

AUTUMN 2024



# THE MISSING FACTOR

- PROBE Study • Conference Report
- Starting school with a bleeding disorder
- '23 Camp Archives • Tribute: Micheal Lucken



# 6 STARTING SCHOOL WITH A BLEEDING DISORDER

# 15 PROBE AUSTRALIA STUDY

# 16 CONFERENCE REPORT: GENE THERAPY

- 3 **President's Report**  
*Dan Korn*
- 4 **Meet our committee**
- 6 **Starting school with a bleeding disorder**
- 8 **Blueshirts: Empowering tomorrow's leaders**  
*Ben Iglis - HFV Member*
- 9 **2023 Camp Archive Photos**
- 12 **Ask Us**
- 14 **Welcoming Baby Sam**
- 15 **PROBE: Why PROBE is important**
- 16 **Gene Therapy: Conference Report**  
*Adam Field - HFV Member*
- 17 **Tribute: Michael Scott Lucken**  
*Brett Lucken - HFV Member*
- 18 **Notices & Information**

HFV is committed to Child Safety. Our Child Safety Statement is available for review on our website [www.hfv.org.au](http://www.hfv.org.au)

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

Opinions expressed in The Missing Factor do not necessarily reflect those of the foundation, HFA or the Haemophilia Treatment Centres. The content of this publication is provided for information purposes only. All information is provided in good faith but no responsibility can be accepted for inaccuracies that may result from events beyond our control. No claim is made as to the accuracy or currency of the content at any time. HFV do not accept any liability to any person for the information which is provided.

HFV is funded through the Department of Health and Human Services under Blood Borne Virus Sector due to the historical impact of contaminated blood products on the haemophilia community.

HFV supports our diverse community and our magazine reflect topics that impact our community including bleeding disorders, BBVs, mental health and positive health promotion.

Editor: Yarrow Ruane

# PRESIDENT'S REPORT

Hello everyone,

Summer always feels like a quiet period for HFV when you look at the calendar, but in addition to the usual holidays we have been busy behind the scenes. Community Camp is just around the corner as I write this, and we want to put on a great program for everyone in our first time at a new site.

We also had our first face-to-face meetings with each of the HTCs after several years of online meetings due to Covid restrictions. Although I can sense how much pressure the health system is under at the moment just from the fact of how challenging it was to schedule an in-person discussion, I can also sense the genuine care and concern from them for our wellbeing. It was great to talk about what challenges they see amongst our community and how HFV might better support people to face them.

In addition to the HTC events, the HFV committee has had two other in-person gatherings. The first was to salute outgoing HFA Exec-

utive Director Sharon Caris, who has stepped down from the role after a decade and more of dedicated service. We'll certainly miss having her around, but we're also confident Natashia Cocio will do a great job stepping into the exec director role after many years as the development director.

The HFV committee also had an in-person event to welcome back two members who had previously served and are now returning after a few years off, those being Ann Roberts and Erika Mudie. We are so thankful to them for rejoining CoM, and we also would like to thank Bernard Paes, who stepped down from committee, for his contributions as Treasurer.

Aside from the Community Camp in mid-March, we also have World Haemophilia Day coming up on April 17th and our Men's Retreat on the last weekend of May. Please keep an eye out for more details on both of those, or reach out to the HFV office to find out how to get involved.

Although there are other events already on the calendar for later on in winter and

spring, I would love to know what sort of gatherings or info sessions you'd like us to do more of. We can definitely do more than what's planned at the moment.

In particular, the HTC at the Royal Children's Hospital suggested we have some short on-line events after kids' bedtime to support parents of young families. If that's something which would be helpful to you, please don't hesitate to reach out to our office by phone or email and let us know what topics we should focus on with that type of session.

See you at camp,  
Dan



**Dan Korn**  
*HFV President*

# MEET OUR HFV COMMITTEE

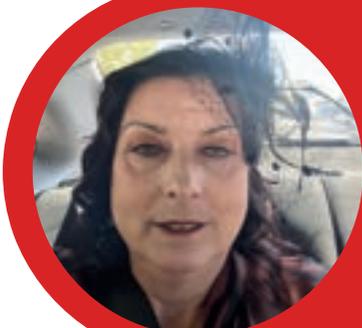
## Dan Korn - President

I grew up in the US and moved to Australia in 2014 after working in Singapore and Cambodia for a few years. Growing up with severe haemophilia B, I knew it would be important to connect with HFV as soon as I got to Melbourne, because the South Carolina Hemophilia Foundation had been so important to me and my family as I grew up. I learned to self-infuse at a camp when I was 10, not at a clinic or at home, and that independence has been indispensable in achieving my dreams. Now I have the chance to pay it back by serving on the HFV Committee and doing what I can to support everyone else's independence.



