National Haemophilia
Haemophilia Foundation Australia
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2017 CONFERENCE

REGISTER NOW!

18TH AUSTRALIAN & NEW ZEALAND CONFERENCE ON HAEMOPHILIA & RARE BLEEDING DISORDERS

LOOKING FORWARD TO CHANGE

Melbourne • 12-14 October **2017**

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CANADIAN CHALLENGE

How is Australia tracking with its MyABDR usage? Can we do better than Canada? This is the question that has been put to HFA by the Canadian Hemophilia Society.

You may be aware that Canada has recently commenced using the system MyCBDR, which is a patient-controlled app and website for people with bleeding disorders to record their treatments and bleeds, and based on the same concept and system as MyABDR. MyABDR data is added to the Australian Bleeding Disorders Registry (ABDR), the system used by Australian Haemophilia Treatment Centres to manage the clinical care of their patients. MyCBDR data is added to the Canadian Bleeding Disorders Registry (CBDR) in a similar way.

Canada is working quickly to register Canadians with bleeding disorders on MyCBDR so that they can start using the system.

In the spirit of friendly trans-Pacific rivalry, the Canadian Hemophilia Society has issued a challenge to HFA to measure the proportion of people in Australia using MyABDR in comparison to the proportion using MyCBDR in Canada.

The competition is likely to run between September to December 2017 and will involve a substantial prize for a MyABDR or MyCBDR user in the winning country.

Is Australia up to it? More soon!

Gavin Finkelstein is President, Haemophilia Foundation Australia

FROM THE PRESIDENT

Gavin Finkelstein

The last few months have been a busy period for us.

WORLD HAEMOPHILIA DAY

World Hemophilia Day was celebrated globally on 17 April. Haemophilia Foundation Australia joined World Federation of Hemophilia (WFH) and the international bleeding disorders community to show support for women and girls affected by bleeding disorders. The WFH theme ***Hear Their Voices*** enabled many women to share their personal stories on the WFH World Haemophilia Day website, stories of living with a bleeding disorder, and how they addressed their situation when they could not access appropriate information, diagnosis, care and treatment. Other women and girls shared their experiences as carers, partners, mothers, and sisters of a person with a bleeding disorder. HFA launched the next in a suite of education resources in development for women and girls, ***Finding out you carry the gene,*** as part of the ***Hear Their Voices*** campaign to present the experiences and stories of Australian women and girls who carry the gene.

We also joined the WFH campaign to light up landmarks around the world in red to raise awareness of bleeding disorders on the day. We pulled out all stops and 11 of the 70 global landmarks lit up red were located around Australia - all free of charge in the spirit of creating awareness and recognition. Thanks to our State/Territory Foundations and the individuals who helped with this. We also launched ***Red Tie Challenge*** in April to raise awareness of bleeding disorders and this campaign will continue for the whole of April each year.

NEW TREATMENT PRODUCTS

As I write this, there is still no funding pathway to new types of treatment products.

Several extended half-life factors are registered in Australia and other novel products are on the way. Clinical trial data demonstrates compelling reasons for some people to adopt them for their treatment. Significant improvement in quality of life and productivity is expected - less infusions, better control of bleeding, better compliance with prophylaxis, reduced infection and thrombotic risk resulting from fewer infusions, less pain, suffering and family disruption, and reduced loss of work and school time. We made a submission to the National Blood Authority stakeholder consultation process about these products in March 2017. The NBA has advised they are currently considering submissions, including those received in April and that they are having further discussions on some matters covered.

We were able to advocate for best practice treatment and funding for extended half-life factors and other emerging products at an event hosted by the Hon Stuart Robert MP and HFA at Parliament House in Canberra on 31 May. The Hon Dr David Gillespie MP, Assistant Minister for Health, welcomed us to Parliament House and spoke about his experience of treating haemophilia patients in the Haematology Unit when he was a doctor at the Royal Prince Alfred Hospital in Sydney. We were pleased that representatives from all sides of government were present to hear the experiences and stories of community members living with haemophilia describing how important innovation in treatment is to individuals and families living with haemophilia. This was a significant opportunity for HFA to explain the importance of new therapies and how they can improve health outcomes and quality of life.

CONFERENCE

Don't forget to start planning for the Australia and New Zealand Conference in Melbourne 12-14 October 2017. HFA will have some limited funding to assist, but we hope you will start putting some funds aside now so that you can be in Melbourne for the conference weekend. The program is looking good, but the friendship and fun is always great when the community gets together!

1. The Hon Stuart Robert MP and the Hon Dr David Gillespie MP
2. L-R: Gavin Finkelstein, HFA President; the Hon Dr David Gillespie MP; Zev Fishman, community speaker for HFA; the Hon Kevin Andrews MP; Dan Credazzi, HFA Vice-President and community speaker for HFA
3. L-R Dr Simon McRae, Haemophilia Centre Director, Royal Adelaide Hospital, and clinical speaker for HFA; Dr Mike Freelander MP; the Hon Dr David Gillespie MP

18TH AUSTRALIAN & NEW ZEALAND CONFERENCE ON HAEMOPHILIA & RARE BLEEDING DISORDERS

LOOKING FORWARD TO CHANGE

Melbourne • 12-14 October **2017**

2017 CONFERENCE

EARLYBIRD REGISTRATIONS CLOSE 31 JULY https://www.secureregistrations.com/HFA2017/

The 18th Australian & New Zealand Conference on Haemophilia and Rare Bleeding Disorders will be held at the Pullman Albert Park, Melbourne, 12-14 October 2017. The theme for the conference is *"Looking Forward to Change"*.

