of 24% (as per my current ABDR card), which means I have mild haemophilia.

I decided that I would like to use my powers for good and joined the HFWA committee in 2005. I'm currently

EER SUPPORT

Vice President of HFWA, and am a firm believer that social networks and supports are vital for women (and families) to thrive, particularly when a chronic, complex and potentially life-threatening medical condition is thrown into the works.

WOMEN'S GROUP MEETINGS

Our Women with Inherited Bleeding Disorder Group (WWIBD) meetings are Perth metro-based events provided by HFWA to allow women and girls affected by an inherited bleeding disorder to come together in a relaxed and enjoyable setting. HFWA hold them approximately every three months and usually as a Sunday morning breakfast. Occasionally we mix it up a little and have afternoon (high) tea or lunch. Our WWIBD meetings are usually attended by anywhere from ten to twenty women, and feedback we have received includes how enjoyable, thought-provoking and beneficial the meetings have been in the past. One of our committee members and a regular attendee to our meetings has commented that the more inclusive names of the women's meetings really encourages women with von Willebrand disorder and other bleeding disorders than haemophilia to participate.

Our meetings provide opportunities to discuss individual experiences and issues important to us. There are many common subjects of discussion, such as how we came to find out our bleeding status and history, approaching doctors and medical staff for assistance in the past and currently, the problems faced when talking to medical staff who don't understand bleeding disorders, our children and their health, travelling with bleeding disorders and other events such as the family camp and how fantastic they are. The discussions are often not lead or instructed by anyone but evolve and grow as the conversations move around the table.

Some crucial points that have emerged from the women's group meetings are the importance of recognizing our own bleeding symptoms, being aware of our own factor levels and, if necessary, having a treatment plan in place.

PEER EDUCATION

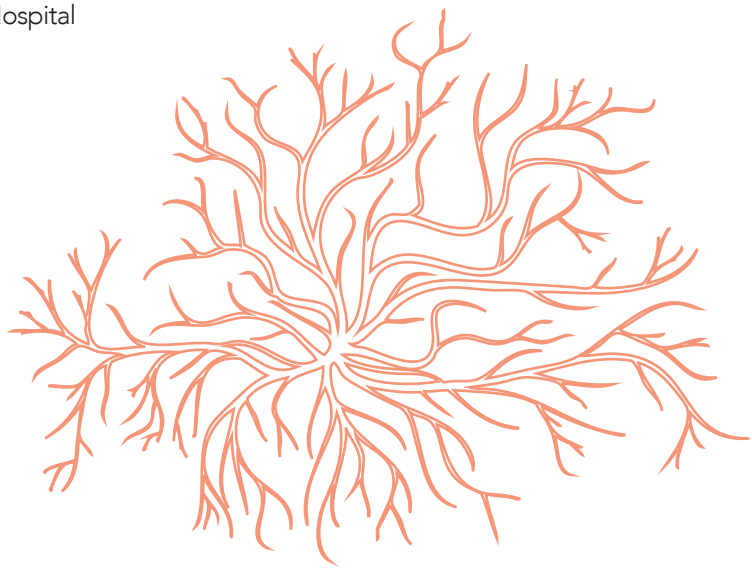
Educational information such as the **Finding Out You Carry the Gene** and **A Snapshot of Bleeding Disorders in Females** brochures are great resources we use to provide a starting point for information when we and other women in our families are identified as carrying the haemophilia gene and want to seek assistance prior to starting a family or when planning procedures, and how to access services at the Haemophilia Treatment Centre. HFWA provided the brochures to our members through a mailout with our newsletters, and emailed links to access the PDFs from HFWA's website. I also take copies of these brochures with me to the women's meetings.

OTHER OPPORTUNITIES TO CONNECT

Our youth group, parent/family meetings and family camps also provide girls and women with opportunities to take part in fun activities and meet other people and families in similar situations.

Robyn Shoemark is Clinical Nurse Consultant, The Children's Hospital at Westmead
Helen Starosta is Clinical Nurse Consultant, Royal Hobart Hospital

LOOKING AFTER YOUR VEINS



Robyn Shoemark and Helen Starosta

Home treatment and prophylaxis have become a way of life for people with haemophilia. It is very important to look after veins as you will need to use them for a long time. While giving factor may be challenging, you or your child's caregivers are the best people to administer factor replacement therapy using veins once you know how to do it.

WHAT ARE VEINS?

Veins carry blood back to the heart and lungs from around the body. They have thinner walls than arteries; they lie closer to the surface and do not pulsate. The veins closest to the skin's surface are used to get blood during a blood test or to put medication into the body.

Having good veins to give factor through is not just about good luck. Learning how to do this properly and then looking after veins is important and requires work.

Have you ever noticed how body builders and brick layers usually have big, strong veins? This is because of the upper arm exercises and work they do. You can make veins bigger in your arms by doing some simple exercises.

EXERCISES FOR VEINS

1. Squeeze a sponge ball in your hand. Start with ten squeezes daily and build up to 50 squeezes per hand daily. This exercise helps to develop the supporting muscles.

