

# National



# Haemophilia

Haemophilia Foundation Australia

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

No. 192, December 2015



## FACING THE FUTURE TOGETHER 2015 CONFERENCE



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## RED CAKE DAY DURING HAEMOPHILIA AWARENESS WEEK

Haemophilia Awareness Week and Red Cake Day were held this year from 11 to 17 October 2015. Haemophilia Foundation Australia and Haemophilia Foundations around the country worked together to raise awareness about inherited bleeding disorders.

There was great interest in the week and we had many supporters to help us fundraise and raise awareness over the week. Red Cake Day was a hit again this year, and proved to be a versatile concept for individuals and organisations along with schools and companies that wanted to do something practical while highlighting the needs of people with bleeding disorders.

The Bendigo Bank branches across Australia joined in partnership to raise awareness and funds, and 100 schools, hospitals, libraries, families and local communities around the country received promotional materials to help them run their own Red Cake Days and Haemophilia Awareness Week activities. They held different types of events, but they all worked together with us to raise awareness about bleeding disorders or host a Red Cake Day. We are grateful for the support and uptake of this exciting event which we hope is becoming a regular feature on everyone's calendar.

### PAINT THE TOWN RED

Neerim South & Bendigo Bank Branches, South Gippsland Region

Now in its seventh year, the township of Neerim South in Victoria once again hosted 'Paint the town Red'. The event is organised by Donna Field and a wonderful team at the Neerim District Community Bank®. We are grateful to the staff at Bendigo Bank Branches who also displayed posters and promotional items to raise awareness about bleeding disorders and helped to raise funds. ❧







## THE RED TRAIL

In its second year, the RED Trail was a 7km walk in Sydney organized by Lyn and her son Jayden. Jayden is 11 years old with haemophilia and together with his family

and friends walks in support of people with bleeding disorders. Around \$10,000 was raised for HFNSW. Thank you to Lyn and Jayden.

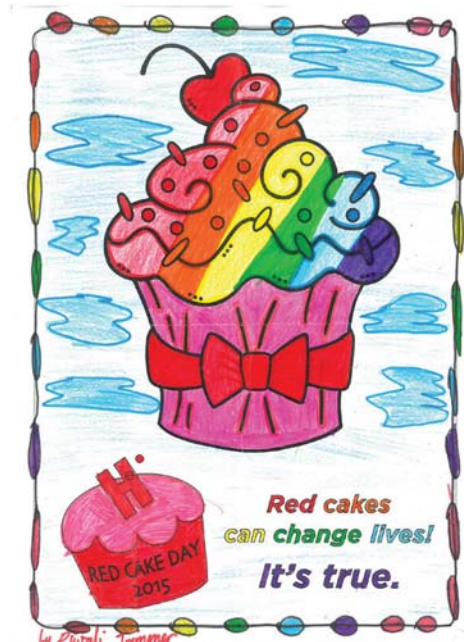
# COLOURING IN COMPETITION

CONGRATULATIONS TO THE WINNERS:

4 and under – Harper, Rozelle, NSW

5-8 years – Kelton, Nayook, VIC

9-11 years – Diwali, Wesburn, VIC





# THANK YOU NEWSLETTER

A newsletter highlighting all the events held during Haemophilia Awareness Week will be distributed to participants soon and will be available on the HFA web site. If you wish to receive a copy please email Natasha at [ncoco@haemophilia.org.au](mailto:ncoco@haemophilia.org.au)

Thank you to everyone who participated in Haemophilia Awareness Week and Red Cake Day activities!

## RED CAKE DAY AROUND AUSTRALIA







# 2015 GOLD COAST CONFERENCE

17<sup>TH</sup> Australian & New Zealand Conference  
on haemophilia & related bleeding disorders



1 – 3 OCTOBER 2015 • GOLD COAST



The 17th Australian & New Zealand Conference on haemophilia and related bleeding disorders was a great success. It was attended by 225 delegates, including people with bleeding disorders, their families and carers, health professionals, policy makers, industry representatives and many other stakeholders who came together to meet, share information and learn from each other.

The diverse program was developed by a multidisciplinary committee chaired by Dr Simon McRae, and covered a range of interesting and challenging topics. We thank all the speakers and session chairs who contributed to our meeting.

## CATCH UP ON THE PRESENTATIONS

Presentations and the abstract book are available to download from our website [www.haemophilia.org.au/conferences](http://www.haemophilia.org.au/conferences)

## CONFERENCE SPONSORS

Thank you to our conference sponsors and supporters.

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### Bronze Sponsors

National Blood Authority, Australia  
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## WHAT DID THE DELEGATES SAY?

"It had the right amount of information for both myself and my girlfriend that didn't know about haemophilia and now know a little more than before. I thank you for that."

"Loved the mix of specialist/carer/personal experience in each session"

"It has made me want to work harder in this therapeutic area."

"A broad range of topics for both health professionals and families."

"Good for networking."

"So glad we got to come. It was also a good way for us to touch base with other families in similar situations which doesn't happen a lot for us and we get a lot out of that."

"It has given me hope that our boys may have the chance to use a longer acting factor in the future and that this will hopefully see even further improvements in the quality of their lives and our lives as carers."

"Broader appreciation of haemophilia from medical and family perspective. Very positive for the future with ongoing improvements in management etc."





# FROM THE PRESIDENT

*Gavin Finkelstein*

## 2015 CONFERENCE

We had an excellent Conference on the Gold Coast. As we were competing with public and school holidays, the AFL Grand Final and other events, as well as the potential for a post 2014 World Congress anticlimax, we felt our numbers held up well. The program session topics were vibrant and inclusive of all interests, relevant and current. I sincerely thank the multidisciplinary program committee members and HFA staff who worked hard to make the Conference a success. For those who were unable to attend, we are pleased to be able to provide summaries and key learning points from some of the Conference sessions in this edition of National Haemophilia. Many of the presentations will also be posted on the HFA website in upcoming weeks.

The vibe at the hotel lent itself to a good conference. It was great to catch up with everyone and it had a real fun and relaxed feel without even leaving the hotel. It was a bit of fresh air, engaging and enjoyable. Congratulations to everyone involved. A conference like this helps to reinvigorate everyone attending and revitalise their interest.



Conference Delegates catching up over lunch

It was also important to see that women's issues have come to the forefront. It was a great opportunity to discuss the real issues for women and see bleeding issues in the context of their lives.

## HFA COUNCIL

The conference was followed by our annual Council meeting and Annual General Meeting - our first since the constitution changes in 2014. These changes had been aimed at encouraging stronger local member organisation participation. I think we achieved that for the first meeting, and we are off to a good start. It was great to have most State/Territory Foundation Presidents, former Delegates and other local representatives around the table. This led to robust discussion and I think it augurs well for a strong and

purposeful future for HFA. I welcome David Fagan as HFA's new Treasurer. He follows Ann Roberts who has served HFA in various office bearer roles over the years. Ann's dedicated service to HFA was recognised at the Conference Dinner when Life Governorship was presented to her. I am pleased to continue for another term as HFA President, with Dan Credazzi as our Vice President.

## MYABDR

A common concern of Council members following the Conference was how people with bleeding disorders can proactively work with their treating health professionals to improve their care and treatment and strengthen government engagement at all levels to support best practice. An important outcome of these discussions was that local foundations will work with HFA to encourage our membership to use MyABDR, and to make sure people record their clotting factor use so that it becomes a regular part of clinic reviews and individual care plans. Monitoring our bleeds is critical to understanding how treatment will work best for us, and how we can get the best out of our treatments, and improve our quality of life. In turn, it makes sense that a clearer understanding of our bleeding patterns helps us to dose at the appropriate times. Most importantly, we need to record our clotting factor use and bleeds, where we have them, so this can be understood and so we get the best treatment advice.

## COMPREHENSIVE CARE

Right from the first Conference session when Prof Alison Street presented on the history and development of haemophilia care we could relate to the progress that has been made with comprehensive care – life without treatment and how things have changed. The importance of comprehensive care was echoed throughout the Conference, yet in a country like ours, where huge amounts of taxpayers' funds are spent on clotting factor, there is a disproportional under-commitment to comprehensive care.



Alison Street presenting on comprehensive care

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Patient responsibility for engaging with comprehensive care and MyABDR were prominent in some conference sessions. With free clotting factor treatment and comprehensive care, the patient also has a responsibility to contribute to their own care. It's their part in helping the treating team to manage their condition in the best way possible by providing the information that the team needs. Recording with MyABDR is an important part of the clinical process. You may not realise you are getting a target joint unless you are recording bleeds and your product treatment usage, and if you do record, the clinical team will be able to review this with you and develop a management plan. There is a gap if this isn't recorded. But getting involved in your own care is to your own benefit and will only help with your treatment regimen.

Please speak to your treatment centre staff if you are not yet using MyABDR, as this is a critical part of managing our overall care and treatment. The Council is committed to this tool, as we see it is a very important way of ensuring governments understand our treatment needs, and make appropriate budget provision for supply plans. During the Conference you will have become aware of the gaps in services at some Haemophilia Centres. If only we could see some of the savings made on clotting factor tenders being redirected into comprehensive care, especially where services do not exist or are inadequate. Our federation and health funding models makes it difficult, but we must surely impact positively on health outcomes, and budgets if all parts of the jigsaw are put together. This investment in the future is important and will ultimately reduce healthcare costs. We eagerly await the publication of the new treatment guidelines for Australia, and hope this will have a positive impact on men and women with bleeding disorders in Australia, and lead to a body of evidence that supports this.

### HFA FUNDING

At the time of writing HFA is anxiously awaiting the outcome of a major grant application to the federal government for funding for our national secretariat. Without this grant HFA would not be able to represent the bleeding disorders community as we do, and we remain optimistic that our past performance as a national peak body will be recognised and funded

### FUTURE DIRECTIONS

The conference gave our youth a chance to meet up again, following their meetings at the 2014 Congress and some of the training opportunities they have had. I really enjoy the engagement with youth. The Conference brings them together every couple of years; they get to know each other, they discuss their issues, they build themselves a network. This has far reaching implications both for them and for the future for our haemophilia foundations.

