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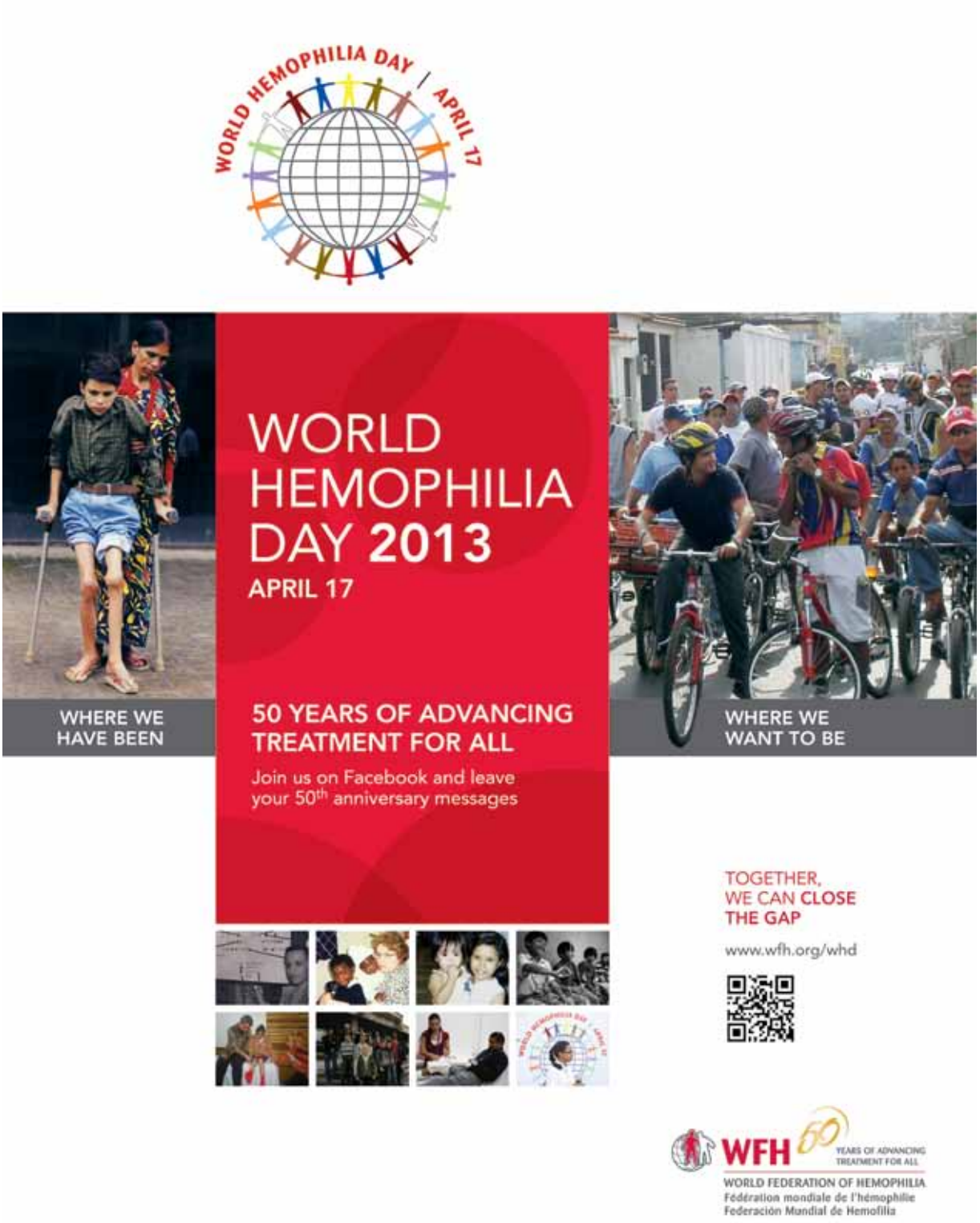

CLOSE THE GAP

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HFA ANNUAL REPORT

Haemophilia Foundation Australia's Annual Report 2012-2013 is available for download from www.haemophilia.org.au. For a hardcopy, call HFA on 1800 807 173.

KEEPING UP-TO-DATE WITH HFA

HFA has made it simple to keep up-to-date with the latest on bleeding disorders.

There are different options that you can choose from, depending on your preferences.

HFA E-NEWS

If you like the latest news to come directly to your email inbox, you can register for the HFA email newsletter.

The HFA e-news has articles of interest to the Australian bleeding disorders community – including the electronic version of *National Haemophilia* - and is circulated free of charge around 12 times a year to anyone who registers.

HOW TO REGISTER

- Go to the HFA web site www.haemophilia.org.au
- Click on SIGN UP FOR NEWSLETTER (top right)
- Enter your name, your email address and tick the box to RECEIVE UPDATES BY EMAIL, then SUBMIT
- OR, contact HFA on hfaust@haemophilia.org.au and ask to go on the e-news mailing list.

NATIONAL HAEMOPHILIA MAILING LIST

If you would like to receive a print copy of *National Haemophilia* as well as the email newsletter – or instead of the e-news - you can also ask to be added to the *National Haemophilia* mailing list. *National Haemophilia* is circulated free-of-charge to mailing list members every three months.

