

National



Haemophilia

Haemophilia Foundation Australia

www.haemophilia.org.au

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NEW LOOK
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Connecting young people with
bleeding disorders

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WORLD HAEMOPHILIA DAY 2016

TREATMENT FOR ALL THE VISION OF ALL
Globally 1 in 1,000 people has a bleeding disorder.
Most are not diagnosed and do not receive
treatment.

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

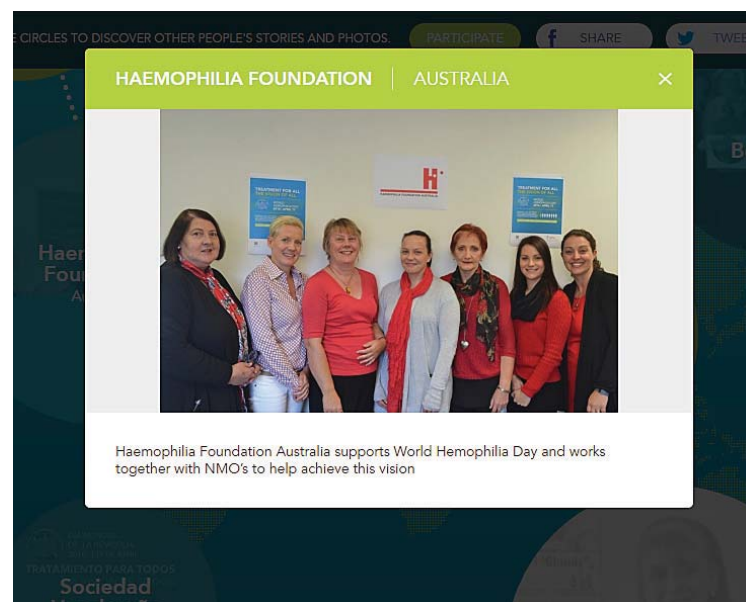
World Haemophilia Day was started in 1989 by the World Federation of Hemophilia (WFH) who chose to bring the community together on April 17 in honour of WFH founder Frank Schnabel's birthday.

In 2016 HFA celebrated World Haemophilia Day to support the WFH goal of Treatment for All.

WORLD HAEMOPHILIA DAY WEBSITE

WFH developed an interactive World Hemophilia Day website to invite people from around the world to connect with each other and share their photos, stories and thoughts on how to achieve Treatment For All - www.worldhemophiliaday.org

HFA staff had a morning tea to celebrate the day and shared our support on the World Hemophilia Day website with other people from around the world.





LIGHT IT UP RED!

Together with other landmarks from around the world, AAMI Park in Melbourne, Perth Bell Tower and the Brisbane Storey Bridge turned red on Sunday 17 April to celebrate being united in support. Next year we are hoping to get all states and territories involved. 🇦🇺

Lit up red!

Above: Bell Tower, Perth

Middle: Storey Bridge, Brisbane

Below: AAMI Park, Melbourne



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 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

Gavin Finkelstein is President, Haemophilia Foundation Australia

FROM THE PRESIDENT

Gavin Finkelstein

ABDR AND MYABDR

I have been talking to you a lot about the Australian Bleeding Disorders Registry (ABDR) and MyABDR in many of my recent messages in *National Haemophilia*. I don't mean to sound like a broken record, by going over and over the same things, but the exciting thing about MyABDR is that it is continually developing and improving! And, it is designed to be helpful for the people who use it. You will read more about how the MyABDR development has progressed later in this edition.

One of my regular conversations when I meet with people in our community is about how we can measure treatment success in Australia - so that governments can assess, and be reassured that their expenditure on haemophilia treatment products represents value for their money as part of overall health care costs in Australia. When I talk about this, many people in the bleeding disorders community are aghast! They KNOW their treatment works. Many, like me have lived in the days when there was no treatment with concentrates or later, when treatment was rationed for lack of supply. We know our bodies, we know what it takes to treat a bleed, how long it takes to recover and how we should keep our bodies strong to prevent bleeds. Right?

But with more specific record keeping about our bleeds and communications with our treaters we can better understand our bleeding patterns and how best to prevent or treat bleeds. We can work with our treating clinicians to make sure we are treating at the right time, and with the right amount of factor. Home therapy was liberating for us all those years ago, because it allowed us to use our judgement and treat at home. And now, several

Haemophilia Centres in Australia have arranged for their patients to have their clotting factor delivered to their home or to their workplace. This helps families and individuals to get on with their lives, without the frequent trips to hospitals or blood banks to collect their factor. But our treatments are expensive. We are lucky that we live in Australia where they are funded by governments and provided to us free of charge. It is entirely reasonable that we take responsibility and demonstrate our personal accountability for the clotting factor we use.

BENEFITS OF RECORDING

I hear of more people who use the information about their bleeds they have recorded on their MyABDR app in reviews with their treating team at haemophilia clinics and see how useful a tool it is for all concerned. We are keen to see more Haemophilia Centres using ABDR and MyABDR in partnership with more of their patients. I know in some Haemophilia Centres this comes down to limited staff resources at their end but in time the benefits will be so obvious that we hope this problem will also be resolved.

The Canadians have adopted the ABDR data system and the Canadian bleeding disorders community is moving towards MyABDR. My counterpart Craig Upshaw at the Canada Hemophilia Society has challenged us to a competition to see which organisation can encourage the most people to register and use MyABDR! More on that later!

The big picture benefits of ABDR are already playing out. The pooled data in the registry can tell us about the Australian bleeding disorders community more generally. It helps governments and health service

providers and organisations like HFA know more about the community, and enables everyone to plan for services and activities needed for the best outcomes for the health of individuals and their families and carers. HFA uses the data for government submissions about health care generally and more specifically for funding grants that enable us to provide support to the community.

For governments it is important to keep tabs on the amount of treatment product that will be needed for future treatment, so they can budget for this, and ensure supply plans that will accommodate our future needs. Some of this data is published by the National Blood Authority in the ABDR Annual Report. The data reported is carefully considered before publication to make sure it cannot identify individuals and provides the overall picture we require. There is a very robust governance framework for the ABDR and MyABDR and strictly enforced rules about privacy and access to information about individuals. HFA is a part of this framework and Sharon Caris, Executive Director is a member of the ABDR Steering Committee.

HFA is keen to use ABDR data to understand more about the bleeding disorders community and their treatments and how we compare with other countries. Every year HFA requests data to be released for the World Federation of Hemophilia (WFH) Global Survey. WFH publishes this data every year to show the level of treatment around the world, to support advocacy and development where it is needed and to provide data that can be used to support existing levels of care in countries and value for money and cost effectiveness.



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The Australian Haemophilia Centre Director's Organisation (AHCDO) uses the aggregated ABDR data for benchmarking and research and we support this.