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

We are excited to announce that Dr Paula James, Medical Director of the Women and Bleeding Disorders Clinic at Kingston General Hospital, Canada, will be speaking at the Conference about women and bleeding disorders and Dr Justin Coulson, one of Australia's leading parenting experts, will open the Conference with an exciting plenary, speaking about his program, '21 Days to a Happier Family' with special considerations for families with bleeding disorders.

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

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

The program will include a range of expert speakers: people living with bleeding disorders as well as health professionals and others presenting from different perspectives.

COMMUNITY FUNDING

HFA has allocated funding to assist community members with expenses to attend the Conference. Haemophilia Foundations may also provide funding - contact your local foundation for more information.

For details and an application form for HFA funding go to www.haemophilia.org.au/conferences or call HFA on 1800 807 173 for a form to be emailed or posted.

ABSTRACTS

We are calling for abstracts. Abstracts may be accepted for a presentation in the main conference program or will be presented as a Poster in the Poster Exhibition.

We encourage abstracts relevant to clinical practice and care, laboratory science, research, policy or living with bleeding disorders or treatment complications.

Form can be downloaded below at www.haemophilia.org.au/conferences. There will be prizes for the Best Abstract, and the Best Poster.

Submit your abstract by Friday 30 June 2017.

REGISTRATION

Registrations are now open and can be made online at https://www.secureregistrations.com/HFA2017/.

More information can be found on our website www.haemophilia.org.au/conferences.

We look forward to seeing you in Melbourne.

WORLD HAEMOPHILIA DAY

Every April 17 World Haemophilia Day is recognised worldwide to increase awareness of haemophilia and other inherited bleeding disorders. This is a critical effort since with increased awareness comes better diagnosis and access to care for the millions who remain without treatment.

HEAR THEIR VOICES

In 2017 the international theme was HEAR THEIR VOICES.

HEAR THEIR VOICES was a global campaign to come together on World Haemophilia Day to show our support for the millions of women and girls affected by bleeding disorders.

The World Federation of Hemophilia (WFH) produced infographics to raise awareness about issues faced by women and girls affected by bleeding disorders. For example, a major concern is that many women with bleeding disorders do not recognise that they have bleeding symptoms and do not seek medical advice. As a result they can have untreated heavy menstrual bleeding or excessive or prolonged bleeding after medical or dental procedures, surgery, injuries or childbirth.

Sharing personal stories is an important way to acknowledge the experience of women and for them to feel more connected with other women in similar situations. The WFH World Haemophilia Day website provided an opportunity for women around the world to share their stories and explain how bleeding disorders have affected their life.

Read the stories from women worldwide at www.worldhemophiliaday.org

HFA celebrated World Haemophilia Day with the launch of a new The Female Factors resource – ***Haemophilia: finding out you carry the gene.*** In this booklet Australian women talk about their reactions to diagnosis, their thoughts and tips on managing feelings and where to go for information and support. To download visit https://tinyurl.com/carry-gene.

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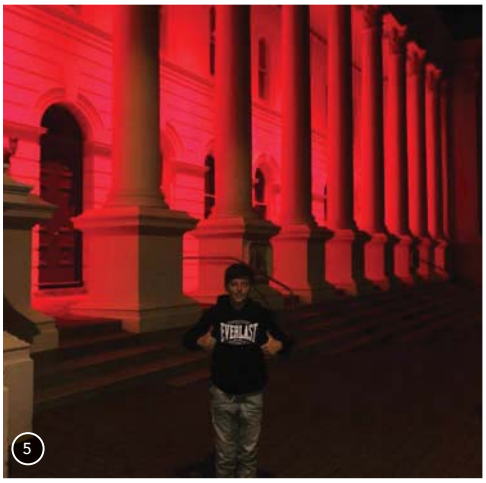
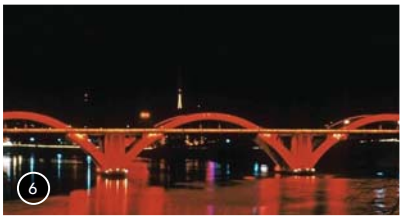
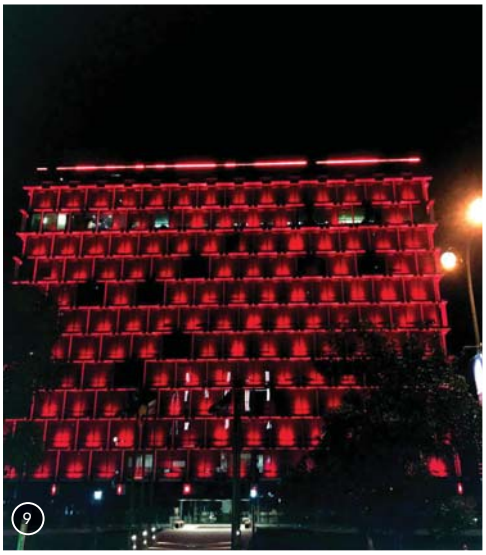
LIGHT IT UP RED!

Together with other landmarks from around the world, Australia had a landmark in each State and Territory turn red to celebrate World Haemophilia Day.

Thank you to the people who attended the landmarks on the night and shared their photos.







