

THE **MISSING** FACTOR

How to safely
exercise in a gym
AND GET RESULTS

Finding out you
carry the gene

HOLDING BACK
THE YEARS
Living longer &
living well with HIV

connect • support • empower



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18th Australian & NZ Conference on
Haemophilia & Rare Bleeding
Disorders

HAEMOPHILIA FOUNDATION VICTORIA INC

13 Keith Street
Hampton East VIC 3195
Phone: 03 9555 7595
Fax: 03 9555 7375
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

Sharron Inglis

TREASURER

Zev Fishman

GENERAL COMMITTEE:

Kate Apted

Karen Donaldson

Donna Field

Ben Inglis

Dan Korn

Erika Mudie

Matthew Powell

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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.

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Editor: Julia Broadbent



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Victoria acknowledges the
support of the Victorian
Government.



PRESIDENT'S REPORT

CONNECT SUPPORT EMPOWER

Winter is almost here. Time to curl up on the couch with a blanket, cup of cocoa and Missing Factor for a good read.

We are delighted that the 18th Australian & New Zealand Conference on Haemophilia & Rare Bleeding Disorders is being held in Melbourne during October. We encourage as many members as possible to attend this conference. It is a unique conference as the program is tailored to both patients and health professionals. We will get to hear about the progression in new treatments, people living with bleeding disorders will be presenting as well as expert health professionals.

For those of us who have attended these conferences previously we really can't recommend the benefits of attending enough. It is an opportunity to hear first hand of what is in store for the future and an opportunity to connect with others from our community and hear their stories. HFV has some funding available to assist with the costs of registration (form enclosed) so please consider making the most of this opportunity in joining our staff and committee on our home turf.

We have recently just held our annual newly named 'Community

Camp'. We have an article in this edition about the camp so all I will say is that it was a great success with many families attending, a few new faces and a wonderful supportive atmosphere. I did raise the concern at camp that HFV may not be in a position to fund this camp as an annual event due to the financial burden. This is an issue that the committee will address in the coming months but it is our obligation as the committee of management to oversee the correct use of member funds. Bearing this in mind we hope that members may take this opportunity to 'step up' in the fundraising arena and try to assist HFV in some way. We know that it can be difficult to secure a spot at your local Bunnings for a sausage sizzle but it can be a great way to earn \$1000. It would only take a few members running sausage sizzles to make a huge difference to the viability of an annual camp. Other easy fundraising opportunities include a gold coin donation at your child's school – kids can wear a touch of red. Cake sales at work during Haemophilia Awareness Week is another opportunity to assist. If the financial burden of our Community Camp is lessened we should be in a position to continue to run as an annual event rather than every 18 months or two years.

Please take time to read all about our Haemophilia Red Charity Ball and think about how you can be a part of the night. This event has been organised by some amazing women from within our community who have really stepped up to the challenge of supporting our community. We hope as many people from our community as possible can help to support this event which is aimed at providing financial support for specific workshops at HFV camps. Do you know a business that could make a donation? What about taking some time to seek out donations from local businesses. Especially those in rural communities - there may be a tourist attraction or a B&B to offer a weekend accommodation? How about a table of work friends and extended family? I am sure everyone has something to offer so I look forward to hearing all about your support. Many thanks to the subcommittee for all their amazing efforts. It will be a great month to be a part of so don't miss out.

Stay warm and look after yourselves and your loved ones. Look forward to seeing you soon at one of our HFV's events.

Leonie Demos
HFV President





We all have a story to tell. We may not believe that our own story is relevant or inspiring or interesting but the reality is that we do live interesting lives, we all have faced challenges, overcome road blocks and gained successes – however insignificant they may be.

I have worked for HFV for more than 10 years now and feel very privileged to be part of this community, to have heard the many stories of people's everyday lives - the struggles and achievement. I have been so grateful that some of those people were willing to share their story with our community through our magazine. They have had a tremendous impact on us as it is these stories that bind us together. I can tell you about new treatments, changes in healthcare policies and mental health advocacy programs - all extremely important and valuable information but the glue in our fabric is our ability to connect on a personal level and it is through our shared experiences that this is possible – our stories, our journeys.

Over the years I have heard many people's stories – some just snippets but usually I get a true sense of their journeys. Of course, it is not always related to a bleeding disorder, often their bleeding disorder

is just a small part of their lives and sometimes it can become overwhelming but it is the bleeding disorder that binds us together.

I have spoken to mothers and fathers, husbands and wives – their journeys are different, the same path but different experiences. Those with bleeding disorders themselves or parents of children with bleeding disorders. Some people like to talk about their experiences, others don't want to dwell.

I meet mothers of children with bleeding disorders. Often they have a history of haemophilia in their families - their father or brother. For these women, their journeys can be complex. The challenges of the past have impacted them greatly as they navigate the world of haemophilia that has a bright future. I believe there is an understandable reluctance for some of these women to reflect on their past as their experience growing up with haemophilia was very challenging and so they are reluctant to bring any negative connotations of haemophilia into their child's world.

Siblings need a louder voice. Their journey is so different from their siblings but needs to be validated.

A mother tells me of her eldest son's concern over his younger sibling's haemophilia. He has always looked out for his brother, attended many hospital visits as a young child, keeping an eye on his brother at school, just felt a big sense of responsibility over him. Now both in their 20's he is still much more concerned over his brother's bleeding episodes than his carefree sibling is himself. Both have been impacted by a bleeding disorder, both have a story to tell.

I remember a few years ago when discussing the wonderful new facilities at the RCH an older member talked about when he was a small child and in hospital for an extended period of time. It was back in the days when visitors were only permitted on a Sunday. He would lie in bed for hours and listen for his mother's footsteps coming from down the corridor. His heart would race when he heard her footsteps, only to be followed by the deep disappointment as it would be some other child's mother. Sadly some Sundays his mother would not be able to visit.

I vividly remember how everyone in the room was so moved by this reflection. We could all empathise with the bitterly deep disappointment felt on that day. It was just

a spontaneous comment but it bound us together for a moment. A small fragment of this person's life was shared and in turn made me more aware of the journey that many adults in our community have travelled as children. The impact and guilt of that missed visit for his mother would have been profound. I am sure his experiences as a child through adversity taught him not only empathy but resilience. He is kind and generous spirited, has a most wonderful sense of humour and a most positive outlook on life.

I know many people feel they don't have the skills to write their own story and yes, I understand that in sharing your story you may feel exposed, even vulnerable, but you may find that the benefits of sharing far outweigh the hurdles.

You may inspire others with your story – you don't need to have had an unusual story for it to inspire others. Small reflections can have impact. Just the fact that another person can identify with that journey means it has impact.

Empowerment – sharing your story can be empowering. It may be the first time you have put down

in words your journey and given yourself that time to reflect. It gives you the opportunity to unpack some of the emotions that you may have held at bay. You can reflect on where you are at now, achievements, hurdles that you have overcome.

Acceptance – putting pen to paper can help with acceptance. Writing your story can be a cathartic exercise in acceptance. You may never have really thought through whether you have accepted where you are at in life so putting pen to paper can be a step towards that.

Adversity – understanding that you have experienced adversity. Again another benefit in sharing your story is that you can reflect on any adversity you have overcome.

Often we are too busy to reflect, or feel that if we open the lid we may never get the lid back on, but reflecting on and accepting that you have experienced adversity and grown from it can be powerful.

I know that many of you are very time poor with work and family life but if you feel that you can share a bit of your journey with the rest of

our community please just give me a call. I can keep your story anonymous if you prefer and if you don't enjoy writing I can easily chat with you over the phone and piece your story together myself. You don't need to share your whole life story...a short reflection on an experience you had may be more than enough to provide some benefit to others.

Your stories are the life blood of our organisation. They keep us connected, connected with the past and connected for the future ahead.

Julia Broadbent

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The 2017 | 2018 Entertainment™ Memberships are now available!

