HAEMOPHILIA FOUNDATION VICTORIA INC

SUMMER 2017

THE MISSING FACTOR

The REAL impact of diagnosis

A BRIGHT FUTURE AHEAD...
The Conference of HOPE

STOP, LOOK & LISTEN to your kids

connect • support • empower

HAEMOPHILIA FOUNDATION VICTORIA INC
CONNECT • SUPPORT • EMPOWER

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HFV is committed to Child Safety.
Our Child Safety Statement is available for review on our website www.hfv.org.au

The Missing Factor is the official publication of the Haemophilia Foundation Victoria (HFV) with four issues annually.

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

VICTORIA State Government

Haemophilia Foundation Victoria acknowledges the support of the Victorian Government.

PRESIDENT'S REPORT

CONNECT SUPPORT EMPOWER

SUPPORTING OUR FAMILIES WITH INHIBITORS

On the 20th October I had the absolute pleasure of attending The Haemophilia Red Charity Ball. It was the most amazing night and a huge success for our organisation. On page 8 you can read all about the night but below you will find the speech our president, Leonie Demos, made on the night. The majority of the audience knew little of bleeding disorders and the impact they can have on families and so Leonie's heartfelt speech gave a real insight into our community.

It is a privilege to speak to you as President of HFV. I am the proud mother of two sons. One with haemophilia and one without. We have no family history and our journey has been a long one to get to here tonight. Everyone's journey is different with similar experiences but different challenges. One thing that is shared is the determination our community has to not let haemophilia define us but to continually improve a quality of life as best we can given the cards we have been dealt.

You have heard from specialist clinicians that guide the medical teams at both haemophilia treatment centres being the Alfred and Royal Children's Hospital. In Victoria, we are blessed with amazing medico and allied health teams that take amazing care of our families especially our boys. But they can only look after the medical needs and not all the other complications that come from living with a chronic illness in family life.

Sadly, many of our community have needs beyond medical treatments and that is where HFV plays a vital role. HFV's mission is to connect, support and empower.

Connect families with others that have a shared experience. Connect those in rural and remote areas of our state to extra services if possible. Connect young boys dealing with haemophilia to other young boys so they feel less alone and less scared of their future. Connect through the community camp which is one of the most important events of the year. Families come together to talk, laugh and cry as they share their challenges in a relaxed but supportive environment

Support comes through the peer support programs we try to run. Supporting mums with a ladies lunch where they may get to have a break with a massage and a lunch and for one day forget their troubles and chat to other mums with shared experiences. Support through grandparent gatherings to talk about how helpless they may feel watching their children and grandchildren struggling with the complexities of life with haemophilia.

Empowerment we hope comes from leadership we nurture through HFV activities. Our medical teams do an amazing job in teaching our community on how to deal with their condition, how to inject themselves with a needle or when to come to the hospital for a bleed into the joints or muscles. But knowing the medical response does not prepare you for the advocacy you will need to protect yourself from discrimination and prejudices.

Attending a national conference last week hearing young people share their stories of losing employment once their condition was disclosed. Hearing from young people that can't travel because they are denied travel insurance. Hearing how older men have never been given opportunities in workplaces because of their disorder. Hearing the too many stories of the discrimination faced by our community in the 80s and beyond as they contracted HIV through their medical treatments and have faced years of not only health challenges but years of discrimination and judgment by others and denied many opportunities. Empowering others to know their rights and give them a voice to face the challenges of life is a very important part of what HFV do.

Our goals to connect, support and empower seem like three simple words to many sitting here tonight but for many in our community they are enormous challenges to

face and they need the support we at HFV can give through the generosity of others to support our work.

Our community is diverse and their challenges are many. HFV support anyone in Victoria living with an inherited bleeding disorder.

Many have haemophilia, others have less known disorders like VWD and Glanzmann disease. Some have inhibitors where the treatment product doesn't work for them and they have significant challenges just to get through each day.

Some women have severe bleeding that they are not able to enjoy life without many days in bed from menstrual pain and excessive bleeding.

Some live in remote areas where a trip to hospital means 6+ hour return trip as they can only go to one of our HTC for the specialised care they need.

Too many in our community have lost loved ones through the contraction of HIV, Hep C and other complications through contaminated product from having a bleeding disorder. It is for one particular loss of Antony Hill that one family have very generously donated towards tonight in loving memory of their brother whom they still miss deeply.

HFV provide support through as many ways as we can in our attempts to connect to our community. We have a small amount of money we can give for emergency support.

For some they need help to buy a fridge to put their medication in. Or help to pay for the swimming lesson that may help with the recovery from a bleed or period of immobility.

A fare for a bus from the country to be able to visit their family in extended hospital stay.
Paying for TV hire for someone in the Alfred Hospital for weeks on end due to a bleed to help pass the time and combat the boredom.

Assisting in the costs of a mobility scooter for ageing members that can no longer walk.

New challenges for older men in aged care who have been able to self-inject to manage their condition for years but can no longer due to frailty of veins or Alzheimer.

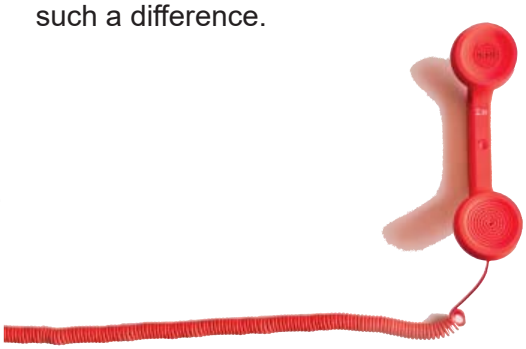
And the list goes on and on.

At HFV we can make a little bit go a long way and as a result of tonight we are excited by the prospect of what can be done with your generosity and kindness in supporting HFV tonight.

Our community is diverse and so are their challenges. We are so lucky to receive the medical care we do and the collaboration and support shown by all in the treatment centres.