## Donna Field - Vice President

Hi my name is Donna Field & I am the Vice President on the HFV Committee. I am married to Grant & we have two children, Emma & Adam (who has Haemophilia Severe Type A). We live on a hobbyfarm with a menagerie of animals in West Gippsland. I am a qualified horse riding instructor/coach & have had a love of horses from a very young age. I have been involved on the HFV Committee for 10 years? Prior to Covid I held a "Paint The Town Red" event in our local town for over 15 years as a HFA fundraiser. One of my main goals is to continue to advocate for people with Bleeding disorders & to increase the awareness in the Community.



## Leonie Demos - Committee Member

Our family have been a part of the HFV community since my son was diagnosed with Haemophilia A thirty years ago. After benefiting from the amazing events and peer support programs from HFV we received across our H journey I decided to join the Committee to learn how I could contribute to the important work and support others in return. I had the privilege of being the President for many years and I am now excited to remain on Committee with other inspiring folk and dedicated staff to do whatever I can moving forward. Our community needs HFV to remain a vital and agile organisation and hope others are encouraged to join us in the work. Look forward to meeting new people at our next event!!



## Ann Roberts - Committee Member

I have rejoined the HFV committee, in the past been I've been involved with the bleeding disorders community for a number of years so it all feels quite comfortable. I have 4 boys and one daughter with the youngest son having severe Haemophilia, I now have 7 grandchildren. It has been amazing to see the huge changes in the treatment products over the years. My reason for rejoining is to ensure that you all continue to have the best treatments which requires constant surveillance of treatment developments as well as government funding policies.



## Ben Inglis - Committe Member

Hi everyone! My name is Ben and I've been a part of HFV for as long as I can remember. I've been going to the community camps since I was about eight years old. Through the years I've gained so much from being a part of this community and love any and all opportunities to give back. I hope I'll get to see and meet as many of you as possible through the events we have coming up this year!



## Zev Fishman - Treasurer

Warm greetings! I'm Zev Fishman, born in 1951 and embracing life with Haemophilia A Severe. I'm happily married with three wonderful children: Matthew (44), Daniel (42), and Alana (38). Beyond that, I'm blessed with the laughter and love of three beautiful grandchildren. I'm still active in the workforce, and look forward to working with HFV again.



## Erika Mudie - Committee Member

I became part of the bleeding disorders community when I met and married Dan (president). HFV was one of the first community groups we connected with when we moved to Melbourne 10 years ago. I'm particularly passionate about advocating for women in the bleeding disorders community. The ways women are affected are so layered and bridges generations. They carry our legacy and they hold our future. Hobbies include: running, being a catmom, half-finishing craft projects.



## Christopher Phong - Committee Member

Hi, I'm Christopher and I am 23 yrs old with Hemophilia A. I'm currently studying interior design and architecture as well as working part-time in hospitality. Almost two years ago I joined the subcommittee so that I could understand and learn how to work as a team, discussing different subjects with different opinions on certain events that we organise as well as to get involved with the people who had made HFV events possible (such as the family camps and blue shirts program). These events had made an impact in my life in a way where before I had gone to these events, I did feel very alone in a sense that people from my school or outside of my school didn't understand my bleeding disorder nor did they really even know about it. But after going to more of these events, it's very comforting knowing that I could joke around and relate with others who have similar or the same bleeding disorder as I do. It builds a lot of camaraderie amongst us and it just feels comforting knowing that there are and have been people who have gone through similar struggles as I have.



# Starting school with a bleeding disorder

By:

Janine Furmedge

Jaime Chase

Starting childcare, kindergarten or school - or high school - can be both an exciting and daunting transition for children and their families.

When a child has a rare bleeding disorder such as haemophilia, there is additional anxiety for both parents/guardians and educators. Parents may worry about entrusting the care of their child to others. Most educators will not have experience with bleeding disorders and are often worried about what this might mean for the inevitable falls and scrapes in the playground and be unsure about including children in activities and sports.

