

THE MISSING FACTOR

The real impact
of living with
INHIBITORS

BLOOD, SWEAT
& GEARS

Inspiration for our
kids & community

connect • support • empower



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15-17 Men's Retreat

APRIL

5-7 HFV Community Camp

17 World Haemophilia Day

JUNE

2 Geelong Regional Visit

13 Cranbourne Outer Metro Visit

JULY

25 Epping Outer Regional Visit

27 Ladies Day (date TBC)

OCT

10-12 National Conference (Sydney)

13-19 Bleeding Disorders Awareness
Week

20 Walk for Bleeding Disorders
(date TBC)

NOV

17 AGM & Christmas Picnic at
Melbourne Zoo



Haemophilia Foundation Victoria
acknowledges the support of the
Victorian Government.



PRESIDENT'S REPORT



A very happy new year to everyone and welcome to HFV for 2019. It has been great to recharge our batteries, but it is now full steam ahead as we plan for the upcoming year.

Firstly, we are excited to welcome 2 new members to our committee. Cara Gannon and Adam Zulawnik have just joined our committee. Both will bring new perspectives as their involvement with bleeding disorders is very different. The committee is currently doing a self-audit to check in on our strengths and weaknesses with the hope to do some training to address any gaps in our work. As you know the committee take their responsibility to good governance as a critical part of our work and therefore, we are always looking for ways to improve our work to support you as our members better.

2019 is shaping into another busy and hopefully successful year. Community camp is nearly here so get your registrations in. This year we are doing "Survival" – something many in our community are very apt at doing in life but this will be a fun theme with challenges and a lot of laughs so please join us. Doesn't matter what your age, ability or story is we invite you to be a part of the HFV family at camp and meet a lot of other beautiful people that also share some of your life experiences. If you are not sure what to expect check out the youtube:

youtu.be/oiFj9aZMWLk

The Men's Retreat is soon upon

us as well. This is a very successful weekend of bonding and mateship with men across our community. Other states are trying to find out more about our peer support weekends as the word has travelled that these are important events on the HFV calendar to support. If you think you may be interested in these or any events, please call the office as we are always up for a chat and to answer any queries.

These are exciting times for those living with bleeding disorders globally. Many within our community are participating in various trials which are closely monitored and supported by our HTC. If you have any questions about possible treatments, we strongly encourage you to discuss with your health team. Trials are complex and the hospitals have many hoops to jump through as safety is paramount. We know there is often much discussion about opportunities but the safest place to gather your information regarding any treatment options is your health care team. We at HFV are here to support in any way we can and empower your advocacy so if you are not sure again, we encourage you to give us a call.

Speaking of advances in treatments please consider attending the National Conference in October in Sydney. HFA provide a fantastic program that brings medical and consumers together to hear the latest developments in treatments and pain therapies as well as many other related discussions. More to come in later editions but just to flag this for

your diary planning and maybe think about a few days R&R on either side of the jam-packed weekend.

Our committee and staff are always discussing best ways to offer you connections, support and the advocacy to empower you for better health outcomes. Our new Strategic Plan has been finalised and the committee will be checking in with our goals regularly to make sure we deliver on what we promise. We have started a new sub-committee for 'Membership Engagement' We need to develop a strategy around how to best measure what we do and match it to what you need. Erika and the team are developing a member's survey to start this process. Please take time to complete this survey when it comes to you. Evaluating our programs is critical to the quality of the work we do as well as the continued funding so never hesitate to provide us feedback, complete surveys and let us know your thoughts in any way you are comfortable. If you are interested in joining this sub committee please just call our office. Members can be co-opted into subcommittees and we would love to hear from you especially if you have specific skills around engagement and marketing.

One last piece of exciting news is I am about to go on an amazing adventure. As the HFV representative at HFA council I will be travelling to Myanmar next week

with a representative from HFNSW. Australia and Myanmar are exploring the possibility of twinning between countries and I will be visiting for a short visit to assess and discuss what may be possible. I look forward to the opportunity and will bring back to our community the stories of bravery and resilience that I am sure will be apparent. As a developed country with medical needs at our finger tips I am so privileged to meet others in an emerging country that have just celebrated opening their first treatment centre. I look forward to the opportunity and to sharing my learnings back to HFA and HFV to enrich our community and to consider ways to support our shared community in Myanmar.

Enjoy the last days of extended sunshine and the welcoming of the autumn leaves. Please take time to enjoy the magazine and think about what events you can support with HFV. Stay well and stay in touch and hope to see you at one of our events in the next few months.

Leonie Demos
HFV President

relaxation meditation mindfulness

GUYS

are invited to attend the

Haemophilia Foundation Victoria

2019

WITH

MEN'S

RETREAT

BLEEDING

DISORDERS

FRI 15 - SUN 17 MARCH, 2019

LOCHINVER FARM HOMESTEAD, CARISBROOK

FOOD & ACCOMMODATION PROVIDED BY HFV

bookings essentials through trybooking

www.trybooking.com/xuto

There are still a few places available for our wonderful Mens Weekend Away!

If you are in need of a relaxing weekend away and a chance to recharge the batteries with a great bunch of guys then give us a call or book directly through Try Booking. www.trybooking.com/xuto

If you would like to chat with Zev, our HFV member who convenes the weekend just give him a call on 0419 552 695. We always like to see new faces so if you're in need of some time out we'd love to see you. You can come for a day or one night if you just want to get a feel for it!

BOOKINGS STILL OPEN!
13 guys already booked

FATIGUE...

what a yawn!

We all get tired. We overdo things and feel physically exhausted. It happens to us all.

But something that most of us living with a chronic, painful condition experience, and that can be hard for others to really understand, is fatigue.



Fatigue is that almost overwhelming physical and mental tiredness. It may be caused by lack of sleep, your medications, depression, your actual condition (e.g. rheumatoid arthritis) or just the very fact of living with persistent pain.

