Haemophilia Foundation Victoria Inc — *Achieving the extraordinary together*

THE MISSING FACTOR

Introducing our new HFV Patron... Dr Alison Street AO

NEW HEP C DRUGS TO GO ON THE PBS

Showcasing the new **HFV STRATEGIC PLAN**

A time of remembrance for our community

contents

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DIARY DATES

RCH Teachers Seminar —
Fri 19th Feb

Men's Retreat —
4th - 6th March

HFV Family Camp —
1st - 3rd April

Bunnings Sausage Sizzle Eltham —
Sun 3rd April

Grandparents & Friends Lunch —
Sun 17th April

World Haemophilia Day —
Sun 17th April

A word from *our* president, Leonie Demos

Committee of Management

President
Leonie Demos

Vice President
Sharron Inglis

Treasurer
Zev Fishman

Executive Member
Jodie Caris

General Committee
Kate Apted
Karen Donaldson
Donna Field
Ben Inglis
Fiona McDonnell

Happy New Year and hope 2016 brings good health, happiness and good fortune.

HFV will be busy planning for the many activities in our calendar and hope you will be able to be a part of the year ahead. The Family camp in April will be the first big activity and we would love to see many new faces along with our return families. The subcommittee has been working really hard to plan the camp and it will be so much fun so book your place to join us. As always if finances are a problem please contact Andrea or Julia at the office to discuss. The staff are very discrete and your confidentiality will always be paramount.

The start of a year is time to reflect on where we have come as well as where we want to be. 2015 was a very busy year for the Committee with many achievements to share. Live Well Grants have been extended to incorporate previous Bursary grants. The committee acknowledge that Bursaries in the past have been important to families to assist with educational expenses the Committee has made a tough decision and now HFV offers one grant process under Live Well Grants. We encourage any member to apply if they are in need of assistance as always. However now the committee feels the policy and application process is solid and accountable in a way to ensure the fund is available for those in need the most. Along with the new policy the Committee has increased the pool of funds available to members. Staff and I are very happy to discuss any of these changes so don't hesitate to contact us.

HFV launched our new Strategic Plan at the end of last year to members and stakeholders at our end of year celebrations. We are very proud of this document as this sets the goals and direction of HFV for the coming years. Please take time to have a look and provide feedback on your thoughts both critical and other. The strategic plan is to show you as members what the committee's intentions are and to demonstrate that our organisation is focused, in touch with member's needs, financially responsible and strengthening connections with stakeholders and allied health organisations. Your comments are very welcome as is your time if you wish to be a part of these exciting plans.

HFV also announced at the end of 2015 some very exciting news – HFV has a new Patron. Dr Alison Street is known to many of you for her many years of tireless work in supporting many in our community through her years as leading the HTC team at the Alfred. Dr Street is passionate in protecting our community and encouraging the best health outcomes as possible moving forward. Sharon Inglis (vice President) and I have meet with Dr Street on several occasions to discuss HFV and the many challenges facing our members. Dr Street has agreed to be the Patron of HFV and we look forward to working together in the upcoming year. HFV would like to sincerely thank Dr Street for her generosity in accepting our patronage and value her expertise and time as we work towards strengthening HFV for challenges to come.

As one of our key stakeholders HFA continues it's tireless work to advocate for all with bleeding disorders and take on many battles at a national level. As President I now sit at the table for national council and I am very impressed by not only the amazing foundations in other states across Australia but the incredible team at HFA. With funding always an issue HFA manage to run national campaigns on the smell of an oily rag and

the staff continue to be effective in so many ways that really make a difference for our community. A special mention to Suzanne for her exceptional work in the submission to government regarding treatment for Hep C. Please take time to read articles in both HFV and HFA newsletters to really understand and appreciate the enormity of the recent decision by government to provide treatments for those with Hep C. These decisions don't just happen in a vacuum but only after very crafted and strategic advocacy by many. Suzanne and the team at HFA are to be truly congratulated for the extra effort and the legacy of this decision to so many in our community. Again the power of the voice of our community is heard through agencies that are so vital for community and yet another demonstration on why we must all be vigilant and strategic in planning and activities and never miss an opportunity when it comes. Well done and thanks on behalf of all at HFV.

Blood brothers camp was a huge success near the end of last year. Investing in our young men and siblings is key in any succession planning and the Blood Brothers camp has been a very worthwhile and valuable activity in our calendar. A safe place for young men to bond and communicate about any issues whether health related or not. The strength of any agency in sustaining what may come is to have leaders ready to step up if needed. Those attending the camp along with the many talented siblings and family members that are part of our family camps and other activities are our future at HFV. We welcome and appreciate their contribution and are very excited in plans to build their skills as key part of our Strategic Plan. Many thanks to those leaders, Penny McCarthy for attending and running a valuable session and Purple Soup for the great effort. Keep it up!

As we begin 2016 there are so many new and exciting plans at HFV. A day in partnership with the team at the Alfred to provide resume skills, legal information on your rights in the workplace and the importance of investing in yourself workshop is one initiative in the planning. The multidiscipline meetings at RCH will continue with HFV as a partner to be available for families and promote our services and an opportunity to meet and greet families and encourage a connection. As mentioned the family camp is soon approaching. If you haven't been before take the plunge and join us this year. I guarantee you won't be sorry.

In 2015 HFV Staff and Committee defined our vision to three simple but powerful words – **connect, support** and **empower**. I challenge all members to make 2016 the year that you join in HFV's vision. Connect at a camp or a lunch that you have never attended before and enjoy the company. Support our strategic plan and learn how you can also make a difference no matter how small to someone in our community. Empower yourself in seeing what you are able to do when working with those that share your challenges in living with a bleeding disorder. The challenge is there. Make it a new year's resolution you are proud to make. Enjoy the fabulous newsletter and all the great articles to learn and share. Hope to see you soon at a HFV event soon.

Leonie Demos

HFV BUNNINGS SAUSAGE SIZZLE

SUN 3rd April
ELTHAM BUNNINGS

CALL FOR VOLUNTEERS!!!

HFV have been selected to run a sausage sizzle on Sunday 3rd April at the Eltham Bunnings.

Our grandparents group coordinators are running the event and are looking for other members to help assist during the day. Any members are welcome to help out.

Unfortunately this day clashes with our Family Camp and we are unable to change the date therefore many of our members will not be available to assist.

A roster will be set up for 2 hourly slots running from 8am until 4pm.

It is a great opportunity to raise awareness and connect with others in our community

If you would be able to assist please contact
Jackie Touzeau on 9439 9007
or the HFV office on 9555 7595

NEW HFV PATRON
DR ALISON STREET AO

Dear members, supporters and friends of Haemophilia Foundation of Victoria.

Julia has asked that I write a letter about my connection with the community and role as the incoming patron. First I must thank the HFV committee for inviting me to take on this auspicious position and I am deeply honoured to so do.

