National Haemophilia
Haemophilia Foundation Australia
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SUPPORT RED CAKE DAY DURING HAEMOPHILIA AWARENESS WEEK!

CONTENTS

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6 REASONS TO ATTEND WFH 2014 WORLD CONGRESS IN MELBOURNE, AUSTRALIA

1 PARTICIPATE IN THE LARGEST INTERNATIONAL MEETING FOR THE GLOBAL BLEEDING DISORDERS COMMUNITY
and network with thousands of members from around the world

2 GAIN KNOWLEDGE
of cutting-edge scientific research and clinical trials, profiling future advances in treatment products and clinical care.

3 SHARE INSIGHTS
on holistic patient healthcare issues and multidisciplinary care.

4 EXCHANGE WITH HEALTHCARE PROFESSIONALS AND PATIENTS
on challenges and solutions to improve treatment and care throughout the world.

5 COLLABORATE WITH LEADERS
of various stakeholder groups to ensure ongoing innovation that advances the WFH's vision to achieve Treatment for All, laying the foundation for the next 50 years.

6 DISCOVER MELBOURNE
with your family before or after the congress.

NEW HAEMOPHILIA BOOKLET

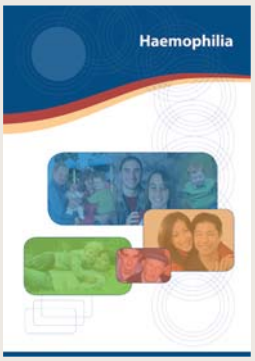
The revised 2013 version of HFA's Haemophilia booklet is now available. It has a revised inheritance diagram and carrying the gene section.

Our thanks to the expert and consumer review groups!

The booklet can be downloaded from the HFA web site – www.haemophilia.org.au >Publications.

Print copies of the booklet are also available from:

- Haemophilia Centres
- Free-of-charge from HFA - email hfaust@haemophilia.org.au or call 1800 807 173.



WFH 2014 WORLD CONGRESS UPDATE

With less than 8 months until Congress, it is time to confirm your plans, take advantage of the earlybird registration which ends 11 November 2013 and make your bookings.

The Congress is truly an opportunity of a lifetime – it is the first time we have had the international haemophilia congress in Australia. It is a great opportunity for Australians to participate in the largest international meeting for the global bleeding disorders community and to network with people from around the world.

REGISTRATION AND ACCOMMODATION

Register early for the WFH World Congress 2014 and save!

Registrations are now open – you can register at http://www.wfh.org/congress/en/registration/how-to-register.

Get in early to save on the earlybird fee. **Earlybird ends 11 November 2013.**

Check out the accommodation and housing options online from September 11 http://www.wfh.org/congress/en/housing/accommodation.

There are plenty of accommodation options to suit your needs and budget near the Congress Centre.

Haemophilia Foundation Australia (HFA) has a competition open to all Australians and New Zealanders who register *earlybird* for a prize of:

- One (1) return economy airfare from your closest capital city to Melbourne, Australia in May 2014.
- One (1) x Earlybird Congress Registration cost reimbursement
- Accommodation voucher from a hotel of your choice to the value of A$500
- Return airport transfers in Melbourne
- One (1) x Gala Dinner Ticket on Thursday 15 May 2014

HOW TO ENTER

1. Register by November 11th 2013 via www.wfh2014congress.org
2. After you receive your registration confirmation, forward this to hfaust@haemophilia.org.au
3. Your confirmation will be automatically placed in the draw
4. The competition closes on November 11th 2013.

For terms and conditions visit - http://tinyurl.com/HFA-registration-competition

"I was greatly honoured to be able to attend the WFH 2012 World Congress. It has renewed my determination to work towards improving the care of people with haemophilia and other bleeding disorders in Australia as well as all over the world."

Ann Roberts

"My expectations of the conference itself were mixed. I was unsure what value it could have to me, let alone me to it. Initially I introduced myself as just a parent. By the end I had shared the stories, experience and knowledge of many."

Liz Bishop

"It was an incredible experience that taught me much…"

Jenny Lees

ATTENDEE	EARLY		REGULAR		LATE		ON-SITE
	November 11, 2013		March 14, 2014		May 2, 2014		
	Member	Non-member	Member	Non-member	Member	Non-member	
Delegate (doctor/industry)	$650	$740	$780	$870	$910	$1,000	$1,110
Allied Health	$275	$365	$365	$455	$455	$545	$605
Person with bleeding disorder and family members	$125	$215	$185	$275	$250	$340	$400
Accompanying person	$160	$160	$190	$190	$250	$250	$310

The WFH 2014 Medical and Multidisciplinary Program Co-chairs, together with their enthusiastic and diversified Committee, have created an outstanding program track for multidisciplinary healthcare professionals, caregivers, and people with bleeding disorders.

Following are some confirmed sessions:

Black 'n blue and golden: ageing gracefully with hemophilia

Chair: Anne Duffy, Psychotherapist, Irish Haemophilia Society, Dublin, Ireland

Session overview: The objective of the session is to explore some of the challenges of ageing with hemophilia while at the same time bringing to light coping skills which, developed over time, will benefit people with haemophilia as they age.

Recipes for healthy living – beyond the vegemite sandwich

Chair: Robyn Shoemark, Clinical Nurse Consultant, Haemophilia/Haematology, The Children's Hospital at Westmead, Sydney, Australia

- Topic 1: How nutrition affects coagulation

Speaker: Joann Deutsche, MSc, Health and Science University, Portland, USA

- Topic 2: The effect of obesity on joints & osteoporosis

Speaker: Kristy Wittmeier, PT, PhD, Physiotherapy Innovations & Best Practice Coordinator for Health Sciences Centre and the Winnipeg Regional Health Authority, Winnipeg, Canada

- Topic 3: A real concern in PWH

Speaker: TBD

Session overview:

While proper nutrition involves more than the food pyramid, patients with bleeding disorders may have some inherent concerns, even when diet appears to be adequately managed. This session will provide a better understanding of the links between nutrition, the coagulation system, and patient well-being. These include dietary deficiencies/concerns in the bleeding disorders population; how obesity can magnify joint concerns; and suggested strategies to prevent and treat nutrition-based health-related issues such as anemia, osteoporosis, and haemophilic arthropathy.

We should talk: sharing information with carriers and those who care for them

Chair: Pamela Wilton, RN, CRE, London, Canada

Topics and Speakers: TBD

Session overview:

Carriers and healthcare providers should be aware of the potential risk factors and know when and where to get information, support, and care. The objective of this session is to share new information and science about issues related to carriers; to identify potential resources in the bleeding disorders community for carriers; to increase recognition of possible signs and symptoms of trouble for carriers; and to stimulate discussion amongst healthcare providers and carriers.

"Inhibitors - Cellular aspects and novel approaches for tolerance"

David W. Scott, PhD. Vice Chair for Research, Department of Medicine, University Uniformed Services School of Health Sciences (USUHS), Bethesda, MD, U.S.A.

Given the importance of the subject of inhibitors to this field at present, the Congress program will have three major talks on this subject. The focus of this talk is to present the cellular aspects of the immune response that has not been very well understood so far. Using this knowledge, the objective is to find innovative ways for immune tolerance induction.

"With blood in the joint: What happens next?"

Carl Blobel, MD, PhDSenior Scientist, Hospital for Special Surgery, New York, NY, USA.

This plenary will address how joint bleeds could trigger joint disease, even if the bleeds are too small to notice. Essentially, blood in the joint could elicit an inflammatory response that attacks the joint. If this hypothesis can be experimentally confirmed in animal models, novel anti-inflammatory interventions at various stages – apart from clotting factor concentrates – could potentially be introduced to prevent the debilitating effects of haemophilic arthropathy.

"The future of hemophilia prophylaxis with novel therapies"

Manuel D. Carcao, MD, MSc. Paediatric Haematologist/Oncologist, Haematology/Oncology, The Hospital for Sick Children, Toronto, Canada.

With the advent of long-acting factor concentrates, the haemophilia community will need to develop a new mindset regarding management of haemophilia patients, particularly the initiation and maintenance of prophylaxis. Concepts that have been established with conventional short-acting factor concentrate prophylaxis (e.g. what constitutes full dose prophylaxis vs. escalating dose prophylaxis; what trough level to target) will all have to be revisited. Target trough levels, frequency of infusions, and the implications of these decisions on cost will be discussed. The plenary will also address the role, if any, short-acting concentrates will continue to have in the management of haemophilia patients.

See confirmed key note speakers and brief descriptions on confirmed plenary sessions - http://www.wfh.org/congress/en/plenary-sessions-and-speakers and Multidisciplinary Sessions and Speakers at http://www.wfh.org/congress/en/speakers

MORE INFORMATION

For more information visit www.wfh2014congress.org.

Don't forget to register for the Congress Newsletter via WFH at https://www.wfh.org/en/sslpage.aspx?pid=460&tab=1

Gavin Finkelstein is President, Haemophilia Foundation Australia (HFA)

FROM THE PRESIDENT

Gavin Finkelstein

In this publication you will read about some of the collaborative work Haemophilia Foundation Australia (HFA) is doing at the moment.