Let's Talk Period:

An Interview with PAULA JAMES, MD

As the World Federation of Hemophilia (WFH) gears up for World Hemophilia Day 2017—and its theme of women and girls affected by bleeding disorders—the WFH had the pleasure of sitting down with Paula James, MD, an academic hematologist based in Kingston, Canada, for a question and answer interview. She is the Medical Director of the Inherited Bleeding Disorders Clinic of Southeastern Ontario and the Women and Bleeding Disorders Clinic at the Kingston General Hospital. James is also a clinician scientist with a major focus on bleeding, von Willebrand Disease (VWD) and issues related to carrier bleeding. The WFH is very proud to have her on its von Willebrand Disease and

Rare Bleeding Disorders Committee. We are also very proud that James is one of the first grant recipients of the WFH Clinical Research Grant Program.

James is now working on a project called Let's Talk Period which has the objective of increasing awareness of the signs and symptoms of bleeding disorders. The Let's Talk Period website offers a self-administered bleeding assessment tool (Self-BAT) that helps give people more information and advice about their bleeding and guides them toward the support they need.

During the interview, James was able to provide us with rich insight into the

issues facing women and girls with bleeding disorders. The reality, she explained, is that many women are left undiagnosed and are not getting the treatment they need. Especially when it comes to menstrual bleeding, it is difficult to make the distinction between what is normal—and what is abnormal and requires additional attention. The social stigma surrounding women and girls talking about their period is another barrier in proper diagnosis.

The following is an excerpt from our interview with Paula James, MD, where she shares her experiences regarding Let's Talk Period and the positive impact it's having on the bleeding disorder community.

Q: Why did you decide to study women and bleeding disorders? What interests and motivates you about this subject?

A: My interest in women and bleeding disorders started with patient interaction. It became blatantly obvious to me very early on in my career that women were struggling. In some instances women were being cared for properly, but in many instances they weren't. I realized the frustration around the lack of recognition of the issues affecting women and I wanted to be part of the movement, to make people more aware of the issues at hand and to provide better diagnosis and care for these women.

It's not hard to treat women with bleeding disorders—in fact it's actually quite easy. It's not complicated medicine; we have a whole list of effective treatments we can use. What's important is that we make sure we are identifying the right patients and getting them to the right clinics so they can be cared for properly.

Q: Can you tell us more about the Let's Talk Period Project?

A: I had the general idea for Let's Talk Period five years ago. I was involved in developing bleeding assessment tools—also known as bleeding scores—which quantify the kind of bleeding that patients are experiencing. A lot of work went into validating an expert-administered bleeding assessment tool in primary care offices in Kingston, Ontario, with the goal of increasing referrals for bleeding

disorders. Unfortunately the referrals didn't happen. We still don't recognize how often—when a woman says that she's having problem with her period—that the underlying problem is a bleeding disorder. We decided to go to the general public and put knowledge in the hands of people who might be suffering with symptoms. We took the expert bleeding assessment tool and turned it into something that could be self-administered. This was an evolved optimization process which included many rounds of revisions using feedback gathered from focus groups and from the way patients filled out the tool. We wanted to ensure that the bleeding score from the Self-BAT would be the same as with an expert administered tool. We are now able to provide people who complete the Self-BAT with a printable version of their results. If they find out that their bleeding is abnormal, there is a recommendation to speak with their physician about any concerns they may have.

We decided that we would use the internet—and especially social media—as a platform to get the word out. The website launched in May 2016 and the Facebook and Instagram pages launched in September 2016.

Q: What has been the response from the public? When the WFH shared your site on our social media channels the community reacted strongly with comments and shares.

A: I've been blown away by the response. I never fully understood the power of social media, especially as a

knowledge translation and research tool. I knew it was an important topic, but didn't realize that there would be such an appetite for it.

There has been a steady growth on the website and on social media. As at March, 2017 there have been over 9,124 hits on the website, 1,154 people have taken the Self-BAT and 515 have an abnormal or positive

als in my catchment area would be invited to participate in a study that they would have to consent to and this would fast track them to our clinic for assessment and diagnostic testing. At the end of the test, we would like to build in a link to local clinics as much as we can, so people can have an idea of where they can get specialized care. We would also like to create links with practitioners who

this: pay attention to your bleeding symptoms and seek help if you are concerned. Your symptoms can be easy to treat and there are lots of great options for treatment.

Message from the WFH:

To learn more about the Let's Talk Period project, please visit letstalkperiod.ca. We encourage you



score. Our Facebook account has 587 followers with a reach of 80,344 people. Our Instagram account has 82 followers.

I would never have anticipated the global reach of doing this project—the hits on the website are from 83 countries.

Q: What do you hope for the future of the Let's Talk Period project?

A: I really would like to close the loop with the site. Right now, I don't know anything about what happens to people who take the test and have an abnormal score. Locally we would like to pilot a project where individu-

als are willing to see patients and make the diagnosis.

Q: Do you have a message that you would like to share with the global community?

A: The message that I would like to share with the global community would be the following:

To our community and colleagues, I would say this: Let's Talk period has been a far more powerful tool than I ever imagined. It is a reasonable way to reach individuals who are suffering with bleeding and don't know it.

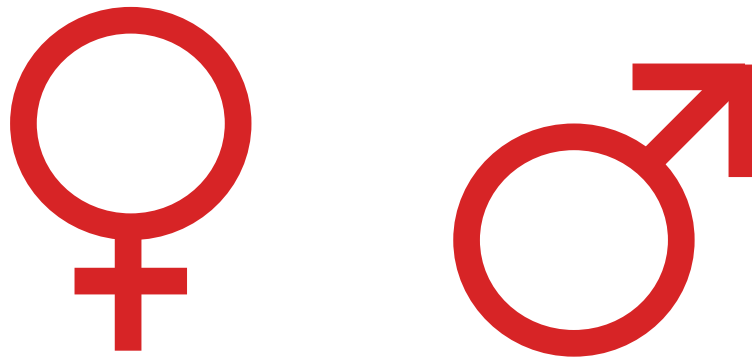
To the general public, I would say

to share this site with your network, to help increase awareness of women with bleeding disorders.

The WFH would like to thank Paula James, MD, for taking the time to share her experience with us on this important project.

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Reflecting on our lives with HAEMOPHILIA



For me growing up I was very aware of the impact of haemophilia. My maternal grandfather had had haemophilia. Unfortunately, he died at a young age from a complication of haemophilia. My mother was only 12. His two brothers also died relatively young from complications of haemophilia. This was devastating for both my mother and grandmother and naturally created a huge sense of fear around haemophilia.

My mother knew from a young age that she may also have a child with haemophilia. When I was born there was a huge sense of relief that I was a girl and that they wouldn't have to face the difficult journey that haemophilia brought in those days. My parents decided that adoption was a good option for them and so my brother arrived.

As a young child I certainly bruised easily and I had particularly heavy periods as a teenager and suffered from anaemia. It never really occurred to me or my family that I may be a symptomatic carrier or as it is now classed as having mild

haemophilia.

When I was 19 I went into hospital for a routine wisdom tooth extraction. After the surgery the bleeding wouldn't stop. It was then that I was tested and we discovered my factor level was 18%. After a week in hospital and considerably more time to recover fully I was left to reconcile what this diagnosis meant for me. It was, of course, quite a confronting time as my family history meant there was a dark shadow of haemophilia bearing down on me.

When I met my husband, Craig, we knew we both wanted children but Craig was very concerned about the possibility of having a boy. We knew early on that we were having a son, so prior to the birth all the correct avenues were followed. Unfortunately, it was a traumatic birth. I required an emergency general anaesthetic, which not only meant an extended recovery time for me but I felt like I missed the initial bonding time with my newborn.

The first few years with Bailey for

us were very hard. It really took a couple of years for us to accept Bailey's diagnosis and get a real handle on it. We immersed ourselves in the hospital appointments and monitoring Bailey's every move. But as time went on, our confidence in ourselves rose and we began to feel positive about the future. Now, it's not often that haemophilia impacts our lives. We have the benefit of our previous experiences and the confidence it gives us, so in hindsight, it really hasn't been so bad.

Through our experiences we have grown from the nervous and anxious parents of the past into the confident advocates of today.

