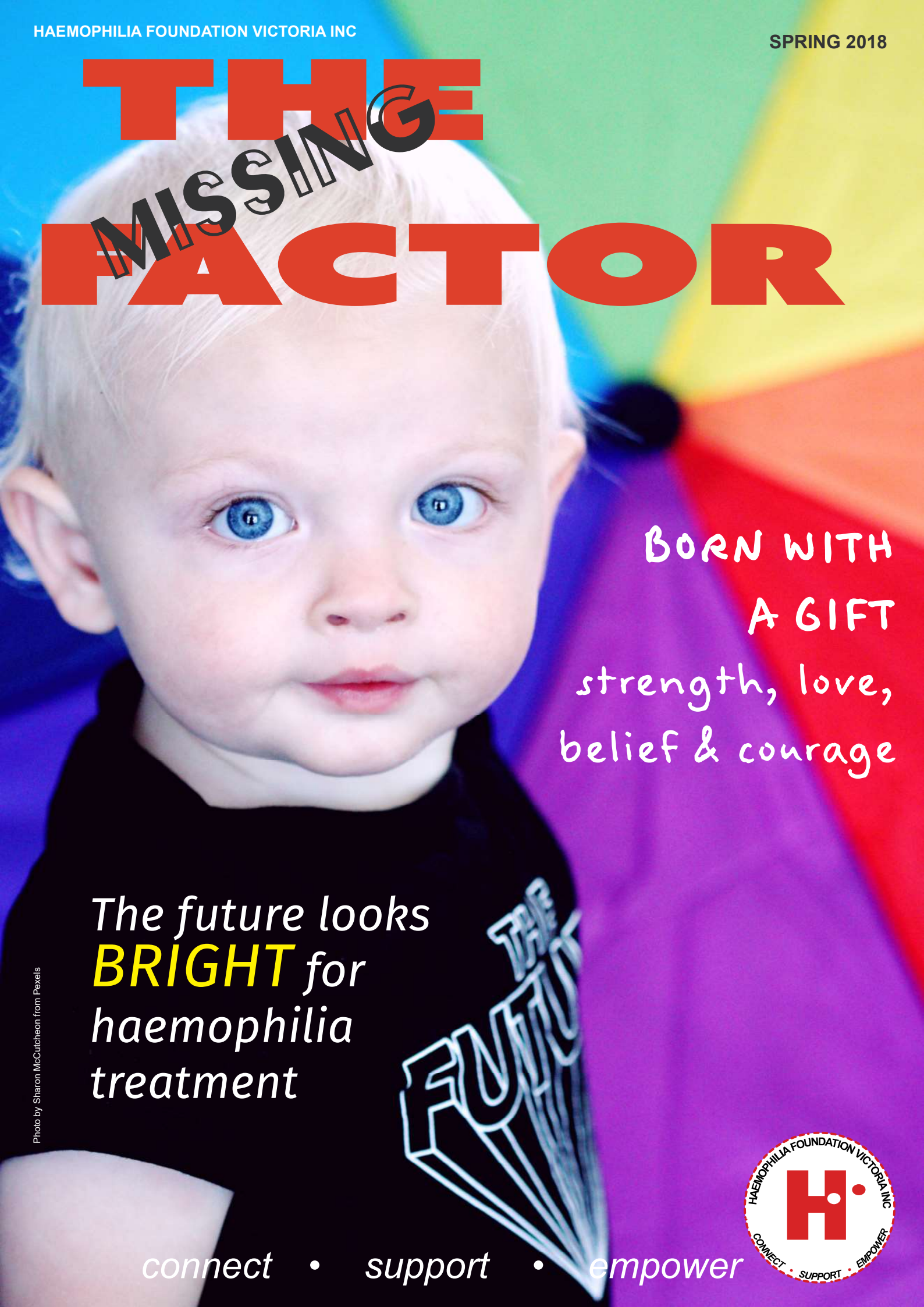
HAEMOPHILIA FOUNDATION VICTORIA INC

SPRING 2018

THE MISSING FACTOR



BORN WITH A GIFT

strength, love, belief & courage

*The future looks **BRIGHT** for haemophilia treatment*

Photo by Sharon McCutcheon from Pexels

connect • support • empower

HAEMOPHILIA FOUNDATION VICTORIA INC

CONNECT · SUPPORT · EMPOWER

SPRING 18

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HFV is committed to Child Safety.
Our Child Safety Statement is available for review on our website www.hfv.org.au

The Missing Factor is the official publication of the Haemophilia Foundation Victoria (HFV) with four issues annually.

HFV is funded through the Department of Health and Human Services under Blood Borne Virus Sector - due to the historical impact of contaminated blood products on the haemophilia community. HFV supports our diverse community and our magazine reflect topics that impact our community including Bleeding Disorders, BBVs, Mental Health and positive health promotion.

Editor: Julia Broadbent

Haemophilia Foundation Victoria acknowledges the support of the Victorian Government.

PRESIDENT'S REPORT

Hooray! Winter is behind us; footy season is nearing finished as we welcome spring and all the fresh energy it brings. My beloved Bombers may not be there for the last Saturday in September as I wished but I am very happy to put the spring in my step and look towards sunshine and blossom.

Things may have been cold outside but inside HFV it has certainly been business as usual. Busy times as always.

Some of the team have travelled into some of our beautiful rural areas to meet some wonderful people that are living with the challenges of a bleeding disorder. Some are existing members and we welcome some as new members. It has been so lovely to meet everyone, share your stories and remind us again of the gaps that are there for some of you as you face the challenges of everyday life, especially when in a remote part of our beautiful state. Overall our regional visits have been a huge success and we will be planning more for 2019 so we hope to meet some of you on your home turf.

Exciting developments at HFV are the more connections we are making with those from the vWD community. Robyn has joined our committee and through the support of our HTC we seem to be slowly connecting more with members that share this disorder. It is exciting times as we embrace new members and share our support to you as a very important part of our extended community.

Behind the scenes the staff and committee continue to work tirelessly to keep the HFV machine chugging along. HFV has submitted our Health Promotion Plan and we are almost ready to release our next Strategic Plan. These are both critical documents that set our direction for future planning and we are very proud of the comprehensive manner we have incorporated the needs of our diverse community and the problem solving we have applied to try to make these both living and practical pieces of work. At the end of the day this work belongs to you as members and stakeholders so always happy to discuss and take on board any suggestions for improvement.

Working with our stakeholders continues to be a priority. Staff will have an opportunity to meet with RCH families after their clinic sessions and we try to meet with the teams at both HTCs as much as possible. If you are visiting, please look out for our team and always stop to introduce yourself and share a chat. In my role as President, I attend National Council for HFA. It is always a privilege to represent Victoria in that space, proudly share the successes for our community but also support the other foundations across Australia. HFA are doing some amazing work and I encourage you all to read their newsletter and access the resources created by Suzanne and the team. Very informative and may be useful for family, friends and those that support you. Well worth a look.

While speaking about HFA please have a look out for the Canoe Adventure being offered to youth across Australia. What an amazing opportunity and a great initiative. A chance for our youth to connect to nature and to each other and is such a fantastic opportunity that we are delighted to support.

HFV is very excited to be hosting two students that are completing their post graduate studies in Genetic Counselling. We thought this would be an amazing opportunity to support students and take the opportunity to connect them with families and our stories to enrich the quality of their experiences and give them a holistic sense of the challenges some of us face with both being a carrier or having a gene that creates a bleeding disorder. Genetics are complex, and the emotions are high so an opportunity to work with students is exciting for us and we hope this initiative is supported by you as our community. HFV may be in touch if your story is relevant to this piece of work so if you are comfortable please support them.

HFV is hosting our inaugural Walk Around Albert Park Lake on 30th September and hope some of you can join us. We would love there to be an annual event each year that raises awareness for Haemophilia and people living with bleeding disorders. We all know red nose day; white ribbon day and we would love nothing more than there to be a day or event that becomes associated with HFV and our community. We will start with a walk and hope you can join us. Our dream is to grow an event into something everyone wants to be a part of. However, like all things they start with a small acorn to grow an oak tree so please help us sow the acorn and join us on the 30th. Love to see you there and all the details are in the newsletter, website and bookings are through **www.trybooking/WACS**

There are so many activities and opportunities to be a part of the HFV journey. We hope you and your family and loved ones can enjoy some of our efforts by being a part of the events and continue to support us by renewing your membership. We encourage you to invite your loved ones to also become members as every contribution is well utilised in supporting the work we do for our community.

