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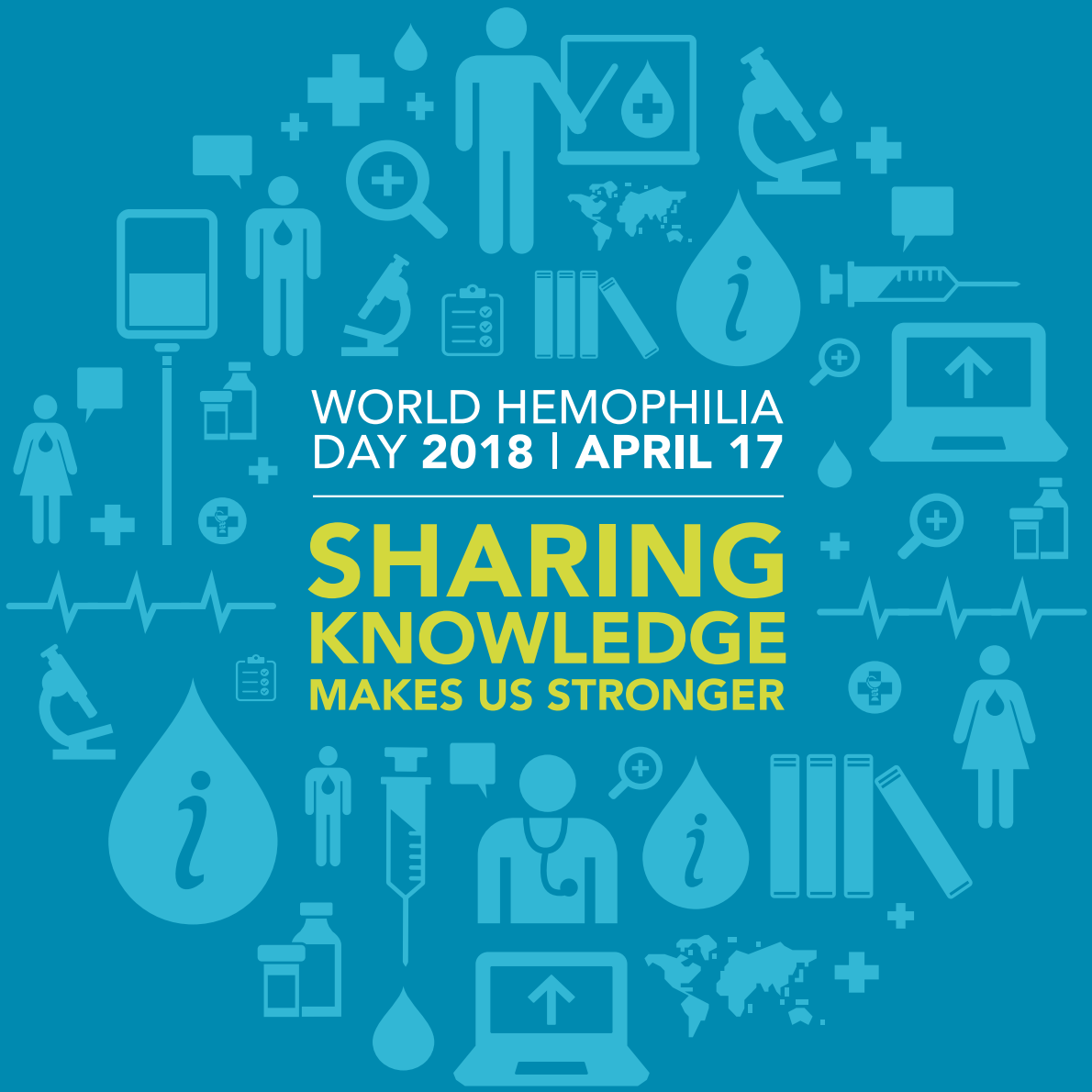

WORLD HAEMOPHILIA DAY 2018

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Team.Factor

Team.Factor was ready to ride in the 2018 BUPA Challenge Tour for its 6th year, but unfortunately the race day was cancelled due to extreme weather conditions. The ride was to be from Norwood to Uraidla, just over 137.40kms in total.

Team.Factor is a group of cyclists led by Dr Simon McRae and Andrew Atkins from the South Australian Haemophilia Centre who ride in the Tour to fundraise for HFA and the bleeding disorders community. The BUPA Challenge Tour is a public race where cyclists can ride the same course as Stage 4 of the Santos Tour Down Under on the same day as the elite cyclists.

"The team was pretty disappointed that the day got cancelled. The ride has such a scenic route and riding for our favourite cause makes it all worth the while." said Andrew Atkins

We thank everyone who made a donation to Team.Factor in 2018 and we look forward to seeing the team ride in 2019.

Gavin Finkelstein is President, Haemophilia Foundation Australia

FROM THE PRESIDENT

Gavin Finkelstein

Hepatitis C is once again in the news. The UK government announced a public inquiry into contaminated blood and blood products in 2017 and more recently that a retiring High Court judge would develop terms of reference and chair the UK inquiry due to commence in May 2018. In the UK, there have been several schemes that provide financial support to people who acquired blood borne viruses through the UK blood supply. In Australia there was a Senate Inquiry into Hepatitis C and the Blood Supply in 2004. There were legal settlements for people in Australia who contracted HIV through their treatments for haemophilia but other than one scheme in the ACT, there has been no financial support for people who acquired hepatitis C through their treatments.

We described the burden of hepatitis C on our community members in *Double Whammy* (2007) and *Getting it Right* (2009), the publications that reported the results of our needs assessment in 2006-9. That burden has remained intense in the years that have followed, and for many people in our community the burden of both hepatitis C and a bleeding disorder has been overwhelming.

You will see what HFA has done in relation to hepatitis C over the years on our website https://tinyurl.com/hfa-hepc-strategy. HFA made a decision to seek government support for an ex gratia recompense scheme in 2010. People living with health issues related to hepatitis C needed assurance that they could provide for some of their financial needs, especially if their illness progressed. We proposed a scheme that would provide financial support to people who continued to suffer from the impact of hepatitis C and in some cases for their families. Although sometimes met with sympathy we failed to get government support for such a scheme. We turned our attention to making sure funding for the new direct acting antiviral (DAA) treatment would be available, when these drugs were so promising after the limited success of earlier treatments. We were pleased these drugs were funded, and we are advised by HTCs and hepatitis clinics that many people with bleeding disorders have now had treatment. We are currently trying to establish how many people have not had treatment or do not know they have hepatitis C and/or their treatment needs.

Many people tell us they have had treatment success with DAAs – and are cured! I am one of these, and after several failed treatments over the years I am amazed by the simplicity of DAAs.

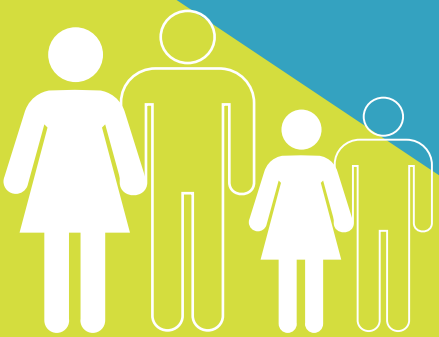
However, hepatitis C leaves an ongoing legacy for some in our community. Some people have been cured of hepatitis C but find they have marked liver cirrhosis and will continue to need monitoring for their liver health into the future. Some have told us that with advanced liver disease from their hepatitis C and the loss of income over their lifetime from symptoms of hep C on top of their haemophilia, they are still struggling to get by, even though they have now been cured. The burden of living with a bleeding disorder and a blood borne virus remains challenging and we are keen to understand the impact on our community and what their needs are.

