

National H Haemophilia

Haemophilia Foundation Australia

www.haemophilia.org.au

No. 185, March 2014

WORLD CONGRESS ONLY TWO MONTHS AWAY!



WFH 2014
WORLD
CONGRESS

Melbourne, Australia • May 11-15



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Haemophilia Foundation Australia

Registered No.: A0012245M
ABN: 89 443 537 189
1624 High Street Glen Iris,
Victoria, Australia 3146
Tel: +61 3 9885 7800
Freecall: 1800 807 173
Fax: +61 3 9885 1800
hfaust@haemophilia.org.au
www.haemophilia.org.au
Editor: Suzanne O'Callaghan



NEW STAFF – INTRODUCING HANNAH

Hannah Opeskin joined the HFA education team in February 2014 as the Health Promotion Officer. She will be working with the team on health promotion resources and communications, particularly social media, and will take a lead role in Factored In and the HFA youth program. She will also be involved in the preparation for World Congress.

Hannah brings some diverse skills and experience to HFA. Originally from Melbourne, Hannah moved to rural NSW to work in local government on health programs across a range of areas, including adolescent mental health, writing the community health magazine, and building a community garden for people with disabilities. She was also responsible for collecting and maintaining population health statistics.

"The most memorable aspect for me was the feedback from people telling me how the programs had changed their lives," said Hannah. "For example, they would email me to say how much they had

learned from a particular article in the magazine, such as alcohol guidelines, and how they had tried out some of the strategies to improve their health."

Working with a rural community gave Hannah the opportunity to experience a variety of targeted programs. The adolescent mental health program focused on encouraging young people to seek help from their GP and local mental health practitioners, and aimed to reduce the stigma associated with mental health. This work took her to about 50 high schools in remote communities. She was also involved in developing an age-appropriate app on seeking help for mental health issues for young people.

Hannah is particularly looking forward to working on the communications materials at HFA.

"Bleeding disorders are such a specialised area," she commented. "I'm really excited about developing communications that target specific groups like young

people or women and seeing whether it meets their needs. With dynamic social media tools like Facebook and Twitter to use, you can really have an impact."

With the World Congress less than a couple of months away, Hannah is keen to get involved with the Australian and international bleeding disorders community and be part of HFA's work on the international scene.

Hannah works Monday, Tuesday and Friday.

She can be contacted at:
T: 03 9885 7800 or
toll free 1800 807 173

E: hopeskin@haemophilia.org.au





FROM THE PRESIDENT

Gavin Finkelstein

At all levels now, we need statistics to prove our case, or, the “evidence”.

As you will see in this edition of *National Haemophilia* it is all systems go at HFA! As a community we should be proud of the work we are doing at present. Our work towards the WFH Congress is intense and vast. The work towards MyABDR is equally complex and busy. Over the years there have been significant challenges for people with bleeding disorders in Australia, and successes!

CHALLENGES AND SUCCESSES

For the State/Territory Foundations and HFA issues like insufficient supplies of clotting factor for home therapy in the very early days, then for prophylaxis and dealing with the product rationing that occurred because of inadequate supplies, dealing with the impact of blood borne viruses and securing government funding for recombinant clotting factors for all in our community are just some of the significant things our community leaders and members have addressed over the years. Many of our volunteers who lead that work are still involved or in touch with local Foundations or HFA, while others have passed the baton to others.

HEALTH CARE COSTS AND DELIVERY

We still have challenges to address. In particular, there are issues with the increasing cost of health care and the complex way it is delivered across our country. With our state/territory and federal governments as payers,

and now local areas involved in some cases, they are all playing a part in funding arrangements for healthcare in general, but more specifically in the payment for treatment and care for people with bleeding disorders. We are fortunate that we have a health system where the government pays for our treatment, otherwise it would be unaffordable to us as individuals. This will never be more evident than at our upcoming World Congress where our Australian members will learn of and see firsthand the challenges for haemophilia communities around the world where their treatment is not a priority for their governments.

It has generally been our policy for issues such as funding and advocacy about standards and access to treatment and care to be part of the responsibility of Foundations rather than individuals in our community who are living with the challenges of a bleeding disorder and its many complications. Our members have given us that mandate. Further we have taken the view that, although clotting factor is an expensive treatment for governments to provide, it is necessary for the treatment of a life threatening bleeding disorder, and that people living with the challenges of a bleeding disorder should not primarily be focussed on the cost of these expensive treatments.