My first contact with haemophilia was through a friend of my brother in his primary school class. He did not have severe disease so fortunately did not have crippling joint deformities as this was before the availability of concentrates in Australia. When I was a second year resident at Alfred Hospital I covered the haemophilia service at night, this was still before concentrates and I would have to thaw plasma and cryoprecipitate in the hospital blood bank to then infuse to patients in the Emergency Department. I did further training at Royal Prince Alfred Hospital in Sydney by which time concentrates were available and patients would come to the hospital ward to collect supplies and self-infuse.

It was only when I returned to Alfred in 1986, after several years further study in the US, that I took on the role of staff haematologist and Director of the Haemophilia Treatment Centre at Alfred. This was eighteen months after Ron Sawers had retired. The community and centre were overwhelmed by the physical and psychological toll of HIV and subsequently HCV infection. It was a tough time for everyone and very few resources were made available to Haemophilia Centres throughout the country. I was very fortunate to have the immediate support and friendship of Professor Henry Ekert at Royal Children's Hospital. And as they say, the rest is history. I was in that position for twenty five years and saw many changes of which the most critical was access to plentiful safe product. There were many people to thank for their dedication and collegiality at my farewell in 2011 but it is never goodbye as shown by your generous invitation to me to be HFV patron!

I had many wonderful opportunities to work with interstate and international colleagues through the Australian Haemophilia Centre Doctors Organisation and through World Federation of Hemophilia. I now look forward to working with HFV committee and members in any way in which I might be helpful, particularly in offering a long-standing perspective of the issues past, present and future that are coming our way.

I do look forward to meeting and working with you and thank you again for inviting me to be your patron.

Alison Street

HFV STRATEGIC PLAN

Our Committee is proud to present our 2015-2017 Strategic Plan to our membership.

Much work went into producing this important document that clearly states our vision, mission and values and identifies our goals, actions and evaluations. Leonie Demos explained in her President's Report that "the strategic plan is to show you as members what the committee's intentions are and to demonstrate that our organisation is focused, in touch with member's needs, financially responsible and strengthening connections with stakeholders and allied health organisations".

We as an organisation are very proud to be able to share this not only with our members but all of our stakeholders.

If you would like to receive a copy of the Strategic Plan in its original format please contact our office at info@hfv.org.au

OUR VISION

Connect, support and empower our bleeding disorder community.

OUR MISSION

Provide support and positive healthy outcomes for those who are affected by genetic bleeding disorders.

OUR VALUES

Values underpin the organisational culture and behaviour of Haemophilia Foundation Victoria. In our relationships with our colleagues, partners and stakeholders and with all those who use our services we are committed to the following values:

Respect • Diversity • Leadership • Responsiveness • Integrity

STRATEGIC GOALS	1 Community ownership and support	2 Strategic education, communication and health promotion	3 Strong collaborative relationships and partnerships	4 Good Governance	5 Financial sustainability
KEY ACTIONS	• Evaluate programs to improve and target most disengaged in our community including those with specific health complications. • Build health literacy framework to inform programs and build capacity for members. • HFV to invest in technology to allow connection with regional representatives especially to support disengaged members isolated socially and/or geographically.	• Develop communication plan to reflect key dates, identify key opportunities to promote awareness of HFV and issue impacting on our community. • Update resources to promote HFV programs and services for distribution to HTCs to encourage engagement with members, allied health workers and the broader community when opportunity arises. • Identify opportunities to promote awareness of challenges faced by our members to promote acceptance especially for those impacted by Hep C and HIV. • Work collaboratively to broaden knowledge of health issues for our community beyond HTCs and encourage a holistic approach to health care.	• Identify and scope key agencies and stakeholders that support HFV goals and programs especially for specific members affected by Hep C and HIV. • Distribute strategic plan and promotional material to identified and targeted services to encourage partnerships and joint ventures in line with HFV goals. • Document both differing and overlapping roles of national agency being HFA and HFV to highlight gaps in services as well as ways to collaborate effectively with limited resources. • Formalise regular stakeholder meetings with both HTCs to discuss issues and work collaboratively where possible to support initiatives that support members of our community.	• Review and update constitution. • Audit current policies and procedures to identify gaps and prioritise development and update of policies. • Identify opportunities to promote member engagement with Committee of Management.	• Identify and scope all possible funding opportunities. • Identify and scope investment opportunities that will yield best returns while maintaining minimal risk. • Maintain strong relationships with all funders.
KEY EVALUATIONS	• HFV have a clear understanding of diversity of community and it's needs including those impacted by HIV and Hep C. • HFV's programs reflect health frameworks from both State and Federal government and align with identified needs of priority members. • HFV offers opportunities for members to build skills and feel empowered to deal with challenges created by their health situation and foster self-advocacy. • HFV have a peer support network across rural and metropolitan area that are trained and supported to connect with community especially those impacted with Hep C and HIV.	• HFV will support initiatives to promote awareness of Haemophilia and related bleeding disorders to the broader community as opportunity arises. • HFV will produce quality communications to promote positive health outcomes to our community and broader community. • HFV will work with stakeholders to promote positive outcomes for members in health setting and broader community to combat issues of discrimination or related stigma.	• HFV will have strong relationships with key stakeholder agencies to assist in achieving goals identified in strategic plan. • HFV will inform relevant partners of objectives and priorities as identified by our work with community and commit to working collaboratively when mutual goals are identified. • HFV will support allied services in joint ventures and initiatives that will benefit either specific or broader pockets of our community.	• HFV will have a constitution, policies and procedures in place that guide and assist achieving goals in the strategic plan. • HFV will have a Risk Management Plan. • HFV will have a sub-committee framework providing opportunities for members to be actively engaged with & pathway to Committee of Management.	• HFV will have funding to enable achievement of goals identified in strategic plan. • HFV will have secure investments with strong performance. • HFV will have strong relationships with all funders.

Achieving the extraordinary together

The following pages include session reports from HFV members who attended the 17th Australian & New Zealand Haemophilia Conference at the Gold Coast

Research based Mindfulness

I was fortunate to attend Dr Ira van der Steenstraten's afternoon practical session of Evidence Based Mindfulness titled "How it can help in your personal and professional life."

Mindfulness has been used as a therapy in mental health for the last two decades. It has proven to be effective in treating anxiety, depression and stress. Mindfulness is now broadly being used in places such as schools, sports, the corporate world and of course in health.

Dr van der Steenstraten described Mindfulness as:
- attention training practices and cognitive strategies
- ignoring unproductive thought patterns and behaviours
- paying attention to the present moment rather than worrying or dwelling on the past or future
- developing an attitude of friendliness toward yourself, as opposed to criticism or judgment

The above are important and not easy to successfully achieve, especially when being touched by haemophilia. As we know, a medical condition certainly adds worry and stresses to our daily lives.

