

THE MISSING FACTOR

SPANNER
IN THE WORKS?

SURFING THE
WAVES OF LIFE

GRATITUDE & ADMIRATION
FOR OUR CFA FIREFIGHTERS

connect • support • empower



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Haemophilia Foundation Victoria acknowledges the support of the Victorian Government.

DIARY DATES

MARCH

20-22 Men's Retreat

APRIL

17 World Haemophilia Day Celebration - Movie & Melbourne Wheel

MAY

7 Moe Regional Visit

JUNE

TBC Ladies Day

JULY

TBC Soccer Family Event

AUGUST

26 Melton Outer Metro Visit
27 Bendigo Regional Visit

OCT

11 Walk for Bleeding Disorders TBC
17 Red Masquerade Ball 2020

NOV

15 AGM & Christmas Picnic

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

PRESIDENT'S REPORT

Happy 2020 to our HFV community. Hope everyone had a safe and restful holiday period and ready for an action packed year.

The year has started well with a very successful camp. Well attended we all enjoyed a wonderful weekend despite the weather creating a few challenges. Lots of activities as well as time to share chats and share tips about the many obstacles we face living with a bleeding disorder. It was very exciting to have so many new faces join us. New families and community members meeting others and connecting to HFV broader family. We welcomed a new family from South Australia which was fabulous. Sadly, South Australia has been without a foundation for many years so it was extra special to welcome our new friends from across the border. We hope next time we will also be able to encourage others from both Tasmania as well as South Australia. It is indeed a big commitment for them to travel but so proud to see how welcoming everyone was to support them and they enjoyed their time from all reports. Great to have Penny from the Alfred join us again as well as Natasha from HFA. We are very fortunate for the ongoing support from our very valued stakeholders.

Men's retreat is soon approaching and for those eligible I encourage you to take the leap and join the guys. Obviously not something I attend but I know from those that do it is an important weekend for laughs and connecting to others that share lived experiences. If you are considering joining the guys please contact the office and have a chat to the staff.

The Committee is gearing up for a big year. As reported last time we said goodbye to a few long standing members at the last AGM. Zev, our treasurer, Sharron, our Vice President and Karen, camp program sub committee leader have all decided to take a break after many years of dedicated service. Each of these remarkable people have done amazing work in their area of expertise and have left enormous gaps in the committee. Fortunately they are all staying connected to HFV and hope to continue to see them all at events

and celebrations. We wish each of these wonderful people well in their next adventures but certainly hope they may again join the committee at another stage if circumstances allow. We would certainly welcome them with open arms.

With all these movements we have had some significant gaps in the committee and was close to not being viable which I'm sure you would agree would be tragic. However I am very pleased to welcome new members to our team. We welcome Bernard, Claire and Chris who have all decided to join us. Again each one will bring their unique perspective to the roles and we are excited moving forward to tap into their skills and hear fresh ideas in future planning. We are also working on securing the role of treasurer with discussions in place for a possible shared role. We will update you when we can. Fortunately, in the transition period Zev is keeping a helpful watching brief over our finances while we set up new processes. Many thanks yet again to Zev for your tireless support. There are still vacancies for the committee so if you are interested please let me or someone in the team know.

We happily announce the new executive with Dan Korn as Vice President, Donna Field as support for treasurer and again you are stuck with me as president for another year.

2020 is going to be huge with another ball on the horizon. October may seem ages away but as we all know it will arrive before you know it. Again, we call on our community to support this fantastic event. Whether it be securing a table when the tickets go on sale or donating something for the silent auction. Every bit you do is greatly appreciated. They say it takes a village to raise a child I can certainly say it takes a community to support a successful ball. Our amazingly talented fundraising committee have demonstrated they are capable of brilliant magic but we call upon our community to support them in any way you are able. We certainly find that experiences such as hotel vouchers, trying something new or weekend activities are the items that sell well. So please take time to consider how you and your extended network can support the ball. We hope

you are there to enjoy the evening. It will be amazing and as a masquerade ball the scene is set for mystery and a lot of fun.

As we know it has been a tough start to the year with our bushfires. We hope you are all safe and well. HFV pride ourselves on being holistic for your well being. If you have been impacted by the fires please do not hesitate to contact us. We have limited resources but will be very happy to assist in any way we can to support you and your family. As we know caring for physical health is important but never forget your mental health. We will all have times when our mental health will be challenged from the many stresses of life. Please consider your wellbeing and develop your own self care plan. Whether it be exercise, yoga, regular cinema outings or Netflix binge sessions we all need a plan. Take time to read the wellness wheel article in this edition and see what tips you can learn from to adapt better self care practices.