Just contact HFA on 1800 807 173 or hfaust@haemophilia.org.au and ask to be added to the print mailing list for *National Haemophilia*.

HFA FACEBOOK PAGE

And if you like to know what is happening as it happens, you can join an active community on the HFA facebook page. It's an opportunity to connect with HFA activities, like Red Cake Day or the World Congress, ask questions, make comments and receive instant updates on new HFA publications and other information.

You can find a direct link to the HFA facebook page on the HFA web site – www.haemophilia.org.au.

Gavin Finkelstein is President, Haemophilia Foundation Australia (HFA)

FROM THE PRESIDENT

CLOSE THE GAP
Campaign 2012•2014

Gavin Finkelstein

During this year and in the lead up to the 2014 World Congress you will hear a lot about the work of World Federation of Hemophilia (WFH). Partly, this is because of our increased involvement as we support WFH to run the Congress in Melbourne in May 2014, but also because WFH is moving forward with very clear and identifiable objectives on its very strong program to improve treatment and care to countries where it is inadequate or unavailable to help achieve this.

Most of our *National Haemophilia* readers will be aware of some aspects of the work of WFH and how it has made an amazing difference to the lives of people living with bleeding disorders and their families around the world. For countries like Australia with an adequate supply of safe treatment products we are fortunate that we can turn our minds to supporting best practice. This involves making sure product is used in the best way, that our community is accountable and that we work with stakeholders to make sure we have good processes in place to evaluate our systems and to find ways together to make sure it is flexible to meet changing needs and, of course, to consider ways to ensure it is sustainable. We know treatment is not just about clotting factor and we now have the have opportunity to work with our treating health professionals to make sure people look after themselves in the best possible way, and that we have a world class system for delivery of services and care. I believe My ABDR will be the next critical step towards this and I look forward to our work on this together.

WORKING TOGETHER WITH WFH

Many of our readers have been involved with WFH as volunteers either in the past or they may currently participate in WFH programs.

A number of Australians who have held key roles in the development of haemophilia care and treatment in Australia worked hard for WFH and this work has been built on over the years. This includes Jenny Ross who was the Executive Director at HFA for many years until her retirement in 2001 and Dr Kevin Rickard, director at Royal Prince Alfred Hospital, in Sydney and now Patron of HFNSW. Some of our Australian health professionals and people with bleeding disorders have been or are currently involved in WFH twinning programs, but others are involved in multidisciplinary and advocacy programs, congresses and meetings or WFH fundraising activities. We are grateful for their input and support to WFH. Recently Sharon Caris, HFA Executive Director joined WFH staff as a presenter in an Advocacy In Action program in Malaysia which was attended by representatives from National Member Organisations in Asia and South East Asia. Many of you know Rob Christie who recently served on the WFH Executive Board as Vice President Finance, and A/Prof Alison Street as the WFH Vice President Medical for many years. There are many ways we can support WFH, and HFA does this in various ways, as does its volunteers.

We are grateful for the input of so many people who help with the work of WFH or who have helped it to grow to its current capacity. I think one of the great successes of WFH is how it has harnessed the expertise of so many volunteers to shape the policy and programs it now provides.

So many of these programs are designed to help specific communities use skills and knowledge to their benefit in their local environment. HFA constantly benefits from the experiences of other National Member Organisations which share their experiences and successes.

CLOSING THE GAP

I believe one of the most ambitious and far-reaching of WFH projects is the Global Alliance for Progress (GAP) in haemophilia which is a 10-year healthcare development project, launched by WFH in 2003. GAP's goal is to greatly increase the diagnosis and treatment of people with haemophilia and other bleeding disorders in developing countries. The project aims to close the gap between the number of people born with haemophilia and those who reach adulthood, the gap between the estimated and actual number of people diagnosed with haemophilia, and the gap between the amount of treatment product needed and what is available. Great progress has been made and so many more people have been able to access treatment around the world.

As regional co-chair of the WFH Closing the Gap campaign, I am committed to raising awareness and increasing support in our region for this important project. I hope that you will join me to give your support on this to WFH and our regional national member organisations so that together we can make a difference to closing the gap.

WFH has developed a series of videos about its work and I recommend that you look at them. These videos demonstrate the valuable work of volunteers and staff of WFH over the years and the changes that have occurred. Please check out the WFH web site and see for yourself what WFH's 50 years history has achieved. You will also notice the video which welcomes people to Melbourne for the World Congress in May 2014. www.youtube.com/user/WFHcommunications#

WFH 2014 WORLD CONGRESS

THE LARGEST INTERNATIONAL MEETING FOR THE GLOBAL BLEEDING DISORDERS COMMUNITY

MELBOURNE, AUSTRALIA · MAY 11-15

FEDERACIÓN MUNDIAL
DE LA HEMOFILIA
2014 CONGRESO MUNDIAL
11-15 DE MAYO

www.wfh2014congress.org

Hosted by / En colaboración con:

HAEMOPHILIA FOUNDATION AUSTRALIA

Organized by / Organizado por:

WFH 50 YEARS OF ADVANCING TREATMENT FOR ALL
WORLD FEDERATION OF HEMOPHILIA
Fédération mondiale de l'hémophilie
Federación Mundial de Hemofilia

MELBOURNE CONVENTION AND EXHIBITION CENTRE
11-15 MAY 2014

This is the first time Congress is to be held in Australia! We have already commenced work with the World Federation of Hemophilia (WFH) to make it the best Congress ever for the 5,000 delegates expected to attend. Committees have been formed and have been meeting. The program is shaping up to offer rich and informative topics in the Medical/ Multidisciplinary program. HFA and our broader communities are playing a key role to assist WFH with the organisation, and we have also formed a local planning committee to make sure we make the experience a great one for Australians and New Zealanders.

We are honored to announce that the Congress President is Gavin Finkelstein and the Honorary Congress President is A/Prof Alison Street.

CONGRESS ORGANIZING COMMITTEE

Chair:
Alain Weill - WFH

Members:
John E. Bournas - WFH
Sharon Caris - HFA
Rob Christie - WFH
Gavin Finkelstein - HFA
Ann Roberts - HFA
Dr John Rowell - HFA
Eric Stolte - WFH
Deon York - WFH
Jens Bungardt - Congress and Meetings Manager (observer) - WFH
Natashia Coco (observer) - HFA
Michel Patte - Director Finance and Administration (observer) - WFH

MEDICAL COMMITTEE

WFH Nomination:
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HFA Nomination:
Dr Chris Barnes - Australia

Medical Committee Members:
Nigel Key - USA
Craig Kessler - USA
David Lillicrap - Canada
Mike Makris - United Kingdom
Flora Peyvandi - Italy
Alison Street - Australia

SUB-COMMITTEE MEMBERS:

Angela Forsyth - MSK Chair (USA)
Sukesh Nair - Lab Chair (India)
Eduardo Rey - Dental Chair (Argentina)

MULTIDISCIPLINARY COMMITTEE

WFH Nomination:
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HFA Nomination:
Sharon Hawkins - Australia

Multidisciplinary Committee Members
Frederica Cassis - Brazil
Lixia Chen - China
Edwin Goh - Malaysia
Assad Haffar - WFH
Jennifer Laliberté - WFH
James Munn - USA
Declan Noone - Ireland
Bradley Radner - South Africa

LOCAL PLANNING COMMITTEE

Chair:
Ann Roberts (VIC)

Secretary
Natashia Coco (HFA)

Members:
Sharon Caris (HFA)
Dan Credazzi (NSW)
Jen Jeske (VIC)
Robert McCabe (WA)
David Stephenson (QLD)
Jonathan Spencer (TAS)
Maria Wensing (ACT)

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INFORMATION AND REGISTRATION

The Congress web site www.wfh2014congress.org is live. The web site is full of information to start preparing for your congress experience.

Get in early as early registration opens on May 11th and ends on November 11th.

Haemophilia Foundation Australia will be running a competition for all Australian and New Zealanders who register for early bird to win a prize of:

1 x Earlybird Registration

Return economy airfare

Accommodation voucher

Return airport transfers

1 x Gala dinner ticket

The competition will be launched in April and full terms and conditions will be published on our web site in April www.haemophilia.org.au.

CALL FOR VOLUNTEERS

We are looking for volunteers to help in a variety of roles in the weeks before and during Congress.

If you would like to express your interest in helping out, please contact Natashia Coco via email at ncoco@haemophilia.org.au or call 1800 807 173.

WORLD HAEMOPHILIA DAY 2013

TOGETHER WE CAN CLOSE THE GAP

The bleeding disorders community marks 50 Years of Advancing Treatment for All on World Haemophilia Day

On World Haemophilia Day, April 17, 2013, the global bleeding disorders community will come together to mark 50 years of advancing the cause for treatment and care for all people with haemophilia and other inherited bleeding disorders.

However, the stark reality still remains that 75 per cent of these people still receive very inadequate treatment or no treatment at all. This percentage is even higher for those with von Willebrand disorder and rare factor deficiencies.

World Haemophilia Day provides the global bleeding disorders community with the opportunity to raise awareness about where we have been, where we want to go, and that together, we can close the gap in care.

"One of the greatest benefits of participating in World Hemophilia Day is the recognition that our community is more powerful when we work together," said Alain Weill, World Federation of Hemophilia (WFH) President. "People from around the world will mark this day and raise awareness about the need to achieve Treatment for All."

On World Haemophilia Day, Haemophilia Foundation Australia will be hosting a morning tea to mark this special day and the 50th year celebrations. If you would like to attend HFA's morning tea please contact Natashia Coco on 1800 807 173. For local events, contact your local Foundation.

During the week, WFH is asking National Member Organisations and the community to share hopes and wishes for the next 50 years through a video message or post on their facebook page - www.facebook.com/wfhemophilia.

Join the international bleeding disorders community on April 17 to mark World Haemophilia Day. Together, we can close the gap in care. For more information on World Haemophilia Day visit www.wfh.org/whd.