We thank you for attending tonight to show your support. If you can dig a bit deeper we do call on anyone in the room who is able to support HFV tonight or ongoing. Please consider buying an auction item, buy an extra couple of raffle tickets, become a member of HFV and receive an amazing newsletter to hear more about our community and our work. Whatever you can do is appreciated by our community and we thank you for just being here tonight.

Our community is very special as we do our best to connect, support and empower through life's journey. On behalf of the families that will benefit from your generosity we say thank you from the bottom of our heart and please be assured that every cent raised tonight will go directly to the community we support and will make such a difference.



As this goes to print I am away with my husband in Italy having the most wonderful time!

Have a very happy and safe holiday time and wishing you good health for the season break.

HFV is the place to be and 2017 was fantastic. 2018 will be even better.

Stay tuned!

Leonie

The Conference of HOPE

In October I attended the 18th Australian & New Zealand Conference on Haemophilia & Rare Bleeding Disorders. I am really grateful for the funding I received to help me get there.

Now, over the years I've been to a few of these wonderful gatherings of brilliant minds and inspirational people, both professional and consumer alike, and left with feelings of hope and encouragement towards a brighter future for those of us living with haemophilia.

From the days of treatment products advancing, plasma based to recombinant, better treatments for hepatitis C and even the complex issue of one day finding a cure via the exciting world of gene therapy, though this seemed to be a pipe dream.

As always the organisers put together a fantastic variety of speakers providing information on where we are heading in our care but also the important personal experiences of living with a bleeding disorder and/or a blood borne virus.

I want to share with you, though not in any technical detail as it's way over my head, the word you rarely hear in the haemophilia world; CURE!

For more than 4 decades we have, sadly, associated Hepatitis C with haemophilia. This has been so debilitating, even fatal, for so many people and past treatment options were often poorly tolerated, lengthy and ineffective. Dr Joe Sasadeusz, the Alfred Hospital Hep C specialist, updated us on where we are now. We've known how advanced the new medications are now for the last few years. Treatment periods have gone from almost 12 months down to as little as 6 weeks, side effects are negligible and the CURE rate is about 95%! In fact Dr Sasadeusz said there were only a couple of people in our community that were still positive.

The bottom line is that, in reality, Hep C is close to being eradicated from our extended family! Wonderful news for us but should carry on into the general population.

Professor John Rasko, from the University of Sydney, presented a talk on Gene Therapy. The Prof was super excited. He has been working towards raising the factor level for most of his working life and has thought to be close many times only to fall at the last hurdle. However, thankfully, he gets right back up and continues on.


Professor John Rasko

John has worked with haemophilia B, reasonably common in dogs and in the early days was looking to raise the level of a severe dog (<1%) to about 2% which would make a massive difference in bleeding terms. He could achieve this momentarily but the factor VII would always return to previous levels.

To cut a long story short, 3 severe dogs in the US have now sustained a factor level of over 50%, effectively curing them of haemophilia B!

Now, I love dogs and I'm happy for them but what about us? The awesome news is the human trials are showing the same results! This was literally breaking news and he said they had actually broken the code!

So now we have to wait a bit, I can't say how long, and we don't know where we're at with haemophilia A but let's be excited for the future, our future.

In the meantime, Dr Huyen Tran, our haemophilia leader at the Alfred Hospital, informed us of the human trials currently underway with extended half-life and new therapies. Essentially long acting factor replacements we may only have to inject, either into veins or fat, once a week or even longer. These are proving very effective and shouldn't be far from being implemented, though there isn't a promised time line.

So this was a conference of great hope and perhaps a future without bleeds.

As a side note, HFA is working towards putting these plenaries online which will give you the actual details on these amazing presentations.

Neil Boal - HFV Member

Grieving the health of our little boy

The real impact of diagnosis

26th of July 2017. Ben and I will never forget that date as it is the day we found out that our baby boy Louis, got diagnosed with severe haemophilia A. Louis was about to turn 6 months old.

Let me introduce ourselves: we are Ben and Claire. We met 10 years ago while I (Claire) was travelling in Australia. We fell in love, got married and have lived a relatively happy life since. This year is our 10 year anniversary and Louis is our first baby. Life as new parents has its challenges but nothing could prepare us for what was ahead. There is no history of haemophilia in the family.

Louis always had bruises: from the first few weeks he was born, we used to swaddle him and he will pull out of it with all his strength, and here we were with a little bruise on his arm. The health nurse did not look worried, so we were not worried.

Until that day where Ben came back from swimming with Louis. Louis had 5 bruises and some black ones behind his knees, caused by the high chair. Our gut feeling told us to call the maternal and child health line - who told us to go to the emergency department straight away. At this point, we were still not worried; Louis looked healthy, he was a happy and striving little boy after all.

After Louis' diagnosis, we felt our world crushed. We do not have words to describe the first 48 hours. We were in shock and we had to share our news with our close friends and family. It was very hard. Since then, we have been on a roller-coaster of emotions: sadness, anger, disappointment, fear...You name it.

Most of all, it is an incredible sadness that is and will be haunting us for a very long time as we are grieving the health of our little boy. We are grieving a 'normal' life, without injections and ongoing worries or trips to the hospital. You see, grieving is a feeling that might eventually fade away with time. I am not sure that our grief will ever fade away but I hope it will become less intense overtime. Life is not just about happy moments; there are also sad times and we will need to learn to live with this particular sadness. A sorrow that a lot of people will not understand. Some days are too difficult and some days we almost forget about Louis' haemophilia. Believe it or not, there

are also some days we laugh about it. It is so important to keep laughing despite everything that is going on. We try to live more in the moment. There is no point of stressing for things that have not happened yet.

One of the first things Chris Barnes told us when we met with him for the first time is that our little boy will have a normal life. The team at the RCH has been a great support through the start of this new journey. We remember coming out from our first appointment with some of the weight lifted off our shoulders.

Both our families live far away, but they have been a fantastic support throughout this new journey. Our friends have done their best, everyone is very busy with their lives. Some people have distanced themselves and some people have gotten closer.

