

THE MISSING FACTOR

*A bright future ahead
with new treatments
now available*

*Advice for newly
diagnosed families*

*World AIDS
Day 2020*

connect • support • empower



SUMMER 2020

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Haemophilia Foundation Victoria acknowledges the support of the Victorian Government.

DIARY DATES

DECEMBER 20

17th HFV Annual General Meeting

HFV is preparing for an **exciting and interesting VIRTUAL AGM** this year, and the Notice of AGM will be EMAILED to you. Please ensure HFV have your current email address.

If you've never attended an AGM due to distance, this AGM is for you and we hope you'll be able to join us! Please go to page 13 for more details.

MARCH 21

12-14th HFV Community Camp - Lake Dewar *TENTATIVE BOOKING TBC (due to COVID restrictions)

At this stage we have a **tentative** booking for our annual community camp. This date will be confirmed in mid to late January and HFV will notify members via email of booking details. If we are able to hold a camp we will be following strict government guidelines around Covid-safe practices. Please see page 17 for further details.

At this stage no other face-to-face member events have been scheduled.

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



As 2020 comes to an end there are many reasons that we celebrate the new year.

There is no doubt 2020 has been the toughest year in my life from a global perspective as we continue to watch thousands impacted by COVID overseas. The numbers of people infected and losing their lives are too large to comprehend as we think about the so many challenges that lay ahead. We also have challenges to consider and I have no doubt for many in our community there has been job losses, health issues and many tough days with isolation and the loss we have all experienced for a life we once enjoyed without question. Seeing family, planning adventures, travelling to other countries and other parts of our own. All things we just 'did' and I am sure from now on will really value.

In amongst the challenges there have been many things to celebrate as well in this edition and the many great articles certainly reflect the many aspects of 2020 to embrace with enthusiasm as part of our memories of a very tough year. Here are a few but I encourage you to read all the amazing things the magazine has to offer.

- RCH have provided the results from a covid poll trying to capture the impacts on families in our community. It includes many positives that has come from this extraordinary year feeling more connected, making healthier life choices and many things that we hope will resonate with you.
- WFH summit articles on Von Willibrand including medical, psychosocial issues, quality of life.
- Alex Coombs from the HTC team at the Alfred has kindly provided a video we have transcribed on career guidance, how to write a resume, tips for interviews as well as the HTC Q&A section.
- Sharron Inglis has contributed an

article to help many navigate treatment options and how to improve our self-advocacy which is so important for life as well as in our health care treatment options.

- The value of our community is reinforced through many articles - what HFV means to others and support for diagnosed families from others who have lived through the experience. Again, the reminder of the strength of our support for each other through the stages and challenges of life.
- Taking time to reflect on the highlights of a very different Bleeding Disorder Awareness week with the challenges of lock-down, and World AIDS day as a time to remember those many lives we have lost in the past through our darker times.

These are just a few articles to highlight with many more to hopefully grab your attention.

Of all the many things to reflect on in 2020 there are two that will stay with me as my highlights.

Firstly, the excitement of the newly signed agreement to fund new treatment options for our community. This is such a significant milestone that I am still not sure we have all grasped the impacts to come. The scientists that have worked tirelessly to develop the products, the medical staff that have advocated and trialled to make this safe as an option, the many hours of discussion in many meetings and the strategic advocacy we as a community have done, means we are starting 2021 with such exciting opportunity for our families that brings tears to even consider the positive impacts this will have to so many. With the exciting new horizon, I like to reflect on where we have been as a community and with treatment options over time. I hope we always share the gratitude of those that have pioneered before us as we move

into the new and exciting horizon for our children and our loved ones. To quote Albert Einstein

“Learn from yesterday, live for today, hope for tomorrow. The important thing is not to stop questioning.”

If it had not been for those that continue to question and hope we would not be on the brink of such an exciting new world of treatments. So, as we all welcome the end of 2020 there is very much to celebrate indeed.

Secondly, the sense of community we share. Despite the need to postpone or cancel most face-to-face events (lucky we got our community camp in) we adapted to the new world. We have again shown our resilience. The Committee has continued to meet and take on all expected from us. Our HTC teams have as always put our health needs first and been there for us as we needed. Our medication has continued to be delivered to our door without missing a beat. HFA have been amazing as always in their continued leadership and support across our nation. Our patron Prof Street has supported our work and continues to be an integral member of so many important networks nationally and internationally.

Our AGM is approaching and in the spirit of adapting we will be hosting a virtual event. Please take time out of your busy lives to support our new initiative. We are very grateful for the support yet again of Prof Street and Sharon Caris, Director of HFA who will be our special guests. We will be hosting a panel discus-

(continued on page 9)

World AIDS Day

2020

THEME
NOW more
than ever

The theme for World AIDS Day in 2020 is ‘Now more than ever’. For the bleeding disorders community this is a profoundly meaningful message.

1st December is a day when we are mindful of the members of our community living with HIV and those with HIV who have passed away.

In the mid-1980s the bleeding disorders community in Australia and internationally was devastated when many people with bleeding disorders acquired HIV through their plasma-derived clotting factor treatment products. HFA’s recent Getting Older report documented the ongoing impact of this epidemic on our community: the trauma and health challenges for those who were diagnosed with HIV and now live with the consequences, and the grief and sadness experienced by those who lost loved ones and friends to HIV. Often forgotten is the emotional impact on the health professionals at the Haemophilia Treatment Centres too, who had cared for their patients with HIV over their lifetime and knew them so well.

The Getting Older report recognised the very positive contributions people with bleeding disorders and HIV have made to our community: the inspiring optimism and generosity of individuals with HIV, in spite of all their experiences, speaking out and providing leadership and a way forward into the future.

Some of the people with HIV who participated in the Getting Older consultation also highlighted other issues that need addressing, including discrimination by health professionals in the wider health sector, based on an unfounded fear of transmission. This can result in barriers to testing and treatment and access to services.