Dr van der Steenstraten continued with a question: "Why train attention?"
Her answer: "How we focus our attention shapes the structure of the brain."
These are pretty powerful words. These words are backed up by current and relevant research in Neuroplasticity. Studies that involve mindfulness and meditation practice and how they positively affect the brain have influenced many practitioners in using this type of therapy.

In our practical sessions we stayed in our seats. I initially expected us to be lying down stretched out on the floor. Dr van der Steenstraten explained that you can be in any comfortable position available to practice mindfulness – and you need to be practical. She used the example of some people at their place of work taking five minutes out of their working day to practice Mindfulness without leaving their desk.

One of the exercises we performed was: closing our eyes and concentrating on our breath only. When Dr van der Steenstraten called out a word, we had to note what emotion we felt. She softly called out "yes" and I felt comfortable and positive. When she loudly called out "no" I immediately felt my defences come up and I felt very uncomfortable. The consensus in the room was a very similar reaction to mine. Dr van der Steenstraten discussed the power of words and the tone in which you deliver these words, and they affect they have on others.

An important part of Mindfulness is 'being non-judgmental'.
- thoughts are just thoughts, not facts
- learn to choose which thoughts to pay attention to
- choose how to react, not automatically

For practical use, a free resource is available for download through The Free Mindfulness Project at:
www.freemindfulness.org
There are selections of exercises including:

- Mindfulness of breath
- Brief mindfulness practices
- Body scan meditations
- Sitting meditations
- Mindful movement
- Guided Imagery
- Self Guided Mindfulness Exercises

The following studies can be useful to refer to for current research on Mindfulness:
1. Hölzel, BK. et al. (2011): Mindfulness practice leads to increases in regional brain gray matter density. Psychiatry Research: Neuroimaging, 191(1): 36 □43.
2. Tang, YY. et al. (2012): Mechanisms of white matter changes induced by meditation. Proceedings of the National Academy of Sciences, 109(26): 10570 □10574.
3. Lazar, S.W. et al. (2005): Meditation experience is associated with increased cortical thickness. Neuroreport, 16(17): 1893 □1897.

Dr Ira van der Steenstraten is trained as a psychiatrist, psychotherapist and family therapist at the University of Amsterdam and the Academic Medical Centre in Amsterdam, the Netherlands.
She is currently working as a Life Coach at Breeze Life Coaching in Brisbane, as well as conducting PhD research on the status of General Anxiety Disorder at the EMGO Institute and VuMedical Centre in Amsterdam.

Karen Donaldson

From a grandparent's perspective

Attending the 17th Australian and New Zealand conference on haemophilia and related bleeding disorders was great. As a grandmother I found the conference to be very informative. I have a 4 year old grandson with severe haemophilia A and seeing there is no family history I have limited knowledge about haemophilia. In fact when my daughter first told me about my grandson's condition I was in shock. At the conference, I met a range of people in the community that made me feel like I could share my experiences and to help me through the rough patches.

Overall the presentation that stood out to me was "Longer Acting Factors" presented by Dr Jamie Price, Claire McGregor and Helen and Felix from Queensland. Firstly Claire McGregor, an adult Haemophilia clinical nurse at Fiona Stanley hospital in Perth, explained the different technologies being used to extend the half life of factor VIII and factor IX. As someone who doesn't work in the medical field, Claire explained it so it was easy to understand. She talked about how the factor VIII protein could survive in the system without being broken down. The different types of technologies were pegylation, fc fusion and albumin fusion. The nitty gritty of these technologies was that the factor protein could piggy back on other proteins in order to last longer.

Ultimately it's not just how the longer acting factor concentrates work, but the effect it has on the people that use them! We heard from Felix, a young man from Queensland and his mum Helen. Felix has been on the clinical trial for a while and his perspective was that his life has changed for the better. He had 52 less needles a year due to being on the longer acting treatment. And to a boy that has a life full of school, friends, sport and other activities he found the new treatment as "life changing." Felix felt more confident when he played soccer that he had better coverage of factor VIII because it stayed in his system for a longer period.

I really appreciated being given the opportunity to attend the conference. The knowledge I gained is priceless. The next wave of treatment that may become possible for my grandson gives me assurance that his life will continue to improve.

By Marilyn McMaster

We're all in this together...

The tag line nailed it. "Facing the future together" is exactly how I felt after attending the 17th Australian and New Zealand Conference on Haemophilia and related bleeding disorders. From the first plenary "Comprehensive care: the journey" throughout each and every lecture I attended from October 1-3; the two things that stood out to me were "we are all in this together" and "let's get excited by what the future holds!" Every presenter not only communicated with intelligence and knowledge in their field but importantly with a passion that made me feel the whole reason for their being was to make my son's life easier. I felt a connection with parents and carers of people with haemophilia that went beyond words and the exchanging of "our stories." I felt like the people who attended the conference because it was their job had their heart and soul invested in this community. I felt proud (and more importantly assured) that I had a son with haemophilia and he is going to be ok.

Obviously the conference is designed to cater for a wide range of people. From those who have a bleeding disorder, their families, through to those in the medical field, those who promote and develop products and the list goes on. I am a mother to a four year old with severe haemophilia A. My son is on prophylaxis and is yet to experience a serious bleed and has not developed inhibitors. We had no known family history, and while I am a carrier of the gene, it goes no further back into our family tree. My son, Kelly, has a little brother Oscar, who doesn't have haemophilia. And as to whether Kelly and Oscar will have a little brother or sister in the future… that it still in discussion stage! My story so far dictates my path through the 17th Australian and New Zealand Conference on Haemophilia and related bleeding disorders.

The first plenary contained presentations from Dr Alison Street (The history of comprehensive care) and Leigh McJames (The role of governments) and within the first hour and half I had so much new information to process and a new perspective! Dr Street's history lesson was so interesting. She spoke about the highs and lows of comprehensive care. The thing that stands out to me is the impact of HIV/AIDS, not only on the haemophilia community but on the progress of comprehensive care. While the community stood together to fight and survive the devastation of HIV, all the headway being made in terms of comprehensive care was put on the back burner for a number of years.

Leigh McJames spoke about his role as head of AHCDO and shared a new perspective about how the role of the government works with the haemophilia community. The standout point from Mr McJames was how essential myABDR is as a tool of communication. It is from here that the stakeholders can see the actual data of how the product is used and can make sure the needs of the community are being met. I know I wasn't the only one who walked away from that thinking I had to make sure that my little corner of the haemophilia community knew how important it is to enter the data after a dose of factor!

From there, my pathway through this conference lead me to learn more about inhibitors and then on to managing pain. Again a bucket load of new information was thrown at me. Dr Lorimer Moseley's presentation alone was worth travelling to the Gold Coast for! He had a captive audience, who relished the entertainment as much as the extremely interesting perspective on what pain is. Later in the conference Dr Jamie Price and Claire McGregor succinctly explained the new world of longer acting factors. It was during their presentation that I was truly excited about my son's future!

