

# THE MISSING FACTOR

***FEAR OF NEEDLES***  
**What can  
parents do?**

Campers shared stories  
**HIT THE MARK**

connect • support • empower





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HFV is committed to Child Safety.

Our Child Safety Statement is available for review on our website [www.hfv.org.au](http://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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# PRESIDENT'S REPORT

*"What good is the warmth of summer, without the cold of winter to give it sweetness." — John Steinbeck*

Welcome to Winter. Although none of us welcome the coldness in our face, it is a great time to snuggle up to a great read with The Missing Factor.

HFV continues to work tirelessly to support the community and hope that some of you will brave the cold weather to join us on the regional visits. We had a great trip to Gippsland in recent weeks and it was lovely to catch up with some of you and meet others for the first time. The next visits will be in the Central, Goulburn Valley and Ovens and Murray regions and I hope that you are able to join us in August. Everyone is welcome including those in the metro area that would like a regional short stay. Think about joining in the fun.

In my role, I am able to work closely with HFA in a national space. It is an opportune time to mention our peak body and to thank them for the tireless work they all do. Sharon Caris leads an amazing team and they work so hard in diverse roles to support the work of HFV behind the scenes. With so many developments happening for our community with new treatment products and trials it is critical that HFV is represented at a national level by HFA to continually advocate for the needs of our community to key levels of government. I attend quarterly meetings with HFA to work closely with the staff and Presidents from other state foundations to ensure we present a united voice nationally, as well as a way to ensure communication from a national space to our state equivalents and as importantly for us to feed your voice to the national collective.

At HFV we will endeavour to keep

you informed of key developments in treatment improvements and other relevant trial information. However, as always, we encourage you to discuss with your health team any concerns or questions you have about the best options open to you. HFV support the HTC's in the amazing work they do along with HFA in their advocacy to government for our community to be able to access the best health treatments possible for them. All of us at times are guilty of a few complaints about our experiences over our health journey about the level of care we think we may not be getting and being what we need. However, I am sure you will all join me in acknowledging the overall level of experience and comprehensive care we, as Australian citizens, enjoy and expect in our general day to day wellbeing.

At our recent fabulous Community Camp we were truly humbled by some new members that joined us. These were members of our community from less developed parts of the world and to hear their stories that they generously shared about their lack of treatment or health care in their homeland was a wakeup call to us all to celebrate the level of care we enjoy and to take a moment to thank those that all work together comprehensively to care and support us, regardless of the occasional hiccup.

Community camp presented many proud moments to me as President. Too many to share but the welcoming nature of our members to embrace others from other lands and not let migration status or language get in the way with welcoming people with a shared life experience of dealing with chronic bleeding disorders made me so proud of HFV and all it stands for in our work of connect, support and empower. Many very proud moments indeed.

The richness of the stories continually shared at camp and HFV gatherings never ceases to amaze me. The generosity of others to share their story and to do so to support others is a privilege to be around. For those that have thought about joining us at an event but haven't quite made it yet I strongly encourage you to join us and meet some of the amazing people we have in our community. I guarantee you will not regret it.

I would like to take time to share a very private but special moment that is directed to some of you that were at RCH during the same time as my journey. For my current paid employment, I have the pleasure of doing some rural visits across Victoria. I walked into one of those agencies this week and was being introduced to their team. I was so delighted to reconnect with Tessa Speller, whom some of you may have known for many years at RCH. Tessa sends her best to those families that she supported and was delighted to hear about HFV's growth and that people are doing so well. On behalf of HFV, I was able to thank Tessa again for the amazing support she provided to many of us in critical times in our lives and reassured her that RCH continues to provide excellent support with Janine and the team, but that she is still often in our thoughts.

Wrap up and stay warm for winter. Enjoy the magazine with a cup of hot chocolate and marshmallows. Take care of you and your families and hope to see you all somewhere soon. Remember anytime you need a chat about anything HFV related HFV and the team are waiting for your call or email.

Leonie Demos  
HFV President

supporting our community TOGETHER

# COMMUNITY

## CAMP!

## To Haemophilia or not to Haemophilia?

The excitement of the family camp still runs high after days in Anglesea, packed with activities for the entire haemophilia community members including families, organisational staff, and professionals. I have decided to share my insights about some of the true benefits that the haemophilia family camp delivers. As a mother of children with haemophilia who have been to the camp, it is easy for me to say how crucial and beneficial this annual program is through experience. Here, I aim to explain the critical role the camp plays in our lives, hoping to convince those who have never been to the camp to come, as well as the government stakeholders to keep valuing the continuity of the program.

### **Staying within social norm – What does ‘How are you?’ mean to me?**

My children and I have faced many challenges throughout our lives in relation to the condition. First diagnosis, bruises, mouth bleeds, worries of how to manage everything, port insertion operations, inhibitors, panics over unknown, protest from your child over factoring, not being able to find veins and missing them! The families you meet at the camp have been through it all. I was asked how our year has been, and we say “all good”, because those events and worries are our social norm. It is very different from when I try to put on a brave mask or

play tough mum. I genuinely feel that there were no dramas, and I have no feelings of “wanting to be understood”. No one is Mr/Ms “oh-you-poor-thing” here. The only time we say ‘you poor thing’ is when we really know what it is like to be in such a situation. No sympathy, only compassion. The camp confirms this and greatly contributes to our mental well-being.

### **Activities – Does haemophilia matter?**

Activities offered at the camp range from gentle exercise including morning walks and yoga, to more physically challenging games such as high ropes and the ‘leap of faith’. The people from Purple Soup and parents have witnessed children grow and develop over the years. My 10-year-old, Yamato, was more willing to observe all the activities at his first camp. This year, when I asked which activities he had participated in, simply because I didn’t see him around until dinner time, it turned out he was busy participating in archery and rock-climbing all under supervision of the youth leaders. The ‘I cannot/may not be able to do something because I have haemophilia’ card cannot be played here, as you see children and adults (with/out haemophilia) so willingly challenging themselves as well as encouraging and supporting one another. My daughter, too, is included. She looks up to one particular youth leader without haemophilia, who

is welcoming, compassionate, and inclusive. Children are empowered by witnessing others challenging themselves and setting a great example on growing up as powerful individuals. In the end, we all help each other build our physical strength and self-confidence, with the camp a perfect platform.

### **Administering Factor – The power of experience**

How convincing would it be if I talked to my sons about the importance of factor and how self-respect leads to a path to becoming a responsible individual. I don’t have haemophilia. I cannot be a role model for the condition. I don’t even know what it feels like when factor flows into a vein. I have no idea what it feels like after a port removal. To increase awareness, I visit my children’s school every year to explain and share haemophilia facts. Children at the school know that Yamato and Hinata need factor every now and then, I need to inject them intravenously 3 times a week, and that Yamato is learning to inject himself. We showed pictures of Yamato injecting himself and children showed a great interest in the process. We explained how I miss the vein every now and then and that veins are sometimes very hard to find, especially in winter, but that we eventually manage to succeed. At haemophilia camp, there is a special room set up where you administer factor. This is where



“seeing is everything” happens. All of us have tried various strategies to help, support, and convince children (and ourselves) to prepare factor independently, help children administer factor by themselves, shift from port to vein, and stop using local anaesthetic cream before injection. For some families, years of stress, trying, suggesting, and encouraging will come to an end here. A very well-known magic trick is whereby children become determined to self-infuse after watching others administering or seeing another child quitting numbing angel/Emla cream before factor. Upon seeing others do their factor, looking cool, children and families want to have a go too. Motivation and courage are what you bring home from camp.