MYABDR

HFA has made a major commitment to MyABDR and I am proud of this work. It has grown from a proposal from the HFA Council in 2011, when delegates saw the value of developing a process for recording clotting factor use so that we can document the ongoing requirements for clotting factor and assist governments to plan for the supply of the treatments we need. A key objective for us is for tools like this to enhance the partnership between people with bleeding disorders and their doctors. There are important questions to consider and you will read about how we are approaching some of these in other articles in this newsletter.

WORLD CONGRESS

You will also see we are pushing the upcoming 2014 World Congress strongly. This is for very good reason. The Congress is the most respected international meeting for the bleeding disorders community. It is more accessible next year to most Australians with bleeding disorders and their families and carers than it will be at any other time - because it is in Melbourne!

I can truly recommend that you consider attending the Congress. We have some funding available to assist you to do so. You will have no better opportunity to find out about what is going on around the world in bleeding disorders, new treatments, new programs and emerging issues. I have said before that it is an opportunity of a lifetime, and this may sound like a cliché, but it really is! World Congresses are inspiring in so many ways. If you doubt this please speak to anyone who has attended and let them tell you about their experience. It can change your whole view on the world. We have made a special effort to raise funds for this very purpose. Don't miss the chance - and if there is any way that HFA can help you get to the Congress, please let us know. HFA staff and volunteers are working closely with World Federation of Hemophilia and this work will intensify as the days draw closer.

HFA COUNCIL RESTRUCTURE

We are also working on our governance so that our organisation is in strong shape to deal with the issues that emerge in the future. Our Council has recognised that we need to sharpen up our decision-making capacity, have sustainable governance processes in place, and ensure that we are truly representative of all people with bleeding disorders.

We are reviewing the structure of Council to see if there are ways to make it more efficient and agile and I hope we will report our progress on this soon.

YOUTH PROGRAM

Another activity I am very pleased about is that we have made great steps with our work with young people over the last 18 months.

The new youth web site, www.factoredin.org.au, is a way for young people to keep connected, and I hope the leadership and mentoring training that we have run in Perth and Melbourne will form the basis of a successful succession plan for HFA into the future!

Please encourage any youth you know to become involved. We will also be encouraging young people with bleeding disorders to attend the Congress as it is a perfect opportunity for them to meet other young people affected by a bleeding disorder from around the world also.

Sharon Caris is Executive Director, Haemophilia Foundation Australia

SOCIAL GATHERING IN SOUTH AUSTRALIA

Sharon Caris

It was great to meet people who have been active in the South Australian bleeding disorders community over the years, and to meet new families at the get together hosted by Haemophilia Foundation Australia (HFA) in Adelaide on 9 August.

The annual meeting of the Australian Haemophilia Nurses Group (AHNG) had been held earlier in the day. This had been a particularly special meeting as it was the 25th anniversary of the group. It was fitting that the very first meeting had been chaired by Dawn Thorp who was a key player in the establishment of the group and specialist haemophilia nursing around the country. Dawn is well known to many people with haemophilia and their families in South Australia as she had looked after many of them in her role as haemophilia nurse at the Royal Adelaide Hospital. Dawn was the guest speaker at the 25th Anniversary meeting of AHNG and she had been delighted to meet up with many former colleagues. Dawn also attended the social gathering on the Friday night and met up with many others she had known through HFSA and the hospital.

SOUTH AUSTRALIAN COMMUNITY MEETING

There were many faces of people who had taken a leadership role in the former HFSA over the years, and everyone was delighted to meet up with former HFSA Patron,

>>

Dr Don Handley and his wife Judy. Dr Handley spoke informally of his connections with haemophilia which stretch back to soon after his medical training when he worked at Oxford, UK at a haemophilia centre established by Dr Rosemary Biggs.

This was to become one of the leading haemophilia centres in the world.

SA YOUNG PEOPLE

The three young South Australian men, Ty, Matt and Griff who had recently attended the HFA youth leadership and mentoring training program in Perth were at the get together and spoke about their plan to arrange some regular catch ups for young people in South Australia. They are each keen to develop connections with other young men and women affected by bleeding disorders, including their siblings and friends who are interested in catching up with others in Adelaide from time to time. So please feel free to contact HFA and we will pass your contact details on to them. HFA has been working in different ways to make it easier for young people to stay connected with the development of the youth website, Factoredin.org.au, and a leadership and mentoring program which has provided training for young men and women with bleeding disorders around the country.

SA REPRESENTATION

HFA is committed to keep in touch with different parts of the community while there is no legally incorporated haemophilia foundation to officially represent people with bleeding disorders in South Australia. We can never know when an issue that requires organised advocacy and representation might arise. We all hope the days of unsafe treatment products are well and truly behind us, and that we will have adequate supplies of the most suitable treatment products to meet the needs of our community, and the services they need to live as independently as possible, but we do need to stay on top of this. This is not so easy if there is not an official group which can come together as a shared voice in South Australia.

HFA has created an observer position on the HFA Council for feedback about South Australia and Paul Bonner will attend the upcoming Council meeting. Paul and Sharyn Wishart have each represented HFSA over the years. They are also the alternate consumer representatives on the Haemophilia Treatment Network in South Australia which includes government officials and haemophilia treatment centre staff. It is important for people with bleeding disorders to have a voice locally and nationally.

Many people said they would like us to organise another similar social activity so that people can keep in touch and HFA plans to do this on an annual basis. So make sure you keep in touch with us so that we let you know!

Abi Polus is the Senior Clinical Physiotherapist in Haemophilia at the Ronald Sawers Haemophilia Centre at the Alfred Hospital in Melbourne, Australia

Ian d'Young is the National Clinical Lead for Haemophilia Physiotherapy in New Zealand. Ian is also the co-vice president of Physiotherapy New Zealand.

Auburn McIntyre is the Haemophilia Physiotherapist at the Women's & Children's Hospital, Adelaide.

Abi and Ian are the co-chairs of the Australia-New Zealand Physiotherapy Haemophilia Group (ANZPHG).

THE DEBATE ON ICE IN HAEMOPHILIA

Abi Polus, Ian d'Young and Auburn McIntyre

PRICE PROTOCOL

P – protection
R – rest
I – ice
C – compression
E – elevation

The application of ice is widely used and recommended as part of the immediate management of a bleed as part of the PRICE protocol. The benefits of using ice on haemarthroses (acute bleeding in a joint) in haemophilia are thought to be a reduction of pain, swelling, inflammation and bleeding[1]. As some members of the bleeding disorders community are aware, the use of ice has recently been discussed in the journal *Haemophilia*.

In 2012 a prominent group of American and Canadian authors wrote a paper suggesting that cooling with ice may prolong bleeding and that its use should be questioned. In a more recent edition of the same journal, a different group of authors have published a counter argument, suggesting that the conclusions made by the authors of the 2012 paper may not be appropriate.

In the original article by Forsyth and colleagues[2], the authors stated that some studies have shown that cooling of blood or tissue with ice can impair blood clotting and therefore prolong bleeding. These studies were drawn from the general literature, that is, studies non-specific to haemophilia.

The authors suggested that these findings were applicable to people with haemophilia and that the use of ice in an acute bleed setting could potentially make the bleed worse by interfering with clotting and the cessation of bleeding. This is not backed up by any hard evidence or experiments. There has been only very limited scientific study, to date, on people with haemophilia and the effect that ice has on bleeds; moreover, it is important to recognise that patients invariably report positive experiences when using ice following a bleeding episode. The article acknowledges that there IS evidence to show that ice can help manage pain in the acute bleed, but point out, correctly, that there is limited evidence that ice can stop bleeding or swelling from haemoarthrosis or improve the overall outcome. That is not to say that it does or does not have an effect, but more research needs to be conducted to prove the efficacy of ice either way at this stage.

The more recent article by Rajamanickam and colleagues[3] addresses the first article and highlights various areas of concern, stating that the authors of the first article had made errors in their understanding of the information and that it was "...inappropriate to conclude that ice could be harmful and therefore not used."

The Rajamanickam group of authors argue that once adequate factor replacement is given the vascular leak will seal; that is, the bleeding will stop. In Australia and New Zealand most patients have access to early factor replacement, either at home or haemophilia treatment centre. Even for those patients who do not receive any factor replacement for various reasons the bleeding usually ceases within 12-24 hours. Once the leakage of blood out of the blood vessel has stopped, which is usually soon after factor has been administered, the argument against the use of ice due to delayed haemostasis is irrelevant.

Rajamanickam and colleagues[3] also raise several other points:

- That the clinical features of an acute bleed are due to inflammatory response to the blood present in the joint, rather than the continual leakage, and that we need to consider the effects that ice will have on that inflammatory process as it is likely that the bleed has already stopped.
- That the methods used by Forsyth and colleagues to draw their conclusions about temperature may also be incorrect – particularly relying on conclusions from non-haemophilia models - when the temperature in a bleeding haemophilia joint may be different (hotter) than in a non-bleeding joint, which would change the results of using ice.
- The need to take into consideration the actual application of the ice through plastic, cloth or a pack and the length of time of the application.
- A small study of 30 haemophilia patients showed very different results: 100% of patients reported a decrease in pain or swelling and 78.6% reported a decrease in their factor usage after the use of ice.