It is exciting to see advances in treatment. Longer acting factors will make a huge difference for some people. Many are already seeing the impact of less infusions through their participation in clinical trials. But I do not believe longer acting factors are the be all and end all of everything for all people with haemophilia. For young families and younger people this could be life-changing; older people who are used to their treatment regimens might be more focused on different aspects of treatment. However, they should be available as a part of a suite of products. Nevertheless, we still see an oral pill or gene therapy as part of the holy grail. And of course what is critical is that we have products which do not increase the risk of inhibitors.

Our priorities are all about having a healthy population that live a full and normal life and contribute to society. It's looking good for the future in terms of clotting factor treatments.

### HEPATITIS C

But I remained concerned about the delays for most people with bleeding disorders to access new hepatitis C treatments. Every day now the Foundation is hearing about the new hepatitis C treatments which are having remarkable outcomes with so few side-effects. They are not yet available in Australia except through clinical trials or very limited compassionate access. People in our community who have been able to access these treatments are seeing their lives turn around. However, at the Conference I heard of so many community members who are falling through the cracks of clinical trials and compassionate access - and that more community members are finding that they have cirrhosis. If you develop cirrhosis, even if you have successful treatment, you will need to be monitored for liver cancer for the rest of your life.

We are excited by the new treatments and people are more prepared to take on treatment. They are also getting older, which is a risk factor for disease progression; they need to be treated now. I am sure it is better for the government to invest in treating people with bleeding disorders now and to save money on more complex care in the future.

### There are some key messages for community members about hepatitis C.

If you have hepatitis C, you need to be proactive, show that you will be prepared to do whatever is required to undergo treatment, and show that you will take care of yourself in the interim. Don't give up at this point; holistic care is really important. Go to clinics, get your liver health checked, manage your lifestyle, make sure you get in the system, and that way you are best placed for treatment when it becomes available. ■



# 2015 HFA AWARDS

*Sharon Caris*

It was a great pleasure to welcome Jennifer Ross AO to the 2015 Conference dinner to present some awards that carry her name.

Jenny was the founding Executive Director of Haemophilia Foundation Australia (HFA), and is well known for the work she did to establish HFA and more importantly for her work to improve treatment and care for people with haemophilia. She led and supported the community through the terrible pain and sadness after the shock that HIV had impacted the bleeding disorders community so greatly, and worked hard to establish HFA as a strong organisation that could advocate for its needs and educate the community and other stakeholders.

## JENNIFER ROSS AWARDS

The Jennifer Ross Awards are given by the HFA Council in recognition of outstanding or significant contribution towards the work of Haemophilia Foundations and/or Haemophilia Centres which is beyond the normal expectation of the person's professional role or for special service to people with bleeding disorders and their families.

It was fitting that The Jennifer Ross Award could be presented by Jenny and the HFA President, Gavin Finkelstein at the Conference Dinner to the following counsellors for their service:

**Maureen Spilsbury**, counsellor at the Royal Brisbane & Women's Hospital and Queensland Haemophilia Centre for service to the bleeding disorders community in Queensland and leadership as chair of the Australia/New Zealand Haemophilia Social Workers' and Counsellors' Group and contribution to HFA services and education programs over many years.

**Leonie Mudge**, counsellor at the Royal Prince Alfred Hospital, Sydney, NSW, for her service as a counsellor to

the bleeding disorders community in Victoria and NSW, leadership of the Australia/New Zealand Haemophilia Social Workers' and Counsellors' Group and contribution to HFA services and education programs.

**Clare Reeves**, counsellor at HFACT, for service to the bleeding disorders community in ACT.

**Sharon Hawkins**, who left her position earlier in the year, was also given a Jennifer Ross Award for service as a counsellor to the bleeding disorders community in Western Australia, leadership of the Australia/New Zealand Haemophilia Social Workers' and Counsellors' Group, contribution to HFA services and education programs over many years as well as representing HFA as co-chair of the WFH 2014 World Congress Psychosocial Program Committee. Sharon's award will be presented to her in Perth soon.

## HFA VOLUNTEER AWARD

**Ron Lees** from the ACT was presented with the HFA Volunteer Award for his tireless service to the ACT bleeding disorders community over many years.

## LIFE GOVERNORSHIP

Gavin Finkelstein and Jenny Ross presented HFA Life Governorship to **Ann Roberts** for her dedicated leadership to the HFA Council as President, Vice President or Treasurer over many years and her long term commitment to HFA's goals and objectives.

Ann's HFA Council colleagues acknowledged her enormous contribution when she completed her final term as the Delegate for Haemophilia Foundation Victoria (HFV) after the 2015 HFA Annual General Meeting. Ann handed her role as HFV Delegate over to Leonie Demos, President of HFV. ■

Ann Roberts receiving her Life Governorship from Jenny Ross and Gavin Finkelstein



# A NURSING PERSPECTIVE

Robyn Shoemark

When I reflected on my time at the Conference I realised what a great relationship there is within the bleeding disorder community, health care professionals and the pharmaceutical companies. The Conference theme of *Facing the Future Together* was evident for those attending.

For all of the health professionals, things kicked off on Thursday with their annual face to face meetings. The Australian Haemophilia Nurses Group (AHNG) met for their yearly meeting with elections of the new Co-Chairs, Penny McCarthy and Anne Jackson, followed by updating terms of reference, completing the yearly objectives report and discussions with the National Blood Authority and HFA.

The Australian Haemophilia Nurses Group 2015



With an early start on Friday morning, breakfast meetings for some, the Conference was officially opened by Gavin Finkelstein, HFA President.

## Von Willebrand disease

*Chair: Dr Catherine Harris*

*Personal Stories: Bobby, ACT; Sally, NSW*

*Diagnosis and testing - Dr Ritam Prasad*

*Treatment and Management - Dr Susan Russell*

For many, von Willebrand disease (VWD) is often seen as the little cousin in the bleeding world of haemophilia, sometimes misdiagnosed or only seen as a mild bleeding disorder. This session informed the delegates about the diagnosis, testing, treatment and management and what it is like to have or live with VWD in the family.

The session opened with Bobby sharing her life story. In a wonderfully animated presentation, Bobby walked us through her life with VWD. From the agonising teenage years through to her life today, Bobby has had many obstacles and managed to overcome them all. She talked about the trials of menstruation, wisdom teeth extractions and about her journey to wanting to start her own family.

Through all of that came her ‘wonder drugs’, as she called them, that helped her manage her bleeding symptoms to become the woman she is today.

Next, Sally, who is the mother of a young daughter with Type 3 VWD, shared her story with us. She told it from her perspective: what it was like to have the diagnosis for her daughter and what this meant for them as a family. Her daughter is now in the process of learning self-infusion and starting her own journey with VWD.

In the rest of the session Ritam Prasad covered diagnosis and testing, which helped us all to understand the science and numbers behind the scenes, and Susan Russell spoke about treatment and management.

## Making informed family planning decisions

*Chair: Dr Susan Russell*

*Prenatal/PGD testing - Peter Field*

*A journey through genetic counselling and prenatal diagnosis - Pauline McGrath*

*Role of Haemophilia Centres in genetic counselling - Robyn Shoemark*

The Saturday morning plenary was all about making informed family planning decisions.

This session covered prenatal/pre-implantation genetic diagnosis (PGD) testing and Peter Field gave a great overview about the methods and costs of a PGD cycle. Pauline McGrath followed with a journey through genetic counselling and prenatal diagnosis. As a counsellor she talked about how everyone has a different path to take and informed us of the options available for family planning.

I then presented from a nurse’s perspective. As the first point of call for most patients and their families, we are often asked what is available, who should we talk to, what are our options, when should we test our girls? Nurses are usually the ones taking the bloods for genetics so this is when we need to think about what our answers will be when we are asked the many questions that patients and families have. We need to be informed so that we can pass on that information correctly. There are many things that need to be considered such as consent, when we test, how we inform results, how we coordinate testing of sisters and other extended family members. Girls, whether they are known or suspected carriers, should all have their factor levels checked and then have further testing when they reach the age of consent to determine carrier status. It is always better to know if you are a carrier before starting a family or falling pregnant. Ultimately, everyone needs to be informed and education should be an ongoing process where the individual/family is involved at every step.

All in all it was a great conference and for many has changed our ideas of what is in the future for both people with haemophilia and health care workers. Many thanks go to the organisers, the presenters, and everyone who attended and made the meeting what it was.

See you in 2017 for the next conference. ■



# THE PHYSIOTHERAPY PERSPECTIVE

Cameron Cramey

## The history of comprehensive care

- Dr Alison Street

The Conference opened with a fantastic overview of the history of comprehensive care from Alison Street. We learnt about the initial development of cryoprecipitate, the early models of comprehensive care in Los Angeles and Oxford in the early 1960s and the emergence of similar models in Australia during the early 1970s. She described the impact of the HIV and hepatitis C epidemics of the late 1970s/early 80s and the impact this had on patients, their families, and treatment centre service provision. With development of virally inactivated plasma derived and then recombinant products through the 1990s the concept of comprehensive care was again back on the radar. This has led us to where we are today – comprehensive care is more than just patient and product. Our current system is perhaps too factor focussed; funding needs to better reflect staffing required to provide optimal long term patient outcomes through active engagement with their medical and allied health team.

## Mild haemophilia

Chair: Penny McCarthy

Mild haemophilia across the life span - Penny McCarthy

Mild haemophilia in children - Dr Jamie Price

Personal story - Nathan, SA

Inhibitors, treatment in adults and genetic testing - Dr Simon McRae

People with mild haemophilia have bleeding issues too! I think this was one of the most important take home points from the session on mild haemophilia and inhibitors. It is important that people with mild haemophilia understand their condition and know how to identify and manage a bleed – it only takes a single bleed episode not managed correctly to cause long term issues. Without the experience of managing previous bleeds it's important to understand that sometimes you may not be able to return to your chosen pursuits as rapidly as you would like. Make sure you seek advice from your treatment centre. We also learnt about the risk of developing inhibitors, how your haematologist may be able to perform genetic testing to better define this risk, and the effect an inhibitor can have on your bleeding phenotype. The effect of this was brilliantly highlighted by an entertaining and informative talk from Nathan. He described his experience of a delayed haemophilia diagnosis and subsequent challenges he faced when he developed an inhibitor which resulted in conversion of his mild haemophilia to a severe bleeding phenotype.