Put a spring in your step and get along to one of our many activities. Stay well and stay connected and hope our paths cross soon as part of the HFV team.

Leonie Demos

Born with a gift

strength, love, belief & courage

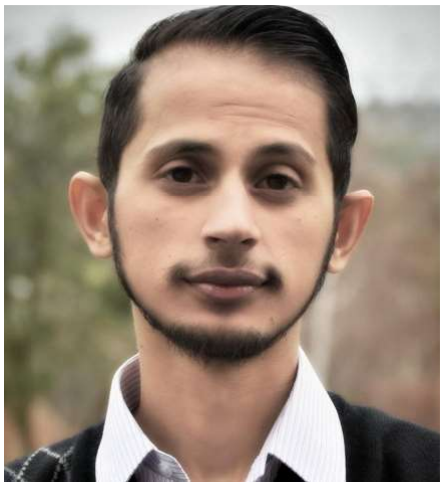
Sam, is a HFV member and attended our last Community Camp. So many of our community members were touched by Sam, his experiences growing up in a country with limited treatment options, the challenges he faced and his positive outlook on life.
Sam has kindly shared his story and powerful message with us.

Haemophilia is a blood clotting disease that everyone understands but how it can affect someone very few people understand. Me and my family are the best examples of it. I, Sam Hussain, belong to one the most remote inaccessible, autonomous tribal area of Orakzai agency in Pakistan called FATA (Federally Administered Tribal Area) and I was born in one of the prominent, most educated and politically influential family in the tribal area of Orakzai agency. That might sound fascinating but it came with a price to pay in my country and my family has paid a big price for having a prolonged conflict with extremist groups due to our progressive political stance such as staunch advocates of modern education, especially for girls. The extremists took our freedom and haemophilia took our happiness.

My elder brother, a haemophilia patient, was just a kid when he contracted HIV from contaminated blood products at one of the leading hospitals in the country. The doctors said he would die soon but my father is a warrior, he kept his son alive for years whilst in such circumstance where on one hand, the extremists never stopped attacking my father and on other my father spent every penny he could to save his child. People said to him why are you doing this, the kid cannot survive? But my father replied, “I just want to save a human life”. Unfortunately, my 18 year old brother died in his mother arms and the happiness of our family died with him that night.

Another child, Sam Hussain, was already born with a gift that nobody would ever want, also known as haemophilia A severe. My father left the country as he was faced with constant threats and his life was in danger. I was growing up with a vicious blood clotting disease without any treatment. But luckily, I was born in a progressive family. They explained to me at a very young age that if I didn't want pain then don't play. Playgrounds became monsters and books became my friends.

It doesn't matter where you live, pain will find you and I know the horror of haemophilia pain. I know how it feels when your joint is bleeding, but the nearest hospital is miles and miles away. You must walk through the fields in the pouring rain with the terrible pain in your joint and when your feet stick in the mud then you realise how lucky those people are



who have the privilege of home treatment. It is even more painful when sometimes your sick mother has to carry you on her shoulders for miles in the pouring rain to the hospital and that mother must donate her blood to you. Then you realise how lucky those born in first world countries really are.

What could be sadder, the fact that there was no treatment for haemophilia or that healthcare and funding practices, I felt, were questionable?

Due to the absence of medical treatment, my knee joint became targeted but because of the lack of knowledge around haemophilia doctors didn’t treat my joint suitably so it is now damaged. They put a back slab incorrectly to my joint that made me paralyzed for years. They gave me a wheelchair and said you can never walk again. When I tried to walk with crutches or stick my other joints started to bleed and when I asked for treatment they said to bear the pain.

Their numerous mistakes, no treatment and unprofessionalism

forced me to never go back to them, but it was already too late. Most of my vital joints were affected and some said I wouldn't walk again and others simply said you would never pursue your studies with such health. But my father trained me to fight and my mother taught me to love. My parents belief in me gave me such courage that I broke my stick and stood on my feet and dismissed the word 'failure'. Although most of my joints are damaged and haemophilia affects my life very badly I never give up. I never gave up on studies and I never gave up on walking again.

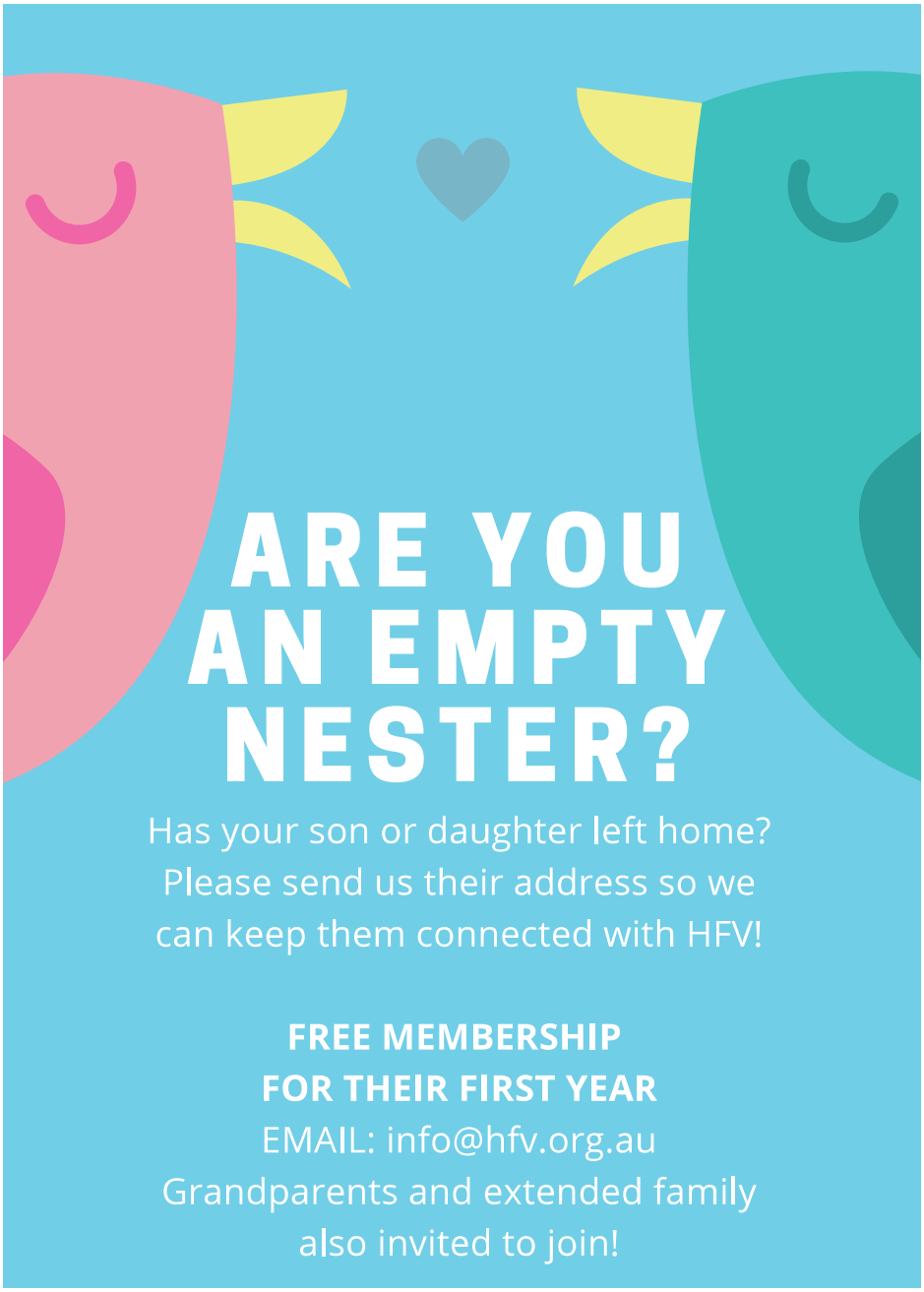
I came to Australia for higher education and this is where I first met healthy haemophiliac patients. This is when I first saw specialist doctors and nurses who knew how to treat haemophiliac patients and they were truly focused on the patients wellbeing.