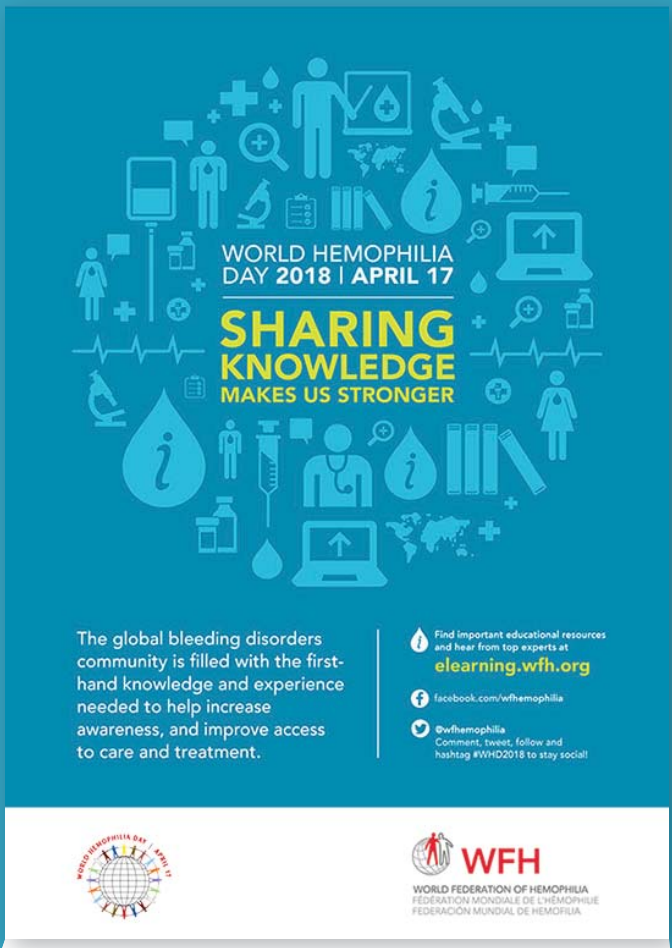
We are also soon to investigate the needs of older people in our community more generally. We want to understand more about older people in our community, and how they are coping with the burden of long term outcomes of a bleeding disorder. For many, the legacy of hepatitis C is bound up with this, but for everyone living with long term joint damage and pain, and the consequences of financial instability and other social and psychological difficulties, there is another set of complexities to face as they age. We will make sure everyone has a chance to make comments and contribute to this work.

WORLD HAEMOPHILIA DAY 2018

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

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





In 2018 the theme is SHARING KNOWLEDGE MAKES US STRONGER

On World Haemophilia Day share your personal experiences and knowledge with one another.

HFA will be celebrating peer support and bleeding disorders awareness on World Haemophilia Day by launching a series of new personal stories.

LIGHT IT UP RED!

Landmarks and monuments in Australia and around the world will support World Haemophilia Day by changing their lighting to red on April 17.

Show your support on the night, and post photos on our Facebook page of you and your friends at the landmark. #WHD2018

Keep an eye on our website and Facebook page for a list of locations that will be supporting the day.

- WFH World Hemophilia Day page – www.wfh.org/whd
- WFH Facebook page - www.facebook.com/wfhemophilia
- HFA's Facebook page - www.facebook.com/HaemophiliaFoundationAustralia.

Suzanne O'Callaghan is HFA Policy Research and Education Manager

GENE THERAPY

Suzanne O'Callaghan

Mark Lee and family, Prof John Rasko and Daniel Credazzi at the haemophilia B study press conference

For a long time gene therapy has been hailed as a potential 'cure' for haemophilia, but the expectation had been that viable treatment would be many years away in the future. In December 2017 two international experimental gene therapy studies published successful results, creating a great deal of publicity and excitement that a cure for haemophilia might finally be within reach.

ABOUT GENE THERAPY

Dr Glenn Pierce, Medical Member of the World Federation of Hemophilia Board of Directors, spoke with HFA about the background to these current gene therapy studies and what it means for people with haemophilia.

HFA: What is gene therapy?
Glenn Pierce: Gene therapy means a drug therapy that delivers a gene, made of DNA, to treat a disease, instead of a protein or small molecule. In the past, proteins such as factor VIII and factor IX, have been used to treat haemophilia. In work over the last 30 years, scientists have investigated using the DNA for factor VIII or factor IX to treat haemophilia in animals and humans.

HFA: How does gene therapy work?
Glenn Pierce: DNA can't be delivered orally, and when delivered intravenously, needs to be protected or it will be destroyed in the bloodstream. Viruses have evolved over hundreds of millions of years to deliver their genes into our cells. They are very efficient, which is why so many viruses cause so many infections in us. Scientists have harnessed several viruses and removed their genes to insert the factor VIII or factor IX genes. One virus in particular, adeno-associated virus (AAV), has proved to be very effective in delivering new genes to animals and humans. Thousands of mice have been cured of their haemophilia, and several trials are underway in humans.

HFA: What will the outcomes be for people with haemophilia?
Glenn Pierce: Early clinical trials in haemophilia were not successful but addressed many technical problems that needed to be overcome. More recent clinical trials using AAV-Factor IX have produced factor IX levels averaging 30% in persons with haemophilia B for at least one year. Likewise, a different biotech company has used AAV-factor VIII to produce on average 100% factor VIII circulating levels for at least one year. Many questions remain, including how long it will last and to monitor for long term safety.

HFA: What are some examples of gene therapy trials internationally now?
Glenn Pierce: Three companies are in advanced clinical trials and can be followed for clinical progress: Spark Therapeutics, BioMarin, and UniQure.

Dr Glenn Pierce, MD PhD, is Medical Member, USA, of the World Federation of Hemophilia Board of Directors and is on the Medical and Scientific Advisory Council of the National Hemophilia Foundation (NHF), the medical body which makes policy for the American bleeding disorders community.

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"We now know how to beat the immune response to achieve what may be a permanent cure"

A 'CURE'?

Media stories about the two gene therapy trials spoke of them as "a breakthrough" and "a giant leap forward" in the search for a cure for haemophilia. But what is meant by a 'cure' for haemophilia?

In gene therapy this varies between studies. Around the world there are a number of gene therapy studies at different stages of development, and each study has its own measurements of success. The two gene therapy studies that published results in December are some of the most advanced: one trial in the UK studying haemophilia A and the other in the USA, Canada and Australia studying haemophilia B. Both of these studies were able to demonstrate that:

- For most, factor levels could be increased and sustained at the mild haemophilia range or higher for at least one year
- Prophylaxis treatment could be discontinued for all participants
- Nearly all participants had no f urther bleeding episodes. [1,2]

HAEMOPHILIA A STUDY

The haemophilia A gene therapy study took place across multiple centres in the UK and was sponsored by BioMarin Pharmaceutical. 9 men with severe haemophilia received a single infusion of AAV5 to deliver an altered human factor VIII gene into their body. One received a low dose, one an intermediate dose and 7 received a high dose. They were followed for a year.