## HOW TO EDUCATE SCHOOLS?

Providing information for schools and childcare is a key role of the Haemophilia Treatment Centre (HTC) with the goal to support parents, allay the fears of educators and for children to have a safe, active and full school life. Depending on the size of the school, key contacts may include teachers, first aid officers and a school nurse.

Some of the key messages provided to schools include:

- Most students with haemophilia can lead healthy and active lives and participate fully in the school community
- Appropriate activities and sports are encouraged to promote physical and mental health
- A student with haemophilia will NOT bleed profusely from a simple fall in the playground or a minor cut or injury
- Standard first aid is the same as for any other student
- A knock to the head or major injury requires prompt medical attention which may require factor replacement
- In the instance of an injury, contact the parent or guardian immediately.



Most childcare centres and schools will request a medical 'action plan' for children with a medical condition. Your HTC can provide an action plan with key information about your child's bleeding disorder, how to recognise a bleed, appropriate first aid and when to call the parent/guardian or an ambulance in the rare case of a significant injury (emergency management).

## LOCAL SCHOOL RESOURCES

Each state and territory has its own way of managing health conditions in schools.

Speak to your local Haemophilia Treatment Centre or your local Foundation about resources and education for schools on haemophilia that is suitable for your child. They may have a school pack that they will tailor for your child. Some may be able to work with you to provide an education session for the teachers and/or students in the school, or to develop an individualised plan in collaboration with you and the school. They may also offer other types of education, such as an annual seminar for teachers.

This is an example of an HTC information page for teachers. There are short videos of children with haemophilia answering common questions from teachers -

<https://tinyurl.com/RCH-HTC-teacher>

For information on sport and exercise for young people with haemophilia, visit the online video set and toolkit *On the move with haemophilia*. This is aimed at parents, teachers and coaches, and is available on the HFA website - <https://tinyurl.com/HFA-OTMWH>.

## WHAT DID THE SCHOOLS SAY?

Typical feedback from educators after a haemophilia information session:

*'I was really nervous about having a child with haemophilia in my class. Today has put me at ease.'*

*'I feel better prepared to look after and enjoy the company of the child in my care.'*

*'Key message that I learnt today: that a child with haemophilia will not bleed to death if they fall over in the playground. There is no need to panic if the child is hurt.'*

## STARTING HIGH SCHOOL

Starting high school is such an exciting time for young people and their families - but it may be filled with a bit of apprehension too! The school is likely to feel and be a lot bigger than their primary school and it can be easy to feel a bit lost and nervous when they begin.

Orientation days are a fantastic way to feel more comfortable in the environment. Another way to ease transition is for parents and guardians to chat openly and honestly about what high school might look like and what ways you can troubleshoot any issues.

### Tips and tricks for high school

- Tell your HTC your young person is transitioning to high school. The sooner they know, the more time they have to help with transition.
- Find your contact! Help your young person connect and feel comfortable with their year advisor, First Aid Officers and/ or Wellbeing Officer. This is the staff member who will be your and your young person's contact for school issues, further support and firsthand knowledge of bleeding disorders.
- Some young people may need access to the bathroom during school time due to heavy periods. Discuss this with the school and check if your HTC may need to provide support or advice.
- Make sure your young person keeps sanitary items readily available for school in case of flooding. A key contact at school is very useful for this issue.
- Make sure your Emergency plan is up to date and completed by your HTC as required.
- Your HTC will offer school education sessions, either pre-recorded, virtually or in person.
- Plan ahead - work with the school and your young person regarding camps, excursions and sporting events so everyone is prepared.
- Talk to your young person about wearing a MedicAlert® ID bracelet or necklace or something similar. Make sure the emergency screen on their mobile says they have a bleeding disorder and that they carry their ABDR patient card in their wallet or have a photo of their ABDR card on their phone.

## ENCOURAGING INDEPENDENCE

High school is a time where young people start to move away from their parents and caregivers and start to exert independence. Sometimes this is a difficult time for the parents/caregivers, especially in the context of a bleeding disorder.