But the reality is that governments in Australia do have to divide up the “funding cake” across people

with competing needs because government resources are not unlimited. They do make decisions that mean some people with other rare diseases in Australia may not have access to the treatment they need. Many families in the bleeding disorders community will remember how terrible it is when a treatment could be available but it is not provided on the grounds of cost.

We know the value of clotting factor treatment. It sounds like a no brainer that anyone could think there might be reasons not to fund haemophilia care and treatment in Australia. But as a community we need to play our part to make sure governments have the information they need when they are making decisions about what share of “the cake” should be allocated for haemophilia treatment products and for them to know that investment is providing “value for money”. It is no longer enough for us to say clotting factor is important because it stops bleeding and that it makes it possible for us to live better in our challenging lives. At all levels now, we need statistics to prove our case, or, the “evidence”.

ABDR - AN EVIDENCE BASE

The Australian Bleeding Disorders Registry (ABDR) generates a range of data on the number of people with bleeding disorders in Australia and about some aspects of the clinical care of those people. What had been missing from this data is data that demonstrates how

We believe the data that will come from MyABDR will help health professionals and their patients improve care and treatment on an individual basis.

effective treatment is for patients. So much more can be learned by health professionals if they record and understand the right sort of information about our treatment and care needs and can see that information in reports and graphs, particularly when the outcomes of treatment for patients can be compared and measured. Further, the records about the treatment needs of individual patients can help to estimate the amount of clotting factor that needs to be purchased and budgeted for by governments.

MYABDR

Our community has always agreed that the ABDR is a valuable resource for these reasons. But to understand more about what individual patients need and the benefits or outcomes of their treatment more information is needed. MyABDR has been developed so that individuals can provide details themselves about their bleeds and the treatment they have at home. This will help them review their treatment plan with their health professionals.

I am proud of the initiative taken by the HFA Council in 2011 when it recommended a recording tool for patients to record their bleeds and treatments – a tool that could be used to improve their clinical care and also provide data for governments that they need to allocate sufficient resources for care and treatment and to understand the needs and requirements of patients. Since that Council meeting in 2011, the MyABDR project has evolved with the support of all governments around Australia and the National Blood

Authority as well as Haemophilia Centres and our own members. It has been developed carefully to ensure the most critical two elements are protected - that the tool improves care and treatment, and that patient confidentiality is protected.

We believe the data that will come from MyABDR will help health professionals and their patients improve care and treatment on an individual basis. They will be able to collect and record important information about our bleeds and treatment that helps us individually, but that aggregated and de-identified data can also be understood in way that demonstrates the importance and value of the health care to us. This is the sort of information that governments need to justify how the “share of the funding cake” is allocated – so our voice will be heard through the strength of this data.

So I urge you to find out more from your Haemophilia Centre or HFA and sign up for the MyABDR app or web site, or use the paper based recording diaries (see page 8) so that you and your health professionals can have your input into the data that is generated – and make your contribution to the national voice!

MyABDR is a tool we can be proud of. Developing it has been a joint effort by health professionals at all Haemophilia Centres, the National Blood Authority, governments which have funded it and made a commitment to it, and of course, HFA. I hope you will also take this tool up as it is rolled out in your state/territory.

WORLD CONGRESS

With the Congress on our doorstep and just around the corner I urge you to come to Melbourne to learn more about these and other developments. But there is much more for us to do there. Along with sharing our culture and warm hospitality, we need to get more of a view of our members about the novel longer acting clotting factor treatments that might become available soon around the world, how to measure best practice care and treatment outcomes and what are some of the new issues on the horizon for our community. I hope to see you there! 

WFH WORLD CONGRESS – LESS THAN 2 MONTHS AWAY!

On Sunday May 11 2014 the WFH World Congress starts in Melbourne. This is less than two months away. The Congress is a unique experience and it is truly a celebration of what the worldwide bleeding disorders community has achieved as well as a flag for the important work still to be done to achieve the WFH vision, *Treatment for All*.