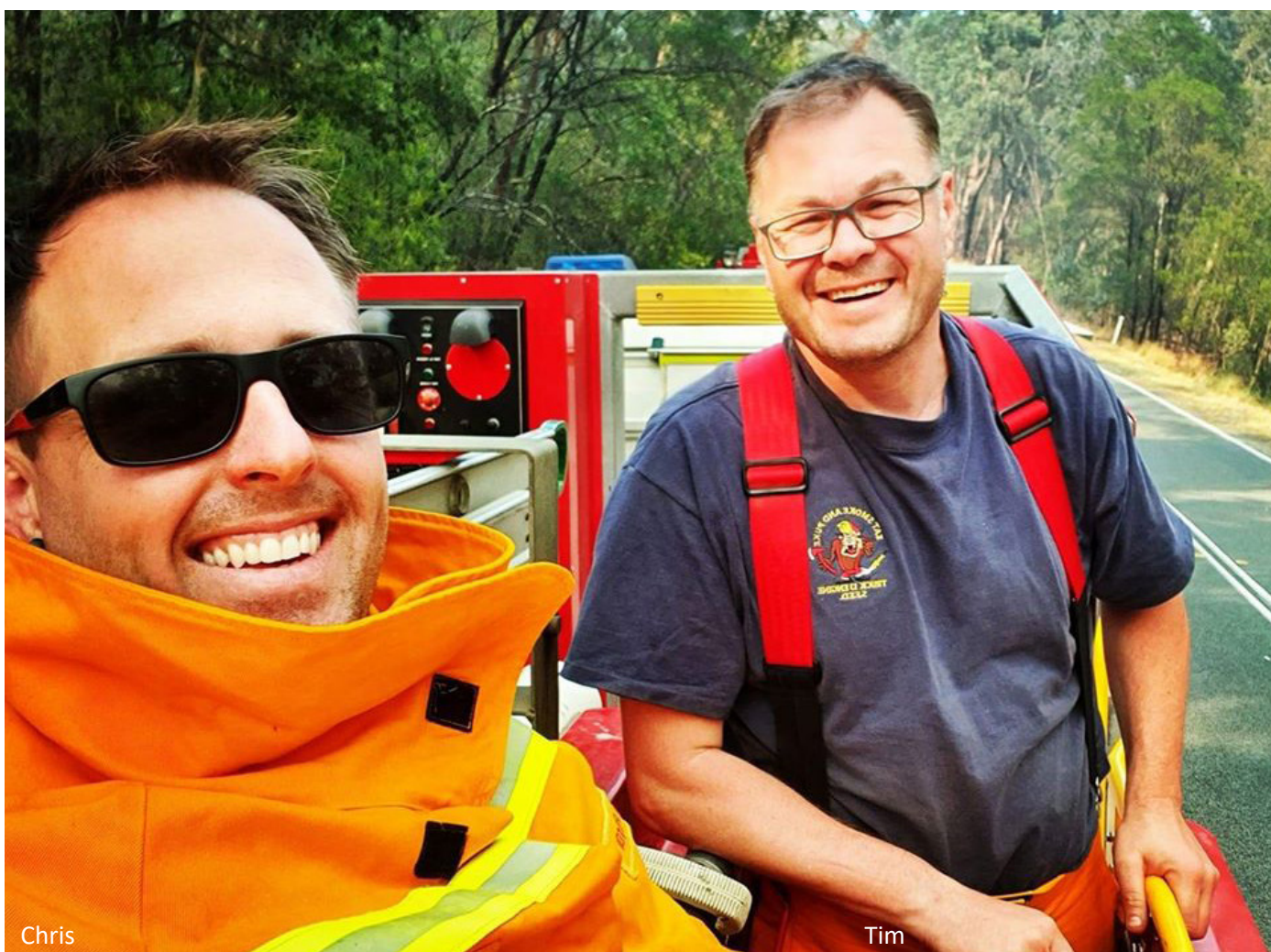
We are hoping to be able to offer more events during the year for families and loved ones. We are fortunate to have a diverse community to call upon and we are hoping to sort a family fun indoor soccer game.....stay tuned. If you can assist in organizing events and outings please give us a call. At the end of the day I remind you that HFV is a group of volunteer community members trying to make a difference for others that share a bleeding disorder.

Enjoy the magazine which is again packed with useful articles and thought provoking material to support all of us. 2020 will be a huge year. Regional visits, camps and peer support days, a fundraising ball, Albert Park walk and a World Congress in June in Kuala Lumpur....so much to think about and all great reasons to stay connected to HFV. Renew your membership and buckle up as it is going to be a great ride. Bring on 2020.... Stay well and look forward to seeing you around at our events.

Leonie Demos
HFV President

GRATITUDE & ADMIRATION FOR OUR CFA FIREFIGHTERS

I recently received this photo from Tim Marchinton from Purple Soup. Many of you know Tim very well from our camps. Tim is with Chris who is a HFV member, CFA volunteer and has haemophilia. They met by chance fighting the recent NSW bushfires. I certainly felt a huge sense of pride and gratitude on seeing this photo knowing that members of our community are represented at the CFA. I have since been in contact with Chris to get a better understanding of what his role is and the impact of the fires on those on the front line.



Chris

Tim

How long have you been involved in the CFA.

I have now been with the CFA for 13 years.

What training was involved?

At a minimum (to actually attend an incident) wildfire fire fighter training but after that training is ongoing from learning how alarms and sprinkler system works, wearing breathing apparatus, first aid medical response, to large scale incident management for such fires as you have been seeing in the news.

Has having haemophilia caused any challenges for you with regards to your CFA work?

I have disclosed my condition to CFA when I joined, and not had any challenges for doing so, just a Medical clearance from the doctor stating that I can undertake the work involved and the responsibility is on me to notify about any problems or bleeds I may have.