Both papers stated that further investigations were required to determine how best to test whether ice is effective.

It is important to remember that just because the active bleeding has been stopped, it does not mean that the effects of a bleed are not still present, and felt. This has the ability to damage joint and muscle tissue as there will still be blood within the joint which then has to re-absorb, and that this can last days and even weeks. It should also be noted that the sooner the bleed is stopped with factor replacement, the less physical effects it has and the better the overall outcome.

ANZPHG VIEW

The use of ice has been hotly debated at two recent world conferences and also within the Australian and New Zealand Physiotherapy Haemophilia Group (ANZPHG). The consensus of the ANZHPG is that treatments should be continually assessed and reviewed so that the best care is delivered to our patients. The Australia and New Zealand Physiotherapy Haemophilia Group collectively endorse the article by Rajamanickam et al[2] regarding the benefits of the use of ice following factor replacement therapy and very strongly agree with both articles that more research is necessary.

So please continue to use ice in the way that you have been advised to by your physiotherapist, but we encourage you to talk to your therapist and doctor about the benefits or if any ill effects are experienced.

REFERENCES

1. d'Young AI. Domiciliary application of CryoCuff in severe haemophilia: qualitative questionnaire and clinical audit. Haemophilia. 2008 Jul;14(4):823-7
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3. Rajamanickam M, Michael R, Sampath V, et al. Should ice be used in the treatment of acute haemarthrosis in haemophilia? [comment] Haemophilia. 2013 Jul;19(4):e267-8. doi: 10.1111/hae.12163. Epub 2013 Apr 16.

MYABDR PROJECT UPDATE

Work on the MyABDR project is progressing at a rapid pace.

COMMUNITY CONSULTATION

Obtaining feedback from potential users to help tailor the new MyABDR app and web site has been an important step in development. During July and August 2013 the MyABDR Project Team conducted an online community survey, with questions about how people currently - and would like to - record their home therapy, the devices they would use to record, other similar systems they might have used, their preferences about possible options, and other questions about functionality.

The community survey was promoted widely and more than 80 people from around Australia responded. This has provided the development team with some very valuable information. Survey responses came from a diverse group and covered a range of home treatment experiences: both haemophilia and von Willebrand disorder; severe, moderate and mild disorders; all age groups; and sampling from states and territories around Australia.

Survey responses highlighted what would be important about the MyABDR app and secure web site for community members:

- *"Ease of use and having accurate information available to my doctors and other trained staff"*
- *"Security/confidentiality/software stability and consistency"*
- *"I would use as I would like to be able to keep track of bleeds, what happened & treatment and have this information available to doctors who treat my son."*
- *"How much easier/quicker it is than using paper!"*
- *"I think a phone app would be brilliant, easy to access as always have phone on me. And also easy to pull up info on phone."*
- *"Make sure there is enough space to record any extra information or comments."*
- *"As long as it's user friendly for 2 users, I would be very happy to use. At the moment I am using a self made spreadsheet and hand recording everything."*
- *"I would use anything that is going to help me record these treatments in our busy lives."*

Our thanks to those who participated in the survey for their thoughtful and informative answers. Some took the opportunity to offer to be involved in further discussions and to test the prototype. It was great to have such an enthusiastic response. We are still looking for volunteers who treat at home to test the prototype, so if you would be interested, please contact Suzanne O'Callaghan at HFA on socallaghan@haemophilia.org.au or phone 1800 807 173.

A STAGED APPROACH

Development of the MyABDR app and secure web site will need to proceed carefully to make sure each function works in a range of situations and devices and to integrate it with the existing ABDR (Australian Bleeding Disorders Registry) system used by Haemophilia Centres.

Michael Linegar, MyABDR Project Manager at the National Blood Authority, outlined the steps for development:

"The first release will concentrate on ensuring the important things are easy to use and understand. This will include things like recording treatments, bleeds, product stocktaking and family login switching.

Extensive consultation and testing will be performed by patient and parent volunteers and the specialist health professional groups as part of this initial release to make sure we have the basics right. Once there is confidence in that, we're really keen to turn our attention to other high value enhancements that can be delivered in future phases. The potential capabilities for MyABDR are very exciting but it will be a step-by-step approach to ensure we don't lose sight of what is practical for as many people as possible.

Security and privacy capabilities are being built in from the ground-up as it was with the ABDR itself. There is absolutely no compromise here. It is taken very seriously by the whole development team."

WHAT IS MYABDR?

MyABDR is a collaborative project between Haemophilia Foundation Australia (HFA), the Australian Haemophilia Centre Directors' Organisation (AHCDO) and the National Blood Authority (NBA) to develop an app for smartphones and a secure web site for people with bleeding disorders or parents/caregivers to record bleeds and home treatments. There will also be a paper-based recording system. This project will also have considerable input from the specialist haemophilia nurse, data manager, physiotherapist and social worker and counsellor groups.

The app and secure web site will link directly to the Australian Bleeding Disorders Registry (ABDR) - this is the system used nationally by Haemophilia Centres for clinical care of their patients. The ABDR is overseen by the ABDR Steering Committee, which includes AHCDO, NBA and HFA membership and deals with issues such as privacy and data accuracy.

WHAT'S THE POINT OF THE NEW APP AND SECURE WEB SITE?

- To make it quick and easy for people to record their bleeds or treatments, stocktake and update their contact details
- Haemophilia Centres can keep track of what is happening for their patients to see if there are any problems or treatment plans need adjusting
- Haemophilia Centres won't need to re-enter or upload patient diaries into the ABDR

HAEMOPHILIA CENTRES

When the MyABDR app and web site are operational, they will enable patients to add data about their bleeds and home treatments directly to the ABDR. The information will be added to the patient record, but identified as patient-entered data. For Haemophilia Centres, this project is a chance to develop a clinical tool for both patients and the health care professionals who provide their care, with reports about bleeds and treatments both can access and discuss together. Haemophilia health professionals are also very involved in the discussions about how to integrate MyABDR with the ABDR system used at the Haemophilia Centre so that they can see at a glance who has entered information and can keep track of their bleeds and treatments.

Through the MyABDR patient-entered records, the specialist doctors at Haemophilia Centres will have increased awareness of bleeds occurring and how the bleeds respond to treatment.

Dr John Rowell, Director of the Queensland Haemophilia Centre, is Chair of the ABDR Steering Committee which oversees the MyABDR project, and commented, *"MyABDR will give valuable data on the incidence of bleeds and their sites – which will provide a greater and prompt insight into the response to treatment and if treatment is failing. This may be related to the development of an inhibitor or a need to increase the dose or frequency of doses for more significant bleeds. MyABDR will be a valuable communication tool between the person with haemophilia and the health professionals in the Haemophilia Centre – but, of course, should not replace a phone call if a serious bleed or injury occurs. MyABDR may also provide valuable information to the user about what may precipitate bleeds and ways to avoid those situations or prepare for them."*

Some Haemophilia Centres have already been using similar systems developed by pharmaceutical companies with their patients and see the value of being able to develop a national system that integrates into the ABDR. Megan Walsh, Clinical Nurse Consultant at the Haemophilia Centre at the Alfred hospital in Melbourne, is a representative on the ABDR User Reference Group which is being consulted about how to develop the ABDR system to accommodate MyABDR.

"At The Alfred we have been using a similar system for some years now. It actually makes clinical management better and easier. We have information about patients' home treatments and bleeds much more quickly now and can follow up with the patients if we see a problem bleed starting to occur. Both patients and Haemophilia Centres can see overall trends. Our patients love being able to look back over their own treatments and bleeds and understand what has been happening and it is a very useful clinical tool for haemophilia staff."

FOUNDATION INVOLVEMENT

For the project to be a success, it has been very important for community members to participate in the consultation and be involved in the development. State and Territory Foundation representatives have been working hard to keep local members informed about the project and opportunities to participate, and have circulated emails and newsletter articles.

Shane Meotti from HFWA commented, *"we had almost immediate feedback from a community member after we sent out an email about the survey, saying they had already done the survey and were loving being consulted. It's great to see their enthusiasm."*

For HFA, there are a number of broader issues to address as well. *"This is all about having strong and effective partnerships, where there is respect for the range of requirements and needs. For the community, for example, careful management of individual privacy and data security is paramount to bring confidence for people who will use MyABDR,"* said Sharon Caris, HFA Executive Director.

MORE INFORMATION

For more information about the MyABDR project:

- Visit the HFA web site at www.haemophilia.org.au/myabdr
- Or contact Suzanne O'Callaghan at HFA on socallaghan@haemophilia.org.au or phone 1800 807 173.

- It will facilitate notifications about product batches, so people will be able to receive information about products or recalls
- De-identified information about the amount of product being used can help the government to stocktake and plan for purchase of future supplies
- The pooled de-identified information can be used nationally by specialist clinicians and researchers to see trends and patterns for bleeds and treatments – very important for improving treatment and care in rare diseases like bleeding disorders!