Members of the HFV and the HFA have been an incredible ongoing support. I remember sending an email to the HFV the first week we found out to seek help. They got me in touch with other mums. The support from this small community has been enormous and we are forever grateful to have found such an amazing group of people. They were able to liaise the grandparents too. Haemophilia does not just affect only a person, it affects a whole community of family and friends.

Louis has been doing the best out of all and probably wonders what is all that fuss that is going on around him. He is starting to crawl and is bruising more. Some days we see a new bruise and we are able to respond in a calm and controlled manner. Some days, it is just all too much and I burst into tears as it is a reminder of what his life is going to be: watching out for bruises. We know the hardest is ahead, as Louis has not started his treatment yet.

We always thought we knew how much we loved Louis. His haemophilia has made us realise how much more we love him; he is just even more special in our eyes now.

Claire - HFV Member

We all have a story to tell. If you would like to share your story with our community, please email julia@hfv.org.au
Many thanks.

IT WAS AN AMAZING NIGHT AND I COULD NOT HAVE BEEN MORE PROUD OF EVERYONE.

The Subcommittee showed what a group of motivated and talented mums can do if they join forces. We all know about the resilience we have as a community. The subcommittee showed us all that anything is possible if people are prepared to work together and work smart to 'achieve the extraordinary'.

The fundraising was important and will make an enormous difference to HFV and the programs we can offer. Dare to dream and they have made it possible!

There are so many to thank including our young leaders that again showed us all how haemophilia does not get in the way of good humour and the ability to have a fun time but to show everyone how incredible they all are. Many thanks to Ben, Christopher, Tim and Scott.

To Tim at Purple Soup. Again showing us the partnership approach and his belief in HFV and all we can achieve together. Tim was so generous on the night donating his time and 2 Murder Mystery pack for the auction. So generous and very much valued by us all at HFV.

To Julia and Andrea that continue to go above and beyond for us. Working so hard leading up to the night and still working throughout the packing up. We are truly blessed to call you part of our HFV family.

To all those that gathered donations and worked tirelessly to bring them together. Amazing!

To all our partners at the HTCs and our Patron Alison Street. So amazing to share the night with you. Bit of dancing. Lots of laughs but most importantly you show us how lucky we are to have the teams behind us supporting through the health system

To Julia and Janine from the RCH who couldn't join us. The video you produced that we shared was amazing. The emotion in the room was electric as everyone watched in silence listening to our boys and how they continue to amaze all of us with their strength and their character.

To the families and friends that shared in the celebration. The love and support you provide to us all is critical to all of us surviving the challenges of living with a bleeding disorder. You support us and give us the safe place to on occasion just say 'it is all too hard'. Having you in the room was so important. Important for us to be able to share our stories and important for us to be together in a very special moment in time

I have no doubt that everyone that attended had a fantastic evening without exception. The ball demonstrated the love and respect we have for each other and the strength in character and determination to connect, support and empower each other throughout our journey. I am so proud to be trusted with the role as President and this night confirmed for me and anyone else in the room what an extraordinary community we are.

Everyone should feel extremely proud of what was achieved. It will be the talk of the Haemophilia Foundations across Australia as I will be bragging to them of how proud I am of our community.

Leonie Demos

A word from our Patron, Dr Alison Street

John and I were delighted to attend the Red Ball last month. The celebrations were great expressions of HFV's commitment to its mission and vision. To remind you, our mission is to provide and support positive health outcomes for those affected by genetic bleeding outcomes and our vision is to connect, support and empower our bleeding disorders community. All attendees were living the experience of these aspirations that night and my thanks go to everyone involved in the grand production of this event.

A mission statement defines the objectives of an organisation. A vision statement defines its desired future position, concentrating on mid and long-term goals. Vision provides a source of inspiration and directs clear decision-making criteria by which to determine the strategy and business of an organisation.

Words matter and ours have been carefully selected to reflect the long-standing core values and aspirations of HFV. We wish to connect to bring people together so that relationships are established. We want to support to help and assist people in many ways and we aim to empower in making members stronger and more confident in controlling their lives and claiming their rights.


Leonie Demos & Alison Street

It's a powerful statement to take HFV and its partners into an exciting future for treatment and care of people with genetic bleeding disorders.

Can I again thank all involved with HFV for the honour and opportunity to be your patron. I wish you all safe and happy holidays and hope that 2018 brings us increased opportunities to connect, support and empower members of our very special community

Alison Street

MyABDR UPDATE

Do you have one of these emergency patient cards? Every patient should keep their card in their wallet for emergencies. It will have your haemophilia details and treatment, and our contact details. If you would like to order one, it can be ordered through the MyABDR or ring the data manager on 03 90765242.

Front of Card:

ABDR

Ronald Sawers Haemophilia Centre
The Alfred hospital, Melbourne, VIC
Haemophilia Centre Ph: 03 9076 2178
On-Call Haematologist (A/H) Ph: 03 9076 2000

Your Name
DOB: MRN: ABDR ID:

Diagnosis: **Factor VIII Deficiency (Haemophilia A)**
Severity: Mild Factor Level: 5%

Inhibitor Status: **Never Present**

Card Issue Date: 20/10/2017

Back of Card:

Treatment Guidelines

Product:
DDAVP (Synthetic Hormone)

Treatment Comments: (Factor doses rounded up to the nearest vial size)
Suitable for DDAVP 0.3mcg per/kg for minor procedures. Please seek specialist advice after initial dose. (Tranexamic acid also suitable.)

MyABDR: www.blood.gov.au/myABDR **MyABDR Support Ph: 13 000 25663**

As a result of the new privacy laws that came in to effect at the beginning of 2015, ALL patients (or their parents/legal guardians) on the ABDR (Australian Bleeding Disorder Registry/ database) are required to sign a consent form or give verbal consent to be on the national database.

Please ring the Alfred Hospital Haemophilia Centre, data manager on: 03 90765242 to consent, and please check if your family members have consented too. Thanks.