‘There needs to be a concerned education campaign

for health professionals to educate them about the low risks of HIV infection when the patient is well suppressed.’

TAKING ACTION

On World AIDS Day we are encouraged to educate ourselves and others about HIV.

In Australia HIV infection is now usually well-managed with treatment. However, the Getting Older report reminded us how important it is to acknowledge the experiences of our community members with HIV and the impact these experiences have had on them. We also need to recognise the impact on those who love them and care for them: their partners, family, friends and carers.

Hearing their stories and learning about the impact of HIV on them in the past and now is an important part of acknowledgement in our community. Foundations are also conscious of making sure there is always a supportive environment at community events. Wearing a red ribbon on World AIDS Day can help to raise awareness and reduce discrimination by demonstrating solidarity with people with HIV.

World AIDS Day challenges us to take action – and by this action to ensure that people living with HIV can participate fully in the life of the community, feeling supported and free from judgement, stigma and discrimination.

Suzanne O’Callaghan
Haemophilia Foundation Australia

ADVICE FOR NEWLY DIAGNOSED FAMILIES



from families
who have shared
your journey...

“

“Don't be afraid to let siblings know the truth when something is happening with their brother, like a bad bleed. Let them be involved with treatments and whenever their brother has a bleed because they are part of the family and they would prefer to know and deal with it their own way.”

Violette - sibling

“I would like to share the importance of taking time to familiarise 'haemophilia new normal', and always stay in touch with our own emotions, needs and capacities.

As we all know, the current pandemic challenged us to adjust to the new normal. We have our ups, downs, challenges, frustration and hope.

As it may be a surprise and a shock to us at the beginning, we all take time to familiarise this new normal. When we do that, we need time and also listening to ourselves and look after ourselves.

Finally the most important aspect for me is to trust your children. We feel worried and wonder what may come next, but each and every time children affirm that they are amazing and show us what can be done. Your journey will confirm this statement. Trusting your children's abilities to be able to handle this condition, and they handle it so well.

We gain more appreciation and gratitude through our journey, which is an added bonus to our lives!”

Mother of two boys with haemophilia

“My best advice as a parent would be: Go to camp!!!!!! It was the best thing we ever did for our family. It connected us with other families that understood our life, our struggles and celebrated all of our achievements (such as learning to do our own treatment) with us. We have made the most amazing friends and support system for our whole family through camp.

Never be afraid to reach out for help from people at HFV and ask lots of questions at doctors appointments. Being informed helped us as parents to feel like we could be a part of our son's journey.”

Mother of a boy with haemophilia

“If the boys want to be involved in their treatment and needles or watch let them from the very start. Don't hold them down or hide it from them. Let them have as much control as they can have.”

William - boy with haemophilia

”

SESSIONS FROM THE 2020 WFH VIRTUAL SUMMIT

VON WILLEBRAND DISEASE

A CLOSER LOOK

Dr Paula James is a haematologist from Kingston, Ontario and has a special interest in Von Willebrand Disease. Dr James has developed a self-BAT tool available through the Let's Talk PERIOD website that enables patients to take a bleeding score to their GP to assist in evaluating a patient's bleeding history. Dr James discussed the importance of diagnosis at this WHF Summit session and below are some key points from her session, however for an accurate account of this session please view through the WFH Virtual Summit website (registration is free).

www.wfh.org/virtual-summit

VWD is an autosomal inheritance, in contrast to haemophilia which is sex linked. In order to diagnose VWD patients need to have specialised blood work done for testing as VWD does not show up in standardised blood testing and the blood work has to be handled by an expert lab.

The rate of VWD is 1 in 1000 but far fewer individuals are diagnosed. There are many barriers to diagnosis such as lack of understanding about normal and abnormal bleeding, lack of access to self evaluation and very expensive lab tests.

A relatively new tool for self evaluation with regards to bleeding is available through a website called Let's Talk PERIOD (www.letstalkperiod.ca) which has a self-administered bleeding assessment tool (self-BAT) that calculates a bleeding score for you. An abnormal self bat score is a good predictor for a VWD diagnosis.

Dr James highlighted that it is important to diagnose VWD as it can have a very negative impact on the quality of life for individuals. Symptoms are treatable and bleeding can be prevented, particularly during surgery or procedures.

Issues that can arise from VWD include iron deficiency. A test to measure the amount of ferritin in the blood is the best way to identify low iron. People with VWD should regularly have their ferritin levels checked and iron replacement therapy given if needed.

VWD is an important bleeding disorder. Patients benefit from accurate diagnosis and effective treatment.

Bleeding Symptoms

- Heavy periods ← ♀
- Nosebleeds
- Bruising
- Excessive bleeding from cuts
- Oral cavity/post-dental procedure
- GI bleeding
- Post-operative
- Post-partum ← ♀
- Joint and muscle bleeds (in severe cases)



Dr Paula James
Professor, Department of Medicine,
Division of Hematology
Queens University, Ontario, Canada

SESSIONS FROM THE 2020 WFH VIRTUAL SUMMIT

Jeanette Cesta is the Executive Director of the VWD Connect Foundation and also a person living with VWD. Jeanette's presentation focused on the impact of VWD on relationships and quality of life, and highlighted the shared goal of all multidisciplinary team health professionals in improving the quality of life for individuals living with VWD. Below are some of the key points made during her presentation, however for an accurate account of this session please view through the WFH Virtual Summit website (registration is free).

www.wfh.org/virtual-summit



Strong Relationships

Strong relationships contribute to the health, happiness and wellbeing of individuals and there is a strong link between a good level of self-esteem and relationship satisfaction.

IMPACT OF LIVING WITH VWD AND SELF-ESTEEM

Marginalisation & Invalidation: It is very hard to move forward if you are not feeling validated and feel marginalised. These feelings can have a negative impact on a romantic relationship. There are also physical impacts of VWD that can affect your self-esteem such as extended periods, visible bruising and possible limitations around exercise. A sense of independence is also really important within a support system.