2. Place a tourniquet around your upper arm. It should be tight enough so that your veins stand out in a few minutes, but not so tight that you can't feel a pulse at the inside elbow. Squeeze your fingers in and out with/without a sponge ball until your arm gets tired. Loosen the tourniquet and rest a little, then repeat this exercise again. If you do this frequently, at least twice a day, it will improve your veins.

How do these exercises improve your veins?

When you do these exercises, your muscles tighten, clamping off veins that run through them. This makes all the blood that flows into the arm return through surface veins. This causes veins to become larger and stronger, making them easier to find and use.

Remember, it's like any other exercise. It only works if you do it regularly, and it will certainly help with your infusions.

VEIN ROTATION

Medicines that are given through veins can irritate the walls of the veins. Changing which veins you use can help decrease irritation and scarring.

When you put a needle in your skin, it leaves a small hole that needs to heal. The same is true with your veins. You can keep your veins in good shape if you let them heal before you use them again. If you don't let your veins heal, you may be at risk of collapsed veins or infections.

Rotating your vein is often recommended, where you let one spot heal while you use another. A vein usually takes a couple of days to heal. It is also useful to have a backup vein that is used to being injected in case you have issues with your regular vein.

TIPS FOR TREATMENT

What can you do to make things go more smoothly when you need treatment?

The following are tips and tricks which may help you:

- **Clean** – Always wash your hands before you start and have a clean area to make up and give your factor.

- **Drink plenty of fluids** – make sure you have enough to drink before you try to give your factor so that your veins are plump and bouncy.

- **Keep warm** – if you are cold, your veins will shrink and will be much more difficult to find. This is sometimes a problem in winter so it helps to put on a jacket to keep warm. Have a warm shower or bath. A warm breakfast or cup of hot chocolate/milo will warm you from the inside. If you are still having problems then a heat pack over the vein you are using is a great way to warm you up and help make it easier to find your veins.

- **Environment** – makes sure there is good lighting where you are sitting and you are comfortable and relaxed. If you are stressed or scared then your veins know this and make it more difficult to find them. Sit somewhere comfortable and if you need to be distracted, turn on music or the TV. Take a few deep breaths before you start if you need to calm yourself.

- **Exercise** – being fit and healthy means you will have better veins. A healthy weight range also makes it easier to find and feel your veins. Just before you have your factor, doing a quick round of exercise such as running on the spot or star jumps will help get your blood pumping and make finding your veins easier.

- It is better to use a **plump bouncy vein** that you can feel than a vein you can only see. If a vein is plump and bouncy it will be easier to access than a vein that is visible but flat. Take your time to feel and get to know your veins and the direction they are running.

- **Position** – make sure you have your arm below the level of your heart. Dangling your arm over the edge of the bed/chair before you access your veins will allow gravity to increase blood flow to the area and the vein. After applying the tourniquet squeeze a rubber ball or make a fist or flap your arms up and down to help increase blood flow.

- **Use distraction** for small children – TV, DVDs, iPad, toys, bubbles, Buzzy Bee, another person. Anything your child likes is helpful.

- **Pain relief** – using anaesthetic 'numbing' creams. Remember to remove and clean the area well. Finding the veins is easier if the cream has been removed for around 10 mins before trying to use the vein.

- **Avoid pressure** on the needle insertion site during an infusion or when taking the needle out. Remember to release the tourniquet before you start infusing your factor.

- **Apply pressure** after the needle is removed to make sure the bleeding has stopped. If you do not apply adequate pressure for long enough then you may get a bruise over the vein making it difficult to feel when you next need to use it. Using a pressure band aid will help prevent bruising. Looking after your vein makes it much easier to find the next time you need treatment.

- **Rotate vein sites** as needed – you may not need to do this but if you are having problems with the vein, it is always good to have an alternative to use.

- If you need a **blood test** – ask the health professional you are seeing if you can access your vein yourself or if they could use a different vein to your regular vein.

- **Ask for help** – sometimes you will have problems despite your best efforts. Remember, it is ok to ask for help if you are having problems.

For more information about looking after your veins, talk to the haemophilia nurse at your Haemophilia Treatment Centre.

Auburn McIntyre is the Haemophilia Physiotherapist at the Women's & Children's Hospital, Adelaide

WHY IS MY CHILD LIMPING?

When your child's joint and muscle pain is not a bleed

Auburn McIntyre

In this article we will be looking at particular musculoskeletal matters that can occur in all children and adolescents, not just those with haemophilia. These conditions cannot occur once you become an adult as they relate to growth and growing bones and muscles.

BONES

Children's bones are softer and more pliable than adult bones. As a result, the bones of younger people can bend and children have "green stick fractures", something adults can no longer have. A little like a young tree, the bark can peel down, rather than cleanly snap.

Secondly, the long bones (e.g., the thigh, shin and arm bones), have growth plates at both ends. The long bones become longer and wider with growth. The bones of the lower leg grow most, noticeably around the knee.

Some bones, like the pelvis, knee and heel bones, have special growth plate areas where strong muscles and ligaments attach, called an "apophysis". The growth plates are weaker than the ligaments. Occasionally a strong force can pull strongly at the anchor point causing pain, swelling and weakness. This saves the ligament and muscle from being damaged but is painful and causes weakness of the muscle. Apophysitis sites are discussed a little later.