How do you manage your haemophilia when you are deployed?

Mostly the deployments only last a

few days but recently I was deployed to NSW originally for 3 days but that turned to 5. I have my prophylaxis before I go and take enough for the week and if needed I have prophylaxis in a cooler bag with me.

Where have you been deployed and how long for?

I was deployed to NSW Blue Mountains in December for 5 days the first and longest time I have been away since the kids have been born. Charlotte is 5, Oliver is 4 and Georgina will be 2 on ANZAC day. Over the years I have been involved with over 1000

fires including Black Saturday.

Is your employer supportive of your CFA volunteer work and what work do you do when not volunteering?

Until recently I was a driver for Veolia Waste who were very supportive of my volunteer role at the CFA. I now work in operations as a logistics officer managing trucks.

Can you describe what it is like as a volunteer CFA fire-fighter?

My role with the Brigade is as the 1st Lieutenant in charge of operations and running the brigade that consists of 70 members. Also, as the most senior rank within my brigade, the main roles on a fire ground that I have been involved with are fire prevention (both education and practical), crew leadership (in charge of the crew and truck), driving, assisting with establishing containment lines, fighting the fires. More recently I have been coordinating crews to and from the Gippsland fires, so far I have sent over 30 members to over 60 fires throughout December and January.

Obviously, these recent fires have been totally devastating. As bystanders we watch the news and see the enormity for the fires. Do you have a sense of that when you are in the zone or are you just focused on the job at hand?

Generally, for me, the training kicks in and you just do what you're there to do. Sometimes you might sit in the truck and wait for the fire to come and think you're wasting time but the guy in the house that hasn't slept for days can now sleep because we are there to help and let him rest.

Can you describe the scene and the heat of the fires?

There is no real time to think about that sort of stuff, there's a task that needs to be done. The heat can be unbearable at times and the scene can be hectic, but you do what you can to do your job.

Do you come across wildlife in need?

All the time, CFA trucks have wildlife kits in them but just like if it was a person - it's a life and we treat it the same as we would a person.

What are the best ways we can support our CFA volunteers in the future?

Attend their events or donate via the CFA website either to the Brigade or to the CFA as a whole.

Do you have a message for the community - what we should be doing for the future?

Get on the CFA website and see what you can do around



your home to make it safe for the season and all year round and teach your own family on what to do if there is a fire in your area.

What message can you share about living with a bleeding disorder?

I have not let things get in my way, I wanted to play football so I became an umpire. I wanted to join the army, but couldn't so I joined the Army Cadets. There are always other ways to get involved, you just need to see it from another angle.

You had a surprise meet up with Tim Marchinton, could you share a bit about that?

Tim and I have kept in touch since I was at a HFV youth camp back in 2007 but I was surprised to see him away and great to catch up whilst we had down time! Tim was on a truck as a crew member and I was the driver for another truck. We still continue to speak and I plan to get the family down his way and catch up out of uniform.

Many thanks to Chris for sharing his journey and thanks to both Chris and Tim for their commitment to the CFA and the incredible work they do.

WAYS TO DONATE TO THE CFA

www.cfa.vic.gov.au/about/victorian-bushfire-relief/donate

Currently there are 4 different donation options available:

- Donate to affected families and communities
- Donate to support the wellbeing of the volunteer firefighters
- Donate to CFA to continue the work they are doing to protect lives and property in Victoria
- Donate to help CFA Brigades fund their work in the local community

WHEEL OF WELL-BEING

BODY. MIND. SPIRIT. PEOPLE. PLACE. PLANET.

Research is showing us how our health and happiness can be boosted by doing certain things on a day-to-day basis.

The Wheel of Well-Being is your guide to some of them.

Start WOWing yourself now!

BODY: Be active...

Your body is the engine that powers your well-being. It's designed to move. Physical activities like walking, waltzing or wii-ing can positively influence the way you think, feel and function. Practicing an activity you enjoy for 30 minutes a day, 5 days a week, is a necessary ingredient for a long and happy life. Start Wowing your Body now.

PLANET: Care

Keeping our blue planet in tip-top shape is the best recipe for world well-being. It can sometimes feel like a hopeless task, but small positive changes like getting on your bike and switching off your charger, can make a big difference. Start Wowing your Planet now

PLACE: Take notice...

Noticing nature helps us press the pause button. It reduces the stress of our 21st-century 'hurry-worry' lives. Savouring our surroundings gives us, quite literally, more breathing space. Start Wowing Places now.



MIND: Keep learning...

Studies are showing that life-long learners are some of the healthiest, happiest people around. Our well-being can improve by taking up a new hobby, practicing the piano or even struggling with Scrabble. Start Wowing your Mind now.

SPIRIT: Give...

Did you know that giving to others does amazing things like reducing your blood pressure and improving your sleep? Practicing random acts of kindness, volunteering time, or simply saying 'thank-you' all work wonders for your well-being. Start Wowing your Spirit now.

PEOPLE: Connect

Close relationships with friends and family can add up to 7 years to our lives. That's the same benefit as giving up smoking! So plan a party or get together for a gossip to connect more with the people around you. Start Wowing People now.

