

Factor Matters

Haemophilia
Foundation
NSW



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Volume 33

*Exciting new therapy options
for Hep C*

- *Celebrating Life & New Leap Year*
- *November Family Camp*

- *Young Members Contribute
& More*



About Us

HFNSW is a not for profit organisation that provides support programs and advocacy for the NSW bleeding disorders community, their families and carers. While specialist doctors and nurses provide world class medical and social care for our members, our mandate is to support the full range of other important things for the bleeding disorder community such as: community participation, physical & emotional support, advocacy, education and financial assistance to members, their families and carers.

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Bio-Research & Art Concepts
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On the cover: Depicted in true Sydney NSW style is the Harbour ablaze with elaborate firework displays to celebrate the bringing in of a New Year and this a unique leap year - well underway. For the bleeding disorder community in particular it also celebrates an invigoration of life-itself and the successes of new antiviral treatments just made available for the cure of HCV in older people with bleeding disorders, infected years ago, before the development of highly purified and recombinant virus filtered and inactivated clotting factors. The pink balls at the top of the picture depict the extremely tiny HCV virus (or HIV) that have very similar shapes but on a sub-microscopic scale. On the bottom half are reflected images of those pink virus-like balls but much lower intensity and visibility, to symbolize their reduction after beginning treatment with the new highly effective HCV antivirals, and the beginning of a new life for many - without HCV.

Dr Garry Lynch, BioMedical Research & Concept BioArt,
University Academic & Educator Dip. Int. Dig. Media (EDC),
B.Sc(Hon) (Flinders), PhD (Monash)



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There's plenty of good news this quarter! Longer acting factors are being trialled here at home and the new Hep-C treatments are available to all from 1st of March.

If you have Hep-C, we encourage you to visit your GP, Liver Clinic or HTC to get up to date tests and get in the queue as it will be a first come first serve situation. This is actually a result of many years' worth of advocacy and a multi-pronged approach from different parts of the community, the health sector and within government. Suzanne O'Callaghan at HFA did a wonderful job of finding and publishing our community's stories. Thank you to those of you in NSW who participated in the effort. It proves that our diligent, professional and patient approach worked as those in our community who need it now have access to a potential cure.



Dr Khoo, on 'New Treatments' at Camp

And the future's not over yet....At our AGM and as updated at Family Camp, Dr. Khoo from the RPA provided us insights into the new treatments that are currently being trialled, some right here in Sydney including longer acting factors 8 & 9.

'Recently, I've had the good fortune to attend some very interesting meetings and I thought I'd pass on what I've learned. Last week, I attended a national focus group which included haematologists, CNCs, HFA, NBA and five men (aged 14 to 40) who've been on longer acting factor trials. By all accounts, the new longer acting factors are "stronger". That is, they last longer, and that extra, prolonged coverage has many

follow on benefits which up until now were hard to articulate. A few of the men reported a feeling of increased confidence and ability to commit to things; a reduction of the background fear threshold for parents; the ability for parents to return to work on a more permanent basis; and, less bleeds because of the longer life. Thanks to our NSW members who participated in these trials and conversations. Along with our colleagues at HFA and the other State Foundations, we are advocating with the right people in government to add these new treatments to our available options.

Finally, thanks to all those NSW members who are using the MyABDR app! The benefits of its clinical use are emerging and it's actually turning out to be a better way to account for treatments, notes, bleeds, all in a secure way. If you haven't tried it yet, you should. Just send an email to your HTC to request a login. And as if you needed another reason to start using the MyABDR app, I know that nationally, we are currently in second place behind the Victorians in terms of % uptake!

Warm regards,

Dan.





It was a very welcome Christmas message for our community: on 22 December 2015 Australian Minister for Health Sussan Ley announced that new breakthrough hepatitis C treatments will be available on the PBS from 1 March 2016.

These medicines are:

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

"This is fantastic news for people with bleeding disorders and hepatitis C," said Gavin Finkelstein, President of Haemophilia Foundation Australia.

"They have been waiting so long for access to treatment to cure their hepatitis C. Many have seen their liver disease progressing and were despairing. This decision by the Government will change people's lives and we would like to congratulate Minister Ley for seeing the process through to make these treatments available and affordable to all Australians with hepatitis C."