MUSCLES

Strong skeletal muscles are essential for good movement. Poor muscle development and poor fitness is associated with poorer long term health. It is not possible to bulk muscles until puberty, hence it is recommended free weights and a variety of activities rather than machines and specialized sports are employed prior to puberty (approx. 10-14 years). A great variety of activities establishes the framework for good strong muscle fibre development.

Education and awareness of growth spurts is important as fitness is needed for long term health. Gaining skills through a variety of sports before a child is 10 years old helps skills and works all muscles. It is important to be aware of growth spurts but not worry about them.

Tell your physiotherapist and doctor if your child is growing rapidly.

Work-life pressures can mean it is difficult for parents to provide their child with a large variety of activities but variety enhances strong development of many leg, arm and trunk muscles and assists the body to develop co-ordination, balance and strength.

GROWTH SPURTS

Adults shrink, only children grow.

A growth spurt, around 10-15 years in boys, poses some risks to children and adolescents as bones grow at different rates to muscles. The early part of a pre-pubertal growth spurt is marked by rapid growth of the legs. The difference between the bone and muscle growth can create problems with general flexibility, co-ordination, muscle power and strength.

Children and adolescents can become clumsy during periods of growth. They are more at risk of injury.

Mechanical stress (tractioning, pulling and tugging), often due to over-use by training the same muscles too frequently, can cause over-use pain. This is called **traction apophysitis** and can occur at sites commonly affected by haemophilia, such as the elbow, ankle and knee. A sudden, strong and forceful action of a muscle that attaches to the soft area of the growth plate may cause that attachment area to pull off completely. This is known as an **avulsion fracture**.

In the pelvic area this can be when muscles of the trunk attach at the iliac crest. If they are over worked or worked suddenly, pain can occur along this area. The Ischial tuberosity has the hamstring muscles attached to it. Over stretching or a sudden movement against force can cause an avulsion fracture.

The anterior superior iliac spine has the sartorius muscle, a hip-lifting (flexor) and turning muscle which can also detach part of the bone when the leg kicks a heavy wet ball or the hard ground.

Physiotherapists often want to know "how the injury happened" and "what where you doing when…..". This is to try and determine if the sudden pain is a bleed or something else. Sometimes X-rays are required to determine if the pain is due to a fracture. Many things can cause pain, not just a bleed.

At the knee there are two common sites that can become sore and painful. The names attached to these injuries are Osgood-Schlatter disease and Sinding-Larsen disease. They are locally painful, can be sore with running, when touched and working the quads (quadriceps femoris) muscles. These injuries are usually due to over-use and tight muscles.

Down at the foot, the heel reacts to tight calf muscles pulling on bone, for example, with running, jumping or even walking. This can result in pain, swelling and is often worse after rest, again usually when muscles are tight pulling and tugging occurs. Local pain, sometimes stiffness and swelling can result.

The above injuries relate to tight muscles pulling on softer bony growth plates, during a period of growth, or a sudden action of the muscle which can pull the soft bone off its harder base. They generally cause local tenderness, swelling or pain, **not** whole knee swelling as in a bleed - for example, a local area of pain at the heel or under the arch, **not** the whole ankle. They can hurt and lead to you being unable to lift a leg or walk. They require proper assessment.

Factor replacement therapy may make some difference; due to perhaps some bleeding of the body part involved but it will not be the same as in a bleed to a joint or muscle. The problem will reoccur and not settle with re-use.

Children with suspected bleeds should always be reviewed. Growth spurts are times when other issues arise and proper assessment is critical.

True joint bleeds improve with factor replacement therapy. They require proper PRICE (Protection Rest Ice Compression Elevation) and rehabilitation afterwards to improve the muscle power, strength and flexibility that is **always lost** after a bleed.

A period of relative rest and specific exercises are required for apophysitis and growth plate injuries. They may even require an orthopaedic review and an X-ray.

CHILDHOOD HIP ISSUES

Other than psoas muscle bleeds, the hip region is commonly less problematic for people with haemophilia. A bleed into the ankle, knee or elbow is much more problematic.

However, in children the hip region can be a site of other musculoskeletal issues.

Infections can occur in this area and also in other joints. This may be after a viral illness such as a cold or ear infection or even a recent open wound. A child might limp or complain of groin or knee pain and have restricted movements. Commonly the 3-10 year old age group is affected. Adults can also get joint infections but many typesw are more common in children.

Children should never have a temperature or be unwell with a haemophilic bleed.

Boys, 10-15 years old, are 60% more likely than a girl to develop a slip of part of the hip bone, (a *slipped upper capital femoral epiphysis*). This can occur suddenly and they will have a quick onset of pain and loss of movement and function, or it can occur gradually over time. Both result in restricted hip movements. Sometimes the leg may appear shorter and the child

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will limp. There is a heightened risk if children are overweight. Treatment is generally surgical.

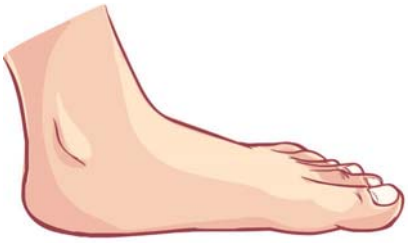
Some children will complain of knee pain when the problem is actually in the hip joint. Both joints should always be checked.

