

National Haemophilia

Haemophilia Foundation Australia

www.haemophilia.org.au

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THE LARGEST
INTERNATIONAL
MEETING FOR
THE GLOBAL
BLEEDING DISORDERS
COMMUNITY

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NATIONAL WEBSITE LAUNCH



Haemophilia Foundation Australia is excited to announce the launch of our new website www.haemophilia.org.au.

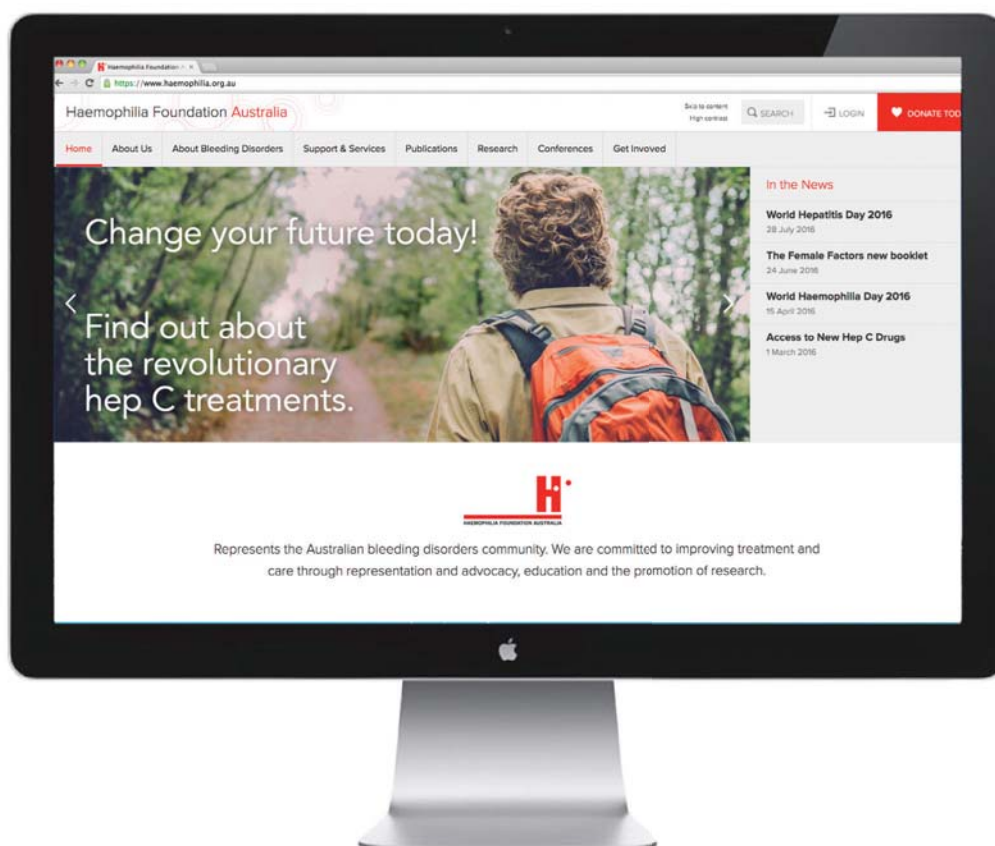
Please have a browse on our new website and explore the information. We hope you like the new look and feel.

This project is an initiative for both HFA and State/Territory Foundations and is the result of several years of concept development with HFA Council. With the agreement of State/Territory Foundations this project

has also resulted in new websites for all State/Territory Foundations, with a consistent style and some shared information, for example, information on bleeding disorders provided by HFA.

The Factored In youth [website www.factoredin.org.au](http://www.factoredin.org.au) was also redeveloped and this went live in May 2016.

This project has been made possible by a grant to HFA from the Australian Government Department of Health. 





FROM THE PRESIDENT

Gavin Finkelstein

TREATMENT PRODUCT SAFETY

It was interesting that the World Hemophilia Congress in Orlando was held not very far from the Kennedy Space Centre, in Florida. Unfortunately I didn't have a spare day to travel to the visitor centre there, while in Orlando, but many Congress delegates did take a day tour and have talked about their informative and fascinating visit. People involved in space flight and investigation take what most of us would see as enormous risks in their work. One of the Congress speakers was Michael Lutomski, a former employee at NASA who talked about assessing and managing risk in space. The disasters of the Space Shuttle Challenger Program and the HIV/AIDS contamination of blood products in the 1980s taught us many lessons. The catastrophic outcomes in both areas demonstrates the importance of how risk is approached, tolerated and managed. Continuous risk assessment and management is a core principle for treatment product safety.

We now have safer treatment products for bleeding disorders since those dark times. HFA will not forget the experiences of Australian men and women who continue to live with the consequences of blood safety problems in the past. Currently, we are working with the community to ensure prompt access to the new direct acting antiviral (DAA) treatments for hepatitis C. As we also look to the future, lessons from Australia and around the world continue to remind us that we should not be complacent. What will haemophilia treatment and care look like in Australia? What should it look like? These are two very different questions. Are we aspiring to world's best practice?

EMERGING TREATMENT PRODUCTS

Later in this publication I reflect upon the emerging new treatment products. The development of recombinant clotting factor products a generation ago marked the availability of new treatment products, that were not only considered potentially safer than their plasma alternatives because they were manufactured in laboratories but this promised increased supplies. This became true for developed countries like Australia but World Federation of Hemophilia (WFH) still estimates 70% of the worlds' bleeding disorders population

remains undiagnosed or untreated partly because of their high cost. We have a long way to go in that respect and I am deeply committed to steps HFA can take to contribute to WFH's work.

But globally, change is around the corner. Gene therapy has been 20 or more years away for most of my adult life. We are getting closer, with promising reports, but I believe it will still be some time before it is safe, effective and affordable. However extended half-life clotting factors are now used in several countries. They are not funded in Australia by governments, but the experience of people who remain on extension studies following their participation in clinical trials tell us of their experiences. Extended half-life means less infusions. This has a great impact on the lives of many who tell us it is not just a convenience factor – they already know they are having less time off from work or school. Some report more effective management of their bleeding disorder due to the way the product works in their bodies and the closer relationships and monitoring with their treaters – and their files are starting to show they have less bleeds every year. This is good for them and in the long run, must surely be good for the budget for clotting factors! HFA is very keen to make sure the Australian patient community has timely access to a range of treatment products and we will work with clinicians and governments to ensure we do not fall behind.

NEW TREATMENT GUIDELINES

The recent publication of the *Guidelines for the management of haemophilia* in Australia by the Australian Haemophilia Centre Directors' Organisation (AHCDO) in collaboration with the National Blood Authority (NBA) - with its focus on the importance of comprehensive care for people with inherited bleeding disorders - is a positive step towards achieving best practice for all in our community. The recommendations of this publication alongside our commitment to the Australian Bleeding Disorders Registry (ABDR) and to MyABDR, so that the data recorded by individuals about their bleeds and treatment can be used by them and their treating health professionals to better understand their treatment needs, is critical to achieving this. ■

Help improve the lives of people with a bleeding disorder and support **Red Cake Day** during **Haemophilia Awareness Week**



*We are calling on our friends and supporters to take part in **Red Cake Day** during **Haemophilia Awareness Week!***

Red Cake Day during Haemophilia Awareness Week is an opportunity for individuals and families as well as Haemophilia Foundations and other organisations to take part in a campaign to raise funds and awareness about haemophilia, von Willebrand disorder and other bleeding disorders during the week of **9-15 October 2016**.