Debbie Tenace

CONNECTING with our community

Ladies Day Out 2017

Come and join Michelle, Karen, Donna and many other ladies from our community for a lovely day out at The Docklands.

Saturday 9th Sept

11am - 2.30pm

We'll be heading to ArtVo - a new immersive art gallery or 'trick art' gallery followed by a short stroll to CARGO, a stylish waterfront restaurant, for lunch.

ArtVo - 26 Star Cres, Level 1,
Harbour Town, Docklands

Booking are essential through the HFV office

on 9555 7595 or email info@hfv.org.au

More information will be available on our website soon



OUR HAEMOPHILIA & HIV COMMUNITY

We are delighted to report that since Matt Powell organised a Road Trip for members of our community affected by HIV and Haemophilia there have been a further two events.

Both of these events have been well attended lunches where participants were invited to bring their partners.

This has been a wonderful opportunity for members of our community who have been deeply affected by HIV to connect with others that have shared their journey.

If you would like to contact Matt Powell please do so through our HFV office.

GRANDPARENTS & FRIENDS LUNCH



You are invited to join Marie, Jackie and other grandparents and special friends of HFV families for lunch at the Brandon Hotel.

This is a wonderful opportunity for extended care givers in our families to meet each other and share the highs and lows faced by themselves and their loved ones. The benefits of connecting with other families and hearing about achievements and successes and sometimes hurdles that have been overcome can be immense.

WHEN: 12pm Sunday 6th August 2017

WHERE: Brandon Hotel, Carlton North

Bookings are ESSENTIAL 9555 7595

Please advise of any dietary requirements

**CONNECT
SUPPORT
EMPOWER**

TRAVEL INSURANCE:

Why it's a must

Preparing for a holiday is usually when you start pinching pennies. As your departure date looms, you might be tempted to slash items from your 'must-get' list. Sometimes this will be a good call. Do you really need a \$500 raincoat in the tropics? Or three brand new bathing suits? Other times, cutting corners will be a decidedly bad call. Case in point: travel insurance.

Travelling without insurance is a huge risk. Costs for cancellations, theft, accidents, injuries and illnesses can run into the tens of thousands of dollars. Travelling without adequate insurance is also a risk. When shopping around for different policies, be sure to take a magnifying glass to the small print.

PRE-EXISTING CONDITIONS

Most travel insurance policies exclude pre-existing injury or illness. Broadly speaking, this means 'an injury or illness for which you have received medical treatment or have taken medication in a specified period of time before the policy starts'. Warning: the definition of 'pre-existing' can differ between policies, as can the 'period of time'; for some policies this means 21 days, for others six to 12 months.

In short: be sure to carefully check all definitions before signing on the dotted line and discuss your concerns with the insurer. Some policies will be able to cover certain pre-existing conditions, like diabetes, epilepsy and asthma. In these circumstances, the insurer might request information from your doctor to ensure the medical condition is well controlled. Other insurers might be willing to extend their cover for a higher premium.

Also be aware that many policies have a general exclusion for serious pre-existing conditions, like mental illness. However, a recent case — *Ingram v QBE* — has challenged this alleged discrimination.

Ingram v QBE Insurance

Student Ella Ingram was forced to

pull out of a university trip when she experienced depression for the first time. When QBE denied her travel insurance claim on the basis of its mental health general exclusion, she challenged them in the Victorian Civil and Administrative Tribunal (VCAT) — and won.

QBE argued that the exception under the Equal Opportunity Act (that is, lawful discrimination) applied because it was supported by actuarial statistical data. However, when the company was unable to produce evidence of this data, VCAT ruled in favour of Ms Ingram.

Had Ms Ingram not taken out travel insurance, she would not have been able to make a claim in the first place, let alone challenge the decision at VCAT where she was awarded remuneration to cover her lost travel costs as well as compensation.

OTHER EXCLUSIONS

Some travel insurance policies exclude certain 'high-risk' activities, such as extreme sports, and/or activities in particular countries. For example, in Thailand or Indonesia your policy might not cover injuries caused by riding a motorbike.

Think about what type of activities you intend to participate in, and where, and check the small print for exclusions. You might need to pay a higher premium to cover that part of your trip.

CHALLENGES AND REVIEWS

If your insurer denies your claim, you have the right to challenge their decision and ask for a review. The travel insurance industry is covered by the General Insurance Code of Practice, which gives access to a reasonably user-friendly review process.

If you do have cause to mount a challenge, it's a good idea to seek independent legal advice, even if just for general guidance on how to manage the process.

CAUTIONARY TALES

The Australian Government's Smarttraveller website has many cautionary tales about travellers with no insurance, inadequate insurance or who had insurance claims denied because they disregarded their policy's terms and conditions, for example, drinking alcohol while under the legal age in their holiday destination.

Maurice Blackburn once acted for a client who suffered a collapsed lung while flying domestically in the USA. After hospital admission and surgery, the medical bill came to more than US\$50,000. Fortunately, our client had travel insurance. When their insurer argued that a pre-existing condition had culminated in the collapsed lung, we were able to produce medical evidence to the contrary. As a result, the insurer paid the claim in full. Had our client not taken out travel insurance, the financial implications would have been dire.

CHECKLIST

Follow these steps to make sure you're adequately covered and to avoid nasty travel surprises:

- do your research and shop around
- visit Choice to compare different policies
- read the small print with a careful eye on definitions, exclusions and all terms and conditions
- ask the insurer for clarification
- ask about higher premium options to get the cover you need.

A holiday should be the time of your life, not the cause of crippling financial loss. Skimping on travel insurance can result in significant costs that can run into the tens of thousands, or more. Protect yourself and your family. Spend a little now — and save a lot later.

Kim Shaw is a principal in Maurice Blackburn's Melbourne office.

- See more at: www.mauriceblackburn.com.au/blog/2016/april/05/travel-insurance-why-its-a-must/#sthash.AWh3WIE.dpuf

Recipients DOUBLE as WFH Humanitarian Aid Program EXPANDS

It has only been one year since the expansion of the World Federation of Hemophilia (WFH) Humanitarian Aid Program. In that short period of time, the number of recipient countries has already increased from 58 to 63, while delivered donations reached a landmark of 100 million international units (IU), with over 6,000 people receiving much needed treatment to date. As part of their commitment to donate up to 500 million IUs over five years, shipments of clotting factor concentrates (CFC) from Biogen and Sobi have now been delivered to the areas most in need in developing countries around the world.

“With the expansion of the WFH Humanitarian Aid Program, Senegal has improved accessibility to treatment by providing surgeries for people with hemophilia, establishing a new prophylaxis program for children, and finally helping improve government involvement to ensure the sustainability of the treatment for patients,” said Saliou Diop, MD, Director of the Senegalese National Center of Blood.

The increase of CFCs channelled through the WFH Humanitarian Aid Program means that there has been a significant increase in the number of patients treated globally—from 1,425 in 2015 to more than 4,000 so far in 2016. For the first time with the program, there was also remarkable product utilization reported for prophylaxis treatment, with 897 patients and 10.2 million IUs utilized and reported to date. Product utilization has also been remarkable for surgeries, with 559 surgeries and 4.4 million IUs utilized and reported to date. Of these

surgeries, 18% were lifesaving interventions and the rest were able to improve the physical functioning of the patients—with many able to walk after a lifetime confined to a wheelchair.

The lack of access to care and treatment in developing countries is an urgent and important public health challenge, as the cost of treatment is prohibitively expensive for the majority of those affected with a bleeding disorder. Due to the limited access to diagnosis and treatment in many developing countries, people with severe hemophilia in these areas often do not survive to adulthood.

Since the WFH Humanitarian Aid Program was launched in 1996 and before the expansion of the program, over 322 million IUs of CFCs have been distributed to over 90 countries, helping over 100,000 people with hemophilia. For many developing countries, product donations are often the only source of treatment product for patients with hemophilia and other bleeding disorders.

The WFH receives requests, many urgent in nature, from our national member organizations (NMOs) and from recognized hemophilia treatment centres (HTCs) around the world.