### ***True meaning of understanding – Sharing a sense of achievement***

Yamato started to self-administer factor without the use of local anaesthetic cream, and I was watching him prepare. There were a group of boys watching Yamato. They were complementing how “pro” he was at attaching the tourniquet and the precision and angle of the butterfly needle landing into his vein. When there was a flush back into the tube of the needle, the boys cheered with loud happy voices and tremendous excitement. Then I saw the biggest smile on Yamato’s face I have ever seen. Who on earth has ever been so excited for my son for doing factor. I thought I was. I thought that the children at the school who shared and understood Yamato’s journey were. The camp showed me that the boys at the camp were the ones who truly understood how special his life with haemophilia is. Knowing the frustration, experiencing worries, understanding nervousness, not being able to find a vein, leakage, having to have to attempt it again – the lot. In a sense, the cheer sounded almost like cheers

coming from team members after a successful goal in football. I found that they are team mates in life and, as long as their life with haemophilia continues, they shall continue to share this true sense of achievement.

### ***The power of siblings and children without haemophilia – Lest we forget!***

Boys will be boys, and haemophilia camp definitely delivers a focus on the well-being of each individual. I observed that having haemophilia does not really matter when it comes to making friends. Everyone interacts great with one another, regardless of haemophilia. It is clear that children do not discriminate and that the camp values inclusiveness and ensures that individuals feel secure.

### ***Possible outcomes – An effective approach towards educating all***

What haemophilia camp offers is an extremely effective way of educating the community. Education about social interaction, resilience, self-autonomy, self-confidence, physical strengths, self-respect in relation to managing the condition, independence, motivation and compassion. These life skills will reduce the risk of, or help avoid, managing issues which we may experience, such as depression, anxiety, panic attacks, social isolation, self-accusation, as well as poor management of the condition itself. I cannot thank the staff and the families enough for their dedication and the love they put into our community.

Nao Ikoma  
HFV Member

**We all have a story to tell. If you would like to share your story with our community, please email [julia@hfv.org.au](mailto:julia@hfv.org.au)**



## PREVENTING FEAR OF NEEDLES:

# WHAT CAN PARENTS DO?

**Dr Moana Harlen is the Senior Psychologist Haemophilia at the Queensland Haemophilia Centre, Lady Cilento Children's Hospital, Brisbane**

### FEAR OF NEEDLES

I can't say that I have heard any child or adult say they like having a needle, can you? Fear of having a needle is a matter of degree. So at one end of the spectrum there are those individuals who have no fear and simply shrug their shoulders and say "it's not that bad" and will go through the procedure without any hesitation. Whilst at the other end of the spectrum there are those individuals who have an intense, irrational fear of needles (needle phobia) and will become extremely anxious at the mere thought of having a needle and will do anything to avoid having a needle. Most children and adults will sit somewhere between both ends of the spectrum.

For children with bleeding disorders, having frequent needles as home therapy and/or as hospital procedures may increase their chances of having traumatic needle experiences where they experience it as painful and highly distressing. Such experiences can increase their chances of developing a strong fear of needles which can become problematic in managing their bleeding disorder. The good news is most children do not develop this strong fear of needles, although there are still many things that parents can do to increase the likelihood that their child will not develop a needle phobia and to increase their resiliency.

### FEAR IS A NORMAL RESPONSE TO THREAT

Firstly it helps to understand the



physiological and psychological mechanisms at play with anxiety around having a needle. When a human's mind perceives some level of threat from the environment, be it real (about to have a needle or there is a growling dog nearby) or imagined (thinking about having a needle or picturing being bitten by a dog) this will trigger fear which involves 3 types of responses.

- **Physiological responses within the child's body:** e.g. the stress response is triggered in the part of the brain called the amygdala which is responsible for emotional arousal and sends signals to other parts of the brain so that stress hormones (e.g. adrenaline and cortisol) are released preparing the body to run away to safety (flight), to fight or freeze. Think of the last time you were afraid and how your body responded. Most people notice increased heart rate and breathing and feeling more energised. Vision and hearing become sharper etc. An anxious child will feel pain more acutely than a more relaxed child. Don't be surprised if your child wants to go to the toilet or complains of a sore tummy before a needle; that's part of the stress response.

- **How the child feels and thinks:**

A child may think anxious thoughts such as "This is going to hurt" "People are going to hold me down like last time and I don't like it". Such thoughts can come from previous experiences of pain and distress or from overhearing others talking negatively about having a needle or perhaps they saw someone else become distressed when having a needle. Worry increases feelings of anxiety.

- **How the child behaves:** e.g. When a child starts to kick, struggle and/or is screaming and crying it is important to view their behaviour as due to being afraid rather than thinking they are misbehaving.

### HELPING YOUR CHILD TO FEEL SAFE AND SECURE AND TO MANAGE THEIR EMOTIONS

Prevention is the key. The main aim of teaching your child to regulate their emotions is to increase their sense of control and their sense of safety whilst being accessed. The idea here is that instead of being a "helpless recipient" they can be an "active participant". You do not need to wait until your child is going to have a procedure or until they become afraid to introduce these strategies you will probably find you are already doing a lot of them but



it's nice to know you are on the right track.

### For a child to feel safe and secure they need:

**1. To be able to predict what is going to happen.** This is why providing children with routines is important. They know what is going to happen next based on what they are doing now e.g. after breakfast I brush my teeth and then I can play. This reduces fear of the unknown.

- Making treatment predictable is important for this reason. It helps to keep things the same as much as possible so where, when, who and how treatment is done. This will help your child's thinking and feeling, e.g. "I have my factor before (or after) breakfast".
- Create steps in treatment that your child knows and they can say what is happening next; make it a fun thing.
- Be honest about what is going to happen if in a hospital setting; prepare them for the procedure. Best not to say "it won't hurt" or "you won't feel a thing". Better to say "you might feel a little sting but you'll be fine".
- Counting 1, 2, 3 and pushing the needle on 3 so they will know when the needle will go in. They can count as well. "Ok, let's count together 1, 2, 3".

**2. Some sense of control over what is going to happen.** Having a sense of control is important for children and adults. So offering some choices during treatment where practical, e.g. if a child has a port they could be offered the choice of lying down or sitting up or which toy they would like. If a support person is helping they could ask if the child would like to hold their hand or rub their leg. A child about to have a butterfly needle could be offered the choice of which vein they prefer or which song would they like to hear or sing. For adolescents allow them to have as much control as possible.

**3. To have calm parents even when things aren't quite going to plan.**

Adults teach children how to man-

age their emotions by showing and talking about how they manage their own emotions. Adults can often role model being anxious and are not aware they are doing so. Therefore it is important for adults to act calm even if they don't feel it inside whatever the emotion might be, e.g. anger, anxiety, or sadness. If a child sees a parent with a worried look on their face then they will think they have something to worry about. It is OK to say if you are nervous so long as you follow up with how you are going to cope. Remember children learn by watching how others react. Behave the way you want them to behave, so kind smiles, calm voices and doing some deep breathing yourself.

**4. Distraction strategies.** This helps keep a child's mind occupied so they pay less attention to the needle. This is a very effective pain management strategy. Distraction is best started prior to the access to help keep them relaxed for a longer period of time and used all the way through the procedure until it is all over. There are many distraction strategies suitable for different ages.

### FOR VERY YOUNG BABIES AND TODDLERS

- Nursing/holding
- Soother
- Blowing bubbles or party blowers. You can keep this as a special activity for treatment so the novelty takes longer to wear off.
- A noisy interactive toy to encourage them to look away
- Sing favourite songs or make up a song about having factor, e.g. Think of a fun upbeat tune like "you are my sunshine" or the Bingo song and change the words to something about its factor time again.
- Use your smart phone to play their favourite songs or cartoons as it is easy to hold in front of their face. Again they could have a special one just for treatment time.