Penny McCarthy is Haemophilia Clinical Nurse Consultant at the Ronald Sawers Haemophilia Centre, Alfred Health, Melbourne

A TWINNING VISIT TO VIETNAM….. SAME SAME BUT DIFFERENT!!

Penny McCarthy

In October 2012 I attended my second 'twinning' visit to the National Haematology Institute for Blood Transfusion (NHIBT) in Hanoi, Vietnam. This was part of a four year formal agreement between the NHIBT and the Haemophilia Centre at The Alfred in Melbourne to work in partnership which has been organised by the World Federation of Hemophilia.

Education sessions at the twinning visit

WHAT IS TWINNING?

The Twinning Program of the World Federation of Hemophilia (WFH) was established more than 15 years ago. This program aims to improve haemophilia care in emerging countries through a formal, two-way partnership between two haemophilia organizations or treatment centres for a period of four years. Twinned organizations or haemophilia treatment centres work together and share information, resulting in a mutually beneficial partnership. It is a great way to transfer expertise, experience, skills, and resources.

Source: World Federation of Hemophilia www.wfh.org

In Vietnam the physicians and physiotherapists are well trained in western-style medicine; however, the nurses have not had the same access to education. Traditionally Vietnamese nurses had been taught by physicians, becoming very skilful proceduralists but without the emphasis on developing professional nursing expertise.

This is defined by the Royal College of Nursing as "the use of clinical judgement in the provision of care to enable people to improve, maintain, or recover health, to cope with health problems, and to achieve the best possible quality of life, whatever their disease or disability, until death."[1]

The visit consisted of a team from The Alfred of two haematologists, Associate Professors Huyen Tran and Alison Street, a haemophilia physiotherapist, Abi Polus, and me, a haemophilia nurse. We spent five days teaching and conducting workshops to assist this emerging Haemophilia Treatment Centre to improve diagnosis and treatment for people with inherited bleeding disorders. While my colleagues were running parallel workshops, if we had time we chipped in and did what we could to give each other a hand. This was particularly the case with the physiotherapy sessions, as so many patients had questions about the exercises.

My brief was to assist the nurses to prepare a program to educate their patients and families for the introduction of 'home therapy' to those who could afford factor concentrate. This was to give people with haemophilia access to early treatment which is essential in haemophilia care. The aim was for the people with haemophilia to initiate treatment at home and then proceed to the hospital.

The nurses needed to be confident in preparing the patient, or parent, for what is essentially a medical procedure to be performed by the patient at home.

The education included recognising a bleed; when to commence treatment; storage, reconstitution, and administration the factor concentrate, and - the hardest skill of all for a patient or parent – intravenous (IV) cannulation with a butterfly needle to themselves or their child.

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Penny McCarthy, Abi Polus and Huyen Tran under the Welcome banner at Hanoi

Waiting for outpatient appointments

It was important the nurses understood the need to set up the policies, structure and guidelines required to support these programs.

The plan was to conduct a workshop, and also spend time in the wards with the nurses. This looked good on paper - however, we take for granted how easy it is to be nurse in Oz!

Normal staff patient ratio on the haemophilia ward in Vietnam was four nurses to care for 30 inpatients and between 20 and 30 outpatients, both adults and children, all requiring treatment with either factor concentrate or cryoprecipitate. The Haemophilia Unit takes up half a floor of this new hospital. Most of it is six-bed wards. Adults and children share rooms. Only one room has air conditioning, but that was an extra cost. In fact the patients had to pay for everything including food, medicines, band-aids® and needles! The outpatient treatment room had six beds, but there were often three to four people in each bed as there was no other seating.

The nurses had little if no English language, which was a challenge for their education.

The doctors had translated the basic information on haemophilia into Vietnamese, which they had learnt well, but none of it was on nursing care. An eye opener for me was the realisation that nurses could not easily access information on the internet as most of the articles are in English. For the nurses to be released from their duties to attend the sessions was not an easy task, but they were keen and many came in from leave.

I was so impressed by this group of nurses. With very limited basic equipment the patients were beautifully cared for. The Vietnamese nurses were very skilful at gaining IV access, often using needles that were not made for IV use but was the only equipment available. I was also impressed by the people with haemophilia, particularly the children who would sit still while these painful procedures were being performed.

The people with haemophilia and their families showed incredible patience and resilience. They would spend hours and hours waiting for treatment, often sharing a bed due to overcrowding.

Moreover, the treatment was only whatever they could afford. The local haemophilia foundation had set up a library for the children to use while they waited. There were no televisions or toys to play with other than a chess board. You can imagine their delight when we gave out red HFA balloons to play with. However, at 5 o'clock much of the hospital shuts down, and the patients are allowed to turn on the television as the electricity demands are less at this time.

The trip was exhausting but so much fun! There was lots of hand waving and laughter but with some fabulous interpreters I think I fulfilled the brief. Hopefully the nurses are better prepared to teach the people with haemophilia and their families all about home therapy!