Mental health and disability insurance:
Understanding your rights

Josh Mennen recently presented at the haemophilia conference on Insurance and Superannuation. Josh's presentation was very insightful and provided us with a greater understanding of what is available to us through our superannuation funds.

Whilst we still have a long way to go, people are becoming more open about discussing mental health issues. Stress, depression and anxiety are no longer as taboo as before and a more mature conversation is developing. In fact, each year approximately one in every five Australians will experience a mental illness. That makes mental illnesses the third leading cause of disability in Australia.

Insurers have become wary of mental health disability claims and it can be difficult to get cover for such claims. What many people don't know is that the automatic insurance provided through your superannuation fund will often pay out much needed funds if you cease work due to a mental health condition.

When applying for a stand-alone policy, you need to disclose any mental health issues you've had. As a result, you might see a hike in your insurance premium, or you may face a mental health exclusion, which means you can't get insurance cover on claims that relate to your mental health.

Disclosing a pre-existing illness or injury

Traditionally, when you buy insurance, you take out a policy directly with an insurer. As part of that process, you complete an application and disclose your pre-existing medical history. The insurer then reviews your application as part of its underwriting process to determine whether to offer you a policy and on what terms.

If you tell the insurer about significant symptoms or a diagnosis of a psychological nature, it may not offer you a policy or may include a mental health exclusion clause. It's because the insurer may consider you an unacceptable risk.

If you fail to disclose your medical history and later make a claim, the insurer may try to cancel your policy and deny your claim – even if the cause of your disability claim doesn't relate to your pre-existing condition.

Covered by superannuation insurance

The good news is that most super funds provide automatic insurance cover for total and permanent disability (TPD), which will pay a lump sum benefit if you can no longer work due to injury or

illness, including a psychological illness. You receive cover simply by being a member of a default super fund, called a MySuper product. This type of insurance isn't underwritten in the same way as direct insurance policies. It can even cover claims for conditions that existed before you joined the super fund.

For example, we recently represented a client who experienced depression during a divorce in his 20s. He made the choice to see a psychologist and take antidepressants. When he later applied directly to an insurer for disability insurance, the company rejected his application because of his prior mental health issues.

Later, at age 37, he witnessed a nasty accident in his workplace and developed post-traumatic stress disorder (PTSD) that caused him to stop work. We investigated his super insurance entitlements and discovered he was eligible to claim a TPD lump sum of $100,000, which had been automatically underwritten when he joined his super fund. We helped him make a successful claim which allowed him to pay off his mortgage and keep his home.

Claiming your benefits

Whilst every policy is different, to win a TPD benefit you're usually required to provide medical evidence supporting that you'll never return to the work you're suited for by education, training or experience. That usually pays a one-off lump sum benefit.

Some super funds provide income protection insurance as well as TPD. That pays a monthly benefit if you can't perform the duties of your usual occupation. These benefits can be payable for two years, five years or sometimes to the age of 65, as long as you continue to meet the policy definition.

Some funds provide both income protection and TPD, but will stop income protection payments if you're paid a TPD benefit. Seeking legal advice before making a disability claim can help you maximise your full insurance entitlements.

If you're a member of more than one super fund, like many Australians are, there's a good chance you can make more than one TPD claim if you have to cease work. It's important to get advice and make sure you find all insurance benefits your entitled to claim.

Balancing wellbeing in the workplace

You don't have to tell your employer about a medical problem unless it poses a risk to your workplace safety. If you have a mental health issue, you should discuss it with your doctor before deciding to inform your employer. Although most employers may be sympathetic and understanding, this isn't always the case. It's not unusual for employees who disclose a mental health condition to face discrimination. This can include:

> being targeted for redundancy
> being overlooked for promotion
> being demeaned or ridiculed
> not receiving a pay rise.

If this happens, you may have a claim for unlawful dismissal or workplace discrimination. You may also be entitled to income protection or TPD insurance benefits if you stop working.

Keep in mind that sometimes making an unfair dismissal or workplace discrimination claim can disadvantage your disability insurance claim. That's because a workplace discrimination claim usually involves you claiming that you're medically able to do your job. A life insurance company may use that as a basis for denying a disability insurance claim, which requires evidence that you can't do your job. It's important to get legal advice before you resign, stop working or pursue any claim against your employer.

When looking for the right insurance to cover your mental health, it pays to speak with a legal professional. Find out more about your superannuation insurance entitlements.

by Josh Mennen
Maurice Blackburn

> *Josh Mennen is a Principal in the Superannuation and Insurance practice in Maurice Blackburn.*

> *Josh presented at the recent Haemophilia Conference on the topic of Superannuation and Insurance.*

> *Maurice Blackburn provide many other relevant articles and information through their website and blog.*
www.mauriceblackburn.com.au/blog

Josh Mennen | Principal
Maurice Blackburn Lawyers

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LAST MINUTE EVENT
BOOK NOW
Bookings closing soon
with limited places available

GUYS & GALS

You are invited to

BRING A BUDDY

to our 2017 YOUTH activity

DIALOGUE IN THE DARK ©
DIALOGUE SOCIAL ENTERPRISE

BRING A BUDDY or just come along and join us,
Tim from Purple Soup and other youth at The Docklands for
DIALOGUE IN THE DARK, LUNCH AND GLOW GOLF!

Time: 10.45am - 2.30pm

Date: Saturday 9th December

Where: Outside Dialogue in the Dark

(Harbour Town, Level 1, 29 – 31 Star Crescent, Docklands VIC 3008)

For ages 13+. This event will be supervised by HFV staff and
Tim from Purple Soup will be joining us!
Contact for the day is Julia 0410 247 908
Places are strictly limited and bookings are essential
through TryBooking by 5th December...please contact Julia if booked out.

www.trybooking.com/SYKZ

purple PAPARAZZI

make your next event a flashy affair

Your HFV Red charity ball photographs are now ready to view and purchase at:
http://purplepaparazzi.fotomerchant.com/portfolio/gala-balls/hfv-gala-ball
The digital images are available for download for $20
and the 8x12 prints are $35 each plus postage.
50% of all image sales will be donated to HFV
Warm Fuzzies, Tim 0405 696 701

Lochiver Farm Homestead, Carisbrook • NO COST - Free accommodation & food • Relaxation & Massage

HFV provide accommodation and meals at NO COST to participants.