To order your free promotional items, download an order form from www.haemophilia.org.au or email donate@haemophilia.org.au

GET IN QUICK - STOCKS ARE LIMITED!

How can I get involved?

- Organise a **Red Cake Day** at your home, workplace, school, kinder or community group.
- Order free napkins, pens, tattoos, stickers and colouring sheets and pencils to make your **Red Cake Day** extra special!
- Display free posters, postcards and newsletters and raise awareness about haemophilia, von Willebrand disorder and other bleeding disorders.
- Tell all your friends, family and colleagues about **Haemophilia Awareness Week** and encourage them to hold their own **Red Cake Day** event!



Like HFA on Facebook
www.facebook.com/RedCakeDay



Follow HFA [@Haemophilia_Au](https://twitter.com/Haemophilia_Au) and join the conversation at [#redcakedayhaemophilia](https://twitter.com/redcakedayhaemophilia)



HAEMOPHILIA FOUNDATION AUSTRALIA

For more information on Haemophilia Awareness Week and Red Cake Day, visit www.haemophilia.org.au or call HFA on 1800 807 173



Connecting the Dots

Haemophilia Awareness Week
9-15 October 2016

HAEMOPHILIA AWARENESS WEEK

Haemophilia Awareness Week is an opportunity for individuals and families as well as Haemophilia Foundations and other organisations to take part in a campaign and activities to raise awareness about haemophilia, von Willebrand disorder and related inherited bleeding disorders throughout Australia during the week of 9-15 October 2016.

HFA is calling on our friends and supporters to help us celebrate Haemophilia Awareness Week by taking part in **Red Cake Day!**

FREE PROMOTIONAL ITEMS

To order your free promotional items, visit www.haemophilia.org.au/redcakeday



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www.facebook.com/RedCakeDay



Follow HFA [@Haemophilia_Au](https://twitter.com/Haemophilia_Au)
and join the conversation at
[#redcakedayhaemophilia](https://twitter.com/redcakedayhaemophilia)

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- Tell your friends, family, colleagues about Haemophilia Awareness Week and encourage them to hold their own Red Cake Day event!

Once again Bendigo Banks across Australia will be supporting Red Cake Day. Pop into your local branch during the week.

FOR MORE INFORMATION

- visit www.haemophilia.org.au/redcakeday
- or call HFA on 1800 807 173
- or email Natashia ncoco@haemophilia.org.au.



WFH 2016 WORLD CONGRESS

The World Federation of Hemophilia 2016 World Congress was held in Orlando, Florida, USA from 24 to 28 July 2016.

The WFH World Congress is the largest international meeting for the global bleeding disorders community. Health professionals, researchers, scientists, government and industry representatives come together with national haemophilia organisation leaders, and other people with bleeding disorders and their families to discuss and learn about the latest issues in bleeding disorders. Presentations, workshops, symposia, and exhibits feature

cutting-edge trends in research and treatment and care for bleeding disorders, as well as the experience of the person with a bleeding disorder. In addition, the Congress provides many opportunities to network, share experiences and make new friends during the social events.

In this special Congress feature, Gavin Finkelstein, HFA President, and some of the Australian haemophilia health professionals and researchers who attended give a snapshot of some of the key sessions in their interest areas. **H**



REFLECTIONS ON THE CONGRESS

"Sometimes as a clinician in bleeding disorders - and at times as expressed to me by my patients - it can feel quite isolating and like you are the only one. For me, having the opportunity to participate in such a unique conference has been simply inspiring. Finding myself immersed and part of this community where individuals are so dedicated, innovative and engaged gives me a new sense of purpose and fresh fuel to continue to work within this special area of haematology."

James Slade, Advanced Practice Nurse, Haemophilia & Bleeding Disorders, The Canberra Hospital

*"As I write this, bleary-eyed and sleep-deprived from staying up all night watching our Australian athletes compete at the Rio Olympics, I reflect on my attendance at the World Congress and can't help but draw so many parallels between the two events. At the Olympics, there are 11,559 athletes, representing over 200 countries and at the Congress over 5,500 participants representing 130 countries. Both the athletes and the people with bleeding disorders are supported by a team of family, medical personnel, researchers, scientists and administrators, all with the one goal of working together to maximise the outcome. The President of the International Olympic Committee, Thomas Bach, revealed the Rio 2016 Olympic Slogan as **Un Mundo Novo – A New World**. The New World speaks of new friends, creating new families, breaking down barriers, adopting new attitudes all based*

*upon the desire to change. How similar to the WFH vision of **Treatment For All** in which one day, all people with a bleeding disorder will have proper care, irrespective of where they live."*

Ali Morris, Senior Musculoskeletal Physiotherapist, Princess Margaret Hospital for Children, Perth

"I am excited to see that the new treatment possibilities are turning into realities. After so many years of attending World Congresses and hearing about these treatments as hypothetical, optimism is now giving way to real world studies. I am hoping to see these treatments brought to Australia and that this will translate into a robust discussion with a focus on best practice treatment and outcomes for each person receiving treatment."

Sharon Caris, Executive Director, Haemophilia Foundation Australia

HOST COUNTRY NETWORKING RECEPTION

To provide a relaxed but energising environment for Congress delegates to meet and talk with each other, the host country organised a reception at one of Orlando's world-renowned attractions: Epcot, a theme park at the Walt Disney World Resort. Australian delegates took the opportunity to catch up with some of their international colleagues – and to take a trip down memory lane with some of their favourite cartoon characters. **H**

Sumit Parikh and Minnie Mouse



Ali Morris with Pluto



Suzanne O'Callaghan is HFA Policy Research and Education Manager

CONGRESS: AN INTERVIEW WITH GAVIN FINKELSTEIN

Gavin Finkelstein, HFA President, spoke with Suzanne O'Callaghan about his experiences at the WFH Global National Member Organisation (GNMO) training and the World Congress

Suzanne: What was your overall impression of GNMO training?

Gavin: As always, it was great to meet the other GNMO delegates – to spend time with them, to see what is happening in everyone's countries, to swap ideas. A lot of sharing also happens outside the sessions when you are chatting afterwards; for example, we spent some time after a session on volunteering discussing how you get people involved in your organisation.

The GNMO training was handled a little differently this Congress. It was at the Gaylord Palms Resort and Convention Center, which is where the National Hemophilia Foundation (NHF) Annual Meeting was being held. GNMO members shared some of the scheduled NHF sessions and were invited to visit the events like the NHF Meeting opening ceremony and the trade exhibition.

The NHF Meeting was larger than the conferences we are used to in Australia, with about two thousand delegates. And the trade exhibition really highlighted how differently the health system works in the USA. Insurance companies play a large role in treatment decisions as they pay for the treatments, and pharmaceutical companies market their products directly to the patient and their family. Being used to the system in Australia where the discussion about which treatment product is best for you is between you and your doctor and pharmaceutical companies are not permitted to promote prescription medicines to the general public, that is, to patients, it was quite confronting for me to see the type of promotional merchandise used to market treatments to patients – to children and their parents. We don't see promotional merchandise branded for prescription medicines in Australia and there was not as much of a focus on the medical benefits of the treatments as I am used to.

Suzanne: What sessions stood out for you?

Gavin: There was a plenary on haemophilia treatment by Glenn Pierce, a man born with haemophilia who is a US doctor on the WFH Executive Board, and has worked for many years in haemophilia biotechnology

research and development. He started at the beginning of haemophilia treatment and covered the last 70 years of development, right up to where we are currently and what the future holds. It was really well done: he was very clear and explained things like what factor deficiencies are with diagrams, and included information that was relevant to everyone, which was great for such a diverse audience.