Fatigue can make everyday activities seem too hard, and can get in the way of you doing the things you enjoy. The good news is there are many things you can do to manage fatigue.

They include:

- **Exercise and being active** – while this may sound like the last thing you should do when you're feeling fatigued, exercise can boost your energy levels, help you sleep better, improve your mood, and it can help you manage your pain. If you're starting an exercise program, start slowly, listen to your body and seek advice from qualified professionals.
- **Frankie says relax** – listening to music, reading a book,

taking a warm bubble bath, meditating, deep breathing, visualisation, gardening, going for a walk...they're just some of the ways you can relax. By using relaxation techniques, you can reduce stress and anxiety (which can make you feel fatigued), and feel more energised.

- **Eating a well-balanced diet** – this gives your body the energy and nutrients it needs to work properly, helps you maintain a healthy weight, protects you against other health conditions and is vital for a healthy immune system. Make sure you drink enough water, and try and limit the amount of caffeine and alcohol you consume.
- **Pace yourself.** It's an easy trap to fall into. On the days you feel great you do as much as possible – you push on and on and overdo it. Other days you avoid doing things because fatigue has sapped away all of your energy. By pacing yourself you can do

the things you want to do by finding the right balance between rest and activity. Some tips for pacing yourself: plan your day, prioritise your activities (not everything is super important or has to be done immediately), break your jobs into smaller tasks, alternate physical jobs with less active ones, and ask for help if you need it.

- **Get a good night's sleep** – it makes such a difference when you live with pain and fatigue. It can sometimes be difficult to achieve, but there are many things you can do to sleep well, that will decrease your fatigue and make you feel human again.
- **Talk with your doctor about your meds** – sometimes fatigue can be caused by medications you're taking to manage another health condition. If you think your medications are causing your fatigue, talk with your doctor about alternatives that may be available.

So that's fatigue...it can be difficult to live with, but there are ways you can learn to manage it.

Lisa Bywaters
Musculoskeletal Australia

www.msk.org.au

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INHIBITORS

The REAL impact of living with inhibitors

I felt before I had children that I knew all there was to know about Haemophilia. My younger brother was diagnosed when I was 12 years old and I often took time off school to stay in hospital with him when he had bleeds, so thought I knew everything!

As I found out, I may have thought I knew everything, but little did I know the importance of travelling with an icepack, panadol and Transaexamic acid tablets, the Sunday afternoon RCH runs as soon as you put a roast in the oven and the middle of the night screaming wake ups with a joint bleed!

I was pretty relaxed when we were told the day both our boys, Harrison and Callum, were born that they had severe Haemophilia A (like I said I thought I knew everything!). I felt prepared in the sense that nothing was going to happen until they started moving around, so we had plenty of time to prepare for it. Never mind that bleeds started early from kicking the cot sides or rolling over a toy.

The first moment my husband, Matt, and I both thought 'it's started' was sitting in the RCH at 3am while the emergency doctors tried to find someone who could locate a vein in my then chubby 12 month old. This wasn't an isolated incident with either of our sons, but we learnt very quickly the art of distraction.

Haemophilia life with Harrison was pretty standard, nothing out of the ordinary. However, we first



noticed something just wasn't quite right with Callum end of 2015 when he was 4 years old. He had had a few port infections up until that time, but on the whole like Harrison nothing too extreme. All of a sudden he was having bleed after bleed. We spoke to Dr Chris Barnes and Janine at the RCH and they wanted to keep an eye on him, maybe he was being a bit more active than normal. In mid 2016 the bleeds were still coming so Janine suggested we do inhibitor and half life levels (the time/rate at which the factor is used up by the body) tests to see what was going on. Both tests are done around "normal" treatment times and couldn't be done if he was having extra treatments for bleeds. All up it took about 3 months for the tests to be completed.

I will never forget receiving the call from Janine in late December 2016

to say that not only did he have an inhibitor, but his half life was a fraction of what it should be. From then on, his inhibitor and half life worsened and as a result so did the bleeds. He had bleeds in his





perineum from the car seat belt or even sitting on a motorbike (a bike that wasn't turned on or going anywhere), attempting to kick a football or even running saw him in bed for over a week. At one point it seemed that even a trip to the supermarket would result in a leg bleed of some sorts by that night.

The only way to treat inhibitors is to tolerise the body to accept the factor again. So in January 2017 Callum started an adult dose of factor 8 every day, which he had been on until November 2018. Having product every day acts both like a prophylaxis and treatment at the same time, but he would still have bleeds. He has changed product a few times, as one stopped working all together and then in July last year he started (and remains) on a plasma based product called Biostate. At the time of switching over to this new treatment, I was hesitant to say the least. I come from a time of the blood borne virus era. My own brother contracted Hepatitis C from his first treatment when he was 11 months old. However, given how Callum was at the time, I had no choice but to start

with the new product and keep reminding myself that times are not like they were.

He is now on treatment every second day and it shows. He has had two big bleeds in the last month (buttock and thigh) and is back to being covered in the big, ugly looking purple soft tissue lumps and bumps everywhere. On the up side his inhibitors has finally returned to what it was two years ago, but his half life remains very short, so the factor is not hanging around

in his body for long. It is unknown how long it will take for the half life to return to normal...annoying!

The constant bleeds over the last few years put a toll on his veins to the point they just gave up, so in February 2017 he had emergency surgery for his second port in, during a weeks stay in the RCH for a hip bleed and kidney stones (yes this kid had it all!). As much as I don't like the port (personal reasons...we had just got rid of it in early 2016), it has been a god send. Daily treatments are punishing on the veins and the port had made regular treatments so easy. Unfortunately, because it was being used so much, it has had its moments where it needs a break so we would have to rotate arms each day.