While some young people crave freedom and independence, others may need that extra push to become confident and self-motivated. Wherever your young person sits on this spectrum, there are ways everyone can help young people thrive. Skills you can help your young person practice are:

- Being independent at home - learning to cook, being responsible for cleaning areas of the home, doing their own laundry
- Managing their time - becoming responsible for their own work and study and learning how to create, maintain and stick to a timetable is very helpful for high school life
- Increasing confidence - learning to deal with new situations, meeting new people
- Being responsible - looking out for their friends and themselves
- Taking responsibility for their bleeding disorder - making their own appointments, attending part or all of their clinic appointments by themselves
- Having a sound knowledge of their bleeding disorder and what this means to them
- Being responsible for their own treatment, as applicable.

Other ways to encourage independence are to create clear boundaries which may evolve as your young person gets older. These include:

- Going out with friends - where are they going and how late can they be. They need a person in their group who knows about their bleeding disorder. Discuss who it will be and how they will help in case of an incident/accident
- Contacting when they are out - when and how they should check in
- Using social media devices - what platforms are okay and any device-free times.

## IT IS OKAY TO LET GO!

As a parent or guardian you want your young person to grow into a confident, capable, knowledgeable adult. Your HTC wants this too! When you begin to progressively let go and allow your young person to become more independent with life with a bleeding disorder, you learn to trust them and they learn to trust themselves.

High school will be a bit of trial and error on both sides of you and your young person. With a bit of trial and error and help from your HTC, your young person will learn to trust themselves and the decisions they will make both about their lives and their bleeding disorder.

High school is an amazing time of growth for a young person. With the steady guidance of parents, caregivers with the support of the HTC, they can learn, grow and go on to great things.

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BY: BEN INGLIS

BLUESHIRTS TEAM LEADER

# Blueshirts: Empowering Tomorrow's Leaders

The HFV Youth Leadership Team was created six years ago to create a space for the parts of our community who were growing out of childhood but weren't a part of the "adults" yet.

The idea behind the program was to provide these members with greater opportunities for personal and professional growth, as well as chances to engage and network with others of a similar age group at HFV events and programs.

As the program grew, the purpose of the team grew with it. This process has been led and guided by members of the Youth Leadership Team at any possible opportunity.

With the guidance of our members, the team now has an official HFV Youth Leadership Team Handbook, official Youth Team communications, several youth-focused events each year, and the return of the HFV Youth camp. We also have many new plans and prospects for the future that we are working towards.



This includes certified training in life- and workplace-relevant skills, team exclusive activities, and opportunities to join the HFV committee and subcommittees.

Since the creation of the team two of our members have joined the HFV committee and the majority of HFV events have involved representation from the Youth Team in its organisation and running. We are always ready and willing to hear from those who are curious about joining the team!

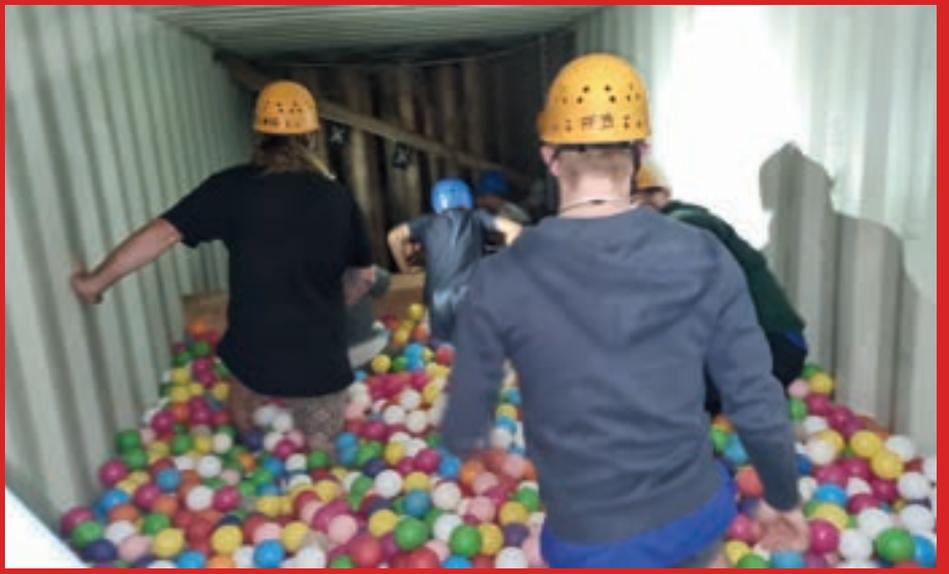
If you are between the ages of fourteen and thirty and think you have something you could contribute or think the team could help you then please reach out! This is a program we have built to support people like you to build your skills (in life and on your resume), make meaningful connections, and empower you to support our community.