I was very happy to see kids playing extreme sports which I never thought in my life a haemophilia patient could do. On my trip with Haemophilia Foundation Victoria, I saw kids doing rock climbing and other activities. I was both surprised and happy to see haemophilia patients enjoying their childhood - which I never did.

Sadly, there are still a few patients that fail to understand the importance of all these facilities and medical treatments the government is providing, and others that simply refused to listen to their doctors. They take it for granted. Oh! They don't understand what is like to live without medical treatment. In all the time I've been living in Australia, I never missed a single appointment at the haemophilia centre nor would I disobey my doctors or nurses instructions and I am very thankful to the Australian government, haemophilia centre, haemophilia foundation and my doctors and nurses, they are all trying hard to make my life better and support me in every way. Of course, they can't undo the damage that has already been done by haemophilia, but they are at least trying.
I religiously follow my doctors/ nurse instructions because I know the importance of treatment.
I just want to say a few words to those who take the gift of access to home treatment and world class medical professionals and treatment centres for granted.
"The things you take for granted, someone else is praying for."

Sam Hussain

We all have a story to tell. If you would like to share your story with our community, please email julia@hfv.org.au



Upskilling ourselves for a BRIGHTER future

We are well aware of the excellent level of healthcare we receive in Australia compared to many of our international bleeding disorders community and we continue to be very grateful for that.

Children and adults with bleeding disorders receive an exceptional level of care for their physical health but we all know the health dollar is stretched beyond its limits. We, as a foundation, are aware that most families do struggle with the impacts of haemophilia on their family life at one time of another. There are specific times on the haemophilia journey when we can expect these challenges to arise and sometimes they catch us off guard when we are more relaxed.
It is important to recognise that it is perfectly normal for family members to go through times when they feel they may not be able to cope with their child's condition and the burden of being 'the strong one' or the primary 'treating' parent can feel too much.

Over the years, I have come to understand that a chronic condition impacts all members of the family and at various times all members could benefit from support. Support can be through a number of different avenues but all with the same goal. In my mind I see a venn diagram with different areas overlapping. It comprises of your nuclear family, extended family, community, HFV, GP, allied health, and importantly the HTC team. All these different groups are part of our support network which we need to utilise for the best outcomes for our families. I see at camps the benefits of peer support that are provided to members (sharing treatment techniques, meditation benefits etc). The RCH team are of course crucial in the management of your child's bleeding disorder but they are limited with their access to mental health support and we need to be more pro-active at engaging with services that are available to us. Through our GP's we can access psychologists and other allied health professionals for ourselves as well as our children. If the provider accepts the medicare benefit as full payment for their service there will be no out-of-pocket costs (you would need to check prior to your appointment) otherwise there may be an out-of-pocket cost.

I am a great believer in the benefits of psychology. I see it as an upskilling opportunity that gives you the tools to manage the challenges you face in life – for life! If we have those skills we will be able to manage our mindset better and have a positive affect on our families. We know that children are directly influenced by us as parents, so if we are anxious they will often feed off that. If we can learn skills to manage our anxieties and general mental health better, our kids, partners, parents and friends will all benefit.

And let's not forget the GP. With the rise and convenience of drop-in bulk billing general practices many of us don't have a regular GP but if you don't have a regular GP it might be worth investing some time in finding someone you trust and have a good rapport with. To have an established relationship with a GP who knows your history can be quite reassuring…sure you may not always get to see them but they can become an important part of your support network.

Any GP will be able to connect you with a psychologist in your area that has experience with families with chronic conditions. So maybe it's time to reflect on our own mental wellbeing and take some steps towards upskilling ourselves for a brighter future.

Julia Broadbent

WE NEED YOUR HELP

Genomics in Practice

Over the next few months, two students will be joining Haemophilia Foundation Victoria as part of a placement for their graduate studies. Abbie and Ben are studying Master of Genetic Counselling at The University of Melbourne. Genetic counsellors are healthcare professionals who specialise in providing support and information about genetic health. This placement is intended to provide these students with the opportunity to further their understanding of community based healthcare, observe how a support and advocacy organisation functions, as well as to contribute their time and knowledge to assist HFV in meaningful ways.

Here is a message from Abbie and Ben...

We are very much looking forward to our placement at HFV. We feel that it will enhance our understanding of bleeding conditions and broaden our understanding of the role genetic health plays in the community.

We are very friendly and would be more than happy to provide more information about our studies and future careers to anyone. We hope we'll have an opportunity to speak with people in the community and would also like to thank HFV for accommodating us for our placement experience.

To make this a worthwhile experience for Ben and Abbie and for HFV we **NEED YOUR HELP!**

We are asking if any HFV families would be willing to connect with Ben and Abbie either in person of over the phone and share their journey with their bleeding disorder, the impact on diagnosis, any genetic counselling advice you may have received at the time and your general lived experiences of a bleeding disorder either as a person with a bleeding disorder or a parent/sibling.

This interaction will give Abbie and Ben an in depth understanding of the needs of those with a genetic condition and positively impact the outcomes of future clients of these students.

If you can spare a few minutes of your time, during the day or after hours, please contact HFV on 9555 7595 or email julia@hfv.org.au

** On page 12 is an article about genetic testing which highlights the crucial need for more genetic cousellors*

WFH CONGRESS 2018

The future looks BRIGHT for haemophilia

"The future looks bright for haemophilia," said Marijke van den Berg, MD, WFH Vice-president Medical, during her plenary lecture addressing past, present and future treatment developments in haemophilia.

Van den Berg first talked about the disparities in clotting factor concentrate uptake between developed and developing countries and stated that this must change. She then went on to describe how prophylaxis has brought great advances in the treatment of haemophilia, particularly severe cases in which an increase in trough level to two or three per cent results in a dramatic reduction in bleeding. "However, prophylactic treatment took a long time to be accepted," said van den Berg, "as did the recognition of the need to start prophylactic treatment early." "We are moving from a model of shortage to a model of plenty," said van den Berg, "but this explosion of new therapies makes treatment choice ever more important." Van den Berg described the need for treatment to be individualized according to age. "There is pharmacokinetic variability between products, so you must take this into account and dose accordingly."

It is also necessary to properly address the rebalancing of hemostasis. "Hemostasis is complex," she said, "and a low level of rebalancing can lead to a high risk of bleeding and thrombosis."

Van den Berg then discussed up-and-coming therapies, including the promising drugs emicizumab and fitusiran, both of which are in clinical development. The subcutaneous route of administration of these drugs will further facilitate treatment, and the recent explosion of new products for haemophilia will make it easier to individualise treatment and lower the disease burden.

Van den Berg talked about the exciting area of gene therapy, focusing on two recently published early-stage clinical trials of gene therapy in haemophilia A and B. These trials demonstrate that gene therapy brings about sustainable levels of factor VIII and factor IX. However, immune response to the adeno-associated viral vector remains an issue for the majority of patients and therefore alternatives are needed. Nonetheless, she believes that gene therapy will deliver a cure for haemophilia in the near future.

Van den Berg concluded by discussing the under diagnosis of people with haemophilia in developing countries. Low-dose prophylaxis for children will allow a new generation to survive to adulthood with limited arthropathy, consequently making them ideal candidates for gene therapy.

Melody Watson

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Mitch Semienchuk, Editor, Hemophilia World Online, wishes to thank Georghia Michael. PhD, for her contributions to this article.

WFH CONGRESS 2018

Gaining insight into the complexity of PAIN in patients with haemophilia

Nathalie Roussel, Assistant Professor at the Faculty of Medicine and Health Science, University of Antwerp, Belgium.

Roussel first talked about the prevalence of chronic pain in patients with haemophilia. Clinical studies have shown that 35% of people with haemophilia experience pain in five or more sites across the body. “This may indicate that something unusual is happening,” said Roussel, “as pain may be occurring in unexpected sites and not only in the affected joints.”

The assessment of pain in haemophilia is not well established and there is no consensus in pain management across 22 European haemophilia treatment centres surveyed. “To achieve consensus, there needs to be a better understanding of the pathophysiology of pain in haemophilia,” said Roussel.