SURFING THE WAVES OF LIFE

This is Will Donaldson. Many of you know young Will from our community camp and he was very much missed at camp this year but Will had received a very special invitation to compete in the State Championships for Surfing in Phillip Island. Will is an avid surfer and spends many hours in the water every week, come rain or shine. As much as we missed having Will and his family at camp this year we were so proud that he had the opportunity to compete at this level and not only represent himself but all those with haemophilia. Will is an exceptional role model and shows us that haemophilia is just a small part of who he is.

Like all of us with a health condition Will does have challenges along the way. A recent impact injury during a competition in Jan Juc stopped him from competing in the finals. He had worked so hard to get to the finals he was suitably devastated so surfing with haemophilia certainly isn't an easy road but his passion remains strong. Will manages his haemophilia to enable him to do the things he loves and builds on his resilience when things don't work out. I really look forward to watching Will grow up and follow his dreams, whether that be in surfing or other passions that he finds along the way. Maybe someone reading this will be inspired by Will and give surfing a go!

It is so wonderful to hear about all the different passions that our HFV kids have. I know we have some very talented musicians, artists, athletes, poets, cooks and the list goes on! If you would like to share something you are passionate about please contact julia@hfv.org.au as it is such a pleasure to share stories about people's lives and the activities that provide pleasure or motivation for when challenges arise. We also love to hear from siblings. Siblings often have very different experiences and offer a huge amount of support to their families, so please share what your journey is like as the brother or sister of a child with a bleeding disorder.

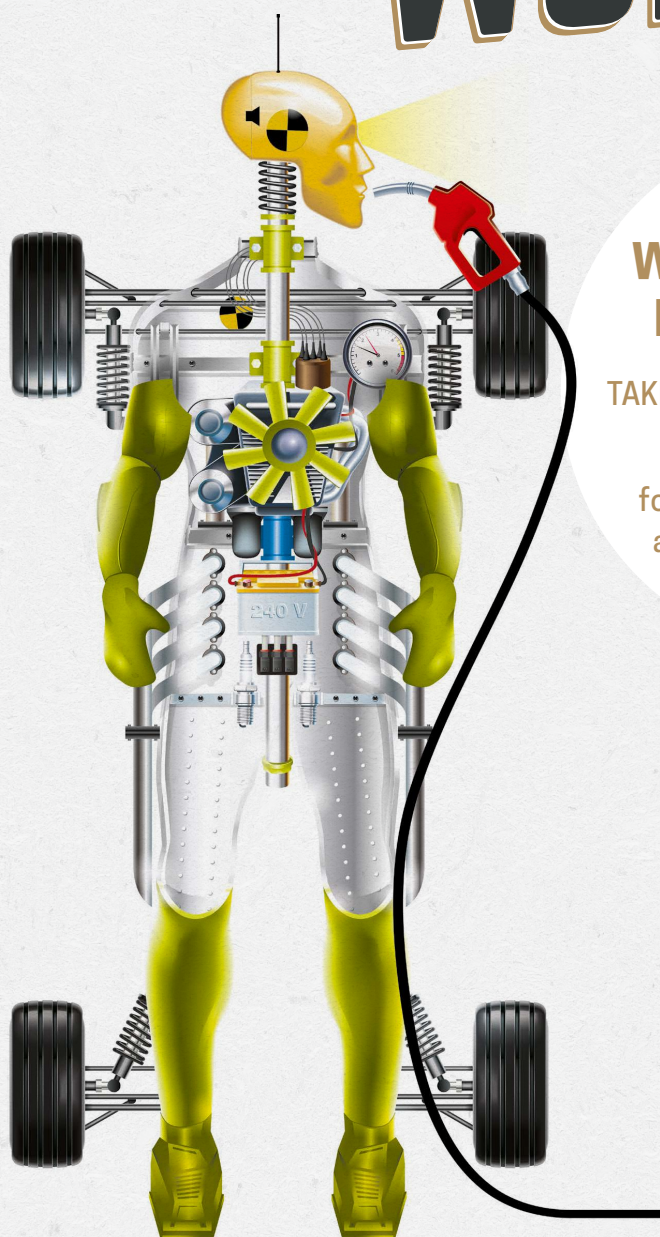


Pre-surf treatment



MEN'S HEALTH TOOL BOX

SPANNER IN THE WORKS?



**WHEN WAS YOUR
LAST SERVICE?**

TAKE CONTROL OF YOUR HEALTH

Visit malehealth.org.au
for maintenance details and
a road map to good health



SPANNER IN THE WORKS is an initiative of the Australian Men's Shed Association. To subscribe to the 'Spanner in the Works?' monthly newsletter send the word 'subscribe' and your email address to info@malehealth.org.au

SPANNER IN THE WORKS?

Us men can generally be quite particular about our machinery. It doesn't matter if we're farmers, office workers, timber workers, truck drivers, miners, corporate leaders or car owners – when a service is due on our machinery, we either do it ourselves, or we get a mechanic to do it. By following the proper servicing schedule, we can keep our machinery in peak condition and prevent costly repairs or damage before they become major issues.