There were also other good sessions. There was a session on outreach and engaging with rural and remote communities and the role of foundations in supporting the Haemophilia Centre work to identify where patients are located and individualising their management plan to suit their location. This is important to help to prevent health problems for them in the future. There was another good session on strategic planning, and I am following up on the information from that as it's a difficult area for everyone. Some of the American chapters do very good work in social media, so there is also information to learn from there.

Suzanne: What was the most memorable aspect of the World Congress?

Gavin: I found it to be a very interesting Congress. It seemed to me that there were a lot more sessions on different classes of treatment products and that the emerging products presented are more diverse and innovative. These ranged from the extended half-life products to the other new treatments that are injected sub-cutaneously rather than into a vein. Gene therapy was another interesting area. It has been a long road, with some encouraging results now – but the question of when it is likely to be available still remains, with a common view being that it is still about 10 or more years away. There are also a few new bypassing agents for inhibitors that can also be used by people without inhibitors and may become more generally available.

Suzanne: You attended the session on hepatitis C treatment. What were the take home messages?

Gavin: The presentations on hepatitis C were fascinating. As in Australia, they were talking about eliminating hepatitis C completely: with a very simple treatment that has few and minor side-effects and success rates of more than 90%, there is a real opportunity now for everyone to have treatment and



potentially be cured. Once the bulk of people have been treated, the issue in the future will be about prevention because the treatment is working really well.

At Congress there were very few people who had completed treatment and not been cured, which is fantastic for the bleeding disorders community. Hep C treatment is having a significant impact in Australia – but also developing countries are having great results, because the multi-level pricing structure has meant that it is affordable there. Over the last 12 months the availability of these new treatments has exploded worldwide, and this has meant we are getting a much better sense of the typical experience: people have been waiting for these treatments to become available and have now started to access the treatment, and they tolerate it well, they continue working and live their life as they normally would. A few new hep C treatment products were also discussed – for example, velpatasvir, which has high cure rates for all of the different genotypes. This includes improved cure rates in genotypes 2 and 3, which is significant because some of the existing treatments have been a bit less effective in these genotypes. But what this means is that there is a range of treatments now, so that treatment can be individualised for more effective results.

Gerard O'Reilly from Ireland told his story to give the patient perspective and I found this to be quite inspiring. I have known him for quite a few years and he has lived through some awful times. In many ways the things he said in telling his story epitomises the stoicism and toughness of our community. He has HIV and hep C, he ended up having cancer and a liver transplant, and he is still going along and smiling and living his life. He told the story about his recent treatment experience. After his liver transplant, he had hepatitis C treatment, but unfortunately, with the extra complications of a transplant, relapsed after treatment. He expects to start retreatment in September. His story about his treatment made the whole experience real – it's really important to have this perspective as well as the technical information. And it highlights the importance of treating hep C for people who are co-infected, because now that their HIV is often well-managed, it is the hep C that is dangerous to their health.

In Gerard O'Reilly's presentation he commented that the cost of hepatitis C treatment is prohibitive in Ireland and I was very aware how fortunate we are in Australia to have the new hepatitis C treatments available to everyone

on the PBS. A key message for me was that we have this window of opportunity for hep C treatment, and we as individuals need to step up and take action now. Treatment is now in tablet form so it's not difficult to manage in your life. So I think it is terribly important that everyone does take the step to access treatment – it's a responsibility to yourself; to make the difference to your life.

Suzanne: Which other sessions did you find valuable?

Gavin: There was an interesting session on ageing; they discussed the need for older men to take advantage of the benefits of what the new treatments can bring them – and the improvements to their quality of life and their length of life; but also the need to educate the younger generation about what the older guys have experienced so that they understand their own community and celebrate their achievements, and understand that the work to advocate for best practice treatment will continue for their generation as well.

The other important session was the women's issues. The issues that they face are very different to men, with both their bleeding problems and how individualised their treatment plan needs to be. The Congress session highlighted that so many factors need to be taken into account over their lifetime, with changing hormone levels, menstruating, whether they are pregnant, growing older, menopause etc. In the last 10 years we have become more aware of the issues for women, and it is a very significant area for our community. Aspects of this are new in many ways, and I am really conscious that we need to work together closely with our community and our expert health professionals to understand and improve the situation for all women in our community.

Suzanne: Why do you think the World Congress is important?

Gavin: The World Congress brings everyone from around the world together and you feel very much part of the global community. Everyone is working together with a single goal of dealing with bleeding disorders and how best to manage them. Coming together and seeing people from other countries and how they deal with adversity is what drives us onwards – it's inspiring and hearing what others face gives us a real perspective on our own issues. ■

James Slade is the Advanced Practice Nurse, Haemophilia & Bleeding Disorders at The Canberra Hospital. He works as part of the Haemophilia Treatment Centre team caring for both paediatric and adult patients diagnosed with a bleeding disorder

CONGRESS – A NURSING PERSPECTIVE

The WFH World Congress is an opportunity for clinicians from all fields of care, patients and their carers along with industry to share their research, innovation and ideas on a global stage. The Congress provides an incredible learning opportunity that for me resonates long after its conclusion.

NURSES PROFESSIONAL DEVELOPMENT DAY

Sunday was set aside as an opportunity for professional development, with a nursing workshop set around key areas of treatment. This year there was also an interesting opportunity to discuss with the editors of the journal *Haemophilia* who provided tips on getting your research published. For the first time this year the WFH nurses working group were able to incorporate nursing sessions daily, as well as a full day's workshop on Sunday, providing us with an even greater platform for presenting our work. This is a trend I hope is continued in Congresses to come.

FREE PAPERS: CLOTTING FACTOR CONCENTRATES

A couple other sessions that were further highlights for me were surrounding new and innovative products currently under clinical trial: one for haemophilia B and the other for haemophilia A.

Once-weekly dosing with a long-acting glycoPEGylated factor IX, nonacog beta pegol (N9-GP), maintains time with high mean trough levels in previously treated adult, adolescent, and pediatric patients with severe/moderate hemophilia B – Results from two phase 3 clinical trials

– Guy Young, USA

Dr Guy Young on behalf of his group presented updated data on two phase 3 clinical trials for a long-acting factor IX product. The focus of this presentation was on going beyond the current common idea that prophylaxis with standard factor IX should be aiming at trough levels above 1%. Dr Young asked are we setting targets too low and with the use of longer acting products could we as a treating team aim for trough levels greater than 15% and what would this mean for our patients. The results of this trial are encouraging: in two of the phase 3 trials the N9-GP factor has been providing effective once weekly prophylaxis in both adults and adolescents as well as in children. The thoughts behind these trials were aiming to increase trough levels while keeping to a minimal infusion schedule, but at the same time maintaining or exceeding current expectations of treatment. So far results are very exciting and encouraging with the once weekly regime potentially shifting patients from a severe/moderate haemophilia B range into a non-haemophilic range for a substantial time period throughout the week.

Updated results of an ongoing long-term phase 1/2 study of emicizumab (ACE910) in hemophilia A patients with or without inhibitors

– Keiji Nogami, Japan

Another exciting product in development is the ACE910 monoclonal antibody that was created as a humanised bispecific agent (binding to two different agents in humans) against factor IXa and factor X. Its main purpose is to mimic activated factor VIIIa – to carry out a key role in the clotting cascade that is normally carried out by factor VIII, which is deficient in haemophilia A. Factor VIIIa is the activated FVIII molecule which then continues the activation pathway in the coagulation cascade. The principle of this bispecific antibody is based on the hypothesis that, in the chain of steps in the clotting cascade where factor VIII is a co-factor for factor IXa (the activated form of factor IX), the next steps in the clotting cascade are enhanced by interactions between factor IXa and factor X. ACE910 is therefore designed to promote blood clotting in people with haemophilia A, and – because it is different in structure to factor VIII, it is anticipated that it will not create inhibitors to factor VIII.