1. Darwin Convention Centre
2. Adelaide Oval
3. Telstra Tower, Canberra
4. Bell Tower, Perth
5. Launceston Town Hall
6. William Jolly Bridge, Brisbane
7. Story Bridge, Brisbane
8. AAMI Park, Melbourne
9. Council House, Perth

RED TIE CHALLENGE

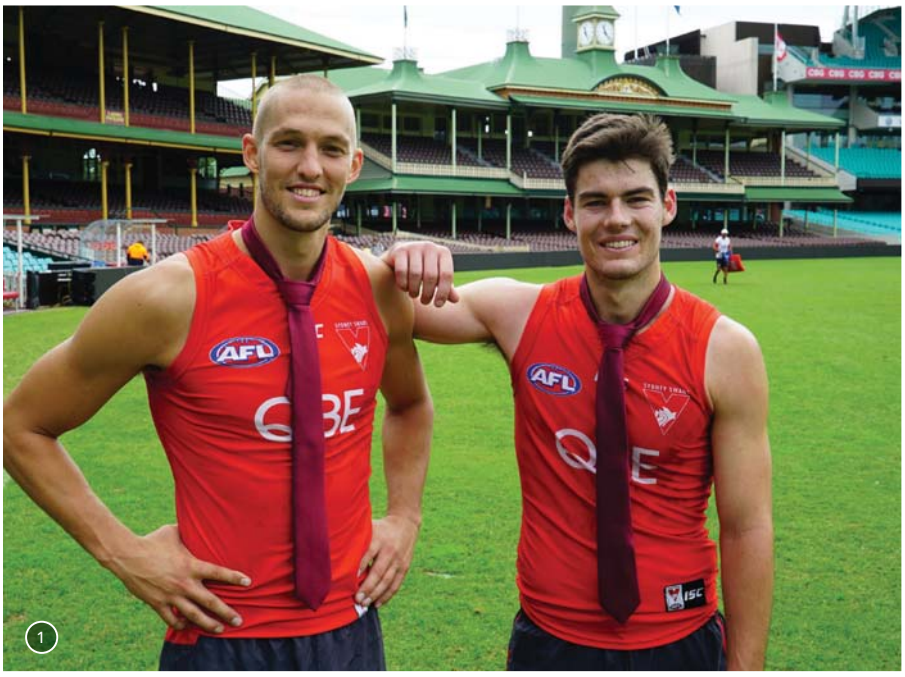
What is the RED TIE CHALLENGE? The HFA Red Tie Challenge asks you to wear a red tie during the month of April to raise awareness about bleeding disorders and recognise World Haemophilia Day.

The RED TIE CHALLENGE was created by the National Hemophilia Foundation (NHF) in the United States. NHF selected a Red Tie to symbolize the blood ties that bind our community. Based on the success of NHF, and with their agreement, HFA launched its own Red Tie Challenge in April 2017.

It was great to see people and companies taking on and supporting the Red Tie Challenge in Australia

Show your SUPPORT for the BLEEDING DISORDERS COMMUNITY!

TAKE THE #RedTieChallengeAUS
haemophilia.org.au/redtie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1. Sam Reid and George Hewitt from the Sydney Swans show off their red ties
2. HFA Council,
3. HFNSW,
4. AHCDO
5. HFA, and special friends
6. Saus and
7. Captain Oates frock up in their red ties for World Haemophilia Day

Penny McCarthy and Megan Walsh are Clinical Nurse Consultants at the Ronald Sawers Haemophilia Centre, Alfred Health, Melbourne

10 YEARS OF HOME DELIVERY

HOME DELIVERY

Home delivery of clotting factor replacement therapy is a service that needs to be arranged by treating health professionals. It may not be suitable for everyone. In some Australian states and territories there are different arrangements in place from those described in this article and home delivery may not be available to you. If you have any questions about home delivery, speak to your treating team at your Haemophilia Treatment Centre.

It been nearly 10 years since home delivery of recombinant factor concentrates became available in Victoria. Some families probably accept it as a normal part of haemophilia care and assume it has always been there! We thought we would reflect on the impact the home delivery program has had on our Centre.

REDUCING THE WORKLOAD

One of the biggest changes was reducing the workload for the blood bank staff at our hospital. Previously the vials would arrive from the pharmaceutical company, have to be unpacked, entered into the computer system and put in the fridge, which also involved stock rotation. Once the blood bank staff received a release order from the Haemophilia Treatment Centre (HTC) they would then have to collect the vials from the fridge, dispense them via the computer, sign them out in a log book and give them to the patient waiting at the window.

As an isolated occurrence it would not be too onerous, but with over 100 patients on home therapy all using approximately 12 vials a month, it became 1200 vials each month for blood bank to handle twice, and store in the fridge. This was overwhelming for a small staff in a small area, with a small fridge, running a very busy blood bank service that already cross-matches approximately 1200 units of blood each month. As many HTC patients were working, many wanted to collect their product after-hours from the blood bank. However, this became problematic as there was only one staff member working, who was dealing with all the demands of the hospital. If a major trauma incident was being managed by the hospital, the staff member had no time to dispense the factor and the patient was turned away.

CONVENIENCE

We feel the biggest benefit to patients has been the convenience of home delivery and less interruption to everyday life. Regular product delivery has improved the management of haemophilia by patients at home and anecdotally we have seen an improvement in joint health. There is no more running out of factor and missing doses.

The team made the decision early that all patients using treatment at home, and where delivery was available, would be transitioned to a home delivery service. Many embraced the change: no trudging to the hospital monthly; no paying for expensive car parking (if you could find one!). However, others felt some loss with not coming to the hospital regularly and were slow to join. Initially for some, sticking to a nominated delivery day and time frame each month was challenging. However, as delivery windows became more attractive and after hours deliveries were introduced, we now have all of our patients using product at home on home delivery. To date no one has asked to go back to the old way of collecting from the hospital.

COMMUNICATION

In our Centre the nurses decided to manage the home delivery orders. This has been an interesting addition to our work and has highlighted to us much about the

"If we note a move from the prescribed treatment plan or increased bleeding, we contact the patient to check everything is OK"

challenges of managing haemophilia at home. We realise that our patients would prefer to keep phone conversations to a minimum, so SMS messaging from our computers has been a great success for all. The monthly contact by SMS has also kept a line of communication with the nurses and fostered a relationship with patients many of whom we may only see once a year. We often get a little message or query with the product order reply. For example, 'Happy Easter' or 'How do I organise travel letters? Or 'How do I see the doctor?'.