Lorimer Moseley explaining 'danger' brain messages

## Improving outlooks for pain in haemophilia

Chair: Abi Polus

Humans: The best protectors yet - Prof Lorimer Moseley

Managing pain in haemophilia - A/Prof Carolyn Arnold

This informative session got us thinking up what 'pain' really is and its prevalence within the bleeding disorders community. We learnt that up to 50% of people with haemophilia suffer from chronic pain and it's more common amongst those with severe haemophilia or a lack of access to effective factor replacement. Joint haemarthrosis and synovitis are a significant cause of much of the ongoing pain, so utilisation of a multi-faceted management approach (rheumatology, orthopaedics, pain physician, appropriate physical activity and exercise prescription, and pain education) is recommended to optimise management of this pain. Lorimer Moseley provided an overview of current pain science understanding. He discussed the concepts of 'danger' messages rather than pain being sent from the tissues; and provided multiple examples of how the brain interprets these 'danger' messages differently depending on environment, context, mood and a host of other variables. He discussed the concept of 'helpful protection' and 'unhelpful protection' and how the latter tends to be present in chronic pain. We learnt that by better understanding this process we can get improved control over chronic pain.

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## Being active for children, teenagers and young adults

Chair: Wendy Poulsen

Purpose of prophylaxis treating after injury - Dr Chris Barnes

Adventure therapy success in supporting people living with a bleeding disorder - Tim Marchinton

Personal experience - Ben, VIC

Gym training – What are the right exercises for me? - Cameron Cramey

Personal experience - Ty, SA

There's more to being active than simply playing sport! During this session we heard from a couple of clinicians about the benefits of exercise and physical activity for our general wellbeing and joint health. The pros and cons of weight training were discussed and the importance of having a supervised programme when embarking on a new exercise regime. Appropriate timing of factor therapy for people participating in sporting pursuits was also discussed. However maintaining an active lifestyle can be challenging at times for people with a bleeding disorder, and more importantly than reduced physical capacity, this can lead to reduced self-esteem and social isolation. Tim Marchinton spoke about the role of Adventure Therapy and the psychosocial, emotional and physical benefits for people with bleeding disorders and their families seen through these programs. Ben and Ty both spoke brilliantly about their personal experiences and challenges they faced in balancing their bleeding disorder, physical activity and social pressures.

## Getting Older

Chair: Leonie Mudge

Clinical issues - Dr John Rowell

GPs and Men's Health Checks - Olivia Hollingdrake

Personal experience - Mike, QLD

Falls prevention/keeping mobile - Rebecca Dalzell

With the near normal life expectancy for men with haemophilia, this was a fantastic session with great suggestions for how to optimise health as people age. John Rowell discussed some of the complex medical issues associated with ageing and Olivia Hollingdrake presented a study that she had done at the Queensland Haemophilia Centre, with Beryl Zeissink. This study looked at the amount of knowledge that men with bleeding disorders have about standard recommended men's health checks, and if they are accessing their local GP to get these done. Results indicated that there was a moderate level of awareness; however there are several tests that people were unaware of. Regular GP contact check-ups were recommended.

Mike from Brisbane gave an inspiring presentation, sharing his personal experience. He encouraged all those who attended to not fear growing older, but to face it with a positive, proactive approach. Rebecca Dalzell was the last presenter and gave an overview of the physical challenges that ageing presents. She discussed joint and muscle changes, osteoporosis, balance and falls prevention. She also presented some results, and a film, from a program she ran in Brisbane called 'Strong Bloody Men'. This was a 10 week wellness/exercise program, based in the community, specifically designed to address osteoporosis, balance and falls prevention in the haemophilia population. Results showed improvement over the 10 weeks in falls risk, balance and function, and the men reported many positive health benefits. She challenged all those present to consider a bigger picture, more preventative approach to managing those in the more mature years, rather than just focusing on acute issues.

I would like to thank everyone at HFA and the many other people involved in putting together such a high quality conference in what was a lovely venue. 🍷

The panel discussion about pain





# THE PSYCHOSOCIAL PERSPECTIVE

## Genetic Counselling Services Workshop

Chairs: Maureen Spilsbury, Dr Desdemona Chong

### Mona Chong

Dr Desdemona Chong is Clinical Psychologist with the Queensland Haemophilia Centre, Royal Brisbane & Women's Hospital.

This workshop provided a safe and confidential platform for women from the bleeding disorders community to share their experiences as young mothers, mothers/aunts of adult sons with haemophilia, and women carriers who are considering children. There has been an unmet need for this segment of the community to express their needs and concerns and find mutual support in their common carrier status experience. Women in this group have been underrepresented in programs and resources. They deserve more attention for the many hats they wear as members of the community.

Women shared their personal experiences around genetic counselling, family planning and bringing up children with haemophilia. It was widely acknowledged that each experience was unique and personal and no one decision was more justified than the other. The session was understandably emotional for some attendees as they expressed their heartfelt emotions in front of the group. It was heartening to see attendees extending support to one another, even after the workshop had ended.

It is important for women to process their individual psychological and emotional experiences. Women who wish to get more help and support are encouraged to approach the psychosocial worker in their Haemophilia Centre for advice on where to go next. Alternatively, they can speak to their local GP and ask to be referred to a community psychologist.

Women carriers who are interested in being put on a mailing list can contact Mona at [desdemona.chong@health.qld.gov.au](mailto:desdemona.chong@health.qld.gov.au). She will put you in touch with an attendee who has volunteered to manage this list.

## Managing your headspace for adults

Chair: Clare Reeves

*The new age challenge: haemophilia and growing older - Sarah Elliott*

*Evidence-based mindfulness and how it can help in your personal and professional life - Dr Ira Van der Steenstraten*

### Sarah Elliott

*Sarah Elliott is the Northern Outreach worker for the Haemophilia Foundation of New Zealand*

Sarah Elliott presented an outline of her study to investigate the impact of the unique issues and challenges facing men aged 45 years and over who are living with haemophilia, including their perceptions of supports and services available to them in New Zealand.

Some initial findings, and recommendations based on these were:

- Family is the biggest support system identified, so service providers need to keep family involved where and how possible
- Connectedness to other men with bleeding disorders is also very important to this group, such as sharing, comradery and knowing they are not alone. Service providers need to find multiple opportunities to connect older men with bleeding disorders with one another in appropriate and relevant ways
- These men value social participation in communities; they enjoy being involved with groups, clubs and teams. Services need to encourage and support men with haemophilia to connect with different social groups, and plan around these where possible
- This group holds a lot of very real fears, and there are many unknowns for them.
- Therapeutic support may be needed to help work through their fears, and practical planning and preparing for the future is important to try to prolong and increase their independence.
- More exploration and research is needed around spirituality, religion and connectedness to culture, as these could be used as a support mechanism for those who are open to it.

This group had positive mental and emotional health, and depression was extremely low. Perhaps there are other

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factors in New Zealand that may be contributing to this group's wellbeing and lack of overriding depressive factors, such as a positive outlook to life, a variety of learned coping strategies, or ways of maintaining wellness (or decreasing stress) and resilience. However, it is imperative there are standardized tools and clear processes to deal with those with emotional concerns.

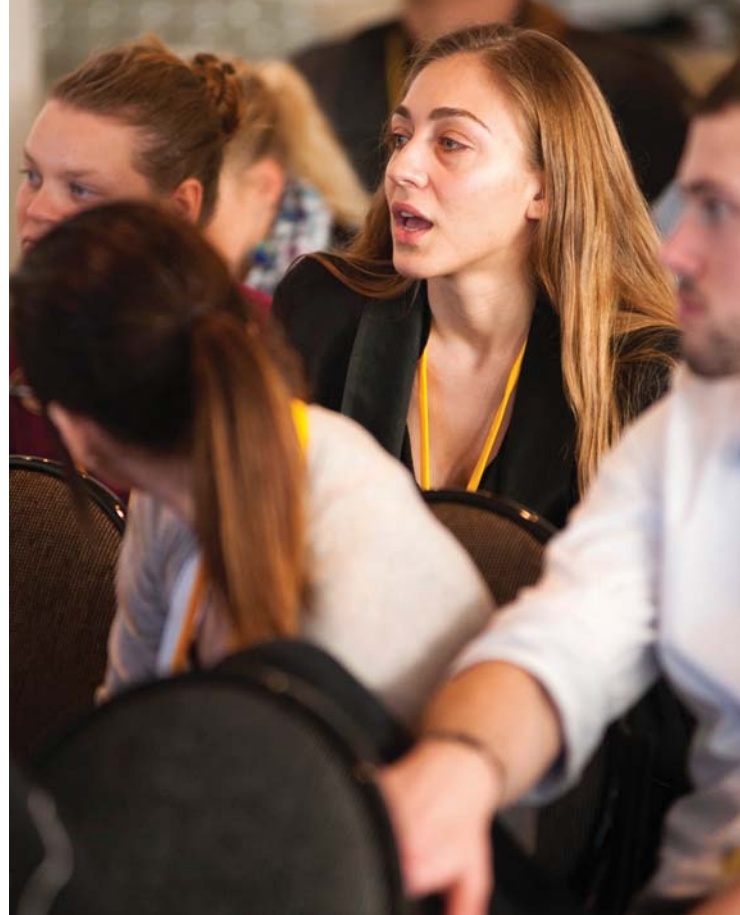
Dr Ira Van der Steenstraten is a psychiatrist, psychotherapist, and family therapist and presented to the conference about mindfulness and why it is an effective strategy to use.