The Congress program is rich in content for all delegates – whether you have a bleeding disorder, are a parent or carer of a child with an inherited bleeding disorder, health professional or a stakeholder – this Congress will have something for everyone.

IT'S NOT TOO LATE TO REGISTER! LATE REGISTRATION ENDS MAY 2, 2014

With a person with a bleeding disorder and family member registration you can attend the Opening Ceremony and Cultural evening part of your registration. The Farewell dinner will be held on Thursday 15 May and is \$95US per person. The dinner is a great way to say goodbye to old and new friends, and reflect on the past week.

AUSTRALIAN MEET AND GREET FUNCTION

A meet and greet will be held on Sunday 11 May at 3.30pm. This is free for all Australian Congress Delegates, but RSVP is necessary. Please RSVP to hfaust@haemophilia.org.au. It will be a great time to make connections - new and old - and get a taste of what you are going to experience for the next week.

If you require further information please visit www.wfh2014congress.org.au or contact Natasha at HFA on ncoco@haemophilia.org.au or phone 03 9885 7800.

VOLUNTEERS

We still require more volunteers. Whether you are someone who simply enjoys the excitement of volunteering for big events, or you have a specific interest in bleeding disorders, your contribution as a volunteer will be crucial to the success of our Congress. This is a great chance to experience the excitement of an international event as well as make a really valuable personal contribution to the bleeding disorders community.

For more information visit www.haemophilia.org.au/eventsandawards/volunteers and you can fill out an Expression of Interest form online.



**WFH 2014
WORLD
CONGRESS**

Melbourne, Australia • May 11-15



SPEAK OUT: CREATE CHANGE

By getting involved and becoming connected, you make us stronger as a community. Speak out. Create change for all people with inherited bleeding disorders.

WORLD HEMOPHILIA DAY 2014 | APRIL 17

www.wfh.org/whd



facebook.com/wfhemophilia

[@wfhemophilia](https://twitter.com/wfhemophilia)
Follow the latest World Hemophilia Day development at #WorldHemoDay



COLOURING IN COMPETITION

Haemophilia Foundation Australia has launched an exciting **colouring in competition "What's your Dream"**. The competition is supported by the Octapharma Group.

The Colouring In Competition is open from 13/10/2013 to 17/04/2014 and to children from any country in the following three categories:

**Category 1:
children aged under 4 years**

**Category 2:
children aged 5 to 8 years**

**Category 3:
children aged 9 to 11 years**

There are great prizes for each category including an IPod Nano, an Apple voucher or a Toys R Us voucher.

The colour in sheets will be judged at the 2014 WFH Congress in Melbourne from 11-15 May 2014.

A colour in sheet has been inserted in this edition of National Haemophilia.

To download extra sheets and terms and conditions visit tinyurl.com/HFA-colouringin-competition.

For more information contact HFA on hfaust@haemophilia.org.au or call 1800 807 173.



Sponsored by **Octapharma**

Organised by **HAEMOPHILIA FOUNDATION AUSTRALIA**



SAVE THE DATE

Haemophilia Awareness Week and Red Cake Day will be held from 12-18 October 2014.

To be added to our mailing list email your details to ncoco@haemophilia.org.au or call Natasha on 03 9885 7800.



MYABDR LIVE!

Suzanne O'Callaghan

WHAT IS MYABDR?

MyABDR is an app for smartphones and/or a computer web site to people with bleeding disorders or parents/caregivers.

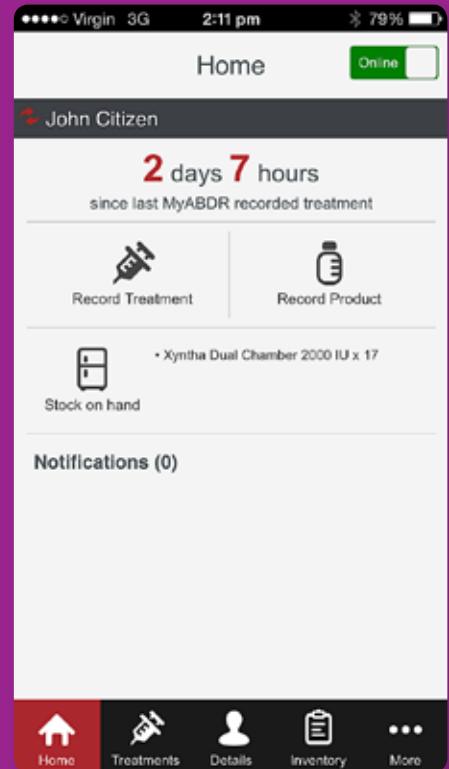
This exciting new online tool is a quick and easy way using to:

- Record treatments and bleeds
- Manage stock of treatment product
- Share the information with your Haemophilia Centre
- Update your contact and personal details.