For more information:  
Email: [info@HFV.org.au](mailto:info@HFV.org.au)  
Phone: (03) 9555 7595

# '23 HFV CAMP







# ASK US



*I am just wondering if there is much benefit in going to a Haemophilia community camp?*

The Haemophilia Community Camp is a highlight for many people in the community year, and has fun activities, a chance to meeting new people, talk about all sorts of things relevant to people with bleeding disorders, and get some updates about what is happening in the bleeding disorders world. You may not realize this, but attending camp has a big impact on wellbeing, coping with a bleeding disorder, and being able to manage all sorts of challenges.

Those in the community lucky enough to attend camp have a big advantage over those who don't. It is a subtle impact, and not immediately obvious. However, it shows in how well a person manages their own treatment, what they do when something goes wrong, and how comfortable they are dealing with the hospital and all team.

Camp is one opportunity to talk to others who have similar experiences, have a shared condition, and understand a lot more about bleeding disorders than the general population. The youth leaders are my favourite thing about Community camp, they bring all the energy, the understanding, and are so welcoming. The little kids look up to them, and can't wait until they can join the youth leaders, The great thing is that it is over a weekend, and it is always fun to get out of town, and you can go for a day if that works better for you.

# MILL VALLEY RANCH

HFV COMMUNITY CAMP  
15 -17 MARCH 2024



Get ready for the adventure that awaits at our HFV Community Camp in March. Don't miss out on the chance to make memories that will last a lifetime - we can't wait to share this unforgettable experience with you!



(03) 9555 7595



info@HFV.org.au





# Welcoming BABY SAM

From HFV Participant to Family Leader Tim's journey within HFV stands as a testament to the enduring spirit of community and leadership. Since childhood, him and his family have been a part of the fabric of HFV, embracing its values and fostering its growth. As a young participant, Tim's enthusiasm and dedication earned him the respect and admiration of his peers. His journey embodies the transformative power of service and connection. Now, as Tim welcomes the newest chapter of his life with partner Lauren and baby Sam, HFV stands united in celebration and support. Together, we honour Tim's journey—from participant, youth leader and mentor to family leader—and eagerly anticipate the adventures that lie ahead for him and his growing family.



# WHY IS PROBE IMPORTANT?

HFA is building evidence about the needs of men and women affected by haemophilia in Australia with the PROBE Australia Study and they would really appreciate your help.

## WHAT IS THE PROBE STUDY?

This study is co-ordinated by Haemophilia Foundation Australia and is an internationally recognised and validated questionnaire. It collects data on the impact of haemophilia on the quality of life of both men and women who are affected, either because they have haemophilia or carry the gene. It compares their experience to people who do not have a bleeding disorder.

So far HFA have only had around 150 men and women complete the PROBE survey - they need at least 400 for good data.

## WHAT DO WE DO WITH THE DATA?

PROBE data is high quality and credible and HFA and Foundations use it in many ways. You may have seen some of the data from the 2019 PROBE Australia Study in reports and conference presentations. Some examples include:

- In discussions and submissions to government, to advocate for people with bleeding disorders about new treatments and services
- In the HFA Getting Older report, to underline the issues for physical function and pain, and for people with mild haemophilia, women, hepatitis C
- At the 2023 Australian Conference on Haemophilia, VWD and Rare Bleeding Disorders conference in the plenary on mild haemophilia
- International meetings to discuss the issues for people with mild haemophilia
- HFA have had a poster on 2019 PROBE data accepted for publication at the 2024
- WFH Congress in Madrid - this is a peer-reviewed publication.

## HOW CAN YOU HELP?

Please consider completing the current PROBE Australia survey as soon as possible - and you don't need to have a bleeding disorder to contribute!

If you don't have a bleeding disorder, you can be a health professional, someone interested in haemophilia, or any adult Australian really. The comparison group is a slice of the Australian general community.

PROBE is voluntary and anonymous, so it is up to you - but we would really value your support.