WORLD CONGRESS

I am about to head off to represent HFA at the upcoming WFH 2016 World Congress and General Assembly of World Federation of Hemophilia in Orlando in July. One of the hot topics will be data, evaluating and measuring treatment outcomes. I also look forward to reporting more about the treatment pipeline. Unfortunately most people in Australia still do not have access to longer acting treatment products, unless they are on clinical trials or extension studies associated with a trial. We have approached the National Blood Authority seeking access to the products that are registered for use in Australia without success. We will continue this work.

I am pleased to report that one of our emerging youth leaders, Sam Linnenbank, has accepted my invitation to attend the General Assembly in Orlando to represent HFA as the alternate voting delegate. Sam is a member of HFNSW, and a participant in the HFA Youth Lead Connect program. Sam won a Go For It Grant to attend the Congress, and the HFA Council took the opportunity to invite him to participate in the General Assembly. I look forward to working with him at the General Assembly. ■

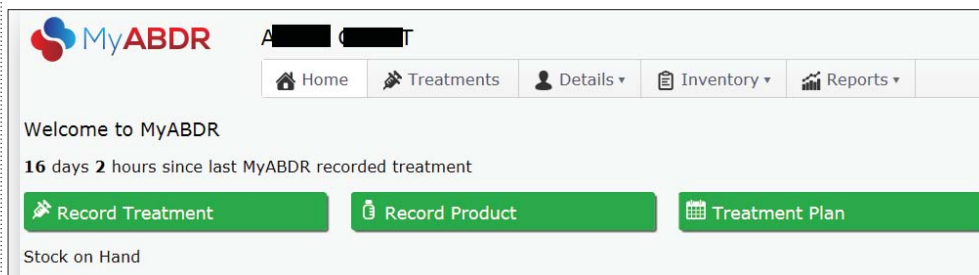
MYABDR UPDATE



From the HFA and National Blood Authority MyABDR Team

NEW FEATURES!

- Better, faster syncing
- Export your treatment records to MS Excel
- New graph on web version – treatment and bleeds PDF
- Clearer buttons on website



New look website buttons

WHAT'S NEW?

A new version of the MyABDR web application will be released on 20 June 2016. The major improvements and features included in the update are:

- **Treatment and Bleeds** report which allows MyABDR users to generate, display, and export a formatted PDF report of their treatments and bleeds for a specified date range
- **Export to Excel:** data Extract report which allows MyABDR users to download and manipulate an Excel spreadsheet containing a comprehensive extract of treatment and bleed data for a specified date range
- **Clearer action buttons on website** - the look of the buttons on the website home page have been modified slightly so that they look more like buttons rather than title headers
- **Date recording** – the day of a treatment or bleed is now displayed in addition to the date when entering date fields
- **Fixes to the MyABDR website graphs** – graph colours have been fixed for the following graphs: Bleeds Over Time; Product Treatment Over Time; and Time to Treatment.



Support Team member:
Danny Mamic

“ I like knowing that the work we do is helping to make life easier for patients with a bleeding disorder.”

MEET THE SUPPORT TEAM

Support Team Member: Danny Mamic

Tenure with the National Blood Authority: 10 months

Interests outside of work: Family, health and fitness, sport, and reading.

Q: Why do you like working in the MyABDR Support team?

Danny: I like working in the Support team because I get to meet and help a variety of people. I also enjoy working with ICT (Information and Communications Technology) systems like MyABDR and I like knowing that the work we do is helping to make life easier for patients with a bleeding disorder.

Q: Describe how you resolve a typical MyABDR support request.

Danny: When I receive a request for help from a MyABDR user, I gather the relevant details regarding the issue from the user by chatting to them over the phone or by writing them an email – usually:

- The type of app they use, web or smart phone
- The error message they are receiving
- When the issue occurs
- How long and often it has been occurring
- The type of phone they use
- And a screen shot of the error.

A lot of the time I will be able to resolve the issue on the spot by logging into the user's MyABDR account or by walking the user through a process that they may not be aware of.

If I cannot resolve the issue, I then create a ticket in our issue management program Jira for our developers to action. Once the issue has been assigned to a developer for investigation I monitor the ticket in Jira and follow up with the developer if necessary.

Finally, once the issue has been resolved, the ticket gets reassigned to me with details on the cause and solution of the issue. I then contact the user and inform them of the outcome.

As a side note, the Support team also print and dispatch the ABDR patient cards.

Q: How do you manage the MyABDR user's privacy?


Danny: Having access to the ABDR is a very privileged role, only permitted to specially selected National Blood Authority technical support staff for the purposes of supporting and maintaining the ABDR. This role is taken very seriously. While we need access to the ABDR to answer users' questions, the MyABDR Support team must also be responsible for keeping information about users confidential. We undergo a high level security clearance with the Australian Government Security Vetting Agency and all of our actions on the ABDR are tracked individually.

NEED HELP?

Please do not hesitate to contact the MyABDR Support team if you have any questions or concerns. Meghan, Danny, Andrew or Rebecca will be available and happy to assist you.

T: 13 000 BLOOD / 13 000 25663

E: myabdr@blood.gov.au

Available 24 hrs a day, 7 days a week. 

HEP C NEWS

NEW TREATMENTS ON PBS

From 1 May 2016 another new Direct Acting Antiviral (DAA) hepatitis C treatment has become available on the Pharmaceutical Benefits Schedule (PBS):

- **Viekira Pak®** (ombitasvir, paritaprevir, ritonavir, dasabuvir - tablets with or without ribavirin) for the treatment of hepatitis C genotype 1

This is a welcome addition to the other new hepatitis C treatments that were listed on the PBS in March 2016.

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

Another DAA combination treatment **Zepatier®** (grazoprevir/elbasvir) will be going before the Pharmaceutical Benefits Advisory Committee (PBAC) for approval in July 2016. HFA will be making a submission to PBAC about this treatment.

Zepatier has completed trials in people with HIV/HCV co-infection and in a cohort of people with bleeding disorders. The co-infection trials showed high success rates.¹ The results of the trials with people with bleeding disorders were released at the EASL International Liver Conference in April 2016: 93% of the cohort achieved a virologic cure; and the treatment demonstrated good safety, few side effects, and did not affect bleeding disorder-related bleeding or management of the underlying bleeding disorder.²

WHAT IS SPECIAL ABOUT THESE NEW TREATMENTS?

The new treatments have revolutionised hepatitis C care. They have high cure rates – more than 90% across the entire hep C population:

- Genotypes 1-3 – oral treatment with tablets; no interferon injections
- Shorter treatment courses – usually 8, 12, or 24 weeks
- Fewer and usually only minor side-effects
- People with cirrhosis still have relatively high cure rates but need specialist and individualised care and monitoring.



Many thousands of Australians have started the new treatments since 1 March – we hear from Hepatitis Australia that more people were on treatment in March 2016 than for the entire year in 2014.

WHAT IF YOU HAVE A BLEEDING DISORDER?