Jeanette Cesta - Executive Director
VWD Connect Foundation
(Patient based organisation in the USA
serving the severe VWD community)

VON WILLEBRAND DISEASE PSYCHOSOCIAL ISSUES

Financial issues: Financial issues can have a big impact on a relationship not continuing and the financial burden of chronic illness can affect relationships.

Reproductive and genetic issues: People have to consider reproduction as well as disclosure in romantic relationships. Also genetic counselling is an important consideration when living with VWD.

Parenting

We all face challenges of wanting children to be independent but we also want to protect them from the world. As a parent raising children with VWD we need to help them to develop into independent mature patients. They need to learn about their medications and their condition. It's incredibly important to educate families with VWD to ensure when their children become adults they are independent and responsible for their own care.

It is important to address psychosocial relationship challenges for people with VWD as it helps to strengthen relationships so they are not roadblocks but building blocks to help improve their quality of life.

There are incredible opportunities to enhance the life of someone living with VWD by validating them, by not having them feel marginalised, by supporting and encouraging their independence but also being there when they need a helping hand.

The motto of the VWD Connect Foundation is 'it's not complaining...it's reporting'. This is a crucial message for patients to embrace when thinking about their medical providers. It is important to recognise that we will not fully understand VWD until it starts with the patients coming forward and reporting their symptoms and not feeling like it's not important and to have great communication with your medical providers.

SESSIONS FROM THE 2020 WFH VIRTUAL SUMMIT

WHAT DOES QUALITY OF LIFE MEAN TO YOU LIVING WITH A BLEEDING DISORDER IN A CHANGING WORLD?

Nathalie Roussel currently works as full-time Assistant Professor at the Faculty of Medicine and Health Sciences, University of Antwerp. As head of the division of Musculoskeletal Physiotherapy, she combines teaching, research and clinical work. In this session A/Prof Roussel looks at quality of life, living with haemophilia and pain. This article covers some of the main points discussed, however for an accurate account of the session please view through the WFH Virtual Summit website (registration is free).

www.wfh.org/virtual-summit



What is Quality of Life?

Quality of life (QOL) is a subjective multidimensional concept that defines a standard level for physical, emotional, material and social well-being. It is complex because it is subjective for all people.

Mental health is one part together with physical and social aspects. When considering mental health we talk about cognition (or beliefs), emotions and behaviour. Cognitions are based on previous experience and give us our own idea about what is happening. We can have emotions, fear, anxiety, joy, happiness and these will be translated in a specific behaviour. A good example of these is when a patient has an increase in intensity in pain by referring to a previous experience. They think it is a bleed and so have a behaviour that is adapted to a bleed but it might not be appropriate if it's not a bleed.

These cognitions, emotions and behaviour are really important when talking about mental health as they may change over time and they can be part of a management strategy. How we manage pain in haemophilia and how we think about pain influences the pain sensation. If we think the pain will not go away, it will increase the pain sensation. If we think about the pain for the whole day it is catastrophising and will also have an impact on the pain sensations. Pain can also

influence negative emotions and are linked with our behaviour.

These three things, cognitions, emotions and behaviours can be changed through treatment strategy to assist patients with haemophilia and VWD.

A most important discovery over the last 10 years is neuroplasticity of the brain, meaning good training can improve how we manage pain. When improving mental health we want to change belief and emotions and it is through creating new connections in the brain.

QOL might be highly impacted in people with bleeding disorders considering pain, joint issues, mobility. Older patients have a greater impact on QOL and a decrease in mental health for those who have target joint issues.

The good news is there are pain predictors of positive treatment outcome in chronic pain - physical activity (which can block the pain pathways hampering the pain signals), depression, pain catastrophising, self-efficacy.

Some people with haemophilia have a fear that loading the joints might be a problem. The first step is to discuss with patients with haemophilia about pain and physical activity otherwise there may not be treatment adherence.

Depression and pain catastrophising: people who are depressed or ruminating have a less positive treatment outcome. This is some-



thing that can be changed in treatment by explaining the mental health factors and the neuroplasticity of the brain to patients.

Self-efficacy is inner belief that you can change something yourself to change the situation as opposed to fatalism. Self-efficacy is very important in managing chronic conditions. You cannot change the structure of the joint in those with haemophilia but you can change the self-efficacy to help manage the condition.

Mental health is really important in managing chronic conditions and patients with better coping strategies such as exercise and physical activity manage better. This is all part of a pain management plan in which these beliefs, emotions and behavioural aspects are considered.

Finally, in pain, **context** is really important.

Natalie Roussel
Associate Professor
University of Antwerp
Head of Division of Musculoskeletal
Physiotherapy

Did you know
you can watch
WFH Virtual
Summit sessions
ON DEMAND



www.wfh.org/virtual-summit

(continuing from page 3)

sion, and this will be an opportunity to ask any question of either of our guests or myself representing the committee. If you have any questions you can send them through before or during the event. We hope you can join us as we are sure there are many things to learn.

With all AGMs we are electing the new Committee for the coming year. We have been very blessed at HFV to have a dedicated and stable committee and I would like to take this time to thank them for all their efforts. Each member brings their own expertise and without exception each member speaks up to support the work of HFV and goes above and beyond to keep the organisation ticking over. There has been no other year to demonstrate this as much as this year so with much gratitude I thank my fellow members on the committee and hope you continue to support HFV with your nominations and time for 2021.

My last thank you is for the dynamic duo who are our staff at HFV. Andrea and Julia are truly phenomenal in their work. Despite so many challenges in their lives this year they have both continued to keep HFV not only operational but have adapted to all the challenges without missing a day of service for our community. Both Andrea and Julia, please know your hard work is valued so much not only by the committee, our stakeholders but also our whole community. Your welcoming manner and 'can do' attitude is amazing and this year has been displayed over and over again. With a full heart of gratitude, we sincerely thank you.

Wishing you a safe and happy holiday period. Regardless of what your family celebration may look like this year it is likely to be impacted by the hangover of 2020 and the ongoing challenges. We hope you can gather with your loved ones and take time to really celebrate a job well done in surviving an extraordinary year. Most importantly be safe, be healthy and share some positive time of reflection on the year that was and hopefully will never be again.