## WHO CAN COMPLETE THE SURVEY?

Adult (18 yrs+) men and women living in Australia

Who have haemophilia/carry the gene OR who do NOT have a bleeding disorder (comparison group)

## HOW TO DO THE SURVEY?

It's very easy! Go to:

[myprobe.org](http://myprobe.org) for the web version

Or download the myPROBE app from Apple Store or Google Play (Android)  
Or ask HFA for a print survey pack  
If you have already done the survey, perhaps you could share it with family and friends and encourage them to complete it too.

## QUESTIONS?

If you have any questions:

Visit [www.haemophilia.org.au/probe](http://www.haemophilia.org.au/probe)

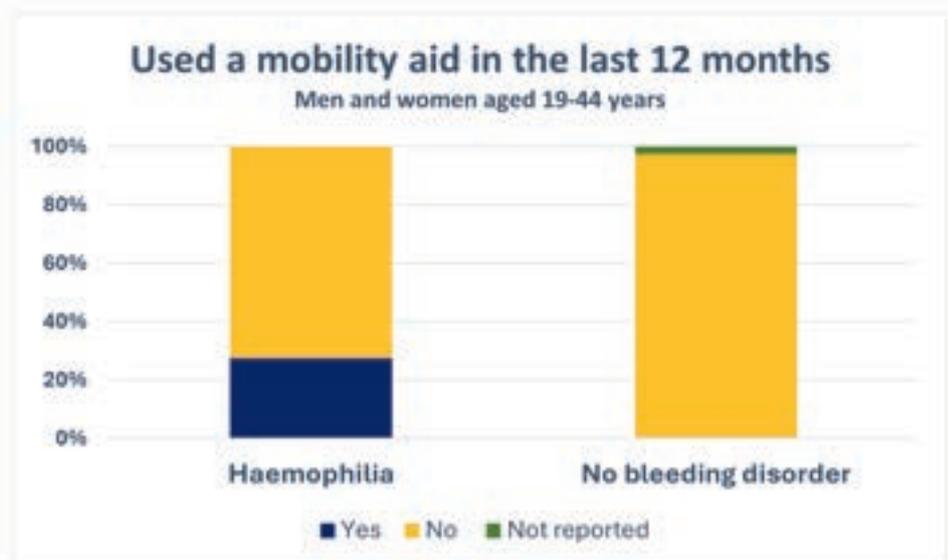
Or contact Suzanne at HFA:

E: [socallaghan@haemophilia.org.au](mailto:socallaghan@haemophilia.org.au)

T: 1800 807 173



## PROBE data speaks for itself



# Conference Report

Contributor

Adam Field - HFV Member



Greetings everyone, Adam here. In August 2023, I had the privilege of attending the Gene Therapy session at the Australian Conference on Haemophilia, VWD & Rare Bleeding Disorders.

The session delved into gene therapy, a process involving the insertion of the factor IX/VIII gene into a virus, which then enters cells to produce the factor IX/VIII Protein. It's akin to bioengineering on a micro-level and has been undergoing global testing on individuals with haemophilia. The presenters provided an insightful overview of considerations individuals need to weigh before pursuing gene therapy.

## Key takeaways

Committing to gene therapy necessitates a significant level of clinical follow-up. However, success is not guaranteed, and results can vary. Risks include potential reactions, liver toxicity, long-term thrombosis, malignancy, and the potential loss of expression. Nevertheless, a less toxic, non-viral version of gene therapy is on the horizon, indicating the rapid evolution of this field.

## Surprising Revelations

Individuals undergoing gene therapy may need to forego casual pain relievers like Panadol. Additionally, sperm freezing becomes necessary due to the process's toxicity, and in some cases, steroid use may be required. Notably, women are presently excluded from certain aspects of gene therapy.