We have noticed many people are creatures of habit. The patients who record each treatment and reply to the SMS messages in a timely fashion appear to be managing their condition well. If all of a sudden this pattern of behaviour changes, it often signals something has changed in their life. This could be happy or sad event: for example, a new baby or job, illness or dealing with elderly parents; it could be anything that is providing a distraction. A quick question of 'R U OK?' can be enough to let them know we are here to help. As we are organising the monthly home delivery, it prompts us to check the individual treatment records before the order is processed. If we note a move from the prescribed treatment plan or increased bleeding, we contact the patient to check everything is OK and offer further intervention as required, such as 'How is the elbow bleed settling? Can we make you a physio appointment?'

STREAMLINING

Providing the patients with delivery calendars (we ask the pharmaceutical company to provide them for the patients) has assisted our patients in being organised to receive the deliveries on the scheduled delivery day in the delivery window. The introduction of after-hours delivery windows from 6-8pm three evenings per week or on a Saturday morning (depending on the company whose product you use) has decreased the number of missed deliveries. This is important to keep the costs down and to ensure the service is maintained.

A noticeable change has been the reduction of stockpiling, now that patients trust the system and know they will receive factor as required each month. This in turn has reduced wastage as the vials are now rotated regularly and not hiding in the back of the fridge and accidently expiring.

ABDR AND MYABDR

For us the ABDR (Australian Bleeding Disorders Registry) has been another useful tool to manage treatment at home. We now have one place where all the factor treatment information is stored. This includes order forms and patient treatment records (MyABDR) and a real time factor inventory for each patient. We use the ABDR constantly: we now have two computer screens at each desk so it is readily accessible all day, providing up-to-date information about our patients. The MyABDR app is constantly being updated and tweaked making it more user friendly. Most of our patients find it very easy to use now.

Good communication between the HTC, pharmaceutical company, patient and support from the National blood Authority has been the key to ongoing success of this program.

Sometimes it is not all smooth sailing, and a little intensive encouragement is required by some to get their order in on time, MyABDR records up-to-date and be home to sign for the delivery. However, we think that HTC staff and patients would agree that this program that we now take for granted has been a very positive addition to managing haemophilia at home.

Johanna Newsom is Senior Physiotherapist at Children's Hospital at Westmead, Sydney

WFH MUSCULOSKELETAL CONGRESS 2017

Johanna Newsom

The 15th WFH International Musculoskeletal Congress was held in Seoul, Republic of Korea 5-7 May 2017. Over 250 delegates attended, representing more than 40 countries on all 6 inhabited continents. All delegates had a particular interest in the management of joint and muscle complications as a result of haemophilia, and with the Congress proudly and deliberating promoting a "musculoskeletal-family feel", input from every delegate was encouraged and welcomed, which led to some interesting and robust discussions!

The JW Marriott Hotel in Seoul was the venue for this year's Congress. Located on the southern side of the Han River, in an area developed primarily for the 1988 Summer Olympic Games, we found ourselves in a region known as Gangnam – perhaps best known by the delegates because of the iconic 2012 K-Pop hit "Gangnam Style" by Korean artist Psy. And this song became the unofficial anthem of the Congress, getting some good air time at the official conference dinner.

CONGRESS MILESTONES

Opening with a session titled "Driving ahead with one eye on the rear view mirror", some of the long-standing members of the World Federation of Hemophilia (WFH) Musculoskeletal Committee reflected on its humble beginnings in 1977 when a small group of six interested clinicians met in the lounge room of an inspired orthopaedic surgeon. This led to official recognition by the WFH in 1984, and the commencement of regular musculoskeletal congresses in the 1990s. This session rounded out with presentations predicting the future of both physiotherapy and orthopaedic surgery in haemophilia – fortunately, both sounded exciting and promising. These gave a good teaser for the highlight sessions to come – the effects (and costs) of exercise and training, debate around definitions and management of synovitis, and an amazing opportunity to "talk to the experts" with a consultation corner discussing complex cases and issues that are too often ignored.

EXERCISE AND TRAINING

It is well-established now that being as fit and active as possible is ideal for people with haemophilia – most people won't complete a visit to their HTC without being asked about their physical activity and ability to participate. This is commonly followed up with advice from the team, and even specific exercises and activities often recommended by the physio. Appropriate exercises and activities can be one of the most effective (and cheapest!) methods of managing haemophilia and minimising bleeds, pain and other problems.

In this session, we heard about how to plan an exercise program safely, including the vital step of having a physio or other expert globally evaluate the entire musculoskeletal system (screening for previous injuries, damage and other issues with joints, or muscle weakness) before commencing a new activity. We discussed safe ways to progress activities and train harder to get fitter and stronger, and talked about how the muscles, joints and bones respond to training. We also heard about some scenarios where poor training technique lead to injuries and problems – a good reminder to us all to take it easy and listen to our bodies (and the haemophilia team) when we decide to hit the gym!

Australian physiotherapists at the WFH MSK Congress

SYNOVITIS

Synovitis is a term commonly heard in haemophilia circles. Defined as an inflammation of the synovium, or joint lining, it is known to occur as a result of bleeding into joints. With only one or two bleeds, the hope is that this synovitis resolves, but with more and more bleeds into the same joint, the synovitis becomes chronic and can pose a much bigger challenge to treat and manage. Chronic synovitis is thought to be the starting point for serious degeneration and damage in a joint.