THE MYABDR APP AND SECURE WEB SITE WILL BE:

- Optional
- Secure
  You will need to login on your smartphone or computer with a personal password and the ABDR is protected with the highest level of security
- Private
  Identifying patient information will only be accessible in the ABDR by your Haemophilia Centre and specially selected NBA technical support/helpdesk staff authorised by the ABDR Steering Committee for the purposes of supporting and maintaining the ABDR.

Grainne Dunne is Clinical Nurse Consultant Haematology/Apheresis, Sydney Children's Hospital

ISTH 2013 – GETTING THE MOST OUT OF A LARGE CONFERENCE

Grainne Dunne

The International Society of Thrombosis & Haemostasis (ISTH - www.isth.org) is an international, not for profit, organization comprising of the world's greatest experts in the 'yin and yang' of haematology, i.e. thrombosis and bleeding disorders.

While the ISTH conference can be a little scientific in content, it offers something for all clinicians. Like the World Federation of Hemophilia Congress, ISTH too is a very large conference. This year ISTH had 7,500 delegates registered. In large conferences such as this, your aim is to soak up whatever you can and avail of a great opportunity to network with colleagues and friends – new and old.

For me, I concentrated on the sessions which best suited my needs. Although some of these were at times challenging – and, believe me, jet lag is never your friend in these sessions - I tried to get the most out of these sessions too.

IF THIS IS YOUR FIRST LARGE CONFERENCE TO ATTEND?

- Remember to take time to meander your way through the poster area as well as attend the oral presentations.
- Use the opportunity to network with both national and international colleagues/friends.
- Don't forget to wander through the industry booths so you can discover what's new, what's on the horizon, what you're not exposed to in Australia and of course who has the best coffee!!
- To get the best out of each day's program, you do need to do a little homework first. Scan through what looks appealing on the program. Read the abstracts for what takes your attention. Mark sessions of interest remembering that you can also change your mind later but you now have an advantage by knowing the competing sessions.
- If you have colleagues/friends at the conference, it sometimes helps to check out what they're attending as you may have missed something - plus it can be good sometimes to share your thoughts afterwards on what you both took out of the presentation.
- There will of course be some presentations where your choice of session fails your needs but don't be too disheartened. If you can come home with three to four good learning advancements, messages or ideas which can improve your practice and an overall view of what's ahead in your area, then you have achieved a good conference.

GENE THERAPY

Update on AVV-mediated gene therapy for haemophilia B
Amit Nathwani, United Kingdom;

The highlight of the ISTH presentations for me was the Gene Therapy session.

Professor Tuddenham gave an update on the UK/US gene therapy team's clinical trial results at the World Federation of Hemophilia Congress in Paris last year[1]. Nathwani built on this by reporting on progress since Paris.

In summary, the ultimate goal of gene therapy in haemophilia is for a one-off dose, or intravenous infusion, to be sufficient to increase natural factor production in severe haemophilia patients for life. Currently, researchers are more actively studying haemophilia B (factor IX) as this gene is smaller than factor VIII, and hence easier to work with. The increased production of factor IX that results from gene therapy will be minimal; for example, this trial is seeing 2 - 8% increases in the factor IX level at the moment. However, this increase is enough to change the bleeding status of a patient with 'severe' haemophilia to that of 'moderate' or 'mild' and thus no longer be dependent on regular factor infusions.

Scenes from the ISTH Conference in Amsterdam, with a bicycle park for local commuters

Photos: Grainne Dunne

Haemophilia genes were cloned in the 1980s and a lot has evolved since then. Haemophilia B (factor IX deficiency) has had the greatest success to date.

- In the UK, Dr Amit Nathwani's team has injected close to 10 severe haemophilia B patients with the Adenovirus-Associated virus vector carrying the normal factor IX gene.
- This therapy has been successful in changing the bleeding status from severe haemophilia to mild or moderate haemophilia, reducing spontaneous bleeding significantly.
- Most of these patients no longer need regular prophylactic factor infusions but instead use on demand factor should they sustain an injury or in some cases prior to high impact sport.
- Gene therapy has not only improved the patients' quality of life but has also reduced the high expenditure of such costly haemophilia factor infusions.

A single intravenous injection of the Adenovirus-Associated virus (AAV) vector carrying the normal factor IX gene is enough to work for years. Some patients have been injected 10 years ago.

The AAV is a vector or 'transport medium' used to get the DNA material of factor IX into the cells of the liver. Infusing DNA of factor IX alone into the patient's blood stream would be rapidly broken down so a vector is essential to protect the factor IX DNA while transporting it to the liver cells.

More recently, Dr Nathwani's team has been able to improve their vector by pseudo-typing the vector with an AAV8 capsid (on the outside shell of the vector) to reduce low pre-existing immunity to the AAV8 in humans and prevent it from damage.

- 4 new patients were recruited onto their study using this new improved vector in the past 12 months.
- Steroids are given to patients if their Liver Function Tests (LFTs) increase.
- Of the 4 new patients, 2 have required steroids.
- High dose gene therapy patients who previously had severe haemophilia B are all expressing at least 5% factor IX levels now.

Dr Nathwani's team of scientists are hoping to open a factor VIII (haemophilia A) gene therapy trial in 2 years' time. They are currently working on a vector for factor VIII.

When asked, how long before this factor IX gene therapy could be available to the general market, Nathwani's reply was "Another 5 years perhaps"! We have been waiting for this breakthrough for a long time – it remains to be seen whether his prediction is overly optimistic or accurate!

Gene therapy for haemophilia: state of the art

Thierry Vandendriessche, Belgium

Dr. Thierry Vandendriessche followed in this session to present on his work in gene therapy.

To summarise, Vandendriessche is studying the possibility of improving the AAV vector to produce a greater gene expression and thus a higher percentage of natural factor production by the body. Studies in mice have shown success by producing up to 40% factor IX levels. This level is close to the normal levels in a human. However, changing the vector like this also increases the risk of side effects.

While working to improve the vector for increased gene expression, Vandendriessche's team also discovered that their gene therapy in mice can in fact induce a tolerance to factor IX inhibitors! How very interesting, if gene therapy may also prove to be useful in the elimination of haemophilia inhibitors. If it works out, this will be a big breakthrough in haemophilia inhibitors.

Time will tell!

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Wendy Poulsen is Physiotherapist at the Royal Children's Hospital in Brisbane

WFH MUSCULOSKELETAL CONGRESS REPORT

Wendy Poulsen

It was a wonderful opportunity to attend the recent World Federation of Hemophilia (WFH) 13th International Musculoskeletal Congress 2013 from 18-21 April this year. The meeting was held in the "windy city" of Chicago, Illinois. This is the first time that USA has hosted a WFH Congress, and the tradition of communication and collaboration continued among the many orthopaedic surgeons, rehabilitation specialists, haematologists, scientists, and other professionals from more than 50 countries, who specialize in the treatment and management of people with bleeding disorders.

A major computer crash of American Airlines and savage thunderstorms causing the closure of O'Hare airport and huge flooding certainly caused some early glitches in the arrival of presenters to the first part of the program - but it certainly didn't dampen the enthusiasm of participants.

There were over 360 participants in all, with seven participants from Australia and New Zealand to represent "down under". A highly scientific meeting was provided by the many presenters, and supplemented by 48 poster presentations.

The following is a summary of some of the talks which were relevant to me as a Physiotherapist.

PROFESSIONAL DEVELOPMENT - PHYSIOTHERAPY

Before the meeting started, there was a physiotherapy meeting which provided us with the opportunity of connecting with our counterparts who work worldwide. The first part of the session provided us with the Global Physiotherapy initiative projects which have been occurring for many years. It would have been great to have more information on the content of the courses run; rather than just an overview of where they had been. I know that some of us have been involved in sharing our knowledge in the Philippines and Vietnam and it would have been good to have some information on things that work/don't work, what makes a successful visit; and how to go about the follow-up process to make the visit worthwhile. It seemed that some of the projects worked well and others were not nearly as successful. However what they did say was that finding a tailored solution for each haemophilia treatment centre in this implementation process – with an adequate set up, communication, and co-operation of haematologists and physiotherapists - is still a challenge. But when it works, people with haemophilia worldwide will benefit, running towards optimal functional capabilities and thus, better quality of life.

TO REST OR NOT TO REST

Optimal and functional recovery after each bleed is essential, and integral to this is rest after each bleeding episode. But how much rest is really needed and what is optimal? - because too much rest will decrease muscle strength, decrease muscle volume, shorten muscle length, decrease bone density, and increase the time of recovery.

Why is rest so important after a bleed? This is to allow haemostasis to occur and to unload the injured tissues. But how long do we say to say to rest after a bleed and what is the scientific answer to this question? And what is really rest? Resting a joint or a muscle may comprise immobilisation through casting, splinting or bandaging and combine this with the use of crutches both partial weight bearing or non-weight bearing. The most effective type will be chosen by the Physiotherapist to ensure safe transition back to activity in the most suitable time frame according to symptoms.