Further into my journey I learned about "Making informed family planning decisions" which was both informative and was communicated with a sensitivity the topic warranted. Peter Field, Pauline McGrath and Robyn Shoemark delivered their presentations filled with the facts and figures of PGD (Pre-implantation Genetic Diagnosis). They also discussed the emotional costs of going through the process. Simply put, PGD is the process of finding an unaffected embryo which is then implanted. The realistic outcomes of this process were outlined, including that there is only a 40-50% success rate and that fertile women can react differently to the hormones intended for infertile women, which can impact successful implantation. Financially, PGD can leave the patient with at least $2000-3000 out of pocket expenses. Another option for carriers of a bleeding disorder gene is that of prenatal diagnosis (PND). The presenters took us through the different methods of PND, which involves diagnosing

the affected embryos after the woman has fallen pregnant naturally. However, the parents are then faced with the difficult decision of whether to terminate the pregnancy. The presenters outlined the differences between a geneticist (a doctor trained in genetics) and a genetic counsellor (a professional who communicates with families who have a family history and provides information and support around a genetic diagnosis.) We were also informed of what to expect from a visit with a genetic counsellor. Overall, these presentations were comprehensive and clear.

The presentation titled "Family Matters: Tips, Tools and Strategies to support your child" was definitely a standout for me. The presenters Sarah Elliot, Colleen McKay and Linda Dockrill were excellent communicators in the social work field. In particular Linda Dockrill's presentation will stay with me and I will need to continue to reflect on her words throughout my son's life. Her presentation "Bouncing Back: Increasing resilience in a child with a bleeding disorder" outlined practical strategies to build resilience from when our children are pre-schoolers through to teenagers. There are seven C's of Resilience:

- Competence – notice strengths, help learn from mistakes, empower, avoid sibling comparison, know factor process.
- Confidence – Focus on the best in each child, clearly express, recognise when he has done well, be authentic, do not push.
- Connection – emotional safety in the home, allow your child to express all the emotions (in family meetings for example).
- Character – accentuate the positive, demonstrate community, encourage spirituality (heart and soul).
- Contribution – see and communicate that others in the bleeding disorder global community don't have what we (Australia/NZ) have.
- Coping – Show not tell, model positive behaviours, recognise risk taking is normal.
- Control – He can make a difference and understand that his bleeding disorder doesn't define him!

These little pearls of wisdom will indeed help me and my family in the years to come. All the information, impressions, connections and experiences I gained over the three days will be invaluable to me as a mother of a child with haemophilia. When the next opportunity arises to be involved in a similar experience, I, along with my husband and sons, will be jumping in!

By Tara Horkings

HIGH TEA at *The Sullivans*

Many thanks to the Sullivan family who held a High Tea fund raiser for HFV before Christmas.

This was very generously supported by their family and friends with over $1200 being raised on the day.

The funds raised will go directly to HFV programs and member support.

A big thank you to all who supported this event!

Haemophilia Mother

I vividly remember the day my son, Bojan, was diagnosed with mild haemophilia A. I was standing in the middle of our newly rented suburban apartment in Winnipeg, just recently immigrated to Canada. My husband was on the phone asking: “Ah? Are you sure?” Pause ... sigh ... he put the phone down, sat, staring at the floor and couldn’t say a word. My world collapsed before me. As a physician I instantly knew, but still in shock, standing in the middle of the room, asking him: “Haemophilia, right?” The room became smaller and somehow air became heavier. We looked at each other totally numb and in disbelief.

All our struggles to survive the Bosnian war during the siege in Sarajevo, immigration and my recent diagnosis of a chronic condition were nothing compared to the feeling of loss after hearing our son’s diagnosis. Was it because we were both doctors unaware that he had an underlying condition, or the fact that I didn’t know I was a carrier, or that we were alone in that suburban apartment far away from our family and friends that day? I don’t know and I will never know but it hit us harder and deeper than my understanding goes. I went to my son’s room, I hugged him, I squished him tighter and longer than he wanted. He looked at me with his innocent smiling eyes. He had just turned six.

I was born and raised in Sarajevo, where my husband and I lived and worked. Bojan was born in January 1991 in a Sarajevo hospital, that same night when nurses were carefully listening to the radio when President Bush announced war against Iraq. Was there some kind of warning that one is not aware of, when your major life events collide with the brutality of world politics? I didn’t think much of it at the time! Even his big haematoma during birth didn’t raise any questions for us, nor my skin and eye bleed after I gave birth – I was so happy, I had become a mom!

At the time, I didn’t know I was a carrier. I just raised him that first year, enjoying that first spring: strolling him down the streets of Sarajevo like every other ordinary happy mom. Little did I know that real life events would unfold in front of my eyes as you watch a drama, with no option of a happy ending.

In 1992, Sarajevo was brutally attacked and we ended up being blocked in the city with a little baby. We survived, left Sarajevo and became refugees. I remember how happy I was that we had survived the siege of Sarajevo, hopeful that our lives would finally be restored and happy that we were alive and healthy. We had a big suitcase and hope for a new life in a new country. I never gave up. I thought: “We will survive all this chaos, we are lucky to be alive, we will repair, we will start life again and will continue to fight and live no matter what!”

But I wasn’t ready for this new twist of fate. When my son was diagnosed, all that pain became unbearable and it all resurfaced. Everything I knew about myself was thrown out of balance.

All these wartime memories came to haunt me … All these moments where I realized: ”Oh my God! We were in the war zone with a haemophiliac child!” What are the odds of surviving a war with a child with haemophilia? Some 10,000 civilians, including 1,500 children, were killed in Sarajevo during the 44-month-long siege, mostly by snipers and mortars fired from mountains surrounding the city. UNICEF reported that of the estimated 65,000 to 80,000 children in the city, at least 40 per cent had been directly shot at by snipers; 51 per cent had seen someone killed; 39 per cent had seen one or more family members killed; 19 per cent had witnessed a massacre; 48 per cent had their home occupied by someone else; 73 per cent had their home attacked or shelled; and 89 per cent had lived in underground shelters.

We lived in a besieged city for 31 months with a toddler, without food, electricity and under constant shelling! And we were somehow spared? Survivor guilt mixed with

haemophilia mom guilt stayed tangled in my brain for many years to haunt me more than I would ever want to admit.

From that initial shock of the diagnosis, all my experiences with haemophilia began to be blurry. We went to the hospital for the first time to meet his team of doctors, nurses and physiotherapists. We were new to the country, just here a year, and my language was just good enough to understand the diagnosis. The whole room was spinning around me while we sat in that small hospital room. I wasn't really able to think, or breathe, or understand anything that was said that day. All that I saw in that moment in front of me was nurse coordinator Nora's perfectly calm, dignified composure and her reserved smile and empathetic eyes. She went through explaining to us what we needed to know, gave us a big white binder, and assured us that we would be okay, secure and well taken care of. I went home that day in shock, confused but somehow reassured. She had said, "He is going to be okay." From that moment I hung onto that phrase often: from the time when his muscle tore during a run in middle school, his first iliopsoas bleed, a broken wrist ...