An increasing number of collaborators in the global bleeding disorders community have accepted the challenge of providing a sustainable and predictable supply of donated products. Through the donation

by Biogen and Sobi to the WFH Humanitarian Aid Program of up to 500 million IUs within five years, the three year commitment from Grifols for 20 million IUs per year, the three year agreement with CSL Behring for a total of 10 million IUs, and the agreement with Green Cross for 6 million IUs, there will now be a more predictable and sustainable flow of humanitarian aid donations to the global community. In addition, the continued efforts of the Canadian Blood Services, Biotest, and Grifols with Project Recovery, and the work by the Italian National Blood Services through Project Wish allow for the manufacturing of clotting factor concentrates from previously discarded cryopaste which provide treatment products to countries most in need. These commitments will contribute to the further expansion of the WFH Humanitarian Aid Program.



sion of the WFH Humanitarian Aid Program.

The expansion of this program has increased the possibility of people with bleeding disorders in the developing world—including young children—having continued access to treatment for emergency situations, acute bleeds, corrective surgeries, and prophylaxis.

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Understanding PROBE

(Patient Reported Outcomes, Burdens & Experiences)

As you may be aware HFA has been supporting Haemophilia Foundation Australia with participation in the PROBE Study.

PROBE is a multi-national patient-focused investigator driven research project. It is led by a global team of patient and academic investigators.

According to David Page (Canadian Hemophilia Society Director), lead investigator and former WFH President Mark Skinner recently stated *“PROBE gives a direct understanding of what living with haemophilia means to an individual patient. It will allow us to provide information to each national patient organisation so it can advocate for better care for people with bleeding disorders.”*

PROBE collects patient-reported information on type and severity of haemophilia, years of schooling, marital status, number of children, health problems, need for mobility aids, use of pain medication, impact of acute and chronic pain on daily living, ability to conduct activities of daily living, employment and educational status, history of joint surgery, number of bleeds in the last year, type of treatment, and joint range of motion.

This data will be used to analyse the perspectives of people with haemophilia on outcomes that affect their own life and care. The research will support efforts to improve treatment and comprehensive care programs in Australia and other countries around the world. All data will be kept confidential.

PHASE 1 OF THE PROBE STUDY

Some of you were involved in distributing and completing the surveys for Phase 1. We needed 35-50 completed surveys by the end of 2015 to have enough data to be analysed.

WHAT DID PHASE 1 INVOLVE?

- Seeking ethics approval via Monash University, Melbourne
- Testing how clear the questions were
- Testing the methodology and the statistics that could be gained from the results.

Phase 1 tested a print survey on haemophilia only. Some Australian community members with haemophilia and carers or parents of children with haemophilia completed the draft questionnaire and gave feedback on the questions and instructions. The completed surveys and question feedback sheets were then scanned and transferred electronically to the PROBE research team at McMaster University for analysis.

RESULTS

HFA received a report on the Australian results in January 2016 and was invited to participate in an international meeting where the worldwide results were discussed:

- More than 700 surveys were completed by 15 countries
- Results demonstrated validity and that the research methodology was robust
- Phase 1 data was useful for understanding how to use the potential results but couldn't be used for representation on health issues at this point – we need to wait for phase 3
- Australian feedback on questions was put in a spreadsheet and each comment was addressed by the research team leaders
- As a result of global feedback, new questions were added in Phase 2 for women who carry the gene
- Some other small changes were made to the Australian version of the survey
- For good comparable data, in future Australia needs to recruit more people with moderate haemophilia to complete the survey.

PHASE 2

The next phase involved reproducibility – testing an online version of the survey as well, and retesting the same community (ie, Australia) twice in several months to see whether the results remain consistent. This phase was completed in February 2017.

PHASE 2 OF THE PROBE STUDY AIMED TO TEST:

- Whether the survey questions will capture consistent responses if they are repeated twice in the same Australian community
- The stability of the online survey.

Australia joined a number of other countries in the Phase 2 reproducibility test, including Canada, Nigeria, Poland, United States and Vietnam.

WHAT HAPPENS NEXT

Currently HFA are awaiting the result of Phase 2. HFA will report on the results in National Haemophilia Magazine and on the HFA website www.haemophilia.org.au We look forward to your support during Phase 3 of the Probe study.

WHY IT IS IMPORTANT

Our personal member stories bind us together, they are a way to *Connect, Support and Empower* us but we know that evidence is required by governments when addressing the impact of health conditions. We must embrace opportunities to record the impact of haemophilia to secure the best outcomes for the future. Mark Skinner stated *“We are empowering patients and patient organizations to move advocacy beyond anecdote and emotion to evidence-based arguments.”*

For more information on PROBE please contact Suzanne O'Callahan at HFA on 1800 807 173

AGEING (Dis)Gracefully

As we age, disgracefully or otherwise, independence and the ability 'to do' for yourself is a notion both the old and the young hold dear and not easily prised from our wrinkled hands.

While it has long been recognised that the elderly fare better when they live in familiar surrounds, the prevailing practice for some time has been to find 'a nice home' for them to live.

To counter this and offer older citizens the opportunity to choose, the federal government has recently launched a new website My Aged Care which has an abundance of information to assist in this decision.

The program has a number of facets all aimed at allowing older people to live independently:

- **Help at Home**

This provides assistance via the Commonwealth Support Programme; Home Care Packages and End of Life Care at Home.

- **After Hospital Care**

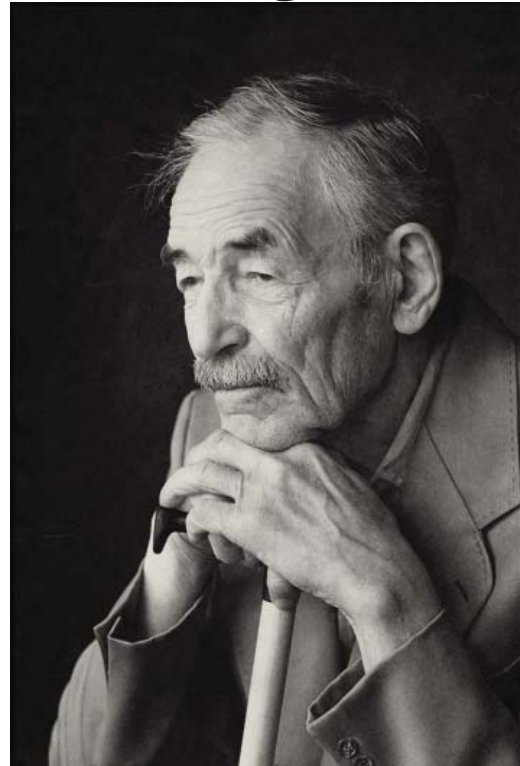
To assist patients transition from hospital to home rather than an aged care facility, extra care may be needed and this program helps in this area for up to twelve weeks.

- **Respite Care**

There are times when both the older person and their carer may need 'time off' to allow the carer to attend to everyday activities or go on holidays while ensuring the needs of their loved one are supported.

There are eligibility criteria (for example, one needs to be 65 years or older, or 50 years or older and identify as an Aboriginal and Torres Strait Islander person, or 50 years or older and on a low income, homeless or at risk of homelessness; still living at home and in need of help at home to continue to live independently to access the Commonwealth Support Programme) and an assessment process to help work out how much help and what types of care and services would best suit the person.

In most instances, there will be fees based on the older person's ability to pay but these are subsidised by the government.



People also have the choice of the service provider they use – and easier to change if circumstances change or the service no longer suits.

An important feature of the programme is being able to support someone at the end of life. By providing support for nursing care, domestic assistance, counselling, personal care and assisting with meals amongst other services, it allows the person a level of dignity and comfort that can give great meaning in those last days.

It is just a matter of fact that we are all marching towards that long, long night but it is reassuring to know we can enjoy the twilight in the security of our own home, surrounded by the familiar and the ones we love.