There appears to be no consensus on how long to rest. We know it is necessary but the science still can't answer definitively. The research in the Netherlands has indicated that the cartilage in a joint may be susceptible to further damage after a bleed for up to two weeks and that one dose of factor does not normalise healing, so we really need to take each bleeding episode as an individual case.

I know from my clinical experience that our children are not resting nearly enough after a bleed. Instead, there is a dose of factor given (which is supposed to fix everything) and consequently we are seeing children with significant joint damage.

RECOVERY FROM BLEEDS

We do know that bleeds deep in the muscles take many weeks to resolve even though full function is reported. Approximately 20% of all bleeding episodes in people with haemophilia occur in the muscles, and are more common in the lower leg than the upper limb. A recent 12 month study of bleeding patterns in children and adults with severe haemophilia found that the order of muscle bleeding frequency was the forearm, thigh, lower leg, foot, hand, back, groin, upper arm, buttock and iliopsoas.[1] Bleeds can be outside the muscle, within the muscle and between groups of muscles and can

go unnoticed for some time before discomfort develops. They can be as a result of direct blow or compression force to the muscle, they can be superficial or deep contusions or a muscle strain where the muscle fibres are over stretched or torn. For as long as the haematoma is present, there is an increased risk to re-bleed. Diagnostic ultrasound or MRIs to confirm presence and continued resolution play an important role in our decision-making to progress rehabilitation and return to full function. The consensus worldwide, however is that there can be many subtle changes when a bleed occurs and that it is imperative to seek the advice of a physiotherapist to ensure full recovery.

WOUND HEALING

Professor Maureane Hoffman from the USA presented an overview of wound healing, and reminded us that the normal phases of wound healing - coagulation, inflammation, migration and proliferation, and remodelling - does not happen in the haemophilia population. Studies in the haemophilic mouse have shown that there is a decrease in wound healing and that wounds tend to get larger and wound closure takes longer. Certainly this should make us think when we are dealing with patients with wounds.

ICE VS NO ICE

The question of ice or not was raised and presented as a lively debate. An article had been published that said we shouldn't be using ice in acute bleeding episodes.[2] This challenged our beliefs that ice is beneficial to control the excessive swelling and pain which are latent signs in a bleed. The article may have been a little premature, even inappropriate. There is some evidence from some randomized clinical studies that cooling can be beneficial in the management of injuries around the joint.[3] Essentially it left some unanswered questions, but what we do know is that further clinical trials of this modality need to be done before we can make such sweeping statements. And if you feel that using ice in conjunction with factor replacement is beneficial to you in reducing swelling and pain and perhaps even decrease the amount of factor used then continue to do so until we have more accurate and scientifically based information. [Editor's note: this debate has been discussed in more detail in the article "The debate on ice in haemophilia" in this issue of *National Haemophilia*.]

OSTEOPOROSIS

Osteoporosis is an underestimated problem in individuals with haemophilia. Repeated studies have shown a correlation with haemophilia and reduced bone density and or osteoporosis, compared with controls.

Contributing factors in this population may include decreased physical activity as a child or adolescent, prolonged immobilization, or even perhaps those co-morbidities including HIV and hepatitis C. Improved screening for early detection in people with haemophilia is needed.

JOINT REPLACEMENT

No MSK meeting would be the same without the prolific presentations on joint replacement including total knee replacement and total ankle replacement. The only news on this was that there seems be varying results from centre to centre, knees seem to have better outcomes than ankles, and that they will continue to challenge the orthopaedic surgeons.

CARTILAGE BREAKDOWN

A very scientific paper (a little over my head!) presented from the Netherlands looked at four biomarkers for cartilage degradation. The study investigates for the first time whether these biomarkers can sense cartilage breakdown immediately after a bleed. What they found in haemophilia patients was that the level of all four biomarkers were elevated 3-5 days after a joint bleed. The study demonstrated that joint tissue damage biomarkers increase after a single joint bleed, both in an experimental and clinical setting. A combined score could therefore be used to detect cartilage breakdown immediately after a joint bleed, supporting early cartilage damage after a single bleed. Let's try to prevent those bleeds from happening!

THE WFH RESEARCH AGENDA

A plenary session was presented by David Lillicrap on the continued support of the World Federation of Haemophilia (WFH). The WFH has a longstanding history of excellence in supporting the care of people with haemophilia and other inherited bleeding disorders worldwide. This program of activities has provided access to care in many countries where treatment has not been previously available. Additional to global treatment access, people with haemophilia have seen incredible advances to further improve diagnostic and therapeutic approaches.

WFH has initiated a new program of activity focused on the support of research into clinical outcomes for inherited bleeding disorders and this is supported by new funding. David Lillicrap suggested that the keys to research success were: that it is useful, relevant and interesting; and novel and feasible. I continue to be encouraged by the constant research that is being done in the area of haemophilia.

The conference provided me with an opportunity to catch up with old friends and make new ones as we all came together with a common interest of caring for those with bleeding disorders.

Melbourne will host the World Hemophilia Congress next year. It is the largest international conference that is dedicated to haemophilia and other inherited bleeding disorders and captures a cohort of international experience that cannot be missed. Put those dates in your diary now and do not miss the opportunity of this international gathering!

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HEPATITIS C TREATMENT - THE FUTURE'S BRIGHT

These are promising times for Australians living with hepatitis C. On 1st April 2013, innovative new treatments for hepatitis C type 1 became available in Australia, and more are expected to follow for all strains as clinical trials continue over the next few years.

It's the first step towards achieving an interferon-free treatment that will significantly reduce the side-effects of hepatitis C treatment, while making the whole process much quicker, simpler, more tolerable and far more effective in curing all strains.

WHEN WILL INTERFERON-FREE THERAPIES BE AVAILABLE?

For now, interferon will remain an essential part of treatment for all strains of the hepatitis C virus. But there has never been a better time to consider getting treated. You can expect to see interferon-free therapies for some strains in the next three years, and by 2018 we are hoping these treatments will be available to all Australians living with hepatitis C.

WHAT TREATMENTS ARE AVAILABLE NOW?

Treating hepatitis C type 1

An innovative treatment plan is now available that combines weekly interferon injections with daily ribavirin tablets, and a course of daily boceprevir or telaprevir tablets.

Treatment plan with boceprevir

- pegylated interferon and ribavirin only for the first 4 weeks
- pegylated interferon, ribavirin and boceprevir for 24 to 44 weeks*

Treatment plan with telaprevir

- pegylated interferon, ribavirin and telaprevir for the first 12 weeks
- pegylated interferon and ribavirin is continued for an additional 12 to 36 weeks*

* The time required to complete treatment will depend on your treatment history and how well you respond to treatment.

Treating hepatitis C type 2 and 3

For now, the treatment plan for Australians living with types 2 and 3 remains the same as it has been for many years. This involves a combination of weekly pegylated interferon injections and daily ribavirin tablets over a period of 26 weeks.

WHAT ARE THE SIDE-EFFECTS OF CURRENT TREATMENTS?

The side-effects from current treatments, which include interferon, can be off-putting when you're considering treatment. However, it is important to remember that everyone is different and side-effects from treatments vary from person to person.

Pegylated interferon and ribavirin side-effects

Mild to severe mood disturbances; anaemia; slow blood-clotting; fatigue; flu-like symptoms; dry skin, rash; insomnia; decreased appetite; weight loss and hair loss. Often, tolerance of treatment reduces the longer the treatment lasts.

Over the last 12 months there have been very exciting reports about new hepatitis C treatments and clinical trials. Some have had very high success rates. Some have been interferon-free. But for Australians with bleeding disorders and hepatitis C, what does it all actually mean? There are many questions:

- Are the new treatments available in Australia yet?
- If the treatments are being studied in a clinical trial, are people with bleeding disorders eligible to participate?
- Are the treatments suitable for someone with long-term infection?
- For which genotypes or strains of hepatitis C are they effective?
- What if you already have signs of liver disease?
- What if you have already had unsuccessful treatment?
- What about side-effects?
- What is the length of treatment?

This recent article from Hepatitis Australia explains the hepatitis C treatments that are currently available and answers some of these questions. It also gives a realistic picture of what is on the horizon with new treatments.

If you are interested in hepatitis C treatment, contact your hepatitis or liver clinic or discuss it with your Haemophilia Centre. Some clinical trials have been open to people with bleeding disorders – check with your hepatitis or liver clinic to see what is available or appropriate. And in any case, make sure you have a regular review with your hepatitis or liver clinic so that you know your liver health status – you may feel well, but you may have had changes to your liver health, and it is important to know where you stand and what your options are.

Boceprevir side-effects

Anaemia (which can be severe) and a change in taste.

Telaprevir side-effects

Rashes (which can be severe) and anal pain/itch.

HOW CAN I MANAGE THE SIDE-EFFECTS?

The earlier you seek advice from your doctor to address side-effects, the better. Early intervention and careful monitoring can often minimise side-effects. In rare cases, treatment is stopped to avoid progression of significant life-threatening side-effects.

It's also important to note that mixing other medicines with hepatitis c treatments can be dangerous. If you need to take any additional prescription or over-the-counter medicines during your treatment, including herbal remedies and complementary medicines, you should always check with your specialist first.

WHAT ARE MY CHANCES OF RECOVERY?