Warmest wishes to you and those you love around you.

Leonie & the team at HFV

TALKING ABOUT A CAREER PATH

During the COVID lockdown The Alfred HTC team have shared some important videos with us about how to manage your health and wellbeing during this challenging time. Alex Coombs took this opportunity to offer some advice about career paths, looking at CVs and resumes and preparing yourself for an interview.

ALEX COOMBS
SOCIAL WORKER

HAEMOPHILIA & OTHER
INHERITED DISORDERS TEAM
ALFRED HEALTH

Hi, I'm Alex, one of the social workers at the haemophilia treatment centre and my topic today is going to be about careers and getting started with your CV or resume.

VIDEO 1: My career path



For those of you who are still in school or the end of your high school studies, you're about to go into year 12 and you are beginning to think what happens after that. You might be at uni and either starting or midway through your course, you may have been laid off unfortunately due to covid or you are thinking about a career change given the changing environment we are all operating under.

This is a time to look at where we

are at now and where we want to be in the future so I have prepared a couple of slides that I will talk from and they can be viewed here: www.hfv.org.au/HFVIC/media/Resources/Finding-Your-Career-Path-Aug-2020.pdf

So I'll start by talking about my own experiences. I used to be a finance officer at the ANZ, straight out of high school.

That was the first thing that I did and I was also going to be an accountant so I entered into a uni degree part-time.

But, I soon learnt that working full-time and trying to study was not a good mix at that stage of my life. I was 17 and I thought I needed to have a bit more of a life and do the wild things that you do when you are 17,18, which I won't go into detail.

But I spent lots of time thinking about where do I go. So I stuck in banking for 14 years and during that time I got involved in some community work as a volunteer and I started doing telephone counselling and other community work in the drug and alcohol field doing outreach work and that led me down the path that maybe I should get out of banking.

Banking paid a minimal wage but

I knew there had to be more to it than the stale environment of banking. No offence to any other bankers out there but it just wasn't the thing for me. So after 14 years I went back to uni at the age of 32 and did a 4 year degree in social work.

And here I am, 20 plus years later. I am a new person and I think this is going to see me out until I retire.

SO LETS TALK ABOUT A CAREER PATH. WHAT IS A CAREER PATH?

A career path can be made up of the positions you hold as you grow into your field. Your first job or uni degree, for example, can mark the beginning of your career path. As you gain additional knowledge and skills you may progress vertically into more advanced roles.

Some employees even move laterally into equal but different job roles as they specialize or move into different career paths.

How do you choose a career path?

Well here are some of my suggestions. Outline your career goals even if you have the barest notion of what that is. Create a 5 year plan and a 10 year plan. Discover your personality type. This might need you to spend time with a career guidance officer or somebody to work out what kind of role you fit.

Review your previous experience, compare job requirements to your education. Assess your current

skill set. Take note of your interests in areas of work, identify your core values.

But what if I don't have a career path or don't know what I am interested in? And here again I have some suggestions.

Talk to people you know and trust their judgement, ask around family or friends, you may know someone in an employment area of your interest. Look at the work they do and imagine yourself doing that type of work.

Again at the end of this slide there are some links for you to follow through.

RESUME & CV

Let's talk about resume and CV now. So there are many versions of what a resume can look like and the web will reveal many formats for you to choose from. Sometimes you may hear the word CV used also and these two words are often intertwined.

So what does CV stand for? CV means curriculum vitae and is Latin for course of life. By contrast resume is French for summary.

Both CVs and resumes are tailored for the specific job or company you are applying to, to represent you as the best qualified candidate and used to get you an interview and do not usually include personal interests. Sometimes personal interests can be added in but it is not essential. These are usually in areas where you are working in some of the more government (based) agencies and they want to know what sort of person they are bringing into a usually smaller employment settings. It is also something that you could throw in at the end of an interview if you feel like it is appropriate.

Whether you are looking for your first job out of high school or uni or changing your employment during your lifetime look carefully for the type of job you are interested in. Over your lifetime you may change your career multiple times, it is often said between 5 and 7 times but I personally think that is a little high. And sometimes there has been talk about every 12 months but during Covid I think it is a bit risky to do that.

Read your advert carefully, specifically the job description and look for a suggested format for a layout that your employer is looking for. The advert should also detail what the employer is looking for in experience, qualifications and if there is a selection criteria, that there is a series of questions or state-

ments that you have to respond to.

Ensure that you read and re-read your CV/resume carefully, spell checks and grammar checks are important to



your prospective employer on their first reading of your job application. And it is often important to include a covering letter as this is your introduction to the employer and can cover why you are applying for this job. It should include a job identifying number and/or name (check the advert) a brief summary of what you have included or attached such as copies of your qualifications or trade certificates.

And also ensure you sign and date your letter. Well that's it for now. Here are some useful links for you and good luck!

Alex Coombs

<https://www.resume-now.com/build-resume?ref=3>
<https://icc.ucdavis.edu/materials/resume/resumecv>
<https://www.thebalancecareers.com/what-to-include-in-a-cover-letter-for-a-job-2060315>
<https://www.aib.edu.au/blog/career-development/changing-jobs-how-often-is-too-often/>

To view this video and other videos in the series from The Alfred Haemophilia Treatment Centre Team please go to:

www.hfv.org.au/publications/digital-stories-1/htc-covid-19-series

COMMUNITY

*and what
it means
to us...*



We often talk about our bleeding disorders 'community' and we understand how important it is for us to connect and stay connected with others with bleeding disorders. We find support in the shared journeys of others and we share advice on how to manage with different aspects of bleeding disorders. It could be the physical impact, social or financial impact. It could be managing the needs of siblings or looking after your own health as a parent. All of these issues can impact your day to day lives managing a bleeding disorder. Young kids look up to the older kids at camp and in turn become mentors themselves as they 'pay it forward'. It is clear to see the benefits our bleeding disorders community bring.