Boys, 4-10 years old, more than girls can develop Perthes, another hip condition with limping, persistent pain and restricted hip movements. Perthes often occurs gradually.

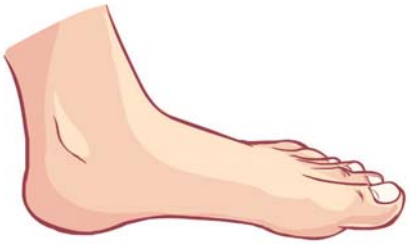
If a child has a slipped upper capital femoral epiphysis or Perthes, they will not respond to factor replacement therapy. If they have a bleed, children should always improve and continue to improve if given factor.

FEET

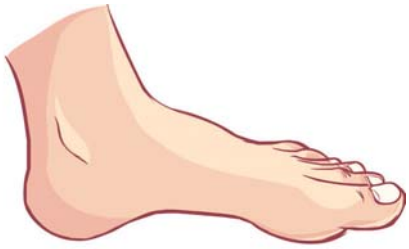
Flat feet, which are normal in children until around 5-7 years, can sometimes lead to stiff feet in adolescence. Why this occurs in unknown and it is not common. When asked to stand on tip toes, children with stiff feet don't show the natural arch that most people get. An orthopaedic review may be required if their feet are causing problems, have calluses etc.



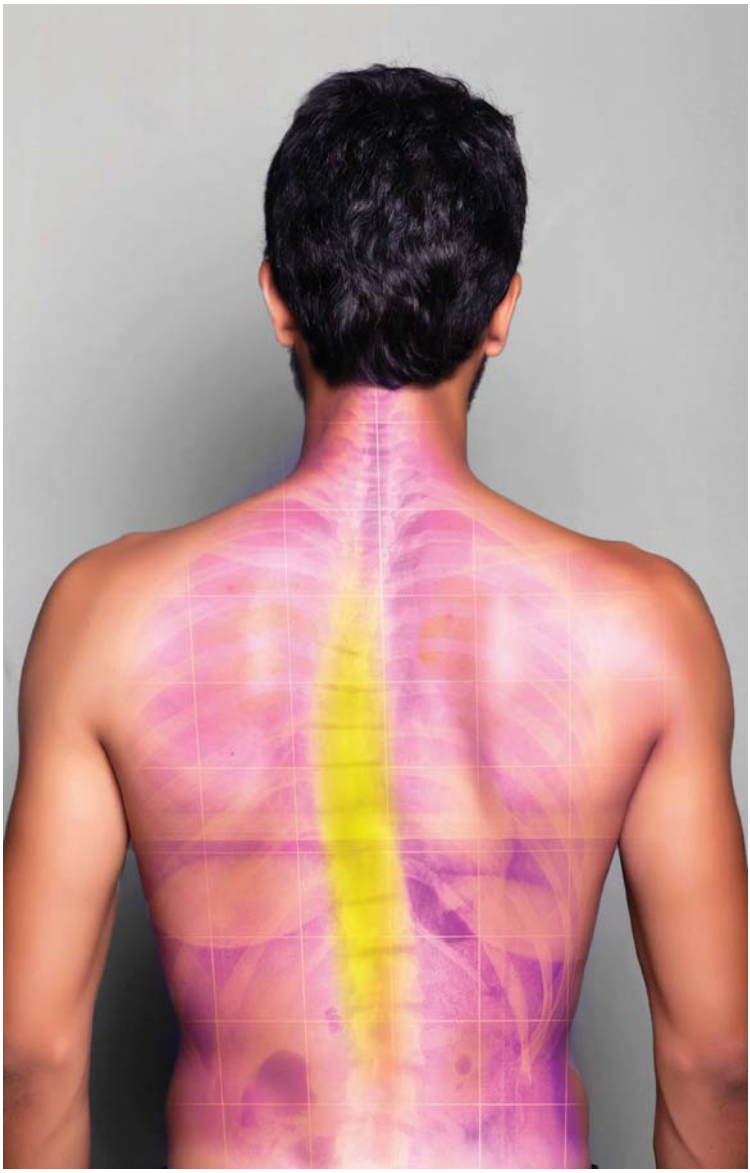
Flat Arch



Normal Arch



High Arch



Scoliosis

SPINES

Children's spines are growing so posture is constantly changing. More girls than boys develop a sideways curve in their spine called a scoliosis but boys can become very round shouldered or kyphotic. They can also develop a scoliosis. These spine conditions may become problematic if they continue to develop with growth. Often they are hidden under clothes so have a look at your child's spine in summer when they are less likely to have so many thick layers on.

IN SUMMARY

Enjoy watching your child grow. It's an amazing process, full of joys as they become better at skills and conquer new activities.

Be aware that all aches and pains may not be bleeds. Take note of the blue alert boxes …….

Contact your HTC if the "pattern" of the problem is different to a normal bleed or if the problem doesn't settle or if the problem reoccurs. Act, don't wait!

Loretta Riley is Advanced Social Worker at the Queensland Haemophilia Centre, Royal Brisbane and Women's Hospital

TRANSITION

Loretta Riley

I am in the process of writing a booklet for young adults who have transferred to the Royal Brisbane and Women's Hospital. When I was asked to utilise this knowledge to write an article for *National Haemophilia*, a colleague of mine at the Lady Cilento Children's Hospital asked me whether I noticed any parallels between writing this booklet and the process of transition. After thinking about it for a while, I realised that there was.