Our most valuable piece of machinery is our own health and wellbeing. If we break down then we're unable to operate all the other machinery that we have. When it comes to looking after ourselves though we're generally not so good! We mostly don't have a "maintenance schedule" and tend to use a "wait and see" approach. If we get aches or pains, or we're going through a tough time emotionally, our attitude is often – "I'll battle through this". We get away with this most of the time.

Only when the aches, pains or difficult emotions are getting the better of us, do we make the decision to do something about it, and get things checked out by our mechanic (our GP).

We wouldn't ignore that timing chain rattle, that bearing rumble in our machinery, or a sudden drop off in our car's performance because we know they often lead to worse problems.

We want to encourage you to pay as much attention to the rattles and rumbles in your bodies as you do to your car or machinery. When we leave things too long before getting help, it can often take a lot longer to fix and sometimes our parts are too worn out to repair fully. This can lead to worry, frustration and long-term health issues. Use this guide to learn more about what you can do to check in on your own health.

"Spanner in the Works?" provides you with a maintenance schedule for your body, and some key health messages in a way that's understandable and achievable. It's not about telling you what to do but sets out some things that you can do (or not do) to improve your health and your chances of a longer, and happier life. Often, minor adjustments can have a major impact on your health, your relationships with loved ones, your friends and your work. Most importantly, we want you to put yourself over the pits each year by getting a full health check through your GP.

AUSTRALIAN MEN'S SHED ASSOCIATION

The Australian Men's Shed Association is the national service provider to more than 1000 Men's Sheds in Australia – providing practical support, specialised services and resources. The organisation aims to provide Australian men with the opportunity to improve their health and wellbeing through participation in the Men's Shed movement – strengthening communities and bringing men together to facilitate positive lifestyle choices and outcomes.

HEALTHY MALE

Healthy Male (previously known as Andrology Australia) is a national organisation that provides easy access to the latest scientific and medical research on male reproductive and sexual health. Our aim is to make this information available to everybody, regardless of gender, age, education, religion or ethnicity. To do this, we collaborate with Australia's leading researchers, specialists, clinicians and educators to develop information that fills the gaps in men's health.

www.mensshed.org
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from Men's Shed

2020 COMMUNITY CAMP

BUILDING FOUNDATIONS TO CONNECT SUPPORT & EMPOWER

Our 2020 Community Camp was based around the theme of building foundations to support ourselves and families. To build on the connections we have made at previous camps and to grow those relationships. The bridge building activities helped us to understand the crucial supports we can have in place to make our journeys easier. We are not alone and there are many supports that will help us along our journey. Our supports

are made up of our treatment centre staff, HFV, HFA, our GPs, our families, friends and the HFV community. Camp provides an opportunity to challenge ourselves, make those important connections and have fun in a safe environment.

We were so lucky this year to have 3 new families attend our camp. I am always amazed by the courage it must take to come to your first camp. These new families had travelled great distances to be with us and they brought so much to camp. We hope they left feeling more connected with us as a community and will come back for years to come.

As always the treatment sessions at camp are highlights. I know many people find this challenging in many ways. It is difficult for parents of young children to watch as this is their future, it is challenging for the boys and parents administering factor in front of a crowd, and some-



times without success. As frustrating as this is for the 'administrator' whether that be a parent or child it is the reality of treatment, sometimes it is not successful, and you might have to try again, maybe even a few hours later. But it is so beneficial for young families to see that. It might take a few attempts, we may need to come back later, that is okay. It is an education session that you will not find anywhere else. Tips and tricks directly from the guys and parents whilst they are infusing. They share challenges they have faced, fears they may have overcome and we couldn't be more grateful. To all those who have sat at those tables and treated yourself or your child thank you for your courage. For all those thinking about attending camp in the future...there is no expectation or pressure to ever treat in an open forum it is always only an opt-in session and if you change your mind half way through you can always opt-out.

To our campers who tried new activities and really challenged yourselves, we are very proud of you!

I often find the days after camp both inspiring and challenging as I reflect and digest all that has happened. Being at camp can be a confronting reminder of the challenges our families face so we always come away having learnt more and with a strong drive to improve our programs and strengthen our community. In

amongst the fun of all the activities, in the conversations on the boundaries is when we often hear the true reality of managing bleeding disorders, other conditions and all the other challenging aspects of life. When talking to one of our campers about challenges they were facing they said "It's just easier to put up a positive happy face and have the struggles hidden a little. And try and keep going with lots of support and positive feedback". This is an incredibly poignant remark. We often try to present ourselves to the world with a 'positive happy face' but I am sure there isn't a single family that attends camp that hasn't faced challenges and keep those struggles hidden a little. Camp is there to offer that support and positivity and be a soft place to fall if those struggles do need to be aired.

Julia Broadbent

A surprise
WEDDING
at camp...

Congratulations
Mr & Mrs
Inglis



This year was a particularly special camp as we were invited to celebrate the marriage of Ben Inglis and Samantha Smith.

There were a few gasps when Ben's 'skit' was in fact a wedding! The sun came out and the setting couldn't have been more beautiful.