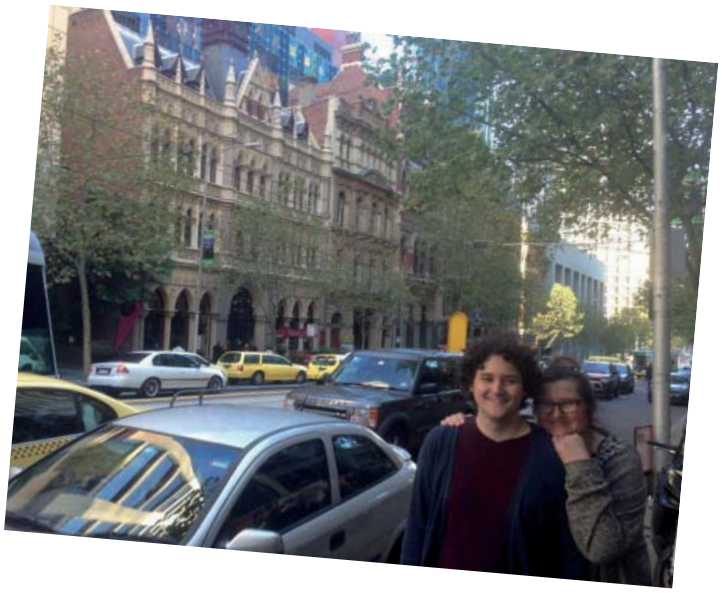
Thanks to Nora (Schwetz), who has since retired, and Rose (Jacobson) – the fantastic Winnipeg nurse duo – and the medical team, we have slowly learned over the years how to manage haemophilia, step by step. Their calm and reassuring voices were everything to me in times of crisis, when I just needed to hear that my son would be okay. There are no words to describe how I feel about the team, the same way you can't explain how secure you feel with your mother or your favourite aunt. I will never be able to express enough gratitude to the team that was caring for us 24 hours a day.

I often felt isolated raising my son. My father was across the ocean and my best friend lived in the U.S. Life was very busy, so between managing life and haemophilia there was never enough time. I was busy learning a new language, studying and working. Needless to say, the diagnosis needed a long time to sink in as well as learning to live with it. While living in a new country with new friends, far away from family, unable to find the job that I was trained to do, with all the twist and turns of haemophilia, I recognized my need to connect with a greater community – that is when "Haemophilia Mother" was born. I needed to talk to other moms and to help them overcome those first feelings of guilt so they could find support with someone who knew and could encourage them that it will get better with time.

When my son was in his 20s, in the fall of 2010, I started a Facebook page called Haemophilia Mother. Its intention was to help support all women, mothers, daughters, and carriers in the bleeding disorder community.

I feel that education, sharing information, and emotional support are all necessary to empower women such as myself, to help prevent us from feeling alone and isolated by the condition. There is that sisterhood and web of connections that is necessary for women to express themselves, to share their struggles, and their victories too. I am excited that my Haemophilia Mother Facebook page (more than 3,040 members as of today) became of interest to an international community of women with bleeding disorders who find this kind of support useful in their everyday lives and health management. Social media is a great way for mothers to feel supported within our community and I believe that advocating for better psychosocial services for women is the next step in improving the lives of women with bleeding disorders.

I clearly remember the day my son was born. I looked into his eyes, and at that moment, I knew that I would forever put myself between him and all the dangers of the world – a fire, a speeding car, a cannonball. I had become a mother. I didn't know it at the time, and I would not have dreamed that, but I was handed a greater, more honourable role – I became a Haemophilia Mother.



By Milena Pirnat

Reprinted with permission from Milena Pirnat & the Canadian Hemophilia Society

Kate Apted – New HFV committee member 2015-16

For days I have been searching for inspiration to write my introduction to you, as a new committee member of HFV. As always, the right thing popped up at the right time, and unsurprisingly, it came via haemophilia. My youngest son, Made (10), had surgery two weeks before the end of his school year and it meant he could not return to school to say bye to his peers and teacher. I collected Made's books and report on the last day of term and sitting on top of the pile were a stack of get well cards made by Made's fellow students. It struck me that 'community' was what I was seeking.

My name is Kate and I am a 42 year old single mother of two boys, Made and Sana (13). Made was diagnosed in Bali with haemophilia when he was only 7-8 months old. The prognosis for Made was dire indeed, as the island's specialist paediatrician had never known of a severe haemophiliac to live beyond 5 years old. Made's Balinese father and I could not afford the regular hospitalisations and blood transfusions he required, and we found Made would end up with bleeds from the transfusions. There was no way we could afford the antiquated factor that was available, and after the only one we purchased, we noted no difference in the severity and frequency of bleeds.

I made a heart wrenching decision to relocate back to Australia after a nightmarish genital bleed Made had at 10 months. I had to abandon all our belongings and assets to family for various reasons; not least I wanted Made to attend an Australian hospital as soon as possible and I had no time to sell our things. As soon as Made was given the clear to fly, the boys and I returned to Melbourne. My relationship with the boys' father deteriorated badly and it was decided he would stay in Bali with his family. My mother generously opened her home to us and we have lived with her since.

While Made was reading all his cards from his peers, I had a peek into a booklet Made had made about himself. One page had a heading of all the people who help Made. Other than myself, Sana and Made's very caring teacher, all the others listed are members of our bleeding community. I honestly had no idea how much haemophilia impacted Made's life, and how important Chris Barnes, Ben Inglis, Xavier Tata and Gabe Lindstrom are to him. On another page, Made listed the HFV family camp as the thing he looks forward to most in the year. The common factor in all this is 'community'.

For years, I rebelled against the idea of being part of the HFV community. I begrudgingly attended camp in 2012 for Made's sake and found that all the demons I carried were all mine. The families in attendance and the Purple Soup team made us feel like we belonged. Made blossomed during that camp, and all the others since, but it became obvious that I could not escape the reality that haemophilia was a part of our family history. How I chose to write the rest of my life was entirely up to me, and I was in no way allowing haemophilia to define us.

I have counted every single blessing since Chris Barnes and Janine Furmedge from RCH reassured me that Made would have a 'normal' life as long as he is supported by our health system. Living in Indonesia taught me that it takes a village to raise a child, and it is no less relevant in Australia. Every single one of us has helped to raise my impish young man. I am raising Made to realise that we belong to a number of communities, more often than not, populated by a silent majority who have no idea they even contribute. It is imperative we maintain, and build upon, these active, vibrant communities we find ourselves in.

This coming year sees me joining the HFV community in a more formal capacity, as a general committee member. Prior to my first meeting, I was unsure how I might contribute and handle the heavy workload, but I left the meeting feeling hopeful that HFV will grow stronger, widen its welcome, and that each of us have a unique contribution to make. It is my dearest wish that each member of our community has a list, like Made's, of people who help us, and that each of us make someone's list.