In the midst of all this 2017 was also the year that he started school. His inhibitor journey has impacted his schooling and he finished the year well behind his

peers. I tried to teach him what I could at home, but there's a reason I am not a teacher and as I'm his mother he's not that great at listening to me! I was told at the end of the school year that he had the worst attendance record the school had even seen, that made me feel so much better! He has now just finished grade 1 and has made some improvements, but again had a fair amount of time off, so still remains behind.

This whole journey has opened our eyes to the struggles and issues that come with having haemophilia and the impact it has on the whole family. There have been birthday parties, family gatherings, school events, play dates you name it that we have missed or late cancelled as Callum has yet another bleed...or the kids birthday party at Supertramp, my worst nightmare!

Unfortunately, it wasn't until the





end of last year that we realised how much it has impacted our other son Harrison. His feelings that we didn't love him, as I was spending so much time with Callum or not knowing that I have made a dash to the RCH during the day and someone else would be picking him up after school. Mind you Harrison also had his issues during the year in 2017, breaking both his arms one after the other!

The inhibitor journey, at its peak, left myself with a severe case of anxiety. I always felt I was in flight or fight mode, ready to pack up at the drop of a hat and rush to the RCH. My mind was always racing with thoughts on what's the traffic like right now (driving up from Geelong), are the school clothes washed for Harrison, work shirts for Matt, is there food in the fridge...it never stopped. It used to drive me insane and I felt I could never relax. I didn't drink any alcohol for over a year, just in case he had a bleed and I do love my wine! My friends were amazing during this time. I have a great small circle of friends that are always there for school runs or hospital visits with the all important chocolate!! I found it very therapeutic talking to my best friend who also has kids with special needs. She completely understood my struggles with hospital stays, anxiety over silly things and the general feeling of helplessness at not being able to fix your child.

I often say that inhibitors adds a whole new level of uncertainty to haemophilia. At the height of our journey I did find it a very lonely one, there are not many out there that are unlucky enough to go through this, so it's hard to talk about the struggles with someone who understands. I did find it comforting talking to two other mums over facebook, one who had been through the journey and the other who was currently in it. The one thing I did discover was that everyone's inhibitor journey is different. At the start we were told he would be back to normal within 6 months, we are now 2 years in! There is no case book on when inhibitors will tolerise or half life return to normal and that is the most frustrating thing.

After going through this, if there is anything I would say to a family whose child has just developed inhibitors, is to get support, get lots of support and friends to help you along the way. It's a struggle, it messes with your everyday life, but you will get through it. Kids are amazing, our boys with haemophilia are amazing, it's hard and it sucks, but you'll get there.

Naomi Grech

If you, your child or your sibling has been through the journey of living with inhibitors and you feel that you could offer support to other please let us (HFV) know. It may just be to chat over the phone but your experience may just offer some comfort to those on this often isolating journey.



19TH AUSTRALIAN CONFERENCE on haemophilia, VWD & rare bleeding disorders

The 19th Australian Conference on haemophilia, VWD & rare bleeding disorders will be held at the Novotel Manly, Sydney, 10-12 October 2019.

Our conferences bring together people with bleeding disorders and their families and carers, as well as health professionals, policy makers and industry. It is a great opportunity to learn, discuss and plan for the future.

The conference is a great opportunity for people with a bleeding disorder and their families - parents, siblings, partners – to attend, learn more information about new treatments, gene therapy, children and young people, sport and living with a bleeding disorder etc..., make connections and become better empowered about your health.

COMMUNITY FUNDING

To assist, HFA has allocated funding to assist community members with expenses to attend the Conference.

HFV members - Conference registration subsidies will be available to assist HFV member to attend the conference. Please register your interest by emailing info@hfv.org.au or contact the HFV office on 03 9555 7595.

For details and an application form for part HFA funding go to www.haemophilia.org.au/conferences or call HFA on 1800 807 173 for a form to be emailed or posted.

MORE INFORMATION

The registration and Information brochure will be available online in March 2019. For more information and details visit www.haemophilia.org.au/conferences.



EXTENDED HALF-LIFE CLOTTING FACTOR Products News

The National Blood Authority (NBA) announced that they will include Extended Half-Life (EHL) factor VIII and factor IX products - treatments for haemophilia A and B - in the next national tender for clotting factors and related products. The tender is currently planned for 2019.

The Jurisdictional Blood Committee (JBC) recently approved the inclusion of EHL recombinant factor VIII and EHL factor IX products in the national arrangements for funding and supply of blood products managed by the NBA. The JBC decision was supported by a Medical Services Advisory Committee (MSAC) assessment of EHL recombinant factor VIII and factor IX products.

The NBA confirmed that the current arrangements

for EHL clotting factor products will continue in the meantime. These arrangements provide temporary access to EHL products for approximately 200 haemophilia patients with high priority needs. Further information about these arrangements can be found at <https://www.blood.gov.au/plasma-and-recombinant-product-procurement>.

For more information about this decision and the tender, see the news item on the NBA website:

<https://www.blood.gov.au/extended-half-life-clotting-factor-products-included-national-blood-arrangements>

Haemophilia Foundation Australia
www.haemophilia.org.au

BLOOD, SWEAT AND GEARS

Inspiration for our kids & community



From the 24th - 27th January HFV had our set on the Cadel Evans Great Ocean

Road Race. As much as we love Cadel we were really cheering for one of our own...a great champion, advocate and role model. Alex Dowsett is a British professional road racing cyclist, who currently rides for UCI World Team Katusha-Alpecin. He has had major wins in Grand Tours, Stage Races, One Day Races and Classics and holds the World Hour Record..and he has severe haemophilia A.

One of our HFV families, who are cycling enthusiasts, made contact with Alex through Facebook just to say they would be in Torquay cheering him on. Alex very generously invited them to join him for a coffee and

gave 11 year old Will an opportunity to chat face to face with a sporting champion. Here is what Alex had to say about his encounter with Will.