Pain is due to tissue damage and also the perception of tissue damage; therefore, it can be both a sensory and an emotional experience. The physical effects of pain on muscles, movement, and activities of daily living can lead to a reduction in quality of life and feelings of frustration and helplessness.

The traditional view in haemophilia is that acute pain is linked to bleeding and chronic pain is linked to arthropathy. But studies have shown that patients and healthcare providers have difficulty distinguishing between acute and chronic pain, or between pain from bleeding and pain originating from a flare. “Pain is not reliable for diagnosis of bleeding or arthropathy and better diagnostic tools are needed,” said Roussel.

Roussel described the fundamentals of normal pain physiology and pain pathophysiology. “It is a mistake to link pain to damage,” she said. “A patient can still feel pain even if there is no damage upon imaging.” Roussel then elaborated on the concept of abnormal pain physiology, in particular pain hypersensitivity, and how it relates to haemophilia. People with haemophilia experience pain in expected sites (for example, joints), and also throughout the body, which suggests widespread pain hypersensitivity. In addition, people with haemophilia do not experience exercise-induced hypoalgesia, a phenomenon whereby exercise increases the pain threshold. This has led Roussel to question whether there are altered pain mechanisms in people with haemophilia, and whether these alterations are due to some type of cognitive-emotional sensitisation.

Efforts have been made to examine pain coping and pain catastrophizing in people with haemophilia and most published reviews recognize the importance of assessing psychosocial dimensions contributing to pain or acting as a barrier to its effective management. However, there is a lack of studies assessing the effect of stress, negative emotions, and catastrophising on pain sensitivity. Prospective pain investigations in different haemophilia types are also lacking.

Roussel stressed the importance of listening to the pain beliefs of people with haemophilia. She identified several tools, aside from the visual analogue scale, that are useful for assessing pain in haemophilia. Roussel also emphasized the need for appropriate treatment plans with targeted medication tailored to specific pain types, and consistency in the messages conveyed to people with haemophilia.

Melody Watson

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WFH CONGRESS 2018

GENE THERAPY — trail blazer to game changer

Great strides have been made over the previous three decades in the field of gene therapy, with several gene therapy products being approved by regulatory authorities for other genetic diseases and complex disorders. It is encouraging that sustained therapeutic factor VIII and IX expression levels are being achieved through gene therapy in people with severe haemophilia A or B. In front of a packed auditorium, Thierry VandenDriessche, MD, PhD, Director of the Department of Gene Therapy and Regenerative Medicine at the Free University of Brussels said, "Gene therapy for hemophilia holds great potential but issues remain."

The challenges that need to be overcome to maximize the benefit of gene therapy for people with haemophilia include interpatient variation in factor expression, response durability, safety considerations and risk of inhibitor development. Whether the procedure is applicable to children, people with inhibitors, and/or those with a preexisting immunity to the adeno-virus-associated viral vector (AAV), including people who already received gene therapy for haemophilia, still needs to be addressed.

Mechanisms to enhance factor IX expression are being explored for haemophilia B. Methods include adding a promoter, modifying the vector to remain undetected by the immune system, and incorporating the highly active Padua variant of factor IX.

"Gene therapy is more challenging for haemophilia A due to bottlenecks of factor VIII production at the transcriptional, translational and post-translational level," said VandenDriessche. However, a pivotal clinical trial using codon-optimized AAV serotype 5 recently published promising results in men with severe haemophilia A.

VandenDriessche ended the session on lentiviral vectors, a promising technology with several improvements over AAV. Current lentiviral vectors

have the potential to sustain factor expression long-term since these are liver-directed therapies and pre-existing immunity is not an issue.

Melody Watson

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WFH CONGRESS 2018

Patients INFORM health policy decisions

No one has better knowledge of life with chronic disease than those directly involved—the patients, their families and those who care for them at home. They have good and bad experiences of using treatments, hospitals and clinics, and importantly, are aware of their own preferences. “This unique patient perspective is now considered credible and legitimate. It can be used to inform health policy and decision making,” stated Karen Facey, an independent consultant at the Health Technology Assessment Agency in Scotland. “Doing so will allow policy makers to provide better value for their patients,” Facey added.

Clinical evidence will never tell us exactly how treatments work in every setting. In recent years there has been increasing recognition of the patient voice in evidence-based policy making. “How can patients improve the quality of evidence?” asked Fischer. Identifying priorities for research, making content more accessible and understood by all and ensuring that research outcomes align with public needs are all positive ways that patients can enhance evidence.

The Patient Reported Outcomes, Burdens and Experiences Study (PROBE) is a good example of how people with haemophilia have collected data on outcomes they deem relevant to their lives. The rarity of haemophilia makes it even more important for patients to take part in policy making and influence their disease area.

Barriers to patient participation in health policy development are still present. Technical demands and a lack of time and resources can make patient engagement difficult. Eliminating bias and maintaining scientific integrity can be challenging. Tools to evaluate the impact of patient participation are lacking. Nonetheless, patients will always have the power of lobbying and a strong media appeal to position them for policy making.

Robert Davies

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Mitch Semienchuk, Editor, Hemophilia World Online, wishes to thank Georghia Michael. PhD, for her contributions to this article.

Genetic Testing

& the possible impacts on mental health

Genetic testing continues to revolutionise healthcare, yet there are a range of secondary consequences with the potential to impact positively or negatively upon mental health.

These impacts can affect casual users of genetic testing services through to individuals and families that are dealing with a rare genetic condition.

Each instance comprises its own unique and important considerations. Unfortunately, the mental health impacts of genetic testing are often overlooked or not even considered, and in Australia the healthcare system struggles to provide adequate, accessible and appropriate support services.

As genetic testing becomes more embedded in our daily lives we need to carefully consider and prepare for the consequences moving forward.

Below, we explore some brief scenarios that touch on the different mental health impacts that can result from genetic testing.

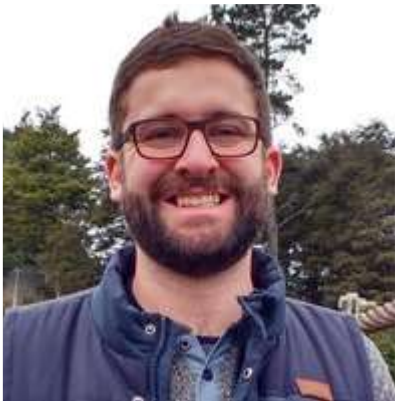
Direct-to-consumer testing*

Sharon is an office worker with no family history or association with a genetic condition. She has recently become interested in tracing her family tree and purchases an ancestry DNA test through a popular website. When Sharon receives her results, there is also information about her risk profile for developing Alzheimer's Disease. The report indicates that Sharon is at increased risk of developing Alzheimer's Disease and although the information presented is not highly technical, she is worried about the results and is not sure what the increased risk means for her or her family.

Even the scientific community is only beginning to understand exactly how the presence of specific gene variants might relate to a disease.

This makes it very difficult to understand and clearly explain the consequences of these complex results. Without a proper understanding or awareness of what the results mean, individuals can become worried and stressed about their results and often overestimate the negative health consequences.

This is exacerbated by the lack of regulation in Australia around the information and professional advice direct-to-consumer DNA testing companies are required to provide before or after a test. This is particularly concerning for at-risk populations, which in some cases have been shown to react poorly when receiving perceived 'negative' genetic health test results. One such population is those with a predisposition to depression. Even before the onset of symptoms, being told they are at an increased risk of developing depression can leave them feeling like they have no control over their condition and can even trigger the onset of symptoms. Conversely, genetic testing results can also have positive effects. For instance, individuals who have a family history of Alzheimer's Disease and receive results indicating they're at decreased risk of developing the disease may find comfort



and reassurance in the results.

Furthermore, results indicating an increased genetic predisposition to alcoholism may prompt some individuals to take affirmative action or initiate positive lifestyle changes to counter this.

Pregnancy testing

Simone and Greg were expecting a child and based on the advice of their obstetrician get non-invasive prenatal testing conducted. The results indicate that their child is very likely to have Down Syndrome. After further testing to confirm the diagnosis and multiple consultations with a genetic counsellor they make the decision to terminate their pregnancy. Simone and Greg are confident that they made the right decision and feel that they were provided with adequate support and advice. However, despite their informed decision they're still struggling to deal with the grief they feel months afterwards.