Current research shows that training your attention and doing selected mindfulness and meditative exercises can reduce stress, anxiety, and depression, boost the immune system, and strengthen your ability to focus your attention where you want it to be. It has even been shown to change the architecture of your brain.

Evidence has shown that meditation is no longer just for "hippies" and its benefits are now widely accepted by scientists and the general public both young and old. Mindfulness training programs have been implemented in schools, hospitals, sports, corporate business, and the military.

There are many verified benefits to mindfulness training:

- Training your body to be non-judgmental creates space to allow new opportunities to arise
- If your mind or body is in discomfort and you try to ignore it or resist it then it will only increase stress
- Mindfulness can help you accept situations



- It teaches that your thoughts are something you have but not what you are. You cannot stop your thoughts but you can gain control by learning not to listen to them
- Mindfulness techniques can be particularly effective for people suffering a chronic condition. ■

## GO FOR IT GRANTS

**Have you ever wanted to be daring and take on a challenge?  
Or do something that's a bit scary?  
Or try something new?**

Everyone experiences obstacles at some time, but you'll never know what you can overcome and achieve unless you Go for it!

The Haemophilia Foundation Australia's new Go for it Grants program aims to assist people living with bleeding disorders take the first step towards achieving their goals.

### WHO CAN APPLY?

The grants are open to anyone who has, or is affected by, a bleeding disorder.

There are 2 x \$5,000 Go for it Grants on offer to provide winners with the financial support to help pursue their dreams.

What do you want to try? From study to advance your career, increasing your confidence and leadership skills with a public speaking course, or training to be the next sports star - the Go for it Grants can take you one step closer to realising your dream.



For a copy of the guidelines and application form:

- Visit the HFA web site - [www.haemophilia.org.au](http://www.haemophilia.org.au)
- Or contact HFA on 1800 807 173, email [hfaust@haemophilia.org.au](mailto:hfaust@haemophilia.org.au)

**Applications close 10 January 2016.**

Don't wait – just Go for it!

The Go For It Grants are supported by Pfizer.



# A PERSPECTIVE ON BLOODBORNE VIRUSES

## HEPATITIS C

*Chair: Suzanne O'Callaghan*

*Hepatitis C: medical issues for PWBD and treatment, incl direct acting antivirals - A/Prof Simone Strasser*

*Personal story of a person living with HCV - Dave, QLD*

*Hepatitis C progression - barriers to monitoring liver health and treatment - Mary Fenech and Beryl Zeissink*

*Mona Chong and Suzanne O'Callaghan*

Simone Strasser and her colleagues have had a long history of treating people with bleeding disorders and hepatitis C at the Royal Prince Alfred Hospital, Sydney, and she presented an optimistic picture for new treatments available for people with bleeding disorders and hepatitis C. The recent clinical trials of new direct acting antiviral (DAA) treatments that she presented, such as Harvoni® and Viekira Pak®, demonstrated very high cure rates with few side effects and greater tolerability. These treatments are generally in tablet form over a much shorter time-span than previous treatments, eg 12-24 weeks, leading to a much higher quality of life than interferon-based treatments. This means people can continue with their daily routine and work while receiving treatment. While these treatments are not yet available on the Pharmaceutical Benefits Scheme, the expectation is that they will be available next year.

A major take home message was the importance of keeping up with liver health checks. These can show whether liver disease is progressing – she gave examples of her patients who had developed cirrhosis even though they felt well – and the hepatitis specialist can then quickly investigate treatment options. Liver cancer caught early can be treated readily; and a liver transplant can also be considered if necessary. A liver health check is also a first step in assessment for hepatitis C treatment, and it is important to have completed this step as soon as possible to be considered for the new treatments once they are available. Fibroscans are now widely available and are used in a non-invasive, painless and short procedure to measure liver stiffness and gauge the level of liver disease.

In the second half of the session Dave, a community member with VWD and hepatitis C, and Mary Fenech, his hepatitis nurse, and Beryl Zeissink, his haemophilia nurse, discussed their approach to his recent hepatitis C DAA treatment through a compassionate access scheme. They highlighted the importance of staying in close

contact with the clinic during treatment as individuals need to be monitored and have regular blood tests.

Dave explained how straightforward and reassuring he found this, particularly as his treatment was easy to take and caused few side-effects. Mary Fenech pointed out that individuals who had developed cirrhosis prior to treatment would require six-monthly ultrasound liver scans post-treatment to continue to check for changes to the liver.

All in all, it was an uplifting and exciting session with a very hopeful message for people with bleeding disorders and hepatitis C.

## HIV

*Chair: Leonie Mudge*

*The legacy of HIV for the bleeding disorders community - Leonie Mudge*

*HIV – An update on treatment and the burden of co-morbidities, including hepatitis C virus co-infection - Dr Krispin Hajkovicz*

*Ageing/disability, resilience and HIV – psychosocial issues - Lynne Heyes*

*Suzanne O'Callaghan*

Leonie Mudge commenced the session with an acknowledgement of the impact of HIV on the bleeding disorders community since it was first diagnosed in the mid-1980s and its ongoing legacy, both for those who live with HIV and those who lost family members or friends to the epidemic.

Today the situation for a person with a bleeding disorder and HIV is very different. Krispin Hajkovicz, an infectious diseases physician who provides HIV care at the Royal Brisbane & Women's Hospital, gave a stimulating update on the current state of play with HIV.

Treatment for HIV now is usually a single-tablet regimen combining drugs from 3 classes, such as Atripla®, and the newer Stribild®, Eviplera® and Triumeq®, enabling people with HIV to take one tablet a day. The newer treatments are potent and well-tolerated and it is unusual to see drug failure in this group. The newest class of HIV drugs being trialled – and possibly the last new class to be approved in the foreseeable future – are maturation inhibitors that interfere with the final step of HIV maturation. No other class of drugs has this kind of action.

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# Lifestyle issues are still high on the health list, with diabetes being a common complication and smoking the most significant health risk in HIV.

Krispin Hajkowicz presenting on HIV



With many people with HIV very stable now, the question has shifted to how much monitoring is required. Krispin Hajkowicz noted that while a viral load test is valuable and should be undertaken every 6 months, a CD4 count test is now much less important if a person is stable.

Lifestyle issues are still high on the health list, with diabetes being a common complication and smoking the most significant health risk in HIV.

For people with bleeding disorders and HIV, managing HCV co-infection is high on the agenda. Some community members have already had successful treatment for their hepatitis C, but in HIV/HCV co-infection the success rates for interferon-based treatments have been very low. He explained that the new DAA treatments are good news for people who are co-infected, with outcomes similar to those who only have hepatitis C, and that drug-drug interactions are not a major issue as they can be overcome with good choices. He referred interested delegates to the CEASE study at the Australian Kirby Institute, which is aimed at eliminating co-infection.

While he was very hopeful about the potential of the new DAA treatments to cure his co-infected patients, he also remarked on the frustration of having bleeding disorders patients with advanced disease falling through the cracks of special access because their co-morbidities and liver disease complications make them ineligible. HFA is also aware of this issue; it is a solemn reminder of the need for access to the new hepatitis C treatments in Australia without delay. ■

#### REFERENCES

The Kirby Institute for Infection and Immunity in Society, University of NSW.  
CEASE: Control and Elimination within AuStralia of HEpatitis C from people living with HIV - [tinyurl.com/Kirby-CEASE](http://tinyurl.com/Kirby-CEASE)



# A WOMEN'S PERSPECTIVE

*Suzanne O'Callaghan*

## **Women bleed too**

*Chair: Joanna McCosker*

*Managing bleeding problems: menorrhagia and pregnancy - Dr Stephanie P'Ng*

*Personal experience - Elyse, QLD*

*Question and Answer Panel*

*Nurse - Dale Rodney*

*Outreach worker - Linda Dockrill*

## A key message for women was the importance of having good communication between her Haemophilia Centre and her other treating specialists

Women and girls' experience of bleeding disorders is a new and developing field and this session covered a lot of ground, with many valuable contributions from affected women in the audience.

Stephanie P'Ng began the session by highlighting that menorrhagia is relatively underdiagnosed as a symptom of bleeding disorder, although it is very common in von Willebrand disease and a significant issue for up to 57% of women who carry the gene for haemophilia. Its effect on quality of life is substantial, leading to anaemia for some and preventing women and girls from participating fully at work, school, in their recreation and sport.

Definitions of menorrhagia in the past have been unclear, but are now becoming more specific, for example:

- Heavy menstrual bleeding >7 days
- Loss of blood <80ml (how many products did you use?)

For women with bleeding disorders, there is also the question of their other bleeding symptoms and the need to clarify whether they are having other bleeding episodes indicative of a bleeding disorder, eg, after dentistry, surgery or childbirth.

For females with bleeding disorders, management of their bleeding symptoms is complicated by their hormonal and other gynaecological and obstetric issues. Stephanie P'Ng outlined current approaches to treatment in Australia and the potential for using oral contraceptives

to manage bleeding; and that it is unusual to need to resort to factor treatment, but this can be useful, especially if a woman is trying to become pregnant.

A key message for women was the importance of having good communication between her Haemophilia Centre and her other treating specialists to prevent bleeding complications: her gynaecologist, obstetric team, and other specialists, particularly surgeons.

Elyse, a young woman with both haemophilia A and VWD, then told her personal story. She spoke about the lack of understanding she experienced at school, and with some health professionals, especially in the private health sector. Travel insurance has also been a challenge for her, but after many years with same company and no claims, she has been able to have excess removed.

Elyse's story sparked a stimulating discussion. Questions about her unusual combination of bleeding disorders prompted the explanation from a geneticist in the audience that females with bleeding disorders can have their chromosomes skewed when more of their normal chromosomes are turned off and more of their altered chromosomes are turned on. Some women then made the point that everyone's experience is different and it is important to make sure you don't rely on other family members' experience to make your own decisions. And possibly the most interesting tip for the day for this audience was that menstrual cups are available in Australia (check the internet!) and are very helpful for measuring as well as preventing blood from coming through on clothes. ■

# HFA WOMEN AND GIRLS' PROJECT UPDATE



## WOMEN'S PROJECT

Understanding bleeding disorders in females is a relatively new field and this has been very challenging in the development of the HFA resources for women and girls!