There was a lot of debate around how to decide when synovitis becomes chronic synovitis, and what assessments we can use to help make that distinction – the Haemophilia Joint Health Score, a comprehensive clinical assessment, and imaging (like X-rays or MRIs) all seem to have their part to play… the take home message is that regular check-ups will help to identify any early changes in the joint lining, and the information gained from these assessments will help to tailor an individual treatment program for anyone who appears to have inflammation in their joints. So it is important to keep those clinic appointments!

TALK TO THE EXPERTS

Several speakers from different countries presented cases to help us all learn from each other in an incredibly thought-provoking session. There was lively discussion around various surgical approaches, timing and style of physiotherapy and rehabilitation, and the need to take into account how easy it is to access factor.

One of the most memorable quotes of the conference came from a UK orthopaedic surgeon who was talking about questions he had learnt to ask over years of treating haemophilia patients. Specifically discussing elbow issues and loss of movement and flexibility in this joint, he talked about asking patients "Can you reach both ends of your alimentary tract? That is, can you put food in, and deal with the other end when it comes out?". In a nutshell, this simple question highlighted the functional impact of joint bleeds and damage, and how patients and clinicians need to be open and honest about the issues they are facing, and help each other to set realistic goals and look for solutions together.

Seoul was a wonderful choice of location, and the Congress had plenty of South Korean influence throughout - some amazing catering, fascinating insights into the haemophilia treatment centres in Seoul, and a cultural show at the Congress dinner that had us all participating and clapping along. The Musculoskeletal Congress is an invaluable addition to the WFH calendar for clinicians with an interest in the impact of haemophilia on joint and muscle health, and the intimate nature of the Congress provides ample opportunity to meet people from other countries and discuss the management practices being used around the world. There is plenty of interest and exciting research coming up in this area, which can only be to the benefit of all people involved in the world of haemophilia – and it is so exciting that Australian clinicians have the chance to attend and learn from these events, and that HFA supports us in sharing that knowledge!

Johanna received partial funding from Pfizer and Novo Nordisk to attend the 2017 WFH International Musculoskeletal Congress.

Sumit Parikh is the AHCDO ABDR Senior Research Fellow

AHCDO PROPHYLAXIS STUDY

Sumit Parikh

> "Overall the proportion of patients receiving prophylaxis (according to disease severity and age) compared well with other developed nations."

Prophylaxis is considered standard of care in all children with severe haemophilia. However, the timing of commencement, dosing regimen and continuation of prophylaxis into adulthood varies for each individual patient.

Last year AHCDO conducted a large retrospective study characterising current practice with regards to the use of prophylactic clotting factor infusions in patients with haemophilia A and haemophilia B in Australia.

Overall the proportion of patients receiving prophylaxis (according to disease severity and age) compared well with other developed nations. Prophylaxis in children and young adolescents with severe haemophilia A and haemophilia B was near universal, which is an impressive achievement and cast a positive reflection on the delivery of multidisciplinary haemophilia care in Australia.

ADHERENCE

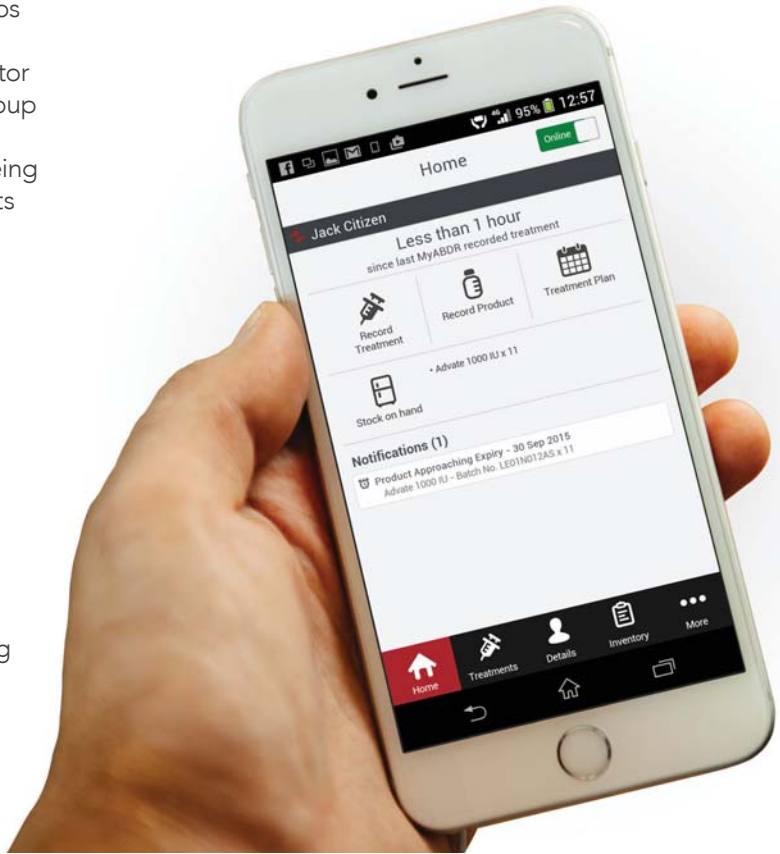
Adherence to prophylaxis among different age groups was also evaluated as part of the study and was determined by the ratio of observed to expected factor usage. Young adults were the most non-adherent group to prophylaxis and this was clearly evident from the results. As a consequence of this, despite patients being able to self-administer factor, non-adherence prevents them from achieving the real benefit of prophylaxis treatment (reducing bleeds and better quality of life).

This study provided a valuable insight into the current prophylaxis practice in Australia plus an opportunity to take this further and formally assess the real benefit of prophylaxis.

BLEED OUTCOMES AND MYABDR

The biggest challenge to formally assess the real benefit of prophylaxis is the need to actively monitor bleed outcome. MyABDR is a secure app for smartphones and a website for patients with bleeding disorders to self-record their home treatments and bleeds. However, the uptake of MyABDR has been disappointingly low, which means that a reliable assessment of how effective the prophylaxis treatment has been for patients cannot be determined.