One of the major benefits of genetic testing is that it can empower individuals to make informed decisions about their health. In the above scenario, adequate support and advice was provided so that an informed decision could be made. However, the choice to terminate a pregnancy is already

a difficult decision and is certainly not made any easier just because genetic data and informed advice underpinned the final choice. In this case, it would be extremely difficult to reconcile the loss of a pregnancy whilst also dealing with the societal stigma associated with these decisions. This can result in feelings of blame, guilt and frustration which aggravate rather than help the situation and can also cause anxiety about future pregnancies.

Rare genetic conditions

Latisha is a 34-year old woman and has lived with an undiagnosed genetic and debilitating health condition her whole life. After two misdiagnoses growing up, doctors identified the genetic mutation responsible for her condition when she was 28. Initially, this provided Latisha with a great sense of relief that she could finally put a name to her condition. As a result, she joined an online community of people with similar mutations and was taken more seriously when talking to people about her condition. However, due to its rare nature there is little to no awareness of her condition among healthcare professionals and a lack of feasible treatment options.

The pathway to diagnosis for many with rare genetic conditions is long and challenging, producing feelings of anxiety, stress, emotional exhaustion and frustration. When combined with the burden of physical symptoms associated with many conditions, there can be significant negative impacts on mental health. It is also well documented that poor mental health, particularly over long periods, can have detrimental effects on physical health as well.

With advances in genomic testing there has been a considerable rise in the number of rare genetic conditions identified and diagnosed. This can provide a great sense of relief for patients and their carers/family, who over many trying years have had to deal with little to no useful information about their condition and a healthcare system where they often fall through the cracks. Putting a name to a condition can also help release blame or guilt from individuals/families and allows those affected to seek out and form support networks with people who have a similar condition. Although a diagnosis provides some benefits, there can also be a range of associated negative outcomes.

Despite a result, the care or availability of treatment options for a rare disease hardly ever changes, which after years of build-up and hope seeking an answer can lead to further despair, anger or depression. Moreover, due to the rare nature of these conditions there is often poor awareness among healthcare professionals. This results in a lack of information and co-ordinated support for these individuals resulting in feelings of isolation, disappointment and exasperation.

Adding to this, approximately 75% of rare diseases affect children (80% of which are from genetic causes), leaving a large network of carers, family and friends also confronting a mental health burden.

Understandably, this can result in similar feelings of frustration, stress, guilt and denial. This not only affects individuals but adds undue pressure on family relationships.

More needs to be done

Despite the obvious benefits of genetic testing, there are a range of secondary mental health factors that need to be considered to ensure all individuals are provided with the right information and adequate support.

At the moment, the healthcare system in Australia struggles to do this, with the availability and accessibility of appropriate services a major issue. As genetic and genomic testing is used in new and novel ways, this deficiency will be exacerbated by a new wave of emerging mental health issues on top of those we already face.

With increasing access to genetic information by patients, healthcare professionals and the general public, there needs to be a move towards targeted education around genetic testing. For instance, many GPs have little training or knowledge regarding the results and counselling associated with genetic testing, and GP appointments rarely have enough time for adequate discussion, leaving many people with no avenues for support. This highlights a need to increase investment in genetic health services (such as genetic counsellors) to meet demand, but also more widely increase awareness and knowledge of genetic testing. Additionally, stricter regulations should be placed on direct-to-consumer companies to enforce a stronger duty of care towards their clients to avoid a reliance on the healthcare system to deal with the aftermath.

Building on this, there are an increasing number of situations that the healthcare system has only recently started to encounter. A perfect example of this is the rapidly increasing availability of pre-natal testing and the subsequent termination of pregnancies.

The widespread capacity for parents to make these choices is relatively new in the healthcare setting and as a result there is a need for a boost in targeted mental health support services for these individuals.

Finally, it is important to continuously consider and raise awareness of the mental health impacts of genetic testing on individuals or families that are affected by

a genetic condition. Our current healthcare system often leaves these people isolated and with few options to seek help.

We still have a long way to go in appropriately addressing, supporting and delivering the right services for those that bear this burden.

If you're worried about your mental health please contact your healthcare provider. Better Health Victoria also provides access to a range of mental health support services (https://www.betterhealth.vic.gov.au/servicesandsupport/mental-health-services).

For more information about direct-to-consumer genetic testing, non-invasive prenatal testing (NIPT) and to explore these issues further have a look at the Centre of Genetic Education (http://www.genetics.edu.au) or the GSNV website.

For further information and support about rare genetic conditions and the associated mental health impacts have a look at Syndromes Without A Name Australia (https://swanaus.org.au/), read the Rare Disease UK report on the mental health impact of living with a rare condition (https://www.rarediseases.org.uk/our-work/living-with-a-rare-condition-the-effect-on-mental-health-2018/) and have a look at Carers Victoria website (http://www.carersvictoria.org.au/).

**Scenario 1 is based on an article published in the following case study: Mason, Paul H. "Personal genomic testing, genetic inheritance, and uncertainty." Journal of bioethical inquiry 14.4 (2017): 583-584.*

Christopher Richards PhD

Program Manager, Clinical Infectious Diseases Research,
Murdoch Children's Research Institute
Department of Paediatrics,
The University of Melbourne

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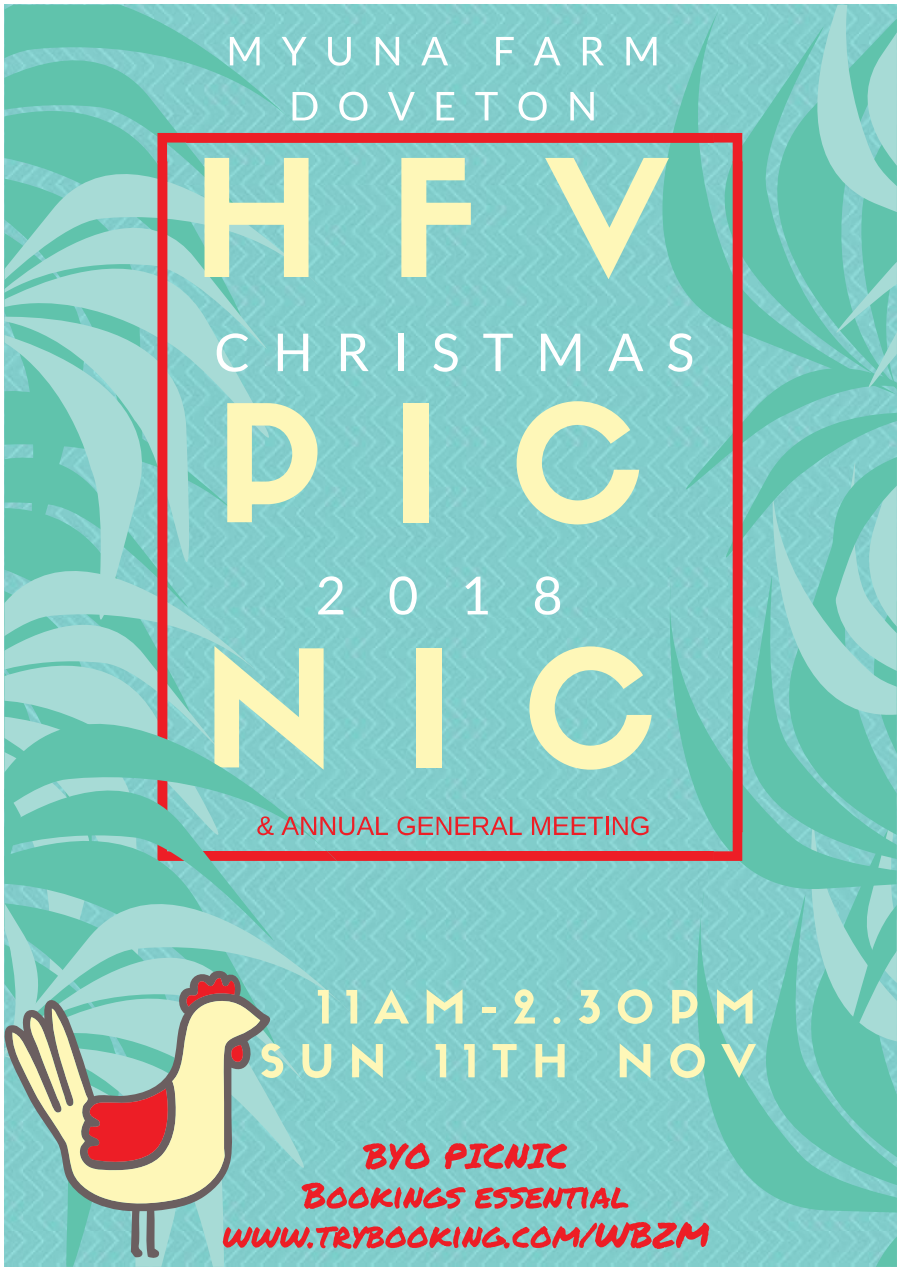


Help raise awareness of people living with bleeding disorders in Australia by participating in an event for BLEEDING DISORDERS AWARENESS WEEK!