Before I share my learnings, for those who may be unsure of what 'transition' is – it is a gradual, coordinated process which involves a young person, their families or carers and health professionals, which results in a young person's care being transferred to (in our situation) the adult Haemophilia Treatment Centre.

BE PREPARED OR PLAN AHEAD

In writing the booklet, I read a lot about what other Haemophilia Treatment Centres in Australia were doing and looked at resources that Victoria, Canada and Ireland had already published. I spoke to people who had gone through the transition process and found out what they wish they had known about and I asked staff what information they thought was important.

Just like writing the booklet, transition requires some preparation and planning. No doubt, through your time with the paediatric Centre, staff there have been preparing you to take an active role in your treatment. They have probably started to ask you more questions. You may have been taught to do your own infusions. None of these things happened overnight. There was some planning and some preparation involved.

Planning ahead allows you to practice some things before your care moves to the adult hospital. You can practice being prepared for your appointments, for example having all your information up to date in MyABDR. By having a list of questions to ask or things to remember that you take with you to your appointments, it can help with remembering things that happen months earlier and may also help you to feel more confident. These are some things you can practice in the years before you transition to the adult Centre and will help you in your clinic appointments.

Some Haemophilia Treatment Centres across Australia have a shared clinic once a year where you get to go to the adult hospital and meet the adult Centre staff with the paediatric Centre staff there at the clinic or you might go to a day or night event where you meet the adult Centre staff and maybe get a tour of the hospital. All of this helps you with preparing for the transition to the adult hospital.

SET GOALS

In transition, as in many areas of life, it is helpful to set goals and you can do this early as well. There is no need to set a lot of goals to achieve before you turn 17 – some you will already be working on, some you can keep working on when you transition across to the adult Centre. In writing booklets, this article, in my work, it has helped me to meet timelines, especially when I am feeling a little overwhelmed.

It works best when I break the goals into smaller goals, which are more manageable. You may have heard of SMART goals. Goals work more effectively

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when they are **Specific, Measurable, Achievable, Relevant/Realistic and Time Bound**. So, for writing the transition booklet, I had a grand plan to have the booklet completed, printed and sent out by January (I started it in late September). This wasn't realistic in the end. I didn't factor in all the extra research I needed to do or the processes involved in having it reviewed. I also didn't have uninterrupted time – I had to keep doing all the other bits of my job. So, I reviewed my goals, fixed up my timeframes and looked at it more realistically. We understand that sometimes things happen beyond your control.

So, a transition goal might be going to a clinic appointment on my own. So if we break it down into a smaller goal to assist with achieving this, one example may be:

- **Specific** – I will ask the paediatric Centre doctor one question
- **Measurable** - I will do it at my next clinic appointment at the Children's Hospital
- **Achievable** – it is something I can do. I will write the question down and take it with me in case I get nervous.
- **Relevant/Realistic** - The doctor always asks if I have a question and taking this step will help me feel more confident talking to the doctor on my own
- **Time bound** - I have an appointment in 3 weeks, so I can do it then.

It also may help if you are particularly nervous to practice with a family member.

REMEMBERING TO DO WHAT YOU PLANNED TO DO

I usually have a number of projects, phone calls, appointments to do all in the same week or even same day. Sometimes, I forget to do some things that I had planned to do, so I have a number of strategies to help. In writing the booklet, I booked appointments into my calendar, wrote myself 'to do lists' and ticked them off when I completed each task. I also used post it notes (which were helpful when they stayed where they were supposed to). The same ideas can be applied to preparing for transition and beyond.

Writing appointments into a diary, on a calendar or into your smart phone calendar are all helpful tools (as long as you regularly look at your diary for example!). Using the MyABDR app or website also helps you keep a track of what treatment you have had, whether you have had any bleeds and what your stock level is like. Parents or other family members may be able to assist you with this in the beginning. This also helps with being prepared for your clinic appointment! You might already be using some tools to help you with study, remember when you need to do your part time job or where and when your sport fixtures are happening. A number of the things you do to help you remember these things can be used to help remember your appointments and other tasks you do to look after your health.

YOU DON'T HAVE TO GET IT 100% CORRECT THE FIRST (OR SECOND) TIME

It took me a few goes at writing the booklet to get it to a point where I was happy with it, and that was even before I showed anyone else. There were things I forgot to add in, some things changed while I was writing it and I forgot to take them out. Other people are now reading it and they have suggestions to make it even better.

It is the same in transition. You may need to practice things a few times (sometimes many times) before you feel confident. The staff at Haemophilia Treatment Centres understand that you are learning. We all make mistakes, we all have times when we forget to ask or tell our doctor/nurse/physiotherapist/social worker/psychologist/counsellor something – and we usually remember it as

IT'S OK TO ASK FOR HELP

we are going home or sometimes just as we have walked out the door, or hung up the phone. Sometimes we need a little more time to understand what's being said, or we need to practice the technique. It is OK to need more time to practice or build your confidence or not do something perfectly every time.