There are a lot of resources and support material available for patients and their caregivers to assist in using the MyABDR application and its features and it is in everyone's best interests to take advantage of this and make the most of the application. This is because the usefulness of the 'MyABDR' application is not restricted to self-assessment but it also builds the knowledge base to be able to determine the effectiveness of various treatments provided to patients with bleeding disorders. The community could gain enormously with individualised prophylaxis, emerging extended half-life products and other novel treatment regimes, however this cannot be ascertained without being able to formally assess the treatment outcomes.



Suzanne O'Callaghan is HFA Policy Research and Education Manager

HEP C UPDATE

Suzanne O'Callaghan

It has been welcome news to hear from Haemophilia Treatment Centres that most of their patients with hepatitis C have now been treated or have appointments with their hepatitis clinic to discuss treatment, and that nearly all of those who have completed treatment have been cured.

HEP C REMINDERS

While the success of the new treatments has been very exciting, Australian hepatitis clinicians and Haemophilia Treatment Centres have a few reminders for people with hepatitis C:

- **Don't wait until you have symptoms of liver disease to start treatment.** Liver disease with hepatitis C can advance silently and you may not be aware that you are developing advanced liver disease such as cirrhosis or liver cancer
- There have been good cure rates for hepatitis C treatment in people with cirrhosis – BUT **treating hepatitis C BEFORE you develop cirrhosis** usually means a **shorter course of treatment and very high success rates**
- **Make sure you go back** to the doctor treating your hepatitis C or hepatitis clinic nurse **for your final results 12 weeks AFTER completing treatment**. This will tell you for sure whether your hep C has been cured. These treatments have not reached a 100% cure rate yet and if you have not been cured, you and your doctor will need to look at other treatment options
- **If you have cirrhosis and have successful treatment, you will still need to have liver health checks regularly** to check your liver health and keep an eye out for signs of advancing liver disease or complications that can be managed.

WHAT'S STOPPING YOU FROM TREATMENT?

The Australian Government has committed to eliminating hepatitis C in Australia by 2026. We believe we can achieve this much earlier in the bleeding disorders community.

If you have hep C, talk to your doctor about treatment. It's easy and it could save your life.

KEY MESSAGES

- Don't wait until you have symptoms of liver disease to start treatment
- Treating hepatitis C BEFORE you develop cirrhosis = shorter treatment course + very high success rates
- Make sure you go back for your final results 12 weeks AFTER completing treatment
- If you have cirrhosis and have successful treatment, you will still need to have liver health checks regularly

HFA is keen to make sure that every Australian with a bleeding disorder and hepatitis C has the opportunity to access treatment as soon as possible. We are aware that for some people there are barriers that stop them from accessing the new treatments.

If you or someone you know have a problem that is stopping you from accessing hepatitis C treatment, we strongly encourage you to talk to your Haemophilia Treatment Centre or your local Foundation or HFA to see what solutions can be found.

Thanks to Hepatitis Australia for permission to adapt the World Hepatitis Day 2014 poster.

NOhep

NEW HFA WOMEN'S BOOKLET

thefemalefactors

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

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

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

HOW TO OBTAIN THE BOOKLET

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

ACKNOWLEDGING THE EXPERIENCE OF WOMEN

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

"When I was diagnosed I felt gutted."

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

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

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

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

THE FEMALE FACTORS RESOURCES

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

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

And in development:

- Diagnosis
- Symptoms, treatment and care
- Family planning, pregnancy and birth
- Telling others
- nformation for teenage girls and young women
- For more information about the HFA ***The Female Factors*** project, contact HFA:
  Suzanne O'Callaghan (adult women) – socallaghan@haemophilia.org.au
  Hannah Opeskin (young women/teenage girls) – hopeskin@haemophilia.org.au
  T: 1800 807 173

Hannah Opeskin is Health Promotion Officer, Haemophilia Foundation Australia

YOUTH **UPDATE**

Hannah Opeskin

YOUTH LEAD CONNECT

Youth Lead Connect (YLC) is a leadership program developed by Haemophilia Foundation Australia (HFA) to build education and life skills for young people with bleeding disorders. The program began in 2015 and follows an application pathway similar to a job application process. The program encourages youth to step up in their local community and increase both their personal and leadership growth.

Youth Lead Connect participants are currently working with HFA and their local Haemophilia Foundations to develop appropriate goals and determine which achievements are best suited to their personal abilities and their Foundation's needs, as well accommodating for skills building and personal growth. This includes learning how to have a leadership or mentoring role in their local community, how to work with their local Haemophilia Foundation and achieve mutual goals and objectives. Participants also have an opportunity to experience and understand the processes that are involved with planning and developing appropriate activities including the role of Haemophilia Foundation Committees.

YLC participants gain unique knowledge into how their Foundation works and the ways in which important goals are driven. They work towards mutual goals with their Foundations and assist their Foundation, using their existing skills to increase their leadership and mentoring capacity or work on and develop additional skills.

Goals in the process of development include:

- Two youth and one mentor are working together and with their Haemophilia Foundation to assess whether there is interest for a youth event and how it should run. This has so far involved one youth writing an Expression Of Interest for the Foundation newsletter, and will also involve writing a proposal to Foundation. After an initial strategy meeting between the two youth, one youth will present to the Foundation Committee meeting on their findings and suggestions.
- Several YLC participants are writing a personal story for Factored In. Personal stories help youth connect with each other and are an important part of peer support, mentoring and leadership in the community.
- One youth is working with their Foundation to assist the Foundation's daily technology outputs and further utilise their technology skills. This includes assisting with the website, by helping keep it up to date with the latest information and documents.
- One youth is working with their Foundation to advocate for young people who live in non-metropolitan areas of their state/territory to be involved in a local youth event, including contributing ideas about suitable locations and activities.