THERE ARE MANY WAYS YOU CAN GET INVOLVED IN BLEEDING DISORDERS AWARENESS WEEK

- *Set up an information stand in your workplace, school, hospital or library*
- *Participate in Red Cake Day*
- *Hand out promotional items in your local area or school*
- *Items can be ordered OR can be downloaded*
- *Ask your class or school to participate in the colour-in competition and complete the word find (can be downloaded)*
- *Organise a casual clothes day at your workplace or school*
- *Organise a luncheon or sausage sizzle*
- *Set up a fundraising page – this way people who cannot attend your event can donate as well - https://nfp.everydayhero.com/au/haemophilia-foundation-australia*

Contact HFA for promotional items or go to the HFA website: https://www.haemophilia.org.au/get-involved/events/bleeding-disorders-awareness-week

AIDS 2018

22nd International AIDS Conference
Amsterdam, Netherlands
23-27 July 2018
Breaking Barriers Building Bridges

Professor Sharon Lewin's insights from the 2018 International Aids Conference

Doherty Institute

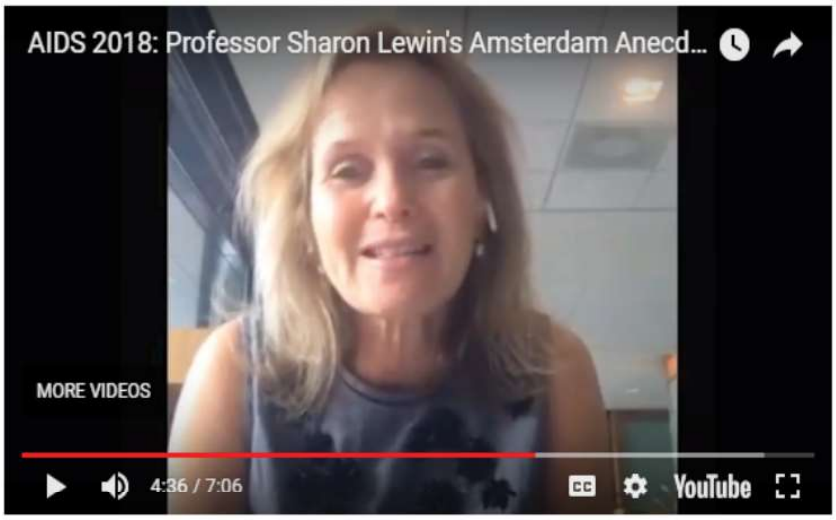
We asked the Doherty Institute's contingent who headed to Amsterdam for the 22nd International AIDS Conference to share their insights. On the final day of AIDS 2018, we spoke to Doherty Institute Director, Professor Sharon Lewin via Skype about her key takeaways from the conference.

From a research perspective, she spoke about the move to two HIV drugs when traditionally treatment required three, and summarised two studies that were presented at the conference on HIV cure research, unfortunately both had disappointing results.

What makes these International AIDS Conferences unique is the emphasis on community, and AIDS 2018 was no exception with some very powerful talks by those living with HIV.

And lastly, Professor Lewin proudly highlights the talented bunch of researchers at AIDS 2018 from the Doherty Institute.

Reproduced with permission from Doherty Institute



It is well worth watching Professor Lewin's summary of the conference, the details are below.

https://www.doherty.edu.au/news-events/news/aids-2018-professor-sharon-lewins-amsterdam-anecdote

Here are some of Professor Lewin's comments from the video regarding the conference.

"Now is not the time to pull out funding for HIV. There were some pretty sobering statistics about contributions of international funders to the HIV response and how that has declined…if anything this is a time that we need more investment."

"Discussions around new treatments – Traditionally treatments always used 3 drugs but over the last few years there have been more studies showing that 2 drugs might be possible. It is a big deal for the whole world because it reduces cost and reduces the risk of toxicity."

"Cure Research – the results of 2 big clinical trials were disappointing"

"We had some very powerful talks from community members that have participated in studies….a community perspective has been really valuable for us as researchers…it allows researchers to get a broader perspective on what's going on in the broader HIV response, what it means to so many people living with HIV and I hope it is very inspiring about why their work is so important."

ABOUT HFV LIVE WELL FUNDING

GRANTS TO BENEFIT OUR COMMUNITY

PURPOSE

Live Well Grants are available to members of Haemophilia Foundation Victoria Inc. (HFV) that have a bleeding disorder or an immediate family member impacted as a result.

The purpose for the Live Well Grant is to provide an opportunity to assist with an expense that would otherwise not be possible without assistance from HFV under this program.

AMOUNT

Although there is no absolute limit, as a guide, previously approved Live Well Grants have generally been for amounts of between $50 and $500.

HOW TO APPLY

Individual members must complete the application form:
www.hfv.org.au/HFVIC/media/Resources/Live-Well-fillable-application-2018.pdf

Please attach supporting documentation including a letter of support from your Haemophilia Treatment Centre where appropriate.

Completed Applications should be returned to: HFV, C/- Executive Assistant, 13 Keith St, Hampton East, or email: andrea@hfv.org.au or fax: 03 9555 7375. If you are unsure whether you have a suitable expense to apply for, chat with Andrea as she will be able to give you an indication of whether it would be a suitable application.

CONFIDENTIALITY

The committee will always make decisions under rules of confidentiality at all times.

When reviewing each application the potential benefit to the applicant member with regard to improving a health outcome or enjoyment of life given other health issues caused by the bleeding disorder will be considered.

Please note all applications are deidentified to protect applicant privacy. Only the Executive Assistant will know the name of the applicant.

From the HFA and National Blood Authority MyABDR teams

With privacy and cyber security in the news at the moment, it is a good time to have a reminder of the security and information protection arrangements in relation to MyABDR.

Firstly, there is no link between ABDR and My Health Record, which are completely separate systems. MyABDR links only to the Australian Bleeding Disorders Registry (ABDR), the system used by Haemophilia Treatment Centres (HTCs) for the clinical management of their patients.

How is my health data protected with MyABDR?

MyABDR and the ABDR have been developed to have an extremely high level of data protection. They have one of the highest levels of security available in Australia and are not connected to any other database. Data protection includes:

- highly secure user passwords, and a PIN for the MyABDR app
- encryption for data transfer between MyABDR and the ABDR
- 3 levels of firewall for the ABDR and 24 hr security monitoring
- very limited direct access to the ABDR and only to authorised users.

Who can access my personal information?

Only authorised staff from your HTC, the National Blood Authority (NBA) and the Australian Haemophilia Centre Directors' Organisation (AHCDO) can directly access your data, and only to perform specific roles.

If you have consented, your HTC team may send some of your personal health information and treatment plan from the ABDR to other health services involved in your care, if relevant - for example, if you are having surgery and your surgeon and haematologist are liaising about treatment to prevent bleeding. This process is also very important if you need emergency treatment for a bleed and go to a different hospital to your usual HTC hospital.

Any concerns?

If you have any concerns about MyABDR and ABDR data, don't hesitate to speak to your HTC team, HFA (T: 1800 807 173 or hfaust@haemophilia.org.au) or the NBA MyABDR Support team (T: 13 000 25663 or myabdr@blood.gov.au).

There are great benefits for your health and wellbeing to recording with MyABDR and it is important to us that you feel confident using it!