Ben shared these words with us...*"The love and support I have felt through 15 years of camp has been a huge part of who I am. I know this is real because even in the fewer years that Sam has been here she has felt it too. I cannot keep her away anymore than I can keep myself away. I love each person here and we could think of no people closer to us than those right here, right now. Thank you for coming to our wedding!"*

To Ben and Sam, we felt privileged that you chose to share your special day with you HFV family. Wishing you both all the very best for your future together!





Achieving the extraordinary together





ASK US

Q AND A'S WITH ALEX & JANE - ALFRED HOSPITAL HTC TEAM



I am up late and find it hard to go to sleep at night, what could help me? Sleepless in Shepparton

Dear Sleepless in Shep,
Sleep is so important for people with bleeding disorders, and sometimes the pain, recovery from bleeds can cause you to have difficulties with sleep. About one in three people in general have insomnia at times. "Insomnia is a symptom, not a disease. It means being concerned with how much you sleep or how well you sleep. This may be caused by difficulties in either falling or staying asleep." If you have had sleeping problems for a long time you might benefit from some professional help. You can start by talking to your GP and maybe getting a referral to a sleep disorder clinic.

There are some good simple strategies to help you to improve your sleep. These can be surprisingly challenging as they involve changing your habits and routines, but it is definitely worth giving it your best shot as they can make a huge difference. People keep themselves awake by worrying about going to sleep. Remember that not having enough sleep will not cause you any more harm, and if you can't sleep then if you are resting you are getting some of the benefits of sleep anyway.

Home remedies for short-term insomnia.

Reducing anxiety and sticking to a day–night routine can improve sleep quality. Suggestions include:

- Don't nap during the day.
- Cut down on smoking and drinking.
- Avoid tea, coffee and other caffeinated drinks before bed.
- Don't exercise strenuously before bedtime.
- Do something to relax, such as meditate or have a warm bath.
- Only go to bed if you feel sleepy.
- Go to bed later.
- Stop reading, worrying or watching television in bed and limit your activities in the bedroom to sleeping and sex.
- If you can't sleep, get up, go to another room and do something else until you feel sleepy again.
- Get up at the same time every morning regardless of how much sleep you have had.
- Avoid 'judging' your sleep on a day-to-day basis.

Treatment for long-term insomnia

Insomnia that has persisted for years needs professional support and a lot of patience. It might take some time to re-establish normal sleeping patterns.

Some of the techniques used by a sleep disorder clinic might include:

- A sleep diary, to help pinpoint the pattern of insomnia
- A program of mild sleep deprivation
- Medication to help set up a new sleeping routine
- Exposure to bright light in the morning
- Behavioural therapy.

Your HTC social workers are well placed to support you in working on this issue, so pop in or call and have a talk about what's going on for you.

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

References:
<https://www.betterhealth.vic.gov.au/health/conditionsandtreatments/sleep-insomnia>

LIVE WELL FUNDING

HAEMOPHILIA FOUNDATION VICTORIA

**Have you been affected
by the bushfires?**

**The LIVE WELL program may be able
to offer some assistance to you.
Please contact us to discuss ways
we may be able to help.**



What's it all about?

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. The program aims to improve the health and well being of members. Although there is no absolute limit, as a guide, previously approved Live Well Grants have generally been for amounts of between \$50 and \$500.



There are a few important points:

- Live Well is available to current HFV members. (The membership fee may be waived due to financial hardship)
- Any application received will be de-identified meaning only the Executive Assistant (Andrea McColl) will know the name of the applicant
- Those with bleeding disorders and their carers can apply
- Amount guide \$50 - \$500

What has been applied for previously, including partial subsidies:

- Wheelchair modifications
- Wheelchair hire
- Swimming lessons
- Crutches
- Orthopaedic mattress
- Handrails
- Ankle brace
- Shoe orthotics
- Massage
- Long term hospital admission TV hire



Application forms can be found on our website under services.
www.hfv.org.au/support-services/services

Connect Support Empower

Friday 17 April



Join us to celebrate **World Haemophilia Day** on Friday 17 April 2020 with the Australian Premiere of Bombardier Blood followed by a ride on the Melbourne Wheel as it turns red in support of the day! This is a family event.



Bombardier Blood is a powerful documentary about Colorado-based Mountaineer Chris Bombardier, who has never let haemophilia stop him from climbing some of the world's tallest mountains. In 2017, Chris partnered with filmmaker Patrick James Lynch, who also has haemophilia, to film his journey through Nepal to summit the world's tallest peak, Mount Everest.

Tickets are on sale -

<https://www.trybooking.com/BIPRL>

\$28A and \$23C inc Movie and Melbourne wheel ride (movie only tickers are available)

(Pls note this is not a fundraising event, ticket price are cost neutral.)

massage relaxation meditation mindfulness

GUYS

are invited to attend the
Haemophilia Foundation Victoria

2020

WITH

MEN'S

RETREAT

BLEEDING

FRI 20 – SUN 22 MARCH, 2020

LOCHINVER FARM HOMESTEAD, CARISBROOK

FOOD & ACCOMMODATION PROVIDED BY HFV

DISORDERS

For bookings please go to www.trybooking.com/BHEUJ

For more information contact Zev Fishman on 0419552695 or speak to our HFV staff on 9555 7595

THE HAPPINESS INSTITUTE

Dr Tim Sharp is Australia's very own 'Dr Happy', at the forefront of the positive psychology movement as founder of The Happiness Institute. Dr happy presented at the recent Sydney Bleeding Disorder conference and offered a real insight into happiness and practical ways to achieve it. It was both fascinating and uplifting and we came away with the skills to bring a little bit more happiness into our lives and the lives of those around us.