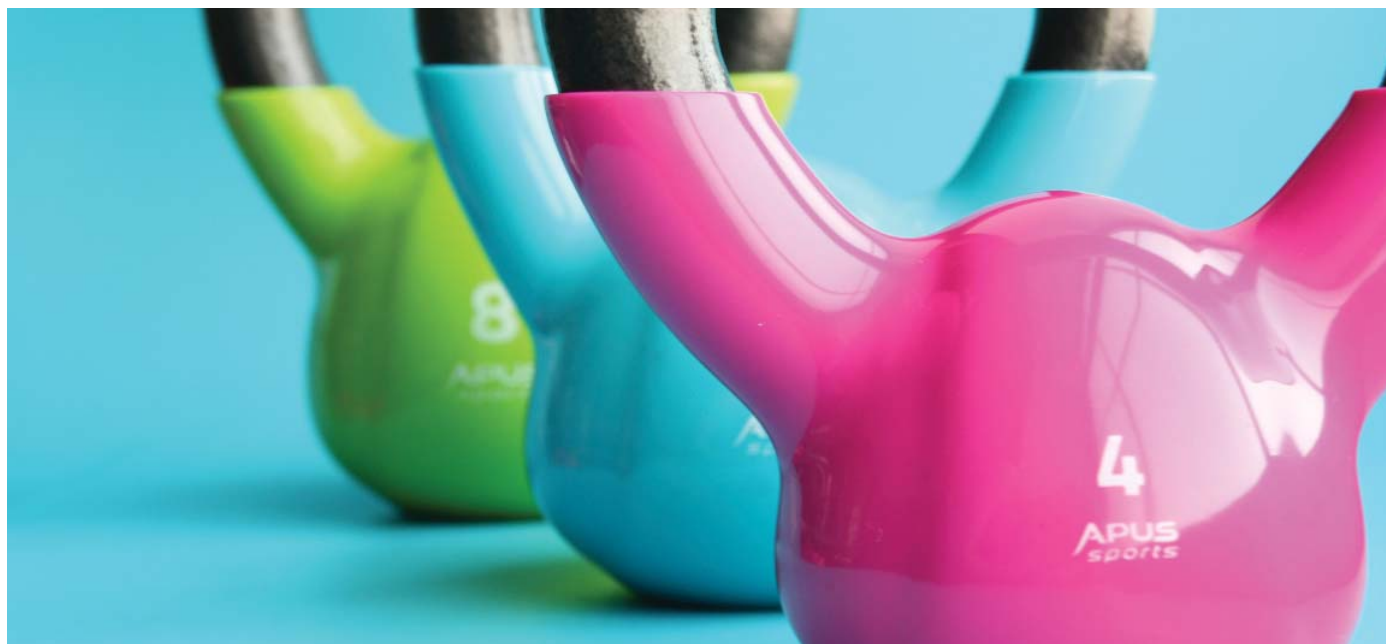
By Denise Sheard

Reprinted with permission from

The CIA 'Chronic-ile Magazine', Chronic Illness Alliance

How to safely exercise in a gym AND GET RESULTS

Abi Polus and Ian d'Young



Exercise is not just important when you are recovering from a bleed. A sedentary lifestyle (i.e. people who sit around a lot) is linked to decreased strength, balance and coordination, and this may increase the risk of injury and bleeding in people with haemophilia (PWH). 'Couch potatoes' are thought to be at a much greater risk of having a joint or muscle bleed when exercising or playing sport than people who are fitter.

Being fit, having strong muscles, good balance and a good pattern of movement is therefore considered to be protective for your joints: in other words you are less at risk of having a bleed in the first place. We all know about factor prophylaxis, but we call exercising to protect your body and reduce your risk of problems before they start 'prophylactic exercise'. It is very important for all PWH, regardless of whether you have had a joint bleed before or not.

Having exercise as part of your lifestyle keeps you fit and looking good, but also keeps your joints and muscles in their best possible condition, even if you already have joint damage from bleeding when you

were younger. This means that by exercising regularly you do as much as you can to reduce the risk of having a bleed by keeping fit and strong, as well as helping your body recover fully after a bleeding episode.

BUILDING MUSCLE POWER AND FITNESS

Your muscles respond to the demands that you place on them. If you spend all day in front of a screen, you will have a body and muscles that are perfectly equipped for sitting. If you cycle for 30 minutes every day, your body will adapt to this. In order to get bigger, stronger, more powerful muscles, and increase your endurance, you need to increase the demands you put on them. This can be done in a variety of ways: using weights (own body weight, free weights, or machines), or repetitive use, for example, the recurring muscle actions used in walking, running, cycling, or using the cross trainer. If you want to lose weight then the energy you expend must be more than the amount you put in (the amount of energy provided by what you eat; calories and kilojoules are a

measure of this energy). If you want to 'bulk up' then you need to increase the demand on your muscles in a way that is safe and will not increase your risk of bleeding. The results you get from the gym depend not only on what you do, but how you do it. The speed and intensity of the exercise will influence which type of muscle fibres are recruited and the results that you get.

So what actually happens when you work out? In order to build muscle you need to load them to the point of hypertrophy (this is when the muscle mass - the size - will increase). What actually occurs is micro-trauma; small tears occur within the muscle tissue. These increase muscle growth as the tears give rise to an activation of a complex process of cells being activated, multiplying and travelling to the site of the damage and helping regeneration. This also results in inflammation to help contain and repair damage and 'mop up' the waste products. At the same time, hormones and cytokines, including growth hormone and growth factors are released, which help the muscles increase. Muscle hypertrophy occurs

when the muscle goes through the processes of healing itself, not when you are actually working out. For this reason, rest between exercise sessions is essential.

If the demands on a muscle are too great, for example building up your exercises or weights or distance too fast or too lifting too much too soon, this will cause the muscle fibres to be overused and to tear too much. This can cause bleeding in the muscles. In a nutshell; in order to increase your muscles you have to subject them to micro-trauma. If you subject them to too much you may cause a bleed or other muscle damage.

IMPACT ON JOINTS

Another thing to consider is the state that your body is currently in. Joints may be vulnerable to repeated impacting stresses that are above their ability to cope with. This is even more of an issue if the muscles are not working correctly to support the joint or if the joint already has damage. Again this may cause a bleed or worsen joint damage.

WHAT TYPE OF EXERCISE SHOULD PEOPLE WITH HAEMOPHILIA NOT DO?

The type of exercises prescribed should be considered. In building muscle, if the aim is to break down tear fibres in order to get hypertrophy, this may cause a bleed, especially if done too fast or with weights that are too heavy or with incorrect technique. Additionally, over stretching a muscle may cause stress and potential bleeding to a muscle. If a joint is contracted or fixed it should NOT be stretched beyond its usual limit or into pain. This will cause a bleed and potentially further damage into the joint. Contact sport is usually discouraged due to the increased potential for injury, although this is not always an absolute. Contact the local Haemophilia Centre physiotherapist for advice on contact sports.

Boxing training can be of great cardiovascular benefit but a blow should NOT contact you. Any sport where the aim is to land a blow on a client's body should NOT be done by people with haemophilia.

If you are recovering from orthopaedic surgery, post-surgical exercise regimes are encouraged, but be aware that rehabilitation may be slower than the non-haemophilia population for

joint surgery.

It is recommended an assessment with a physio is performed prior to the gym program.

It is important to keep the muscles strong that surround joints with existing damage. It is also important to select exercises that are appropriate for the level of existing dysfunction that may be present. Ignoring previous injuries that have not been correctly rehabilitated or where damage is already established may make the joint vulnerable to further damage or bleeding. After an injury or bleed either in the muscle or joints, the surrounding muscles weaken rapidly due to immobility, as a response to pain, and inflammation. If these are not properly rehabilitated with physiotherapy and an exercise program they are unlikely to correct themselves. This is why it is important to make contact with your physiotherapist after any bleed and make sure that you rehabilitate back to the level where you can safely exercise. Pre-assessment should involve identification and specific strengthening of weak muscles, identification and a stretching program for tight structures, correct timing of muscle activity, proprioception (feedback from the joints to the brain that help prevent injury) and balance.

If you have had a bleed or injury recently, your exercise program will be different when you are recovering from a bleed compared to when you are getting fit or playing sport. It is very important that you talk to your physiotherapist and rehabilitate the bleed properly before starting a new sport or exercise. Remember, doing too much too early can lead to another bleed.