The 2 men who received low or intermediate doses had factor levels that remained at 3% or lower (moderate haemophilia). Of the 7 men who received high doses, 6 gradually increased to normal factor levels and had maintained this a year after treatment. Prior to the gene therapy treatment, all 7 had been on prophylaxis treatment. By 22 weeks after treatment, all 7 participants no longer needed to use factor VIII treatment.[1]

'When we started out, we thought it would be a huge achievement to show a 5 per cent improvement, so to actually be seeing normal or near-normal factor levels with dramatic reduction in bleeding is quite simply amazing,' said Prof. K. John Pasi, Director of the Haemophilia Centre at Barts Health NHS Trust and one of the trial investigators.[3]

HAEMOPHILIA B STUDY

The haemophilia B gene therapy trial was a collaboration between the team led by Prof. John Rasko at the Royal Prince Alfred Hospital in Sydney and multiple centres in the USA and Canada, and was sponsored by Spark Therapeutics.

In the study 10 men with haemophilia B and factor levels below 2% were treated with a single infusion of AAV with an altered factor IX gene. After treatment all had a substantial increase in their clotting factor IX (9) levels, which were sustained at a mean of approximately 30%, ranging from 14% (mild haemophilia) to 81% (normal range). As a result of this treatment nearly all had no further bleeding episodes. 8 out of 10 have not used clotting factor replacement therapy since then. Only one participant needed to use factor replacement therapy for bleeds after treatment, but used 91% less factor than before. There were no serious side effects.[2]

Although this was a small study and has not yet had long-term follow-up, Professor Rasko sees this as a major step in haemophilia treatment. 'We now know how to beat the immune response to achieve what may be a permanent cure,' he said.

Professor Rasko explained that the success of this small clinical trial can now pave the way for a larger study in haemophilia B with long-term monitoring. His team at RPA and their collaborators in the USA and Canada will also be commencing a similar small experimental clinical trial in haemophilia A in 2018.

'LIFE-CHANGING'

Before receiving the experimental gene therapy treatment, Australian clinical trial participant Mark Lee, 38, had severe haemophilia and clotting factor infusions up to three times a week since birth. Since the gene therapy injection his factor levels are in the normal range and he has not had any bleeds.

'This is life-changing for me. I spent my childhood wrapped up in cotton wool, unable to play football or do any of the things my mates could. I would always remind myself that there were people worse off than me, but it was still disappointing," said Mark Lee. "I have two daughters who are carriers for haemophilia, but now I know that if they have affected children, it could be one injection and they could live normal lives. This goes beyond our little family currently. It will have a positive impact on all generations to come.'

Mark commented that it is sometimes the little things that show how much difference this has made to his quality of life. He travelled by plane to the Sydney press conference to present the results. 'I always used to wait for other people to get off the plane,' he said, 'but this time, I stood up, gave my knee a little wriggle and walked straight off with all the other passengers.'

LIMITATIONS

There is still a long way to travel with both of these gene therapy trials. Both studies were very small – just 9 to 10 people with haemophilia – and before these treatments can be made widely available, there will need to be studies of much larger groups of people with haemophilia who, along with these participants, will need to be monitored for at least 15 years to confirm the results and check for other complications.

Inclusion criteria were also very strict and limited the number of people who could participate and use the treatment. Both studies used an adeno-associated virus (AAV) to transport the corrected gene to the participant's liver. AAV is a small virus that is not currently known to cause disease, but many people with haemophilia may already have been exposed to AAV and their immune systems could reject it. To take part in these trials, participants needed to be AAV negative. There are a number of gene therapy studies around the world using variations on AAV to deliver the gene within the body. All these studies have similar exclusion criteria, including other requirements; for example, participants also have to be adult males with severe or moderate haemophilia, without active hepatitis and have no history of inhibitors.[4,5] A next step for the haemophilia A AAV5 study is to trial a high dose in a small number of people who are AAV positive to see what the outcome is.[6]

FOR THE FUTURE

Apart from AAV, other types of gene therapy are also being studied, some with very promising results. Researchers are working on a range of methods to deliver the corrected gene within the body: lentiviruses have been used successfully in dogs with haemophilia; platelets derived from hematopoietic stem cells (which produce blood cells) are also being investigated to transport the corrected gene directly into the blood stream. Other forms of gene technology are also being researched, including gene editing and other novel approaches.[5]

Daniel Credazzi, Vice-President of Haemophilia Foundation Australia, who has a son with haemophilia, welcomed the breakthroughs, saying: 'The real potential of a cure with safe and effective gene therapy is very exciting for people living with this chronic condition, and for their families. My wife and I have been looking forward to this news since our son was diagnosed with haemophilia 13 years ago. We are grateful to all the courageous people who have participated in gene therapy trials.'

MORE INFORMATION

For people with haemophilia in Australia, these are exciting times, with a range of new ground-breaking haemophilia treatments coming on to the market as well as the first indications of success in these experimental gene therapy trials. If you have questions about experimental gene therapy or other new haemophilia treatments, talk to your specialist haemophilia doctor (haematologist).

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Sharon Caris is HFA Executive Director

PARTICIPATING IN RESEARCH

Sharon Caris

We are seeing many new opportunities for community consultation about treatment products.

This is due to more and more products entering the market leading to increased industry competition, and complex government processes for funding new medicines. The treatment products need to be registered as safe and effective, and government payers need to decide whether to fund them.

It can be difficult to measure cost effectiveness, and compare outcomes and costs as the new therapies continually add more possibilities and potential outcomes. We are rarely comparing apples with apples these days, but governments must make decisions around what they will pay for from the submissions put before them. We need to influence this.

It is more important than ever for the community to express its voice, and for individuals to explain their treatment needs and what they want to achieve from their clotting factor or other therapy. In recent years, more and more Australians with a bleeding disorder have had the opportunity to participate in clinical trials. This is a courageous decision as it carries risks. It is often quite onerous, with lots of visits to the HTC, lots of recording keeping.

Sometimes the outcomes of a new treatment to different stakeholders are very obvious, at other times less so; data is needed to justify expenditure. We need to make sure what makes a treatment valuable to patients and their families is factored in to cost-effectiveness evaluations of our medicines. Treatment product users and/or carers may value less infusions, improved vein health, higher trough levels resulting in fewer or no bleeds, and this must be translated into a metric that justifies expenditure for payers before they will be funded.

It is more and more important for our community members to express their views and share their experiences about living with a bleeding disorder, what they think is most important for their treatment and treatment outcomes. But our community has had to deal with a lot, and we observe many of our members are uncomplaining and stoic. Some are tired of providing their views, while others don't think their views would make a difference. But we are very much at the pointy end now. We need people to respond, because their views may well tip the scales, and make the very difference we are seeking.

It is the personal experiences that are often missing from some research project reports. We need to increase participation, and get the views of the people using the treatments. It is their experiences that are so important for informed decision making and advocacy.

But how can we do this? How can we get their views? Participation in research is one way that information can be collected and passed on to decision makers. The research may be our own, or it may be academic research, or research undertaken by pharmaceutical companies seeking information to guide their decision making about their treatment products or their future pipeline.

To encourage people to understand how research can lead to better treatments and care and to learn about opportunities to participate in research, HFA has a section called PARTICIPATING IN RESEARCH on the HFA website - https://tinyurl.com/HFA-participate-in-research. We often list research that people may wish to be involved with and highlight new studies in our e-news and on our Facebook page. If you are interested in contributing, please take the time to have a look and consider whether you will participate.

RARE DISEASE DAY

On 28 February 2018, people living with or affected by a rare disease, patient organisations, politicians, carers, medical professionals, researchers and industry around the world came together in solidarity to raise awareness of rare diseases. The wider community was invited to learn more about rare diseases and help overcome the isolation often experienced by people living with a rare disease and their families.