During this pandemic we have all had time to reflect on what is important in life. For many we have felt more isolated than ever but it may have helped to clarify what is important to us. Many of us have 'slowed down' and despite the anxiety that Covid and the implications on our economy, lives and world we know, we feel less time pressured. I feel calmer in my day to day life. The rat race of family life with multiple sports and community group activity drop off and pick ups became quite overwhelming for me at times, meaning 6 journeys a night and trying to cook

a meal in between. I certainly don't want to return to that. I have enjoyed the time with my family and have found myself being bored on occasion...what a luxury! I am acutely aware that my kids are getting older and our time together will be less, so I am grateful for this opportunity to spend time with them. As my kids are older and fairly independent now I feel the Covid experience has been much easier than for many with young children many of whom have found it to be a very challenging time.

So, despite 'slowing down' and the opportunity to almost reset myself I have been reflecting about what it is that I have missed the most. Seeing family and friends is at the top of the list. But there is a deeper realisation of how important communities are in our world. In most aspects of our lives we have these micro communities. From your friendship groups, school parents, sporting clubs, work colleagues, the 5pm dog park crew. Throughout our lives there are many communities that we are part of and they all play a small part in making us feel whole, supported and valued.

I have been reflecting on how important the other school parents were to me when my kids started primary school. We had moved to a new area and embraced the oppor-

tunity to connect with other 'prep' parents. School drop off and pick up became really important to my mental health. It was 15 minutes (or more) giving me a much needed chance to de-stress, debrief and have a laugh about the often mundane parts of family life and it would hold me in good stead for the rest of the day.

Those friendships and connections have increased to my wider community. I am now so grateful to see the friendly face of an old acquaintance with some shared history and I have missed that during covid. These small interactions that create foundations of support and wholeness, really clarifies for me the importance of community and it is these interweaving communities that help define who we are. My family is not affected by a bleeding disorder, my connection is through my role at HFV but the HFV community and the connections I have within this community are still very important to me, the relationships I have made and the support those people provide to me is part of my wholeness.

This brings me back to our bleeding disorders community and why it is so important for us to stay strong. During the last few months I've gained a very small insight into the complicated and arduous process of

funding for new treatments. This process can take years and involves many different parties from both state and federal government, pharmaceutical companies, HFA and other key stakeholders. After a nerve-racking wait we were delighted to hear that the funding of Hemlibra (Emicizumab) had been approved.

Our involvement in the process may have been minimal but impactful nonetheless. In advocating for this treatment we engaged with HFV members who had trialed this treatment and we produced short videos highlighting the incredible impact these treatments had had on their lives. The videos were shared with the Victorian Minister of Health. We also contacted specific members who may have had strong personal reason to see this drug funded for our community and asked them to contact their local MP and help champion the cause.

Without the Foundation, our network of members and supporters, we would not have been able to advocate in this way. We would not have had the knowledge or ability to make a difference. We will never know for sure what our impact was in the whole scheme of decision making around the funding of Hemlibra but our knowledge of our community is power, our stories are compelling, our voices are loud and as a united community we are strong.

Community is the foundation to society and the fabric of that is what binds us together. It is important for us to value what we have and ensure we stay connected, supported and empowered as a community for the future. "Alone, we can do so little; together, we can do so much" – Helen Keller.

I hope during Covid and moving forward we have all learnt what is important to us. For me, that is community.

Julia Broadbent
Communications Coordinator - HFV

Haemophilia Foundation Victoria

Annual General Meeting

2020

THURSDAY 17th DECEMBER
7pm - 8pm

Our HFV Committee are delighted to be able to invite you to attend our **Virtual AGM**.

This is our first year offering online attendance and we are pleased that this will really open up the event to everyone in our community, rural, regional and metro members alike.

***Featuring a 'hot topics' panel discussion with
HFV Patron, Dr Alison Street AO
& HFA Executive Director, Sharon Caris***

This year we have an exciting AGM, including a panel session with our patron, **Dr Alison Street** and HFA Executive Director, **Sharon Caris**, together with our president Leonie Demos and vice president Dan Korn. Alison has a wealth of medical knowledge gained over her many years of service within our community here and abroad. Sharon also has an incredible understanding of our community and had steered us towards success on many fronts. Both Alison and Sharon will be sharing their expertise in our Q and A session - not to be missed!

There will also be an opportunity to connect with other HFV members over Zoom after the formal sessions have concluded.

Bookings are essential through TryBooking.
www.trybooking.com/BNEQH

Please find the official notice of AGM enclosed in this edition of the Missing Factor.

NEW TREATMENT UPDATE



Photo by Karolina Grabowska from Pexels

HFV advocates to help ensure a range of best practice treatment products are available and publicly funded for the Victorian bleeding disorders community. Some of our community members were willing to help us advocate for extended half life clotting factors (EHLs) earlier this year, and more recently for Hemlibra to be made available for those Haemophilia A patients with and without inhibitors who need it.

It is not HFV's role to recommend specific treatment products as this must always be a careful decision made by the patient (or carer in the case of a child) with his/her treating doctor.

Both Victorian HTC's practice patient centred care and decisions regarding suitable treatments are always made on an individual basis.

In light of the new treatments becoming available to patients it is important that you attend your clinic session to discuss options that may be available to you. There are many important aspects to new treatments that need to be considered and discussed, particularly with Hemlibra as this is a subcutaneous based treatment and works in a different way to the more conventional prophylaxis treatments we are familiar with. These considerations may include what that process will look like to transition to a new treatment such as monitoring requirements, suitable dosing, possible side effects

If you have any questions about new treatments contact your HTC team either by phone or email and they will be more than happy to answer your questions.

Below are some key points available on the National Blood Authority website regarding Hemlibra.