### FOR OLDER CHILDREN

- Talking and questioning them. What's their favourite subject or hobby? Can they count backwards or some simple arithmetic if they like maths.
- Music
- Hand held games, find it books
- Guided imagery – imagining a favourite or happy place
- Doing deep or tummy breathing
- Being massaged by parent

**5. Play therapy** – Children learn through play and play is very therapeutic. You can buy a teddy bear and sew a pretend port on its chest and this can be used to familiarise your child with having a port. Young children love role plays and using their imagination. You can use the bear as a role model and pretend to talk to teddy and say how good he is at sitting still. Your child could pretend to give teddy their factor and take teddy through the same steps your child will be going through. The same can be done for any upcoming medical procedures.

**6. Emotional support** – this is a big one. It is very, very important to identify and acknowledge how your child is feeling. If you see them upset or afraid, let them know you understand they are afraid. This helps them to become aware of their emotions which is a necessary step for them to be able to manage emotions.

- A word of warning here, do not confuse empathy with sympathy, it is unhelpful to say comments like "you poor thing" or "my poor baby" as this can lead to them feeling sorry for themselves. It is much more empowering for a child to hear "I can cope" messages which will help them to grow up believing they can cope with haemophilia. It's a matter of finding the balance between empathy and setting limits. A matter of fact approach is more helpful, for instance, "I know that you don't like this and that's OK (empathy) but you have to have your factor so that you can run around and play, so remember your job is to help

Mummy or Daddy by lying nice and still so we can get it done quickly and easily (setting limits)".

**7. To learn coping strategies** – as children grow older they learn to self-soothe rather than rely on their parents to regulate their emotions. Sometimes they need some extra strategies to increase their coping ability whilst being accessed. Lots of practice is needed for these strategies to become more automatic so the more they practice (in a fun way) in daily activities and games the easier it will be for them to apply the coping strategies when starting to feel anxious. The point of the strategies is to prevent the anxiety from getting so big that they cannot cope.

**Relaxation strategies** – you can teach young children relaxation through games like "sleeping tigers" or "statues" so they practice lying still. Older children can use guided imagery or progressive muscle relaxation.

- Tummy breathing – deep breathing helps to relax the body or reset the stress response. Young children can learn to take slow deep breaths by blowing bubbles very slowly so they don't pop.

**Using coping language** – when children feel scared or nervous they can use coping words to help themselves feel better. Children learn positive self-talk from what they hear others say to them and about them.

- During procedures tell them specifically what they are doing that is helpful and praise them, e.g. "you are a being very brave right now, good job" or "what a great statue you are, lying nice and still for Mummy or Daddy, well done"
- Examples of positive self-talk or helpful thoughts are "I can do this", "it might hurt a bit but I'll be fine", "I did OK last time"
- For an older child you could mention that you noticed how anxious they were and how proud you were that they did it anyway.

#### **Using rewards to help your child achieve goals (setting limits).**

Reward charts work well for 4-10 year old children. This provides a non-punitive strategy to deal with difficult behaviours during treatment:

- If a child is not lying still or doing something that is making access difficult then you could use a

reward chart where they can earn stickers each for doing the helpful behaviour. Once a child earns 3 stickers for the week they can get a special reward (doesn't need to cost money, doing something fun with someone etc.).

- With young children you need to provide the reward immediately after they have shown the behaviour you wanted. Never take away a sticker once they have earned it.

These are the many things you can do at home to help your child learn to cope with needle access and to reduce the likelihood of your child developing a needle phobia. In a hospital setting you can advocate for your child if they are particularly anxious. Talk with your Haemophilia Treatment Centre staff to see if a procedural plan can be tailored so medical staff can minimise distress as much as possible during needle procedures.

Dr Moana Harlen







On April 17, 2018, the global bleeding disorders community came together to promote and encourage 'Sharing Knowledge' and the role it plays in building a stronger community.

World Hemophilia Day is an opportunity to help people with bleeding disorders live healthier, longer and more productive lives by educating and empowering them through knowledge sharing, information exchanges, education, and training. This is possible because the bleeding disorders community is rich with experience and wisdom that can help increase awareness and improve access to care and treatment.

"World Hemophilia Day is a wonderful opportunity for our community to make its presence felt," explains Alain Weill, President of the World Federation Hemophilia. "Our focus this year is on Sharing Knowledge because we are convinced that knowledge and education are key drivers in stronger support for patients in our community. The WFH has a long history of collecting data and sharing knowledge. The WFH World Bleeding Disorders Registry (WBDR) is an example of how data collection will be used to advance the understanding and care of people with hemophilia worldwide. An accessible patient registry strengthens our capacity to identify, diagnose, treat, and care for people living with hemophilia and other rare inherited bleeding disorders"

In addition to the WBDR, the WFH Annual Global Survey collects basic demographic information and data on access to care and treatment products in order to provide hemophilia organizations, hemophilia treatment centres and health officials with useful information to support efforts to improve or sustain the care of people with bleeding disorders.

To ensure all members of the bleeding disorder community have access to important clinical and patient focused information, the WFH developed the WFH eLearning Platform. The platform features more than 500 important resources—in six languages—including guides, fact sheets, videos, articles, games, and interactive modules that are downloadable for free, and are well-suited for any learning style or area of interest.

For more information, go to [www.wfh.org](http://www.wfh.org)

## DID YOU KNOW

you can browse over 500 resources by filtering your search by category, resource type and language?

Visit the WFH eLearning Platform at [elearning.wfh.org](http://elearning.wfh.org) to explore.

#WHD2018

INTERACTIVE RESOURCES, ONLINE GAMES & EDUCATIONAL MODULES are all just a click away on the WFH eLearning Platform.

[elearning.wfh.org](http://elearning.wfh.org)

#WHD2018

## DID YOU KNOW

that in rare cases a person may develop hemophilia later in life? Learn all about the inheritance and spontaneous occurrence of hemophilia on the WFH eLearning Platform.

[elearning.wfh.org](http://elearning.wfh.org)

#WHD2018

## DID YOU KNOW

that inhibitors are actually antibodies made by the immune system of a person with hemophilia against the factor proteins found in treatment products? Find out more about how inhibitors occur and how they can be treated on the WFH eLearning Platform.

[elearning.wfh.org](http://elearning.wfh.org)

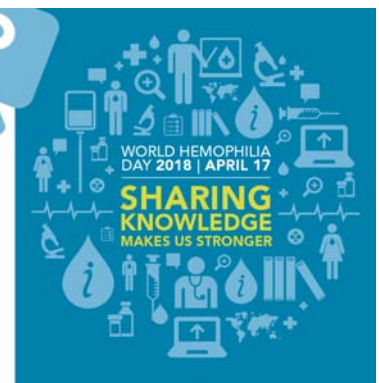
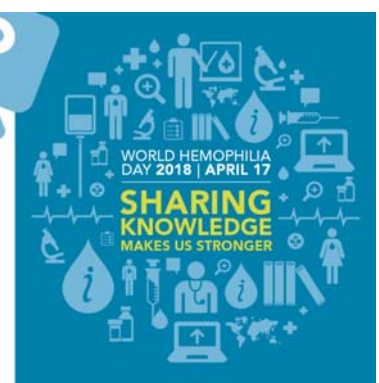
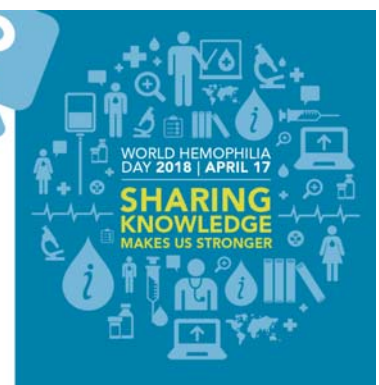
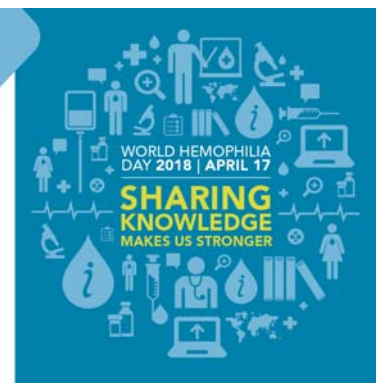
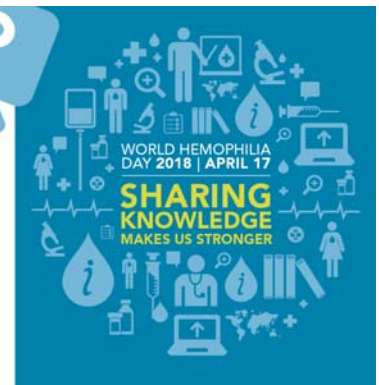
#WHD2018