HFA has had initial discussions with the Australian Haemophilia Centre Directors' Organisation (AHCDO) and hepatitis and HIV/HCV co-infection specialists:

You would need to have a recent liver health assessment before you could be considered for treatment. Don't wait; if you haven't already, make your appointment now!

- **Don't know where to start?** Ask your Haemophilia Centre about a referral
- **Do you have hepatitis C?** Make an appointment with your hepatitis or liver clinic to discuss your treatment options
- **Do you have HCV/HIV co-infection?** Talk to your HIV or infectious diseases specialist about the new treatments. There may be some HIV drug interactions to take into account as well as other factors, and they will work out the best treatment regime for you
- **Do you have more advanced liver disease/ cirrhosis?** Talk to your hepatitis or HIV specialist about liaising with your Haemophilia Centre in case of complications
- **Not ready for treatment?** Make sure you still have your liver health checked regularly and stay in touch with your hepatitis clinic about what's new
- **Be proactive with your appointments.** There are a lot of people waiting for hep C treatment. If you have an appointment, make sure you keep it if at all possible. If you need to change it, contact your clinic in advance so they can reschedule you and put someone else in your place. And follow up with them if you haven't heard back from them
- **And for comprehensive care, talk to your Haemophilia Centre** first and let your Centre know about your liver test results or how your treatment is going to make sure they stay in the loop.

For more information, visit the HFA website page on the new hep C treatments - www.haemophilia.org.au/bleedingdisorders/hep-c-treatments

#TIMEFORACTION



WORLD HEPATITIS DAY

World Hepatitis Day will be marked globally on 28 July 2016.

In 2016 the Australian World Hepatitis Day campaign will focus on promoting the new treatments.

As a Partner in the national World Hepatitis Day Campaign, HFA is 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.

As part of this campaign, HFA and the team from Haemophilia Foundation Victoria are developing a short YouTube video about the new treatments for people

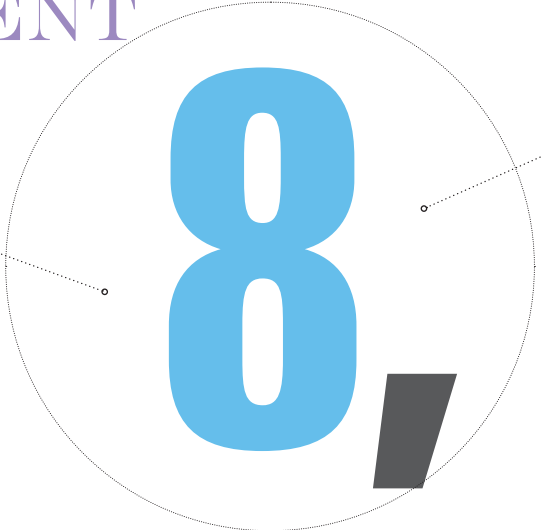
with bleeding disorders. Watch out for the new video which is soon to be released – a Q & A interview with Dr Joe Sasadeusz, an HCV/HIV co-infection specialist in Melbourne with a long history of working with people with bleeding disorders and HFA.

For more information about World Hepatitis Day, visit the Hepatitis Australia website – www.hepatitisaustralia.com #

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GETTING READY FOR HEP C TREATMENT



8,

Mona Chong

It is indeed an exciting and hopeful time for many who can now access new treatments for hepatitis C under the Pharmaceutical Benefits Scheme. The new treatment regimens promise a higher cure rate with minimal side-effects and short treatment durations - taking away many barriers for our community. It is important to be ready to take advantage of this opportunity.

1) What is the process like?

Hopefully you have already booked an appointment to see your hepatitis clinic! Talk to your Haemophilia Treatment Centre about a referral if you don't know where to start. They might recommend that you get a 12-month referral from a GP to cover all of the visits for your treatment.

Moving forward with treatment, you will need to make time to attend appointments at the hepatitis clinic and pathology services to prepare for treatment, and monitor your progress and response. The number of visits you will need to make will depend on your individual health. People with no complicating factors won't need many visits. Others will need to have more intensive monitoring and follow-up.

Overall, the feedback from people who are having treatment is that it is a reasonably straightforward and easy process.

2) How does this new treatment compare to previous interferon-based treatments?

The number of tests and appointments will depend on your liver health and other complications. Side effects, if any, are usually minor.

This means that compared to the previous interferon-based treatments, the length of treatment is shorter, there are fewer appointments and you are likely to be able to continue a normal life while on treatment.

3) How long is the course of treatment?

The new treatment courses are shorter – 8, 12, or 24 weeks. It depends on factors like your genotype, your liver health, whether you have had unsuccessful treatment in the past and other existing complications.

4) What does the treatment involve?

Medication for people with genotypes 1, 2 and 3 is now in tablet form. There are no injections. A small number of people with other genotypes may still need to have a combination treatment with interferon for a successful result.

Your treating doctor will also need to assess any other treatments you are on to see if they are compatible with the new hepatitis C treatments.

5) What about side effects?

There are few side effects and they are usually minor. They can include headache, nausea, diarrhoea, insomnia (sleeplessness), fatigue and, with ribavirin, anaemia. If you have any side effects – and many people don't – remember to talk to your treatment team to get some help with managing them.

People on treatment have reported little psychological impact. If anything, you may just require some practical support, e.g. to get to appointments or to be reminded to take your medication.



12

OR



24

6) What if I have some problems, e.g. difficulty getting to appointments?

Speak with your Haemophilia Treatment Centre to see if they can provide support or help to problem-solve any barriers preventing you from seeking treatment.


7) What can I do to maximise success?

Besides keeping to your medication schedule and attending all your appointments, it is also a good idea to reduce alcohol intake to get the best out of the treatment. Talk to your Haemophilia Treatment Centre if you have other concerns.

HELPING THE SYSTEM TO WORK

Because of the ease of treatment and the higher success rate, there are a lot of people waiting for treatment. It is important to be proactive about your appointments and keep them.

- If you are unable to attend an appointment, let the clinic know in advance so that you can be rescheduled. Otherwise you run the risk of being removed from the system.
- If you have not heard from the clinic for a couple of weeks, it is best to follow up with a phone call and check when your next appointment is.

It's by everyone working together that we can make this a success for all. 

Thanks to Dr Joe Sasadeusz, Infectious Diseases Specialist, and Megan Walsh, Clinical Nurse Consultant, Ronald Sawers Haemophilia Centre, from the Alfred hospital in Melbourne; and community members currently on treatment, for their helpful comments on this article.

HEPATITIS C TREATMENT— A PERSONAL STORY

David is an Australian community member. He spoke with Suzanne O’Callaghan from HFA about his experience of treatment with one of the new hepatitis C direct acting antiviral (DAA) regimes

David has von Willebrand disorder. Like many people with mild bleeding disorders who have only had the occasional blood product treatment, he never really thought that he might have been at risk of infection with hepatitis C virus from his treatment. New safety precautions for blood products were introduced in the early 1990s and after a few years the issue of hepatitis C for people who used blood products before 1990 no longer made news in the media. For David, it was off the radar.