IT'S OK TO ASK FOR HELP

In writing the booklet, I wasn't (and I still am not) an expert in transition. So, I needed to ask for help. Sometimes it was easier to ask (for example, asking about other Centre's transition programs) and getting some information from someone I had heard speaking about transition. Other times, the people I asked were busy. But this didn't stop me as I worked out that it was important to ask for help and I know that my booklet will be much better because I asked other people for help. Dr Timothy Sharp (a psychologist who specialises in happiness) has written that one of the most powerful tools for living a happier life is to "ask for and accept help".

It is the same with transition. It is not a journey you have to do on your own. Just like climbing Mt Everest – you have help along the way. The skills you develop which will help you with transition start before you even realise it. You learn them from your parents, from school and from the Children's Hospital. You are learning to become more independent (although I think maybe the correct word is interdependent) from when you are small. None of us can do everything on our own and sometimes we get stuck, and we need some extra help.

If we use the goal above of 'going to a clinic appointment on my own': you might have been working towards that goal, asking more questions on your own, you might even have time with the team on your own without a parent for some of the appointment. But, you might need to have some surgery or some dental work done. Asking a parent to come to the appointment where you talk about this with the Haemophilia Treatment Centre is a positive thing. They can help you remember what you have to tell the Haemophilia Treatment Centre so they can give the best advice. They can also help with remembering what you need to tell the doctor or dentist. They might need to help you with the logistics of getting home from that appointment. It doesn't mean that you haven't met your goal; it means that you understand when you need help and know where you can get help from.

Health professionals are like Sherpas on Mt Everest. We help you make the journey – sometimes we give you more help, like putting a ladder across a crevice (which might be like helping you achieve your goals – or even helping you write down or think about your goals) and sometimes we are there just to support you along the path.

We understand that there may be a lot of changes for you all at the same time – with leaving school, starting a new adventure with further study or work, perhaps moving out of home, learning to drive and also moving to a new hospital and treatment team. The Children's Hospital team will have been preparing you during your time with them, and moving to the adult Hospital team is another step in this journey. We are all here to help make your journey as smooth and as safe as it can be. Hopefully as you can see, the skills you learn can be used throughout your life.

SOURCES

The Royal Children's Hospital, Melbourne. Transition: For young people - www.rch.org.au/transition/for_young_people

Dr Happy (The Happiness Institute) - www.drhappy.com.au

Sick Kids (Canada): Transition tools - www.sickkids.ca/good2go/for-youth-and-families/transition-tools/index.html

Irish Haemophilia Society: Transition - www.haemophilia.ie/living-with-haemophilia/young-adults-with-haemophilia/transition

2018 GO FOR IT GRANTS

Everyone experiences obstacles at some time, but you'll never know what you can overcome and achieve unless you ***Go for it!***

The Haemophilia Foundation Australia's **Go for it Grants** program is open for applications!

WHO CAN APPLY?
If you have a bleeding disorder or are affected by a bleeding disorder two **Go For it** grants of $2500 each are available.

The **Go for it Grants** can take you one step closer to realising your dream.

See the application form on www.haemophilia.org.au/awards.

Applications close on 30 August 2018.

NEW ABOUT BLEEDING DISORDERS BROCHURE

Ever wanted a simple brochure about bleeding disorders to show people at a fundraiser or people in the general community who are interested?

HFA has produced a new brochure, ***About bleeding disorders***, that explains what bleeding disorders are, with brief but up-to-date information about inheritance and treatment. It also covers commonly asked questions.

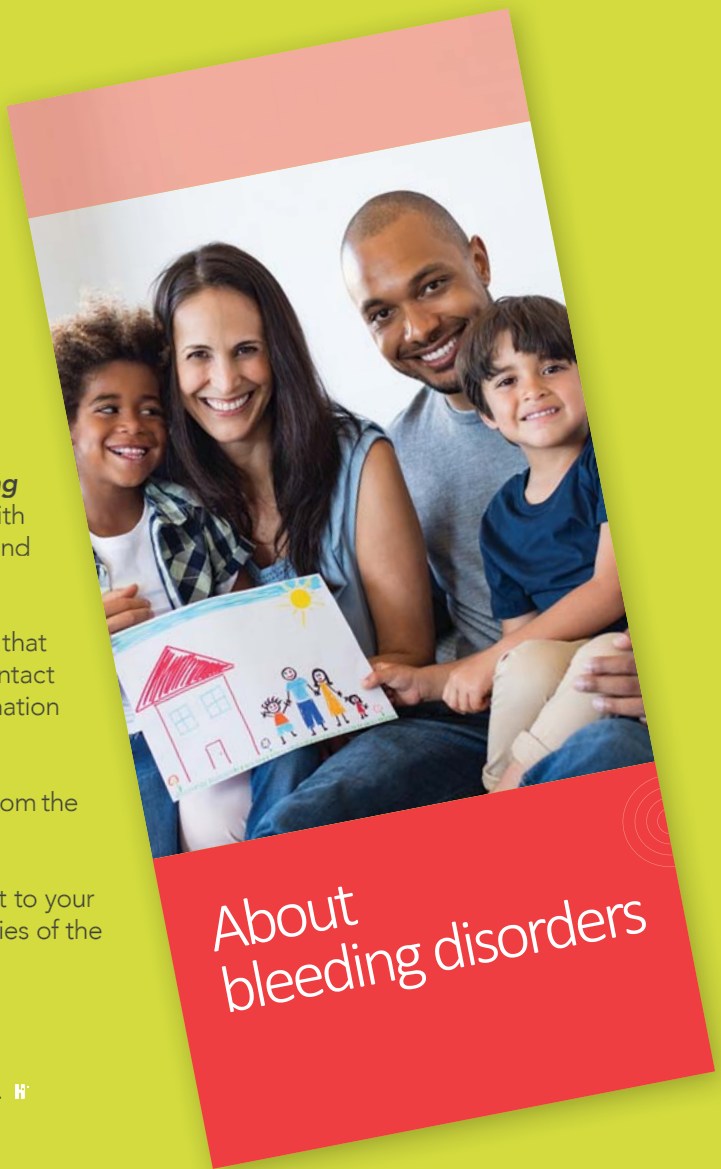
There are versions for each state/territory Foundation that include the Foundations' role and activities and their contact details. HFA has a generic national version with HFA information and contact details on it.