Pharmacokinetic parameters indicated that the half-life of ACE910 was approximately 3 weeks for both single intravenous and subcutaneous administrations which in the current and future potential of haemophilia A treatment is very exciting. It was also presented that effective haemostatic levels might be maintained by once-weekly subcutaneous (injection just under the skin) administration of ACE910. Being able to inject subcutaneously is an important option for people with haemophilia A who are struggling with vein care. ACE910 can be used to treat both people with or without inhibitors effectively.

CONCLUSION

This is the second time I have had the opportunity to attend a WFH World Congress; the first was Melbourne in 2014 when my involvement in bleeding disorders had only just begun. WFH Congress in Orlando this time around was truly inspiring, providing on more than one occasion information overload, and further highlighted that there are nowhere near enough hours in the day to do it all. Yet it is comforting to know that there are so many of us that work so hard and are just as passionate about bleeding disorders to continue to produce such high quality education as demonstrated here. Bring on WFH Congress 2018 in Glasgow Scotland. 🏠

Alison Morris is Senior Musculoskeletal Physiotherapist at the Princess Margaret Hospital for Children, Perth, Western Australia

A PHYSIOTHERAPIST'S PERSPECTIVE

The Conference organisers had put together a fantastic program of plenary and discipline-specific sessions combined with a large number of excellent poster presentations, satellite symposia and a full schedule of social events. For me, the greatest challenge each day was to decide which sessions to attend.

Achieving the impossible: The Marathon Experience – Luigi Solimeno, Italy

Prior to the opening of the Congress, I attended the Musculoskeletal Professional Development Day with a presentation by Dr Luigi Solimeno from Italy. In 2015, he ran alongside eight of his bleeding disorder patients as they completed the New York Marathon. These eight men all with haemophilia (4 severe, 2 moderate and 2 mild) were aged between 23 and 51 years of age and had a wide range of joint pathologies including multiple joint replacements. They undertook a comprehensive 12 month training program under the guidance of a physiotherapist before completing the event. Issues, challenges and complications were openly discussed including one runner sustaining a stress fracture of his femur, which subsequently required joint replacement.

The presentation elicited considerable discussion including some strong criticism from those in the audience that felt that this project was ethically wrong. The Italian team reiterated that they were definitely not advocating all people with haemophilia could or should complete these types of events; it just demonstrated what could be achieved by a dedicated and motivated group of individuals with a structured, well supervised physical preparation and adequate treatment/prophylaxis. I was unsure where I sat regarding the ethics of the project. However, I envisage that in the future, as the younger generation grow up with less or ideally no joint pathology, we are going to see more and more of them choosing to follow their dreams of participating in events in which they may have been previously excluded. The take home message is to liaise closely with the Haemophilia Treatment Centre team in discussions regarding physical activity.

Engaging people with hemophilia through the use of Point of Care Ultrasound – Sandra Squire, Canada

Point of Care Ultrasound (POC-US) was the focus of multiple presentations and posters at the Congress and it was exciting to see the progress that has been made in incorporating this into standard care in countries such as

“Findings of a pilot study showed that the patients valued the opportunity to visualize the status of their joints and this led to better engagement.”

the USA, Canada and the UK. POC-US is an ultrasound examination designed to complement a physical examination. It is performed and interpreted in the clinic setting, therefore being time and cost effective. When following specific protocols, it is reliable for evaluating and monitoring joint status over time and in differentiating between a bleeding joint and arthritis. In addition to providing another objective measure of joint status of the ankle, knee and ankle, a major benefit of POC-US is the increased patient compliance that appears to be associated with it.

Vancouver physiotherapist, Sandra Squire, gave an exciting presentation the use of Point of Care Ultrasound to engage people with haemophilia in their care. Findings of a pilot study showed that the patients valued the opportunity to visualize the status of their joints and this led to better engagement. Patient adherence with physiotherapy treatment protocols following muscle and joint bleeds was also thought to be improved using this visual feedback tool. Physiotherapists know that pain is an unreliable measure to guide return to activity and using POC-US to show resolution of bleeding could be extremely helpful. The need for quality assurance, training and recognition of the limitations of POC-US was conveyed by a number of the presenters and was also raised frequently by members of the audience.

A number of Australian physiotherapists have recently undertaken training in the performance of some aspects of POC-US and are involved in the implementation of hospital protocols around its use and the purchase of suitable machines. Ask the physiotherapist at your Haemophilia Treatment Centre about the current state of play regarding this exciting tool.

Role of Family: Prophylaxis a right, a duty, a choice? – Megan Adediran, Nigeria

Having positive role models is an important part of an individual's personal development and there was no

“In addition to the **fantastic educational sessions**, there was also a **full social program** providing opportunities to catch up with friends from **around the world**, make new ones and **develop new professional links**.”

shortage of role models presenting at the WFH Congress. Those that attended the Melbourne Congress in 2014 may remember the passionate speech Megan Adediran gave at the Opening Ceremony. Megan told of her personal fight to gain access to treatment for her two young sons born with severe haemophilia, involving personally writing to over 60 Federations asking for assistance. She subsequently became the founder of the Haemophilia Federation of Nigeria and has worked tirelessly to promote access to care ever since. This speech had a profound impact on me and it was therefore with great excitement that I looked forward to her presentation on prophylaxis. Again she didn't disappoint, despite a technical issue resulting in her slides not loading. Undeterred, she proceeded to tell another heart wrenching story of a young girl, with no consistent access to factor, facing amputation of her lower limb to manage a pseudotumour. Megan advocated for the family, managed to secure regular access to factor and a promise of a period of conservative treatment. The end result was that the young girl has now returned to school and is participating in normal childhood activities!!

Plenary - Empowerment through self-care

- Patrick Lynch, USA

Patrick Lynch is another young man who ticks all the role model boxes especially for those young men growing up with a bleeding disorder. In his presentation he started by outlining his struggle in accepting his brother's death as a result of an intracranial bleed whilst at University. Why had his brother, who had the same condition, was brought up in the same environment with the same education made the decision to stop his prophylaxis/self care regime – an act that Patrick would never have considered? Patrick has subsequently gone on to redefine self care from complying with your treatment regime to giving back to and empowering the community. Based upon the TV series, *The Office*, he has filmed a mini-series *Stop The Bleeding* which uses humour in an attempt to engage young people at risk.

In addition to the fantastic educational sessions, there was also a full social program providing opportunities to catch up with friends from around the world, make new ones and develop new professional links. Since returning, I have already received emails from physiotherapists in the Netherlands and the USA providing further information on innovative treatment approaches. Overall, the World Congress was an amazing five days from which I benefitted so much both educationally and personally. I would like to



Left to right: Charlotte Bradley-Peni (Senior Social Worker, Perth), Gavin Finkelstein (President, HFA) and Ali Morris at the Networking Reception at the Epcot Centre Disneyworld

thank HFA for their financial assistance in enabling me to attend the Congress and look forward to getting back into the hospital and playing my small part in improving the lives of those in Australia living with bleeding disorders.