You will need to start at a gentle level of exercise and gradually increase this as your body recovers after a bleeding episode. Exercise is very important, but it needs to be the right sort of exercise. Forget the idea 'no pain no gain'! It's 'NO GAIN WITH PAIN', so remember to tell your physiotherapist if an exercise is painful or if you are becoming tired or sore. It is also important that when you start a new sport or exercise program you choose your day wisely. If you take regular prophylaxis, it is sensible to start a new exercise program on the days that you have your factor. Generally, it is a good idea to administer factor an hour before you

start your new program. Remember that taking factor the night before you exercise does not give you any protection!

If you have mild or moderate haemophilia and take factor 'on-demand' (i.e. only when you need it), then you may not need to take factor beforehand because your exercises will be gentle to start with and should not lead to any bleeding. Check with your Haemophilia Centre. Your physiotherapist can help to develop a sensible exercise program that is safe and suits you. It is important that you start gently, with the supervision of your therapist who can make sure that you are doing the exercises correctly.

WARMING UP

Before you start your exercise program it is very important that you prepare your muscles and joints. This helps to reduce the risk of injuries and will help you to perform your exercises better. Start by warming up your muscles and joints with a little 'cardio'. If you are exercising in a gym, use the treadmill, cross trainer, bike or rowing machine for around ten minutes. Alternatively, you can mix things up a bit and try a little time on each machine. Start gently, and slowly increase the intensity.

You will know that you are warmed up if you are starting to sweat and puff a little bit. If you are going swimming or plan to work on your arms in the gym, make sure you use your arms in the warm-up too!

A cross-trainer, rowing machine or simply swinging your arms when you walk will get your arms as well as your legs ready for exercise.

STRETCHING

Once you start to get warm and puff a little bit, you are ready for part two of your warm-up: stretching. Muscle is a little bit like chewing gum. If you stretch the gum when it is cold, it can snap. In the same way, if you stretch a muscle when it is cold, it is much easier to have an injury. This is why making sure you have warmed up well before stretching is so important in order to lessen your risk of a muscle injury.

Don't let yourself cool down too much when you are stretching. Many people feel like taking off layers of clothing after spending time on the treadmill or bike. Try to avoid this – peel off layers after stretching, not

before. When you perform a stretch, remember that you should feel a gentle pull in the muscle, but it should not hurt. If your stretches hurt you are doing them too hard and you will need to check with your physiotherapist that you are doing them correctly.

When you first start your program, hold each stretch for 10 seconds but don't overdo it - stretches as part of a warm up shouldn't take too long and in most cases three stretches for each muscle group on each side is all you need to do. Eventually you will aim to hold your stretches for 20 seconds, however you may not get to this point for some time. Remember, do not push to pain – if it hurts, ease off!

Remember that as every person is different, every exercise program will be different and will need to be tailored to your needs.

WARMING DOWN

Once you have finished your program, it is important that you warm down to prevent stiffness in your muscles.

When you start a new exercise plan, it is very common to feel a little muscle stiffness the next day. Physiotherapists often call this 'DOMS' or 'delayed-onset muscle soreness'. In most cases, this feeling of soreness the day after exercise only lasts for a short time and generally only in the first week or so of starting a new program.

By warming up and down sensibly, you can help to minimise this stiffness. Warming down simply involves repeating what you did in your warm-up, but this time, because you are already warm from your exercises you can start with the stretches and then finish with around ten minutes of 'cardio' – i.e. a brisk walk, riding your bike, or using the cross trainer or treadmill in the gym (or a little of each for variety!).

HOW OFTEN SHOULD I EXERCISE?

When you are recovering from a bleeding episode you will notice that your exercise program will be different compared to when you are exercising to move better or become fitter and stronger. This may be because you will need to rest certain parts of your body while keeping up with exercises to the unaffected parts of your body. In this situation your physiotherapist will tell you how often to exercise when you are recovering from a bleed or injury. Generally young people should be active for around 60 minutes of daily activity in order to gain the health benefits of exercise; however, this can be a mix of both low and high intensity exercise. For example, swimming or a gym program might be considered 'high intensity exercise', while a brisk walk around the park might be considered 'low intensity'. It is a good idea to have a variety of these types of exercise in your program, which will also help to keep things from getting boring. If you are starting a new exercise program to improve strength, flexibility, balance or your cardiovascular fitness when you have not had a recent bleed or injury, then aim to repeat the program three times per week initially. Try riding a bike, having a swim or going for a brisk walk on the alternate days to add a little variety.

If you take regular prophylaxis, then do your exercises

around an hour after you had your factor initially. As you get fitter and stronger, you can gradually increase the number of times you do your program from three to five times per week and from there to every day. This doesn't mean you need to go to the gym every day, but repeating your exercise program 'little and often' can be a very useful way of making sure your body is in top shape.

WHAT ABOUT REPETITIONS?

The number of 'reps' you do for each exercise will depend on your own situation. Often this number will be determined by what is felt to be safe by your physiotherapist and by listening to your body.

If you start to feel discomfort this is normally a sign that you have done enough for the moment. Remember, when you are recovering from a bleed you may only be able to do a small number of reps.

Start slowly and gradually build up your program – it is much safer to build up an exercise program over two or three months than to start too hard and find you've had a muscle strain or another joint bleed.

One of the best ways to start is to use gravity or the resistance of your own body weight in very simple, practical exercises. You do not need to use expensive equipment, and generally the simple exercises are the safest. Don't be fooled though – simple exercises can also be very effective, as well as being easy to do at home.

LISTEN TO YOUR BODY

Be sensible and listen to your body.

If your body is telling you that an exercise is hurting you or starting a bleed, listen! Never keep exercising through the pain – remember, it's NO GAIN WITH PAIN!

Every person is different and every person may react differently to a type of sport or exercise, so it is important that you listen to your body. If you notice a bleed or sustain an injury every time you ride your bike or go for a run, your body is telling you that this is not the right type of exercise for you.

Talk to your physiotherapist about alternative sports or activities.

Abi Polus is the Senior Clinical Physiotherapist in Haemophilia at the Alfred Haemophilia Centre in Melbourne, Australia.

Ian d'Young is the National Clinical Lead for Haemophilia Physiotherapy in New Zealand. Ian is also the co-vice president of Physiotherapy New Zealand.

Abi and Ian are the co-chairs of the Australia-New Zealand Haemophilia Physiotherapy Group (ANZHPG)



HFA launched the new The Female Factors booklet

FINDING OUT YOU CARRY THE GENE

NEW HFA WOMEN'S BOOKLET

Finding out you carry the gene for haemophilia can raise a lot of different feelings, even in women and girls who suspected they might carry the gene.

HFA's new booklet *Haemophilia: Finding out you carry the gene* explores the responses of Australian women and girls. It covers:

- How to know if you carry the gene
- Common reactions to finding out you carry the gene
- Where to go for information and support

HOW TO OBTAIN THE BOOKLET

- A copy of the booklet is an insert in this issue of *The Missing Factor*
- Download the *Haemophilia: Finding out you carry the gene* booklet from the HFA website - <https://tinyurl.com/carry-gene>
- Contact your local Foundation or HFA (email hfaust@haemophilia.org.au or phone 1800 807 173) for print copies

ACKNOWLEDGING THE EXPERIENCE OF WOMEN

The booklet topics and content were developed from the suggestions and feedback of the HFA Women's Consumer and Health Professional Review Groups. These are volunteers, and include women who carry the gene and specialist health professionals, and we appreciate their time and expert advice greatly.

Quotes and personal stories contributed by Australian women who carry the gene form a very important aspect of the booklet. These acknowledge the varied experience of women and girls when they are diagnosed and the very strong impact that diagnosis can have. For the women who were involved in the booklet, sharing personal experiences is a powerful way of supporting each other and the wider community of women and girls who carry the gene. They were keen to share the message that women in this situation are not alone; and told their story and outlined the strategies they used to manage their diagnosis in the hope that it might be of value to other women. Our sincere thanks to these women for their generosity in sharing their experiences.

"It wasn't any great surprise – this just became a bit more information to help with decisions."

"When I was diagnosed I felt gutted."