The women and girls in our review groups have put together questions to be answered, which involves developing some sections from scratch using expert advice. Rather than releasing the sections as two finished booklets, which was our original plan, we are now going to release the sections as standalone fact sheets. Together they will still make up the booklets but can be read on their own – and we can release them as we get each one finished.

HFA has been fortunate to be able to contract Sandy Breit to assist with our work on the women's project and developing the women and girls' resources. Some of you may recall Sandy from her time at HFV, where she worked as a Haemophilia

and Hep C Counsellor from 1991 - 2008. She organised a number of information sessions on VWD and women who carry the haemophilia gene, and was also involved in establishing a women's group. Sandy has also worked as a Counsellor and Support Worker at Cystic Fibrosis VIC, SIDS and Kids, VicDeaf and has more recently worked with families whose babies have been diagnosed with a hearing loss through the Victorian Infant Hearing Screening Program.

## HOW TO BE INVOLVED?

Thanks to the women who have agreed to be part of the project and share their experiences or contribute to the new HFA education resources!

If you are a woman who carries the gene or have bleeding symptoms, and would like to be involved in the project, it's not too late - contact Suzanne O'Callaghan at HFA:

E: [socallaghan@haemophilia.org.au](mailto:socallaghan@haemophilia.org.au)  
T: 1800 807 173

## You can:

- Tell your story for National Haemophilia and/or the new resources

And/or

- Contribute by giving your ideas or comments on the draft resources.

## INFORMATION FOR YOUNG WOMEN AND TEENAGE GIRLS

HFA is also working on information resources specifically targeted at young women and teenage girls in the 13-25 age group. These are being developed in addition to the new booklets for women.

For more information about this project, contact Hannah Opeskin at HFA:

E: [hopeskin@haemophilia.org.au](mailto:hopeskin@haemophilia.org.au)  
T: 1800 807 173



# MYABDR UPDATE



From the HFA and National Blood Authority  
MyABDR Team

## WHAT'S NEW?

A new version of the MyABDR app was released on 19 October 2015, bringing you more improvements and features including:

- The 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.

**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 of 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 below number 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](http://www.blood.gov.au/myabdr)

Or

ask Suzanne at HFA to send you a copy –  
[socallaghan@haemophilia.org.au](mailto:socallaghan@haemophilia.org.au);  
ph 1800 807 173

## MYABDR AT THE 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.

Getting started with  
the MyABDR app

**6** easy steps for  
recording treatment

**STEP 1 > Download MyABDR app**

**STEP 2 > Register**

**STEP 3 > Login to MyABDR**

**STEP 4 > Add stock to inventory**

**STEP 5 > Record a treatment**

**STEP 6 > Recording a bleed**

## MYABDR FOCUS GROUP

The Conference was also an opportunity to have a session with some of the MyABDR Focus Group. 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 available 24/7 and will be happy to assist you.

T: 13 000 BLOOD / 13 000 25663

E: [myabdr@blood.gov.au](mailto:myabdr@blood.gov.au)

Available 24 hrs a day, 7 days a week. 



# HEP C NEWS

Time is running out for many people with hepatitis C and bleeding disorders. On 30 September 2015, Haemophilia Foundation Australia joined Hepatitis Australia and 25 other health organisations in an open letter to Australian Health Minister Sussan Ley urging action to make new curative treatments available to Australians without delay.

The letter acknowledged Minister Ley's commitment to improving the lives of Australians and urged her to intervene to bring the Government and pharmaceutical companies together to "expedite price negotiations and confirm the addition of new breakthrough hepatitis C medicines on the Pharmaceutical Benefits Scheme without delay."

Four new hepatitis C treatment combinations have now been recommended for listing on the Pharmaceutical Benefits Scheme (PBS) by the Pharmaceutical Benefits Advisory Committee (PBAC) and yet, after nine months or more, none are available yet on the PBS. These treatments are already available in many other countries, including the United States, Great Britain, Egypt, and India.

"Access to these treatments is absolutely critical for Australians with hepatitis C. My community members with bleeding disorders and hepatitis C have been waiting for these treatments for too long. Every delay puts their health and their lives more at risk," said Gavin Finkelstein, HFA President. "Government funding is needed urgently to list these medicines on the PBS. These treatments can cure hepatitis C – and if they are not on the PBS, these treatments are just not affordable for most Australians with hepatitis C."

## GOVERNMENT RESPONSE

Hepatitis Australia received a response from the Minister which stated that:

- 'A medicine cannot be listed on the PBS without a recommendation from the PBAC and neither the Government nor my Department interferes in the independent process of the PBAC.'

- 'My Department is progressing the listing of these medicines as swiftly as possible in line with PBAC recommendations. The listing date will depend on the successful negotiations with the sponsors of these medicines.'

Bearing in mind the PBAC approval and PBS listing processes, Hepatitis Australia does not expect the new treatments to be listed on the PBS before February 2016.

You can read the full open letter to the Minister and the update on the government response on the Hepatitis Australia website – [www.hepatitisaustralia.com](http://www.hepatitisaustralia.com).

HFA will continue to advocate for these medicines to be made available as soon as possible.

## WHAT CAN YOU DO IF YOU HAVE HEPATITIS 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:

- 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. ■



# WORLD AIDS DAY

World AIDS Day is marked internationally on 1 December.

This is a time to raise awareness in the wider community about the issues surrounding HIV and AIDS. It is a day to demonstrate support for people living with HIV and to commemorate those who have died. Wearing a red ribbon is a way that you can show solidarity and raise awareness of HIV.

This is also a time when we remember the members of the bleeding disorder community who were affected by HIV when in the mid-1980s HIV was transmitted through some batches of clotting factor treatment product. The legacy of this tragic episode lives on in our community, especially for the people who lost partners, family members, children, patients, colleagues and friends.

Some people with bleeding disorders continue to live with the challenges of HIV; and we acknowledge the individuals who inspire us by their positive attitude, resilience and determination to build a better future.

In 2015 the World AIDS Day global campaign continues the theme of:

## Getting to zero

- Zero new HIV infections
- Zero discrimination
- Zero AIDS related deaths

## What can you do?

- Be aware that HIV still exists in the community
- Take action to prevent transmission of HIV by promoting safe sex practices
- Support and understand people in your community living with or affected by HIV
- And uphold the right of people living with HIV to participate in the community free from stigma and discrimination. **H**

WORLD  
AIDS  
DAY 2015



GETTING  
TO ZERO



Australian haemophilia nurses at ISTH. Left-to-right: Olivia Hollingdrake, Robyn Shoemark, Claire McGregor, Natalie Gamble-Williams

Susan Dalkie is Bleeding Disorders Nurse and ABDR Data Manager at the Royal Darwin Hospital

# ISTH 2015 CONGRESS: REACHING FOR UNPRECEDENTED PEAKS

*Susan Dalkie*

Every two years ISTH the International Society on Thrombosis and Haemostasis (ISTH) holds an international conference in the area of thrombotic and bleeding disorders. This year I was honoured to be able to attend the ISTH 2015 Congress in Toronto, Canada.

In June 2015 just over 7000 health professionals flocked to Toronto from all over the world to attend the conference as well as to meet and network with other health professionals with a similar interest in this field.

There were educational sessions and presentations from the world's leading experts and hundreds of poster presentations on display, as well as a two day nursing session. It was good to be able to wander around and read the posters during the breaks from the educational sessions and what I liked the most about the poster presentations was that each poster had a bar code that you could scan which then enabled you to upload a copy of the poster onto your smart phone or electronic device for future reference.

For me professional networking was just as important as attending the lectures. I come from a very small centre and found it beneficial to speak to my international and Australian colleagues about new ideas and advances in practice and what they may be doing in their centres that could be adapted to ours. Networking and meeting other delegates face-to-face makes it a lot easier to pick up the phone or write an email to them in the future.

The two day nursing session was an opportunity to listen to other nurses from around the globe present interesting talks on the challenges and advances in nursing care relating to thrombosis and haemostasis. It was also lovely to see several Australian Haemophilia Nurses presenting and sharing their knowledge to the group about their practices and experience relating to bleeding disorders in Australia.

To reap the benefits of such a large conference I decided that I needed to stick with topics that were relevant to my clinical practice in inherited bleeding disorders.



# There are exciting times ahead regarding these advances as ultimately they will give the patient a better quality of life

## Half-life extended factor VIII for the treatment of haemophilia A

Andreas Tiede, Germany.

I found this presentation particularly interesting. The presenter touched on a range of factor VIII half-life technologies briefly, but focused in on PEGylation and highlighted the results and comparison of research associated with these products and how well they managed to extend the half-life of factor VIII.

PEGylated products have been around since the early 1990s. PEGylation is defined as the modification of a protein, peptide or antibody fragment by linking one or more polyethylene glycol (PEG) chains. These chains can alter the physiochemical properties of molecules such as their size or electrostatic binding capabilities. Most proteins or peptides targeted in this process have dramatically increased their half-life. What this means for the factor VIII molecule is that by using PEGylated products they can extend the circulating half-life of factor VIII and reduce dose frequency by increasing the drug stability and enhancing the protection from degradation, which in turn will decrease excretion of the drug from the kidneys.

The presentation compared the results from studies of three different PEGylated products: N8-GP (NN7088, turoctocog alfa pegol); BAX 855; and BAY 95-9027.

Interestingly all three PEGylated products showed an increase in half-life compared to conventional therapies but it did not exceed 18 hours. It is believed that this may have something to do with the von Willebrand Factor (vWF) half-life clearance: all of these molecules are bound to vWF which can't exceed its half-life as this is not altered by the molecules. The studies also showed that by using the PEGylated products patients are able to achieve longer dosing intervals (prophylaxis 1 dose every 4 days) and higher trough levels can be achieved (8% median trough level before the next dose).