Alison was funded by HFA to represent the Australian and New Zealand Physiotherapy Haemophilia Group at the WFH 2016 World Congress. #

Charlotte Bradley-Peni is the Senior Social Worker at the Haemophilia and Haemostasis Centre, Fiona Stanley Hospital and Haemophilia Treatment Centre, Princess Margaret Hospital, Perth

A PSYCHOSOCIAL PERSPECTIVE

Charlotte Bradley-Peni

Haemophilia Foundation Australia recently provided me with the opportunity to attend the World Congress in Orlando, Florida 2016. It was a pleasant surprise to find that unlike other large international meetings the community played a major role in bringing the Congress together. During the build up to my attendance I made the decision to focus on transition as a major psychosocial learning goal. However as day one progressed so too did my understanding.

PSYCHOSOCIAL PROFESSIONAL DEVELOPMENT DAY: LET IT GO

Chair: Anne Duffy, Ireland

Sunday's Psychosocial Professional Development Day "Let it Go" mapped the haemophilia journey focussing on the holistic psychosocial approach, dealing with stigma, sexuality and the use of humour in healing and coping with a chronic illness. This proved that the patient journey is based on not a single point in time but rather a lifelong continuum complicated by uncertainty and frustration, hope and successes. As a result I opened myself to the possibilities and in turn was introduced to a world of historical events that have led to improved health care, accountability, dedicated medical professionals and proactive community members who continually advocate for treatment for all. I was also reminded that treatment is not readily available in many regions leaving a considerable gap between those who have access to treatment and those that do not.

Throughout the week each presentation introduced a unique perspective on haemophilia and other bleeding conditions. Above all I was introduced to a community built on resilience in the face of adversity.

HEMOPHILIA: A BLESSING OR A CURSE

Chair: Robyn Shoemark, Australia

Young adult with haemophilia

– *Chanthearithy Run, Cambodia*

Among the inspiring presenters a young man, Chanthearithy Run from Cambodia, took us on a journey of what it means to have haemophilia in a developing country. To begin, he displayed a black and white photograph of his humble beginnings. This allowed the audience to note the reality of his upbringing which would later lead to incredible achievements. A small proportion of his story was not unlike other young men within the

bleeding conditions community. Chanthearithy recalled his experience with multiple knee bleeds, a head bleed and many aspirations throughout his earlier years, a harsh reality of the condition for him. However, Chanthearithy's overall experience proved somewhat removed from the experience of young Australians. His arduous hospital admissions, one of which spanned over one year, painted a clear picture of the difference in health care resources between Australia and Cambodia. He described his experiences as particularly difficult and it was not until 2009 that he was diagnosed with haemophilia. Without access to Government funded factor, Chanthearithy discussed the limiting effects of his condition and his decision to take preventative measures. "Starting at zero", he reports that he has overcome the harsh reality of his condition following a fitness regime based on the understanding that a strong body would lessen the likelihood of bleeds.

As a result of integrating daily exercise including swimming and basic body movements Chanthearithy reports that he has minimised his bleeding challenges. As he discussed his accomplishments, his next slide displayed a photograph of a fit and healthy young man, an image that would easily challenge many of our famous Australian athletes! Adding to his success and despite his incredibly humble beginnings Chanthearithy has graduated with a Bachelor of Law from the Royal University of Law and Economics in Phnom Penh, Cambodia, has continued his studies in the English Language and continues to play a major role in the Cambodia Hemophilia Association. An inspiring story of an incredible young man who has fought to overcome the barriers placed in front of him as a result of his condition.

SHOWCASE THEATRE: JEANNE WHITE-GINDER, MOTHER OF RYAN WHITE

Congress was teeming with stories of positive outcomes and forecasts for future treatment. However, as I meandered through the exhibition hall another inspiring young person caught my attention. Sadly he was unable to present his journey in person, instead his mother Jeanne White-Ginder delivered her son Ryan White's story. This heart wrenching account of a boy who lived until the age of 19 years silenced the room. Jeanne spoke of her son's battle with AIDS following a transfusion of HIV-infected clotting factor during the 1980s, a sad reality associated with treatment of that era. Her story touched on the discrimination fuelled by a community that lacked education and associated understanding. It painted the

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picture of Ryan's fight for equality and his eagerness to promote understanding. Ryan's determination ultimately led to the Ryan White Comprehensive AIDS Resource Emergency (CARE) Act USA, one major accomplishment among many achieved by this courageous and resilient young man. Sadly this account of discrimination, heart ache and the loss of a son is a story of our time, one that is in living memory. Despite advances in modern medicine this was a stark reminder that we as a community comprising of members and professionals must continue to advocate on behalf of oneself and others promoting wider community understanding thus ensuring progress towards equality and treatment for all.

FAMILY CAREGIVING AND BLEEDING DISORDERS – HELPING PARENTS COPE

Chair: Sylvia von Mackensen, Germany

"Bouncing Back": how to develop resilience in your child with a bleeding disorder

– Linda Dockrill, New Zealand

Each of the above personal accounts were based on stories of individuals from two vastly different worlds. However, both had one major similarity, resilience.

Unsurprisingly day four introduced a presentation that explored this very attribute and the important role it plays when human beings are faced with adversity. Social Worker Linda Dockrill of the Haemophilia Foundation of New Zealand provided an education session on parents developing resilience in their children with bleeding disorders. Linda's informative presentation explored Ginsburg's Seven C's of Resilience which identifies competence, confidence, connection, character, contribution, coping and control as the primary base for fostering resilience. Linda's presentation guided the audience through what it means to be resilient and how this can be 'learned'. She noted the significance of learning how to thrive despite life's challenges, the importance of empowering young people to make their own decisions and allow expression of emotion which will

ultimately aide in the young person feeling comfortable reaching out during difficult times. Linda's discussion additionally focussed on understanding the importance of personal contribution which serves as a purpose and motivation as well as the importance of learning to cope effectively with stress.

Both Chanthearithy and Ryan transformed their experience of haemophilia and associated conditions to a cause for change. Their stories reflected the points in Linda's presentation on developing resilience. With the support from their personal networks each demonstrated competence and confidence in their fight for the greater good exemplifying what one individual can achieve in the fight for better outcomes for themselves and the wider community. Each young man demonstrated innate control of their situation and coped with a journey otherwise foreign to those around them. Ultimately they contributed to their community, promoting positive change and hope which in Ryan White's case reigned over 25 years and counting.

My overall experience of Congress was motivating. I was provided with the opportunity to meet some of the most inspiring proactive people forging change within the bleeding conditions community. I had the great pleasure of spending time with parents' and family caregivers, hearing their stories of guilt, hope and triumphs, learning from veteran psychosocial practitioners and forming several working relationships that can only strengthen our international partnerships. Above all I encountered the real meaning of resilience and global community. For now I am looking forward to actioning the education I received and intend on feeding my experience back to Fiona Stanley Hospital, Princess Margaret Hospital and the HFWA all of whom provided exceptional support with my trip to Orlando.

Charlotte was funded by HFA to represent the Australia/ New Zealand Haemophilia Social Haemophilia Social Workers' & Counsellors' Group at the WFH 2016 World Congress. #



Dr Moana Harlen is Senior Psychologist Haemophilia at the Queensland Haemophilia Centre, Brisbane

FAMILY FUNCTIONING

Moana Harlen presenting at the World Congress

Moana Harlen

What a privilege it was to be able to present at the WFH World Congress in Orlando. I was very humbled by the many presentations I attended particularly the personal stories shared by patients and family members. I was invited to speak on Family Functioning as part of the psychosocial session on family caregiving and bleeding disorders. My presentation is summarised below.