HAEMOPHILIA & RARE BLEEDING DISORDERS CONFERENCE 2017

This year, the Australian & New Zealand Conference on Haemophilia & Rare Bleeding Disorders will be on 12-14 October and held in Melbourne.

Youth session – busting myths

Similar to previous conferences, there will be a youth session, but this time it will be a bit different! This session is all about busting myths to do with living with a bleeding disorder. The session will cover a wide range of topics including sport, employment, discrimination, sex, tattoos and more.

The only way you'll find out what the truths are, is if you attend!

There may be some funding available, so if you're interested in attending the conference, visit the HFA website: www.haemophilia.org.au for more information about how to apply.

YOUTH NEWS

GEOFF

Travelling is one of the most rewarding experiences I believe you can have in life. It is important you don't let your haemophilia stop you from exploring the world! I myself have haemophilia and I am a massive believer in not letting that get in the way of anything. A few simple steps can be taken to ensure that you are able to stay on top when away from home.

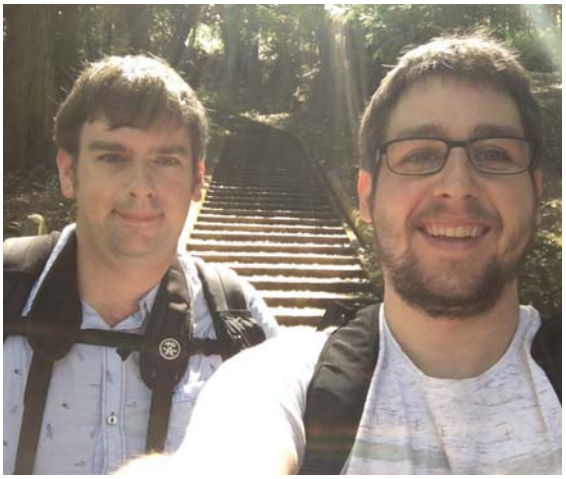
*I encourage you to speak to your Haemophilia Treatment Centre about where you plan to travel. They will be able to help you prepare any documents that you need and they will be able to help you plan for your visit and let you know what to do and how to be prepared for particular countries or airlines.***

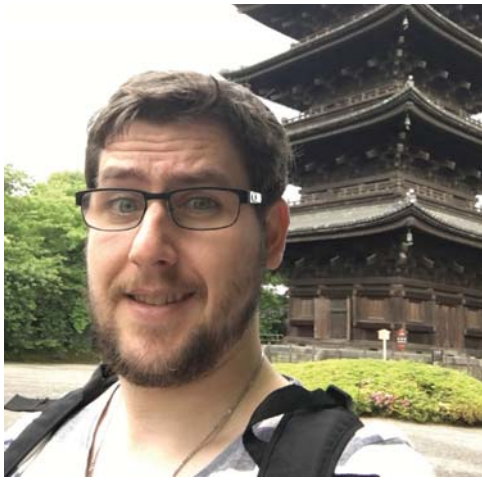
When transporting product, chances are you don't want to end up in a foreign prison! Best way to avoid any hold ups is to ensure you have tonnes of documentation explaining why you have the gear. I just declare my treatment to anyone who might find it in my bag. I find language barriers can cause confusion, so being overtly open about transporting medication defuses any possible issues. Again, your Haemophilia Treatment Centre will be able to provide you with all the necessary documentation about your treatment.

The least fun thing to have in the back of your mind but perhaps the most important, is to be a little bit careful. You are likely thousands of kilometres away from home and when travelling it is easy to get carried away in a good moment. The last thing you want to do is end up with a bad injury in a foreign country; immerse yourself in the culture and experience everything you can, but it pays off to double check your decisions.

Get out there!

YOUTH TRAVEL STORIES





SAM

I have severe haemophilia type A, and I formerly had an inhibitor, which was treated when I was 15. But, long story short, I am now on prophylaxis and my friends and I recently decided that we would like to travel to Japan for 5 weeks over the December-New Year period.

Which meant that I would now have to work out how I was meant to transport what amounted to a "Shedload" of factor VIII, and what, if any regulations there were for

1. Taking factor out of Australia, and
2. What Japan required in order to bring it into the country.

GETTING ORGANISED

My first port of call was my Haemophilia Treatment Centre and the team and my second port of call was the Japanese Embassy.

In terms of taking factor out of Australia, there weren't any documents which I needed to complete. However, you should always double check to make sure this is the case with your treatment team and social worker.

BUT I was required to complete documents in order to bring my factor into Japan. The application is called a Yakkan Shoumei, and the form basically required me to complete it, and provide some documentation and information about the products, a letter from my specialist confirming I needed the products, and to advise how much I was bringing into Japan (also including details about needles, syringes and alco-wipes), and my flight details (when I was arriving and leaving).

I had to post this to Japan, including with it a self-addressed envelope, and a "Coupon international de réponse" (basically a stamp which they use on your envelope to return the certificate back to you).

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YOUTH NEWS

SAM CONTINUED...

MY PLAN FOR PACKING

I did take one spare treatment with a couple of spare syringes and needles "just in case".

But all was well, kind of, my application was approved, and I was ready to move forward with planning my trip. But I had to pack a lot of factor. I also had to pack a sharps container and warm clothes, because as you might not know, Japan is in the northern hemisphere, and December/January is actually winter time.

And while some might be travelling for skiing, I was sightseeing with friends. So I had to fit all of the above with jumpers, long sleeve shirts, pants and jeans, scarf, puffy snow jacket, thermal cloths, boots (hiking boots) sock and undies, and my regular toiletries for 5 weeks of travel, and any cords for the electronic items I was going to take as carry-on (psp, phone, camera, Wi-Fi router, power board & power plug converter).