No PEG related safety issues resulted from any of the trials and there were no unexpected findings relating to inhibitors. It cannot as yet be predicted what the long term effects of PEGylated products will be although it is known that the larger PEGs accumulate in the body and these effects are currently unknown. Patients can develop anti-PEG related immune responses such as with PEG-asparaginase. If such a response was to occur with these particular molecules then there would be a dramatic reduction in its half-life. It is predicted that

with the rate of technology in finding new treatments for haemophilia A, patients would not be exposed to a lifetime of these products therefore reducing the risks of these possible adverse events.

The ISTH Congress was truly amazing. Medical advances and technology in inherited bleeding disorders are steamrolling ahead and there are exciting times ahead regarding these advances as ultimately they will give the patient a better quality of life. Attending conferences such as ISTH is a wonderful way to soak up and share all of this new information and I valued the opportunity to attend. #

### REFERENCES

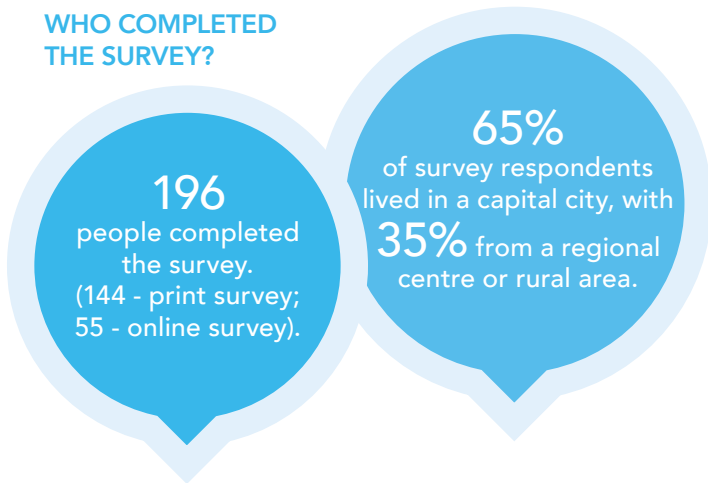
Tiede A. Half-life extended factor VIII for the treatment of haemophilia A. *Journal of Thrombosis and Haemostasis*, 13 (Suppl. 1): S176–S179.

Veronese FM, Pasut G. PEGylation, successful approach to drug delivery. *Drug Discovery Today* 2005;10(21):1451-8.

# HFA NATIONAL MEMBER SURVEY 2015

Hannah Opeskin and Suzanne O'Callaghan

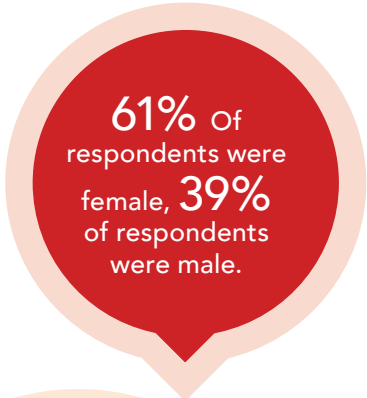
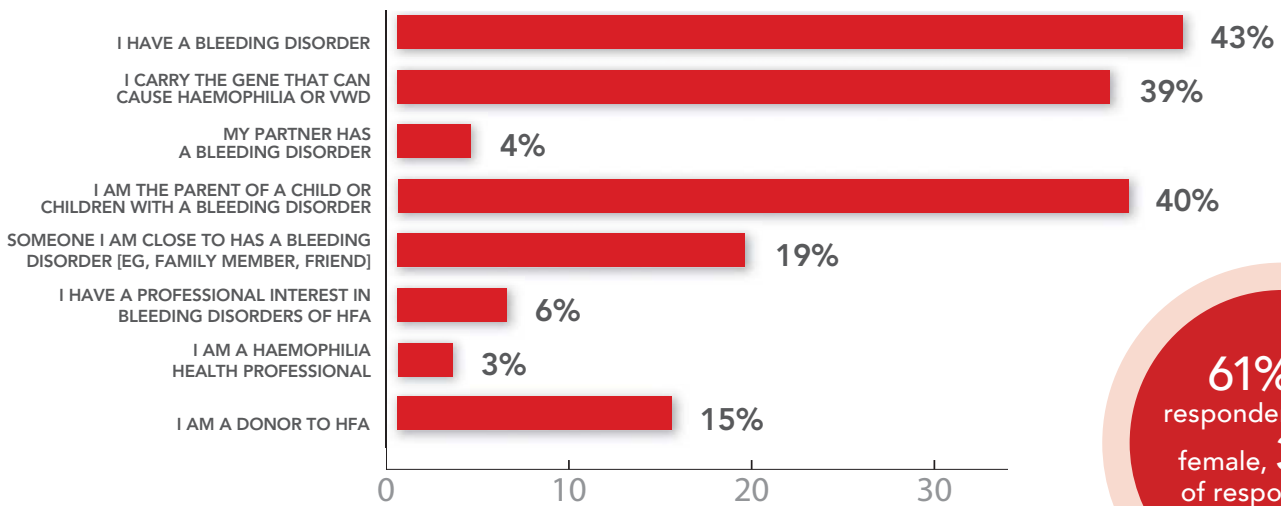
## WHO COMPLETED THE SURVEY?



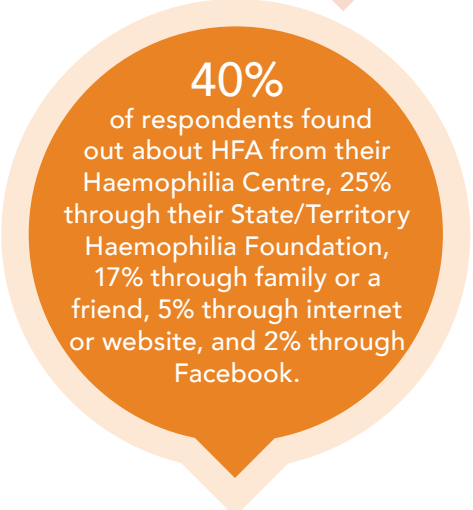
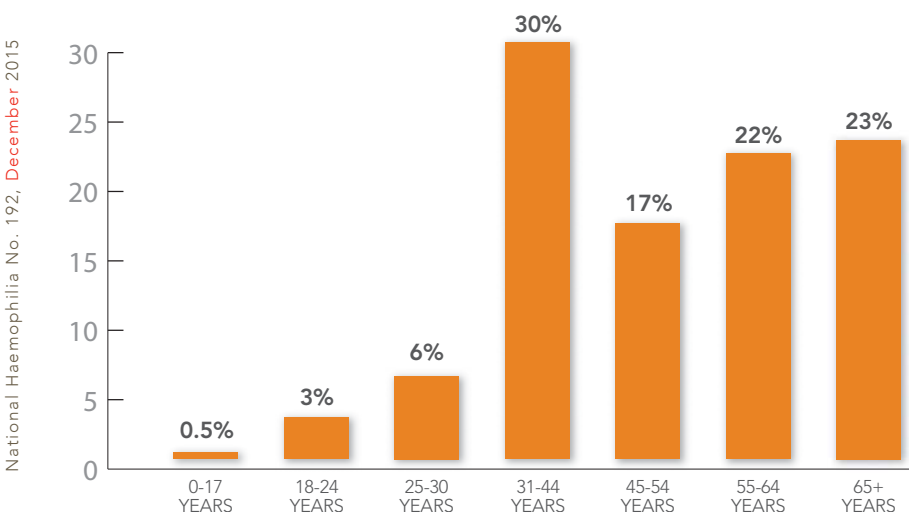
What do community members and National Haemophilia readers want or expect from HFA? What direction do they think HFA should be going in?

In June and July 2015 HFA conducted a national member survey to see how well we are meeting community needs and where we need to develop our role and activities.