'This today has made my whole trip, meeting young Will, an 11-year-old surfer from near Torquay, Victoria. Like me he's also got severe haemophilia A, and I guess also like me it's clearly not stopping him competing in the sport he loves.'

Haemophilia has come such a long way in such a small space of time. If I was born 5 -10 years earlier it would've been a different story for me, and haemophiliacs born later and later have such bright prospects, which is incredible to see.

It's the stories and examples like Will that let others know their youngster with haemophilia won't be restricted in their life ahead and sends a message that they will grow up with the same opportunities to lead as normal lives as possible with a condition that was once hugely debilitating - and that's all any parent wants for their kid, equal opportunities.'

Karen Donaldson, Will's mother, spoke afterwards about their meeting:

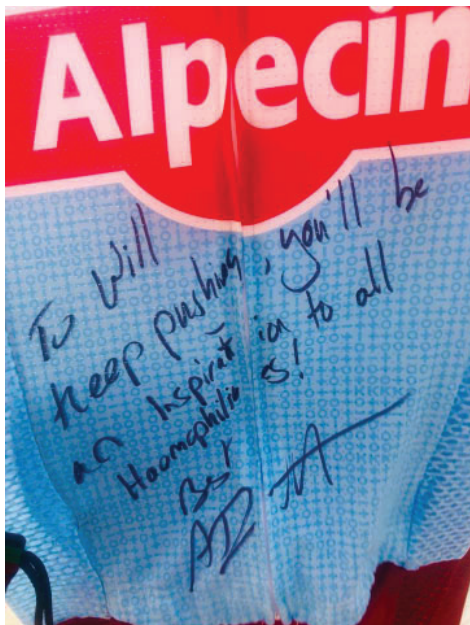
'We have been very fortunate to meet this incredible human who has inspired many people including kids with haemophilia. To reach the top level of their sport with a condition we know is difficult to manage at the best of times is such an incredible achievement. Thank you, Alex Dowsett, for stealing some of your time and for encourag-



ing Will to drive forward in sport and conquer to the best of his ability, despite having haemophilia. I hope you heard us cheering loudly at the Bell's Beach climb!

I enjoyed the connection and interest Alex had with Will when they met up. They discussed the frequency of prophylaxis, the issues associated with self-infusions, target joints and how to combat rigorous training with the important timing of factor administration.

It seems kids with haemophilia do tend to grow up quickly, as Alex suggested. It's not often you would have such mature discussions with an 11-year-old.



What a positive and humble person Alex is. To give up his time to have a meaningful discussion with a local 11-year-old boy is something pretty special.'

Many thanks to The Donaldson Family for taking the time to support Alex and represent HFV and our community. Thanks to HFA for sharing Alex's words with HFV. And a huge thank you to Alex Dowsett for being such an incredible inspiration to the bleeding disorders community worldwide, kids and adults alike!

BOOKING OPENS! HFV Community Camp 2019

...it's for **EVERYONE**, old, young,

singles, couples & families

**FRI 5TH APRIL - SUN 7TH APRIL
ADANAC CYC, YARRA JUNCTION**

YOU are invited to attend the 2019 HFV Community Camp at Adanac CYC. Yarra Junction in the beautiful Yarra Valley!

We often think of camps in terms of kids and action based activities. It is true to say we do have an action packed weekend that builds resilience, confidence and self worth but there are much deeper outcomes that we



gain from attending. Our camps are for **ALL MEMBERS IN OUR COMMUNITY** to connect, support and empower themselves and each other. There are many families with grown up children, singles and couples that can attend and benefit from the social connection we make with each other. It can be a relaxing weekend away, you can sit on the deck and enjoy the views, connect with others and reflect.

It is easy to dismiss the camp - it's not for me...but it is for you and for every other member of our community. We all benefit from the experiences and support of those around us so if you have not made it to camp yet, if in the past you have thought it's not for me...think again and let this be the start of a new and more fulfilling journey with the HFV community.

**Bookings are essential and through
www.trybooking.com/ZTIG
or search HFV camp on Trybooking**

NEW RESOURCE

Telling others

How do you tell a new partner about your bleeding disorder? Or your daughter that she may have a bleeding disorder or carry the gene? When are you required to tell someone about your bleeding disorder?

Telling others about bleeding disorders: information for women, girls and their parents is the latest resource in HFA's The Female Factors project.

- A copy is enclosed for you to share with family and friends!

Visit the www.hfv.org.au under PUBLICATIONS > WOMEN WITH BLEEDING DISORDERS to view it online or download it.

Telling others includes:

- The pros and cons of telling others
- The range of situations where you might disclose
- Talking to your daughter about her bleeding disorder
- How to prepare to disclose
- When you are required to disclose
- Personal stories and tips from other Australian women and parents.

DISCLOSURE AND THE LAW

HFA has also developed information about disclosure and the law for both women and men in consultation with legal experts. This is available on the HFV website under ABOUT BLEEDING DISORDERS > DISCLOSURE.

Thanks to the many people who contributed to the development of Telling Others: Marg Sutherland, health educator, who wrote it; the women, parents, health professionals and legal experts who reviewed it; and the women and parents who very generously shared their experiences and tips in personal stories and quotes.



Telling others you or your daughter have a bleeding disorder or carry the gene that causes a bleeding disorder is something you will probably have to think about from time to time. Perhaps you already have. Sometimes telling others is straightforward, but there can be times when it's not so easy.

The following information can be used by women, girls and their parents to consider some of the issues about telling others (disclosure). It looks at some of the pros and cons of telling others, and presents a range of situations where disclosure might come up. There are suggestions on how to prepare, and what

information is most useful to share with others. It also talks a bit about protecting your rights, including your right to privacy.

Although **Telling others** has been prepared with women and girls in mind, it may also be useful for men with a bleeding disorder. Their daughters, sisters or nieces may be affected and sometimes they may be the best informed family member to take the lead in talking to them about what this means.