David was feeling fine. He didn’t even know he had hepatitis C. By co-incidence he underwent a series of tests for another health problem and it was then that his doctors found that he had hepatitis C. On reflection, David realised that he probably acquired hepatitis C in the early 1980s.

“I went for about 20, 30 years without even knowing,” he said.

His Haemophilia Centre made a referral for him to visit the hepatitis specialist at the liver clinic. They wanted to check how his liver health was going with his hepatitis C.

“They looked at my liver by ultrasound and they saw I had a bumpy looking liver, like cirrhosis of the liver,” said David. “The specialist wanted me to go on treatment, but this was the 12 month treatment with a lot of side-effects. So I told her that it wouldn’t be for me.”

GOING ON TREATMENT

Fortunately for David, the liver clinic was able to organise access to Viekira Pak®, one of the new direct acting antiviral (DAA) treatments, which was not yet available on the Pharmaceutical

Benefits Scheme but provided by the pharmaceutical company under an early access scheme.

David had a treatment program worked out for him that took his cirrhosis into account. This meant he would need to take about 12 tablets a day for 24 weeks - 6 months. David lives in a regional town, a few hours away from the hospital.

“I had to go down and see the hepatitis nurse practitioner and the hepatitis specialist every month, and I had to collect the medication at the hospital pharmacy,” remembered David. “I had to have blood tests every month, but I had them done in my own town and they sent the results to the hospital. So I had to travel to the hospital about 8 times altogether – and it’s not really that bad.”

In between the visits the hepatitis nurse practitioner and David kept in contact by phone, especially if she noticed changes in his blood results or he became aware of side-effects.

“For a little while the haemoglobin wasn’t exactly what the nurse practitioner wanted, so she monitored it very closely and I had to have blood tests every two weeks just for a bit, and sometimes had to adjust the dose of one of my tablets. I was worried that the treatment wouldn’t work but she reassured me that I could afford to reduce the dose for a little while without risking a cure,” he commented. “For 4 months I went straight through with no problems at all, but then I started turning a yellowish colour, which they had to sort out. I didn’t want to say anything about it, in case they stopped the treatment, but my wife knew better!

“And if you don’t know if you have hep C, get tested. It was just a fluke thing that I found out.”

That was the only side-effect I had over the whole treatment.”

Twelve weeks after treatment, David had another blood test (a Hepatitis C RNA Viral Load) and visited the hepatitis specialist, who told him he had successfully cleared the virus.

“I feel a lot better knowing I don’t have hepatitis C anymore,” David said. “I’m going to be around a bit longer!”

AND FOR THE FUTURE?

Because he had already developed cirrhosis, David will need to have liver health checks regularly for the rest of his life to monitor his liver health and keep an eye out for signs of advancing liver disease or complications which can be managed.

His tips for other people with bleeding disorders and hepatitis C?

“Just do treatment. They are so much better now. Don’t even hesitate.

“And if you don’t know if you have hep C, get tested. It was just a fluke thing that I found out. But if I had known earlier that I had hep C, I probably wouldn’t have cirrhosis of the liver because I could have had it treated back years ago.

“So if you have hep C, take care of it. Don’t wait!”

The following article is adapted from the article published in *Bloodline* vol. 44 no.1, March 2016, the journal of the Haemophilia Foundation of New Zealand (www.haemophilia.org.nz), and is reprinted with permission

Catherine Pollard is Advanced Physiotherapy Clinician for Haemophilia Auckland/North Land Region, New Zealand

WALKING ANALYSIS AND HAEMOPHILIA

Catherine Pollard

Research has shown that after bleeding episodes there are subtle joint changes that cause alterations in patterns of walking. This can occur even in young children with haemophilia. Increasing our awareness of this and ensuring proper assessment and rehabilitation following a joint bleed may minimise these changes and reduce the risk of further bleeding episodes and damage.

When a joint bleed occurs, blood starts to leak into the joint space. Blood is not normally present inside the joint and the presence of even a small amount can produce lasting damage to the joint. When the bleed has stopped and the blood is removed from the joint, the pain eases and range of motion returns. Once this has occurred it is easy to presume that the joint is back to normal.

BLEEDS, JOINTS AND WALKING PATTERNS

However, research of walking patterns in haemophilia has demonstrated that even in young children, bleeding episodes early in life can produce subtle changes in how the joints and muscles work to produce movement.⁵ For example, when comparing boys with haemophilia to boys the same age but with no health concerns, there were differences noted in how the muscles surrounding the ankle and knee are activated. Boys with haemophilia also had less movement in their hips, knees and ankles and tended to walk with their knees slightly bent.^{2,4,8} These small changes in how the joints move can increase strain on muscles, ligaments and cartilage and increase the loading pressures through the joint. Ultimately this may leave the joint more vulnerable to structural overloading and synovial pinching, with the increased risk of further bleeding episodes and damage.⁷

HAEMOPHILIA PHYSIOTHERAPY SUPPORT


For best management at the present time a specialist haemophilia physiotherapist can provide advice and support to recover from a bleeding episode quickly and rehabilitate the muscles and joint back to optimal function. Physiotherapists are trained to observe walking patterns and joint movements and can identify factors which may leave a joint more vulnerable to future bleeding episodes, as well as teach you how to help reduce these risks.

A new approach being explored is the development of three-dimensional gait analysis. This utilises multiple video cameras pointed at different angles to record a person walking, and has made it possible to identify small changes in joints and muscles. Three-dimensional gait analysis provides information to clinical staff that would be undetectable just by watching the child during normal functional activities.¹ This could prove to be very useful as it may take years before the resulting damage shows up on X-ray or through clinical examination. Three-dimensional gait analysis is not yet widely available in Australia or New Zealand but may be in the future.

If you are unsure who your local haemophilia physiotherapist is, please contact your Haemophilia Centre for advice. **H**

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in this issue of National
Haemophilia – an information
liftout from The Female
Factors project

the**female**facto**rs**

THE FEMALE FACTORS

AN UPDATE ON THE HFA WOMEN
AND GIRLS PROJECT

“Until I made contact with HFA
I felt as if I was the only person
on earth with undiagnosed heavy
bleeding problems. It would be nice
to help others too so that no one has
to suffer in silence.”



What does it mean to live with a bleeding disorder or carry the gene if you are female?

What do you need – or want – to know?

What are the experiences of women and girls affected by bleeding disorders?

How will it help to share these experiences?

WHAT IS THE FEMALE FACTORS?

The Female Factors is the Haemophilia Foundation Australia (HFA) women and girls project.