FAMILY CAREGIVING AND BLEEDING DISORDERS – HELPING PARENTS COPE

Chair: Sylvia von Mackensen, Germany

Family Functioning

– Moana Harlen, Australia

At the paediatric Queensland Haemophilia Centre located at the Lady Cilento Children's Hospital in Brisbane we provide an individualised parenting program called the Family Factor program. It utilises an integrated framework to provide psychosocial support to the children with haemophilia and their families who come under our care by assessing, setting goals and providing support in different areas of family functioning. The framework draws on what we know to be of importance to meet the developmental needs of children, and the many factors that can impact on a parents stress levels that in turn can make parenting much harder. The ultimate aim is to optimise development outcomes for children who have haemophilia.

Our centre conducted a small pilot project in 2013-2014 with Dr Paul Harnett from the University Of Queensland School of Psychology to assess the usefulness of the program to meet the needs of families with children up to 12 years of age who had severe haemophilia and were on prophylaxis.

Five domains of family functioning were assessed which included child functioning, parenting stress, daily hassles, social supports and significant life events. Prophylaxis adherence and haemophilia-related Quality of Life were also assessed. Assessment findings showed that the parents who participated perceived their child with severe

haemophilia as generally doing well in areas of emotions, behaviour, friendships, and helpfulness. However some parents reported their child as having very high activity levels and difficulties with attention span.

The domain of family functioning that appeared most compromised was that related to the parents' own wellbeing in the form of stress experienced around parenting, daily hassles of parenting and support. For instance seven of the ten parents reported experiencing high levels of stress specifically related to parenting their child with haemophilia. What was interesting was that even though parents were experiencing high levels of parenting stress this did not appear to impact too greatly on maintaining prophylaxis treatment as all parents reported adhering to the prophylaxis regimen over this period.

Further follow up assessment was conducted where necessary and collaborative goals set with the families in specific domains of family functioning considered to be impacting negatively on the family. Although the parents did not report too much difficulty with managing the behaviours of their child with haemophilia, some did want to set goals around improving the behaviour of and/or their relationship with a sibling of the child with haemophilia.

Interventions included psychological interventions to improve parental coping skills, child behaviour management, and enhancing social supports. The level of intervention varied depending on the goals set and ranged from a few supportive phone calls to weekly home visits or phone calls over a few months.

For the families of our centre the integrated parenting framework has been useful in identifying the specific areas of stress families are experiencing particularly around parenting, managing stress and social supports. Providing an individualised program that sets collaborative goals and provides psychosocial support in these different domains is considered important in helping parents cope and thus enhancing family functioning. **H**

Sumit Parikh is the ABDR Senior Research Fellow at the Australian Haemophilia Centre Directors' Organisation (AHCDO)

THE HEALTH DATA AND TECHNOLOGY PERSPECTIVE

Sumit Parikh

Attending World Federation of Haemophilia (WFH) 2016 was a very rewarding experience: it provided me with an innovative and comprehensive overview of the latest developments, current patient healthcare issues and the challenges ahead in the management and treatment of patients worldwide. Presentations, workshops, symposia and exhibits featured cutting-edge trends in research and treatment for haemophilia and other inherited bleeding disorders in addition to networking opportunities and patient experiences. Amongst many sessions covering a wide range of topics, I was particularly intrigued by multidisciplinary sessions which provided new insights and valuable information on issues relating to the use and management of health data, which is a key area of my work.

GET NET-SMART

Privacy Protection, assessment of online information and using web-based tools in bleeding disorders care

Chair: David Silva Gómez, Spain

The Virtual Clinic Experience – Benefits and Challenges presented by electronic engagement between PWBD and Treatment Centres...the view from both sides

– Deborah Gue, Canada

Deborah Gue, Clinical Nurse Specialist and Nurse Co-ordinator for the British Columbia Adult Bleeding Disorders Program, highlighted the benefits and challenges presented by electronic engagement between patients with a bleeding disorder and Haemophilia Treatment Centres (HTCs). Despite technological advances there are many avenues like prevalence, cost, time, privacy, intrusiveness, user experience, data quality and impact on goals to explore in order to identify the most effective mode of engagement (e.g. letters, email, smartphones, social media, videoconferencing and blogs). There is no doubt that web-based tools and smartphone apps have been widely accepted in bleeding disorders care and are proving to be very effective. HTCs are responsible for exploring options with patients, seeking their preferences, documenting, re-evaluating and adjusting accordingly. However, patients must consent to electronic communications if they deem it appropriate and need to engage proactively to provide relevant feedback. Technology does offer opportunities to improve patient care; however, these opportunities

also bring risk and to protect patient privacy limitations are put upon health-care providers. In conclusion, for the best outcome it is essential that the ground rules for electronic communication should be agreed to between the HTCs and their patients through a signed agreement and that patients must make informed decisions about using electronic communications with their HTCs.

MONITORING PROGRESS THROUGH DATA

Chair: Andrew Brewer

Where to begin

– Adriana Linara, Colombia

Dr Adriana Linares, Associate Professor of Pediatrics at the National University of Colombia, South America, discussed some very important objectives of data collection including the purpose and benefits of data. With prophylaxis as an example, data can provide answers to key questions like when and how to initiate prophylaxis, which is the most appropriate dosing regimen for prophylaxis, how personalised treatment regimens be developed, how can adherence to treatment be optimised and how treatment of patients with inhibitors be managed.

As outcomes in haemophilia are difficult to measure, it is very important for the patient groups and organisations involved to come together to consider which data and outcomes are to be collected. There are many benefits of collected data in terms of basic and/or general information, including the ability to review specific outcomes and results from current practices and these can be very useful in treating and supporting patients. The standard procedure of data collection for analysis involves anonymising data, regulating data access and storing data securely. This puts emphasis on patients to provide significant clinical information to create better treatment outcomes for the wider community of people with bleeding disorders.

In conclusion, data collection is deemed as the first step towards identifying knowledge gaps and comparison of results - so patients working together with HTCs and getting this right could definitely be considered a milestone in itself. #

HEP C NEWS

ANOTHER NEW TREATMENT RECOMMENDED

In July 2016 the Pharmaceutical Benefits Advisory Committee (PBAC) recommended that another new Direct Acting Antiviral (DAA) combination hepatitis C treatment be made available on the Pharmaceutical Benefits Schedule (PBS): **Zepatier®** (grazoprevir/elbasvir).

Zepatier has completed trials in people with HIV/HCV co-infection and in a cohort of people with bleeding disorders, with high cure rates, few side effects and good safety in people with bleeding disorders.^{1,2} An important difference is that Zepatier is effective in genotypes 4 and 6 as well. The PBAC took this into account in its recommendation, saying that there is “a clinical need for treatment regimens that do not contain peg-interferon” and recommended Zepatier as an interferon-free treatment for these genotypes. However, the PBAC did not recommend listing Zepatier to treat genotype 3 due to “insufficient data.”

This recommendation will now go to the Australian Government Minister for Health to consider pricing matters and make a decision about funding for the new medications to go on the PBS.

There are now several new hepatitis C treatments listed on the PBS in Australia. Some are used in combination with each other:

- **Harvoni®** (sofosbuvir with ledipasvir)
- **Sovaldi®** (sofosbuvir)
- **Daklinza®** (daclatasvir)
- **Viekira Pak®** (ombitasvir, paritaprevir, ritonavir, dasabuvir - tablets with or without ribavirin)
- **Ibavyr®** (ribavirin).

Treating people with HCV genotype 3 is still an area where clinicians think there could be some improvement. With the current treatments available in Australia cure rates for genotype 3 are slightly lower than those for genotype 1.