Most of these treatments can be taken orally, with the most common course of treatment being as short as 12 weeks.

"This combination of breakthrough cures has a success rate of more than 90 per cent across the entire hep C patient population and is faster and has fewer side effects than anything currently available," said Minister Ley.

Listing the new medicines on the PBS will mean that people with hepatitis C will only pay the normal PBS co-payment for these treatments: for 2016 the

co-payment is \$6.20 for concessional patients and \$38.30 for general patients each time the medicines are dispensed by the pharmacy.

"HFA will continue to work with expert health professionals and health services to make sure that people with bleeding disorders can access treatment when needed in a timely manner," noted Gavin Finkelstein. "For our community members, the message about being proactive with your hepatitis C care is even more important now: look after your liver health, make sure you have had your liver health checked and talk to your hepatitis C clinic about your treatment options."

AND IF YOU HAVE HEP C?

In the meantime, if you have hepatitis C and a bleeding disorder, remember that you would need to have your liver health assessed before you could be considered for treatment – don't wait; if you haven't already, make your appointment now!

- Make sure you have your liver health checked regularly
- If you don't know where to start, ask your Haemophilia Centre for a referral
- Stay in touch with your hepatitis clinic about what's new
- Don't forget to go to your appointment with the hepatitis clinic after your liver health check, even if the fibroscan shows your liver health is stable at the moment
- And for comprehensive care, let your Haemophilia Centre know about your liver test results or how your treatment is going to make sure they stay in the loop.

HEP C - A LEADING CLINICIAN ADVISES...

A/Prof Simone Strasser is Senior Staff Specialist in the AW Morrow Gastroenterology and Liver Centre, and the Australasian National Liver Transplant Unit at Royal Prince Alfred Hospital and the University of Sydney.



Simone gave a most informative talk at the 17th Australasian & New Zealand Conference on Haemophilia & related bleeding disorders, held on the Gold Coast 1-3 October 2015.

She outlined the major revolution in treatment for Hepatitis c which is now available – scripts can be dispensed under the PBS from March 1st 2016. Essentially the new interferon-free anti-viral medications now available target a range of genotypes and are suitable for those with cirrhosis and some co-morbidities. There are huge advantages to having treatment.

Interferon free treatments have very few side-effects, have an exceptionally high response rate, can be given to patients before and after liver transplant, can treat patients with chronic kidney disease and are equally

effective in patients with HIV co-infection. Most people require only 12 weeks of treatment. People living remote to a liver clinic may be able to access the new HCV treatments through their GP who will consult with a liver specialist

- Adherence is important in all medical regimes
- Lifestyle management (cease smoking, cease alcohol, reduce weight & increase exercise) and management of cardiovascular risk factors are important.

She concluded:

- Hepatitis C can be cured in almost everyone! SVR (Sustained Viral Response) = cure
- Interferon-free treatments offer a high chance of cure with excellent tolerability
- Eradication of HCV markedly reduces the chance of developing liver failure or liver cancer
- People with cirrhosis should however continue to have long-term surveillance for liver cancer even after HCV has been eradicated.

People with bleeding disorders and HCV should:

- Have their liver disease status checked, through referral to a Liver Clinic
- Have treatment for HCV
- Update their Haemophilia Treatment centre about their progress

HEP C - A MEMBER REFLECTS...

This issue of *Factor Matters* marks an important turning point regarding a couple of “elephants in the room” of the bleeding disorder community for the past almost 40 years.

Those elephants being the blood borne viruses HIV (the Human Immunodeficiency Virus) and HCV (Hepatitis C Virus) which blind-sided people living with a bleeding disorder (their families and others) when they emerged from the shadows and were carried along as uninvited guests in blood transfusions and treatments of the late 1970's and early 1980's. The emergence of those viruses, and HIV in particular, and the deadly diseases they cause prompted a scurrying and rallying together of many of the best and brightest medical and scientific minds of the time to try and sort out what the hell was going on and how to fix it. To say that: “EVERYONE was in the dark” on what was

happening, is an understatement. To myself it remains mind blowing how fragile, volatile, confusing and confronting it was at the time, where lots of little pieces of information tangentially different and weird kept filtering in, and rather than helping build a clear picture of what was going on added to the confusion and fuel to the fire of knee jerk ideas and responses some rational



and based on fact - but some not. It was a time of limited real information, but often replaced by considerable disinformation and emotion.