You can also read the HFA version online or download it from the HFA website (look under PUBLICATIONS).

If you would like copies of the brochure that are relevant to your state or territory, contact your local Foundation. For copies of the national version, contact HFA on:

T: 1800 807 173 | **E:** hfaust@haemophilia.org.au

Or view it online at www.haemophilia.org.au/publications.



Kassy Drummond is Health Promotion Officer, Haemophilia Foundation Australia

Youth Update

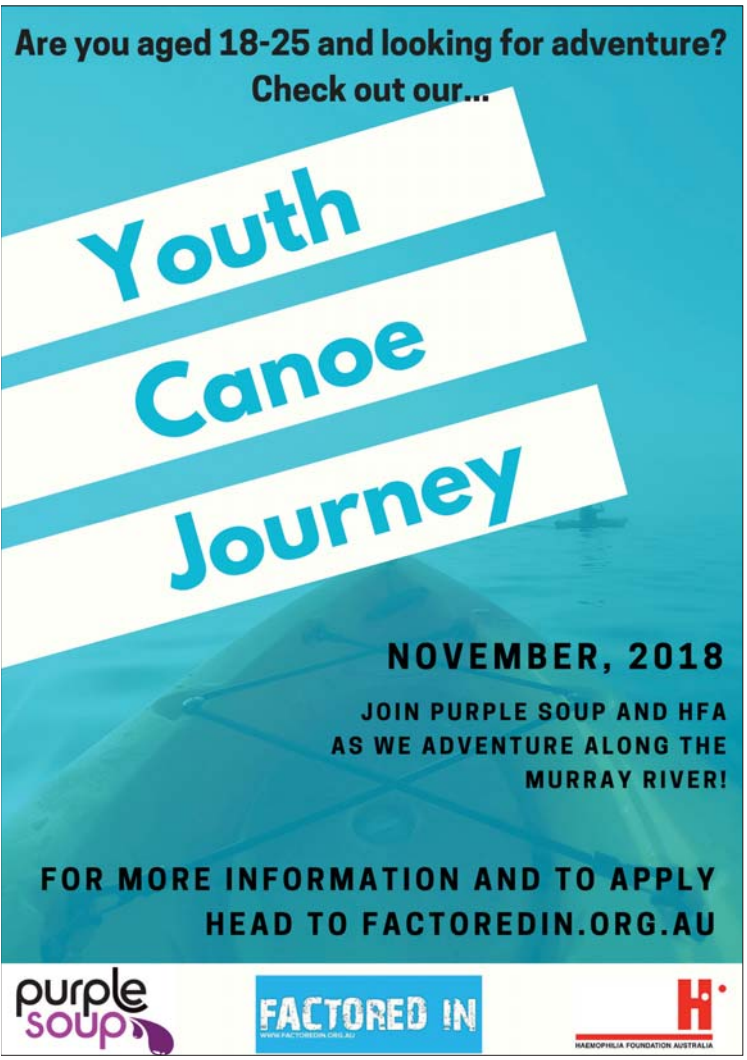
Kassy Drummond

YOUTH•LEAD•CONNECT

YOUTH LEAD CONNECT

Youth Lead Connect (YLC) is a leadership program developed by Haemophilia Foundation Australia (HFA) to build education and life skills for young people with bleeding disorders. The program began in 2015 and follows an application pathway similar to a job application process. The program encourages youth to step up in their local community and increase both their personal and leadership growth.

We are currently in the process of contacting the 2017 YLC participants to find out what stage they are up to with their goals. It's looking like most of them may be ready to graduate soon!



Goals currently being worked on include:

- Several YLC participants have written a personal story for Factored In. Personal stories help youth connect with each other and are an important part of peer support, mentoring and leadership in the community.
- A few youth participants worked with their Foundation to advocate for young people who live in non-metropolitan areas of their state/territory to be involved in a local youth event

The Youth Lead Connect leadership training will be taking a rest in 2018 as we have something else planned, but it will return in 2019.