Assistance with transport may be available.

BOOK NOW!!!

For all men with bleeding disorders aged 25+

HFV Men's Retreat

23-25th Feb 2018

Haemophilia Foundation Victoria Inc

Join other men with bleeding disorders for a relaxing weekend away.

Benefit from massage and relaxation sessions.

Contact Zev Fishman on 0419 552 695, the HFV office on 9555 7595 or speak to the Alfred Haemophilia Team

STOP, LOOK & LISTEN to your kids

Dr Justin Coulson recently presented at the 18th Australian & New Zealand Conference on Haemophilia & Rare Bleeding Disorder.

Dr Justin Coulson is one of Australia's leading parenting experts and is a highly sought-after international speaker and author. He and his wife Kylie are the parents of six daughters. Yes… six. And yes, they're all from the one family, and no, they aren't disappointed, nor are they going to try for a boy.

Justin's session covered many of the concepts raised in his article below. It was an opportunity for all of us with children, with or without health issues, to reflect on how we parent and whether we are parenting effectively and giving our children what they really need.

It was an insightful, positive and impactful session and a wonderful plenary to kick start the conference.

Some years ago I came across a parenting questionnaire developed by thoughtful, careful researchers. One of the questionnaire items asked, "Do you stop and pay attention to your child when your child wants/needs you?" As a parenting expert I knew there could only be one answer. "Yes, of course I do" I told myself.

The question got under my skin a little bit though, for two reasons. First, I knew deep down that it wasn't true. But second, am I supposed to stop what I'm doing every time my child needs me and pay attention? I'll never get anything done! And won't that spoil my child, creating an entitled and narcissistic little emperor or empress who thinks I'm only there to do her bidding?

I spoke to my wife, Kylie, and asked her what she thought. "I know I'm supposed to always be there, and I'd like to say I am… but I'm probably not" was her reply. She added, "Is it even realistic?"

That night, Kylie sat with our children and asked them if they believed that we were always there for them, ready to listen and pay attention when they wanted us. The answers surprised us, none more so than this from our 7-year-old daughter:

"When you are busy you don't listen to me properly. Like when Dad's on the computer or you (mum) are doing craft you're not available to me. It feels like those things are more important than

me." She added, "Even when you say you're listening to me, you're not, because you're not focused on me. You keep doing what you were doing."

Ouch!

Just as dollars are the currency of our economy, attention is the currency of our relationships. Too often our relationships are in the red. We are not giving them enough attention – or the right attention, and it dilutes our ability to help our children.

Stop, Look, and Listen

When we cross the road, we stop, look, and listen. It helps us to navigate a physically hazardous or challenging situation. Relationships with our children can be like crossing the road. If we aren't willing to stop, look, and listen, we may miss something important heading our way and we, or our child, or even our family, could get hit by it.

Perhaps it is a friendship challenge, an issue at school, or a toddler feeling like she needs to be comforted. Maybe it's a teen who is thinking about doing something unsafe with drugs or sex. Or it could be as simple as a child who wants us to acknowledge him as a person but doesn't know how to communicate that need.

A rod for our backs?

So will stopping and paying attention to our children make life easier? Or will it just lead to more interruptions and selfish children?

Researchers have uncovered a surprising finding. Children whose parents are willing to stop, look, and listen tend to become less needy. These children learn over time that when they need their parents, they'll be there. They feel secure in that relationship. Conversely, children who have parents who push them away, say, "not now", or tell them to "hurry up" all the time worry about whether their parents will be available and they become more needy.

When our child wants us, it can be easy to pretend to be listening while we continue to scroll through our Facebook feed. We might even turn our body and shoulders towards our child and mumble "uh-huh" as they tell us about their day or whine about their sibling. But, as my daughter so poignantly pointed out in her interview with her mum, we're not really listening. And that leads them to act in ways that demand our attention… but it's not really the kind they want.

How does it feel for you?

Perhaps you have talked with a spouse or partner, or a friend, and they've been distracted while you poured out your heart. Chances are you felt frustrated. Perhaps you even felt that you could not trust that person with your challenges and vulnerabilities? Our children feel the same way.

To build strong, trusting relationships with our children the simplest things we can do is this:

STOP. Stop what you are doing. Completely. Put down the phone. Turn away from the screen. Turn down the stove. (But keep your eyes on the road if you're driving!)

LOOK. Look at your child in the eyes. You might crouch down so you can hold hands. Make that visual connection.

LISTEN. Keep that mouth zipped. Just listen. Keep looking at your child and really pay attention. (This works for spouses and partners too.)

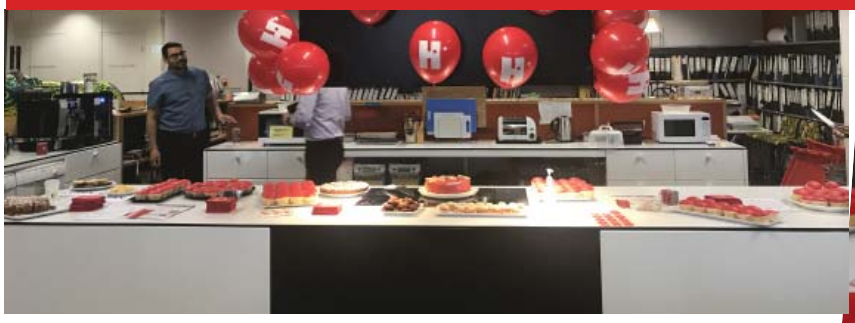
Stop, look and listen makes people feel valued. They feel important. They know they matter. It creates resilience. It strengthens relationships. It makes families happier. Try it today and watch how much better life feels.

www.justincoulson.com
www.happyfamilies.com.au

Please go to Dr Justin Coulson website for more information and advice on parenting.