The name was chosen by the women and girls participating in the project and shows our commitment to developing information and education resources that acknowledge:

- The range of altered factor genes causing bleeding disorders that affect females in our community: factors I, II, V, VII, VIII, IX, X, XI, XIII, and von Willebrand factor
- The many factors females need to deal with to manage their bleeding disorder and carrying the gene.

The project is developing specific information and education resources for Australian women and girls

affected by bleeding disorders as a priority. These resources include personal stories and tips.

The Female Factors project aims to support Australian women and girls with inherited bleeding disorders by:

- **Increasing their understanding** of their bleeding disorder, treatments and strategies to manage it
- **Helping them to feel more connected** with each other by sharing personal stories with others in similar situations
- **Developing high quality, evidence-based information** that they can show to other doctors, nurses, etc who provide their care.

WHO IS INVOLVED IN THE PROJECT?

HFA is collaborating with a number of expert review groups to develop the information:

- **The Women and Girls review groups:** women affected by bleeding disorders; young women and girls and their parents
- **Specialist health professional review groups:** haematologists, haemophilia nurses, social

>>

More information was at the top of the Australian women's priorities for how best to improve this situation

workers and counsellors, and physiotherapists, and genetic counsellors (and other specialities that we will consult in the future as needed!).

WHY THE NEED?

HFA's community consultation has highlighted that information for women and girls with bleeding disorders is a priority area of need.

In a 2002 HFA survey of women with bleeding disorders¹, 51 women responded:

- 59% were diagnosed between the ages of 18 and 40
- 32% were diagnosed when their child was diagnosed with a bleeding disorder, 48% due to bleeding symptoms or excessive bleeding after surgery, dental work or childbirth, and 18% due to a family history of a bleeding disorder
- In 56% of cases they did not expect their diagnosis.

Of these women, 41% were treated by their general practitioner (GP) rather than a haematology specialist. However, the Royal Australian College of General Practitioners acknowledged at the time that due to the rarity of bleeding disorders, no training was provided to GPs on haemophilia or von Willebrand disease (VWD). This was reflected in the women's comments about their GP's lack of knowledge about their bleeding disorder. Some thought this had a negative impact on their diagnosis and referral. Many women also spoke about their difficulties in being 'taken seriously' by health professionals, as some of their treating doctors held the belief that women cannot have a bleeding disorder.

As a result, many of the women experienced isolation and had fears about and problems with:

- Invasive procedures that pierce the skin or mucous membrane such as surgery, and other medical and dental procedures
- Women's health and reproductive issues such as menorrhagia (heavy menstrual bleeding), childbirth, unnecessary hysterectomies, concerns about their children, family planning and 'carrier guilt'
- Blood borne viruses
- Travel
- The impact on their work and family
- Explaining bruising; disclosure/telling others.

This is similar to the experience of women with bleeding disorders in other developed countries such as Canada.²

More information was at the top of the Australian women's priorities for how best to improve this situation.

Our ongoing consultation with women has also pointed to other important topics to cover:

- Inheritance patterns
- Understanding how the altered gene is expressed in females
- Diagnosis and genetic and factor level testing
- Managing bleeding symptoms
- Treatment options.

PROGRESS TO DATE

HFA has put together basic information for women and girls:

- **Haemophilia** booklet (2013): updated information on carrying the gene and haemophilia in females, inheritance, genetic and factor level testing, family planning, pregnancy and childbirth, treatment
- **Von Willebrand disorder** booklet (2010): section on special issues for women and girls over their lifetime
- **Living with mild haemophilia: a guide** booklet (2011): section on special issues for girls and women.

We have also sourced and published women and girls' personal stories about living with a bleeding disorder:

- Haemophilia - do you catch it? (*National Haemophilia*, Jun 2015)
- Haemophilia - when your daughters bleed too (*National Haemophilia*, Mar 2015)
- Haemophilia - all in the family (*National Haemophilia*, Dec 2014)
- Living with VWD - Susie's story (*National Haemophilia*, Sep 2014)
- A story from the other side – Molly's story of having haemophilia (*Factored In*, 2012)
- Be kind to yourself – Jenna's story of living with VWD (*Factored In*, 2012)

EDUCATION RESOURCES IN DEVELOPMENT

The next stage of The Female Factors project is to publish a series of information resources targeted specifically at adult women and another suite for young women and teenage girls.

These resources cover two main areas:

- Haemophilia: carrying the gene
- Living with a bleeding disorder (from a women's perspective)

They will answer women and girls' questions on a range of topics, for example:

- An introductory snapshot of bleeding disorders in females
- Inheritance patterns
- Understanding how the altered gene is expressed in females
- Diagnosis and genetic and factor level testing
- Symptom management in day to day life
- Treatment options
- Telling others
- Emotional issues relating to their bleeding disorder, including "carrier guilt"
- Navigating the health system and comprehensive care.

The resources will initially be released in topic sections as they are developed. Then when all the topics for each area have been published, they will also be put together into a booklet.

The resources will be high quality evidence-based information, but each topic will be like a magazine lift-out, with coloured blocks of information, tips and personal stories. The resources can be downloaded as PDFs from the HFA website (www.haemophilia.org.au) or the Factored In HFA youth website (www.factoredin.org.au).

How did we come up with this idea? Our thanks go to our dedicated review groups. They have provided:

- Key messages
- Topics and questions to cover
- Decisions about the look and feel of the resources
- The health professionals advise on accurate, evidence-based information and current practice in Australia, along with knowledge from their clinical experience
- The women and girls contribute personal stories and tips from their own experience.

They also review the resources as they are developed and make sure they are accurate, relevant and speak to the needs of Australian women and girls.

We have been lucky to have Marg Sutherland working with us as a consultant, writing the psychosocial sections of the resources. Marg is an experienced educator and counsellor with an interest in women's health, well known to some of us for her sensitive work in the bloodborne virus sector and at the Australian Research Centre in Sex, Health and Society, La Trobe University, Melbourne. She is working closely with the women's review group, haemophilia health professionals and HFA to make sure the resources reflect the experiences of women and girls in our community and are appropriate to their needs. #

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INFORMATION FOR WOMEN AND GIRLS WITH BLEEDING DISORDERS

Looking for HFA's most up-to-date information on women and girls with bleeding disorders?

- Visit the Women with bleeding disorders section on the HFA website – www.haemophilia.org.au
- Visit the GIRLS sections on the Factored In website – www.factoredin.org.au

What will you find there?

- Introductory information
- Personal stories
- The new resources when they are published

HOW TO BE INVOLVED?

If you are a woman or girl who carries the gene or has bleeding symptoms – or the parent of one – it's not too late to be involved.

You can:

- Tell your story for National Haemophilia, or Factored In, or the new resources (you can be anonymous!)

And/or

- Contribute by giving your comments on the draft resources.