At last a new beginning for many – without HCV.

Garry

Dr Garry Lynch, Vice President of HFNSW



Everyone was very welcoming



HFNSW Family Camp 2015

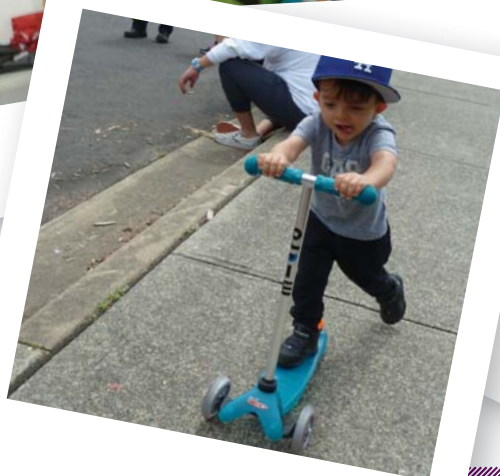
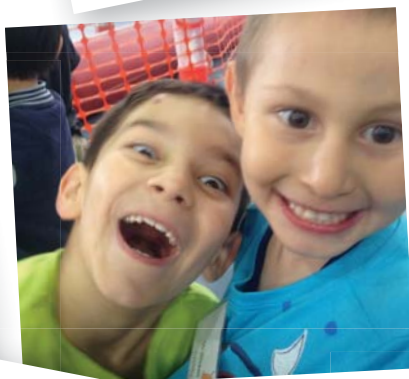




Childcare in a safe environment and lots of kids to play with.



Enjoyed everything including activities, information sessions, kids entertainment, food, games





*Our Camp's CNC's
Steve & Robyn*



*CNC's Robyn & Steve:
Camp Self Infusion Workshop*



*One of many spontaneous
informal Camp Consultations*



*Dr Liane Khoo's session on
'Trends & New Treatments'*



*CNC Robyn Shoemark's session
on 'Family Planning'*



Thx Clinicians!

The Camp Of 2015!



YOUNG MEMBERS CONTRIBUTE

A big thank-you to our Family Camp Volunteers Hamish Robinson & Sam Linnenbank.



Hamish up at 7am Sunday, helping supervise Angry Birds (allowing parents some prospect of a sleep in!)



Sam's professional swimming background encouraged us to expand the Pool sessions from 1 to 3 (at no extra cost!)



Or here, Hamish helping to model & mentor self-Infusion.

TO YOUNG LEADERS

& Congratulations to both on their successful applications to participate in HFA's youth leadership and mentoring program, **YOUTH-LEAD-CONNECT**. They have already completed their first face-to-face session – a training weekend in Melbourne.

Want to hear more... if you are 13 to 30, I hear you may catch them on FACTORED IN.



Sam and Hamish.



Emu Gully 'Odyssey' - In Just Two Days?

On the 31st of October to the 1st of November, I attended the **Haemophilia Foundation Queensland's annual Youth Camp** located at Emu Gully. This was in part thanks to the financial assistance of HFNSW.

My Sydney flight arrived at 1:30 at Brisbane Airport, where I was met at 4pm, then on to Emu Gully by 8pm. After being introduced to old friends and new, it was time for bed to get some much needed shut-eye for the busy weekend ahead. The next morning we were greeted by our Group Co-Ordinators: Dave and Maddy. We were briefed on the themes and the ideas behind the whole camp and the individual activities. The camp was based around an ANZAC theme, and all of the activities promoted the character values of **Courage, Mateship, Perseverance and Sacrifice**. All of the activities incorporated either one or many of these ideals.