THE HAPPINESS INSTITÜTE

Achieving happiness requires nothing more than practicing a few simple disciplines, every day.

At The Happiness Institute, we believe happiness is something you choose. And we've specifically chosen the word "choose" because each of its letters stands for one of our key happiness strategies.

- C = Clarity (of goals, direction and life purpose)**
Happy people set clear goals and determine clear & specific plans to ensure these goals become reality. So clarify your life plan now (because no one else will do it for you!).
- H = Healthy Living (activity & exercise, diet & nutrition, and sleep)**
Health forms a crucial part of the foundation to happiness. It's hard to be happy if you're literally sick & tired all the time. So do whatever you can to be healthy and you'll also boost your chances of being happy.
- O = Optimism (positive but realistic thinking)**
There's no doubt that happy people think about themselves, others and the world differently. Among other things, they search for more positives. The good news is that this is something you can learn to do so start practicing now.
- O = Others (the key relationships in your life)**
Research strongly indicates that happy people have both more and better quality relationships. So make sure you devote time to developing and fostering your key relationships.
- S = Strengths (your core qualities and attributes)**
Rather than spending all their time trying to "fix" their "weaknesses", happy people spend more time identifying and utilising their strengths. Find out what you're good at and do it as much as possible.
- E = Enjoy the moment (live in, and appreciate the present)**
The past is history, tomorrow's a mystery, and today's a gift – that's why they call it "the present". Live in the moment and enjoy life more.

**So CHOOSE to be happy now!
Because life's too short not to be happy.**

Dr Happy is the best-selling author of multiple books and a regular on Australian and International TV, Dr Happy is widely regarded as a leader in mental health and the authority on all things happiness in Australia. With three degrees in psychology (including a Ph.D.) and an impressive record as an academic, clinician and coach, Dr Happy is a passionate professional with a wealth of experience both on the field and in the media. Actively involved in research, education and practice, he is the founder and CHO (Chief Happiness Officer) of The Happiness Institute, Australia's first organisation devoted solely to enhancing happiness in individuals, families and organisations.

FOR SOME REALLY VALUABLE RESOURCES, PLEASE GO TO WWW.THEHAPPINESSINSTITUTE.COM

EQUITY FOR PEOPLE LIVING WITH A RARE DISEASE



EQUITY FOR PEOPLE LIVING WITH A RARE DISEASE

is equitable access to **diagnosis, treatment, health, social care and opportunity**

What equity means for people living with a rare disease?

Equity in practice means meeting people's specific needs and eliminating barriers preventing their full participation in society. For people living with a rare disease equity means social opportunity, equitable access to health and social care, diagnosis and treatment.

On Rare Disease Day we call for action for people living with a rare disease to have equal opportunities to realise their potential for participation in family, work and social life.

The long-term goal of Rare Disease Day over the next decade is increased equity for people living with a rare disease and their families.

The challenge

The **300 million people** living with a rare disease around the world and their families face common challenges in their daily lives. As a vulnerable and neglected population they face social isolation.

There are over **6000 rare diseases** that are chronic, progressive, degenerative, disabling and frequently life threatening. Due to the rarity of each individual disease and scattered populations, expertise and information is scarce. In health systems designed for common diseases patients face inequities in accessing diagnosis, care and treatments.

People living with a rare disease also face discrimination at work and school. In a EURORDIS [Rare Barometer survey on 'Juggling care and daily life: The balancing act of the rare disease community'](#) 94% of the respondents who reported difficulties in accessing higher education declared that the disease has limited their professional choices.

Key statistics on rare diseases

- Over **300 million people** around the world are living with a rare disease.
- There are **over 6,000** identified rare diseases.
- **72%** of rare diseases are genetic
- **70%** of genetic rare diseases start in childhood.

Research recently published in the European Journal of Human Genetics, article authored by EURORDIS-Rare Diseases Europe, Orphanet & Orphanet [Ireland "Estimating cumulative point prevalence of rare diseases: analysis of the Orphanet database"](#).

OUTER METRO & REGIONAL VISITS 2020

We currently have Moe, Melton and Bendigo marked as our regional visits locations for 2020.

We are planning on visiting Moe on Thursday 7th May. We will be offering members and their partners / families in the Moe area, an opportunity to join us for dinner at a local venue.

Information will be mailed directly to potential participants. If you are in the area and would like to attend and do not receive an invitation please contact our office on 03 9555 7595.

We would love the opportunity to meet with you and get to know you, share a little about our HFV programs and learn about the challenges you may be facing living with a bleeding disorder.

Check our website for further details www.hfv.org.au.

If you live within a 75km range of Moe you should receive an invitation. If you live further a field you are more than welcome to attend - just give us a call!