In 2018 the theme for Rare Disease Day was *'With research, possibilities are limitless'.*

Rare disease research is crucial to providing patients with the answers and solutions they need, whether it is a cure, treatment or improved care.

Because of the nature of rare diseases, the dynamic between patient and research is a bit different in rare disease than in more common diseases. Rare Disease Day 2018 was an opportunity to recognise the essential role that patients play in research. They advocate for research. They often fund research. Patient groups often partner in research projects. Patients participate in clinical trials and social and market research related to rare diseases.

Join us in making the voice of rare diseases heard!

For more information visit www.rarediseasedayaustralia.com.au.

Suzanne O'Callaghan is HFA Policy Research and Education Manager

PROBE STUDY UPDATE

Suzanne O'Callaghan

Between September 2016 and February 2017 HFA took part in the second phase of the multi-national PROBE (Patient Reported Outcomes Burdens and Experiences) Study to test the PROBE survey in Australia.

The PROBE study aims to give HFA and haemophilia organisations around the world access to good quality data about the treatment and health experiences of people with bleeding disorders. It is very important to validate the research methodology by testing it to make sure the study is recognised internationally as strong data and that it works for Australians.

WHAT IS THE PROBE STUDY?

PROBE is a patient-focused research project l ed by a global team of patient and academic investigators, including Mark Skinner, former WFH President, and Assoc Prof Alfonso Iorio from McMaster University, Canada, who have worked closely with HFA on the Australian arm of the study. The research will support efforts to improve treatment and comprehensive care programs in Australia and other countries around the world.

In the future the PROBE study will cover the range of bleeding disorders. The initial stages of the survey (Phases 1 and 2) tested the research methodology in haemophilia and allowed people with haemophilia to report their haemophilia severity, treatment history and the impact of haemophilia on their daily life.

This data will be used to analyse the perspectives of people with haemophilia on outcomes that affect their own life and care. It is particularly important data to have when HFA tries to understand what the issues are for our community, and will enable us to quantify and represent these issues in a robust and credible way to our Council and others, such as governments or treatment and service funding bodies.

PHASE 2

Phase 2 of the PROBE study aimed to test:

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

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

In Australia, there were two survey rounds in Phase 2 to compare results:

Round 1: 20 September - 12 December 2016

Round 2: 16 December 2016 - 22 February 2017

Survey participants were welcome to complete both rounds. Participants lived in Australia, were adults (18 years or over) and had haemophilia or carried the gene; or were the partner, family member or caregiver of someone with a bleeding disorder, but did not have a bleeding disorder themselves. These two groups were also compared with each other.

ETHICS APPROVAL

HFA worked with Monash University in Melbourne to obtain ethics approval for Phase 2, including the data handling processes.

We are grateful to Dr Liz Bishop from the Michael Kirby Centre for Public Health and Human Rights at Monash University for her support of the ethics process and her advice.

RESULTS

Australian survey participants for phase 2:
People with haemophilia/carry the gene – 51 (required = 50)
People without a bleeding disorder – 52 (required = 50)
TOTAL – 103 (required = 100)

Results of the international study are currently being collated and analysed.

PHASE 3

Phase 3 is the final stage of implementing the study around the world and is due to commence in 2018. When this begins in Australia, we will be inviting all adult community members with haemophilia or who carry the gene, or are the partner, family member or caregiver of someone with a bleeding disorder, but do not have a bleeding disorder themselves to complete the survey.

When all the survey results for phase 3 have been entered and then analysed by the McMaster University and international PROBE team, HFA will be given access to the de-identified Australian and international data through a secure dashboard where we can compare answers to specific questions in the survey, for example, how many people with haemophilia in a particular age group have pain management problems as compared to other ages. This will be invaluable data for our work to improve treatment and care.

ANY QUESTIONS?

For more information, please contact Suzanne O'Callaghan at HFA:

E: socallaghan@haemophilia.org.au
T: 1800 807 173
Or visit the PROBE study section on the HFA website - www.haemophilia.org.au/research/probe-study

Beryl and Alex at Queensland Haemophilia Centre

Beryl Zeissink is Clinical Nurse Consultant – Haemophilia at the Queensland Haemophilia Centre, Royal Brisbane & Women's Hospital

A DAY IN THE LIFE OF A HAEMOPHILIA NURSE

Beryl Zeissink was interviewed by Suzanne O'Callaghan, HFA

What does "patient-centred care" involve for people with bleeding disorders? Beryl Zeissink, haemophilia nurse at the Queensland Haemophilia Centre, explains some of the complexities:

- Helping individual patients to negotiate the health system and making sure it works for them.
- And the bigger picture of best practice care. This also involves providing data and support to various administrators, and keeping up and contributing to expertise as a haemophilia nurse both in Australia and at an international level. It is crucial if the system is to work effectively and so that care is always improving.

STREAMLINING THE DAY

The day starts early. 'One of the elements that makes me love my job is its unpredictability,' said Beryl. 'There are components of the day that can be planned for, like clinics and booked visits, but due to the very nature of haemophilia there is always the unexpected.'

On a normal day Beryl (and/or Alex, who is the other nurse with the haemophilia team) will commence work at 7am by checking messages on the answering machine and returning phone calls. 'I usually wait until 8 am to call people back unless they say it is urgent because I figure people might still be asleep. Just because I start at 7 doesn't mean everyone else is awake!'

These phone messages can vary, from needing a new prescription to people who have experienced a bleed overnight and did not go to the Emergency Department, particularly people with a mild disorder who realise they need a treatment but require assistance to infuse. 'We encourage people to come in as soon as a bleed starts and as early as possible to get them in the queue for a Day Care Unit bed before it gets too busy,' explained Beryl. Co-ordinating with the haematologist's schedule is another influencing aspect: 'We might also time their visit for when the doctor is available.'

Communication is very important. 'It always helps if people leave a message with a bit of information so that I can judge the urgency and know how to prioritise the call back, particularly if I am juggling multiple things at the same time,' said Beryl.

On Monday Beryl emails the HTC team on what is scheduled for patients that week.

If a patient has a planned surgery, Beryl's day will kick off earlier. 'At our hospital we also come in at around 6.30am if one of our patients is booked for surgery to prepare them for theatre. This fits around how their admission works at

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our hospital, because they are usually admitted on the day of surgery. We need to work closely with the timing of the surgery list and co-ordinate their factor infusions to make sure their bolus dose [single large dose] is given at the right time, an hour before surgery, to give them the best protection. We prefer them to be first on the list because that makes the time of their surgery more certain.'

Another regular activity of a morning is a ward round of hospital inpatients with bleeding disorders by the Haemophilia Treatment Centre team. 'We like to follow up our patients who are in hospital to see how they are going. There is usually the haematologist, nurse and social worker from the HTC, along with junior doctors from the treating team in a non-haematology ward, for example the orthopaedic team might join the round in a surgical ward if the person has had something like a joint replacement.'

PLANNING FOR CARE

Haemophilia Treatment Centres provide comprehensive care. This often involves considerable liaison with the treating doctor and the patient and working with the patient on how to negotiate the system.

During the day Beryl may be taking a call from a surgeon preparing for surgery and taking their contact details and information about the patient so that the haematologist can call them back, or depending on the type of surgery, the surgeon may want to discuss the surgery with Beryl. Or she may be organising a factor treatment with a patient before a dental or medical procedure such as a colonoscopy. Sometimes they will need to liaise with the GP or a private surgeon so that they can administer the treatment product, and the patient will need to come and collect the product beforehand.