We did a myriad of activities and trials. My favourite of which was "The Tunnel Rats of Vietnam" where we had to crawl through concrete pipes placed under ground that twisted and turned, went back up to the surface and down. I crawled through mud on my back, climbed up a steep pipe using only my hands and knees before I had to use rock-climbing hand-holds to navigate the inside of a water tank that was knee deep in dark muddy water. After a swim in the dam and a lovely dinner thanks to the wonderful chefs, it was time for us to go on a night walk. We had to carry one of the members of our party on a stretcher the whole night, including down a giant slide, through a bunker, and a maze where we weren't allowed to talk at all, and the toughest, was up a steep hill. All of the hard work and

heavy lifting was worth it for the end of the walk, because we got to ride in the back of an old Vietnam War era troop-carrying truck all of the way back to the campsite. After some supper it was time for bed, and boy did we all sleep.



*Vietnam War era
troop-carrying truck.*



The infamous "Mud Course".

Too quickly, Sunday came, but there was a sadness around camp in the morning. This was the last day of camp, it had come too soon. All was not lost though, because when we met Dave in the morning, he prepared us for our first activity of the day.

The infamous "**Mud Course**".

Unfortunately due to injuries sustained on the day before I was unable to actually do the course with my fellow campers, so I became the *designated camera man*. The "Kokoda Mud Trail" consisted of about 40 metres of waist deep mud, mud hills, climbing under and over wooden poles and random holes that you could fall in and cover yourself even more thoroughly in mud. After a quick shower in the dam, we had lunch and then our final activity. The Twister Buggies! After a few lightning fast laps in the little buggies, 4pm had come, and it was time to high-tail it out of there to get to the airport on time. After some teary eyed goodbyes, we packed up the van and headed out on the road. The weekend was over, and I was very grateful to have been a part of it.

Having a Camp for 'youth-only' allowed participants to create new relationships outside of their existing social circle, grow together and tackle the challenges they can face with their disorder, physically as well as mentally. A key component of the HFQ camp was the fact that it was very physical, kids were running around, hurting themselves (accidentally) and doing physically strenuous things with no-one telling them '.. you can't!'. It lets kids be themselves away from their parents constantly hovering over them, like they tend to do at Family Camp.

Another concept that I feel will benefit children with bleeding disorders is the values and ideology that the ANZAC focused camp delivers to them, with the themes of self-sacrifice and courage a really important part of the experiences that can help shape them into better people. It also might help the parents, with them sending their kids off to have fun and raise hell knowing that they are being taken care of by proper recreational educational facilitators.

Any feedback or questions welcome.

Sam. (slinnenbank@gmail.com)



From the HFA and National Blood Authority
MyABDR Team.

WHAT'S NEW?

A new version of the MyABDR app was released on 1 March 2016. The major improvements and features included in the update are as follows:

- Significantly reduced synchronisation time for users of the mobile application
- The ability to request patient cards from the new **Request Patient Card** menu on the **Details** page in the mobile app
- Automatic syncing upon changing or uploading any data
- A pop up message to let users know if their new treatment or stock change will result in a negative stock balance
- A small indicator to let users know when a record is not successfully synchronised

Please ensure that you update your MyABDR app to take advantage of these new enhancements.

USER TESTING AND FEEDBACK

In January 2016 a group of MyABDR users generously volunteered their time to test the latest update to the app. The feedback received was generally positive with most testers noting the improved syncing.

Do you have any feedback to give regarding MyABDR? We are constantly looking for ways to improve the system so if you have something to share please contact the MyABDR Support Team on the details below.

OFFLINE MODE AND SECURITY

Offline mode is a feature within the MyABDR app which enables users to access their account and view and enter records while not connected to a network. The purpose of this function is to allow users to keep up to date with their treatment or product entries when



data is secure. Please refer to your phone's user manual to update your security settings.

NEED HELP?

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

T: 13 000 BLOOD / 13 000 25663
E: myabdr@blood.gov.au
Available 24 hrs a day, 7 days a week.



'As I (generally) infuse every 2 days I've noticed the sync-ing time has really reduced on my smartphone app.

The app instantly stores a lot of information and is very useful.

I encourage you to use it.

*This data can then contribute to the informed advocacy to maintain funding for treatment products. The government knows from the **depersonalised** data collected that their funding is well spent.'*

Hamish.