The success of your treatment will depend largely on your commitment to taking your prescribed medicines regularly, so be sure to follow your doctor's instructions consistently. Results from current hepatitis C treatment plans show an average 70% to 80% success rate among patients.

However, there are some factors which could influence your treatment outcomes, for better or worse. Examples include:

- People in the early stages of liver disease generally have higher cure rates.
- People with hepatitis C type 1 with a 'CC' result from an IL28B blood test are more likely to achieve a cure.
- Pre-menopausal women tend to respond better to treatment than men or post-menopausal women.
- People with fatty liver disease, heavy alcohol consumption, hepatitis B or HIV co-infection may have a reduced chance of achieving a cure.

To gain a better understanding of how well you're likely to respond to current treatments, make an appointment with your doctor.

HOW IS RESPONSE TO TREATMENT MONITORED?

Your response to treatment is monitored by taking blood tests at intervals to measure the amount of virus present in your blood. What your doctor will be looking for is a Sustained Virological Response (SVR) – this means that the virus drops to undetectable levels while you are undergoing treatment and remains undetectable six months after you complete the treatment. In a word, it means you're cured.

WHAT IF TREATMENT DOESN'T WORK FOR ME?

No response

In some people, treatment can fail to reduce the virus significantly within the first few months of treatment. If this happens, your treatment will be stopped.

Partial response

In others, the amount of virus does drop, but never reaches undetectable levels. If the virus remains higher than recommended at key milestones, your treatment will be stopped.

Relapse

In this instance, the initial response is good. The virus drops to undetectable levels while you are on treatment, but the virus becomes detectable again when tested six months after completing treatment.

If your treatment doesn't result in a cure this time, remember there is hope on the horizon as innovative new treatments are made available to Australians with hepatitis C over the next five years. So, be sure to stay in touch with your doctor for regular liver health checks and updates on the release of new treatments offering higher cure rates.

DO I NEED TREATMENT NOW, OR CAN I AFFORD TO WAIT?

Although cure rates are the highest they've ever been, it's easy to understand why you might prefer to wait for new treatments with higher cure rates and fewer side-effects. However, waiting up to five years for interferon-free treatment may pose a risk for some people.

To find out just how urgently you need treatment, you should arrange a comprehensive liver health assessment with your doctor.

GET TESTED

A liver health assessment involves a clinical examination and blood tests. Increasingly, doctors are also using fibroscan tests to assess the urgency for treatment. Similar to an ultrasound, this quick, non-invasive test measures the level of liver scarring to determine the severity of liver disease. However, it is not yet available everywhere.

WHAT FACTORS INFLUENCE THE URGENCY FOR TREATMENT?

It stands to reason that the more significant the liver scarring is, the more urgent treatment becomes. The speed of liver disease progression is also a key factor. If you have had a hepatitis C infection for over 20 years, or also have hepatitis B or HIV infections, you may experience a more rapid progression to moderate or severe liver disease.

If you have moderate or severe liver scarring, any decision to delay treatment has to be carefully balanced against the risks of putting off treatment. If left for too long, there is a chance that treatment may no longer be a safe or effective option.

If, following a comprehensive assessment and discussion with your doctor, you decide to delay treatment, it's vital that you have a liver health assessment at least once a year, preferably including a fibroscan.

WHAT'S DOES THE FUTURE OF HEPATITIS C TREATMENT LOOK LIKE?

The future of hepatitis C treatment is looking very bright. Clinical trials are currently taking place all over the world, testing combinations of new drugs, some with pegylated interferon and some without.

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The ultimate goal is to make interferon-free treatment available to all Australians living with hepatitis C by 2018. But over the next five years, you can certainly expect to see:

- Reduction in the complexity of treatment over time
- Reduction in treatment times for those who respond well to treatment
- Improvement in the tolerability of treatment as antiviral medicines with fewer side-effects become available
- Increased cure rates for all types of hepatitis C
- Interferon-free treatment for some people within three to five years

Federal Government approval may delay the release of new drugs, however, Hepatitis Australia will continue our work to ensure Australians gain access to innovative new hepatitis C treatments as soon as possible.

To find out what groundbreaking developments in hepatitis C treatment will mean for you, your treatment and your cure, make an appointment with your doctor to have your liver assessed and discuss your treatment options.

WORLD HEPATITIS DAY

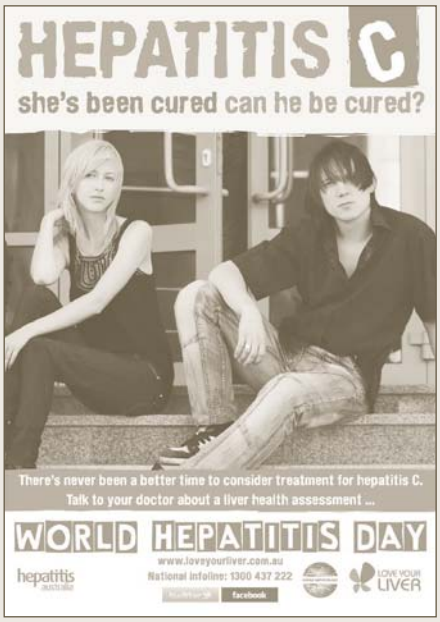
World Hepatitis Day was celebrated globally on 28 July 2013.

The Australian theme in 2013 was "Learn to love your liver on World Hepatitis Day" and had a focus on maintaining or improving your liver health. The national campaign aimed to raise awareness of liver health with the general community and present viral hepatitis B and C neutrally as health conditions linked to liver health. The intention of this is to normalise viral hepatitis and reduce stigma.

Around Australia there was a variety of awareness-raising events and activities. Events ranged from informative workshops and education sessions to cooking demonstrations, photographic exhibitions, story-telling sessions, information stalls and Love your Liver lunches, picnics and bbqs.

As a Partner in the national World Hepatitis Day Campaign, HFA worked with Hepatitis Australia on the annual national awareness campaign and is committed to reducing hepatitis C stigma and discrimination and improving liver health in Australia. HFA and State and Territory Foundations published articles in their newsletters and e-news, and HFA put up a window display for the people who pass by the office in High St.

Some State Foundations also got into the spirit of the general wellness message and had morning teas with cupcakes and forums on improving your wellbeing



The HFA facebook page also became a place to highlight local World Hepatitis Day events and activities and remind community members to spread the message in their community about the importance of liver health.

INTERESTED IN MORE INFORMATION ABOUT LIVER HEALTH?

- Visit the Lover Your Liver web site (www.loveyourliver.com.au)
- Download delicious liver-friendly recipes from the web site
- Catch up on the latest research about liver health
- Take the liver quiz on the web site.

More information about World Hepatitis Day is available on the Hepatitis Australia web site – www.hepatitisaustralia.com .

Kate Lenthen is Senior Social Worker at Sydney Children's Hospital, New South Wales

PARENT PEER SUPPORT

Kate Lenthen

Living with a chronic illness can be isolating both for the patients and their parents and carers. This is especially true for carers of young children living with haemophilia. And even more so for first-time parents, when their child is diagnosed shortly after birth.

At Sydney Children's Hospital (SCH) in Randwick, we treat approximately 80 -100 children with bleeding disorders per year. However, despite this large number, it's very rare for the patients and families to meet each other. Most are able to manage their care as outpatients, coming to the day unit and clinic at different times.

To deal with this, in 2006 the Clinical Nurse Consultant, Grainne Dunne, and I started a parents and carers support and psycho-educational group for the families attending SCH. The group is attended by carers (parents and grandparents) and over time, the members have reaped the benefits of peer support and ongoing education and information. Speakers in the past have included: a geneticist; a psychologist; a dentist; a university student living with severe haemophilia; and a representative from Sydney IVF – just to name a few.

After an 18 month hiatus, our group came together again in August this year. We had 10 members attend – including parents and grandparents. Carers came from Sydney and more regional locations, and their children were aged between 6 months and 13 years old. All children had either severe haemophilia A or B.

Dan Credazzi is both a dad of one of our patients and the President of Haemophilia Foundation NSW. Dan started off the formal part of the morning with a presentation on what the national and NSW Haemophilia Foundations do. He explained where the funding comes from; new initiatives in the world of haemophilia; and what supports families can access. This information was really helpful for all who attended. A discussion opened up about the upcoming annual family camp in November. Those who had attended before were able to share their positive experience of camp for the families who had never been. And we also started to discuss next year's World Federation of Hemophilia Congress in Melbourne. There was lots of excitement and interest shown from the families, who were also encouraged to look out for funding opportunities that may be available through HFA.

The next speaker was Dr Gnana Spaile, the dentist in the Hospital. The title of her presentation was "Dental care for a healthy mouth". The message in this talk included general dental care for all children, as well as extra information about oral hygiene in the context of caring for a child with a bleeding disorder. Dr Spaile provided tips on dental products that are available for oral health, and ways to reduce mouth problems that would be more problematic for people living with a bleeding disorder.

Carers were able to participate and ask questions throughout.