For more details about how your MyABDR and ABDR data is protected, visit the MyABDR privacy and security article on the HFA website - https://tinyurl.com/my-abdr-privacy

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APPLICATIONS EXTENDED UNTIL 21ST SEPTEMBER

DON'T MISS OUT!

Have you ever wanted to be daring and take on a challenge?
Or do something that's a bit scary?
Or try something new?

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 assists people living with bleeding disorders take the first step towards achieving their goals.

www.haemophilia.org.au/get-involved/awards/go-for-it-grants

Our staff and committee have recently attended our second group of regional visits to the North East and Central regions of Victoria. We offered a number of locations and we had a good response, with a couple of visits areas combining to provide the best outcomes for peer support.

Andrea and I headed to Shepparton and met with a number of families, mostly new to HFV. For us as staff it was a real pleasure to be there and hear the stories they shared. It was such a mixed of people with different bleeding disorders, experiences and challenges.

There was a family with vWD who shared their experiences and we are very keen to get involved and increase awareness of the condition within the community, amongst medical professionals and advocate for those with the condition.

A young farmer had recently learnt that he had mild haemophilia. In retrospect this new diagnosis made sense as he had had a number of 'episodes' throughout his life. Their concerns as a rurally based family with young girls was having an emergency plan in place as they had intermittent mobile reception and the potential difficulty for emergency services to locate their property.

A gentleman with a platelet disorder attended with his wife. They shared their experiences and challenges and all were keen to hear about everyone else's journeys.

We also had the benefit of a family already connected with HFV attend. They added another dimension to the visit sharing the benefits of HFV and the experiences of a family history of haemophilia, the challenges they have faced and continue to face and of course their successes and positive outlook on life.

As staff, we couldn't have asked for a better visit in terms of engagement and it really highlighted how important it is for us to get out into our community and connect people together. From an organisational perspective we learn so much from these visits and the people we meet. We hear about what the challenges can be for regionally based members and we take that information back to our committee and as appropriate our HTC's to look at ways we can help improve the health outcomes for our community.

Our president, Leonie, and treasurer Zev, had the pleasure of attending a visit to Ballarat. This was a smaller group but equally beneficial to all who attended. This visit comprised of families affected by haemophilia and von Willebrands. We are glad to have been able to connect with more people with vWD. As you may know we do have a committee member with vWD but have until recently felt that we didn't have a good representation or understanding of vWD to be able to support members. Over the last couple of years we feel that we are connecting with more and more people with vWD and are learning through their shared experiences which is so valuable to us as an organisation. We are looking to establish a vWD peer group in the near future so please let us know if you would like to be involved!

Thank you to all of you that attended these visits. Your participation was so beneficial to us and your peers and enables us to ***connect, support and empower*** our community.

We are very much looking forward to meeting more members at our next regional visit later this month to the Western regions of Victoria.

ASK US...

Q & A's with Alex & Jane

QUESTIONS FOR THE ALFRED HTC TEAM

As a person with a bleeding disorder am I able to apply to the NDIS?

"It's complicated" is my personal experience with it as a social worker and person with permanent disability.

It's complicated is an understatement as there's so much bureaucracy and untrained people working in this area of doing assessment no one is getting the same outcomes.

Be patient as you work your way through the paperwork, have clear reason(s) as why you are applying, what your goals are and what you need.

The best advice for those who think they wish to apply is to go to these links:

https://www.ndis.gov.au/people-disability.html

https://www.ndis.gov.au/people-with-disability/access-requirements/completing-your-access-request-form

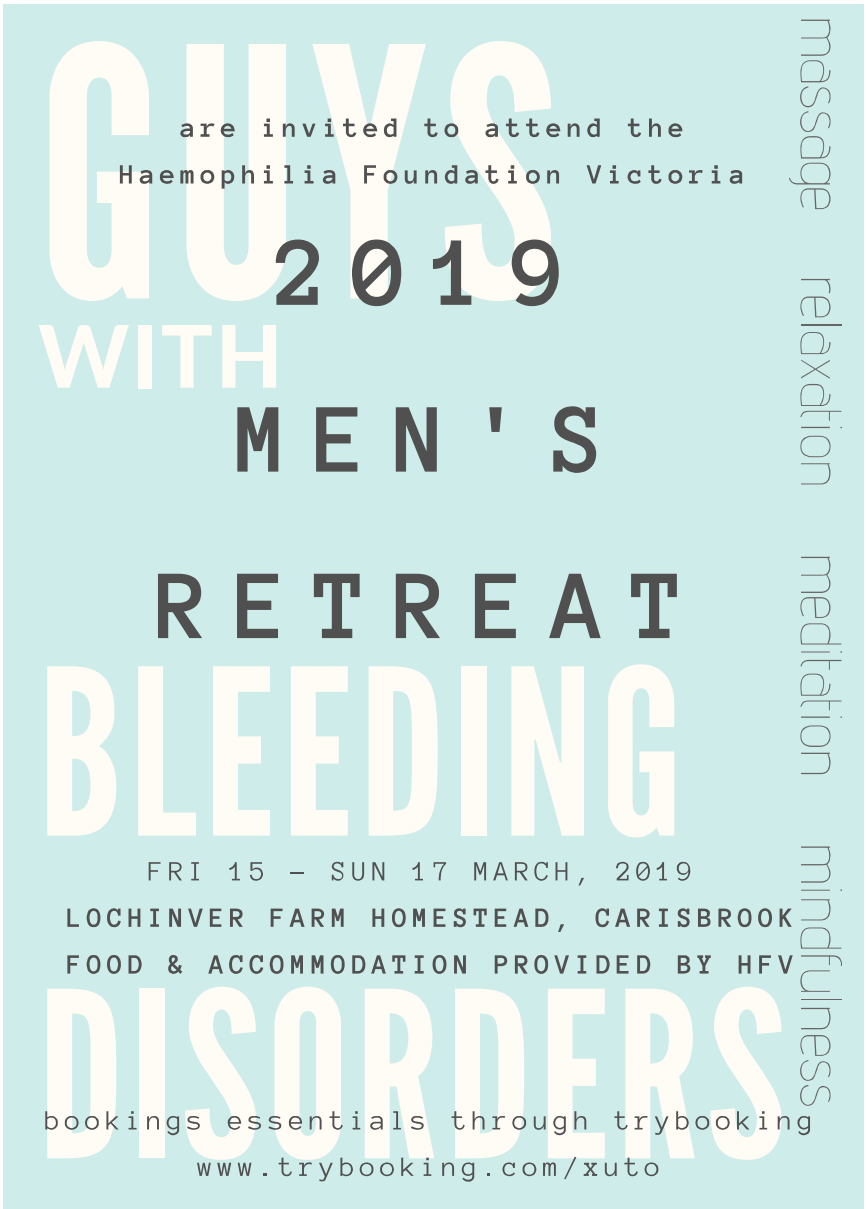
Once the applicant has put in their request form they can ask for the NDIS to call them to discuss it further

If you are a viewer of the Q&A program on ABC, if you can access the 25/6/18 episode it may give you some insight into the experiences of others with their application to the NDIS.

Is the Telehealth system available to me from the HTC

The HTC team has investigated the use of the Telehealth system for hard to reach and rural patients.
We have yet to determine under what circumstances and guidelines is it appropriate for the HTC to utilise it to work with patients. It is a matter for further discussion.

Please send your questions for the next edition to Jane, Alex or to the HFV team by the 1st November. You can remain anonymous, use an alias or just your first name.
J.Portnoy@alfred.org.au,
A.Coombs@alfred.org.au
or julia@hfv.org.au



HFV Noticeboard

To post a message on our noticeboard, please email our HFV office at info@hfv.org.au or call 9555 7595

GRANDPARENTS EVENT 2018

CHANGE OF DATE TO SUNDAY 30th SEPTEMBER

This year, we are hoping that many of our HFV grandparents will come along to support our Walk Around Albert Park on Sunday 30th September 2018. This way, our grandparents not only get to spend time with other grandparents but also some quality time with their grandchildren too!

If you can't manage a walk around the lake, no problem, you can join other HFV 'non-walkers' at our meeting point.

There will be a sausage sizzle after the walk and a few local coffee shops close by so if you feel like heading out for a coffee with other grandparents after the walk this will be a great opportunity!