PS; And if you have any problems, doubts or questions.. the 24/7 MyABDR support team are really helpful!

The World Federation of Hemophilia Global Forum held in November 2015 was packed full of information, in fact so much, that it was hard to keep up!



As ever, it is confronting that despite increased global supply of recombinant clotting factors and some innovative humanitarian programs, there remains significant unmet need in the developing world. With only 30% of the

global haemophilia community accessing appropriate treatment, there is potentially huge demand for both recombinant and plasma derived factor VIII, but the ongoing huge challenge is to find ways and motivation for the manufacture and supply of treatment that is affordable and accessible to those who need it.

Safety is linked to supply. For those without access to a supply of safe treatment, there is a need for both of these aspects to be addressed. While the historical concerns about blood product safety are somewhat more reassuring now we have appropriate viral inactivation and donor selection strategies in place,

there is no place for complacency – there are new viruses capable of emerging in biologicals at any time. The ongoing challenge and worry remains the complication of inhibitors developing in people using clotting factor and whether these can be prevented or reversed.

The discussions around new products and longer acting clotting factors and gene therapy are very interesting and challenging. The holy grail of gene therapy continues to be elusive on a large scale, although there have been some successes with small groups of patients. Many countries are caught up in discussions about how to evaluate the benefits and costs of longer acting factors. This is a challenge that HFA is also considering in our local environment. Other novel products such as subcutaneous antibodies and oral treatments are also in different phases of development.

As I was hearing about products in development I reflected on how pleasing it is that Australians with bleeding disorders have had access to clinical trials if they wanted to participate in recent years, and are familiar with some of the newer options. Keep in touch with your haemophilia centre to hear about new opportunities for new treatments or clinical trials.

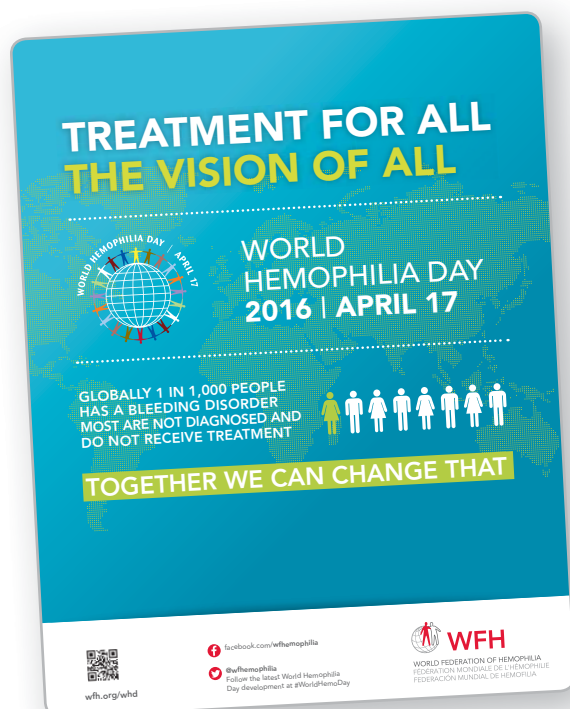
Warm regards,

Sharon

Executive Director, HFA



HAEMOPHILIA FOUNDATION AUSTRALIA



“Speaking of ‘Global’..

Imagine combining your support, with a celebration.

Well, look-out... a Global Feast is coming!

More info in National Haemophilia



Since our last Factor Matters another World Aids Day passed, 1st December 2015.

With this in mind, we acknowledge the longstanding work of Dr Roger Garsia, and "the team" he shaped & lead.



Dr Roger Garsia

When mysterious cases of HIV shook Australia in 1982, Dr Roger Garsia was among the first to establish HIV services at RPA. He was also instrumental in the development of NSW HIV policy and strategy, chairing the statewide advisory committee, and

advanced our understanding of the disease through epidemiology, clinical, social and virology research.

His enormous contribution over the past 30 years was recently acknowledged at a ceremony marking his retirement from his post at Sydney Local Health District.

Having served as a senior Staff Specialist in immunology since 1978, Associate Professor Garsia will now become Associate Dean of the Central Clinical School at the University of Sydney.