(Here is Kate challenging herself on the High Ropes at our 2015 Family Camp)

The Blood Brothers Youth Camp...

Why do we think it is so important?

Our fourth Blood Brothers Camp was held in Portsea at the end of November. We have been very fortunate to have received funding for all of our Blood Brothers Camps through Health Condition Support Grants provided by the Victorian Government and through HFA. The HCSG are no longer available and HFV is currently looking for other avenues to be able to fund this camp in the future as it has been recognised as a crucial event in the HFV calendar.

We are so lucky that the benefits of prophylactic treatment mean there is potentially much less time spent in hospital for people with haemophilia but with haemophilia being the rare disorder that is, the opportunity to meet others with the condition is limited. Andrea and I have been participating in the Multi-Disciplinary sessions that patients now attend at the RCH. Families are invited to come and meet with us during their break whilst waiting for their review. It has been interesting to learn that often these young boys have not met another person with haemophilia. They attend their appointments at the RCH but often they can be like ships in the night just passing each other in the corridors. The RCH team have given us this wonderful opportunity to potentially meet with other families, tell them a bit about HFV and help connect families and boys together. Already we have found that families are more than happy to hang around and have a chat. At our last session we had all the families who had attended appointment join us and all connected with each other and more importantly the boys connected and were off playing on the outdoor equipment – the older ones looking out for the younger ones – which was so nice to see. What this face to face interaction meant was those families are more likely to attend our camps, both family camps and youth camps for the older boys. In fact a number of boys signed up to attend the youth camp on the spot and another two families decided to attend the family camp.

At the family camp our youth play a vital role in running sessions with the younger kids. It gives them a sense of responsibility, ownership and an opportunity to connect with their peers. The younger kids enjoy the company of the youth leaders and can aspire to be like them.

The Blood Brothers camp is a different experience for youth. They have a real opportunity to connect with their peers. There is the aspect of independence being away from their parents and responsibility in managing their condition. The carefully chosen activities they complete on camp aim to improve their confidence and resilience. The boys understand that they are not the only ones experiencing a bleeding disorder and can see how the others have overcome challenges. And most importantly there is a bond between these boys that comes from the shared experiences of having haemophilia.

So, if you are at the RCH for a multidisciplinary session please come and say hi to us – hopefully we will be able to connect you up with other families who are also there. If you have not attended a family camp before please consider coming to Forest Edge in April – come for just a day if you would like to try it out and finally if you have a son or grandson with haemophilia who is aged between 12-18 please encourage them to attend a youth camp. It really does offer them another positive outlet during a time when they can become disengaged with family or school.

Julia Broadbent

MyABDR update

From the HFA and National Blood Authority MyABDR Team

WHAT'S NEW?

An update to the MyABDR web version was released in October 2015, bringing you more improvements and features including:

- Ability for users to request their own updated emergency patient card and whether they would like it sent to their Haemophilia Treatment Centre or directly to their own nominated delivery address – click on the ***Details*** button.
  Please note: all card requests will always be checked by staff at your Haemophilia Treatment Centre.

The next release is scheduled for January 2016 and will be a release specifically for the smartphone app looking at how, when and why the app syncs and doing a complete review to enhance the process of saving and updating your data.

Make sure you update your MyABDR app to take advantage of these new enhancements and fixes. These improvements are always developed in response to user feedback so please call the HELP number below to tell us about how the app works for you.

If you need some help with getting started, there is also a new quick reference guide: ***6 easy steps for recording treatment with the MyABDR app***.

Download it from the web site – www.blood.gov.au/myabdr
Or ask Suzanne at HFA to send you a copy – socallaghan@haemophilia.org.au;
ph 1800 807 173

MyABDR AT THE HFA CONFERENCE

MyABDR was the focus of the National Blood Authority booth in the exhibition at the 2015 Gold Coast Conference.

The MyABDR support team enjoyed meeting with new and existing users to fill you in on the latest developments and what is planned, get your feedback and suggestions, and to help you with any queries. If you are interested in joining the focus group all are welcome please register your interested with Suzanne at HFA.

MYABDR FOCUS GROUP

The Conference was also an opportunity to have a session with some of the MyABDR Focus Group members. Thank you to the participants who gave feedback on proposed enhancements to MyABDR and worked through ideas on future development. This was very helpful!

NEED HELP?

Don't hesitate to contact the MyABDR Support team with any queries. Meghan, Danny, Lachlan or Rebecca are always available and happy to assist you.

T: 13 000 BLOOD / 13 000 25663
E: myabdr@blood.gov.au
Available 24 hrs a day, 7 days a week.

Steven Taylor's (HFV Member) inspiring presentation on his Blood, Sweat & Gears fund raising challenge was selected for the Poster Exhibit held at the recent Gold Coast Conference

Rice University researchers solve long-standing mystery about haemophilia protein

Rice University scientists have solved a long-standing mystery about where the body stores and deploys blood-clotting factor VIII, a protein that about 80 percent of haemophiliacs cannot produce due to genetic defects.

For years, conventional medical doctrine was that factor VIII was made in the liver, but studies over the past 10 years showed it was made in endothelial cells — the cells that line the walls of blood vessels — in the liver, heart, intestines and other organs. The new study, which is available online in the journal PLOS ONE, offers the first clear images of where factor VIII is stored within those cells. Researchers found the protein is both stored and secreted from a specialized organelle inside the cells that is also known to store and deploy another important blood-clotting protein called "von Willebrand factor" or VWF.

"Great clinical advances have been made over the past 50 years in spite of our lack of understanding of where factor VIII was made and stored," said study co-author Dr. Joel Moake, a haematologist with appointments in Rice's Department of Bioengineering and Baylor College of Medicine in the Texas Medical Center. "Understanding how the body makes, stores and deploys the protein will be increasingly important in the future as physicians look to develop gene therapies that could free patients from a reliance on regular injections of factor VIII."

Haemophilia is caused by recessive genetic defects on the X chromosome, which means that men typically suffer from haemophilia, and women usually act as carriers. Haemophilia A, the more common form of the disease, accounts for about 80 percent of known cases. Haemophilia B, the less common form, is caused by defects in clotting factor IX; the disorder is widely known to have affected Queen Victoria's descendants.

Factor VIII is a prominent component of a variety of specialized proteins involved in clot regulation. Some of these signal where wounds occur, others attract clot-initiating cells called platelets and many act only to break up clots or destroy their clot-forming relatives. Factor VIII, a signaling protein, is one of several that act in concert to produce a signaling "cascade," an amplification process that allows the body to quickly transform a weak signal from a tiny cut into a blaring clarion call to rapid action.

Factor VIII was identified in the 1950s, and clinicians have used it to treat patients for decades, both by isolating it from donated blood and by producing it through biotechnology. Today, many haemophiliacs live symptom-free, thanks to regular injections of factor VIII.