National supply arrangements for Hemlibra (emicizumab)

- Hemlibra will be available under national supply arrangements from 2 November 2020
- Hemlibra will be available to prevent or reduce the frequency of bleeding in severe or moderate haemophilia A patients without inhibitors, and in haemophilia A patients with inhibitors
- Hemlibra will be available through specialist clinicians at Haemophilia Treatment Centres
- Distribution arrangements will support local delivery for patients who can appropriately self-administer Hemlibra at home, with ongoing clinical oversight from a Haemophilia Treatment Centre. This will include distribution through a community pharmacy, or home delivery on an exception basis within a defined set of eligibility criteria.
- The timing of transition arrangements for Hemlibra will take account of the need for appropriate clinical oversight of transitioning patients, and the efficient use of stock of current products already held by Haemophilia Treatment Centres and patients, and stock required to be held in Australia under NBA contracts

www.blood.gov.au/national-supply-arrangements-hemlibra-emicizumab



Let's Talk Hep

Hepatitis B and C are viruses that can damage your liver and lead to liver cancer...

You've been cured of hep C! How is your liver going?

Ask your doctor if you still need regular liver checks.

hepatitis
australia

worldhepatitisday.org.au/quiz
#LetsTalkHep | 1800 437 222

H
HAEMOPHILIA FOUNDATION AUSTRALIA

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RCH COVID-19 PANDEMIC POLL

EFFECTS ON AUSTRALIAN CHILDREN & FAMILIES



“Australian families have found some silver linings in the challenges of the COVID-19 pandemic”

Despite the hardships, Australian families have found some silver linings in the challenges of the COVID-19 pandemic, with the majority reporting their family unit is more connected, spent more time together and used their time at home to consider what’s important in life.

Almost half of parents (42%) say they are now more connected to their child, with most having spent more time reading (51%) and playing games (68%) together, and 66 per cent have developed new positive family habits since COVID-19.

Unsurprisingly, children spent more time on screens for entertainment (51%), spent less time

being physically active (42%) and ate more unhealthy food (25%) during the pandemic. In fact, only one in 10 children got enough exercise each day.

However, positive habits were also reported, with the vast majority of children (78%) utilising digital media to stay connected with their friends and extended family. Three-quarters of parents (75%) said their child was able to learn well remotely using digital devices.

Most parents (70%) also tried harder than usual to feed their children healthy food and taught children cooking skills, with 63 per cent of kids being more involved in preparation of food at home. Poll Director, Paediatrician Dr An-

thea Rhodes, said parents spending time with their child reading books, playing games or exercising are some of the best ways to create positive relationships, and these activities also come with benefits for both physical and mental health.

“As we continue to adjust to life through the different stages of the pandemic, one helpful thing parents can do is focus on how they can continue with these positive new habits and activities,” Dr Rhodes said.

“If kids have formed unhealthy habits during the pandemic, the best way to get back on track is to re-establish a routine that works best for you and your family. This

could be cutting down on screen time and replacing it with some exercise, or setting boundaries around a healthy bedtime.

“We should also try to remember it’s ok to feel a bit lost during the pandemic. Parents may need to go easy on their kids, and themselves, and it’s reasonable to relax the rules at home for a while. However, as we all adjust to a ‘new normal’ it will be really important for families to find a way to get back into healthy habits, as this will help not only your child, but you too.”

Concerningly, the report also shows of the one in five (20%) children who became unwell or injured since the onset of the pandemic, one third (31%) had healthcare delayed or avoided by parents.

Reasons for this included parents being concerned that their child might catch COVID-19 at a healthcare facility (59%), wanting to follow government advice to stay home (38%) and not wanting to burden the hospital or GP during the pandemic (28%).

“We understand that parents are worried about COVID-19, but it is never ok to delay healthcare when it is needed. It is important parents are reassured that healthcare services, including hospitals and GPs, are safe places. Extensive precautions are in place to protect the health of every child and family. If your child is sick, please get healthcare without delay,” Dr Rhodes said.

The findings also show the pandemic has negatively impacted the mental health of both parents (48%) and children (36%). Loneliness was a common experience for both parents and children, and strongly linked to a negative mental health impact.

“The pandemic has affected us all in different ways, and for a large proportion of us, the impacts have been negative. People need to look out for each other and find ways to stay connected,” Dr Rhodes said.

“For families facing another period of extended lockdown – this will be harder than ever. But it’s also more important than ever to try each day to fit in some exercise, healthy food, enough sleep and time to connect with others. These are the things that will help keep kids happy and healthy, and parents too.

“If you or your child are struggling please reach out to your local healthcare services and seek support. We know mental health and wellbeing can affect all aspects of our lives and it’s more important than ever to seek help now.”

Reprinted with permission from
The Royal Children’s Hospital’s National Child Health Poll:
COVID-19 pandemic,
Effects on Australian children and families



HFV COMMUNITY CAMP 2021

In adherence with COVID regulations and safe practice our HFV committee are constantly reviewing the viability of running face to face member events.

At time of print we have a **tentative booking** for our annual community camp at Lake Dewar in Myrning (near Bacchus Marsh) from **12th - 14th March 2021**.

Lake Dewar Camp are currently not able to accommodate community groups, only school groups however they anticipate this restriction may ease, allowing HFV to go ahead.

HFV will be very mindful of all the Covid-safe recommendations around our camp activities as will the camp staff and our program will be adjusted accordingly.

If the cases of COVID do increase we do have the ability to postpone the camp. Please refer to our website for updates **www.hfv.org.au**

Camp registration forms will be **emailed** to members mid to late January so please ensure we have your correct email address by sending any updates to **info@hfv.org.au**. The camp registration forms will also be available on the website.

SHARING *YOUR* JOURNEY

SELF-ADVOCACY, SELF-CARE & UNDERSTANDING YOUR TREATMENT OPTIONS

My name is Sharron. I am 50 years old. I have a husband and 3 children. I also have mild haemophilia A. My father has haemophilia, and so does my eldest son.