Not an easy feat. Not even mentioning one very important factor (pun intended). My factor needs to be refrigerated. Some of you may have seen the fridges which you get at hotels… How the "heck" was I going to fit all this in a tiny fridge while travelling?

Well I had a plan! While I was required to arrive with my factor packaged up "as is" in the event that it was checked, I would arrive and re package it myself when I arrived at the hotel on the first night, and through some trial and error I found I could fit it all.

And the great thing was, as the trip progressed the amount of factor and equipment reduced even more, until it was all gone, and the "oh no my trip is over" reality hit back in, and all the space formally reserved for factor was taken up by gifts, toys and other random items.

TRAVELLING AROUND JAPAN

During this trip my friends and I travelled from Sydney to Tokyo to Hiroshima to Osaka to Nagano to Tokyo to Kyoto to Osaka to Mount Fuji to Tokyo back to Sydney.

And while this does look somewhat backwards and forwards, and it is, we were travelling with only a rough plan, which left us with several days which were completely unplanned. I wouldn't recommend this, but we did it anyway, and we decided on and booked these unplanned days roughly half way through our trip, which ended up being an extra day in Osaka, and a trip to Mount Fiji (where we were snowed in by a blizzard but it was a great time all the same).

During this time, we stayed in regular hotels and Ryokans (Traditional Japanese Hotels), and I made sure to check that they all had a refrigerator in them, and in the event I wasn't sure, I contacted the hotel and asked.

While I'm sure that's enough to make you never want to travel, I will say, I went back again this year, following the same process, but this time in spring to catch the end of the Cherry Blossoms in April/May for 3 weeks.

While very few people would say travelling is easy when you have a bleeding disorder, it is good to know that it can be done. All it takes is a little bit of planning and preparation!

So don't let it hold you back from exploring the wide world, and having your own adventures.

PLANNING TO TRAVEL?

Don't forget about travel insurance.

You may be asked to disclose that you have a bleeding disorder and pay a higher premium. Shop around to find the best cover. Make sure you read the fine print and know what you are covered for, and what you aren't (such as riding a motorbike).

For overseas travel you will need documentation for customs and security.

Talk to your Haemophilia Treatment Centre about this at least 3 months before you travel so you have plenty of time to prepare.

* * **Keep in mind that travelling in a developing country can be challenging and many countries don't have haemophilia treatment centres – and there may be no access to clotting factor.**

You might be surprised to learn that the level of care is not the same as what you are used to, or there are costs involved for medical care. It is important to talk to your Haemophilia Treatment Centre as they will be able to help you plan and advise you on what needs to be done and help with the medical documentation required.

Are you travelling soon?
Not sure where to start? Or do you just want to check you have everything you need?

Visit **factoredIn.org.au on** what to do and who to talk to.

Factored In has all the most up to date information about travelling when you have a bleeding disorder - check out the TRAVEL section.

Are you planning to travel overseas?
Do you know what visa you need?

If you want more information, have a good look at the Australian Government website **smarttraveller.gov.au** for advice on travelling to specific countries, visas including studying overseas and things to aware of in the country you're travelling to.

Visit Factored In at www.factoredin.org.au to read the full story of Sam's trip to Japan and other youth stories about their travelling experiences.

CALENDAR

Haemophilia Awareness Week
8-14 October 2017
Tel: 03 9885 7800
Fax: 03 9885 1800
Email: hfaust@haemophilia.org.au
www.haemophilia.org.au

18th Australian & New Zealand Conference on Haemophilia & Rare Bleeding Disorders
Pullman Albert Park, Melbourne
12-14 October 2017
Tel: 03 9885 7800
Fax: 03 9885 1800
Email: hfaust@haemophilia.org.au
www.haemophilia.org.au

World Haemophilia Day
17 April 2018
www.wfh.org/whd

XXX111 WFH World Congress, Glasgow, Scotland
20-24 May, 2018
https://www.wfh.org/congress

Haemophilia Foundation Australia (HFA) values the individuals, philanthropic trusts and corporations which have made donations to support education activities and peer support programs and Corporate Partners that sponsor programs to enable HFA to:

- represent and understand the needs of the community
- provide education and peer support activities to increase independence and the quality of lives of people with bleeding disorders, and their families
- encourage clinical excellence in haemophilia care, and promote research.

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PROBE STUDY UPDATE

PROBE
Patient Reported Outcomes Burdens and Experiences Study

Some of you participated in the PROBE study phase 2 between September 2016 and February 2017 and we would like to thank you for taking the time to complete the survey.

The multi-national PROBE (Patient Reported Outcomes Burdens and Experiences) Study aims to give HFA and other haemophilia organisations around the world access to good quality data about the treatment and health experiences of people with bleeding disorders.

HFA is working with the global PROBE team of patient and academic investigators, including Mark Skinner, former WFH President, and Assoc Prof Alfonso Iorio from McMaster University, Canada, to test the research methodology in haemophilia and allow people with haemophilia to report their haemophilia severity, treatment history and the impact of haemophilia on their daily life.

PHASE 2
Phase 2 of the PROBE study aimed to test:

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

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

Assoc Prof Alfonso Iorio's research team at McMaster University, Canada is currently analysing the results from Phase 2. We will report the results in *National Haemophilia* and on the HFA website later this year.

PHASE 3
Phase 3 of the PROBE study is the final stage of rolling out the study to people with haemophilia around the world, country by country. The work on Phase 3 will commence once Phase 2 has been completed and analysed. Watch this space!

Haemophilia Foundation Australia acknowledges the funding and assistance received from the Australian Government Department of Health which makes this publication possible.