I always learn so much working in these challenging environments and I look forward to my next visit to spend more time with this wonderful team.

REFERENCES

1. Royal College of Nursing. Defining nursing. London: RCN, 2003. <www.rcn.org.uk>

THE VISION AND LEADERSHIP AWARDS

The HFA *Vision and Leadership Awards* is an awards program funded by a grant from Pfizer Australia to enable people who are affected by a bleeding disorder to seek and achieve new goals.

People affected by haemophilia, von Willebrand disorder and other rare inherited bleeding disorders of all ages are eligible to apply.

This is a chance for you to do something you have always wanted to do, but has not been possible because you have not had the financial resources to support your goal. It could be for an education activity or special project to enhance your personal development or career, or to attend a conference or program to develop new skills for leadership and participation in the bleeding disorders community.

WHAT WOULD MAKE A DIFFERENCE IN YOUR LIFE?

Up to five Awards of $2,000 are available for applicants in either of the following categories:

- Young men and women aged 15-25 who have a bleeding disorder or who are affected by bleeding disorders
- Adults aged 26 yrs and over (men or women) with a bleeding disorder or who are affected by a bleeding disorder

APPLICATION PROCESS

Further details and application forms are available on the HFA website www.haemophilia.org.au or the HFA youth website www.factoredin.org.au .

Alternatively you can request an application form from HFA – email hfaust@haemophilia.org.au or telephone 03 98857800.

CLOSING DATE

Closing date for applications: 17 May 2013

2013 'CHANGING POSSIBILITIES IN HAEMOPHILIA®' GRANTS

Following the success of the 'Changing Possibilities in Haemophilia®' grant program in 2012, applications are now being sought for 2013 grants.

Sponsored by Novo Nordisk Australia, and judged by an independent, multidisciplinary panel of haemophilia experts including Haemophilia Foundation Australia, the program encourages healthcare professionals to develop innovative projects for the benefit of their patients, beyond core service provision.

A total of $50,000 will be awarded to practical initiatives that demonstrate the potential to advance haemophilia care.

The 2013 grant program will be open to all healthcare professionals currently providing haemophilia care including nurses, physiotherapists, psychologists and social workers.

"The three recipients last year had initiated cost-effective and tangible projects that could potentially be implemented in other treatment centres, and improve outcomes for people with haemophilia as well as their carers and families," said Dr Simon McRae, Director of the Haemophilia Treatment Centre at the Royal Adelaide Hospital and member of the judging panel. "We look forward to unearthing more exciting work among the 2013 applications."

Submissions for 2013 'Changing Possibilities in Haemophilia®' grants will be accepted from **15 April 2013 until 31 July 2013.**

For more information, and to download an application form, visit: www.changingpossibilities.com.au

This article is abridged from the online article "Test takers", published in *Hemaware*, the magazine of the National Hemophilia Foundation, USA, in October 2011 and is reprinted with permission - www.hemaware.org/story/test-takers

MOLECULAR GENETIC TESTING AND HAEMOPHILIA

Heather Boerner

Leah Brunnings was a healthy 7-year-old when her 10-month-old brother, Zachariah, was diagnosed with severe haemophilia A. It was 1987, and her parents were baffled. As far as anyone knew, no one in the family had the disorder. Leah's mother wondered if it could be a new genetic anomaly or if the gene had been in the family tree for generations without anyone knowing it.

In 1998, the family got its answer when Leah's mother signed up to participate in a clinical trial on haemophilia genetics. Through the trial, the entire family was able to be tested. It turned out Zack's haemophilia wasn't a fluke. Leah's mother was told she had a deletion in her genetic code that causes haemophilia, and Leah's test results showed she carried the mutation, too.

At the time, Leah filed away the information. She was "asymptomatic," which meant she showed no physical signs or symptoms of bleeding. At 18, children were not in her immediate thoughts. "I do remember thinking about the implications this would have on the future," she says. "I knew when I was ready to have kids, it would affect me."

Until more sophisticated testing methods were developed, many women in the haemophilia community had few clues about their carrier status. Before researchers began discovering the mutations that cause bleeding disorders in the 1980s, doctors tried to determine carrier status by measuring factor levels. The trouble was, that didn't always produce accurate results.

Through molecular testing, women and their families can now know with certainty their mutation.

The identification and diagnosis can help women make better health decisions for themselves and their families. For symptomatic carriers, the diagnosis can prompt them to seek appropriate preventive care or treatment for menorrhagia, dental and surgical procedures, and postpartum bleeding.

"Molecular testing has opened up a world of opportunity to provide a more definitive diagnosis," says Kristin Pauly-son Nuñez, MS, CGC, a senior genetic counselor at Duke University Medical Center in Durham, North Carolina. "A clear diagnosis gives women more control not only over their own healthcare, but also their reproduction."

HOW IT WORKS

Mutations in the gene that causes haemophilia are located on the X chromosome. Males have one X and one Y chromosome (XY), and females have two X chromosomes (XX). Males who inherit an X chromosome with a mutation in the gene (also known as a "change" or "alteration") have haemophilia. Females who inherit the mutation are carriers for haemophilia, unless both X chromosomes carry the mutation. In that case, they have haemophilia. Carriers can experience bleeding symptoms and can pass on the gene to their children. Although haemophilia is a hereditary condition, about 30% of the time it's caused by a spontaneous mutation (often in the maternal grandfather of the affected child) with no family history.