## DID YOU KNOW

that von Willebrand disease (VWD) is usually inherited, being passed down through the genes from either parent to a child of either sex? For much more information and resources on the symptoms and treatment of VWD visit the WFH eLearning Platform.

[elearning.wfh.org](http://elearning.wfh.org)

#WHD2018



# ADMINISTERING FACTOR – INTRAVENOUSLY

## Tips from OUR family... to YOURS

In the spirit of the generous sharing of information that we experienced at camp, the Danckert/Ikoma family have shared their tips on administering factor.

Please do share your tips around any aspects of managing a bleeding disorder or health condition with us, whatever age you are, and we can share with the wider community.

CHALLENGES	TIPS
Vein is too small to find	<ul style="list-style-type: none"> <li>• Drink plenty of water (an hour prior preferably)</li> <li>• Sit near the heater</li> <li>• Put a warm blanket on</li> <li>• Have a dance</li> </ul>
Miss the vein, butterfly needle goes in but no flashbacks.	<ul style="list-style-type: none"> <li>• Take the needle out, and have another go at a different vein</li> <li>• Whilst the needle is still under the skin, try change the angle so that you don't have to poke yourself again and again (sometimes it works!)</li> <li>• Try the other vein</li> </ul>
Factor is leaking underneath the skin	<ul style="list-style-type: none"> <li>• Stop, try other veins</li> <li>• Tell yourself it's perfectly alright</li> <li>• Give the vein a rest for a week (try not to use the same vein until the vein heals)</li> </ul>
Younger children interrupt during the factor session	<ul style="list-style-type: none"> <li>• Put the TV on (use what they are interested in to distract)</li> <li>• Provide what interests them before the factor to keep them occupied</li> <li>• Let other siblings/adults to look after them so that you can focus on your factor</li> <li>• If you have the capacity, get them involved assigning them a role, such as finding a tourniquet, pillows or bandage</li> <li>• Get them to remember names (ask if they can remember each equipment. Children are great remembering names. Best time to train a future doctor/nurse/pharmacist!)</li> </ul>
Stressed after mistakes	<ul style="list-style-type: none"> <li>• Remembering EVERYONE has done this</li> <li>• Remembering all these people you have met at the camp have gone through at some stage and you are not the only one</li> <li>• You can memorise this event and see how you can share this story next time we all catch up (by the time we catch up, it is highly likely that we forget)</li> <li>• Let others help you</li> <li>• Deep breath</li> </ul>
Adults administering factor into a child's hand, s/he moves.	<ul style="list-style-type: none"> <li>• Ask if they can stay still</li> <li>• Ask them to place their hand flat on the table (this is Hinata's tip)</li> <li>• Distract them to look somewhere else</li> <li>• Countdown to factor and administer half way counting (in other words, it is called "tricked-ya!")</li> </ul>
<p>As a mum, here is my very personal tip: No matter what, the very worst-case scenario, send them off to the RCH and leave it to a bunch of pros! No worries!</p>	



# ASK US...

## Q & A's with Alex & Jane

### QUESTIONS FOR THE ALFRED HTC TEAM

#### **What do you believe are the most important health issues concerning men and women with bleeding disorders as they age?**

The General Practitioner is so important for people with bleeding disorders as they age. They can do all other age related health checks as for the general population including cardiovascular, skin checks, prostate, bowel screening and the list goes on. We advise that if a test or procedure is bigger than a blood test to let the HTC team know. As people get older there are many other health conditions that can affect you, as well as the progression of any damage to joints that has happened.

#### **What are the specific issues for men aged 35+?**

Men over 35 are well known for not seeking medical care for themselves. They are usually busy with work or family commitments and prioritizing themselves is challenging. However we know that early action can reduce the severity of the problem, and shorten the recovery time. This stage of life is when many men and women have dependents relying on them, financially, with practical care and in their relationships. Taking time off for a medical appointment, a visit to the hospital or to recover can seem impossible. As for specific issues, this age group face the same challenges as the general population, including family planning. A common request by men is for a vasectomy which is complicated by their bleeding disorder.

#### **Are there different issues for men aged 65+?**

The haemophilia population aged

over 65 did not have access to adequate treatment as children. They may have significant musculoskeletal issues and may need to retire early which can cause significant financial stress. Some may also be carers for ageing partners.

They have also had long and complicated relationships with medical care, and not all of it has been easy. Many have negative or traumatic memories of hospital, recent and from long ago, and these can add to a reluctance to address any health concerns.

On the positive side they are able to put more time into their own health and can get good results from their own active involvement in their health and physical activity.

#### **What are the issues or barriers that stop men from reaching out for support?**

Unfortunately, financial issues limit choices and poor mobility restricts transport.

The barriers are less if patients have a good knowledge and understanding of their disease and plan for the long term from a younger age, such as thinking about suitable career choices. Some barriers can be very much dependent on their family situation.

Gender stereotypes exist and some men have been brought up to believe that it is a sign of weakness to address any health concerns. That they should just push on!

#### **What other health conditions should people who are ageing with haemophilia be mindful of?**

Again, people with haemophilia need to be mindful of all conditions that affect the general population as they age. This includes polypharma-

cy, alcohol and drug dependence and mental health issues such as depression and anxiety. Also, poor pain management can lead to other difficulties so it is important to have effective pain management in place.

#### **Are aged care facilities educated in haemophilia care?**

No. This is due to the rarity of the disease and the vast number of aged care facilities. Staff are provided with education on a needs basis.

#### **Can nurses in aged care settings assist with intravenous treatments?**

Rarely. Most are staffed by one registered nurse and care attendants. But often, as a person ages and becomes less active, the need for prophylaxis reduces.

Following the normal process of a nursing home, if a resident is unwell for any reason they are sent to their local emergency department.

If they were to have a bleed, again, the person would be sent to the emergency department.

**Jane Portnoy & Alex Coombs**  
*Social Workers, Haemophilia & Other Inherited Disorders Team*  
**ALFRED HEALTH**

*Thank you to Penny McCarthy, Megan Walsh & Emma Reiterer from the HTC team for their contributions to this article.*

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

# DIVORCED from Hep C

## A personal Story

**Anthony McCarthy is a Victorian community member with haemophilia A**



I'm glad to say that hep C and I have been divorced now for almost 5 years. We are so much better apart. I'm told we first became acquainted sometime in the late 1970s, back when hep C was barely known to science. There was no hep C test and it was clumsily referred to as 'non-A, non-B hepatitis'. I was very young - far too young to be entering into such a relationship. We came into contact through the blood products that were used to treat my severe haemophilia A. Hep C went to work slowly but surely, inflaming my liver, progressively scarring it and toughening it up, when it should be supple and squishy. Hep C was violent and silent, and for most of our time together I didn't even know it was there.