It is private, secure and optional.

Prefer paper to online? A paper-based MyABDR patient treatment diary has been developed alongside as an alternative.

MyABDR is a collaboration between HFA, the Australian Haemophilia Centre Directors' Organisation (AHCDO) and the National Blood Authority (NBA) on behalf of Australian governments.



MyABDR is being rolled out throughout Australia during March and April 2014.

Start-up packs have been delivered to Haemophilia Centres and are available to download from www.blood.gov.au/myabdr.

These include:

- The MyABDR brochure
- Getting Started guides for the app and the web site

More detailed Step-by-Step guides and FAQs are also on the web site for downloading.

HAEMOPHILIA CENTRES AND THE ABDR

MyABDR is a two-way system linking with the Australian Bleeding Disorders Registry (ABDR), the system used by Haemophilia Centres for clinical care of their patients.

When you are in mobile phone range or online with your computer, the entries you make on MyABDR will

upload directly to your record in the ABDR at your Haemophilia Centre. MyABDR also draws on your ABDR record for information like your treatment plan.

At the Haemophilia Centre end, the ABDR system has been upgraded to incorporate a MyABDR section in the menu and the MyABDR records submitted by the Centre's patients, as well as working in with the MyABDR app and web site. The MyABDR rollout includes training for Haemophilia Centre staff to use the upgraded version of the ABDR and

"Because it is electronic, it is portable and gives me easy access to recording when I'm not at home (like on holidays)."

to process their patients' registrations for MyABDR

WANT TO KNOW MORE?

Introductory sessions for the community about MyABDR and how to use it are being held in most states and territories during March and April 2014. All are welcome to attend – go to www.haemophilia.org.au/myabdr for more information or to register your RSVP.

COMMUNITY TESTING

People with bleeding disorders have been involved from early in the development phase. After the MyABDR community survey in mid-2013, there was a national focus group workshop of community members in October 2013. The first prototype was reworked and then a wide group of community members tested the revised version on their phones and computers at home over December and January. Another focus group workshop followed in mid-January 2014 for fine tuning. HFA Council delegates and haemophilia health professionals have also

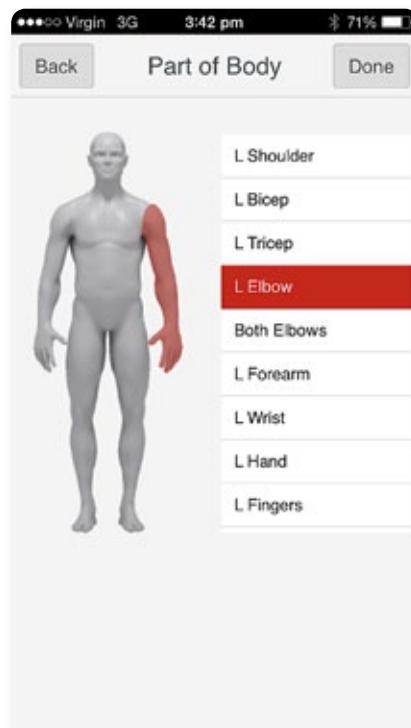
given feedback and suggestions at previews over the last 6 months.

This testing has been done to make sure that the MyABDR product will work well with people's normal treatment and recording routines. There have been lively discussions and suggestions and the consensus is that the product is looking good.

WHAT DID THE FOCUS GROUP THINK?

A small group of individuals with diverse treatment experiences from around Australia met with the HFA and NBA MyABDR project team in January 2014 to do some final testing and feedback. Their comments? They particularly loved:

- Having the details of their treatment and stock on their phone and all in one place
- How easy it was to record
- The quick summaries of their last treatment and stock on hand on the home screen.



"It's much easier having both my children in the one place."

"Less paper!! Yay!! I don't need to carry a book around with details of treatments."