As a child there was so little known about females with haemophilia that my mum and dad were told it was a possibility that my sister and I might bleed to death with the onset on our periods. How shocking! I can't even imagine going through that as a parent. The good news is that my bleeding issues have always been managed well and that the best thing you can do for yourself and your daughters is to learn how to be the best advocate you can be. If you feel that you aren't getting the best treatment to manage your condition or your daughter's condition, educate yourself and be strong in your conviction and know your voice will be heard.

I have always advocated for myself. At times I have needed to remind or guide a GP or dentist to liaise with the haemophilia treatment centre. This usually made the procedure more complicated to organise, but step by step it would be sorted out and I felt safer during these procedures, as every angle was covered.

Over the years I have had bleeding issues with some bumps and needed treatment for some procedures mainly. I had an endometrial ablation (burning of the lining of the uterus),

for heavy periods and I have needed treatment for those procedures as well.

Years ago I had a Mirena IUD to decrease the heavy menstrual bleeding I was experiencing, but I had light bleeding on and off all the time. I had the Mirena removed, and had an ablation done, and an Essure coil device inserted all in the one procedure. The coils were used instead of doing a tubal ligation (tying my tubes for contraception), as it spared me from having a laparoscopy (port holes in my tummy). I only had very light periods after this.

Over time things changed and eventually I was in extreme pain every time I had a period. I was off work once a month, and on strong pain killers that weren't working. I was referred to a gynaecologist in Melbourne that I had seen before. She had been recommended by The Alfred HTC as she had liaised with them in the past.

After reviewing all the options available to me we agreed that a hysterectomy was the optimal option due to the affect it was having on my life and considerations such as family planning were no longer relevant to us. The gynaecologist decided that the best option was a laparoscopic hysterectomy which is 3 port holes in the lower abdomen, each only about 1cm long. The recovery time is usually 4 weeks instead of 6 and there is usually less chance of bleeding. Being a nurse and now a sonographer, I knew most of the choices available but I hadn't thought of a port hole hysterectomy as an option and I was much more confident with that option, as a person with haemophilia. I also retained my ovaries, so I don't require hormone replacement.

With the help of the HTC, a haematologist at my private hospital, and the



anaesthetist, everyone knew their part in keeping me safe. I stayed in hospital for 5 days, and had factor for 10 days. The normal stay time in hospital was 2 days for this procedure.

The surgery went well. I wasn't in much pain. I had factor twice a day, in hospital, and when I went home I continued with factor until day 10. I was also on cyclokapron. I had a drain tube in for 36 hours to alert them of any bleeding however that was only minimal.

I had four weeks off work and was told to do nothing but rest for the first two weeks. I was also on light duties when I went back to work for a few weeks.

I am very happy with the outcome so far from this procedure. I feel that throughout my life there have been good medical interventions to help manage my bleeding disorder. A hysterectomy is really the last resort and not something you would undertake lightly. For many years I felt that hysterectomies were the standard treatment for women with menorrhagia (heavy periods) but this has changed and there are many options depending on your circumstances. For me, at this stage in my life, it has been a good option.

Sharron Inglis
HFV Member



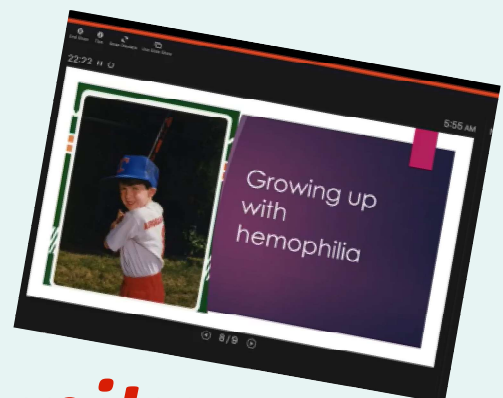
Despite the challenges we have faced here in Victoria during the Covid lockdown HFA were still able to develop a very effective Bleeding Disorders Awareness Week (BDAW) virtual campaign.

There were opportunities for individuals and families to engage in online activities such as a virtual baking session, a Q&A session with a haemophilia physiotherapist and nurse for children and young people, a session for 'getting older' and a live chat with special guest Chris Bombardier from the documentary Bombardier Blood!

All these sessions were huge successes and really opened up the door to more virtual sessions that can unite us Australia wide and give us a stronger voice. The session with Chris Bombardier was particularly fascinating and I would implore you all to download his movie 'Bombardier Blood'. Although the movie is about Chris's challenges as a mountaineer to conquer the 7 peaks, it delves much deeper into the recent history of haemophilia, the impact of growing up with haemophilia for Chris and the disparity in care between countries. It is undoubtedly motivational but in many unexpected ways.

Having the opportunity to listen to Chris speak during the live chat session during BDAW was brilliant. Also, Australian rock climbing brothers Andrew and Scott Godwin who successfully climbed El Capitan at Yosemite National Park in California in September 2019 joined us for the session. It was wonderful to hear about their experiences in achieving such incredible success last year, despite some of the challenges haemophilia had placed on their bodies over the years. For Scott, a target ankle means climbing down is not possible hence abseiling post climb works for him.

It is always so inspiring to hear these stories and journeys and see how having a bleeding disorder is only ever a small part of the picture of who you are and that you can follow your dreams, there maybe adaptations and compromises along the way, but you don't need to limit your dreams and aspirations.



***One Community,
Many Faces!***



ASK US

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



Here is a list of previously feature articles by Alex Coombs and Jane Portnoy (Social Workers, Haemophilia & Other Inherited Disorders Team, Alfred Health) and provide advice and guidance for patients that attend the Ronald Sawers Haemophilia Treatment Centre. These articles are now accessible on our website.

- Hospital appointments during Covid-19
- Life in lockdown
- Sleeping issues
- Ageing and bleeds
- Understanding the Disability Support Pension (DSP), NDIS & MyAged Care
- Mental health and loneliness
- Are you a country patient?
- NDIS and bleeding disorders
- Health issue with ageing with haemophilia
- Transitioning to the Alfred
- Disclosure at work

Please go to www.hfv.org.au/publications/local-resources-publications/alfred-htc-question-and-answer-resources

Mental health and loneliness - March 2019

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

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

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

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

Health issue with ageing with haemophilia - June 2018

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.