Reprinted with permission from Dr Justin Coulson

CELEBRATING
RED CAKE DAY 2017



We held Red Cake day at our work (Irwin Consult). There was a big turn-out – more than 140 people!

A special thanks to Pauline for helping to organise the event and to Maria, Judy, Lisa and Thorsten for baking amazing goodies for the cause.

We raised $383 in addition the board of directors contributed $500 - a total of $883!

Yesterday's event has made more than 75% of attendees aware of Haemophilia that had little or no idea about it.

We all hope the best for my son Robert.

Herbert - HFV Member

A HUGE THANK YOU to all our supporters over Red Cake Day for helping to raise funds for our community and also raise awareness of bleeding disorders within our wider community.

ANOTHER HUGE THANK YOU TO THE FIELD FAMILY!!!

For the 2nd year Donna, Grant, Emma and Adam's annual 'Paint the Town Red' event has received national support from the Bendigo Bank with over $6800 being raised!

This event really highlights their amazing community in Neerim South as they receive so much support from local businesses, their own work places and the local residents.

It was a huge undertaking for Donna this year as she also decided to produce Red Recipe Books which were sold for $10 each. The funds raised for HFA's Red Cake Day are shared throughout the States and Territories with HFV receiving direct funding for select peer support activities. We are astounded by the efforts of the Field Family who contribute in such a big way with their fundraising and awareness activities….year in and year out!

The Horkings & McCann Families join together for a RED Cake Day event in Echuca

We held it on Saturday 14th October. It was well attended by our local community including friends and family, and the boys' school friends. Their school, St Mary's, really got behind Bleeding Disorders Awareness Week giving Kelly and Archie lots of opportunities to talk about haemophilia to all the classes in the school (500+ students) Even very recently I have had mums from the school tell me what an impact the boys' sharing their experience had on their own children. Kasey and I were so proud!

PHOTOS : Archie and Kelly are in front of our stall. Kelly's cousins and Archie's sister were our awesome sales team!

A NEW GUIDE for parents of a child newly diagnosed with haemophilia

The Guide explains haemophilia and how it is managed in plain language for parents who are new to haemophilia, with diagrams, and personal stories, tips and photos from other Australian parents. It includes quick reference cards - an emergency checklist for when a parent suspects a bleed and information on how to recognise a bleeding episode in a small child.

The folder will be distributed to parents and caregivers through Haemophilia Treatment Centres and is also available for downloading from the HFA website www.haemophilia.org.au/publications/haemophilia/new-diagnosed

Recognising a bleed

Check your child daily for bleeds

- when changing their nappy or dressing them
- at bath time

Check them after a fall or bump

- Always have the doctor review them if they hit their head

What to look for

Check all over, particularly their skin, their arms and legs, around their nappy area

- Big bruises, lumpy bruises
- Swelling
- A muscle or joint that is tight and shiny, warm, swollen, or painful
- One arm or leg is bigger than the other
- Bleeding from the mouth or tongue
- Persistent bleeding after blood tests, immunisations, cuts or breaks to the skin, surgery

What are they doing?

- Favouring one leg or arm
- Not reaching for things with the nearest hand
- Reluctant to straighten an arm or leg or unable to kick
- Limping
- Moving differently
- Difficulty in rolling, crawling, standing, walking
- Unexplained crying or irritability
- Telling you they hurt or are sore

Bleeds in these areas are particularly serious

Seek medical attention immediately

Head, eye, face, neck, throat

- Not wanting to eat or drink, vomiting
- Headache, irritable, sleepy, unable to wake
- Difficulty swallowing or breathing
- Unsteady, problems with crawling or walking
- Bleeding from ears or nose
- Seizures, fits

Spinal area

- Weak, numb, tingling in arms and legs
- Back pain

Stomach

- Vomiting or coughing up blood or dark syrupy "coffee grounds"
- Red or brown urine (wee)
- Red or black stools (poo)

This information is for educational purposes only. Always consult your doctor or HTC for assessment and advice about your child's individual situation before taking action or relying on this information.

"Dear Agony Aunt.....
To Whom It May Concern"

Hi to all the varying members of the HFV community in Victoria both affected and living with the variants of bleeding disorders that exist. We would like to offer an "agony aunt' column in the HFV newsletter to provide an chance to ask a variety of questions relating to you or someone you know and living with a bleeding disorder.

Jane Portnoy and I may be known to some of you when attending the HTC at the Alfred Hospital in recent times. Whilst we work with the adult services, we may be able to assist with questions and answers also relating to the Royal Children's Hospital Treatment Centre through our colleagues there. With the changing medical scene over the years, your connection and attendance at the HTC can vary and sometimes you may need to have certain questions answered that may or may not involve the medical team.

We would like you to consider posting questions in the HFV magazine that Jane & myself can attempt to find the right answer to. Sometimes when members attend the HTC, you may not be sure who to ask or feel embarrassed to ask, especially if it's of a more personal or private nature.

Questions can vary from matters affecting your relationships with family or partner, sexual orientation & intimacy and having a bleeding disorder, disclosure issues of your bleeding disorder within the work place, potential partners, varying insurance and legal issues (we have access to lawyers from Maurice Blackburn several times a week) to services with-in the hospital system.

A common issue is around insurances such health, travel & income protection and the need to ensure that you disclose pre-existing medical condition that can bump the premium you pay.

With the recent postal survey on Marriage Equality, it may have triggered some doubts or uncertainties or questions you have been pondering.

We may be able to direct you to other resources and services for more detailed answer.

You can post the question anonymously, using an alias or just your 1st name, it's up to you. We will not use your contact details in print to protect your privacy.

However thereafter, we could offer you a more one on one time if the matter continues to be unresolved.