The factor VIII research in Moake's lab at Rice's BioScience Research Collaborative began in early 2014 based on a hunch by lead author Nancy Turner. Turner, a research biochemist, specializes in the study of endothelial cells. Though all endothelial cells are similar, the human body makes more than a dozen varieties. Each organ has its own special types of endothelial cells, and Turner has become intimately familiar with several of them over the past 25 years.

"Endothelial cells are the gate controllers for the blood system, and to me, they make all the exciting proteins," she said. "They're right on the surface next to the blood, and they constantly interact with the plasma. Similar to circulating cells, they produce their own defensive proteins to fight infections."

Though Turner had not previously studied factor VIII, she had done extensive experiments on VWF, which is made in endothelial cells and stored in specialized organelles called "Weibel-Palade bodies." VWF and factor VIII are often bound together.

Based on her prior work, Turner was intrigued by a pair of 2014 studies that examined factor VIII in mouse endothelial cells and found that factor VIII was produced in the endothelial cells within the liver, and not in the liver cells.

"They stopped short of saying that factor VIII was stored in endothelial cells, but they suggested the possibility," she said. "One of the papers was very elegant, and I liked it a lot, but it made a statement that really bothered me."

The study explained that factor VIII had been found in a half-dozen types of endothelial cell types, but never in "human umbilical vein endothelial cells," or HUVECs (pronounced: HUE-vecks).

"HUVECs are the generic human endothelial cells that (biological researchers) use the first time they do anything," Turner said. "They're cheap. They're easy to work with, and they've been the model for endothelial cells for, I don't know, at least 50 years.

"So far, everything I've ever looked at in endothelial cells has been consistent. The different types might have different amounts of something, but they're very similar. There hasn't been anything that was wholly different from one type to another. Not yet.

"So I thought, 'OK, fine. I'm already doing gene-expression experiments, I might as well just throw factor VIII in there and see."

The experiments she was conducting involved both HUVECs, the type of endothelial cell found in large veins, and "glomerular microvascular endothelial cells," or GMVECs (pronounced: JIM-vecks), which are found in the smallest capillaries of the kidney. Turner was conducting an extensive analysis to see how protein production differed in the two varieties.

She told Moake she wanted to include the factor VIII

gene in their current study, and he was both cautious and encouraging because many other researchers had tried for decades and had not found factor VIII in HUVECs. He also believed that Turner was clever enough to succeed where others had failed.

Turner examined the cells for factor VIII messenger RNA and found that it was present, which meant it was possible that the cells were making the protein. She next ordered a specific antibody that was designed to detect factor VIII. The antibody contained a fluorescent dye that would show up clearly under a microscope if the antibody detected any factor VIII.

"I did the experiment and looked, and not only was it there, but it was bright, easy to see, and it worked perfectly the first time," Turner said. "I thought, 'What have people been doing for 20 or 30 years? Why couldn't they see this?' And then I thought, 'This was too easy. No one is going to believe me.'"

In fact, the early success was so unexpected that Turner at first doubted herself and immediately set about running controls to rule out mistakes. Were the antibodies interfering with one another? Was there any contamination? Was the microscope working correctly? Could the reading be a false positive, an inadvertent result of another reaction she hadn't expected?

"No. 1, I had to convince myself," she said. "I am always skeptical if something is too easy. I have reviewed many, many papers, and I can always find what people do wrong."

Once she had convinced herself, she and Moake had to convince the paper's referees. As she'd expected, they were skeptical. She said the bulk of the work over the past year involved doing a number of controls to remove any doubts about the findings. In the end, the research confirmed that factor VIII was made in both HUVECs and GMVECs. Moreover, Turner found that factor VIII, like VWF, is both stored and secreted from Weibel-Palade bodies.

Moake said the discovery has clear implications for any future treatments that aim to repair the genetic defects in patients with haemophilia A.

"Now that we recognize that factor VIII is normally synthesized in endothelial cells and stored in Weibel-Palade bodies, those become the precise, most effective physiological targets for gene delivery," Moake said.

The research was supported by the Mary Rodes Gibson Foundation, the Hinkson Memorial Fund and Rice University

RICE Press Release
Jade Boyd

See more at: http://news.rice.edu/2015/11/02/study-blood-vessels-store-secrete-key-blood-clotting-protein-2/#sthash.bNDtQJax.dpuf

GRANDPARENTS & FRIEND'S LUNCH

BRANDON HOTEL CARLTON NORTH

SUN 17TH APRIL

Welcome to all the grandparents. We hope you all had a wonderful Christmas and New Year with your family we are looking forward to a positive 2016 starting off with a lunch to be held on Sunday 17th April at Brandon Hotel, Carlton North. It will be great to connect with all the grandparents and share the company, stories and experiences, so come along and enjoy the day. Lunch is provided by HFV.

Later in the year we hope to have a film and lunch day at the Palais Cinema in Whitehorse Road, Balwyn – the tram stops outside the cinema door. It will be a fun day with a natter about the film during lunch. The total cost for the film and lunch will be$15-$20pp. More information will be in the next HFV magazine.

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.

We look forward seeing you and meeting 'new grandparents' at either event.

Bookings are essential through the HFV office on 03 9555 7595 or info@hfv.org.au

Jackie Touzeau & Marie Ramage

DRUGS AND ALCOHOL

Drugs and alcohol affect the body in a variety of ways. Taking drugs and drinking alcohol at a young age can be harmful to your health, and often times are more dangerous for children and teens with bleeding disorders.

Drugs and alcohol can impair your judgment and coordination, blur vision, and slow reaction time. Moreover, if you do get hurt, you're less able to help yourself.

- You may have difficulty seeking medical attention. You may not remember who to call or your list of important phone numbers. You may not be able to explain your condition to others or to medical personnel. If they don't know you have a bleeding problem, they won't know how to take care of you properly.
- Imagine how difficult it would be to self-infuse when you're less coordinated and your reflexes are slow. Ouch!
- Alcohol is a diuretic, which means it causes the body to lose water. This can lead to dehydration, which means your body looses too much fluid, mainly water. Being dehydrated makes finding a vein a chore and a real pain. Double ouch!

There are the obvious dangers when using illegal drugs and drinking too much alcohol. These can include injury, either from loss of balance or consciousness.

- Being drunk or high can weaken inhibitions and judgment and can lead to risky behaviour like fighting and dangerous stunts.
- Drinking and driving is a crime and is very dangerous. You could end up in a car accident, which could greatly increase your risk of injury and severe bleeding.

Similar to aspirin, even drinking a small amount of alcohol can affect blood clotting, taking on the role of a blood thinner.

- If you have a bleeding disorder, drinking alcohol worsens the body's ability to form clots and stop bleeding.
- Interactions between drugs, including bleeding disorder medications, may be unknown and could be harmful and even life threatening.

Reprinted with permission from National Hemophilia Foundation (USA) and Steps for Living

HAEMOPHILIA ...ROAD TRIP

Hello there. My name is Matt Powell and I am Peer Support Worker at Straight Arrows, a government funded Service that provides support for people living with HIV who identify as straight/heterosexual.