This information covers haemophilia, von Willebrand disease (VWD) and other rare bleeding disorders.



HAEMOPHILIA FOUNDATION AUSTRALIA

Telling others about bleeding disorders

Zev's story



Zev and his daughter today

'Make it a family conversation'. This is the advice Zev, a man with severe haemophilia, would like to give to families affected by haemophilia. Zev has two sons, neither of whom have haemophilia, and one daughter whom he realised at an early age would carry his altered gene.

'My kids knew I had haemophilia. We were very open. There were lots of signs because of the bleeds I had before I started prophylaxis [preventive] factor treatment. But they also saw I was ok, that I was working, active, involved in everything.'

'When my daughter was 12 years old we went through a particularly difficult time. My wife passed away. Before then we hadn't discussed with our daughter how she might be affected. But I knew I needed to talk to her because the day might come when she would have some decisions to make.'

'I sat down with her when she was about 15 and told her she had an X that was normal and an X that was not normal. Since then she has

understood the situation if she were to have a child. Her response has been "I'll take that risk". She's aware of the new treatments and, looking ahead, of a potential cure. She isn't fearful of what the future brings if she decides to have children. I don't think she would hesitate.'

Looking back, Zev has a few tips about talking to girls who might have the altered gene. 'I don't think you need to worry a child about heredity, but you might have to talk about periods before they start and encourage her to tell you if she has heavy periods. Then when she starts to date you can talk about how it's inherited. Girls might not want to talk a lot about it but they shouldn't be left to guess.'

'Normalising haemophilia by making it part of general family conversation helps. Often there's no obvious signs of haemophilia with current treatments so men with haemophilia might put it on the back burner. But these conversations need to be had. You shouldn't protect your kids from things that might be necessary.'

Telling others about bleeding disorders

Susie's story

Susie is not new to telling others about her bleeding disorder. As someone with von Willebrand disease, and as a parent of a child with VWD, she has had to advocate for herself and for him on occasion. But after an accident at work she realised there could be times when she might have to rely on others to do the talking for her.

'I fell down the stairs at work. When I came to a stop I realised I couldn't move. I couldn't call out. I could barely even breathe.' Work colleagues came to her aid. They acted quickly and worked through what had happened and what she might need. As the plans progressed and it became clear that she needed medical assistance, the value of disclosure became clear. Susie's manager, who was also the section's first aid officer, already knew what was important in this situation.

'My manager and I had already had many conversations about VWD. We'd talked about my son with type 3. She had supported me when

I needed to take time out for appointments and when I'd needed to field calls from my son's teachers. And these conversations weren't intrusive. They were caring, based on the facts of my situation, my needs at the time and on her needing to know what might be required of her in just such a situation.'

These conversations formed the basis for her manager's quick actions. 'My manager knew to take the extra step of calling the HTC. She spoke with the Haemophilia Nurse to report my injuries and work out a plan.'

Susie had always thought of her conversations with her manager as a way of looking after her own needs. It was later she realised that it was also about looking after her manager. 'By having these conversations I was helping her to do her job properly.' Disclosing at work allowed Susie to gain valuable emotional support but it also made the difference when she couldn't speak up at a vital moment.

'I had already learned to be my own best advocate. But crucially, sometimes you need to plan and have contingencies for others to advocate for you.'



HIV Futures 9:

A national survey of Australians living with HIV

HIV Futures 9 is a survey about the quality of life of people living with HIV in Australia. We are keen to hear from PLHIV all over Australia – men, women and trans and gender diverse people, heterosexual, gay and bisexual people.

If you are a person living with HIV in Australia and aged over 18 years, we'd love to hear from you.

The study provides data to support advocacy, service provision and policy to improve the lives of people living with HIV in Australia.

This is the most influential and important study of people living with HIV in Australia. The study has been running for 21 years

and provides information to support advocacy, service provision and policy to improve the lives of people living with HIV in Australia.

HIV Futures is an important project. It provides information to help governments, clinical services and community groups plan programs and policy.

You can fill in the survey online at www.hivfutures.org.au

The survey will be online until 30th April 2019

For more information, or to request a copy of the survey booklet, contact us:

Ph: (freecall) 1800 064 398 or
Email: hivfutures@latrobe.edu.au

HIV Futures is run by the Australian Research Centre in Sex, Health and Society at La Trobe University. For more information contact Jennifer Power via email to jennifer.power@latrobe.edu.au or ph (03) 9479 8700.

If you have any complaints or concerns contact the Senior Human Ethics Officer, La Trobe University, P: 03 9479 1443, E: humanethics@latrobe.edu.au (SHE CHESC s15/100).

HIV Futures 9 has been approved by the ACON ethics committee (RERC 2018/26) and Thorne harbour Health (THH/ CREP/18/004)

HIV Futures is officially supported by the National Association of People living with HIV Australia (NAPWA), The Australian Federation of AIDS Organisations (AFAO) and the Australasian Society for HIV, Viral Hepatitis and Sexual Health Medicine (ASHM).

by Living Positive Victoria

New HFA AGEING project

Preetha Jayaram joined the HFA team in February 2019 to start work on HFA's new Ageing project.

HFA has received funding from the Australian Government Department of Health to investigate the needs of the bleeding disorders community around ageing and try out some solutions relating to education and peer support. Preetha is leading the project and will be in contact with community members, Foundations, HTC's and other stakeholders to consult about the issues.

With her diverse set of skills and background, Preetha is looking forward to taking on the Ageing project with HFA.

She began her career as a social scientist and anthropologist conducting research into castes, tribes and rural development in Kerala State in India. 'After migrating to

Australia in early 1990s, I continued my research career working with Melbourne's local government community services departments on ageing projects,' said Preetha. 'This involved visiting and talking with many older people in the community – in one project we interviewed around 500 older residents!' Preetha then moved on to curatorial work and digitising the indigenous collection at Museum Victoria. She also had the opportunity to undertake research and community consultations for the Stolen Generations organisation in Melbourne.