Contact:

Women

Suzanne O'Callaghan
E: socallaghan@haemophilia.org.au
T: 1800 807 173 (Mon-Fri)

Young women and girls

Hannah Opeskin
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A LESSON IN PRIORITIES: VOLUNTEERING IN HAEMOPHILIA IN INDIA

Penny McCarthy

In 2013 Subbi (Sulochana B) was awarded an International Hemophilia Training Centre (IHTC) fellowship from the World Federation of Hemophilia (WFH) to the Ronald Sawers Haemophilia Centre at The Alfred in Melbourne for haemophilia nursing experience.

From the outset the team at The Alfred knew Subbi was an amazing character. She is a very well educated nurse; a Professor of Nursing working as a full time academic at Manipal University in India. To our surprise we learned that she volunteers her time in haemophilia care!

HAEMOPHILIA CARE IN MANIPAL

Subbi is the haemophilia nurse co-ordinator at the Hemophilia Society, Manipal (MHS), which is a registered chapter of the Hemophilia Foundation India, New Delhi and affiliated to the WFH. The MHS functions from Kasturba Hospital, Manipal, Manipal University (www.manipal.edu), Karnataka, India. The Manipal University supports the MHS in its various activities for the care of patients with haemophilia and other bleeding disorders.

Each year since her return to India Subbi has invited me to speak at a workshop for nurses and to participate in the family camp which was being run by the MHS. I finally was able to attend in April 2016.

What an experience! It took 22 hours to travel there, with three plane trips and a long car drive.

I was very fortunate to be travelling with Tim Marchinson and his team Ben and Ash from Purple Soup, an Australian-based adventure therapy company who had also attended the family camp at their own expense as volunteers.

Manipal University is a private institution with fee-paying students. It is well respected and it is enormous: it has 25,000 students living on campus. It also has a couple of associated teaching hospitals, one being Kasturba Hospital. One paediatric ward we visited had 120 children plus a parent or two. They were cared for in one large room, but remarkably it was really quiet - until the Purple Soup team entered and had pirate sword fights with every child!

I was very impressed by the level of care the fee paying patients received. I enquired about what happens if they can't pay and was told, "Don't worry! We still care for them."

Subbi and Dr Annamma Kurien do an amazing job to provide haemophilia care. Dr Kurien, a medical pathologist and academic at the University, is also the President of the MHS and dedicates a lot of her time to haemophilia care. They are backed up by the local hospital staff including a paediatrician. The nearest haematologist is an hour and a half away. The Haemophilia



As Subbi said to me,
“We focus on
what we have,
not what we
don't have.”

Treatment Centre appears virtual: it is actually a mobile phone that runs hot 24 hours a day. Subbi takes the call from a patient or a hospital doctor and advises them which hospitals currently have factor available.

HAEMOPHILIA WORKSHOP AND FAMILY CAMP

In addition to her regular teaching commitments, Subbi organised a hands-on workshop for 30 nurses working with patients with haemophilia from different hospitals. This was a substantial feat and received a lot of publicity: the media came and there was an article in the local newspaper. Subbi and Dr Kurien were dynamos: they ran the nurses workshop on Friday morning and then ran the family camp that started Friday afternoon and continued all weekend. Subbi had multiple roles over the weekend camp: she stayed overnight at the camp to provide haemophilia care, was the camp co-ordinator, the swimming pool life-saver, and swimming teacher – and the tour leader for the visitors! On the Monday morning we returned to the hospital and I gave a talk to about 150 nurses about the essentials of haemophilia care.

The team is incredibly dedicated to their volunteer work with haemophilia. They constantly think their way around barriers and use their knowledge and contacts from their academic work, for example, working with the Manipal University Innovation Centre to create jobs that people with haemophilia can do at home. There was very little

funding for the camp so most things were donated. It was held in a school building which the hospital cleaners prepared. The hospital sent 100 mattresses and sheets which were set up in the class room. Caterers arrived with massive pots of very aromatic Indian food for each meal.

The camp was great fun, and we overcame the language barrier with lots of laughing, and hand waving, but we were grateful for the few interpreters we had. These were predominantly university students who volunteered for the camp.

These experiences make you reflect on the challenges faced in other countries. I was so humbled during the opening welcome when Dr Kurien said to the families, “The camp offers you two days a year to put aside your troubles and let the children and adults with haemophilia play and participate. If they bleed we will take care of them.”

My visit to India was inspiring – a real lesson in priorities. As Subbi said to me, ‘We focus on what we have, not what we don't have.’



AHCDO UPDATE



Sumit Parikh joined the team at the Australian Haemophilia Centre Directors' Organisation (AHCDO) as the ABDR Project Officer in May 2016. His primary responsibilities include initiating and leading projects related to the Australian Bleeding Disorders Registry (ABDR).

With a PhD in Health and Medical Informatics and strong background in IT and Statistical Analysis, Sumit brings important skills to the AHCDO research team. His core research areas and expertise include design, development, analysis and evaluation of clinical decision support systems, elearning systems and telehealth. He is involved with education and training for medical staff on Informatics and e-health and also works part-time at the Centre for Eye Research Australia (CERA) as a Senior Project Lead for Cataract Outcomes and Quality of Life projects.

Sumit's work at AHCDO will involve identifying priority research areas in need of development around the diagnosis and treatment of bleeding disorders. He is looking forward to the challenges relating to enhancements and/or improvements for the ABDR in collaboration with the National Blood Authority. ■

NEW STAFF



Jane Turney returned to the HFA team in early 2016 after working for us briefly in 2005.

"I have a member of my extended family who has haemophilia and our families have always been very close," said Jane. "That is what drew me to HFA initially, and makes me so interested in my work at HFA."

Jane's primary role is to manage HFA's Donor Database. She has been actively involved in various charitable groups for the last 10 years, sitting on several committees and driving many successful fundraisers.

"After years of corporate fundraising, I really wanted to get back to more grass roots involvement with the community. I enjoy very much being able to contribute to the work that HFA does and what that can achieve for the bleeding disorders community in Australia."

Jane continues to raise awareness for her chosen charities alongside her commitment to HFA. ■

RIDING FOR HAEMOPHILIA

Megan Sarson is the AHCDO Project Officer who is currently on a 2 year leave of absence.

She has spent most of the past year and a half in Ethiopia setting up a cycle tour business with her husband, Levi, but in June 2016 the couple will be taking time out to ride from Lands End to John O'Groats in the United Kingdom, over 1,000 miles, while fundraising for their favourite charities, including HFA and the Ethiopian Hemophilia Society.

If you would like to support HFA or the Ethiopian Hemophilia Society and give Megan and Levi encouragement to survive the coastal highs and lows of Cornwall, pass through the plains of Cheshire and climb the seemingly endless hills of Scotland, go to their fundraising websites:

To support HFA - <https://give.everydayhero.com/au/megan-and-levi-s-hfa-lejog>

To support the Ethiopian Hemophilia Society - <https://gofundme.com/EHSLEJOG>

You can watch Megan and Levi's progress on their Facebook page from 3 June 2016 - <https://www.facebook.com/ethiocyclingadventures> ■



The Ethiopian Hemophilia Society 2016 World Haemophilia Day event



Megan and Levi cycling in Ethiopia



YOUTH UPDATE

Hannah Opeskin

FACTORED IN

WWW.FACTOREDIN.ORG.AU

The new Factored In has been launched!