I also acquired HIV, but slightly later in life, when I was at primary school. What a dysfunctional threesome we made. I wonder if the hep C infection made conditions in my body more favourable to HIV? But being exposed to HIV, and seroconverting to become "HIV positive", really took the attention away from hep C. There is a particular hype and notoriety surrounding HIV that hep C can't boast. But that suited hep C just fine. It was happy to lurk quietly and do its work. Unlike HIV, which was drama, drama, drama.

I'll never forget the soul-crushing moment, aged about 25 when it hit home that hep C was potentially incurable and fatal. Until then, I'd kind of dismissed it as a less dangerous little brother to HIV. The reality blindsided me during a meeting I attended at the Alfred to discuss treatment options. I was suddenly overwhelmed with sadness and struggled to fight back tears. It was embarrassing with the room full of doctors, nurses, researchers and patients like me. I wish now that I'd allowed myself to blubber away with abandon.

I first went on treatment in 2001, a 48 week course of interferon and ribavirin. It was really tough going, and I experienced a lot of what the doctors called lowered mood. I was depressed, but in denial because I very much wanted to stay on treatment and clear the virus. My blood counts showed a drop in neutrophils (a type of white blood cell) and I needed to go on an additional medication to stimulate their production. Like the Interferon, it was injected subcutaneously into my abdominal fat roll. Talk about feeling like a pincushion, but I got

the job done by focussing on the goal of hep C clearance. Finding out the treatment hadn't worked was a big kick in the guts but I picked myself up and got on with life. My HIV diagnosis had instilled in me a resilience that I drew upon heavily.

It took several years for another treatment option to become available. In that time I married Jennifer (she makes a much better partner than hep C) and we decided to try to have children. Our decision coincided perfectly with the 'chronic viral illness program' then on offer through Melbourne IVF and the Royal Women's Hospital. Suffice to say there was a lot of science involved and not much romance, but here we are now with a 12 year old son and 10 year old daughter and they are both perfect.

By 2005 I was ready to give treatment another crack, this time with pegylated Interferon. It was scary to face the prospect of a return of the depression, but my desperation to clear this virus overruled those fears. I went for it, this time working hard to improve my chances by quitting work and trying to live stress-free and wholesomely. I started juicing organic veggies and meditating daily and I coped much better on treatment the second time. The depression stayed away but the problem with the neutrophils returned. To learn that the treatment had again failed was a disappointment of epic proportions. I felt beaten, and jealous of those others who had cleared hep C.

By 2012, I was approaching the pointy end of a long-term hepatitis C infection and the prospect of a



transplant, though some way off, was very unappealing. I can't say I ever noticed any symptoms directly stemming from hep C; no discomfort, jaundice or pain. Just the less tangible symptoms of abnormal liver function results and fibroscan results showing fibrosis/cirrhosis. I was given the opportunity to go back on treatment that year which was wonderful because I was running out of time. And this time there was new hope. A protease inhibitor called telaprevir was added to the interferon/ribavirin combo. My specialist says it was clunky, but the best cocktail possible given my genotype and history as a co-infected non-responder. Don't you just love medical lingo.

I needed to take telaprevir for the first 12 weeks of the 48 week course. It was a very hard drug to take and I honestly don't think I could've lasted for more than 12 weeks. It would burn my back passage something fierce. To minimise

the burning, I was advised to take the tablet with a good measure of oily food such as cheese, butter or olive oil. It helped somewhat but the oil component was nauseating when I lacked an appetite. The other challenge was taking it 3 times a day. It's quite a challenge to coordinate a tablet every eight hours and around meals and sleep.

But it was all worth it. So worth it. I can't express the joy I felt when my hep C tests started to come back negative. I remember the doctor saying for the first time that my liver function was normal. I couldn't believe my ears. I had to ask, "you mean normal for me?", to which he replied, "no, normal for the population". I was totally floored and thrilled.

So now I'm ecstatic to live with a cirrhotic liver that's not getting any worse. I don't mind having a gastroscopy every two years to monitor varices caused by portal hyperten-

sion. Nor do I complain about needing an abdominal ultrasound every 6 months to watch out for cancers. I treat this as extra time, as extra life with Jennifer and the kids, and life is truly wonderful. I would like to take this opportunity to thank my wonderful doctors, all the nurses, other medical professionals and allied health at the Alfred Hospital in Melbourne. If you are reading this, you know who you are. Thank you. Clearing hep C is the medical highlight of my life.

I understand that the drugs being used to cure hep C are now very easy to take, and practically side effect free. If you are hep C positive and reading this, I can't encourage you enough to get onto treatment and kiss off hep C. It's worth it.

*Reprinted with permission from National Haemophilia, March 2018, the journal of Haemophilia Foundation Australia and Anthony McCarthy*

## HFV Ladies Day 2018

Saturday 16th June, 10.30am - 12.30pm  
Our Lady's Church Hall, 49 Nicholson St, Brunswick East

Tango Dancing & Tapas



Come and join other ladies for a bit of fun and great company! Two left feet...no problem, you'll fit in just fine. Bookings are through TRYBOOKING by 10th June.

[www.trybooking.com/UJTL](http://www.trybooking.com/UJTL)

Strictly limited places. No Charge for HFV members however a donation of \$10.00 would be greatly appreciated in lieu of payment

Please arrive 15 minutes early. BYO Water.  
Dress: Wear comfortable, casual clothing.  
Please bring flat shoes (or socks) and heels.  
Tango Dancing followed by Tapas!!!



# REGIONAL VISITS 2018

We commenced our 2018 regional visit on Saturday 19th May with a visit to Bairnsdale. It was a small gathering but well worth the drive as staff and committee had the opportunity to meet face to face with one of our HFV families for the first time. This was a great opportunity to understand some of the challenges they faced living regionally with haemophilia and we are pleased to say they manage very well, hadn't had too many unscheduled visits to the RCH and weren't fazed by the drive when they did need to attend the RCH. When staying at the RCH they have been able to utilise accommodation at Ronald McDonald House when rooms are available. Interestingly, the family's daughter had recently been diagnosed with a different bleeding disorder...which is always a good reminder to us as a Foundation that we represent all inherited bleeding disorders and need to increase the education and awareness of these other conditions.

The following morning we headed to Traralgon. We had the pleasure of meeting with four families at this visit. Four men and one woman all with haemophilia and another woman with a platelet disorder, meant there was some in-depth discussions around the table about challenges they had and are currently facing with regards to their bleeding disorders. As a foundation we came away with some discussions for our committee on ways HFV can enable better health outcomes for our members in regional settings.

On Sunday afternoon we arrived in Warragul for our final visit. Unfortunately, a couple of our members had been struck down with flu and were unable to attend but we were very glad to welcome 3 families to the visit. The group comprised of a man, teenager and baby with haemophilia, parents, partners and siblings. This was a great opportunity for us to meet up with a relatively newly diagnosed family. We were delighted to hear that they were already connected with another young HFV family and had a long history with another so have already got some good support in place. Two of the families shared a paediatrician who had also suggested they connect up, so were pleased to meet at the regional visit.

We are excited about our upcoming August visits to Wangaratta, Shepparton, Echuca, Bendigo and Ballarat. If you live within the vicinity of any of these towns please book in, through [Trybooking.com](http://Trybooking.com) and join us. We try to book relaxed venues where it is easy to talk and hear. If you know of any suitable venues in your area, please let us know.

Look forward to seeing you soon!