More recently, Preetha has followed her interest in education and has gained qualifications and expertise in education program design and content development for the Vocational Education and Training (VET) sector. She currently also works part-time as the Training and Compliance



Manager for a vocational education provider in Melbourne.

'I love interacting with people and listening to their stories. I have a strong belief in using personal stories to understand and empower the community.'

Preetha enjoys music, art and meditation and values its therapeutic effects.

Preetha works on Monday, Tuesday and Wednesday and can be contacted at HFA office: pjayaram@haemophilia.org.au 03 9885 7800

On the move with haemophilia



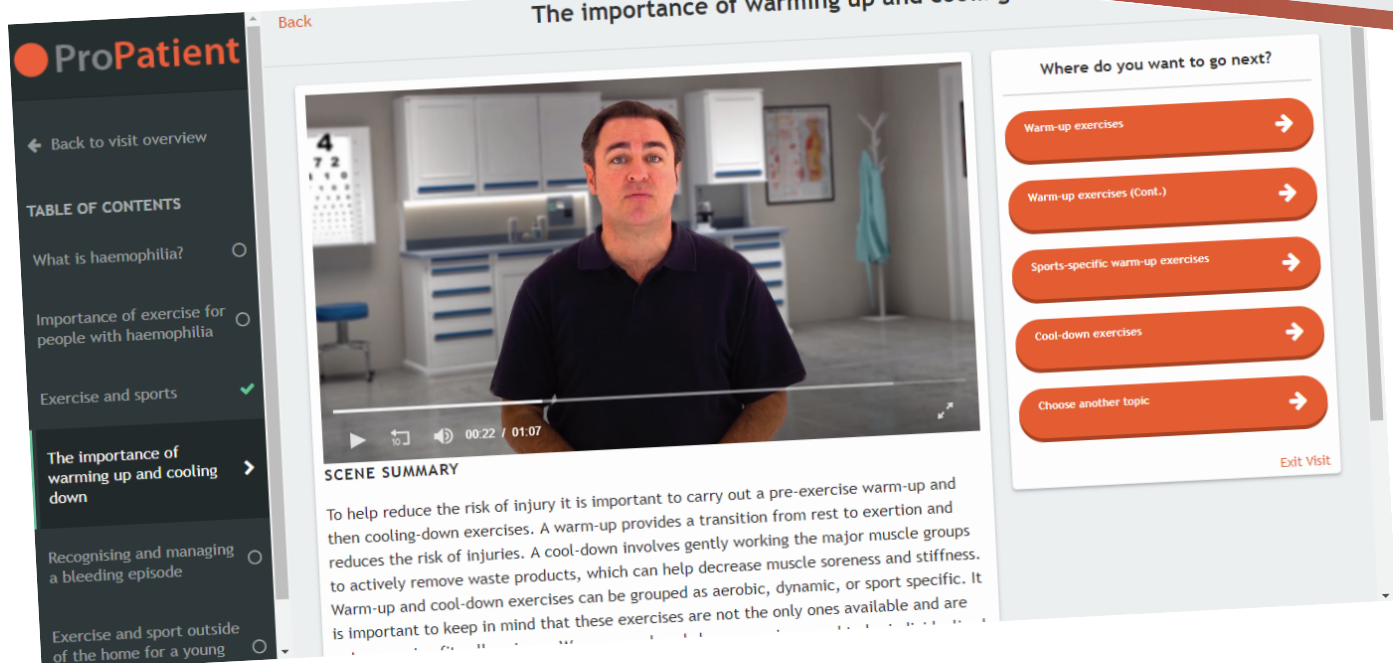
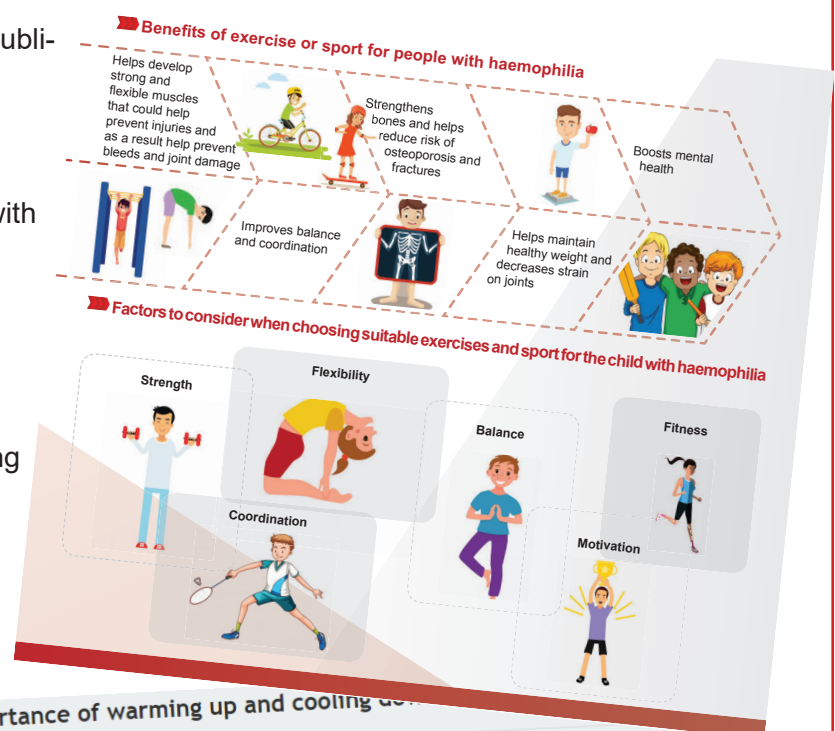
On the Move with Haemophilia is a new online educational program about supporting young people with haemophilia to participate in exercise and sport. It is aimed at parents, teachers and sports coaches and includes a set of videos and a fact sheet.