The Factored In website has been remastered, redeveloped and relaunched with a brand new look! After extensive consultation with the Youth Working Group it was decided that Factored In needed a makeover in order to ensure that the site continued to be user friendly and reflect youth needs. The site now has some great features as well as a modern look, including a featured story and event on the homepage. It also has the latest news and events, and the latest polls for members to take part in!

What is Factored In?

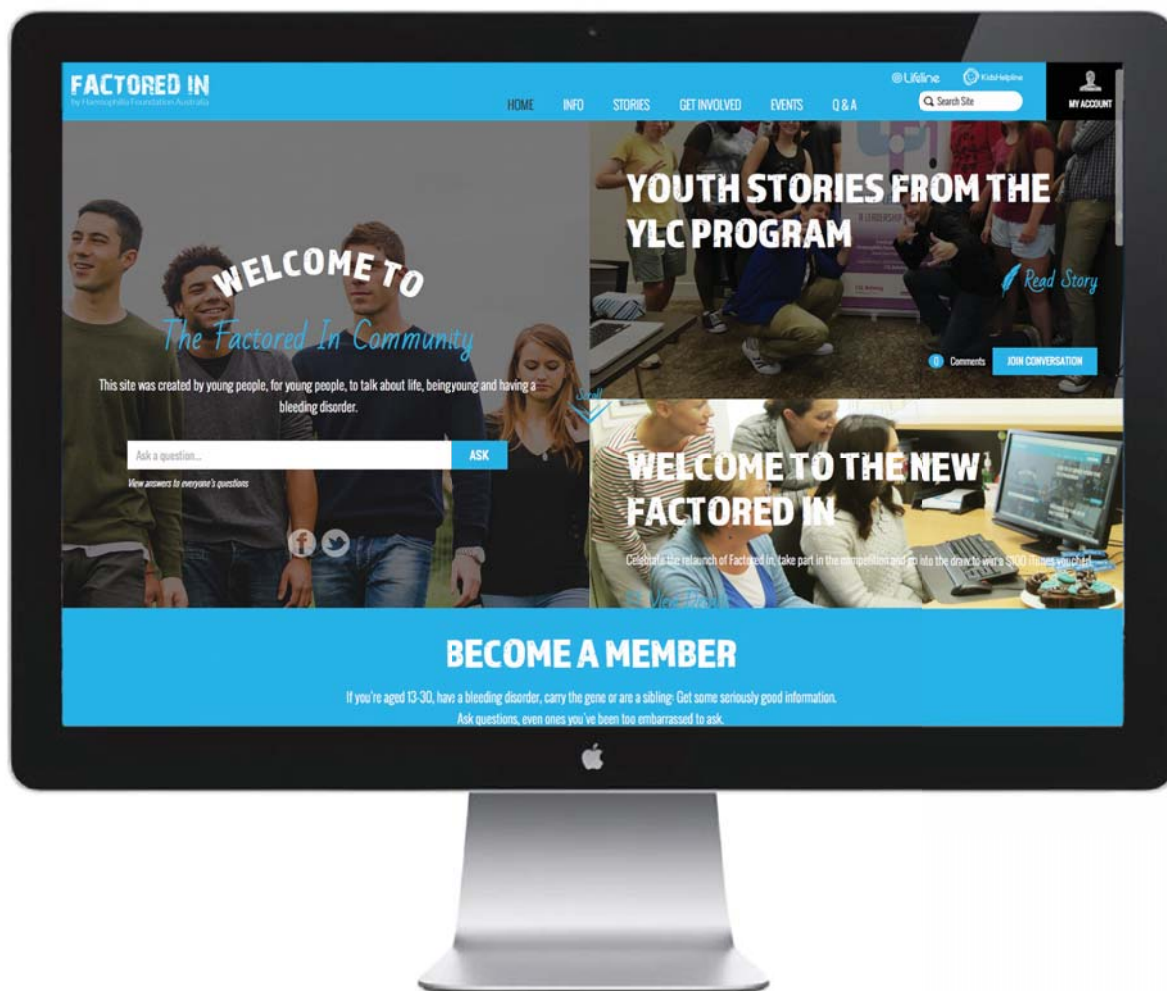
Factored In is for people aged 13-30 who have a bleeding disorder, carry the gene or are a sibling of a person with a bleeding disorder. Here you can find good information, ask questions (even ones you've been too embarrassed

to ask) – and if you're a member, you can take part in competitions and polls, and comment on stories and share your own.

Becoming a member is easy and free with lots of perks - if you're not a member yet and want to join the youth community, head over to Factored In and click on **My Account** to join!

If you are a current member you will need to create a new password by visiting <http://www.factoredin.org.au/my-account/reset-password>