"Roger was a powerful advocate for the establishment of the Needle Syringe Program, and for innovative and multidisciplinary models of care for people with HIV," Chief Executive Dr Teresa Anderson said. "I know he is very proud to be the medical director of our HIV dementia residential care service at Yaralla House, which is the only service of its kind in the world."

Associate Professor Garsia was overwhelmed by the ceremony, attended by NSW Health Protection Director Dr Jeremy McAnulty and the Chief Executive of Positive Life NSW, Craig Cooper.

"It has been a huge honour to have worked with such remarkable colleagues since the beginning of the



HIV epidemic. I am proud to have played a role in the dramatic improvement in the outlook for people with HIV," he said.

In his new role, he is looking forward to taking interdisciplinary care into interdisciplinary teaching by changing curricula and teaching environments for medical and other health science students. "I'm so glad that I'll still be able to work alongside colleagues from the District and HIV sector."

Assoc. Prof. Garsia oversaw the clinical care of affected bleeding disorder patients from the time of their diagnosis with HIV onward.

When approached to be included in this edition of 'Factor Matters', Roger graciously replied he was "honoured" by our acknowledgement, but insisted, **"please emphasize that the teamwork in the centre has been the cornerstone of its success."** At the first clinic back in October 1984 we had a social worker, specialist in psychological medicine and myself involved."

Dr Garsia is planning to continue working with the bleeding disorder patients in the RPA Haemophilia Clinic on the fourth Monday of the month.

Meanwhile, Dr Melissa Corr (psychiatrist) will continue to be involved.

Dr Fred Lee will be looking after patients who attend the Immunology Clinic.



Dr Melissa Corr & Dr Fred Lee

(HFNSW would also like to thank SLHD 'Health Matters' (Sydney Media) for sharing much of the above event with us. Editor)



Health
Sydney
Local Health District



World Haemophilia Day 2016

Support **your** Foundation!

HFNSW Family Camp 2016
Save the dates 11, 12 & 13 Nov

HFNSW Annual Membership
now \$20
(see p15 for details and
all that it covers)

World Haemophilia Day
17th April
Keep an eye on HFA's website
& Facebook page
for information on events like
Light it Up Red! & Global Feast

WFH 2016 World Congress
Orlando USA
July 24-28
(see our back cover)

Congratulations to
Delphine & F-M on the
birth of Maylise, 27/11/15,
'Adien' & Best Wishes for
your return to Europe.



Congratulations to
Sam Linnenbank
On his successful
Go for it Grant



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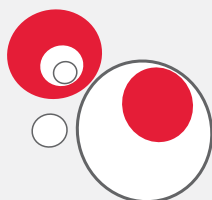
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HFNSW MEMBER SERVICE

Membership \$20 (inc. GST)

HFNSW Annual Family Camp: free of charge for people with bleeding disorders and their families

Newsletter: Your quarterly newsletters from HFNSW and HFA offers information and details of events, personal stories, education, treatment information etc.

Financial Assistance: MedicAlert Bracelets, Shoe rebates, Travel assistance, Education & Training, grants.

Information and Support:

-Education and assistance to members with bleeding disorders and those who also have HIV

-Provide tutors and entertainment to members who might require extended hospitalisation

-Information and social activities for members and their families

-Rural visits to areas of NSW where there are no specialists

HFNSW COMMITTEE...

... is always interested in hearing from its members, community, friends and family. If you want to have a say in how the Foundation delivers its service and shapes its future, please contact the office at coordinator@hfnsw.org.au

Committee meetings held monthly



WFH 2016 WORLD CONGRESS

Orlando, USA · July 24-28

THE LARGEST INTERNATIONAL MEETING FOR THE GLOBAL BLEEDING DISORDERS COMMUNITY

Sign up for the newsletter at www.wfh.org/congress

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FEDERACIÓN MUNDIAL
DE HEMOFILIA
2016 CONGRESO MUNDIAL
24-28 DE JULIO



NATIONAL HEMOPHILIA FOUNDATION
www.hemophilia.org



WORLD FEDERATION OF HEMOPHILIA
Fédération mondiale de l'hémophilie
Federación Mundial de Hemofilia