<https://app.propatient.com/visits/on-the-move-with-haemophilia>

It is also available on the HFA website, under Publications.

The program covers:

- the benefits of regular exercise for people with haemophilia
- factors to consider when choosing suitable exercises and sports
- how to encourage regular and appropriate exercise
- steps to take when a young person has a bleeding episode at school or during sporting activities
- rehabilitation and returning to exercise or sports after a bleeding episode.



www.app.propatient.com/visits/on-the-move-with-haemophilia

Strategic Plan

2018 - 2020



*Connecting, supporting & empowering
our bleeding disorders community*

OUR VISION
Connect, support and empower our community with bleeding disorders.

OUR MISSION
Provide support, advocacy, information, programs and activities which lead to positive healthy outcomes for those who are affected by genetic bleeding disorders.

STRATEGIC GOALS	1	2
	Health Promotion	Community Wellbeing, connectedness & Engagement
KEY ACTIONS	<ul style="list-style-type: none"> Enhance and diversify the provision of information to affected people, their families, carers and general population. Enhance the provision of information about HFV to hospitals, health and education professionals. Promote the need for improved health care for affected people in vulnerable settings. 	<ul style="list-style-type: none"> Create and promote opportunities for members and their families which foster peer support. Develop specific programs and activities which help improve the social inclusion of affected people and their families. Recognise the experiences and contribution of families who have experience of family or friends as a result of a disorder. Enhance opportunities for region members to connect. Develop specific programs and activities for marginalised members and their families and carers.
	<ul style="list-style-type: none"> HFV will provide a suite of information available in diverse mediums for members/ health professionals (hospital settings) and general population that increases knowledge and awareness of HFV and/or bleeding disorders / BBV and health complexities such as liver care, Hep C treatments. Pathways for information referrals are created and accessible for members and community as part of a holistic approach to healthcare. HFV will work in partnership with HTCs and HFA to gather evidence to inform future programs particularly aimed at vulnerable cohorts within our community including rural visits and youth. 	<ul style="list-style-type: none"> HFV promote the opportunity to support program with skill to continue to provide established program with quality eval. HFV will provide safe space to share their lived experience 'champions' to raise awareness to wider audiences. Through shared experience increase knowledge and impact of inhibitors and social inclusion.

Our HFV committee are proud to share with our community our latest 2018-2020 Strategic Plan. This important document guides our decision making, direction and evaluations. It keeps us accountable to our funder and to you, our members.

We align our Health Promotion Plan (required by the Department of Health and Human Services) with our mission statement and goals and carefully map out our direction to create a focused, progressive and achievable path.

We have focused on key cohorts within our community that have been identified as benefiting from targetted support

OUR VISION

Connect, support and empower our bleeding disorder community

OUR MISSION

Provide support and positive health outcomes for those who are affected by genetic bleeding disorders.

OUR VALUES

Values underpin the organisational culture and behaviour of Haemophilia Foundation Victoria. In our relationships with our colleagues, partners and stakeholders and with all those who use our services we are committed to the following values:

- Respect
- Diversity
- Leadership
- Responsiveness
- Integrity

The latest HFV Strategic Plan will be available for viewing on our website in mid March:

www.hfv.org.au/about-us/strategic-plan



NEW RESEARCH AIMS TO UNEARTH 'HIDDEN' HIV

Below is an interesting article about new research into hidden HIV cells.

NAPWHA has developed a website specifically around research into an HIV cure - <http://hivcure.com.au>

For those or you who are interested, this website offers some valuable FAQs and gives some context around research.



Researchers have identified a way to unearth 'hidden' HIV cells, which will provide vital information towards finding a cure for the disease.

The research team, led by The Alfred Department of Infectious Diseases Clinical Research Unit head Dr James McMahon, will use a new method of identifying latent HIV cells that have traditionally been difficult to target.

Once a person with HIV starts treatment, the amount of virus in their blood quickly drops. With regular treatment, the HIV becomes 'undetectable'. However, this doesn't mean that HIV is eliminated from the body. The virus retreats to hiding places, mostly in the tissues, where it lurks and waits. This is HIV latency, which is the major barrier to an HIV cure.

Latent HIV hides in places like lymph nodes and the lining of the gut. Currently, the HIV remaining in these places can only be detected through invasive procedures such as biopsies, which can be risky. They only allow a small part of tissue to be studied and may not sample the exact spot where the greatest amount of HIV is hiding. There's also a limit to how many and how often biopsies can be done.

"We need better ways to determine the amount of residual or

latent HIV in people on treatment and where this virus is hiding if we are to develop ways to tackle this remaining virus," Dr McMahon said.

"This study aims to develop a non-invasive way to see HIV in the body. It will enable researchers to see where and how much HIV remains in people with HIV infection who are on treatment."

The researchers will combine an anti-HIV antibody (called 3BNC117) with a radioisotope or label (called copper-64). Researchers will then inject a small dose of this labelled antibody into study participants. The antibody will bind to HIV and cells infected with HIV and give out a signal that can be detected on a scanner.

The scanner combines Magnetic Resonance Imaging (MRI) and Positron Emission Tomography (PET). The scan will detect exactly where in the body the HIV cells are.

Dr McMahon said the team can then 'wake up' the dormant HIV cells, making the virus more visible to treat.

"We have been able to link radioactive copper to an anti-HIV antibody that binds to the great

majority of HIV cells in an individual. We then do a scan to detect the amount and location of the radioactive copper, and therefore identify sites of HIV," Dr McMahon said.

"We can then infuse the copper-antibody combination with a drug to reverse HIV from its dormant state, making it more visible, and telling us where in the body this latency-reversing drug is having an effect."

Dr McMahon has recently received a grant from the Melbourne HIV Cure Consortium to extend this project.