We would like to thank Marie Ramage and Jackie Touzeau for their involvement in running the Grandparent's Group for the last few years. It has been wonderful to have both Jackie and Marie on the HFV team. We are now looking for a new convenor/s. If you are interested, please speak to Andrea on 9555 7595. The role involves organising the annual grandparents get together. Many thanks.

HFV Ladies Day 2018

YOUTH EVENT

ESCAPE ROOM CHALLENGE

We were delighted to have a great turn out for our last Youth Event. Our Youth were put to the test but managed to escape from the rooms in time to enjoy a bite to eat and a great opportunity to catch up!

HFV BABY & TODDLER GROUP

Establishing a baby and toddler group for families with babies and young children with bleeding disorders

If you are keen to connect with other families with affected by bleeding disorders please email us your details and we can connect you directly.

We already have families keen to connect with others so if you are interested please contact Julia Broadbent at HFV on 9555 7595 or email julia@hfv.org.au

DIARY *DATES*

SEPTEMBER

8 Warrnambool Regional Visit

9 Horsham Regional Visit

9 Ararat Regional Visit

30 Walk for Bleeding Disorders

OCTOBER

7-13 Bleeding Disorders Awareness Week

NOVEMBER

11 HFV Christmas Picnic & AGM

MARCH 2019

15-17 Men's Retreat

APRIL 2019

5-7 HFV Community Camp

HAEMOPHILIA TREATMENT CENTRES

Henry Ekert Haemophilia Treatment Centre

Royal Children's Hospital
Flemington Road, Parkville
P. (03) 9345 5099 E. he.htc@rch.org.au

Dr Chris Barnes | Director Henry Ekert HTC
Janine Furmedge | Clinical Nurse Consultant
Julia Ekert | Office Data & Product Manager
Nicola Hamilton | Physiotherapist
Wade Wright | Social Worker

Ronald Sawers Haemophilia Centre

The Alfred
1st Floor, Sth Block -William Buckland Centre
Commercial Road, Melbourne 3004
P. (03) 9076 2178 E. (03) haemophilia@alfred.org.au

Dr Huyen Tran | Director of RSHC
Penny McCarthy | Clinical Nurse Consultant
Megan Walsh | Clinical Nurse Consultant
Susan Findlay | Secretary
Alex Coombs | Haemophilia Social Worker
Jane Portnoy | Hepatitis C & Haemophilia Social Worker
Abi Polus | Physiotherapist
Frankie Mullen | Physiotherapist
Diana Harte | Psychologist
Debra Belleli | Data Manager

2018-2019 HFV SUBSCRIPTION RENEWALS

HFV SUBSCRIPTION RENEWALS ARE NOW OVERDUE

Your subscription helps to strengthen the voice of the Bleeding Disorder Community. Thank you for your support.

Forms are available through our website as a fillable form that can be emailed to info@hfv.org.au
www.hfv.org.au/get-involved/memberships

HFV MEMBER SERVICES & PEER SUPPORT

Membership Annual Fees:
Standard family membership
$33.00
Concession member
$16.50
Allied Member
$16.50
Youth/Student
Free - for PWDB aged 18-21 or up to 25 years if studying
Organisational member
$55.00
* No joining fee for new members joining at the Standard Family Membership rate.

Ambulance Subscription Subsidy:
To ensure all people with haemophilia have ambulance cover, the Foundation will subsidise Ambulance Subscription Fees to the value of half the family fee.
(Members who have Health Care Cards which also cover their dependants, are automatically entitled to free Ambulance transport for themselves and their families.)

To obtain an Ambulance Subsidy:
Forward subscription receipt (or a copy) to the HFV Office with your contact details. Subsidies will be paid on a reimbursement basis.

Other Subsidies:
- MedicAlerts: A subsidy of 50% of the first purchase price of any MedicAlert, (with the subsidy payment being up to $30 in value and not including the annual fee) is now available. To obtain a subsidy, forward a cover letter and receipt to the HFV Office.

Live Well Funding:
Live Well Funding is open to all current financial members who can apply for funding for any activity or one off item that will assist in the management of their conditions such as mobility support aids, meditation, massage, swimming lessons etc.

Care and Counselling:
This is available through your treatment centre.

Magazine:
Your quarterly magazine offers information and details of upcoming events.

Website - www.hfv.org.au

The HFV Office:
The office is usually open from 8.30 am to 4.30 pm Monday to Thursday. If you plan to come to the office, we suggest you ring ahead to check if the office is staffed.

We are located at 13 Keith Street, Hampton East, Victoria, 3188.

Phone: (03) 9555 7595 Fax: (03) 9555 7375
Website: www.hfv.org.au Email: info@hfv.org.au

MEN'S GROUP

Our current group meet for their Annual Men's Retreat – a much needed weekend away that included massages, relaxation and meditation. In 2017 twelve members attended the retreat, including a number of first timers, all promising to return after making powerful connections with their peers. There are also opportunities to meet for brunch and lunch during the year.

WOMEN'S GROUP

The group meets once a year over lunch and usually get to enjoy an event with a twist. Our most recent event our ladies spent a morning enjoying tango dancing and enjoyed a beautiful tapas lunch together. Many of our ladies also attend our community camp and benefit from the Secret Womens Business peer support session.

The Womens Group have previously learnt circus skills, African drumming, attended relaxing massages, high tea on the Yarra and lunch on the Tram Restaurant…to name but a few.

YOUTH GROUP

The Youth Group aim to meet up a few times a year usually based around an activity like laser skirmish or escape room challenges and then head out for lunch.

We also have our actively involved Youth Leaders who are present at our family camp. They attend specific youth leadership training led by our formally trained youth leaders – an initiative developed by the leaders themselves.

GRANDPARENTS GROUP

The Grandparents and Friends lunch is a great opportunity to connect with all the grandparents and share the company, stories and experiences so please come along and enjoy the day. Lunch is provided by HFV and the company is always good!

The initial impact of haemophilia can be a traumatic and stressful time in our lives and interaction with other grandparents can be a reassuring and rewarding experience.

BOYS GROUP

Our Boys Toys Day Out is a wonderful opportunity for our boys to get together with other boys with haemophilia or related bleeding disorders and to spend the day with their dad or another significant male in their lives…grandfathers, uncles or family friend.
Previously our Boys Toys events have included fishing trips, Go-Karting, Laser Tag and Tree Top Adventures.

CHANGE OF DATE

Sunday 30th September 2018

(due to Albert Park availability)

HAEMOPHILIA FOUNDATION VICTORIA

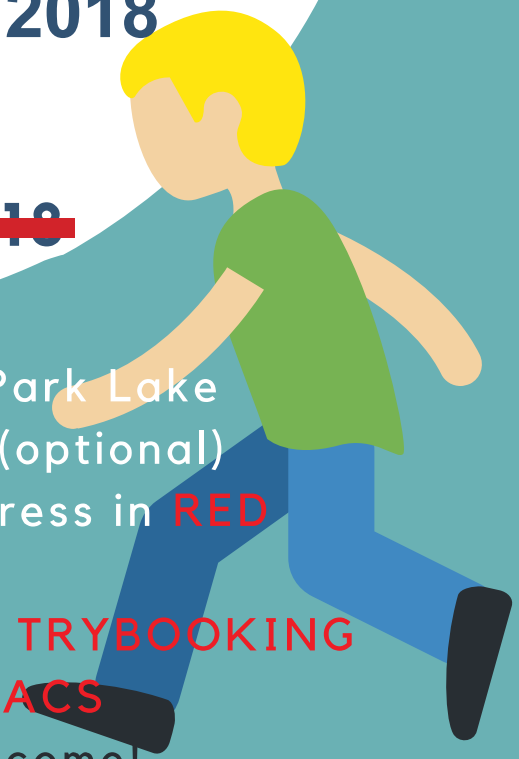
PRESENTS

Annual Walk for BLEEDING DISORDERS

SEPTEMBER 30th, 2018

SUNDAY

~~**OCTOBER 7, 2018**~~



Join us at 10.30am | Albert Park Lake
One lap of Albert Park Lake (optional)
followed by a sausage sizzle. Dress in RED

BOOKINGS ESSENTIAL THROUGH TRYBOOKING
www.trybooking.com/WACS

All family and friends welcome!