"I love the inventory details on the home screen."

"Because it is electronic, it is portable and gives me easy access to recording when I'm not at home (like on holidays)."

More information is available at www.haemophilia.org.au/myabdr.

MYABDR - HOW TO REGISTER

Registering on the app - Download the app from the Apps store (Apple) or Google Play (android). Register online by CREATING AN ACCOUNT.

Registering on the web site -

go to www.blood.gov.au/myabdr and click on NEW USER? CLICK HERE TO REGISTER. You can register on the web site for both the app or the web site – your account will work on both.

After you register, your Haemophilia Centre will process your access to MyABDR.

When?

You can register any time after 28 February 2014.

Before you can use MyABDR, you will need your registration approved by your Haemophilia Centre. This will take place in your state or territory after MyABDR training for Haemophilia Centres and the community has been completed – go to www.haemophilia.org.au/myabdr for the training schedule.

TREATING BLEEDS WITH RICE

Wendy Poulsen and Abi Polus

Are you having bleeds...??

STEPS

- Factor Now
- Start R.I.C.E
- Report Bleed

FACTOR ALONE DOES NOT EQUAL TREATMENT

Physiotherapy means a speedy recovery & a safe return to activities.

TO RECOVER QUICKLY FROM A bleed, OR JUST SPRAINS OR STRAINS

R.I.C.E

- (R)est
- (I)ce
- (C)ompression
- (E)levation

- ✓ Factor in Physiotherapy
- ✓ Factor in a PHONE CALL

Australian & New Zealand Physiotherapy Haemophilia Group

Haemophilia Foundation Australia
www.haemophilia.org.au

FACTOR: Should be administered as soon as possible and bleeds should be reported to your Haemophilia Centre. Always seek additional medical advice if there are continued symptoms of pain, swelling and restricted range of movements within the joint or muscle.

Why? Reporting bleeds to your Haemophilia Centre allows your health care team to identify serious bleeds or cumulative bleeds that may be target joints. With the advances in factor replacement, correct rehabilitation is sometimes overlooked. RICE is vital in the management of joint and muscle bleeds.

REST: A decrease in activity is encouraged for at least 48 hours after a bleed. If the bleed is in the lower limb, crutches should be used while not bearing weight on the limb. Your physiotherapist may use additional splinting or casting to provide support to the joint or muscle and will provide a guide to continued use of crutches and transition back to weight bearing over suitable time according to symptoms. The general rule of thumb is you need to be on crutches until full, pain-FREE range of movement is achieved.

Why? Factor replacement stops the bleeding, but it does not heal tissue. Rest allows the TIME needed to achieve healing of the damaged tissues be factored in to your treatment regime. This helps stop re-bleeding (including small micro-bleeds that can be undetected) from occurring and also ensures that a joint is less likely to have permanent damage. There is evidence to show that walking on or using a blood filled joint can severely increase damage to cartilage.

ICE: Cold in the form of crushed ice, frozen peas or cold packs can be applied to the local area. The chosen product should be wrapped in a cloth to prevent ice burns. There is evidence that cold therapy can assist with a reduction in pain and it is thought that it may lessen localised swelling. It should be applied for no longer than 15-20 minutes and can be repeated every two hours as tolerated.

Why? Ice is well established in aiding pain management, although current thinking is that factor replacement should be administered first.

COMPRESSION: A supportive bandage/tubigrip can provide

additional support to the area. Your physiotherapist can provide you with the best options. Tubigrip should be removed at night.

Why? Compression can stop the amount of swelling and blood present at the site of the bleed. This may prevent further muscle and other soft tissue damage and can reduce how much blood has to be reabsorbed in the joint or muscle.

ELEVATION: Part of body should be above the heart if possible; if in the leg should at least be above the groin.

Why? Elevation uses the principal of gravity to allow drainage from the area of the bleed to lymph nodes in areas such as the groin and underarms where swelling is most effectively absorbed. In combination with Factor, Rest, Ice and Compression it can reduce the bleeding and swelling, and speed up recovery.

Source: Australian and New Zealand Physiotherapy Haemophilia Group

Consult your Haemophilia Centre or health care team for all matters related to treatment. ■

TEAM.FACTOR – THE BUPA CHALLENGE TOUR

On Friday 24 January 2014, a team of 8 cyclists headed by Dr Simon McRae participated in the BUPA Challenge Tour as Team.Factor to raise funds for Haemophilia Foundation Australia.