HFA'S INAUGURAL YOUTH CANOE JOURNEY

This year we thought we'd do something different from the usual Youth Lead Connect leadership training program. HFA has been working with the adventure therapy organisation Purple Soup, on a canoeing trip, scheduled for November this year! This trip will take place over three days, heading along the Murray River between Victoria and New South Wales.

This won't be a normal youth camp. It's designed to challenge participants and build life skills. Participants will be involved with the planning of the trip and will be required to set goals around what they'd like to achieve during the program. They will need to apply and go through an interview to be selected to participate.

For more information, and to apply, head to **factoredin.org.au.** Places are limited!

YOUTH NEWS

Following on from our article in the March 2018 issue of *National Haemophilia*, one of our youth members, Alan, who has severe haemophilia, spoke to us about his tips and tricks for surviving university.

Preparation can be the key for making the transition to university easier. Knowing what services and supports are available to you may increase your chances of success in TAFE or university.

WHY MEET THE DISABILITY TEAM?

In the week before the start of his course, Alan spoke with the university's disability team to discuss his condition and whether there was anything that could be done to assist him.

Young people with haemophilia don't usually think of themselves as having a disability, but at universities and TAFE colleges they are actually entitled to support under the disability program. It's a good idea to meet the disability team when you first start at uni or TAFE. That way you can get to know each other and learn how they can help you if you need it. Often it may be for temporary issues, like managing ssessments and exams while recovering from a bleed.

A disability officer at one Victorian university told HFA, 'universities generally want to do what they can to help people do the best that they can, that's why they have disability teams. It's a confidential service and they'll talk with you about your needs and what they might be able to put in place to give you the best chance at success'.

The types of things disability teams have helped young people with haemophilia with in the past include:

- Parking close to the uni when you are on crutches
- Access to lifts
- All sorts of equipment loans, e.g. a wheel chair
- Negotiating using another classroom or doing classes online when the classroom you need to use is upstairs and you are on crutches
- Organising a writer for exams when you are recovering from an elbow bleed
- Negotiating extensions for assignments when you have a bleed.

For Alan, having this talk lead to access to a room where he could treat himself privately during the semester, and a private room for treatment during exams.

STARTING HIGHER EDUCATION

PEER EDUCATION

Alan found that most of the people he spoke to about his bleeding disorder were supportive about it. It did help that he was studying pre-medicine, as he found the class was soon learning about haematology and he was able to relate his own experience to his course. *'All my friends were welcoming of the condition and it benefited everyone'.*

GETTING TO KNOW PEOPLE

Meeting new people could make anyone nervous, and it might help to remember that most people are in the same boat. Alan said *'While we all were sitting on our lab benches everyone was quite friendly and I made a number of friends in the first day. As the weeks went on it was much easier to speak to everyone and as everyone has similar ambitions we all gelled well.'*

You might remember from the last edition of *National Haemophilia* that Emily had similar feelings about meeting her classmates. Emily offered some advice for people who are just starting out: *'go to all the lectures (even if they aren't compulsory) because it's a great way to meet your course mates'*. She also suggested it's a good idea to get to know your lecturers, something that can be useful for assignment extensions as well as job and further study applications. *'Sometimes you don't gell straight away, and when you are doing a general type course with more subject choice it takes a bit more time to find your tribe, but if you keep talking to people you will find some who are easy to get on with.'*

When asked what advice he'd give to someone with a bleeding disorder starting out at uni or TAFE, Alan said; *'I would just say not to be so nervous and to speak to as many people as possible to be able to connect and network.'* He found it all a little easier remembering that everyone else was probably feeling just as nervous as him. *'The first day was daunting but I was a little excited as anyone would be. Everyone was scavenging to find their class alongside PHD students and other not so new students.'*

"Meeting new people could make anyone nervous, and it might help to remember that most people are in the same boat"

CALENDAR

Bleeding Disorders Awareness Week
7-13 October 2018
Tel: 03 9885 7800
Fax: 03 9885 1800
Email: hfaust@haemophilia.org.au
www.haemophilia.org.au

World Haemophilia Day
17 April 2019
www.wfh.org/whd

ACKNOWLEDGEMENTS

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We thank the individuals, philanthropic trusts and companies which have made donations to support HFA programs, and the following companies that sponsor education programs, conferences or peer support programs run by the Foundation for the bleeding disorders community:

BIOVERATIV | CSL BEHRING
NOVO NORDISK | PFIZER | ROCHE | SHIRE

SOUTH AUSTRALIA **UPDATE**

We were pleased to meet up with a strong group of community members at the Information Evening held on World Haemophilia Day, 17 April 2018, held at the Womens' and Children's Hospital in Adelaide.

The evening was planned by the South Australia Haemophilia Treatment Network and Haemophilia Foundation Australia (HFA). An update on the advances in haemophilia treatment and care were presented by Dr Simon McRae, Director of the adult Haemophilia Treatment Centre at the Royal Adelaide Hospital, Mrs Auburn McIntyre, Physiotherapist, and Dr Heather Tapp, Director of the Haemophilia Treatment Centre at the Women's' & Children's Hospital.

A small group followed on from this to an evening of Ten Pin Bowling where experiences and personal stories of living with a bleeding disorder were shared along with bowling skills!

We look forward to publishing reports about the family day at the Adelaide Zoo held on 3 June 2018 in the next edition of *National Haemophilia*.