## BLEEDING DISORDER STATUS



## AGE OF SURVEY RESPONDENTS



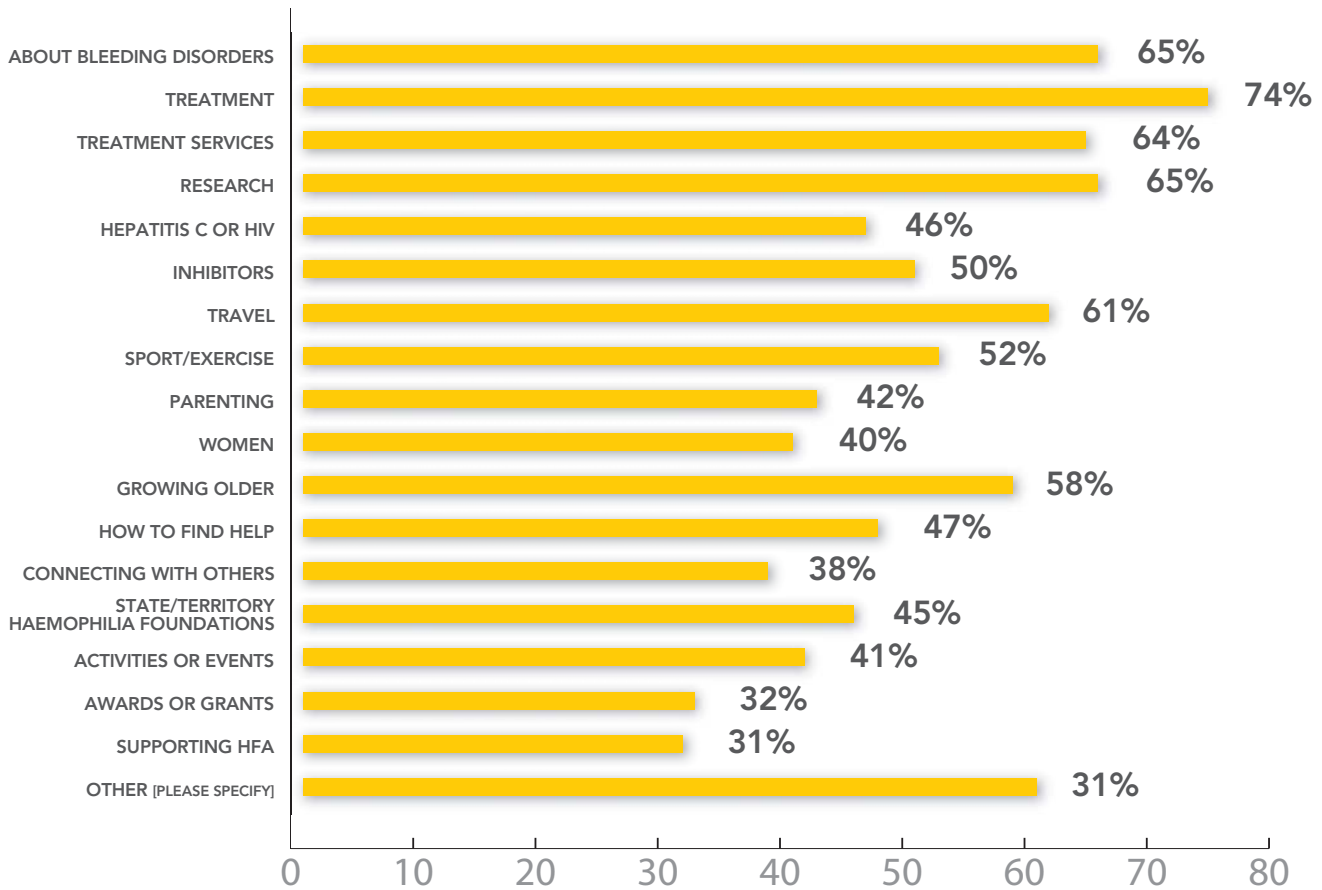


**WHAT DID PEOPLE SAY?**

**89%**  
of respondents found the topic 'treatment and care' of most interest and usefulness in HFA publications. 61% listed safety and supply of treatment as most useful.

**73%**  
of respondents had looked for **information regarding bleeding disorders** in the past year, with 73% finding the information on the internet and 50% finding it in **National Haemophilia**.

**WHAT INFORMATION AND EDUCATION DO YOU THINK HFA SHOULD PROVIDE TO YOU? PLEASE TICK ALL THAT APPLY.**



**PRIORITY AREAS**

People who completed the survey agreed the current HFA priority areas were important and had confidence in HFA's direction with the community. Areas that they rated most highly were treatment and care, safety and supply and promoting research, but they also thought that representation, education and information, youth programs and fundraising were very important. Many were also keen to see an increased focus on women and rural and regional areas.

*"You have been focusing more on women's issues lately which is good. For too long it has been swept under the carpet as a 'normal' way of life for women."*

*"Maybe [more focus on] treatment in isolated rural areas, access to meds and doctors, etc."*

**ADVOCACY**

88% of people who completed the survey noted hearing about HFA's advocacy work in *National Haemophilia* and through State and Territory Foundations (48%). Some suggested more work around travel insurance, research for a cure, community awareness and stigma and discrimination, von Willebrand disorder, and women.

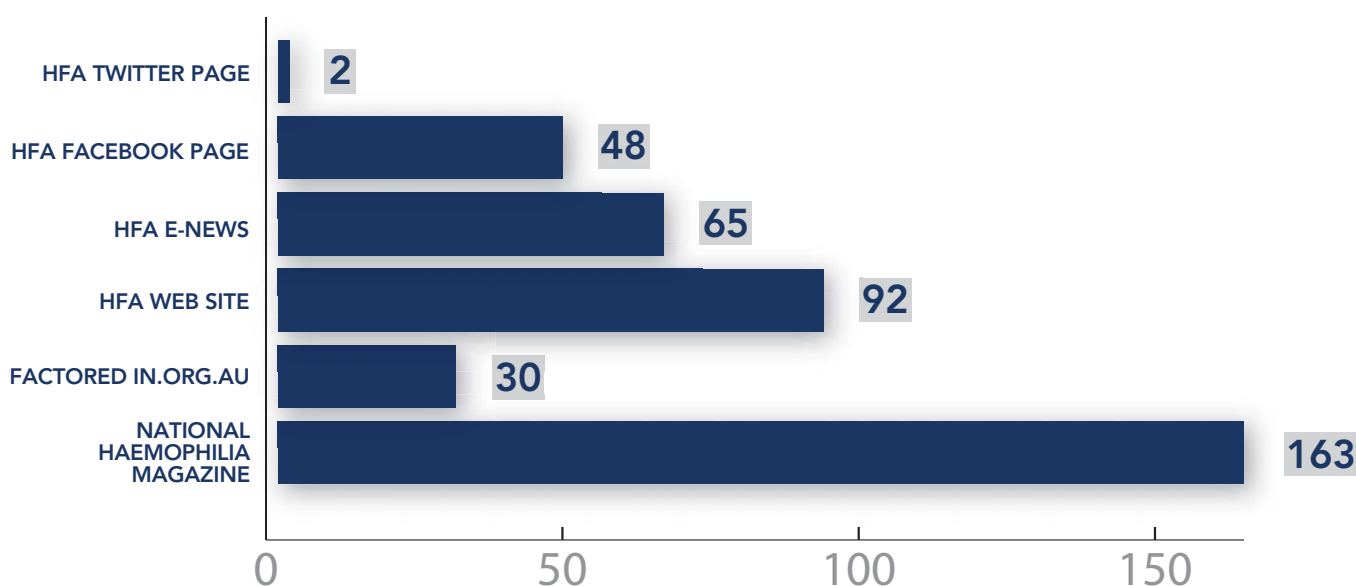
**EDUCATION AND INFORMATION**

70% of people who completed the survey wanted information and education provided in *National Haemophilia* and in the email newsletter (49%). Most look at and read *National Haemophilia* (90%) and the HFA website (58%). Many commented that *National Haemophilia* has all of the information they need and it assists them to feel connected with HFA. Conferences were also a valuable source of up-to-date information.

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“Many commented that *National Haemophilia* has all of the information they need and it assists them to feel connected with HFA”

### WHICH HFA COMMUNICATIONS DO YOU READ OR LOOK AT?



### ONLINE AND SOCIAL MEDIA COMMUNICATION

The HFA website remains a consistently well-respected source of information. HFA’s social media communications are relatively new, especially Twitter, and target specific and growing audiences. Some of the people who completed the survey said they do not use social media like Facebook and Twitter. Others commented that although they have “liked” the HFA Facebook page, it does not come up in their feed often – an indication that HFA may have to look into Facebook post boosting to reach all of its followers. The survey also served to raise awareness about the Factored In youth website, and some who had not been aware of it said they would now take a look.

### OTHER SUGGESTIONS

In general most people were very satisfied with HFA’s work and keen for it to continue. HFA helps to keep them connected and informed and their interests represented. There were a number of suggestions about specific areas to develop further, including von Willebrand disorder,

women and girls, rural issues, young families, information for extended family, and ageing.

### OUR THANKS TO EVERYONE WHO TOOK PART IN THE SURVEY!

*“I think the HFA do a fantastic job and I think that the focus on the younger generation is important.”*

*“Still find it hard dealing with my son having haemophilia. Hope for a cure one day.”*

*“My son died of HIV in 1999 so I no longer have hands on contact. I do still read the magazine and articles to keep up with current info, etc.”*

*“I have 3 girls - their father has haemophilia. Talking to them about the ‘future’, the probability of having kids with the disorder.”*

*“Thank you for everything you do for the bleeding disorder community. You have made lives of so many a much easier road to travel.”* H



# MAJOR BEQUEST BOOSTS HAEMOPHILIA FOUNDATION AUSTRALIA RESEARCH FUND

*Sharon Caris*

It was a privilege to announce at the recent Gold Coast Conference dinner that the Haemophilia Foundation Australia Research Fund would be receiving a significant boost due to a wonderful bequest by Maxine and Alan Ewart from South Australia. Maxine died during 2014 and Alan the year before.

In 1989, when Haemophilia Foundation Australia (HFA) was just 10 years old, the Medical Advisory Panel, now the Australian Haemophilia Centre Directors' Organisation (AHCDO), recommended that HFA establish a research fund. The HFA Council at the time knew this was an important way forward to improve treatment and care, so capital appeal committees were formed by haemophilia foundations around the country to raise funds for research.

The Haemophilia Foundation Australia Research Fund was established in 1994, and the first major grant was made in 1996. Since that time, thirty grants have been made – some small enabling grants and some larger on a range of topics spanning psychosocial research, laboratory research, through to gene therapy. Over the years almost \$630,000 has been distributed to different kinds of Australian based research.

Although there has never been any doubt as to the importance of the research fund, its sustainability has always been a concern and with a modest \$450,000 balance over recent years, the research committee has been somewhat limited in its endeavours.

The bequest of almost \$1.3m from the Ewarts, who were loyal and committed HFA and HFSA volunteers who had worked hard to get the Fund established, has given the HFA Council the opportunity to review the Research Fund, and will go a long way to making sure it meets its objectives.

HFA records are very clear that Alan and Maxine were deeply committed to improving care and treatment and helping families understand more about living with haemophilia - Alan had haemophilia, and he had worked at the University of Adelaide. He was on the HFA Council and attended many meetings and

conferences with Maxine, including World Federation of Hemophilia congresses and meetings in the early history of WFH. They were both active on the HFSA committee taking on office-bearer roles for many years, and Alan edited the HFSA newsletter. Many of the HFSA records we have archived have been written by Alan – they are neat, meticulous for their accuracy and detail and always had a clear education message and evidence of deep insight of the impact of haemophilia on individuals and their families.

We were pleased that Alan's sister Jo and her husband Bill Fuller, their son Andrew Fuller and their son Mark Fuller's partner, Troy were able to travel from Adelaide for the Gold Coast conference Dinner to help us celebrate Maxine and Alan's generosity.

HFA will soon be working with the research and clinical communities and people with bleeding disorders to review and re-develop the Fund. Council wants to be sure it meets the expectations of people like Alan and Maxine when it was established, and that through the research it funds that it will make a difference for people living with haemophilia and related inherited bleeding disorders.