Here is an example...

I am applying for jobs in retail over the university holidays and am not sure how much I should tell the employer about my bleeding disorder?

Dear Paul,

This is a great question.

Legally you only have to tell the employer if it is going to effect your capacity to work, you are applying for a new superannuation, or it is for the police or defense force.

However there was a wonderful discussion at the conference 2017 where many of the audience participants suggested that they had had great outcomes when they told their future employer and took the responsibility for themselves.

They found that they got the respect from their employer, and were able to demonstrate that they were able to do the job. The other benefit was that they were well supported when they needed to take leave due to a bleed.

Good luck with the job seeking.

Please send in your questions by the 1st February to **julia@hfv.org.au or A.Coombs@alfred.org.au & J.Portnoy@alfred.org.au**

Agony Aunt answers will appear in the Autumn (March) edition of The Missing Factor.

ANNUAL GENERAL MEETING CHRISTMAS PICNIC &

What a great day for a picnic!!!

We were again blessed with beautiful weather and even better company for our AGM and Christmas Picnic!

Over 20 families joined us at this amazing park (Royal Park Nature Playground - next to the RCH). If you haven't been it's really worth taking the kids or grandkids for a visit, especially if you are at the RCH for an appointment.

Santa also joined us for a visit and all the children received a special treat from our special guest!

Thanks to Sharron Inglis, Zev Fishman and Andrea McColl for their input into the AGM. Sharron provided an insight into our achievements and highlights for the last financial year and Zev, as the treasurer, provided a financial summary.

Thanks to all our families that attended. We hope to see you all and many more HFV families at our next Community Camp!

HFV Noticeboard

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

Royal Children's Hospital

2018 HAEMOPHILIA TEACHER'S SEMINAR

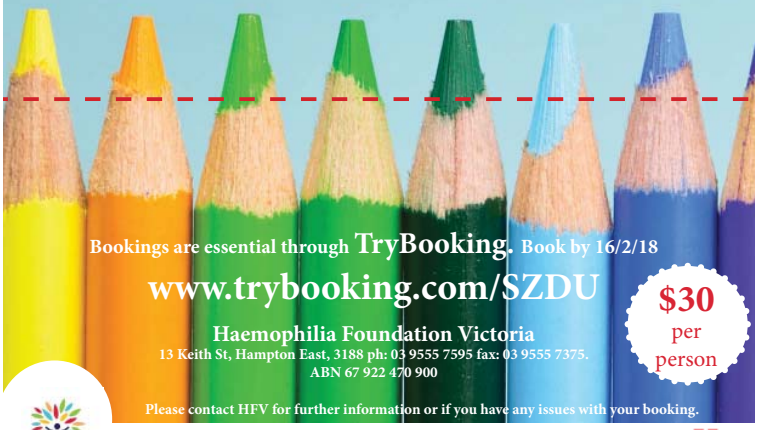
TEACHERS
You are invited to attend the 15th Haemophilia Teacher's Seminar presented by the Haemophilia Treatment Centre Team at the RCH.
Supported by Haemophilia Foundation Victoria.

8.45am — 12.00pm
Friday 23rd February 2018
Vernon Collins Theatre
Royal Children's Hospital,
Level 1, West Building (via Yellow lifts)
50 Flemington Road PARKVILLE

Speaker:
Dr Chris Barnes - Director Haemophilia Centre
Janine Furmedge - Haemophilia Clinical Nurse
Nicola Hamilton - Physiotherapist

Special Guest Speakers:
A primary and secondary school child with Haemophilia

COMMENTS FROM TEACHERS WHO HAVE PREVIOUSLY ATTENDED
- Haemophilia is not something to be scared of!
- I feel assurance that promoting physical activities is the right thing to do
- Listen to the child, he knows his own body
- I now have the confidence to know what to do
- Not to treat kids with haemophilia any differently
- I now know what I need to have in place as my role as his teacher
- The boys were incredible and their stories really highlighted everything spoken about
- I am now comfortable with myself and the idea that I will have to assist our little boy
- I feel much better about dealing with my student in a "non over anxious way"



Bookings are essential through **TryBooking**. Book by 16/2/18

www.trybooking.com/SZDU

$30 per person

Haemophilia Foundation Victoria
13 Keith St, Hampton East, 3188 ph: 03 9555 7595 fax: 03 9555 7375.
ABN 67 922 470 900

Please contact HFV for further information or if you have any issues with your booking.

HAEMOPHILIA FOUNDATION VICTORIA

thefemalefactors

WANT TO BE INVOLVED?

We are looking for women affected by haemophilia, VWD or other bleeding disorders.

Tell your story and have it included in the new resources – it can be anonymous if you prefer – and you can write your story yourself or be interviewed over the phone and/or comment on the draft resources.

Contact Suzanne at HFA on socallaghan@haemophilia.org.au or phone 1800 807 173

HFV OFFICE CLOSURE

The HFV office will be closed from Fri 22nd Dec — Mon 22nd Jan.

Staff can be contacted on 0410 247 908 or 0407 682 910 during that time.

SAVE THE DATE

HAEMOPHILIA FOUNDATION VICTORIA

2018 COMMUNITY CAMP

(formerly Family Camp)

Camp Wilkin ANGLESEA
27th – 29th April

sun, sea, sand
& heaps of fun!!!

BOOKING FORMS TO BE INCLUDED IN THE MARCH EDITION OF 'THE MISSING FACTOR'.

We are planning a WALK AROUND

ALBERT PARK LAKE for 2018 BLEEDING DISORDERS AWARENESS WEEK

We would like to make this an annual event and an opportunity for all our members, families including grandparents, aunts and uncles and even friends to join us.

There will be more information to come but pencil Sunday 7th October into your diaries!