Travel for a person with a bleeding disorder often requires substantial planning. 'We like to have as much notice as we can before someone is going to travel,' said Beryl, 'but while some people will plan ahead, others only give short notice, and that can make real difficulties for them and the Treatment Centre. For example, if someone rings me today to say they are going on a skiing holiday to Canada tomorrow and I have five patients waiting, it ends up being a crisis and they are not going to be in a good position to have all their documentation and treatment needs ready in time!

'What someone needs to do if they are going to travel will generally depend on where they are going and how long for, and also on the individual patient, their diagnosis and their treatment plan. I check with them that they have travel insurance and if they were asked to declare their bleeding disorder and spell out the implications if they haven't. I might advise them to check the location of HTCs on their route, if relevant.

'We have a brochure about travel and I might send that to the patient to have a look at and think about. Someone with mild haemophilia who is going on a 2-week non-adventure holiday to somewhere well-resourced might not need to take factor with them. On the other hand someone with a severe bleeding disorder on home therapy who is carrying their product with them will need a letter from their doctor for the airport security and customs and in case they need medical assistance if they are overseas. They often find that they have more health dramas than usual if they are travelling and need to take that into account. I talk to them about how to pack their treatment product and that they will need to take it on board the plane as hand luggage so that it doesn't get damaged or lost. We discuss what countries they are going to and whether there are reciprocal health agreements and what this means. If they are going to places that require extra documentation to bring in treatment product, they will need a few months to get the official documents organised. Depending on the patient, for example, if they have complications like an inhibitor, and they are travelling to New Zealand or even within Australia, I might be courteous and let the HTCs there know they are coming.'

If one of the HTC patients is moving to the country, Beryl will be in contact with the new health services involved in their care, walking them through the steps and their responsibilities. She will send them information on bleeding disorders from HFA and relevant Queensland Health policies for treatment and care.

CLINICS AND TREATMENT

At different times in their life individuals with bleeding disorders will have different treatment and care needs. The HTC clinics reflect this.

If it is Wednesday afternoon, Beryl will be at the HTC clinic to review existing patients. While the patients are waiting to see the doctor, she might have a general discussion with them, talk about treatment product supplies or MyABDR. It is an opportunity to update contact details on the hospital medical record and MyABDR. In the clinic consultation the data the patient has input into MyABDR will be brought up as graphs as part of the review of their treatment plan. She, Alex and the doctor will have looked at their record to remind them to follow up outcomes from their last appointment, for example, if they have hepatitis C, whether they have attended a hepatitis clinic and results of their hepatitis C tests or treatment.

If it is Thursday morning, it will be the HTC clinic for new patients. While the haematologist and the patient will be working out a treatment plan, Beryl has prepared for the clinic by checking whether the patient has consented to having their data in the Australian Bleeding Disorders Registry (ABDR) and whether they have details of their family tree to see who else in the family might be affected by the bleeding disorder.

Treatment is tailored to the individual. In haemophilia this increasingly involves PK (Pharmacokinetics) blood tests to guide dosage decisions; and for the nursing

team, in conjunction with the haematologist, that means giving results and dose information to patients. DDAVP, often used by people with mild haemophilia A or von Willebrand disorder, also needs to be tested in an individual to see what their response is. The nurses educate patients about what is involved in a DDAVP challenge and organises their blood tests.

Patient education is ongoing and Beryl is always taking advantage of opportunities to incorporate it into her practice. 'Whenever I am doing procedures, I always explain why we do things this way, for example, that when you have an injection to put firm pressure on the site afterwards to prevent bruising.'

With so many tasks to follow up, it is important to have systems to keep on top of them. 'There is a board in our office with a checklist of "things to do"– from chasing up blood tests, who is on a waitlist for surgery and organising ABDR patient cards to making sure that there are current prescriptions at the pharmacy,' said Beryl.

BEST PRACTICE

What constitutes best practice for a haemophilia nurse? 'I do a lot of reading to keep up with things,' remarked Beryl, 'from peer-reviewed journals to the HFA and HFQ newsletters. It is also very important to have the opportunity to attend international and local education meetings, like the WFH Congress, but as a hospital nurse this requires a lot of paperwork and you can't assume that you will attend as it may not be approved.'

As an experienced haemophilia nurse with considerable expertise Beryl also contributes to the national and international knowledge base. At the moment she is Co-chair of the Australian Haemophilia Nurses' Group where national practice issues are discussed, for example, how to implement changes with a new treatment product rollout, or putting together nursing education on other new developments. 'And it is always on my list to write articles!' The list of things to do is always very long, and has to be prioritised, so some things just never get done unfortunately!

Measuring best practice and its impact on patient health outcomes involves statistics. For Beryl and the team this means inputting data about treatments and clinical interactions with people daily. She also supports HTC patients to use MyABDR to record their home treatments and bleeds so that the data can be entered in the national ABDR system. If they are having any problems, she gives them the contact details of the MyABDR helpdesk so that they can sort it out, but will also initiate the call to the MyABDR Support team at the time herself to facilitate the discussion between the patient and the helpdesk and advocate for her patient when they are not confident or time poor and have various issues.

As a senior nurse in a large hospital, Beryl also has non-haemophilia related responsibilities. As a matter of course she needs to keep up-to-date with the range of services and with her mandatory competencies, for example, resuscitation, fire, lifting and child protection. Once monthly she also needs to take her turn on a shift as a Cancer Care Services nurse manager, dealing with admissions, clinic times and re-allocating staff to manage sick leave.

Technically Beryl's day finishes at 3.30pm. But with so much to take care of, it is not surprising that she often doesn't leave on time. 'No matter how you plan your day, it never works out the way you imagined because there is always the unplanned and that involves a complete reprioritising of your day. And self-care is important. I do need to remind myself that I am not a machine and that means finding some time for lunch!'

Hayley Coulson is the Haemophilia Physiotherapist at the Lady Cilento Children's Hospital, Brisbane

ANKLE SUPPORT

Hayley Coulson

The ankle is one of the most important joints of the human lower limb and plays an integral role in our locomotion. Injury to the ankle joint can result in significant functional impairment and decreased quality of life. Unfortunately, patients with haemophilia are at an increased risk of ankle joint injury due to haemarthrosis (joint bleed), resulting in haemophilic arthropathy.

The ankle is one of the most common joints affected by haemophilic arthropathy. Several studies of people with haemophilia have shown that joint destruction identified on MRI is evident before physical signs of ankle joint destruction, such as reduced range of motion and pain.[1,2] This highlights the importance of preventative measures in reducing the incidence of ankle joint injuries.

Experts have long recommended the use of ankle braces for people with haemophilia who are physically active, have a target joint or are prone to ankle injuries.[3] Ankle supports such as bracing and taping have proven to be cost-effective additions in both the prevention and rehabilitation of ankle joint injuries.[4] While taping the ankle does provide effective support the long-term durability of tape is poor and impacts the skin. The brace, however, provides greater protective mechanisms and reduces the risk of ankle injury.[5]

Using ankle support during physical activities, combined with correct management of bleeds, will decrease the risk of further joint damage. If you have been having problems with ankle injuries whilst participating in activities, then this may be a solution to your problem. We are not recommending that all people should wear an ankle brace, only if you have been having issues. Your Physiotherapist can fully assess and identify any weakness in your ankle joint, and prescribe the use of an ankle brace if needed.