# Coming to the EMERGENCY DEPARTMENT

We know that accidents, spontaneous bleeds, and other health related problems sometimes happen. If you have a bleeding disorder even with the best of intentions you cannot always avoid health problems that require a visit to the hospital. For many people with bleeding disorders coming to the emergency department is an annoying (but helpful) fact of life. The thing is that it can be daunting and in fact, many people try not to come to hospital, or put it off hoping that the problem will go away by itself. Unfortunately, they can end up with more serious problems just because they are frightened of what will happen.

I am writing to give you information and an update in the hope that it will make coming to the emergency department a little less scary. The Emergency Department at Alfred Health has just been refurbished and is purpose designed and equipped. It is a busy place, and looks after many patients with all sorts of health problems. Your first point of call is with the booking clerk, where they will take down your details. Then you will go Triage. You are met by a triage nurse who will find out what is going on and why you have come to the emergency department. They have a priority system to make sure that the sickest patients are looked after. There may be a wait until you can be seen. It is really important that you let the triage nurse know that you have haemophilia so that they can ensure you get timely treat-

ment. Your ABDR card is helpful as it gives important information to the doctors. If you have any other recent medical information bring that too. During business hours you should call and let the Haemophilia Team know that you are coming to Emergency (or already here).

The Emergency Department is an integrated service, and they have faster access to assessment services, such as x-ray and ultrasound, and can get specialist consultations as needed. They are also a priority for allocation of beds in the ward if needed.

Even if you come in on the weekend or after hours there are always bleeding disorder specialists on call. Many doctor-to-doctor discussions take place when a patient is in the emergency department, one of the first things that the doctor who meets you will do is to contact the doctor on for our team. They will then find out the details of your bleeding disorder and what we know about your treatment

from your medical records and the ABDR. Please ask the team looking after you any questions you have and let them know if there is something that worries you. You are in good hands but the best care happens when patients and the health team communicate well together. The social workers are useful to help with this communication also.

**Jane Portnoy**  
Social Worker, Haemophilia &  
Other Inherited Disorders Team  
ALFRED HEALTH



# shared tips & suggestions from our **2018 COMMUNITY CAMPERS**



During the last year we have been contacted by a number of families that have been struggling with the challenges of home infusions. This included needle phobia experienced by either the child, parent or both.

We took an opportunity at camp to address these issues as a community and it was led by Tim Demos who shared his journey with self infusing.

Tim, who is now 25 and a paramedic, shared how as a child he developed a very strong reliance on his port and was reluctant to give it up. When the time came, pretty abruptly, for Tim's port to be removed it had a huge impact on him and his family. His mother Leonie said, "we all grieved for the loss of this port, the freedom it had given us, the dread of home infusions and the potential impact on our lives - it really affected us all as a family". To hear this from Tim and Leonie was very powerful. We look at Tim as this confident, easy going, strong guy and assume everything has been plain sailing for him. We look at our president Leonie and see her as a strong leader and can forget the challenges she has faced as a mother of a child with haemophilia.



Tim spoke of the crippling fear of needles that he developed when he began home infusions. The whole process of treatment became very stressful for everyone in their family, so they sought out help. Tim saw a child psychologist and was taught some self hypnosis techniques. He has no anxiety over treatment these days but did share a powerful message, which was echoed by many of the other youth and adults in the room. "We all miss veins from time to time. There is no rhyme or reason to it. We can have gone for 2 months or 2 years easily accessing a vein and then for no reason we miss...not only once but twice or more. It can be easy to feel deflated, anxious and stressed. Remember that this happens to us all occasionally. Relax, go and do some-

thing else for a while and come back to it later with a fresh mindset. It is so important to keep a positive mindset during these times because they will happen and it happens to us all."

Following Tim sharing his experience a community discussion started which was so insightful I only wish I had captured it word for word. Many of our campers shared tips and suggestions for making their treatment work better for them. Here are a few:

- Go for a bit of a run around the garden or play some basketball before your treatment to get the blood pumping
- Have a hot shower. It can help access the veins more easily
- Think about when you do your treatments. Many people do their treatments before school/work. This is generally a very stressful time as we are already feeling stressed about getting to work on time. Consider doing your treatment in the evening when everyone is more relaxed
- If it doesn't work the first or second time come back to it later.
- Don't be disheartened if you miss



a vein. Nurses and doctors can miss veins too. They are sometimes tricky to access. - they can be bouncy or difficult or a bit compromised.

- Remember that it is prophylactic treatment - not emergency treatment so you can always come back to it.
- Learn skills that may help you if you feel anxious.
- Sometimes you know that you or your child are not in the right frame of mind for a treatment session, so come back to it. You are just setting yourself up for disappointment.
- Find the best most comfortable place to do treatment. We know from our camp experiences that the heights of the tables and chairs often make it awkward or more difficult for treatments
- Look at some relaxation methods whether that be breathing exercises or mindfulness before you start treatment
- Be kind to yourself!



Camp this year was, as always, a really positive experience. There was an energy around camp, campers made a real effort to connect with others. But as a staff member, I found this particular session to be so powerful. To have our community share their tips on what works for them and the challenges they have faced or continue to face in such an open and supported way is a credit to our community. We will certainly look at running more sessions that give us the opportunity to share our knowledge and continue to connect, support and empower in such a positive way.

Julia Broadbent  
Communications Coordinator



# SAVE THE DATE HFV Community Camp 2019

...first weekend of the school holidays

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

**HAEMOPHILIA FOUNDATION VICTORIA  
PRESENTS**

## Annual Walk for BLEEDING DISORDERS

**SUNDAY  
OCTOBER 7, 2018**

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

**BOOKINGS ESSENTIAL THROUGH TRYBOOKING**  
[www.trybooking.com/WACS](http://www.trybooking.com/WACS)  
All family and friends welcome!



# MEDICAL WORDS: COMING TO TERMS

*The following article featured in our February 1998 edition of the HFV newsletter. We do occasionally read through the old newsletter and this struck me as an interesting and still relevant article. You can test your general health knowledge. I should also add that 20 years ago our families headed to Shiloh Ranch for the HFV Family Camp. It was an Easter Weekend that included horse riding, yabbing and canoeing. Maybe you were there!?*

The language of science and medicine dates back nearly 2500 years. Medical terminology, a mixture of Greek and Latin word roots, prefixes and suffixes, is used to define parts of the body, disease states, symptoms and treatments.

The reason for the classical Greek and Latin is not to make medical words more difficult; it is quite the opposite. Because these ancient languages are not subject to change as modern language is, they are both more precise and less prone to errors of interpretation. The classical language usage also makes medical-ese an effective international language that allows scientists to communicate with one another using a common system of terminology.

## EXAMINING THE WORDS

You needn't be a language scholar to gain a good working knowledge of medical terms. Many are already familiar part of everyday communication. From therme and metron, Greek words for 'heat' and 'measure', we

get the words thermometer. From heme, meaning 'blood' and rhag, meaning 'break' or 'burst', the word haemorrhage was born.

Other words such as nephrectomy, hemarthrosis, and rhinoplasty are more mysterious sounding. The mystery vanishes, however, once you become familiar with how medical terms are put together. Consider the following examples: An operation ending in 'ectomy' means something is removed; a hysterectomy, then, describes an operation for the removal of the uterus, hystēr being Greek for the uterus. An appendectomy is clearly the removal of the appendix. If you know the word nephron means kidney, you also know that a nephrectomy

is the surgical removal of the kidney.

"Osis" describes some type of condition or illness. Heme, again meaning "blood", plus arthros, meaning "joint", coupled with osis yield hemarthrosis - "condition of a bloody joint". Inflammatory conditions characterized by pain, tenderness, and redness carry and "itis" ending. Hence, dermatitis is inflammation of the skin; arthritis is the inflammation of the joint; and tendonitis is inflammation of a tendon.