Presentations on hepatitis C treatment at the WFH World Congress spoke of the impressive cure rates of the new DAA treatments across all genotypes, and mentioned another new combination treatment velpatasvir/sofosbuvir (Epclusa®) that is highly effective for all genotypes, and also demonstrates increased cure rates in genotype 3.^{3,4} Epclusa was approved by the FDA for the treatment of all HCV genotypes in June 2016 and has been prescribed for treatment in the USA. Epclusa is due to go to PBAC for approval in November 2016. HFA will be making a submission to support this. #

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CHANGE YOUR FUTURE TODAY!

WORLD HEPATITIS DAY



WORLD HEPATITIS DAY WAS MARKED GLOBALLY ON 28 JULY.

In 2016 the World Health Organization committed to eliminating viral hepatitis by 2030. In hepatitis C this means a focus on the new and effective treatments as a cure for all.

With universal access to the new revolutionary treatments for hepatitis C on the PBS, Australia is now leading the way for a NOhep future – a future without hepatitis C. As a Partner in the national World Hepatitis Day Campaign, HFA has been working with Hepatitis Australia and State and Territory Foundations on the annual national awareness campaign and is committed to making a difference on hepatitis C in Australia.

State and Territory Foundation representatives joined HFA in the HFA World Hepatitis Day Working Group to make the campaign more specific to the bleeding disorders community and promote it effectively to the bleeding disorders community around Australia. The Working Group looked more closely at the barriers for the groups identified as not pursuing hep C treatment and has developed a range of strategies to address them.

WHAT HAS THIS INVOLVED?

- Promoting simple key messages about the new treatments

NEW REVOLUTIONARY HEP C TREATMENTS.

- Few or minimal side effects, if any
 - 95% cure rate across population
 - Short treatment courses - 8 - 24 weeks
- Change your future today!

Talk to your hepatitis or infectious diseases clinic about treatment that could cure your hep C.



- Creating a short YouTube video about the new treatments
Dr Joe Sasadeusz, an HCV/HIV co-infection specialist in Melbourne with a long history of working with people with bleeding disorders and HFA, offered to assist HFA in making a short YouTube video answering questions about the new treatments for people with bleeding disorders.
Watch the new treatments video at - <http://tinyurl.com/hepcvideo>
- Developing social media messages to use in the 10 days around World Hepatitis Day
- Inviting community members to consider how we can achieve a future without hepatitis C in the Australian bleeding disorders community

WHAT CAN YOU DO TO HELP?

- Spread the word!
- If you have hep C, make your health a priority.
- Make sure you have a regular a liver health check
- Talk to your hepatitis or infectious diseases clinic about treatment that could cure your hep C
- Many people with bleeding disorders were exposed to hep C. Have you ever been tested? If you used factor before 1993 – even as a baby – you could be at risk. Act now – if you don't know whether you have hep C or not, get tested!
- Is something stopping you from getting hep C treatment? Talk to your Haemophilia Centre about solutions. Change your future today!

WHAT'S NEXT?

The HFA World Hepatitis Day Working Group is continuing to work on the health promotion campaign to promote new treatments to people with bleeding disorders and hepatitis C. We have been pleased to hear from Haemophilia Treatment Centres that most people with bleeding disorders and hepatitis C now have appointments with their hepatitis or infectious diseases clinic or have already started treatment. The focus is now on:

- A simple but more detailed fact sheet and video for people who are still hesitating to have treatment
- Addressing the barriers that some people have experienced – promoting pathways to find solutions
- Finding ways to reach people with mild haemophilia or von Willebrand disorder who may have acquired hep C from a treatment before 1993 and not been aware of it.

Watch this space!

MORE INFORMATION

For more information about World Hepatitis Day, visit the website – www.worldhepatitisday.org.au

TEAM.FACTOR

For the fifth 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 20 January 2017. The 2016 Bupa Challenge Tour will be from Norwood to Campbelltown, just over 157.50kms.

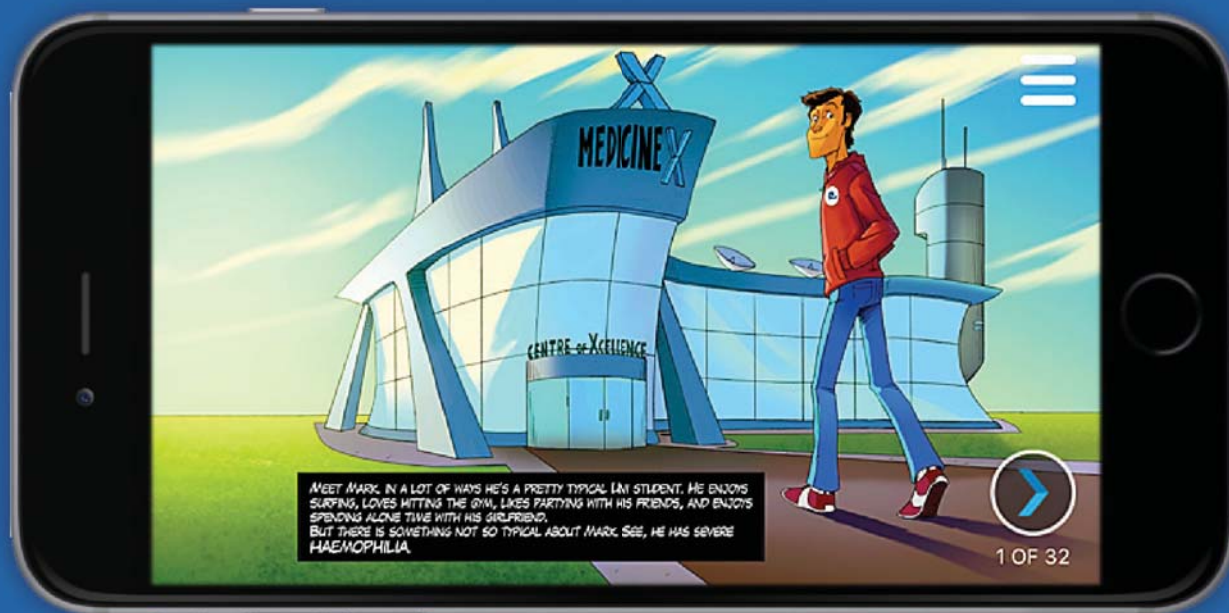
“WE ARE ALL RIDING TO FUNDRAISE FOR PEOPLE WITH HAEMOPHILIA AND OTHER INHERITED BLEEDING DISORDERS – A CAUSE ALL VERY CLOSE TO US.

Please support us during this ride and at the same time support our fundraising for Haemophilia Foundation Australia.”



Team Factor

You can support Team.Factor on their webpage <https://give.everydayhero.com/au/team-factor-bupa-challenge-tour-1>



HAEMOPHILIA XPLAINED

Haemophilia Xplained is an innovative app to explain haemophilia, how it impacts on the body and issues related to living with haemophilia. The app is also available as a website. It is targeted at people living with haemophilia aged 15-18 years, but young adults may also find it interesting to read.

The app explains information about different aspects of living with haemophilia in a high quality comic-book style format. It tells the story of Mark, a uni student, who visits the Lab MedX to learn more about his haemophilia, and uses humour and colourful graphics to explain some of the science in simple language that is easy to understand.

The content has been informed and reviewed by HFA, haemophilia health professionals around Australia as well as selected HFA youth leaders. The young people and health professionals' work was in a voluntary capacity and we are grateful for everyone's input.