"I found out that I carried the gene when I was 12 weeks pregnant. The stress was enormous as I had to make some important decisions fast."

The booklet was launched by HFA on 11 April 2017 as part of the international World Haemophilia Day Hear Their Voices campaign, which aimed to show support for the millions of women and girls affected by bleeding disorders.

THE FEMALE FACTORS RESOURCES

This booklet is part of the suite of resources that will be published in the HFA The Female Factors project. Other resources cover:

- A snapshot of bleeding disorders in females (published June 2016)

And in development:

- Diagnosis
- Symptoms, treatment and care
- Family planning, pregnancy and birth
- Telling others
- Information for teenage girls and young women

For more information about the HFA **The Female Factors** project, contact HFA:

Suzanne O'Callaghan (adult women) – socallaghan@haemophilia.org.au
 Hannah Opeskin (young women/teenage girls) – hopeskin@haemophilia.org.au
 T: 1800 807 173



2017 HFV COMMUNITY & Family Camp

At the end of April we headed to the beautiful coastal town of Ocean Grove for our annual Community Camp at Camp Wilkin. The camp provided great accommodation for us and the activities were all very easily accessible.

On the Friday night our youth leaders cooked up a feast on the BBQs but the highlight was definitely our camp fire. It is a wonderful opportunity for us and the Purple Soup team to set the scene and expectations for the coming days. The kids love the songs, an opportunity to shine and of course there is a deep fascination with the fire!

Saturday morning saw the arrival of Janine Furmedge, familiar to all our RCH families as the haemophilia nurse. Janine so generously offers to attend our camps year in, year out, as an opportunity to connect with families out of the clinical setting and to assist with the treatment session that is run that morning. This year we made the treatment session an activity to signify how important this session is. It is an opportunity for younger boys to watch, learn and ask questions of the older youth and men. Everyone can have a go at trying to access a vein on the dummy models Janine provides. This is often taken up by the dads as well the younger boys.

It can also be quite a challenging session for families and it is important to acknowledge the courage of all those who agree to administer their treatment in an open setting. It is not always

possible to access a vein on the first or second attempt whether that be self-administering or by a parent. It is a reminder that no matter how many times you have done treatment, there still may be some anxiety around that, it may be challenging and that it's not uncommon to feel that way. It may highlight the need to talk about anxiety around treatment more for our community.



After our treatment session we headed to the beach for The Silly Olympics. The rain held off for the majority of the games and we were treated to some fantastic displays of skills and talent amongst the children, the youth's on-land synchronised swimming

was balletic and some of the adults true competitive natures came out in the sack race. Lots of fun, laughter, a little bit of cheating but mostly great supportive team games saw a great start to the day.

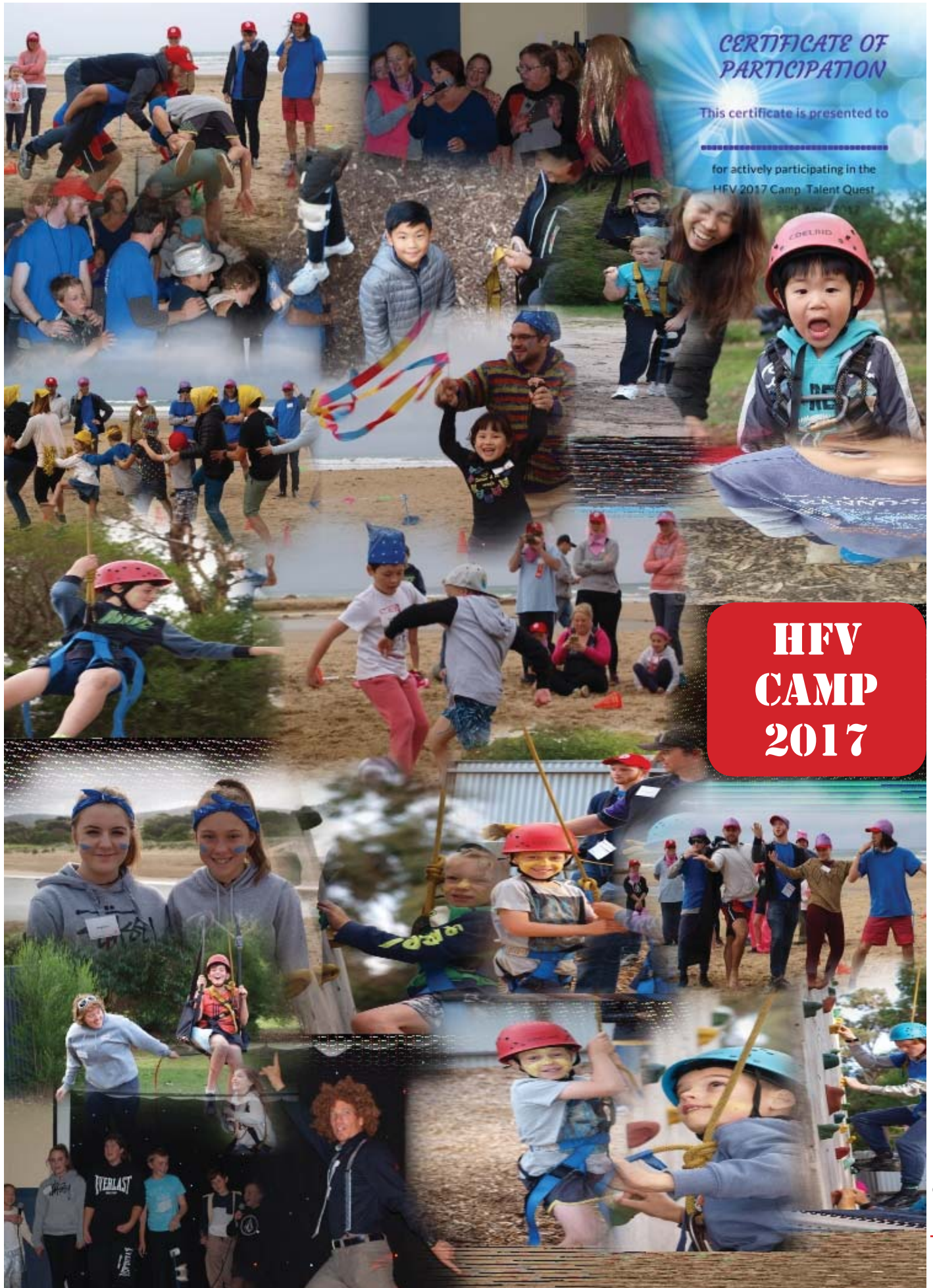
The afternoon was complete with our Secret Women's and Men's Business sessions, which is always a highlight for participants. In the meantime the kids all participated in team building exercises on the low ropes. The Nerf Wars game was a huge hit with the kids and parents alike.

We were very impressed with the caliber of acts at the HFV Talent Show! There were magicians, musicians, singers, dancers, karate displays. Then it was time for karaoke... even the mums entertained us with their Abba rendition! The night ended with a good old knees up on the dance floor including the Chicken Dance!

Sunday was full of outdoor activities and this year we worked in family groups which gave the kids and parents the opportunity to be together, and encourage and support each other.

Our final session gave us the opportunity to look back over photos from the weekend and reflect on the ways we connect, support and empower each other.

We are delighted to announce that Kenneth Yeung, aged 8, was the proud recipient of the 2017 Michael Lucken Camp Spirit Award.



HFV CAMP 2017

HOLDING BACK THE YEARS

Living longer & **LIVING WELL** with HIV

The challenge for the older generation, says Jake Kendall, is — not just to be living longer with HIV — but to be living well with HIV. Not so long ago, ageing with HIV would've been considered an oxymoron. In the early years, it was a rare occurrence; most people lived briefly with HIV before dying from AIDS. These days, effective treatment means people with HIV can expect to live a normal lifespan. But while modern medication works miracles, ageing with HIV brings new complications.