Dr James McMahon

*Printed with permission from
The Alfred*

ASK US...

Q & A's with Alex & Jane

QUESTIONS FOR THE ALFRED HTC TEAM

What kind of mental health concerns do people with bleeding disorders have?

Having a chronic illness makes a person more likely to suffer with mental illness particularly anxiety and depression.

The challenge is to build up your skills along the way. As issues come up find a positive way to deal with them. If there are hurdles to jump, work out what will help, who can support you and what are your options. We know that some people manage certain things better than others.

How can you be one of the ones that gets through rather than struggle with various challenges?

Having support from your own network and/or professional help can make a huge difference. It is important to remember that you do have strengths, and often finding these and building on them is your pathway through a current difficulty.

Loneliness is being recognized as a major issue today. Interestingly the UK Government has appointed a Government Minister for Loneliness. Does loneliness have an effect on my haemophilia, and vice versa does my haemophilia have an effect on loneliness?

Yes and yes, but it doesn't have to stay that way. We know that having a chronic health condition, especially one such as Haemophilia does make it harder to connect with other people. There can be physical challenges to contend with.

We also know that loneliness can contribute to serious health consequences, such as sleep disturbances, substance abuse, depression and suicide. There are small steps that can make a big difference.



Photo by Serkan Gökay from Pixels

Getting involved in something, come to the HFV community camp, find an interest, volunteer, or get a pet are just a few ideas, there are many more.

The solution is a whole community thing, so reaching out to those that you know might be more isolated can make a huge difference.

Jane Portnoy & Alex Coombs
Social Workers,
Haemophilia & Other Inherited Bleeding Disorders, Alfred Health

ARE YOU AN EMPTY NESTER?

Has your son or daughter left home?
Please send us their address so we can keep them connected with HFV!

FREE MEMBERSHIP FOR THEIR FIRST YEAR
EMAIL: info@hfv.org.au
Grandparents and extended family also invited to join!

DO YOU HAVE VON WILLEBRAND DISEASE

We are looking at ways to connect people with vWD through a new peer support group. Please contact HFV and tell us what type of peer support would work best for you ie face to face, via email, conference call and any other suggestions you may have.
email: julia@hfv.org.au or phone 03 9555 7595



We are delighted to invite you to our first get vWD get together that will take place during our Community Camp at Adanac CYC!

If you are interested in meeting with Robyn, our vWD Peer Support Coordinator and others with vWD, please contact Julia on julia@hfv.org.au. It will be held at approx 2pm on Saturday 6th April. You do not need to stay for the whole camp, you are welcome to come for just the vWD get together or the day...whatever you are comfortable with!

HFV Noticeboard

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

NEVER BEEN TO AN HFV CAMP?



check out this video
and see what it's all
about...

<https://youtu.be/oiFj9aZMWLk>

Still not convinced?
...just come for a day!



HAEMOPHILIA FOUNDATION VICTORIA

REGIONAL & OUTER METRO VISITS 2019

DO YOU HAVE A
BLEEDING DISORDER?

You are invited to come
and meet with HFV
committee, staff and
others affected by
bleeding disorders.

Bring your family,
partner or friend and
enjoy connecting with
others from our
community.
Food and drinks
provided by HFV.

GEELONG

**SUN 2ND JUNE 10AM TO 12PM
WHARF SHED CAFE**

CRANBOURNE

**THURS 13TH JUNE 6PM - 8PM
THE SETTLEMENT HOTEL**

EPPING

**THURS 25TH JULY 6PM - 8PM
EPPING PLAZA HOTEL**

BOOKING ESSENTIAL THROUGH TRYBOOKING:
www.trybooking.com/BBFIC

After an extensive year in 2018 touring around many regional towns of Victoria, the HFV committee has decided to start our Regional Visits program with some outer metro areas as well as Geelong.

We are hoping that the visit to Geelong will also attract members from the wider Bellarine region.

We invite all people with bleeding disorders to come along to our visits so if you know of any other people in your area that might benefit from connecting with our community bring them along!

These event are open to singles, couples, families, bring your parents or bring a friend.

HFV covers the cost of food and a welcoming drink.

All invited! Hope to see you there.

The HFV team

HAEMOPHILIA FOUNDATION VICTORIA INC

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EXECUTIVE MEMBER Dan Korn

GENERAL COMMITTEE:

Karen Donaldson

Donna Field

Cara Gannon

Robyn Heal

Erika Mudie

Adam Zulawnik

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.

Opinions expressed in The Missing Factor do not necessarily reflect those of the foundation, HFA or the Haemophilia Treatment Centres. The content of this publication is provided for information purposes only. All information is provided in good faith but no responsibility can be accepted for inaccuracies that may result from events beyond our control. No claim is made as to the accuracy or currency of the content at any time. HFV do not accept any liability to any person for the information which is provided.

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

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Megan Walsh | Clinical Nurse Consultant
Emma Reiterer | Registered Nurse
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

connect support empower

Supporting bleeding disorders community
HAEMOPHILIA FOUNDATION VICTORIA

HFV MEMBER SERVICES & PEER SUPPORT

Membership Annual Fees:

Standard family membership

\$33.00

Concession member

\$16.50

Allied Member

\$16.50

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 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

Website: www.hfv.org.au

Fax: (03) 9555 7375

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 2016 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 day at the Peninsula Hot Springs and enjoyed a beautiful meal together.

They 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 bowling 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.



HAEMOPHILIA FOUNDATION VICTORIA
INVITE ALL PEOPLE LIVING WITH BLEEDING
DISORDERS & THEIR FAMILIES TO ATTEND OUR

2019 COMMUNITY CAMP



FRI 5 - SUN 7 APRIL

ADANAC CYC, YARRA JUNCTION

FOR MORE INFO GO TO WWW.HFV.ORG.AU
BOOKINGS THROUGH WWW.TRYBOOKING.COM/ZTIG