The informal aspect of the group is the peer support. Parent peer support is valuable and significant in meeting the needs for many parents of newly diagnosed children with haemophilia and those whose children are approaching new milestones and transition points in their life. Parents report that sharing daily experiences of caring for the child with another parent who understands reduces their sense of isolation and increases their sense of feeling understood. In our group, carers are able to share experiences of caring for their child; how they administer intravenous clotting factor; how they manage day-to-day life and bleeds; explaining the diagnosis to their children and teaching their children how to self-administer their own clotting factor. Because our attendees care for children over a broad age range, there are always valuable contributions to be made.

Research studies have identified the need to support a parent's capacity to cope with their child's diagnosis and lifelong treatment - and have demonstrated that improving a parent's ability to cope can positively impact on a child's ability to cope.[1]

We received lots of positive feedback from our August group, and we hope to be able to continue to run these groups for a long time to come.

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Natashia Coco is Haemophilia Foundation Australia Development Manager

FOOTBALL UMPIRING AND HAEMOPHILIA

Bryan Sheehan in action. Photo: AFL

Bryan Sheehan, former AFL umpire, spoke with Natashia Coco at HFA about growing up with haemophilia and umpiring.

Natashia: Tell us a bit about yourself and your life growing up?

Bryan: I was born in Dandenong, Victoria, and lived there for all of my childhood. I had three brothers and one sister. I attended the local primary and high schools and completed my VCE (year 12) in 1976.

We were a family that loved our sport, be it football, cricket, golf or watching any other sport. Mum and Dad always encouraged us to be active and be outside rather than watching TV. My three brothers all played competitive sport - football, cricket and basketball - which I found difficult to cope with as I was not allowed to play because of my haemophilia. Having said that, I did from time to time play the odd school footy or cricket match, but Mum never knew.

I was always frustrated at not being able to play, as I was reasonably good at most sports. I was the only child who had haemophilia.

My mother came from a family of 9 sisters and one brother. The girls were all carriers of the gene and later went on to have sons with haemophilia. Our families were always well known at the local Haemophilia Centre, as we all ended up there on many occasions after having bleeding episodes.

Natashia: How did haemophilia impact on you as a young boy?

Bryan: My childhood was pretty normal, but was interspersed with visits to the local Haemophilia Centre. I was always doing things I shouldn't and paid the price. However, I always tried to be normal, even though I knew I wasn't. Visits to the Haemophilia Centre included tooth extractions, bleeding into joints and on one occasion I was hit in the eye with a tennis ball, which caused serious bleeding behind the eye. Doctors decided not to operate for fear of causing more bleeding, a decision which proved to be a good one, as my eye healed naturally.

I was always given cryoprecipitate at the Haemophilia Centre until I had a reaction to it. I must say it was a horrible feeling - I struggled to breathe, came out in a rash and just felt terrible. Mum was with me when it happened and freaked out. Doctors and nurses came from everywhere and eventually settled things down. It was very scary! Today I have recombinant factor VIII.

I can recall one other hospital stay when I had four teeth out at the dental clinic and lost a lot of blood, so much that I collapsed at home and was rushed back to hospital for a transfusion. I never did like the dentist chair!

Whenever I did have a bleed, I was forced to stay home from school, so missed a few weeks, here and there, but generally didn't miss too much school.

Natashia: How did umpiring come about?

Bryan: Given that I wasn't allowed to play contact sport, I started participating in athletics and soon became quite good at it. Every Saturday I would run at Little Athletics and raced mainly in the long distance events. Eventually I progressed into the Senior races, travelling around the country in cross-country runs and track events. I was introduced to umpiring by my running coach, who himself was involved in during the winter months to supplement his training. He said that it would help my running, plus I would get paid as well, which seemed like a good idea.

I joined the Dandenong Junior Football League Umpires Association and started off officiating in the Under 11s on the boundary, eventually progressing to the Under 16s as a field umpire. It wasn't long before I was hooked on umpiring and soon was setting my sights on umpiring at a higher level. After three years at Dandenong, I was recommended to the VFL Cadet squad and umpired Under 19s in 1984 and 1985. I umpired the Under 19 Grand Final at the MCG in 1985 and was elevated to the VFL Senior list in 1986 and officiated in my first Senior game that year.

Natashia: Can you give any advice to other young people with bleeding disorders who aspire to play competitive sport?

Bryan: I never would have imagined that I would have been able to make it to the top of my chosen sport, especially given that I have haemophilia. I certainly wouldn't

Bryan Sheehan in action. Photo: AFL

have made it as footballer. My advice to other people with haemophilia is to look at other ways you can be involved in sport and you never know where it might take you. It could be as an umpire at local, state or national level. It could be as an official, maybe one day going to the Olympics or another international event. Or it just might allow you to still be involved in the sport in which you enjoy.

As much as I was very frustrated at not being able to kick the footy around with my mates, to this day all of my mates are very proud at what I have achieved as an umpire.

Natashia: What is your number one tip to maintaining your health in a competitive sporting environment?

Bryan: Like any athlete you need to look after yourself. I knew my limitations and tried to do everything I could to ensure my body was in good shape. I watched my diet and did gym work to build up my muscles to support my joints. There is no doubt that the healthier I became the less I visited the Haemophilia Centre. I also stopped doing those silly things which could result in me having a bleed.

Natashia: As you become older, have you faced any other challenges with your haemophilia?

Bryan: I have always tried to lead a normal life. Apart from the odd hospital visit, my life has been the same as any other person. Having haemophilia has not stopped me from doing anything, be it at work or at home. Obviously the older I have got, the more I have made responsible decisions about my health and my life.

Natashia: Is there anything you have learned about living life from dealing with your haemophilia?

Bryan: Haemophilia has taught me that no matter what adversity you face, you can overcome anything if you put your mind to it. Whilst I had some restrictions in what I could and couldn't do, ultimately it didn't stop me from still being involved in the sport I loved. I know there are many other young boys with haemophilia (and girls for that matter) who have followed my career and are now aspiring to become AFL umpires, which makes me feel that my life with haemophilia has been a positive and fulfilling experience.

I couldn't have wished it to be any different.

AFL HONOURS BRYAN SHEEHAN

In 2013 Bryan Sheehan became the 13th former umpire to be inducted into the Australian Football League (AFL) Hall of Fame. This reflected an AFL umpiring career that spanned 16 years from 1986 to 2003 and 363 games, including 37 finals and 6 grand finals.

Bryan was honoured by the AFL for the high standard of his umpiring throughout his career and his understanding of the nuances of his role in officiating.

"The secret was to pay the blatant and obvious stuff, have a good feel for the game, and knowing when to intervene and when not to was a key," he said. "I think I had a good relationship with the players and understood the sorts of pressures they were under on and off the ground."

Bryan also helped to introduce the move in 1994 to increase the number of umpires on the ground from two to three.

"I was on the sub-committee and we basically put the document together to where it has evolved today. It certainly prolonged my career, no doubt about that," he said. "If we hadn't have gone to three, I wouldn't have lasted as long as I did because of the speed of the game. When there were two of us, we were running about 21km a game, which was quite taxing on the body."

Bryan took up a role with the AFL as a full-time umpires coach in 2012.

UMPIRING AND HAEMOPHILIA

For the bleeding disorders community, Bryan has been a role model for many years, and not only because of his approach to umpiring. Bryan has haemophilia. His decision to take up AFL umpiring has inspired many young people with bleeding disorders who are passionate about football but need to avoid the high impact injuries that are a feature of this kind of sport.

SOURCE

Ashley Browne. AFL Hall of Fame inductee 2013: Bryan Sheehan, the whistle blower. Australian Football League, 4 June 2013. http://www.afl.com.au/news/event-news/hall-of-fame/2013/bryan-sheehan>

Suzanne O'Callaghan is Haemophilia Foundation Australia Policy Research and Education Manager

YOUTH PROJECT UPDATE

Suzanne O'Callaghan

In August 2013 the HFA Youth Leadership and Mentoring Program began a new phase. Funding for the project was drawing to a close and we farewelled Kate Walton, HFA Youth Project Officer, as she set off for a new position in another organisation. Kate has achieved some great outcomes with the Factored In web site and Youth Leadership and Mentoring training and we wish her all the best in her next venture.

LEADERSHIP AND MENTORING TRAINING

There were several steps to involve young people in the Program. State and Territory Foundations and health professionals recommended young people for the Program. Next the HFA Youth Project Officer spoke to the young people individually. If they wanted to be involved, the young people were then invited to take part in the HFA Leadership and Mentoring training.

The HFA Youth Project Officer led a training weekend in two venues, Melbourne and Perth, during June 2013. Young people attended the venue that was the closest for them.

The aim was to learn more about their roles as leaders and mentors, increase their peer support communication skills, and work with their Foundation to prepare a local 'catch-up' activity. This work would continue with the support of the Foundation after the training.

In all 18 young people attended training in Melbourne and Perth. They were attentive and enthusiastic and commented on how much they enjoyed themselves during the training. The training took a light-hearted approach to very serious subjects, so that the young people had fun and got to know each other while exploring new skills and learning about their community, their Foundation and the complexities of taking on leadership and mentoring roles in the bleeding disorders community. It was an opportunity for them to connect with like-minded young people from around Australia and build new friendships.