TEAM.FACTOR

The team included Haemophilia Centre Director Dr Simon McRae, haemophilia nurse Andrew Atkins, research nurse Donna King, haematologist Uwe Hahn, Dan Drake, Phil Burke and Michael Townsend – all from the Royal Adelaide Hospital.

TOUR DOWN UNDER CHALLENGE

Cycling enthusiasts from around Australia and the world registered to take part in the 2014 Challenge Tour held each year in South Australia. They had the opportunity to ride the same route on the same day as the elite cyclists competing in Stage 4 of the 2014 Santos Tour Down Under.

THE RIDE

Team.Factor rode from Unley in Adelaide and finished in the seaside town of Victor Harbor, south of Adelaide, a total of 154.5km.

"the ride was not quite as hard as I thought it would be, but the finish line was a welcome sight. It was a great way to meet other cyclists and a motivation to stay in shape."

It was a great effort by all the team. A wheel blowout at 120km prevented Michael Townsend finishing, but the rest of the team got through to the end, mixed in with 6600 other riders. The ride started at 6:30am and Dr Uwe Hahn was the first of the group to finish, in just four hours. The rest came through at varying times before the professional riders came through around 3pm

Dr McRae said, "the ride was not quite as hard as I thought it would be, but the finish line was a welcome sight. It was a great way to meet other cyclists and a motivation to stay in shape."

THANK YOU

Thank you to Dr Simon McRae, Dr Uwe Hahn, Andrew Atkins, Donna King, Dan Drake, Phil, Phil Burke and Michael Townsend for participating in the race and raising funds for

Haemophilia Foundation Australia. Also, a thank you to those who made donations and supported the team. To date Team.Factor has raised \$2082. 



Andrew Atkins and Dan Drake

HFSA UPDATE

WORLD CONGRESS

HFA keeps in touch with people affected by bleeding disorders in South Australia in different ways. Recently we have been speaking with many people about the upcoming World Congress in Melbourne and have encouraged people of all ages to consider attending. We expect a large contingent of Australians to come together with people from around the world for the Congress. Although it is the largest global medical and scientific meeting for the bleeding disorders community, the Congress is also for people affected by bleeding disorders – come and hear about state of the art, new treatments as well as how others live well with a bleeding disorder. You will not be disappointed.

HFA is planning a **Meet N Greet** on the Sunday afternoon before the Opening Ceremony of the Congress on 11 May to enable people from around Australia to meet one another. If you feel a bit shy about joining such a large Congress, this is a chance to meet others before

the Congress and make new friends to keep in touch with during the Congress.

HFA has undertaken a special fundraising campaign to generate a funding program to enable community members from all around Australia to attend. So far over \$10,000 has been allocated to South Australians who were keen to attend the Congress and further funds have been set aside.

In a further decision to promote and support more South Australians to be able to attend the Congress, the Haemophilia Foundation Australia (HFA) Executive Board made a decision to withdraw up to \$5000 from the investment funds handed over by HFSA for safe keeping when it officially wound up two years ago. These further funds will be used to help support individuals affected by a bleeding disorder or their carers or a family member to meet the costs of attending the Congress, including for some of their registration, travel or accommodation costs. The formal application process is not onerous and just a

simple application form is needed. It is still not too late, but you will need to get onto it quickly. For a copy of the application form go to the HFA website
[www.haemophilia.org.au/
eventsandawards/hfa-funding](http://www.haemophilia.org.au/eventsandawards/hfa-funding)

HFA is required to set up a treatment room at the Congress for people to administer their clotting factor treatment or get advice if they have a bleed, and for people from overseas who do not bring clotting factor with them and may require it during the Congress. A small amount of clotting factor has been donated to WFH for this purpose. HFA is grateful for the generous commitment of Andrew Atkins, Clinical Practice Consultant, Haemophilia Haemophilia Treatment Centre at the Royal Adelaide Hospital to set up this treatment room which is such an important and unique feature of the Congress.