Word roots are the foundation or "main character" of compound words in the examples below. They are "mini-words" that carry the central meaning upon which

WORD ROOT	COMBINING FORM	MEANING	SAMPLE
aden	adeno	gland	adenopathy
arthr	arthro	joint	arthritis
bacter	bacteri	germ	bactericidal
card	cardi	heart	cariogram
cran	crani	skull	craniotomy
cyt	cyto	cell	cytology
encephal	encephali	brain	encephalitis
enter	entero	intestine	enterotoxin
erythr	eythro	red	erythrocyte
gran	granulo	grainy	granuloma
gyne	gyneco	female/woman	gynecologist
hemat	hemato	blood	hematologist
hepat	hati	liver	hepatitis
oste	osteo	bone	osteocyte
path	patho	disease	pathologist
phleb	phlebo	vein	phlebotomy
rhin	rhino	nose	rhinoplasty
throm	thrombo	clot	thrombosis



the total word is built. When a vowel (usually i, o or u) is placed at the end of a word root, it is then called a combining form. Prefixes and suffixes are other mini words that carry a separate meaning. Prefixes are placed in front of the combining form; suffixes are placed at the end. Prefixes and suffixes are used to say something about the main character. For example, if aden means gland and the suffix pathy means “disease of”, they can be joined to form the word adenopathy which means “disease of the gland”. Lymphadenopathy would specify “disease of the lymph gland”. The prefix peri- in the word pericardium describes the area surrounding the heart (card, cardi). The pericardium is, in fact, a membrane that envelopes the heart. Pericarditis, then, is inflammation (itis) of the membrane that surrounds (peri) the heart (cardi),

Aside from describing a characteristic or condition, additions to a word root can also describe a surgical procedure done on a part of the body. This is particularly true of suffixes. Consider some of the suffixes in the box below.

### PUTTING IT INTO PRACTICE

You can master the vocabulary and the way the roots, prefixes and suffixes are used by paying attention to how medical personnel use them in daily conversation. For example, instead of saying the word bruise, you'll hear the word hematoma, and a chronic joint inflammation will be called a synovitis. Using more medical terms yourself will help you feel more confident and knowledgeable. And by expanding your medical vocabulary, you will also increase your knowledge of anatomy, physiology and disease.

### HEMOPHILIA??

When translated from its Greek components, the word hemophilia presents itself as “love of blood”, which can be confusing because it describes nothing of the true nature of the disease. The suffix -philia, however, can mean tendency toward or affinity as well as love.

The original term for the disorder, hemorrhaphilia, dates back to 1828 and was introduced by a German physician, Dr. Friedrich Hopff. He was describing the hereditary bleeding (ie, hemorrhage) tendency in a paper he had written. Hopff credited his professor, Dr. Schonlein, with its origin. The term was used by Schonlein in a series of lectures on the subject. Hemorrhaphilia was later shortened to hemophilia.

by John A. Lanzon, MT  
Source: Hemalog July 1997

#### PREFIX MEANING

a-, an-	not, without. Atypical means “not typical.” anemia means “without blood”.
ab-	away from: not. Abduct means to move a limb away from the body. Abnormal means “not” normal.
ad-	toward, as in adduct, to move a limb toward the body.
ante-	before. Antecubital, “before the forearm,” pertains to the bend of the elbow where venipunctures are performed.
anti-	against, as in antiseptic (against infection).
dys-	difficult or painful, as in dysmenorrhea (painful menstruation).
hyper-	excessive, as in hyperventilate, to breathe hard; hyperthermia, excessive temperature.
hypo-	under, beneath, or decreased, as in hypodermic (under the skin), or hypoglycemia (low blood sugar).
inter-	between, as in intercoastal, meaning “between the ribs”
intra-	inside of, as in intracellular, “inside the cells”.
post-	after, as in postoperative (after surgery), postpartum (after childbirth), or postfebrile (after fever).

#### SUFFIX MEANING

-algia	pain, Myalgia, pain in the muscle
-centesis	puncture of a cavity using a needle. Arthrocentesis refers to the puncture of a joint
-desis	the fusion of two or more bones. Arthrodesis is the fusion of a joint arising from or formulation of.
-genic	Osteogenic means arising from bone
-genesis	thrombogenesis refers to the formation of clots
-oid	similar to resembling. Sigmoid means shaped like the letter S (from the Greek letter sigma), as in sigmoid action
-oma	tumor (benign or malignant). An osteoma is a bone tumor
-ostomy	the surgery creation of a new, permanent opening. A tracheostomy is a new opening into the trachea (windpipe) at the front of the neck.
-otomy	the surgical creation of a temporary opening



**Australian Men's Shed Association**  
SHOULDER TO SHOULDER

# MEN DON'T TALK FACE TO FACE, THEY TALK SHOULDER TO SHOULDER

The Australian Men's Shed Association is the peak body representing more than 985 Men's Sheds in Australia by providing practical support, specialised services and resources.

At the 2nd National Men's Shed Conference in Manly, September 2007, Professor Barry Golding, a Men's Shed researcher from Federation University Ballarat, stated in his key note address that "Men don't talk face to face they talk shoulder to shoulder". This drew unanimous mutterings of approval from all 350 delegates and the quote became the Australian Men's Shed Associations motto.

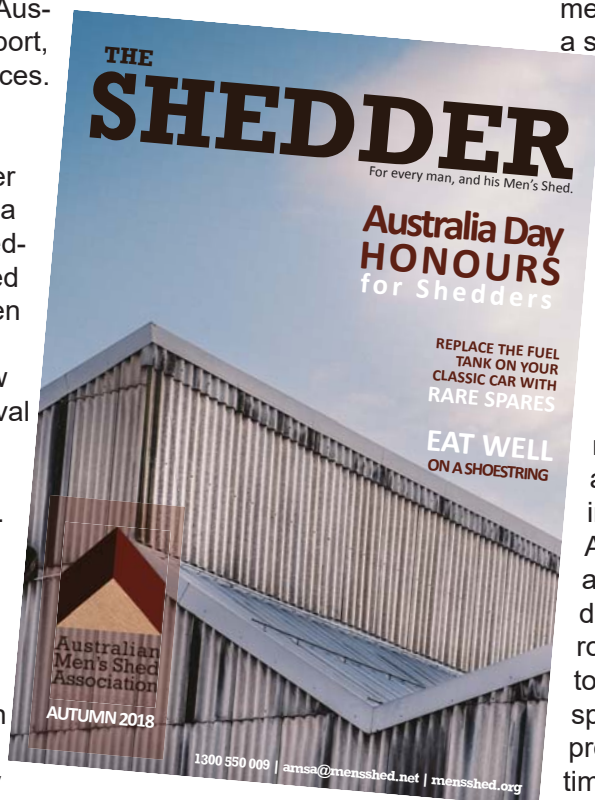
## WHAT IS A MEN'S SHED?

The modern Men's Shed is an updated version of the shed in the backyard that has long been a part of Australian culture.

Men's Sheds are found in many cities and towns around Australia and continue to spring up internationally.

Not all Men's Sheds are the same – if you looked inside you might see a number of men making furniture, perhaps restoring bicycles for a local school, making Mynah bird traps, fixing lawn mowers or making a cubby house for Camp Quality to raffle. You might also see a few young men working with the older men obtaining new skills and learning something about life from the men with whom they work. You might see local elders making traditional weapons or designing arts and crafts. You will see tea-bags, coffee cups and a comfortable area where men can sit and talk. You will probably also see an area where men can learn to cook for themselves or how to contact their families by computer.

So what is so special about the 'Men's Shed'?