I encourage everyone to head to www.factoredin.org.au to have a look! **#**



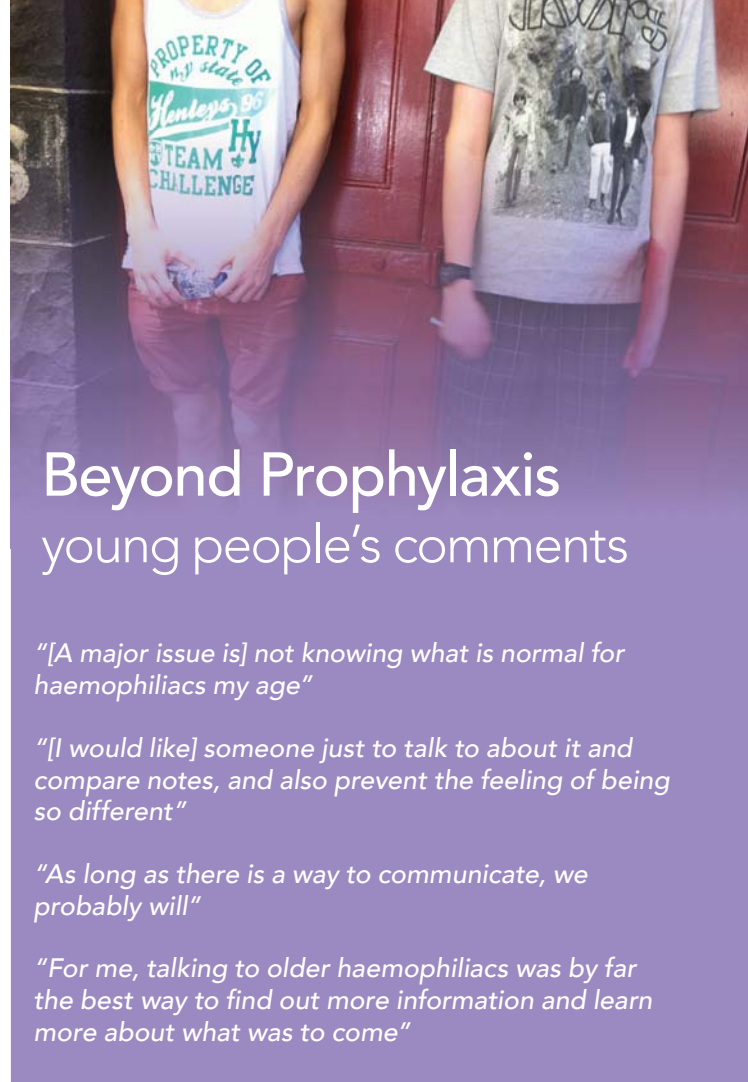
BACKGROUND – BEYOND PROPHYLAXIS

The Haemophilia Foundation Australia (HFA) *Beyond Prophylaxis* youth project (2012) identified a lack of information and understanding about the needs of young Australians with bleeding disorders and a lack of resources to respond to their needs.

As a result, the Project aimed to involve young people in peer education and support, and to equip them with the life skills to manage the reality of living with a bleeding disorder in a positive and affirming way.

The *Beyond Prophylaxis* needs assessment identified that young people's lives were changeable and demanding, but that they wanted to have ways to connect with others to share their experiences and give peer support. *Beyond Prophylaxis* led to leadership and mentoring training where youth could take on roles to support others in their local community or nationally.

The *Beyond Prophylaxis* Project also recommended the development of an online tool where youth could share their stories, connect with the youth community and have access to youth specific evidence-based information; hence www.factoredin.org.au was born.



Beyond Prophylaxis young people's comments

"[A major issue is] not knowing what is normal for haemophiliacs my age"

"[I would like] someone just to talk to about it and compare notes, and also prevent the feeling of being so different"

"As long as there is a way to communicate, we probably will"

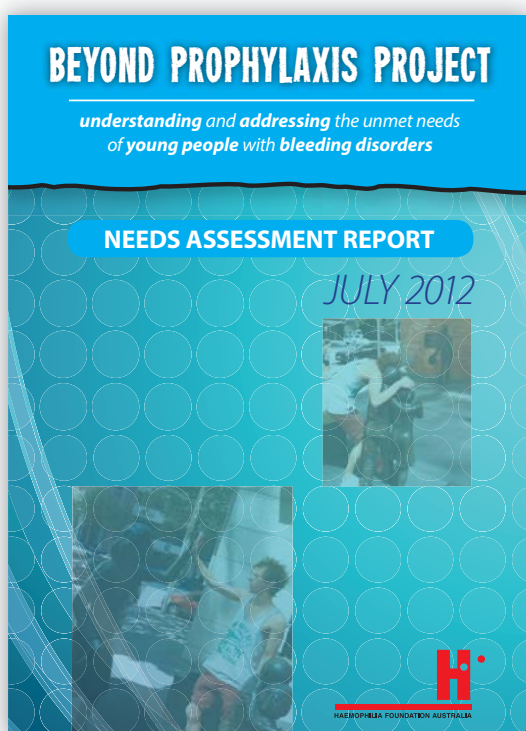
"For me, talking to older haemophiliacs was by far the best way to find out more information and learn more about what was to come"

Many were consulted as part of the project: young people, parents, health professionals, Foundations. They identified reasons that young people with bleeding disorders might be isolated and "difficult to engage": often because they prefer not to identify with having a bleeding disorder or with the bleeding disorders community, or do not find the community activities attractive or relevant to them.

Many of the health professionals talked of young people starting to disengage from haemophilia health services and community at around the age of 13-14 years and there being a life stage when many do not want to acknowledge their bleeding disorder. Even with a strong personal support network, a Youth Committee member described a 'hating my haemo' phase of his life during his teenage years.

The groups noted that isolation from peers with bleeding disorders and community could contribute to the sense of being alone and decrease opportunities for learning effective ways to manage their bleeding disorder from peers, community mentors or health professionals. With the potential for harm that could result from this, it is important to gain a better understanding of how to engage with these isolated and difficult to reach young people and what their current and future needs are.

To ensure peer communication, support and education is sustainable, an ongoing strategy would involve the further development of a leadership and mentoring program that provided skills in this area to a team of young people affected by bleeding disorders.





The HFA Health Promotion Officer spoke with applicants and their referees about their strengths and areas for further development

YOUTH LEAD CONNECT PROGRAM

The Youth Lead Connect (YLC) program developed by HFA builds education and life skills for young people with bleeding disorders.

Application to the program followed a similar process to a job application: youth were required to submit an application form to HFA detailing why they wanted to be involved in the program and how they would use the skills learnt from the training in their local community, they were also required to provide a referee to support the plan.

This application process was important because it gave the participants the opportunity to reflect on their strengths and interests. It also meant that the program could be carefully tailored to the participants, taking into account their strengths and what they would like to develop further, their experiences, past training and interests. This meant the program could be pitched at a much higher level and build on their existing knowledge and experience.

Including referees from their local community was key to ensuring their local haemophilia foundation was able to support the youth participant. The HFA Health Promotion Officer spoke with applicants and their referees about their strengths and areas for further development and confirmed they would be included in the weekend leadership and mentoring workshop.

The workshop was run in February 2015 and was engaging and inspiring for everyone who attended. Critical to the success of the entire weekend was the range of facilitators including the HFA educators, The FRANK Team and Reach with a variety of approaches and expertise to maintain engagement. Youth participants demonstrated that they were inspired to be part of the program and to be a leader or mentor in their community.

Participants were required to identify hurdles that they would complete as part of their training. The flow on effect of Youth Lead Connect is that it opened a dialogue between youth participants and their local haemophilia foundations and encouraged youth to be involved in local community events and activities. It also enables youth participants and their foundation to have a conversation about their personal strengths and interests and how this can be tailored to help their foundation with relevant and useful activities.

I am in regular communication with the youth participants and their local foundations to check all is going well as the youth work on their hurdles. When completed participants will provide a report about their hurdle.

It is exciting to hear of some of the outcomes and achievements so far:

- 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 won 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

We are currently evaluating the YLC program more formally. However, there has already been positive feedback and support from the community, providing momentum for the ongoing development of the program.

The Youth Lead Connect program is supported by an unrestricted education grant from CSL Behring. 

CALENDAR

WFH 2016 World Congress

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

Haemophilia Awareness Week

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

World Haemophilia Day

17 April 2017
www.wfh.org/whd

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



Have you **changed** your **email** address lately?



If you have changed your email address in the last year, please let us know so that we can update our databases!

Email your name and new email address to hfaust@haemophilia.org.au.

Or phone 1800 807 173.

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