I am also a haemophiliac who contracted HIV in childhood as many others did. It was a very hard road to travel (haemophilia is hard enough thank you very much) and many who shared this experience are unfortunately no longer with us.

But for those of us who have survived, we can look back on a life that has thrown up some huge challenges. Wouldn't it be great if all of the guys who have shared this experience could get together and get to know each other? We all have something in common that is very unique.

So here's the idea –
Working with HFV, Alex at Haemophilia Treatment as well as Straight Arrows , I want to organise a very special kind of retreat, and there is an open invitation for anyone in Victoria who is living with both haemophilia and HIV.
We are looking to have a road trip via private bus arriving at a retreat for the weekend. The route we take and the places we stay will be planned by myself at Straight Arrows, in conjunction with any of the guys who want to attend and give input. We would start in the city but then drive through Victoria for a couple of days, picking up guys at various rural locations.

I want to get the word out to all of the guys. Through Alex at the HTC I know the number of haemophiliacs living with HIV. However, confidentiality concerns mean that I cannot contact people directly and I don't not know their identities. I will be sending a letter out to everyone, but will rely on anyone interested to contact me through Straight Arrows.

If this is relevant to you, please contact me at Straight Arrows:

Email – peersupport@straightarrows.org
Straight Arrows 9863 9414
Phone (text only) 0491 153 969

Please note that I work casual hours and as such it can be difficult to get me on the phone. Email or text your interest and your contact details. I will get back to you ASAP

NEW HEP C DRUGS TO GO ON PBS
Update from HFA

It was a very welcome Christmas message for our community: on 22 December 2015 Australian Minister for Health Sussan Ley announced that new breakthrough hepatitis C treatments will be available on the PBS from 1 March 2016.

These medicines are:

- sofosbuvir with ledipasvir (Harvoni®)
- sofosbuvir (Sovaldi®)
- daclatasvir (Daklinza®)
- ribavirin (Ibavyr®).

“This is fantastic news for people with bleeding disorders and hepatitis C,” said Gavin Finkelstein, President of Haemophilia Foundation Australia. “They have been waiting so long for access to treatment to cure their hepatitis C. Many have seen their liver disease progressing and were despairing. This decision by the Government will change people’s lives and we would like to congratulate Minister Ley for seeing the process through to make these treatments available and affordable to all Australians with hepatitis C.”

Most of these treatments can be taken orally, with the most common course of treatment being as short as 12 weeks.

“This combination of breakthrough cures has a success rate of more than 90 per cent across the entire hep C patient population and is faster and has fewer side effects than anything currently available,” said Minister Ley.

Listing the new medicines on the PBS will mean that people with hepatitis C will only pay the normal PBS co-payment for these treatments: currently $6.10 for concessional patients and $37.70 for general patients each time the medicines are dispensed by the pharmacy.

“HFA will continue to work with expert health professionals and health services to make sure that people with bleeding disorders can access treatment when needed in a timely manner,” noted Gavin Finkelstein. “For our community members, the message about being proactive with your hepatitis C care is even more important now: look after your liver health, make sure you have had your liver health checked and talk to your hepatitis C clinic about your treatment options.”

Read Minister Ley’s Press Release – http://tinyurl.com/hepctreatments-dec15

AND IF YOU HAVE HEP C?

In the meantime, if you have hepatitis C and a bleeding disorder, remember that you would need to have your liver health assessed before you could be considered for treatment – don’t wait; if you haven’t already, make your appointment now!

- Make sure you have your liver health checked regularly
- If you don’t know where to start, ask your Haemophilia Centre for a referral
- Stay in touch with your hepatitis clinic about what’s new
- Don’t forget to go to your appointment with the hepatitis clinic after your liver health check, even if the fibroscan shows your liver health is stable at the moment
- And for comprehensive care, let your Haemophilia Centre know about your liver test results or how your treatment is going to make sure they stay in the loop

our community

The Royal Children's Hospital Melbourne

HAEMOPHILIA FOUNDATION VICTORIA

2016 Royal Children's Hospital HAEMOPHILIA TEACHER'S SEMINAR

TEACHERS - you are invited to attend the 13th Haemophilia Teacher's Seminar presented by the Haemophilia Treatment Centre Team at the RCH. Supported by Haemophilia Foundation Victoria.

When: 9am to 12.30pm on Friday 19th February 2016
Where: Royal Children's Hospital Foundation, Family Resource Centre, Level 2, 48 Flemington Road PARKVILLE

BOOKINGS ESSENTIAL THROUGH HFV ON 9555 7595

THANK YOU

There are many people who assist HFV throughout the year in various ways. From our committee members and our peer support group facilitators who give up their valuable time - and their families who support them in their roles to our members who donate raffle prizes year after year like the O'Neill family, the King family and the Thorp family.

We have members who organise fund raising activities year after year such as the Grant family who held a Christmas Breakfast at the end of 2015 and supported by their friends and extended family raised significant funds for HFV programs.

Many families get involved in Haemophilia Awareness Week year after year including the Grechs, the Sullivans and the Fields to name but a few.

Thank you to our members who add a donation to their membership subs - small or large it all helps to run our programs.

And a very big thank you to the extended family members, friends and local communities of our members who continue to support HFV year in and year out by attending these events, donating supplies or donating raffle prizes. It all makes a huge difference in enabling us to support our comminty.

CHANGES TO THE HFV MAGAZINE "THE MISSING FACTOR' PUBLICATION TIMES

Please note our HFV magazine will change to seasonal publication times as of the next edition. This means the magazine will be received by members in early:

- June
- September
- December
- March

HAEMOPHILIA 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

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 |Senior Clinical Pyschologist

HFV MEMBER SERVICES

Membership Fees:

Standard family membership	$33.00
Concession member	$16.50
Allied Member	$16.50
Organisational member	$55.00

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

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

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

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

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 new HFV website is now online. It provides information, details of upcoming events and more. The site is updated weekly.

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

HFV Remembrance Service & Family Christmas Picnic

On the morning of our Remembrance Service we found ourselves in the most beautiful private setting tucked away in a secluded part of the Botanic Gardens. With the sun shining and a water feature nestled amongst the palm trees, it was the perfect setting for this occasion.

The service was led by Neil Boal who took the time to remember those we have lost in our community and to acknowledge our history. Readings were given by Ben Inglis and Scott McDonnell and attendees were invited to light remembrance candles.

The service was followed by our Family Christmas Picnic. As always it was a lovely opportunity for members to connect in a relaxed atmosphere.

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

For all men with bleeding disorders aged 25+

HFV

MEN'S RETREAT

4-6 MARCH

2016

Haemophilia Foundation Victoria Inc

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

State Government Victoria

Haemophilia Foundation Victoria Inc acknowledges the support of the Victorian Government.

Registered No: A0011460L