There are more than 1,000 mutations each that cause haemophilia A and haemophilia B—and more mutations are being discovered.

One type of mutation is an "inversion" of the genetic code, in which sections of DNA are reversed. Two inversions cause 40% to 45% of the cases of severe haemophilia A, says Connie Miller, PhD, team leader for clinical research at the Division of Blood Disorders at the US Centers for Disease Control and Prevention in Atlanta.

Another type of mutation occurs when there are changes to segments of the genetic code. Known as "missense" mutations, they hinder factor VIII (FVIII) and factor IX (FIX) proteins. A "nonsense" mutation causes a premature stop signal, which means that clotting factor protein production is halted prematurely. Nonsense mutations account for approximately 10-15% of haemophilia A and haemophilia B cases, which are typically severe. Other mutations include duplications, in which DNA segments are repeated, and insertions, in which extra pieces of DNA are added. Deletions are mutations in which part of the DNA is missing.

Testing a suspected carrier for the family's known mutation—performing what is called a targeted mutation analysis—often saves money because gene sequencing, which is necessary when the genetic mutation is unknown, can be expensive and can take some weeks to run.

Genetic carrier testing starts with a blood draw. Lab technicians use a centrifuge to separate the white blood cells, which contain the important DNA information, from the rest of the blood.

The proteins are removed from the cells, and the DNA sequences are extracted from the proteins using alcohol, explains Miller. Then, a technician makes copies of the DNA for the extensive screening to come. If the prescribing doctor suspects the haemophilia was caused by an inversion of the genetic code, the lab tech places the strands of DNA on a gel and passes an electronic current through it to separate the size of the fragments. How the strands break into pieces determines whether an inversion is present, says Miller.

If an inversion is not suspected or known, the lab tech applies "primers," manmade polymers that attach to different portions of the DNA double helix, to isolate the part where the mutation might exist. The genetic mutation is identified when that section of DNA is compared with a normal section of DNA.

REFERENCES

Pruthi RK. Hemophilia: a practical approach to genetic testing. Mayo Clinic Proceedings 2005;80(11):1485–1499

HAVE YOUR SAY ABOUT TREATMENT AND CARE!

Do you have a bleeding disorder - or are you the parent of a child with a bleeding disorder?

Want to have your say about bleeding disorder treatments or quality of life issues?

Taking part in research studies is one way to have your say and be heard.

Often we think of research as being clinical trials of new treatments, but research can also be asking for your input about your experiences and views on health care services, care and various types of treatment and medicines.

In Australia decisions about health services, treatment and care are strongly influenced by research in the area. If you participate in research, your contribution could lead to improvements for you and others in the future.

You can find out about current research studies on the HFA web site - www.tinyurl.com/HFA-participating-in-research.

Some research studies are face-to-face or telephone interviews, while others are online and are a quick and easy way for you to contribute.

It's your opportunity to make your views and experiences known!

Red Run Classic

The Red Run Classic will be staged once again on Sunday 19 May 2013 in Brisbane.

For more information or sponsorship opportunities contact Natashia on 03 9885 7800 or email ncoco@haemophilia.org.au.

Information will be on the HFA website once it becomes available www.haemophilia.org.au.

Dr John Rowell is a Haematologist at Pathology Queensland and Director of the Haemophilia Centre at Royal Brisbane and Women's Hospital

MOLECULAR GENETIC TESTING - AN AUSTRALIAN PERSPECTIVE

Dr John Rowell, Director of the Haemophilia Centre at Royal Brisbane and Women's Hospital, has a special interest in molecular genetic testing. He spoke to National Haemophilia about the development of molecular genetic testing in Australia and its outcomes for people affected by haemophilia.

When parents with no family history of bleeding disorders have a child with haemophilia, it can be very perplexing to understand how it happened. Medically it is described as a "spontaneous mutation" in the factor VIII or IX gene – but what does this mean?

Even for the person who has grown up with haemophilia themselves or in their family, it can be a challenge to grasp the complexities of genetics, mutations and haemophilia. Dr John Rowell explained some of the intricacies with haemophilia genetics and how molecular genetic testing has affected diagnosis and treatment in Australia.

NH: When does a "spontaneous mutation" occur?

JR: When we see a young child with haemophilia and there is no evidence of a family history, if a genetic mutation can be determined it is usually present in the mother. The genetic mutation may begin with the maternal grandfather, although the maternal grandfather's factor VIII or IX gene is usually normal. The mutation is actually present at the next step of inheritance – at the mother's conception - and originates from grandfather's sperm. There are millions of sperm produced all the time, so there is a greater chance of a mutation occurring at some stage.

NH: What is different about the genetic mutations causing haemophilia?