Thanks to Wendy Poulsen, formerly Haemophilia Physiotherapist at the Lady Cilento Children's Hospital, for her advice.

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> Some common bleeding signs are a tingling sensation, swelling, warmth, pain with weight bearing and reduced movement in the joint.

Scott Russell is the Haemophilia Physiotherapist at the Royal Brisbane and Women's Hospital

HOW TO REST A JOINT BLEED

Scott Russell

For many people with haemophilia joint bleeds are an unfortunate consequence of the condition. Whether they are spontaneous, due to an injury or increased activity, a bleeding joint can have significant short-term (and possibly long-term) effects. Timely treatment in the form of factor replacement, rest, ice, and compression is important to reduce the bleeding and minimise these consequences. This article also explains the appropriate type and length of rest that should be employed following a joint bleed.

I have pain in my joint. Is it a bleed?

If you are developing pain in a joint, the first thing to determine is whether it is a bleed or not. This can be difficult, especially if the joint has arthritis. Some common bleeding signs are a tingling sensation, swelling, warmth, pain with weight bearing and reduced movement in the joint. Other conditions such as arthritis may have some of these signs but usually to a smaller extent. For example an arthritic joint may feel 'stiff', but you can still move the joint as per normal and it often doesn't respond to factor replacement. There are also many other non-haemophilia muscle and joint conditions that can cause pain.

It's a joint bleed! I have started my factor replacement, ice and compression. How should I rest the joint?

In the early stages it is important to rest the joint. This is done by restricting movement (e.g., by not bending and straightening the joint) and by avoiding weight bearing. For ankles and knees this means you should use crutches (or another suitable mobility aid). For elbows it means avoiding lifting and leaning on your arms. By doing this you minimise the risk of further bleeding and damage to the cartilage.

How long should I avoid weight-bearing?

Ideally, weight-bearing should be avoided whilst there is blood in the joint. This can vary depending on the severity of the bleed, but a good guide is to avoid weight-bearing for at least 2-3 days once adequate factor replacement has commenced. This is normally enough time for the bleeding to stop and pain to subside. If there has been no improvement over this time, then this period may be extended.

If you need assistance with equipment or advice regarding a painful joint, please don't hesitate your Haemophilia Treatment Centre.

Anthony McCarthy is an Australian community member with haemophilia A

CURING HEP C – A PERSONAL STORY

Anth McCarthy

I'm glad to say that hep C and I have been divorced now for almost 5 years. We are so much better apart. I'm told we first became acquainted sometime in the late 1970s, back when hep C was barely known to science. There was no hep C test and it was clumsily referred to as 'non-A, non-B hepatitis'. I was very young - far too young to be entering into such a relationship. We came into contact through the blood products that were used to treat my severe haemophilia A. Hep C went to work slowly but surely, inflaming my liver, progressively scarring it and toughening it up, when it should be supple and squishy. Hep C was violent and silent, and for most of our time together I didn't even know it was there.

I also acquired HIV, but slightly later in life, when I was at primary school. What a dysfunctional threesome we made. I wonder if the hep C infection made conditions in my body more favourable to HIV? But being exposed to HIV, and seroconverting to become "HIV positive", really took the attention away from hep C. There is a particular hype and notoriety surrounding HIV that hep C can't boast. But that suited hep C just fine. It was happy to lurk quietly and do its work. Unlike HIV, which was drama, drama, drama.

I'll never forget the soul-crushing moment, aged about 25 when it hit home that hep C was potentially incurable and fatal. Until then, I'd kind of dismissed it as a less dangerous little brother to HIV. The reality blindsided me during a meeting I attended at the Alfred to discuss treatment options. I was suddenly overwhelmed with sadness and struggled to fight back tears. It was embarrassing with the room full of doctors, nurses, researchers and patients like me. I wish now that I'd allowed myself to blubber away with abandon.

I first went on treatment in 2001, a 48 week course of interferon and ribavirin. It was really tough going, and I experienced a lot of what the doctors called lowered mood. I was depressed, but in denial because I very much wanted to stay on treatment and clear the virus. My blood counts showed a drop in neutrophils (a type of white blood cell) and I needed to go on an additional medication to stimulate their production. Like the Interferon, it was injected subcutaneously into my abdominal fat roll. Talk about feeling like a pincushion, but I got the job done by focussing on the goal of hep C clearance. Finding out the treatment hadn't worked was a big kick in the guts but I picked

"I went for it, this time working hard to improve my chances by quitting work and trying to live stress-free and wholesomely. I started juicing organic veggies and meditating daily and I coped much better on treatment the second time."

myself up and got on with life. My HIV diagnosis had instilled in me a resilience that I drew upon heavily.

It took several years for another treatment option to become available. In that time I married Jennifer (she makes a much better partner than hep C) and we decided to try to have children. Our decision coincided perfectly with the 'chronic viral illness program' then on offer through Melbourne IVF and the Royal Women's Hospital. Suffice to say there was a lot of science involved and not much romance, but here we are now with a 12 year old son and 10 year old daughter and they are both perfect.

By 2005 I was ready to give treatment another crack, this time with pegylated Interferon. It was scary to face the prospect of a return of the depression, but my desperation to clear this virus overruled those fears. I went for it, this time working hard to improve my chances by quitting work and trying to live stress-free and wholesomely. I started juicing organic veggies and meditating daily and I coped much better on treatment the second time. The depression stayed away but the problem with the neutrophils returned. To learn that the treatment had again failed was a disappointment of epic proportions. I felt beaten, and jealous of those others who had cleared hep C.

By 2012, I was approaching the pointy end of a long-term hepatitis C infection and the prospect of a transplant, though some way off, was very unappealing. I can't say I ever noticed any symptoms directly stemming from hep C; no discomfort, jaundice or pain. Just the less tangible symptoms of abnormal liver function results and fibroscan results showing fibrosis/cirrhosis. I was given the opportunity to go back on treatment that year which was wonderful because I was running out of time. And this time there was new hope. A protease inhibitor called telaprevir was added to the interferon/ribavirin combo. My specialist says it was clunky, but the best cocktail possible given my genotype and history as a co-infected non-responder. Don't you just love medical lingo.

I needed to take telaprevir for the first 12 weeks of the 48 week course. It was a very hard drug to take and I honestly don't think I could've lasted for more than 12 weeks. It would burn my back passage something fierce. To minimise the burning, I was advised to take the tablet with a good measure of oily food such as cheese, butter or olive oil. It helped somewhat but the oil component was nauseating when I lacked an appetite. The other challenge was taking it 3 times a day. It's quite a challenge to coordinate a tablet every eight hours and around meals and sleep.

But it was all worth it. So worth it. I can't express the joy I felt when my hep C tests started to come back negative. I remember the doctor saying for the first time that my liver function was normal. I couldn't believe my ears. I had to ask, "you mean normal for me?", to which he replied, "no, normal for the population". I was totally floored and thrilled.

So now I'm ecstatic to live with a cirrhotic liver that's not getting any worse. I don't mind having a gastroscopy every two years to monitor varices caused by portal hypertension. Nor do I complain about needing an abdominal ultrasound every 6 months to watch out for cancers. I treat this as extra time, as extra life with Jennifer and the kids, and life is truly wonderful. I would like to take this opportunity to thank my wonderful doctors, all the nurses, other medical professionals and allied health at the Alfred Hospital in Melbourne. If you are reading this, you know who you are. Thank you. Clearing hep C is the medical highlight of my life.