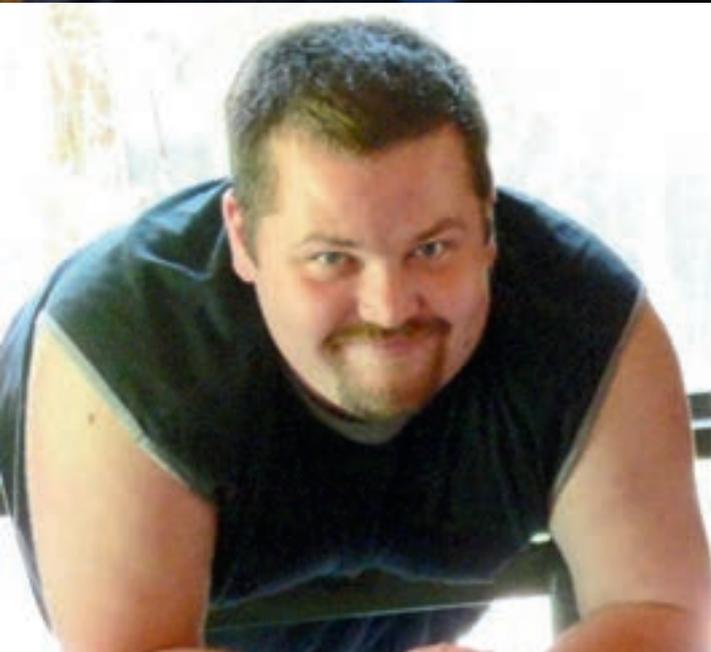
Gene therapy stands as a continuously evolving field, requiring considerations, steadfast commitment, and adjustments to lifestyle. While the future may bring advancements, the present journey embodies a natural sense of uncertainty.

## Highlights

The conference was an enriching experience! It provided opportunities to reconnect with familiar faces, forge new friendships with attendees from interstate, celebrate a peer's birthday at the casino, and gain valuable insights from seasoned professionals. Attending solo was empowering, and the coffee was exceptional! The hand simulator at the stands was a delightful surprise.

Overall, the venue, accommodation, food, and staff service were commendable. Great job at HFA staff for organising a successful conference.





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TRIBUTE:

MICHAEL SCOTT LUCKEN

Into the world on June 25 1983 came our 2nd baby boy,  
 We named him Michael Scott, he was our 3rd bundle of joy.  
 As we, his parents, who are really still so young,  
 Blissfully unaware of what was all to come.  
 As a smiley little baby he was so placid and calm,  
 He had a glint in his eyes that was there for ever, to charm.  
 Adventurism and intelligence, he was sure to be stunning,  
 Rolling, crawling, first step, walking, and then running.  
 It was about now while we had gathered an amount of memorabilia,  
 That to all our surprises and shock, he was diagnosed with haemophilia.  
 In Ballarat the bad news came from a fellow known as Harry,  
 Then in Melbourne even worse from a bloke known as Henry.  
 From here-on, hospitals became our second home,  
 We'd rush to BBH & RCH with an agonizing groan.  
 "Bleed" was a word we would rue every day, even hated,  
 Nose, tongue, cavity, joint and head, nothing was ever over-rated.  
 Toddler and pre-school came and went, the beginning was quite bad,  
 With primary schooling a mental nightmare parents and teachers had.  
 Many hurdles were overcome but bleeds just continued,  
 Mum dealt with them admirably, Michael with fortitude.  
 Fellow known as Harry, "on call" day and night, mostly nights and he did come,  
 Vein searching for treatment is and understatement, "and then some".  
 Bloke known as Henry had amazing knowledge, expertise and foresight,  
 Was on people with haemophilia's side, keeping them alive as their birthright.  
 Death knocked on our doors, front and back many a time,  
 No not yet, intervention, it would appear was divine.  
 Through secondary school with limited mobilities,  
 Being different he got targeted by a couple of bullies.  
 But through all that he endured through thick and through thin,  
 This bravest young teenage took it all on the chin.  
 Into adulthood as all of us do, through trial and error and some frustration,  
 He found his true love, dated, engaged, then married with dedication.  
 April the 5th 2007, came the happiest day of his entire life,  
 Baby daughter came into this world, hugs and kisses to his wife.  
 Dedication is one word, he lived for them both, but being a realist, he knew,  
 It wasn't easy, pain and mobility being the biggest issue.  
 Along with specialists they worked on the pain,  
 And wouldn't you believe it, part of it was a trick of the brain.  
 Now miraculously with minimal pain he could do so much more,  
 Complete with his family he began to go out and explore.  
 Now the thing with 28ish years of continuing pain and restrictions,  
 That in the 6 odd months after he may be freer, may also lead him to forget his  
 afflictions.  
 So here we all are at the date he became absolutely free of all life's woe,  
 A thousand friends, family, Mum and Dad, all our tears still flow.