JR: To give an example, the common genetic mutation in the factor VIII gene is an alteration known as "intron 22 inversion", but it is relatively novel compared to other genetic diseases. How it works: there are repeat sequences within the factor VIII gene that are a 'long' way apart, and in the process of replication of DNA (deoxyribonucleic acid – building blocks of genetic code), parts of the DNA can be attracted to each other and they can cut and recombine the wrong way to create the inversion. This creates a shortened factor VIII message that translates to a non-functional protein, and this is what leads to the blood clotting problems that are symptoms of haemophilia.

NH: What happened in Australia before molecular genetic testing was widely available?

JR: Prior to molecular genetic testing, the process of determining whether an individual was a carrier was by constructing a family tree and testing factor VIII (or factor IX) levels. This gave a probability of being a carrier, but not definitive evidence.

It is important for women who may have had factor levels done in the early 80s to check with their Haemophilia Centre whether the blood test was a mutation test or just a factor VIII level. If just a factor VIII level was done it may be useful to have a molecular genetic test, as this may have significance for their daughters, who may be close to child bearing age.

NH: What has been the impact of molecular genetic testing on diagnosis and treatment?

JR: Molecular Genetic testing has been available in a variety of forms since the late 1980s. Initially the testing was limited to genetic markers associated with haemophilia. This meant that there was a possibility of a minimal error in the process to determine carrier status and genetic testing required a thorough counselling session with individuals having the test. As a result, testing was limited to those with severe haemophilia and family members who may be considering antenatal diagnosis.

In 1992 a novel genetic mechanism causing severe haemophilia A was identified – intron 22 inversion. This enabled accurate confirmation of the genetic mutation in up to 50% of those with severe haemophilia A and accurate diagnosis of possible carriers in their families.

As sequencing technology improved with automated machinery in the late 1990s and early 2000s, it became possible to accurately identify the remainder of those with severe haemophilia A and extend testing to individuals with mild and moderate disease.

Genetic testing has also helped us to understand haemophilia better. The Adelaide research group led by the late Dr John Lloyd and Dr Barney Rudzki investigated the role of genetic mutations in the factor VIII gene linking to variations in levels of factor VIII determined using different blood tests. Their observation accounted for some variations in clinical presentation or bleeding symptoms not previously explained.

Haemophilia is readily diagnosed by coagulation testing. However, genetic testing can enable more accurate diagnosis of specific genetic mutations, where the diagnosis may otherwise be missed or difficult to explain. For example, individuals with the genetic mutations identified by John Lloyd may have normal factor VIII levels when one test is used, yet have symptoms. Genetic testing can confirm that that they do in fact have haemophilia. There is also a variety of von Willebrand Disease (VWD) that is characterised solely by a low factor VIII level. Genetic testing which identifies mutations in the von Willebrand factor gene can more accurately diagnose this condition as VWD rather than haemophilia.

Genetic testing can also be used to predict the risk of inhibitor formation in those with haemophilia, and may impact on the choice of tolerisation therapy and its use. It can be particularly helpful to have genetic testing to identify individuals with mild and moderate haemophilia who may have an increased risk of inhibitors.

This allows the treating haematologist to consider alternatives with intensive monitoring or a more controlled approach with factor replacement therapy. This approach hopefully will reduce the development of inhibitors.

NH: How widely available is molecular genetic testing in Australia?

JR: In Australia most Haemophilia Centres now have access to factor VIII and IX genetic testing. However, sequencing factor VIII (or factor IX) through molecular testing is an expensive process, This may not be an appropriate option for all patients in all Centres, so while molecular genetic testing is widespread, it may not yet be standard practice around Australia. It usually takes some weeks to complete molecular genetic testing through sequencing, but if there was an emergency and this information was required quickly, the turnaround time can be sped up.

NH: Where do people undertake genetic testing?

JR: It is always a good idea to discuss genetic testing with the Haemophilia Centre first. If individuals decide to go ahead with testing, they may also be referred to a Clinical Genetics Service. It is important that a Haemophilia Centre is involved in the genetic testing rather than it being ordered by a GP as the Centre can also discuss the issues associated with bleeding and ensure a family tree is completed.

There are a lot of issues involved and the individual needs to understand the reason for genetic testing and consent to it, rather than be tested without their knowledge or full understanding. Childbirth is another critical time and if a carrier becomes pregnant it is important that she contacts the Haemophilia Centre for an appointment to discuss various issues including antenatal testing and delivery.

NH: What are the benefits of genetic testing?

JR: Genetic testing has a number of benefits for both patients and clinicians:

1. To accurately diagnose carriers - and enable individuals to make informed decisions about having children
2. To provide prenatal diagnosis and PGD (Pre-implantation Genetic Diagnosis)
3. To allow clinicians to consider management carefully in some persons with mutations with a high risk of an inhibitor
4. The genetic mutation may relate to the success of tolerisation procedure for those with haemophilia and inhibitors.

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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.

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

HOW TO SAFELY EXERCISE IN A GYM AND GET RESULTS

Abi Polus and Ian d'Young

Exercise is not just important when you are recovering from a bleed. A sedentary lifestyle (i.e. people who sit around a lot) is linked to decreased strength, balance and coordination, and this may increase the risk of injury and bleeding in people with haemophilia (PWH). 'Couch potatoes' are thought to be at a much greater risk of having a joint or muscle bleed when exercising or playing sport than people who are fitter.