Most men have learned from our culture that they don't talk about feelings and emotions many do not take an interest in their own health and well-being. Unlike women, most men are reluctant to talk about their emotions and that means that they usually don't ask for help. Probably because of this, many men are less healthy than women, drink more, take more risks and suffer more from isolation, loneliness and depression. Relationship breakdown, retrenchment or early retirement from a job, loss of children following divorce, physical or mental illness are just some of the problems that men may find difficult to deal with on their own.

Good health is based on many factors including feeling good about yourself, being productive, contributing to your community, connect-

ing with friends and maintaining an active body and mind. Becoming a member of a Men's Shed provides a safe and busy environment where men can find many of these things in an atmosphere of old-fashioned mateship. And, importantly, there is no pressure. Men can just come and have a yarn and a cuppa if that is all they're looking for.

Members of Men's Sheds come from all walks of life – the bond that unites them is that they are men with time on their hands and would like something meaningful to do with that time.

A good Men's Shed has a Management Committee that has developed a safe and happy environment where men are welcome to work on community projects, specific Men's Shed projects or a project of their choice in their own time and where the only 'must' is to observe safe working practices.... all in a spirit of mateship.

The Men's Shed movement has now become one of the most powerful tools in addressing health and wellbeing and helping men to once again become valued and productive members of our community.

**For more information, please go to [www.mensshed.org](http://www.mensshed.org)**

**To find a Men's Shed near you, go to [www.mensshed.org/find-a-shed/](http://www.mensshed.org/find-a-shed/)**



# HFV Noticeboard

To post a message on our noticeboard, please email our HFV office at [info@hfv.org.au](mailto:info@hfv.org.au) or call 9555 7595

## GRANDPARENTS EVENT 2018

This year, we are hoping that many of our HFV grandparents will come along to support our **Walk Around Albert Park on Sunday 7th October 2018**. This way, our grandparents not only get to spend time with other grandparents but also some quality time with their grandchildren too!

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

There will be a sausage sizzle after the walk and a few local coffee shops close by so if you feel like heading out for a coffee with other grandparents after the walk this will be a great opportunity! There will be more details to follow in the next issue of Missing Factor and available through our website.



## YOUTH EVENT ESCAPE ROOM CHALLENGE

We are running a Youth Event for ages 16+ in Melbourne (14+ welcome to attend if accompanied to venue by a guardian)

Please join Scott McDonnell and other youth for this ESCAPE ROOM CHALLENGE followed by some refreshments, all provided by HFV.

1.15pm - 3.30pm  
SUNDAY 8th JULY  
Strike QV  
245 Little Lonsdale St  
Melbourne

HFV committee member Dan Korn will be in attendance to supervise the event.

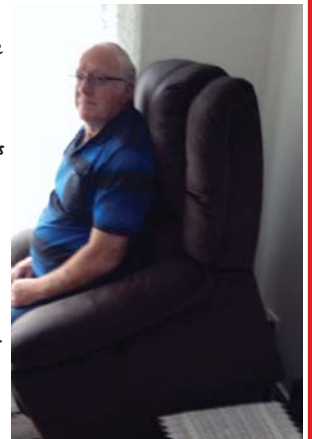
BOOKINGS ESSENTIAL  
[www.trybooking.com/WARY](http://www.trybooking.com/WARY)

Limited numbers so be quick, BOOK NOW!

We want to thank you so much for all your help with the funds for dad's new chair. The chair has a remote which lifts dad up so rather than him struggling with his arms to lift himself, all he has to do is stand up.

This chair is going to be a lifesaver for dad now because he can rest in the fact that his pain will be reduced when even doing a simple task like getting out of a chair. The pressure on his elbow joints will be less now as he doesn't have to push down on his arms and elbows to get himself out of the chair. It also reclines, has lots of different settings and is extremely comfortable.  
- Sharyn

HFV offered partial financial funding through our Live Well Program to assist John with the purchase of this 'lift chair'. If you require any assistance through the Live Well fund please contact HFV or speak to your HTC social worker.



## HFV BABY & TODDLER GROUP

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

We advertised a 'get together' in the last magazine but received little interest. We know there are new families looking to connect but maybe a set date is too difficult to commit to or distance is an issue...so we will try a different approach!

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

We already have 2 families keen to connect with others so if you are interested please contact Julia Broadbent at HFV on 9555 7595 or email [julia@hfv.org.au](mailto:julia@hfv.org.au)

# DIARY DATES

## JUNE

16 Ladies Day Out

## JULY

8 Youth Event 'Escape Room Challenge'

## AUGUST

10 Wangaratta Regional Visit

11 Shepparton Regional Visit

11 Echuca Regional Visit

12 Bendigo Regional Visit

12 Ballarat Regional Visit

## SEPTEMBER

8 Warrnambool Regional Visit

9 Horsham Regional Visit

9 Ararat Regional Visit

## OCTOBER

7 Walk for Bleeding Disorders

7-13 Bleeding Disorders Awareness Week

## NOVEMBER

11 HFV Christmas Picnic & AGM

## MARCH 2019

15-17 Men's Retreat

## APRIL 2019

5-7 HFV Community Camp

## HAEMOPHILIA TREATMENT CENTRES

### HENRY EKERT HAEMOPHILIA TREATMENT CENTRE

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

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

### RONALD SAWERS HAEMOPHILIA CENTRE

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

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



**WFH 2018  
WORLD  
CONGRESS**

GLASGOW, SCOTLAND • MAY 20-24, 2018

Information learned at the 2018 WFH World Congress to be shared in the next edition of The Missing Factor.

### 2018-2019 HFV SUBSCRIPTION RENEWALS DUE 30th JUNE 2018

Subscription renewal forms are included in this magazine and also available through our website as a fillable form that can be emailed to [info@hfv.org.au](mailto:info@hfv.org.au)  
[www.hfv.org.au/get-involved/memberships](http://www.hfv.org.au/get-involved/memberships)



# HFV MEMBER SERVICES & PEER SUPPORT

## Membership Annual Fees:

Standard family membership

\$33.00

Concession member

\$16.50

Allied Member

\$16.50

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](http://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](http://www.hfv.org.au)

Fax: (03) 9555 7375

Email: [info@hfv.org.au](mailto: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.





# REGIONAL VISITS 2018

**11**  
LOCATIONS

<BAIRNSDALE \* TRARALGON \* WARRAGUL>  
<WANGARATTA \* SHEPPARTON \* ECHUCA \* BENDIGO \* BALLARAT>  
<WARRNAMBOOL \* HORSHAM \* ARARAT>

YOU ARE INVITED TO JOIN OUR STAFF AND COMMITTEE MEMBERS  
AT ONE OF OUR 2018 REGIONAL VISITS!

Depending on the time slot HFV will be providing dinner, morning tea or afternoon tea (coffee/cakes/snacks). Once bookings have been made and numbers established HFV will notify you of the venue location.

BOOKINGS ARE ESSENTIAL THROUGH [TRYBOOKING.COM](http://TRYBOOKING.COM)

~~BAIRNSDALE 19/5 6-8PM~~  
~~TRARALGON 20/5 10-11.30AM~~  
~~WARRAGUL 20/5 2-3.30PM~~

WANGARATTA 10/8 6-8PM  
SHEPPARTON 11/8 10-11.30AM  
ECHUCA 11/8 2.30-4PM  
BENDIGO 12/8 10-11.30AM  
BALLARAT 12/8 2.30-4PM

WARRNAMBOOL 8/9 6-8PM  
HORSHAM 9/9 10-11.30AM  
ARARAT 9/9 2-3.30PM

Know a good venue in these towns that is not too loud? (easy to chat and hear)... then please let us know!

MAY

AUG

SEPT