And some of those complications are only just being recognised. Research suggests many of the diseases associated with ageing appear to occur at higher rates among older people living with HIV (PLHIV) than in the broader population. Living with multiple medical conditions — such as cardiovascular disease, cancer, osteoporosis, diabetes and dementia — will become the norm as the HIV population ages. Indeed, according to the most detailed analysis of likely future trends in HIV care for an ageing population yet conducted, the proportion of older PLHIV with at least one coexisting condition will increase from 29 percent in 2010 to 84 percent in 2030. And 28 percent will have three or more additional medical conditions.

Although the findings are based on the clinical needs of Dutch PLHIV (three quarters of whom will be over the age of 50 in 15 years' time), they are relatable, say the authors, to other Western countries with maturing HIV-positive populations — such as Australia.

Many of the health problems among older PLHIV will be driven by various forms of cardiovascular disease (high-blood pressure, high cholesterol, heart attacks and strokes), with 78 percent of older PLHIV having at least one of these conditions by 2030. In addition, the study found 17 percent will have diabetes and 17 percent will have a cancer. But, wait, there's good news, too! Chances are, as someone living

with HIV, your health and well-being is being routinely monitored — far more than the average person's. So if there were signs of anything worrying, your healthcare professional would more than likely pick up on the symptoms. Early detection often means a greater chance of effective treatment.

Speaking of effective treatment, thanks to a new generation of antiretrovirals, many older PLHIV have robust CD4 counts and are able to maintain an undetectable viral load, which we know reduces the risk of illness and infection.

Research also shows us that older PLHIV have better drug adherence than younger people. And as the START study found, treating early reduces the risk of developing non-AIDS events by more than 50 percent.

On top of treatment, there are, of course, other ways you can lower the risk of developing age-related conditions. And, yes — yawn — you've no doubt heard all these recommendations before. But there's a reason for that: they work. First up, if you smoke, stop. Now. No ifs or butts. Minimise alcohol and drug use. At the risk of sounding like your Mum: binge drinking leads to high blood pressure putting you at risk of strokes and heart attacks. Excessive use of amphetamines, such as ice and cocaine, can lead to heart disease.

Those are the don'ts. The dos: exercise regularly — it gets the blood pumping, reducing the risk of cardiovascular disease. Eat well. Choose a diet with an emphasis on fruits, vegetables, whole grains and beans. Fish and lean meat both get the Heart Foundation Tick of approval. As do 'healthy fats' found in olive oil, nuts and avocados. According to the Cancer Council Australia, at least one in three cancer deaths are preventable and the number of cancer deaths could be significantly reduced by adopting a smarter lifestyle. Smoking, of

course, is a no-no; as is unprotected exposure to the sun ("Slip, Slop, Slap", and all that). Excessive alcohol, inadequate diet, and obesity are also triggers for cancer.

Calcium is key to reducing the risk of developing brittle bones, although calcium on its own is not enough to stave off osteoporosis. Vitamin D (salmon, tuna, eggs, cheese) and Vitamin K (herbs, green leafy vegies, asparagus, olive oil) also play an important part in protecting your bones. Omega-3s found in oily fish are beneficial to bones, too.



Regular exercise (three to five times a week for 30 minutes), adopting a Mediterranean diet (olive oil, vegetables, fish, fresh fruit and wholegrain breads etc.) not smoking (ever), and drinking moderate amounts of alcohol (wine especially) have all been found to help reduce the risk of developing diabetes and dementia.

And finally, get out more. Adopt a hobby. Study after study has found people who maintain a social network and engage in activities, not only live longer, but also remain healthier than people who are socially isolated and who do not engage in meaningful pursuits. Many local HIV organisations run support groups and host social events. Ageing — HIV or not — is no bed of roses. But if you take heed of some of the above, hopefully, it'll be a long while before you're pushing up the daisies.

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from NAPWHA



The 18th Australian & New Zealand Conference on Haemophilia and Rare Bleeding Disorders will be held at the Pullman Albert Park, Melbourne, 12-14 October 2017.

The theme for the conference is “**Looking Forward to Change**”.

Over the past 37 years, we have been running conferences that provide current information and resources, discussion on topical issues and looks into the future.

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

The program covers current topics and issues to interest everyone including:

- new treatments for haemophilia
- using data to improve treatment and care
- women with bleeding disorders
- genetic testing
- living with von Willebrand disease
- new approaches to managing pain
- HIV and hepatitis C
- living with a bleeding disorder at different life stages - newly diagnosed, children, adult life, ageing
- issues for families and siblings
- youth matters
- sport and healthy activities
- what is the future like

The program will include people living with bleeding disorders as experts as well as health professionals and others presenting from different perspectives.

Who should attend?

- people with haemophilia, von Willebrand disorder or other bleeding disorders and their families - parents, siblings, partners – all ages
- health professionals – doctors, nurses, physiotherapists, social workers/counsellors and other health care providers
- treatment product producers, suppliers and service providers
- policy makers and government officials
- haemophilia Foundation volunteers and staff

We look forward to seeing you in Melbourne!

Gavin Finkelstein
President
HFA

Deon York
President
HFNZ

Dr Huyen Tran
Program Chair

Conference subsidies are available to HFV members. Please see enclosed form

...I was lucky enough to attend the last haemophilia conference at the Gold Coast. It was such an eye opener into advances in treatment that I came away with a much greater understanding of what lies ahead for my family and this community. The opportunity to listen to health professionals speak along with those personally affected by bleeding disorders was very rewarding.
- HFV Member

diary dates

AUGUST

6 Grandparents Lunch

SEPTEMBER

9 Ladies Day Out

OCT

12-14 Haemophilia Conference
Melbourne

20 Haemophilia Red
Charity Ball

NOV

TBC Family & Community Christmas
Picnic

DEC

TBC 2017 HFV Youth Event

HAEMOPHILIA TREATMENT CENTRES

HENRY EKERT HAEMOPHILIA TREATMENT CENTRE

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

Dr Chris Barnes | Director Henry Ekert HTC
Janine 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
Diana Harte | Psychologist

MEMBER SUBSCRIPTION RENEWALS

Our 2017/18 membership subscription renewals will be mailed to members
in early June. Please renew your membership by the 30th June.

Your membership is vital to HFV. Our membership base provides a platform and voice for our bleeding
disorders community. Strength in numbers is crucial for our ongoing success and viability.

Thank you for your support.

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:

- SOS Talismans are available for purchase for \$15.00 from the office.
- MedicAlerts: A subsidy of 50% of the first purchase price of any MedicAlert, (with the subsidy payment being up to \$30 in value and not including the annual fee) is now available. To obtain a subsidy, forward a cover letter and receipt to the HFV Office.

Live Well Funding:

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

Care and Counselling:

This is available through your treatment centre.

Magazine:

Your quarterly magazine offers information and details of upcoming events.

Website - www.hfv.org.au

The HFV Office:

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

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

Phone: (03) 9555 7595

Fax: (03) 9555 7375

Website: www.hfv.org.au

Email: info@hfv.org.au

MEN'S GROUP

Our current group meet for their Annual Men's Retreat – a much needed weekend away that included massages, relaxation and meditation. In 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.

Friday 20th October 2017

Maia, Shed 14 Central Pier,
161 Harbour Esplanade, Docklands

Dress Code - Formal with a **touch of red**
Bookings NOW available through TryBooking.com

The Haemophilia **Red** Charity BALL

We need your helping hand!

The planning of 'The Haemophilia Red Charity Ball' is well and truly underway and we need **YOUR HELP** to help us raise much needed funds for our Haemophilia Community.

Who do you know? Who do you know who might be able to donate their time or make a donation towards our silent auction on the evening? We are looking for donations big or small that businesses are willing to donate to our cause. If you would like to receive a copy of our Donation Letter and or you have items to contribute please contact Catherine on 0417 575 386 or email catherine@nobleknight.com.au

All businesses will be acknowledged on the evening and promoted on our Facebook page!

Every Donation Helps!

We are also looking at putting together a small visual (DVD) presentation including a small selection of our Haemophilia Community by interviewing them; we are interested in hearing **How Haemophilia affects your life?** If you are interested in taking part please contact Andrea or Julia at the HFV office on 03 9555 7595.

Like and Share us on Facebook "The Haemophilia Red Charity Ball"



We would like to thank you for your support!