The HFV Team



Magical Moments



We are so grateful to Rayleen Slegers from Hummingbird Pictures for volunteering her time to attend our 2020 Community Camp to provide our members with the opportunity to have a very special photo experience. Rayleen creates these magical moments through a mix of the lens, her incredible skill and vivid imagination. Rayleen spent many hours with us getting to know our members and enjoyed creating these magical moments which have been gifted to our participants.

Rayleen covers many aspects of photography including contemporary & glamour, portraits, family and children, real estate & property, corporate and events.

Rayleen has been so very generous with her time to HFV, not only on the day but behind the scenes in creating these magical artworks. If you are looking for photography services in the future please support Rayleen. You can view more of Rayleen's work at: www.hummingbirdpictures.com.au or call 0417 564 634.

We will be emailing campers soon with their individual 'Magical Moment' images!



HFV Noticeboard

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

SAVE THE DATE!

Following on from the overwhelming success of the first Hemophilia Ball we are ready to do it all again!

Come and join us on

Saturday 17th October 2020

THE HAEMOPHILIA MASQUERADE BALL 2020



Located in the Main Ballroom,
Hawthorn Arts Centre, 300 Burwood Road, Hawthorn

HOW CAN YOU HELP MAKE THE NIGHT A HUGE SUCCESS?

We are seeking 'experiences' to auction off on the night....do you have any connections which could lead to items that otherwise be bought or donated. For example, backstage passes to concerts or theatre productions, corporate box seats to events, accommodation availability in any of the most visited areas of Victoria for example Yarra Valley, Great Ocean Road etc.

If you can help, please contact HFV at info@hfv.org.au for further information.



**It's not too late to complete the PROBE questionnaire!
(Patient Reported Outcomes Burdens and Experiences)**

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

Or ask HFA or your Foundation for a print copy



HOW WILL PROBE HELP PEOPLE WITH HAEMOPHILIA?

PROBE is a multinational study where Australians can give evidence about living with haemophilia and the impact of different sorts of treatment on their bleeds, pain and quality of life.

HFA will use the data to better understand current issues - and this data is crucial for our treatment advocacy.

You are invited to complete the survey if:

- you are an adult with haemophilia or carry the gene
- or you are an adult and DON'T have a bleeding disorder (as a comparison group)

Consider being involved to help us with this important study!

HFA have already been able to view some early Australian data results from PROBE. The data is significant and will be crucial in further advocacy for our community. If you haven't already participated in PROBE or know of family or friends with or without haemophilia, please ask them to participate. It would be wonderful to have the full support of our HFV community behind this vital international study. Thanks for your support!

HAEMOPHILIA FOUNDATION VICTORIA INC

13 Keith Street

Hampton East VIC 3195

Phone: 03 9555 7595

Mon - Thurs 8.30am - 4.30pm

* Due to the NBN we can no longer offer a fax service

info@hfv.org.au

www.hfv.org.au

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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

Membership Annual Fees:

\$33.00 Standard family membership

\$16.50 Concession / Allied (Youth Free)

\$55.00 Organisational member

* 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.

MedicAlerts

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.

MEN'S GROUP

Our current group meet for their Annual Men's Retreat – a much needed week-end 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 each alternate year get to enjoy an event with a twist. They have previously learnt circus skills, African drumming, attended relaxing massages, high tea on the Yarra and lunch on the Tram Restaurant.

YOUTH GROUP

The Youth Group aim to meet up during the year to participate in activities like laser skirmish or bowling and 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!

WE ARE CURRENTLY LOOKING FOR A NEW CONVENOR FOR THIS GROUP. IF YOU ARE INTERESTED PLEASE CONTACT THE HFV OFFICE.

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.
This year we are hoping to organise a indoor soccer session - dates to be confirmed!

HFV PLANNER

MARCH	MENS RETREAT 20-22		HFV AUTUMN MAGAZINE	COMMITTEE MEETING 18
APRIL	MOVIE NIGHT & MELBOURNE WHEEL RIDE 17	WORLD HAEMOPHILIA DAY 17		
MAY	MOE REGIONAL VISIT 7			COMMITTEE MEETING 20
JUNE	LADIES DAY Date TBC	WFH WORLD CONGRESS KUALA LUMPUR 14-17	HFV WINTER MAGAZINE	COMMITTEE MEETING 24
JULY	BOYS EVENT Date TBC	WORLD HEPATITIS DAY 28		
AUGUST	MELTON & BENDIGO REGIONAL VISITS 26/27			COMMITTEE MEETING 19
SEPT			HFV SPRING MAGAZINE	COMMITTEE MEETING 30
OCT	WALK FOR BLEEDING DISORDERS TBC	2020 HAEMOPHILIA RED MASQUERADE BALL 17		
NOV	AGM & CHRISTMAS PICNIC 15			COMMITTEE MEETING 18

Please check our website regarding events as all dates are subject to change



Kuala Lumpur, Malaysia • June 14-17

THE LARGEST INTERNATIONAL MEETING FOR THE GLOBAL BLEEDING DISORDERS COMMUNITY

wfh.org/congress

Hosted by



Organized by



WFH

WORLD FEDERATION OF HEMOPHILIA
FÉDÉRATION MONDIALE DE L'HÉMOPHILIE
FEDERACIÓN MUNDIAL DE HEMOFILIA