The web version of the app is available through: www.factoredin.org.au and www.haemophiliexplained.com.au. The app can be downloaded from the Google Play store and the App Store.

Haemophilia Xplained has been created by Medicine X, in consultation with Haemophilia Foundation Australia, and sponsored by Biogen Australia. ■



YOUTH UPDATE

FACTORED IN

WWW.FACTOREDIN.ORG.AU

Factored In continues to be a valued resource among the bleeding disorders youth community.

New content includes:

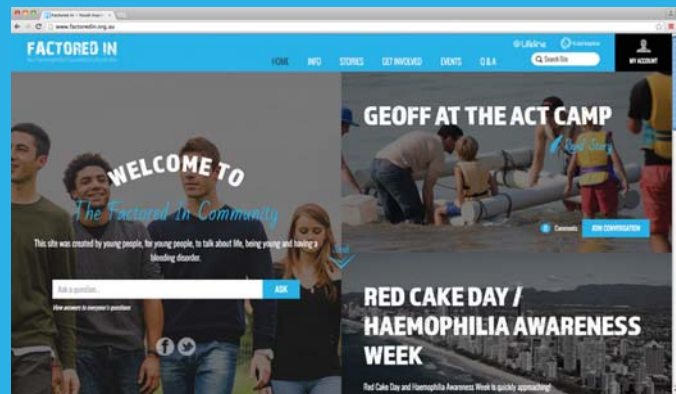
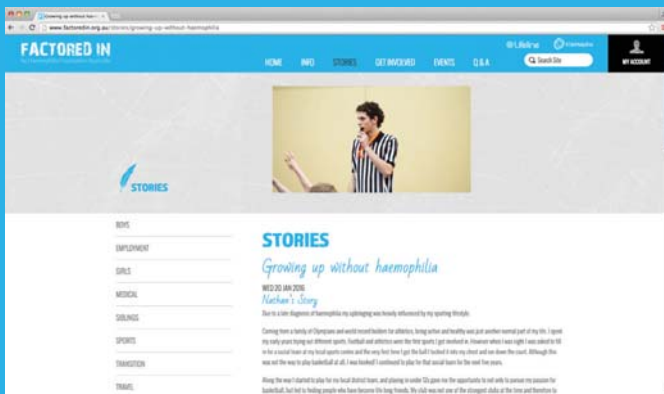
- A personal story about having inhibitors and being an umpire in basketball
- A story about the HFACT camp by an HFA youth leader
- Information about the WFH 2016 Congress Youth Session.

Head over to www.factoredin.org.au to read more.

Content has been generated from Youth Lead Connect (YLC) participants as they submit their reports about attending events and activities as leaders or mentors, and youth moderators continue to promote the website throughout their local community. The Youth Working Group is also involved in continual Factored In development by generating ideas for new content and contributing to stories.

Sharing stories is a great way of keeping youth connected and is an integral part of Factored In. Become a member and share your story!

I encourage everyone to head to www.factoredin.org.au



Youth Lead Connect participants have been thoroughly engaged and already demonstrated significant achievements:

- A YLC participant has taken on a leadership role at a family camp and submitted the report to HFA
- A hurdle for a youth who received an award to attend the 2016 WFH World Congress in Orlando in July is to write a report for publication and present to his local Haemophilia Foundation
- A YLC participant had a specific responsibility for planning and overseeing some of the children's activities at a family camp
- A YLC participant has organised and planned a Women's Brunch that was held in in June
- A YLC participant has helped to run a youth camp in their local foundation

Details of two of these achievements are displayed in **Youth News**.

A five (5) month survey is in the process of being conducted to assess the progress of the participants and understand any issues they might be facing as they work through their hurdles. This will help HFA to identify concerns and develop solutions to any problems. The anonymous online survey will ask participants what has worked for them and has assisted them in developing and completing their hurdles, as well as the challenges they have experienced.

The survey will identify the following:

- Enablers in developing and completing hurdles
- Barriers to developing and completing hurdles
- How HFA can increase the capacity of YLC participants

We are excited to see so much progress already achieved while the program is underway. 🎉

THE HFACT CAMP WAS A HUGE SUCCESS!

Geoffrey



Geoffrey is an HFA youth leader and mentor. Geoffrey attended the HFACT camp in April 2016, was part of the planning committee and facilitated the youth program activities.

THE HFACT CAMP WAS A HUGE SUCCESS!

This was my first experience of being part of a planning committee and going through the process of organising everything from scratch. We were all quite nervous but watching our efforts come together was very satisfying and the feedback we got was great.

The kids loved the dance lessons, Easter egg hunts, surfing, T-shirt designing and soccer. I even overheard parents speaking about hospital experiences and exchanging phone numbers with plans to meet up later. It was cool to see the bleeding disorder community growing in front of my eyes! Choosing to have the camp at the coast meant people from Canberra got to enjoy the beach while at the same time making it easier for those living down there to attend.

The whole reason I got involved in committees was so that I could be a role model for younger kids, and for the first time I really felt like I was achieving this. It was great to show the young kids that even as a haemophiliac, I was playing soccer and surfing and they could too! – and they did!

Overall it was great to be part of the HFACT camp and I look forward to my future involvement immensely. It was a pleasure to work with everyone on the committee and a big thank you to all who helped out.

A BIG SHOUT OUT to Hamish, another HFA youth leader and mentor, for doing a self-infusion demonstration in front of everyone! It went so well, the kids had fake veins strapped on to their arms and they all jostled for a front row seat to watch Ham stick needles in his arm. It was great to show them how easy it can be to manage their own medication. 🙌

FIND OUT WHAT THE YOUTH HAVE BEEN UP TO IN THEIR LOCAL COMMUNITY

SAM AT THE WFH WORLD CONGRESS

Sam

Sam received a Go For It Grant to attend the WFH World Congress in July 2016. To acknowledge his role as an HFA youth leader and mentor, HFA Council also invited him to attend the WFH General Assembly with the HFA President as an Australian delegate. Sam is a passionate and active member of the youth community both Australia-wide and within his home state of New South Wales.

Sam met many new people and attended many of the sessions the Congress had to offer and wanted to use social media as a way to involve other young Australians with bleeding disorders who couldn't attend the Congress to share his experience.

Sam created a Facebook post about his attendance at the youth session:

"It was very exciting and inspiring. It was amazingly inspirational to hear treatment and transition stories from other countries around the world."

The Youth Session focused on transition with a presentation by Jenna who is on the WFH Youth committee.

Another Facebook post captured Sam standing at the Factored In poster written by HFA.

We look forward to hearing more about Sam's experience with a full Congress and General Assembly report coming soon!

Go for It grants are sponsored by Pfizer. 



Sam taking a selfie with the HFA poster about Factored In

CALENDAR

Haemophilia Awareness Week

9-15 October 2016

Tel: 03 9885 7800

Fax: 03 9885 1800

Email: hfaust@haemophilia.org.au

www.haemophilia.org.au

World Haemophilia Day

17 April 2017

www.wfh.org/whd

18th Australian & New Zealand Conference on haemophilia & inherited bleeding disorders

Melbourne

12-14 October 2017

Tel: 03 9885 7800

Fax: 03 9885 1800

Email: hfaust@haemophilia.org.au

www.haemophilia.org.au

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.



CSL Behring



SA UPDATE

We are hoping to have a social get together of South Australians with bleeding disorders before the end of the year.

If there is no time to inform you via National Haemophilia we will let you know by post or email.

If you want us to have your email address, please contact us at hfaust@haemophilia.org.au so we can be sure to let you know sooner about local activities. ❏



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