Bleeding Disorders Awareness Week

WORD FIND CHALLENGE

BLEEDING DISORDERS WORD FIND 2017

Bleeding Disorders Awareness Week
8-14 October, 2017
Red Cake Day

Q	M	F	N	I	N	F	U	S	I	O	N	S	W	M
P	R	O	P	H	Y	L	A	X	I	S	D	F	T	P
V	O	N	W	I	L	L	E	B	R	A	N	D	W	G
E	B	I	I	H	M	S	T	E	L	E	T	A	L	P
P	R	M	G	H	G	C	O	X	C	G	D	G	S	K
H	A	E	M	A	T	O	L	O	G	I	S	T	P	K
L	R	G	H	K	Y	G	J	K	J	F	H	I	O	Y
A	E	X	A	B	D	R	N	P	O	R	T	N	T	P
I	E	F	C	C	J	F	L	V	I	E	C	H	A	A
C	C	P	M	L	V	A	R	T	N	E	B	I	N	R
O	B	L	O	O	D	C	L	O	T	I	H	B	E	E
S	D	A	Q	T	P	T	T	Y	S	F	V	I	O	H
O	C	S	I	T	J	O	V	G	Y	H	E	T	U	T
H	G	M	B	I	K	R	K	N	U	W	W	O	S	E
C	J	A	U	N	N	S	O	P	V	E	S	R	U	N
Y	T	T	O	G	W	Q	B	G	U	H	N	S	I	E
S	C	O	N	C	E	N	T	R	A	T	E	Y	C	G
P	H	Y	S	I	O	T	H	E	R	A	P	I	S	T
C	H	R	O	M	O	S	O	M	E	E	G	E	N	E
H	A	E	M	O	P	H	I	L	I	A	W	B	N	U

ABDR
CHROMOSOME
GENE
HAEMATOLOGIST
INHIBITORS
PLATELETS
PORT
RARE
BLOODCLOT
CONCENTRATE
GENETHERAPY
HTC
JOINTS
PHYSIOTHERAPIST
PROPHYLAXIS
SPONTANEOUS
CLOTTING
FACTORS
HAEMOPHILIA
INFUSIONS
NURSE
PLASMA
PSYCHOLOGY
VONWILLEBRAND

GLOSSARY

ABDR - The Australian Bleeding Disorders Registry (ABDR) is a registry for patients in Australia with bleeding disorders.
BLOODCLOT – The jelly-like mass that results when blood platelets and fibrin mesh to seal a leaking blood vessel.
CLOTTING - The sealing of a blood vessel with coagulated blood.
CHROMOSOME – A structure that carries genes in the cell nucleus.
CONCENTRATE - a substance made by removing or reducing the diluting agent; a concentrated form of something.
FACTORS - A blood plasma protein that is an agent in the clotting process.
GENE – The basic hereditary unit that directs body formation; each gene has a certain position on a chromosome and can reproduce itself.
GENE THERAPY - : A procedure in which normally functioning genes are inserted into one's own cells so that those cells will in turn produce specific protein controlled by the particular genes.
HAEMOPHILIA - A chronic, hereditary blood disorder marked by prolonged bleeding and caused by a defect in aprotein needed for blood clotting.
HAEMATOLOGIST – A doctor with specialist understanding of blood and bleeding disorders such as haemophilia.
HTC – Haemophilia Treatment Centre.
INFUSIONS - Inserting missing clotting factor into the bloodstream via a vein to help stop bleeding.
INHIBITORS - An antibody in the blood that forms in response to infused factor and hinders clotting.
JOINTS - The place where two or more bones come together.
NURSE – a person trained to care for the sick or infirm, especially in a hospital.
PHYSIOTHERAPIST – a person qualified to treat disease, injury, or deformity by physical methods such as massage, heat treatment, and exercise.
PLATELETS - The part of the blood responsible for blood clotting
PLASMA – The part of blood containing the clotting factors.
PORT - A device surgically implanted under the skin in the chest wall to make finding veins easier and to protect veins from continued needle sticks.
PROPHYLAXIS - Infusing clotting factor on a regular basis. The intention is to keep factor levels at a sufficient level so as to prevent most, if not all, bleeds.
PSYCHOSOCIAL – A broad term used to describe a psychologist, social worker or counsellor.
RARE – (of an event, situation, or condition) not occurring very often.
SPONTANEOUS – Bleeds that appear to happen for no obvious reason. This means that there is no specific identified injury that caused this bleed to occur.
VONWILLEBRAND (VWD) - Another type of bleeding disorder. VWD is the most common bleeding disorder worldwide.

diary dates

DEC

9 2017 HFV Youth Event

22 HFV office closes

JAN

22 HFV office reopens

FEB

23 Teachers Seminar

23-25 Men's Retreat

APRIL

27-29 HFV Community Camp

MAY

TBC Ladies Day Out

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 Furmedge | 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

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

HFV FISHING TRIP

A wonderful morning aboard the 'Bella Sandro' for our Men's Group Fishing Trip!

Thirteen eager souls braved the 4am start for a wondeful morning on our beautiful bay. A good time was had by all and we understand there are still many fi sh happi-ly swimming around the bay despite our the groups best eff orts!

HFV MEMBER SERVICES & PEER SUPPORT

Membership Annual Fees:
Standard family membership
$33.00
Concession member
$16.50
Allied Member
$16.50
Organisational member
$55.00
* No joining fee for new members joining at the Standard Family Membership rate.

Ambulance Subscription Subsidy:
To ensure all people with haemophilia have ambulance cover, the Foundation will subsidise Ambulance Subscription Fees to the value of half the family fee.
(Members who have Health Care Cards which also cover their dependants, are automatically entitled to free Ambulance transport for themselves and their families.)

To obtain an Ambulance Subsidy:
Forward subscription receipt (or a copy) to the HFV Office with your contact details. Subsidies will be paid on a reimbursement basis.

Other Subsidies:

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

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

Care and Counselling:
This is available through your treatment centre.

Magazine:
Your quarterly magazine offers information and details of upcoming events.

Website - www.hfv.org.au

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

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

Phone: (03) 9555 7595 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.

The Haemophilia Red Charity BALL

Achieving the extraordinary together