MYABDR INTRO SESSION IN ADELAIDE

As you will be aware, the MyABDR app and web site were released in March 2014. A free community introductory session has been scheduled for the evening of Wednesday 26 March in Adelaide. If you treat at home or have any questions about MyABDR, come along and find out more about this exciting new initiative. Suzanne O'Callaghan from HFA and the MyABDR Support team from the National Blood Authority will be leading the training. We appreciate the help of the Haemophilia Centre teams in organising this – and their recommendations about parking and the menu!

INTRO TO MYABDR SESSION

6 for 6.30-8pm
Wednesday 26 March 2014
Rydges South Park Hotel,
1 South Terrace, Adelaide

More information and RSVP online –
www.haemophilia.org.au/myabdr

Or contact Suzanne at HFA on
socallaghan@haemophilia.org.au,
phone 1800 807 173. ■

WFH YOUTH ENGAGEMENT WORKSHOP

Jenna Lovell

In December 2013, I was given the opportunity to attend the Advocacy in Action - Youth Engagement workshop run by World Federation of Hemophilia (WFH) in Montreal, Canada. The workshop went for three and half days which made for a very quick trip to chilly Montreal, but it was an amazing experience. This workshop was part of a series of workshops WFH has run to increase the skills of volunteers working in their local communities.

The highlights of my trip included meeting other young people with inherited bleeding disorders (all of whom I hope to catch up with in Melbourne in May!). Some of these people came from The Dominican Republic, South Africa, France, Slovenia, United States and Australia to name a few.

I gained a lot of insight about the struggles in other countries where treatment, diagnosis and access to care is unavailable or inadequate. I met quite a few people where access and quality of care was so limited that it was a constant struggle in their everyday life. I recognised that we are generally so lucky here in Australia where there is access to care and treatment, even though there might be some issues for some parts of our community.

I learned that engaging with youth with bleeding disorders is a struggle for many haemophilia organisations around the world. Despite the differences in access to medical treatment, product and other medications, young people all around the world find it difficult to become and remain engaged

with their haemophilia centres and support organisations. In Australia we now have a group of youth around Australia who have had some training and are now looking at their future roles as leaders and mentors. I gave a presentation at the workshop on some of this work in Australia.

It was also great to learn that like Australia, there are some enthusiastic people who are keen to be involved in their state or national organisation, and who want to see the voice of youth heard by our doctors, support organisations and governments. It reinforced that our views matter!

Having young people interested and involved with HFA and the WFH is a goal of both organisations, and this year there are some great opportunities for young people in Australia:

- Get yourself to WFH Congress in Melbourne in May. There will be youth activities and sessions at the Congress where your involvement and views will be the focus!
- Join your state's Youth Mentoring Network and factoredin.org.au
- Check out the new web series by WFH, Young Voices www.wfh.org/en/resources/young-voices

I am looking forward to the Congress and to catch up with my new friends – you will be able to meet some of them too at Congress. I have also been invited to join a panel presentation so I will be doing some preparation for that over the next few weeks! ■

Jenna Lovell is a member of the HFA Youth Working Group



YOUTH MEET & GREET AT CONGRESS

**BEFORE THE WFH 2014 CONGRESS BEGINS
WITH ITS OPENING CEREMONY ON 11 MAY,
HFA HAS ORGANISED A YOUTH MEET & GREET
SATURDAY AND SUNDAY 10-11 MAY.**

Anyone aged 18-30 years registered for the Congress is welcome to attend. Or if you haven't yet registered and need funding for registration let us know!

The Meet & Greet will be facilitated by Purple Soup and is designed to get you out of your comfort zone or show off your talents (hidden or otherwise!) and is also a great opportunity to meet other young people affected by bleeding disorders before the Congress. Depending on numbers and weather, the weekend activities might include:

- A short film festival
- Mad Minute
- An Aussie BBQ bake-off
- The infamous Casino Royale
- The Incredible Race.

Activities will be suitable for everyone.

If you are attending Congress and don't know many people, the Meet & Greet is a great way to ensure there are some friendly faces throughout the Congress.

The Youth Meet N Greet runs from Saturday 10 May - Sunday 11 May and will finish just in time for the Congress Opening Ceremony. The Congress is full of interesting presentations about care and treatment of bleeding disorders as well as on living with bleeding disorders. It is attended by health professionals and people from all around the world who are affected by bleeding disorders. The Congress concludes on the Thursday night with a celebratory dinner!