The HFA Council recently decided that grants made from the revised Research Fund would be known as the Alan and Maxine Ewart Research Grants. ■



For the fourth year a group of cyclists led by Dr Simon McRae and Andrew Atkins will ride as **Team.Factor** to take on the BUPA Challenge Tour in South Australia on Friday 22 January 2016. The 2016 Bupa Challenge Tour will be from Norwood to Victor Harbor, just over 140kms.

They will be fundraising for their favourite cause – Haemophilia Foundation Australia.

### THE RIDE

The BUPA Challenge Ride is part of the Santos Tour Down Under in Adelaide, the first stop on the world elite cycling calendar. It gives regular cyclists the opportunity to ride the same Stage 4 route on the same day as the elite cyclists in the Tour Down Under.

### THE TEAM

Are you a keen and fit cyclist? In 2016 you too can come to South Australia and join Team.Factor in the BUPA Challenge Ride!

Worried that you are not fit enough for the full ride? You do have the option of joining at later starting points and don't have to do the entire distance. Team.Factor encourages you to give it a go. "Even though it's timed,

it's not a race, but a charity/fun ride," says Andrew Atkins, "and everyone rides at their own pace."

To join Team.Factor all you need to do is:

- Register at [www.tourdownunder.com.au](http://www.tourdownunder.com.au) and use team code 'BCT285' when registering
- Email your details to Natasha Coco at HFA - [ncoco@haemophilia.org.au](mailto:ncoco@haemophilia.org.au)
- We can add you to the [Team.Factor fundraising page](#).

### SUPPORT TEAM.FACTOR!

We are calling on all South Australians to come and cheer the team on at key spots in Glenelg, Willunga, Mount Compass, Macclesfield and the finish line at Mount Barker.

Contact Natasha Coco at HFA if you would like to be part of Team.Factor support at the event – email her at [ncoco@haemophilia.org.au](mailto:ncoco@haemophilia.org.au) or phone 1800 807 173.

You can also support Team.Factor on <https://give.everydayhero.com/au/team-factor-bupa-challenge-tour>

Hannah Opeskin is Health Promotion Officer, Haemophilia Foundation Australia

## YOUTH UPDATE

*Hannah Opeskin*

### 2015 AUSTRALIAN & NEW ZEALAND CONFERENCE

Almost 25 young people from across Australia with bleeding disorders attended the 2015 Conference. They took part in the youth social activity and played an active role in the Conference, participating and presenting their stories during conference sessions alongside health professionals.

They told stories about the struggles they have had to endure, medically and personally as well as their amazing strength harnessed to assist overcoming a

myriad of obstacles. Many of these young men and women had never participated in a conference in this capacity before and it was fantastic to see our youth so well integrated into the sessions.

One of the sessions held during the conference was a youth session which covered the topics of risky behaviours, disclosure and being on the move. As well as covering issues such as travel, moving out of home, transitioning across a broad range of areas and looking for an employer that suits you, part of the panel was







made up of Jade and Tim, youth representatives sharing their life experiences in these areas. Not only were youth in attendance, the session also attracted many parents.

As a result of this session, HFA is evaluating existing resources on Factored In to ensure they cover all the issues raised during the session and some, for example, those on employment and disclosure, will be developed further if necessary.

It was fantastic to see so many young men and women attend the conference, the sessions and take part. I hope that everyone returns for the next conference and many more join to discover what a fantastic experience it is.

## FACTORED IN UPDATE

As many youth may already know, the Factored In website is going through a redevelopment where the aim is to make the site more user-friendly and dynamic. As part of the redevelopment, Factored In will also have a few new features, so stay tuned!

For those who don't know much about Factored In:

- Created by young people for young people
- Local events and latest news in the youth community
- Lots of information about living with a bleeding disorder
- Lots of personal stories from young people living with a bleeding disorder
- You can read all the info without being a member
- If you want to join the community, you can sign up to be a member (free!) which means you can tell your own story and make comments on other people's stories and interesting news
- You can become a member if you have a bleeding disorder, carry the gene or have a sibling with a bleeding disorder

Thank you to all the youth who have kindly helped support the redevelopment by giving their honest opinions at the Conference and through email.

## YOUTH LEAD CONNECT



HFA is introducing **Youth Lead Connect** - a new Youth Leadership and Mentoring Program! The program will help build young people's skills and encourage engagement in their local community.

You are eligible for the program if you are aged 18-30 years, have a bleeding disorder, carry the gene or have a sibling who has a bleeding disorder.

The program will involve a training weekend in February and then some tasks involving engagement with your local Haemophilia Foundation. The tasks may include attending an event, helping organise or maybe even helping run an activity and writing a short reflective piece for Factored In – working to your strengths and helping build on the ones you wish to improve. Should you complete all your tasks you will receive a formal certificate!

Entry to the program is through application, so head to the Factored In website [tinyurl.com/HFA-youth-leader](http://tinyurl.com/HFA-youth-leader) to apply via the application form. **Applications close 15 January 2016.**

I encourage all young people to apply!

# YOUTH NEWS

2015 marked the 17th Australian & New Zealand Conference on Haemophilia and Related Bleeding Disorders held on the Gold Coast. The youth session discussed being on the move, disclosure and safe risks, with Tim and Jade representing youth across Australia on the panel alongside a nurse, physio, and psychologist. In other sessions throughout the conference, several youth also shared their stories to parents, health professionals and the community about living with a bleeding disorder.

"I am very grateful to have the opportunity to speak on the panel and represent a female youth perspective. I loved the power of sharing stories and inviting casual conversation around issues such as sexual health, risk, and disclosure.

Not only did we have these conversations with the youth present at the conference but the session also attracted an older audience of parents and guardians that were keen to understand the difference in perspective.

Next time I hope to create even more of a discussion and help facilitate all youth and other participants to voice concerns, ask questions, and share stories."

**Jade**

"I was asked to provide the perspective of a young male with haemophilia in the youth session but the great thing was that I was just one of many young people with a bleeding disorder in the room. I explained my experiences regarding travelling, transitioning treatment centres and moving into adult life but what I enjoyed most was what followed. I learnt so much from the youth session and the entire conference that I encourage all young men and women with bleeding disorders to attend next time if possible. I went into the youth session to share my knowledge and experiences and ended up learning more from the audience than they probably learnt from me!

I hope to see you all there next time."

**Tim**

"It was brilliant to learn about the struggles and breakthroughs within our community, and getting to meet and hang out with others who not only understood what it was like to live with a bleeding disorder, but who also shared my passion for improving the ways in which we care for each other.

My personal highlight was getting to speak on a panel with Ty, talking about taking control of our lives with haemophilia.

If any of you out there have been tossing up whether or not to go to the conference I would seriously recommend it. It's an excellent opportunity to get to know the community that we are a part of and where we stand within it."

**Ben**



## STORIES FROM THE CONFERENCE

"I enjoyed meeting other young and not so young people with haemophilia and hearing about their experiences. I especially enjoyed meeting up with other youth from across Australia, seeing old friends, and making new ones. Some of my favourite sessions included the youth session and how haemophilia can affect me and how to deal with the challenges, including the pain session, concerning the placebo affect and how our brains perceive pain.

I would definitely recommend any youth interested to attend. It was a great experience and I got to learn about our disorder, living with it, and the latest in advancements."

**Cameron**

"I learnt so much and met up with old friends and made some new ones too. There were sessions that catered to everyone's needs and interest. I went to ones aimed towards youth and women with bleeding disorders, where I learnt more about my condition, possible treatments and heard other people's stories about their problems and the hope they have for the future.

It was a wonderful experience and something I greatly recommend to other youth, because the knowledge you gain from the medical professionals and other people in the same situation as you is invaluable. It is also an excellent place to make friends who can understand what you're going through."

**Emily**

"This year I learnt about von Willebrand disease at the von Willebrand disease session. It's something that I've wanted to know more about for a while so I have a better understanding of what is experienced by those with von Willebrand disease. It was also really interesting to hear the stories of 2 very different guys in the being active session, who shared their lives and how haemophilia has shaped the fine young men they have become.

The best part of going to the conference is hanging out with the other youth who all know what it's like to have a bleeding disorder, cos we all do, we always have something interesting to talk about and we always have a really good time."

**Hamish**

"I found the session on the placebo effect to be the most informative, and I also learnt a great deal from the seminar on Family Planning.

The conference was a great experience to bond and learn with others living with bleeding disorders and I'm really glad I was a part of it."

**Zavier**



# CALENDAR

## World Haemophilia Day

17 April 2016  
www.wfh.org/whd

## WFH 2016 World Congress

24-28 July 2016 – Orlando, USA  
World Federation of Hemophilia  
www.wfh.org/congress

## Haemophilia Awareness Week

9-15 October 2016  
Tel 03 9885 7800  
Fax 03 9885 1800  
Email hfaust@haemophilia.org.au  
www.haemophilia.org.au

## CORPORATE SUPPORTERS AND DONORS

Haemophilia Foundation Australia (HFA) values the individuals, philanthropic trusts and companies which sponsor and fund HFA programs to enable HFA to meet its objectives of:

- education and peer support activities that increase independence and the quality of lives of people with bleeding disorders, and their families, and access to best practice care and treatment
- encouraging clinical excellence in haemophilia care, and promoting research
- national representation for the bleeding disorders community.

# Baxalta

# CSL Behring



# Seasons' Greetings



**The staff and Council of HFA wish you the very best for a safe and happy festive season!**

Thank you for your invaluable support of people with bleeding disorders during 2015 and we look forward to partnering with you again in 2016. **Together, we can make a difference!**

  
Executive Director

  
President



The HFA office will close at 12 noon on Thursday 24 December 2015. We will reopen fully on Monday 4 January 2016. During that time if you have any queries or need to contact HFA, please note that messages left on the answering machine will be monitored. If you have an urgent matter please contact Sharon Caris on 0410 419 914. **H**



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Haemophilia Foundation Australia acknowledges the funding and assistance received from the Commonwealth Department of Health and Ageing which makes this publication possible. **H**