I understand that the drugs being used to cure hep C are now very easy to take, and practically side effect free. If you are hep C positive and reading this, I can't encourage you enough to get onto treatment and kiss off hep C. It's worth it.

Sharron Inglis is Vice-President, Haemophilia Foundation Victoria and has haemophilia A

WOMEN AND PEER SUPPORT

Sharron Inglis

PEER SUPPORT FOR WOMEN IN A LOCAL CONTEXT

The importance of peer support for women affected by bleeding disorders was a key finding in HFA's consultation for **The Female Factors Project**. Often feeling isolated and as though they are the only ones with their experiences, women have found connecting and sharing stories to be immensely valuable and greatly empowering. As a way of supporting this, HFA is including personal stories from Australian women with the evidence-based information in all **The Female Factors** education materials. But how are local Foundations exploring peer support for women and what can we learn from their experiences?

This report from Haemophilia Foundation Victoria is the first in a series about local peer support for women from Australian State and Territory Foundations.

Whether we are women who have known about our bleeding disorder from a young age or a diagnosis has come at a time when a child or family member has been newly diagnosed, advocating for our own, sometimes unique, medical needs can be challenging.

My life story and experiences will be different to some of you, as I have known my factor VIII (8) levels have been low since I was three years old. My level of factor VIII at that time was 17%. My sister's levels are also low and at a similar level to mine. My levels now sit around 40%, with the need to have treatment for most procedures.

My dad was known to have haemophilia. We think his mother had low factor levels due to her history, but she was never formally diagnosed. The testing when I was little wasn't as advanced, so I couldn't be tested until I was three. Mum and Dad wanted another child, but didn't want to wait until after the testing. Hence, I was diagnosed as soon as I was able to have the test.

GETTING INVOLVED WITH PEER SUPPORT

I was always keen to be more involved with Haemophilia Foundation Victoria (HFV) and women's issues, but this didn't happen until we moved closer to Melbourne and the kids were a bit older. My background is in nursing, with a more recent change in 2006 to sonography (ultrasound).

At the HFV camps and other peer support gatherings it was great to chat with others about our challenges with haemophilia, particularly women's issues. Many were new to the thought process about women speaking up for their health and specific female issues with possible low factor levels. This spurred me on to become a member on the HFV committee and I am currently the Vice President. This role has really opened my eyes to the plight of women with bleeding disorders on an international level. I have been fortunate to attend national and international haemophilia conferences and recently presented at the Australian & New Zealand Conference on Haemophilia and Rare Bleeding Disorders, sharing a personal account of the impact of a bleeding disorder from a female perspective.

THE FEMALE FACTORS

It was great to meet Suzanne at HFA and be involved with the development of the new **The Female Factors** material on women's bleeding issues. After reading the first booklet, my mum cried. There was finally formal proof in writing to support the bleeding-related issues my sister and I have been through and are still challenged with, and the pain my parents felt with people not believing them. She said it was wonderful to see after over 40 years of fighting for us that there was finally recognition.

I have shown my friends and family the booklets, taken them to the doctors with me, shown other women within the bleeding disorder community, and left them in all the waiting rooms at my work place. One lady bought a copy into her appointment with me in ultrasound and said she had von Willebrand disease (VWD). She didn't know I was the one who placed the booklet in the waiting room. She said, 'this is me. I'm so glad to see something in writing I can show others". Needless to say, I was thrilled that what could seem like a small amount of advocacy on my part could have such a positive impact on others and by sharing information we really can empower others.

I am very proud of the project to give women some recognition and formal information to show others, especially medical staff, so they can receive the correct care they deserve. The myths about women not being affected by haemophilia need to disappear. So, I truly thank all the others who contributed their time and stories for this booklet and urge other women to share their journey with a bleeding disorder in future booklets and magazines.

All our members at HFV received a copy of **The Female Factors** booklets. They have been a great talking point and provide an easy way to talk about the associated issues.

CONNECTING AND SHARING STORIES

At HFV, we have an annual girl's day out which allows all our ladies to let their hair down, get to know each other and bond over common issues. There is always a unique and interesting activity or venue. I encourage all women with bleeding disorders to attend these events or reach out to your local foundation or HFA – they can always connect you up with other women with similar journeys even if they don't have specific programs for women.

Also, during our annual community camp we have a secret women's business time out (child free) to have a nice time for a few hours. It brings up stories of people's experiences as a female either directly or indirectly affected by a bleeding disorder. We often give one on one support to those who are struggling at the time. It is also an opportunity for women in our community to come together and put ideas into action. By the end of one of our camp two years ago, 6 of the mums had got together and formed a sub-committee to organise a ball! And what a ball it was, raising over $30,000 for our community programs. I am constantly amazed by the strength of the women in our communities.

Another area I find rewarding at HFV is the rural visits. We meet some amazing people who are a little more remote than us in Victoria. They often don't get to Melbourne for specialist consultations or HFV events, so we do our best to travel to them. At one rural visit one of the youth said it was the first time he had met someone else with haemophilia. It's amazing to chat to the ladies, mothers, daughters and grandmothers. They have some great stories, although some of them have not had much support outside their families. Some are not sure how to start looking into their own care. We cannot give medical advice, but can listen, tell our stories and point them in the right direction. It's very rewarding.

SELF-ADVOCACY

Our men and boys are very important to us, but we need to be there for them, as healthy and informed women, who are strong enough to advocate for ourselves. As a mum, I know that if my Mum isn't right (or well) the whole family suffers. When our boys move from paediatric care to the adult hospital, it is their time to start advocating for themselves. We can support this by advocating for ourselves and our future health as we age.

I am, of course, writing this from the perspective of a woman in a family with haemophilia. But we are also talking about bleeding disorders such as von Willebrand disease, as this has a big impact on many women's lives. I have had the recent pleasure of getting to know a family affected by this disorder and look forward to their contributions and stories to increase the awareness and understanding of this closely related issue.

I look forward to the next exciting *National Haemophilia* magazine and future HFA publications and hearing other people's stories, as we all have a different story to tell. Remember, we must advocate for ourselves and our families to the best of our ability and share the knowledge: knowledge is power.

NEW STAFF

Two new staff members joined the HFA team in February 2018.

LITSA BANTROUHAS

With her considerable experience in fundraising and donor development, Litsa is enjoying her new role as Fundraising Co-ordinator at HFA.

Litsa will be supporting the Director of Fundraising with direct mail campaigns, events and donor management.

Her new role is an opportunity to bring together the range of her skills in donor management and acquisition, as well as event planning and business development. Litsa spent several years at Methodist Ladies' College managing their bequest program, nurturing existing relationships by organising College tours and participating in Reunion events. She also worked previously in business development in a fundraising consulting firm.

'I really enjoy interacting with donors and finding out their stories,' she said. 'And I love event management and putting on a show for our supporters.'

She is looking forward to the database management aspect of her role at HFA. 'It will be interesting to do the analysis to look more closely at donors and their preferences and how they have responded over the years. It is very important also to develop HFA's bequest and major gift program to support the future of HFA's important work. And to get the message out there!'

At a personal level, Litsa is passionate about yoga. 'It stretches my body and has a bit of a flow, a bit dancy, really! And I do like going on long walks as well'

Litsa works Monday, Tuesday, Thursday and Friday and can be contacted at the HFA office:
lbantrouhas@haemophilia.org.au
03 9885 7800.