HFA still has some funding available, but please be quick.

FOR MORE INFO

Contact Hannah Opeskin
hopeskin@haemophilia.org.au or 1800 807 173
or Sharon Caris on 0410419914 or scaris@haemophilia.org.au

- **HFA Youth Meet N Greet:** Saturday 10 May until Sunday 11 May
- **WFH Congress:** Sunday 11 May until Thursday 15 May
- **Congress dinner:** Thursday 15 May (night) 



Visiting WFH



Workshop presenters



Advocacy in Action workshop participants on the last day

YOUTH NEWS

Youth Delegates share their experiences of Congress in the past

BUENOS AIRES 2010

by Craig Bardsley, Youth Committee member

Having the opportunity to go to the World Congress in Buenos Aires was fantastic for so many reasons, but I think for me the best part was because I got the chance to meet people with bleeding disorders from all over the world.

I spent a lot of time with the other Youth Delegates. There were more than 40 of us, all from different countries. We hung out and exchanged info, including our emails and Facebook pages and mobile numbers to keep in touch with each other – some of the people I'm now in contact with come from countries like the US, Sweden, Poland and Switzerland. The social activities were a great way to get to know each other. One night we all went out for dinner at a big restaurant, and another night we went to a pub and danced. We talked about what Youth Delegates could do in the future - we are even looking at the idea of a "World Youth Committee" where we would be able to have our voice heard on a global stage.

It was amazing to hear how other people deal with their issues and reinforced to me that we are at the top of treatment here in Australia.



Craig Bardsley, Youth Committee member

Robert and friends at the World Congress in Turkey

TURKEY 2008

As a member of the HFA Youth Committee, Robert McCabe attended the World Congresses in Istanbul and Buenos Aires.

The World Congress in Turkey was one of the most amazing experiences I have ever had in my life. I met a lot of people and gained contacts and friendships which will last a lifetime. Haemophilia

became the universal language and broke down the communication barriers between the participants. I was able to meet many other young people who had a connection to the bleeding disorders community. Eventually, we were able to gather a few people together and look at the night life of Istanbul.

For me the most memorable thing about the World Congresses was hearing the stories of those who live in countries that have little to no access to safe treatment products. It really showed how much more work that there is to do. I definitely got a lot out of meeting people from around the world. From treatment providers to people with or who are affected by a bleeding disorder, listening and sharing stories with others shows you how similar and different we all are.



FUTURE DELEGATES SHARE THEIR EXCITEMENT ABOUT ATTENDING THE WFH 2014 CONGRESS

FACTORED IN
WWW.FACTOREDIN.ORG.AU

JENNA

I'm excited to attend a Congress:

I'm excited about going to WFH Congress in Melbourne because I've never been to a Congress before!

I'm most excited about meeting other young people with bleeding disorders and hearing their stories. I've had the chance to participate in a few HFA events over the past few years and the chance to talk to other people who really get my experience is invaluable.

I can't wait to meet you there!



DALE

I'm hoping to meet new people:

I've never been to a Congress before so I'm not too sure what to expect, although I'm hoping to gain a greater insight into haemophilia and other bleeding disorders on a world level. I'm also excited to catch up with old friends and most importantly meet new people who I can share my own experiences with, while maybe learning a thing or two myself.

We as the youth are the future and I urge anyone to join me at Congress as it will be a once in a lifetime opportunity.

See you there!



CALENDAR

WORLD HAEMOPHILIA DAY

17 April 2014

www.wfh.org/whd

WFH 2014 WORLD CONGRESS

11-15 May 2014

Melbourne, Australia

www.wfh2014congress.org

HAEMOPHILIA AWARENESS WEEK

12-18 October 2014

Tel: 03 9885 7800

Fax: 03 9885 1800

Email: hfaust@haemophilia.org.au

www.haemophilia.org.au

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.



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CSL Behring



COLOURING IN COMPETITION REMINDER

Haemophilia Foundation Australia is running an exciting Colouring In competition titled "What's your Dream".

There are great prizes for each category including an IPod Nano, an Apple voucher or a Toys R Us Voucher.

Competition closes 17 April 2014.

See page 7 in this issue for further details.



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