By: Brett Lucken

-NEVER TO BE FORGOTTEN-

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# Notices & Information

## WELCOMING OUR NEW COMMUNICATIONS OFFICER - ZEHRA

Hello everyone!

I'm Zehra, and I'm delighted to introduce myself as your new Communications Officer at the Haemophilia Foundation Victoria.

With a background in science and PR, I'm excited to continue the wonderful work that Yarrow has been doing.

I'm eagerly looking forward to getting to know each of you, sharing stories, and working together to make a positive impact in our community.

Looking forward to the journey ahead!

-Zehra

## WOULD YOU LIKE TO JOIN OUR BLUESHIRTS?

Join Blueshirts, our dynamic youth leadership program at the Haemophilia Foundation! We're seeking enthusiastic youth to help organize events and foster collaborations within our community.

As a Blueshirt, you'll develop invaluable skills in event organization, team collaboration, and community engagement. Plus, it looks fantastic on your resume, showcasing your commitment to making a difference. Seize this opportunity to grow as a leader and leave a lasting legacy in our community!

Apply Now!

Phone: 03 9555 7595

OR

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

## MEMBERSHIP RENEWAL REMINDER

Happy New Year! This year is now well under way. Thank you to those who have already renewed their HFV memberships.

Annual membership renewal is due 30 June each year. Please contact the HFV office if you require a form. If you have not renewed your 23/24 membership, we request that you please do so as soon as possible.



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**VICE PRESIDENT** Donna Field

**TREASURER** Zev Fishman

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Ben Inglis

Chris Phong

Erika Mudie

Leonie Demos

Ann Roberts

VICTORIAN HAEMOPHILIA  
TREATMENT CENTRES



**Henry Ekert**

**Haemophilia Treatment Centre**

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Janine Furnledge | Clinical Nurse Consultant  
Erin Krake | Clinical Nurse Consultant  
Julia Ekert | Administrator/Data Manager  
Nicola Hamilton | Physiotherapist

**Ronald Sawers**

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Ponny McCarthy | Clinical Nurse Consultant  
Megan Walsh | Clinical Nurse Consultant  
Kara Cordiner | Haemophilia Nurse Consultant  
Susan Findlay | Secretary  
Alex Coombs | Haemophilia Social Worker  
Jane Portnoy | Hepatitis C & Haemophilia Social Worker  
Abi Polus | Physiotherapist  
Frankie Mullon | Physiotherapist  
Catherine Haley | Physiotherapist  
Diana Harto | Psychologist  
Dobra Belleli | Data Manager

**Membership Annual Fees:**

\$33.00 Standard family membership

\$16.50 Concession / Allied (Youth Free)

\$55.00 Organisational member

\* No joining fee for new members joining at the Standard Family Membership rate.

**Ambulance Subscription Subsidy:**

To ensure all people with haemophilia have ambulance cover, the Foundation will subsidise Ambulance Subscription Fees to the value of half the family fee.

(Members who have Health Care Cards which also cover their dependants, are automatically entitled to free Ambulance transport for themselves and their families.)

**To obtain an Ambulance Subsidy:**

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

**MedicAlerts**

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

**Live Well Funding:**

All current financial members can apply for Live Well Funding for any item or activity which the applicant anticipates will contribute to a positive health outcome. Priority may be given to funding applications for items or activities related to the management of bleeding disorders and associated health conditions.

**Care and Counselling:**

This is available through your treatment centre.

**Magazine:**

**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 2023, 11 members attended the retreat! Many promised to return after making powerful connections with their peers. There are also opportunities to meet for brunch and lunch during the year.

**WOMEN'S GROUP**

The group meets once a year over lunch and each alternate year get to enjoy an event with a twist. They have previously learnt circus skills, African drumming, attended relaxing massages, high tea on the Yarra and lunch on the Tram Restaurant. If you have an idea for a ladies day, let us know! We are always looking to try new things.

**YOUTH GROUP & BLUE SHIRTS**

After a successful reunion at 2023 camp (with lots of new leaders coming on board) the Blue Shirts are open to new applicants for onboarding. Please contact us via email or phone 03 9555 7595

**GRANDPARENTS GROUP**

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

**KIDS EVENTS**

We have opportunities for kids to connect throughout the year. Recently, several families met for an indoor climbing day. Check out our events schedule for upcoming kid-friendly activities.



Happy  
Easter