KASSY DRUMMOND

Kassy has taken up the role of Health Promotion Officer, leading the HFA youth program and working with the education team on education materials, social media and other communications.

Kassy has a strong interest in health promotion and diverse experience in youth programs, social media and carer services.

She is looking forward to being involved in the development of HFA health promotion campaigns, with their focus on self-management over a lifetime, and not just prevention. 'I am studying this as part of my Master in Public Health, but it will be great to see it in action and be part of it.' She also has a keen appreciation of lively pastimes. 'I used to do cheerleading and tried to get into Roller Derby for a while, but it's been a bit overtaken by study, unfortunately!'

Before taking up this role she worked with YEAH (Youth Empowerment Against HIV/AIDS), helping to train young people to run sexual health workshops, sex education in schools, universities and at events. At YEAH she was responsible for writing online content and managing their social media platforms – Facebook, Twitter and Instagram. Her background in creating engaging content will be very valuable for her work on managing Factored In and HFA's social media communications.

Kassy also worked at Alfred Health Carer Services, triaging calls as they came in with requests for respite care and other carer services. 'I like working with people, hearing their stories, and working with them to find solutions to problems that work for them. Quite often people didn't know what services were available to them and that they could have, for example, a professional to come into their home and spend an hour with the person they were caring for so that the regular carer could go out and do the grocery shopping.'

Kassy works Monday to Wednesday and can be contacted at the HFA office:
kdrummond@haemophilia.org.au
03 9885 7800.

NEWLY DIAGNOSED FOLDER

We are very pleased to announce that the new HFA folder ***Haemophilia - a guide for parents of a newly diagnosed child*** is now available.

The folder was launched in October 2017 at the Kidz Factor Zone, The Children's Hospital at Westmead, Sydney. Dr Julie Curtin, the Haemophilia Treatment Centre Director, was one of the expert reviewers of the folder and presented the folder to a group of parents and health professionals at the launch.

The Guide explains haemophilia and how it is managed in plain language for parents who are new to haemophilia, with diagrams, and personal stories, tips and photos from other Australian parents. It also includes two quick reference cards:

- An emergency checklist for when a parent suspects a bleed
- Information on how to recognise a bleeding episode in a small child.

The folder will be distributed to parents and caregivers through Haemophilia Treatment Centres and is also available for downloading from the HFA website - www.haemophilia.org.au/newly-diagnosed.

We would like to thank the HFA parent and health professional review groups for generously giving their expertise and creative input to the development of the folder. We would also like to acknowledge to the parents of children with haemophilia from our bleeding disorders community who contributed personal stories, quotes and photos.

MYABDR UPDATE

In 2018 there will be further development of MyABDR as part of the National Blood Authority Crimson Project. HFA is looking for a few more MyABDR users to join the HFA MyABDR Focus Group to give feedback on the current MyABDR system and proposed changes.

INTERESTED?

You would need to be:

- Currently using MyABDR
- Prepared to answer questions via email from time to time in the next 12 months
- Perhaps do some home testing of proposed enhancements.

If you would like to participate, please contact Suzanne at HFA on socallaghan@haemophilia.org.au or 1800 807 173.

Launch at the Kidz Factor Zone

Photos: The Children's Hospital at Westmead

YOUTH NEWS

Congratulations to everyone who has recently started, or will soon be starting their higher education journey!

Starting uni or TAFE can be both an exciting and scary time. There are so many things to do to get yourself ready, and having a bleeding disorder may mean that there is a little bit more to consider. We spoke with one of our youth members, Emily, about her experience starting the higher education journey.

Emily, who is now working on her post graduate studies in the UK, has von Willebrand disorder and started her academic career with a Bachelor of Science at the University of Western Australia. She says, 'the main thing that has stuck with me from starting both degrees was meeting everyone and making new friends'

Whilst for the most part Emily didn't find it necessary to disclose her bleeding disorder, there was a few times where it came up. 'At UWA I didn't really think much of my bleeding disorder, until my rowing club found out in 2nd year and asked why I never told them. That made me realise that although I can manage it myself, I should let other people in just in case (especially since it's a sport and we went on a lot of trips away - it also made them add a medical disclosure question to the membership pack).'

She also found that she had to deal with the misconceptions of others, including her teachers. 'As I was studying genetics, I also remember one lecturer telling us that haemophilia was sex-linked and therefore only males could be affected and me trying to explain why that was incorrect.'

Since finishing her undergraduate degree, Emily has begun a Master of Science course. Moving away from home carries lots of challenges and requires preparation. Emily wasn't exempt from this. Since moving to the UK for her postgrad she has needed to find and build a new treatment team for her bleeding disorder, which has not been easy.

Emily's story comes from her experiences with von Willebrand disorder, and are specific to her life. Keep an eye out for the next issue of *Youth News* where we will hear from some students with severe haemophilia and their challenges and tips.

We would like to wish Emily, and all our readers, good luck in their studies this semester.

EMILY'S HIGHER EDUCATION JOURNEY

OUR STUDY TIPS:

- Go to the student social events during the year - O'Week is a good place to start – getting to know other students is key for enjoying (and surviving) uni/TAFE
- Join a club or society – this is another way to get connected with people you have similar interests with
- Read up on your university's special consideration and assignment extension policies - these might save your grades if something unexpected happens
- Go to lectures as often as you can – getting to know your lecturers and tutors is something that might help you out later on. You are also much more likely to retain information if you are physically attending classes and able to ask questions, rather than watching them online (although this may not be possible in some courses).
- If you need to move away for uni, make sure you research your new local Treatment Centre and get in touch before you leave home. Talk to your Haemophilia Treatment Centre about what you will need to do when you move and how to register with your new HTC. You can find contact details of HTCs in Australia on the HFA website at https://tinyurl.com/HTCs-Aus. For details of HTCs in other countries, click on the FIND A TREATMENT CENTRE button on the World Federation of Hemophilia website – www.wfh.org.
- If you need to travel interstate or overseas to take up study, it can be exciting but there is lots of PLANNING to do beforehand. If you are preparing a trip you need to be organised months in advance. Check out our travel tips (located on www.factoredin.org.au/info/travel)

CALENDAR

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

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

Bleeding Disorders Awareness Week
7-13 October 2018
Tel: 03 9885 7800
Fax: 03 9885 1800
Email: hfaust@haemophilia.org.au
www.haemophilia.org.au

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We thank the individuals, philanthropic trusts and companies which have made donations to support HFA programs, and the following companies that sponsor education programs, conferences or peer support programs run by the Foundation for the bleeding disorders community:

BIOVERATIV | CSL BEHRING
NOVO NORDISK | PFIZER | ROCHE | SHIRE

SOUTH AUSTRALIA UPDATE

Look out for details about the next Information Evening to be held in Adelaide for the bleeding disorders community. We have been talking with health professionals at the Haemophilia Centres at the Womens' & Children's Hospital and the Royal Adelaide Hospital and community representatives, and the next information evening will focus on the new treatments on the horizon.

We plan to combine this with a social activity so that everyone can get together afterwards.

We are keen to hear your ideas for the info evening and for the get together, so please email Sharon Caris at HFA with your thoughts and ideas scaris@haemophilia.org.au

Haemophilia Foundation Australia RESEARCH FUND

The Haemophilia Foundation Australia Research Fund funding round for 2018–2019 is now open.

The closing date for applications is 30 June 2018.

See www.haemophilia.org.au/research/research for the application form or contact HFA on 03 98857800.