LIVE WELL FUNDING

HAEMOPHILIA FOUNDATION VICTORIA

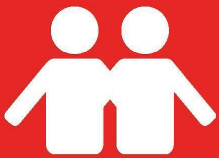


HFV have small amounts of funding available to assist those that need help with costs associated with their bleeding disorder.



Not too sure if you can apply? Here is the following three criteria mostly used by committee to determine suitability of applications:

1. Will it improve a possible health outcome?
2. Are there any other resources available or other funding to the applicant?
3. Will it improve the applicant's quality of life?



The application process is very simple and straight forward and committee really encourage members to consider Live Well program as an option. Items approved in past 12 months include educational resources, medications, home ramps, personal health care, child swimming lessons.

Still unsure? You can send andrea@hfv.org.au a confidential email first. All applications are confidential and de-identified prior to review by the committee.

Go to www.hfv.org.au/support-services/services

CONNECT

SUPPORT

DURING COVID

EMPOWER



**WE CAN
CONNECT YOU
WITH OTHER
HFV MEMBERS**

email info@hfv.org.au



www.facebook.com/HaemophiliaFoundationVictoria
www.instagram.com/haemophiliafoundationvictoria



REACH OUT....there is a
whole community of support for YOU



Patient Portal

Alfred Health has recently introduced a **Patient Portal** that allows you to access your Alfred Health Medical record, anytime, anywhere!

What can I view on my Patient Portal account?

- View upcoming appointments
- View pathology results from tests conducted at the Alfred Health pathology laboratory (14days after a final result has been determined), excluding anatomical pathology and genetic testing
- View letters sent to patient or to referring external providers
- View inpatient Discharge Summaries, medication lists & Nursing / Allied discharge summaries
- Receive secure message from your clinicians
- Registering for Alfred Health's Patient Portal
- Existing Alfred Health patients can sign up to the Patient Portal online by following the instruction below.

Registration is available between **Monday - Friday, 8am - 4:30pm.**

To register, you will need photo ID (such as drivers licence, student ID, passport).

Once you have your ID ready, you can register here which will allow you to join a virtual queue and connect you with our Patient Portal support staff.

You will then be asked your full name, date of birth and home address. You will need a camera and microphone to complete your registration.

Want to learn more?

Please go online and visit AH connect for patient brochures, FAQ's and details on **how to register for the Patient Portal**

Alternatively, you can telephone or email our friendly Patient Portal Support team. Call (03) 9076 5000 or email patientportal@alfred.org.au

We look forward to welcoming you to the **Patient Portal!**



PARKING AT THE ALFRED

When attending the Alfred Hospital for any appointments, please remember to display your disability parking permit at all times wherever you park in and around the hospital.

Also please note there has not been any free parking in & around the hospital for some time.

To avoid a parking fine, please pay the appropriate fee when parking on the street.

Ensure you have your appropriate concession card on hand if asked by the parking inspector.

Any queries, please contact the HTC social worker(s).

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**

PATRON: Dr Alison Street AO

EXECUTIVE ASSISTANT

Andrea McColl andrea@hfv.org.au

COMMUNICATIONS COORDINATOR

Julia Broadbent julia@hfv.org.au

COMMITTEE OF MANAGEMENT:

PRESIDENT Leonie Demos

VICE PRESIDENT Dan Korn

TREASURER Zev Fishman

EXECUTIVE MEMBER Donna Field

GENERAL COMMITTEE:

Cara Gannon

Robyn Heal

Erika Mudie

Claire Brunet

Bernard Paes

Chris Phong

**Henry Ekert****Haemophilia Treatment Centre**

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

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

Ronald Sawers**Haemophilia Treatment Centre**

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

Professor Huyen Tran | Director of RSHC
Penny McCarthy | Clinical Nurse Consultant
Megan Walsh | Clinical Nurse Consultant
Kara Cordiner | Haemophilia 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

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.

HFV COMMUNITY
RECONNECT 2021

LOOKING BACK & RECONNECTING

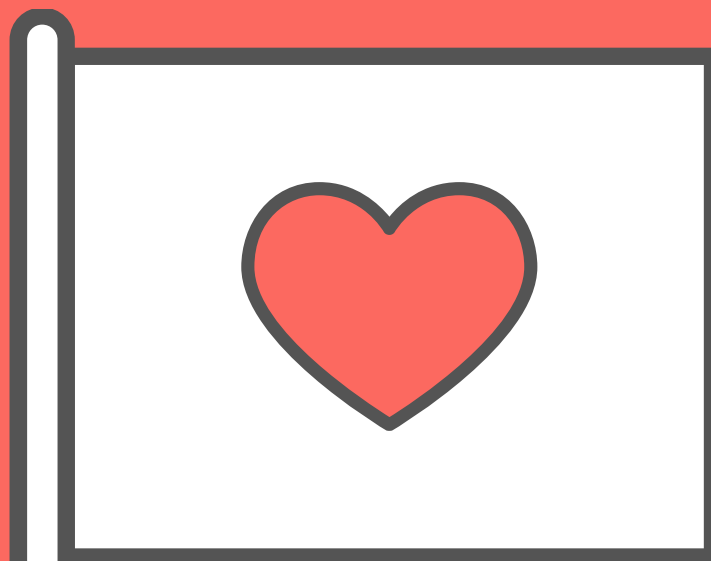
Re-connecting old friends
and acquaintances

HFV will be organising opportunities to reconnect our community.
Did you go to camp in the 80's, were you on the HFV committee in the 60's?
Was your family connected with HFV and have lost touch with others?

We have a unique history with many people crossing paths in both challenging
and supportive times and some have lost contact along the way.

It may be as simple as wanting to know how an old acquaintance is doing
or maybe the opportunity to reminisce over old camp photos together.

Email info@hfv.org.au and register your interest and we'll be in touch!



info@hfv.org.au