Part of the training was to find practical and realistic ways to deal with the kinds of situations they might come across. Older or more experienced mentors from their community were also involved in the training and gave real-life examples of issues like protecting your and the Foundation's reputation, managing boundaries, organising events and working with your Foundation. This made the training information more relevant and made links for future support.

Local Foundations were also very involved and took the opportunity to be available in the training or on email to help the young people begin organising informal "catch-ups" for other young people in their own state or territory.

WHAT THEY LEARNED

The young people were surveyed 6 weeks after the training to see how they were going. Most had already done a lot of work to organise their catch-up. They had met with their Foundation to organise funding and prepare the event. They had worked with their Foundation and their Haemophilia Centre to send out invitations.

The survey asked what they had learned since the training. Many had thought more about specific skills and issues, such as communication, managing privacy and confidentiality, not giving medical advice and the importance of building relationships. They had discovered the challenges of organising volunteer activities and fitting this into a busy personal life, with comments such as "leadership requires really good organisational skills, as [you] need to liaise with many different parties to ensure that the event will run smoothly."

An HFA Youth Leadership and Mentoring Training kit for Foundations and other educators is available from HFA.

WHAT'S NEXT?

The young people who attended training will continue to work with their Foundations to organise activities for young people in their state or territory. Some "catch-ups" have already been held. Others are in the pipeline. This is a time to try out different types of events to see what works best and is the most attractive. It's when young people connect face-to-face that they get the most out of the support and friendship they can give each other. We hope that local communities can help to support and promote catch-ups so that young people can meet and get to know each other.

The Factored In web site (www.factoredin.org.au) will continue as an important place for young Australians affected by bleeding disorders to connect online and find information.

Go to **Factored In** for:

- Personal stories (or upload your own)
- Q & A – ask the questions you always wanted to know
- Read information on bleeding disorders specifically for young people
- To make comments on other people's stories or questions
- Catch up on events and activities for young people around Australia

WORLD CONGRESS

HFA also hopes to organise a meeting alongside World Congress in 2014 for the young people who attended training to get together and review how they have been going in their roles, what they have learned, what has worked (and what hasn't!) and ideas on next steps. There may also be more training for them and others.

Stay tuned for more!

Nathan Mancini won a Vision and Leadership Award in 2012

A TUMULTUS START TO A WRITING CAREER

Nathan Mancini

Three years ago, I started a new chapter in my life. With the last of my VCE exams over, I was only just beginning to think of what was to come next and so looking back it seems quite fitting that it was about that time I discovered I have haemophilia.

Other than a brief mention regarding the Tsar's son in one of my VCE History Revolutions classes, I had never really heard the word haemophilia before and so began to investigate. As it turned out, I was quite fortunate in that my condition was relatively mild so far as bleeding disorders are concerned. There were no great horror stories to prompt my diagnosis. I had played sports all my life and suffered my fair share of injuries on the field, but nothing had ever made me suspect I was anyway different. In fact, I only came to know I have haemophilia after a relative of mine had suffered an abnormally long-lasting bruise in a game of backyard cricket. Indeed, it was quite a surprise to learn the genes in the family, particularly when the person to discover the condition was in his sixties and like me had lived their life completely unaware. I know that I may have to take a few precautions when I reach a grand age, but it is not a daunting prospect. It's not as if I developed a more fragile body all of a sudden because I found out I have haemophilia; for me the diagnosis simply gave me a clearer understanding of my body's strengths and limitations.

As I mentioned, with almost perfect timing in the chronology of my life's narrative, the discovery that I have haemophilia also presented me with an unexpected opportunity. After scouring through the Haemophilia Foundation's web site one night I came across the Vision and Leadership Award, an award for those with bleeding disorders to help achieve their life goals. Being a VCE graduate in the interim months between school and university I realised then that I was in the best possible position to pursue my dreams. Unburdened by study and full-time employment, with nothing but time and an overly active imagination, I was inspired to set out on the hugely ambitious and probably naive task of writing a science fiction novel.

Having always had a passion for history, particularly ancient Rome, I began penning the blueprints of what would be *Tumultus* – a world inspired by my favourite parts of history. Being only seventeen at the time, nothing could have prepared me for the reality of such an undertaking, but once started, I knew I had to see it through. It is only now, after three years of hard work and painstaking editing, that I can say proudly I am the author of a 90,000 word manuscript – *Tumultus: the ultimate spoils* – the first book of my intended series. The novel follows the story of an aspiring senator, who, blessed with the arcane powers of a forbidden technology, descends a path that would name him traitor in order to bring his country back to its former glory.

Despite the difficulties of such a challenge, it has been a very rewarding experience and I am particularly grateful to have been provided the opportunity and support of the Vision and Leadership Award from Haemophilia Foundation Australia to pursue my dream. The Award has so far helped fund the professional assessment services of the Writers Victoria centre, whose feedback gave me fresh eyes for the final edit along with a very positive review of the work's underlying storyline and my writing standard.

Having finalised the manuscript to publishing standard, I am now beginning the long and arduous process of submitting my work to various publishing agencies. It would be a dream come true to have it taken up by a major publishing house, but having worked so hard for this dream, I am fully prepared to self-publish if needed.

I must thank again Haemophilia Foundation Australia for the opportunity provided to me and I cannot wait to be able to share my work with a wider audience – in whatever form it may end up being.

THE VISION AND LEADERSHIP AWARDS

The Vision and Leadership Awards are sponsored by Pfizer.

YOUTH NEWS

The young leaders and mentors who took part in the HFA training talk about the highlights …

LEADERSHIP AND MENTORING TRAINING

"I have for the first time connected with members with the same problems and could answer questions I have had for a very long time."

"The Leadership and Mentoring Weekend was an absolutely unforgettable experience with very like-minded amazing people. With lots of LOLs and serious training, we have become not only great team members but also friends."

HIGHLIGHTS

"ALL ROUND AWESOME"

"With this program I want to help others as much as possible. Because a little support makes a massive difference."

"I've walked away feeling better equipped to, and feeling more confident in being able to mentor youth with a bleeding disorder."

Help people with a bleeding disorder ***Achieve Their Dream*** and support ***Red Cake Day*** during ***Haemophilia Awareness Week***

Red cakes can change lives! It's true.

They can. That's why HFA is calling on our friends and supporters to help us celebrate **Haemophilia Awareness Week** by taking part in our

Red Cake Day!

Haemophilia Awareness Week is an opportunity for individuals and families as well as Haemophilia Foundations and other organisations, to take part in a campaign and activities to raise awareness about haemophilia, von Willebrand disorder and related inherited bleeding disorders throughout Australia during the week of **13-19 October 2013**.

Promotional items will be available for schools, work places, hospitals and community centres. To place an order for items (free of charge), download an order form from our website **www.haemophilia.org.au** or email **donate@haemophilia.org.au**. *Please note that stocks are limited.*

For more information on Haemophilia Awareness Week and Red Cake Day visit **www.haemophilia.org.au/redcakeday** or call HFA on 1800 807 173 or email Natashia ncoco@haemophilia.org.au

Like HFA on Facebook
www.facebook.com/RedCakeDay

Follow HFA **@Haemophilia_Au** and join the conversation at **#redcakedayhaemophilia**

HAEMOPHILIA FOUNDATION AUSTRALIA

CALENDAR

HAEMOPHILIA AWARENESS WEEK

13-19 October 2013
Tel: 03 9885 7800
Fax: 03 9885 1800
Email: hfaust@haemophilia.org.au
www.haemophilia.org.au

WORLD HAEMOPHILIA DAY

17 April 2014
www.wfh.org/whd

WFH 2014 WORLD CONGRESS

11-15 May 2014
Melbourne, Australia
www.wfh2014congress.org

HFA is delighted to announce that it has recently established a Corporate Partnership with Biogen Idec and we look forward to our ongoing work together.

CORPORATE PARTNERS

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

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

BAYER

biogen idec

CSL Behring

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Pfizer

IT'S EASY TO HOST A RED CAKE DAY DURING HAEMOPHILIA AWARENESS WEEK

1. Register your event and order promotional items online at www.haemophilia.org.au/redcakeday
2. Download a host kit
3. Invite family, friends, work colleagues to your event. You can use our invitation cards
4. Bake Red Cakes and host your event. We have a yummy Ruby Red Velvet Cake Recipe in the host kit.
5. Thank the people that came to your day and donated. You can download a thank you card
6. Collect and bank your funds

THERE ARE MANY THINGS YOU CAN DO –

- Set up a stand in your workplace, school, hospital or library
- Hand out promotional items in your local area
- Assist your local haemophilia foundation during the week
- Organise a casual clothes day at your workplace or school
- Organise a luncheon, sausage sizzle or morning/afternoon tea.

Promotional items such as stickers, tattoos, posters, and colouring-in sheets are available.

FOR MORE INFORMATION AND TO ORDER PROMOTIONAL ITEMS:

- Visit the Red Cake Day website at www.haemophilia.org.au/redcakeday
- Or call Natashia at HFA on 1800 807 173
- Or email donate@haemophilia.org.au.

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