Being fit, having strong muscles, good balance and a good pattern of movement is therefore considered to be protective for your joints: in other words you are less at risk of having a bleed in the first place. We all know about factor prophylaxis, but we call exercising to protect your body and reduce your risk of problems before they start 'prophylactic exercise'. It is very important for all PWH, regardless of whether you have had a joint bleed before or not.

Having exercise as part of your lifestyle keeps you fit and looking good, but also keeps your joints and muscles in their best possible condition, even if you already have joint damage from bleeding when you were younger. This means that by exercising regularly you do as much as you can to reduce the risk of having a bleed by keeping fit and strong, as well as helping your body recover fully after a bleeding episode.

BUILDING MUSCLE POWER AND FITNESS

Your muscles respond to the demands that you place on them. If you spend all day in front of a screen, you will have a body and muscles that are perfectly equipped for sitting. If you cycle for 30 minutes every day, your body will adapt to this. In order to get bigger, stronger, more powerful muscles, and increase your endurance, you need to increase the demands you put on them. This can be done in a variety of ways: using weights (own body weight, free weights, or machines), or repetitive use, for example, the recurring muscle actions used in walking, running, cycling, or using the cross trainer. If you want to lose weight then the energy you expend must be more than the amount you put in (the amount of energy provided by what you eat; calories and kilojoules are a measure of this energy). If you want to 'bulk up' then you need to increase the demand on your muscles in a way that is safe and will not increase your risk of bleeding.

The results you get from the gym depend not only on what you do, but how you do it. The speed and intensity of the exercise will influence which type of muscle fibres are recruited and the results that you get.

So what actually happens when you work out? In order to build muscle you need to load them to the point of hypertrophy (this is when the muscle mass - the size - will increase). What actually occurs is micro-trauma; small tears occur within the muscle tissue. These increase muscle growth as the tears give rise to an activation of a complex process of cells being activated, multiplying and travelling to the site of the damage and helping regeneration. This also results in inflammation to help contain and repair damage and 'mop up' the waste products. At the same time, hormones and cytokines, including growth hormone and growth factors are released, which help the muscles increase. Muscle hypertrophy occurs when the muscle goes through the processes of healing itself, not when you are actually working out. For this reason, rest between exercise sessions is essential.

If the demands on a muscle are too great, for example building up your exercises or weights or distance too fast or too lifting to much too soon, this will cause the muscle fibres to be overused and to tear too much. This can cause bleeding in the muscles.

In a nutshell; in order to increase your muscles you have to subject them to micro-trauma. If you subject them to too much you may cause a bleed or other muscle damage.

IMPACT ON JOINTS

Another thing to consider is the state that your body is currently in. Joints may be vulnerable to repeated impacting stresses that are above their ability to cope with. This is even more of an issue if the muscles are not working correctly to support the joint or if the joint already has damage. Again this may cause a bleed or worsen joint damage.

WHAT TYPE OF EXERCISE SHOULD PEOPLE WITH HAEMOPHILIA NOT DO?

The type of exercises prescribed should be considered. In building muscle, if the aim is to break down tear fibres in order to get hypertrophy, this may cause a bleed, especially if done too fast or with weights that are too heavy or with incorrect technique.

Additionally, overstretching a muscle may cause stress and potential bleeding to a muscle. If a joint is contracted or fixed it should NOT be stretched beyond its usual limit or into pain. This will cause a bleed and potentially further damage into the joint.

Contact sport is usually discouraged due to the increased potential for injury, although this is not always an absolute. Contact the local Haemophilia Centre physiotherapist for advice on contact sports.

Boxing training can be of great cardiovascular benefit but a blow should NOT contact you. Any sport where the aim is to land a blow on a client's body should NOT be done by people with haemophilia.

If you are recovering from orthopaedic surgery, post-surgical exercise regimes are encouraged, but be aware that rehabilitation may be slower than the non-haemophilia population for joint surgery.

It is recommended an assessment with a physio is performed prior to the gym program.

It is important to keep the muscles strong that surround joints with existing damage. It is also important to select exercises that are appropriate for the level of existing dysfunction that may be present. Ignoring previous injuries that have not been correctly rehabilitated or where damage is already established may make the joint vulnerable to further damage or bleeding. After an injury or bleed either in the muscle or joints, the surrounding muscles weaken rapidly due to immobility, as a response to pain, and inflammation. If these are not properly rehabilitated with physiotherapy and an exercise program they are unlikely to correct themselves. This is why it is important to make contact with your physiotherapist after any bleed and make sure that you rehabilitate back to the level where you can safely exercise.

Pre-assessment should involve identification and specific strengthening of weak muscles, identification and a stretching program for tight structures, correct timing of muscle activity, proprioception (feedback from the joints to the brain that help prevent injury) and balance.

If you have had a bleed or injury recently, your exercise program will be different when you are recovering from a bleed compared to when you are getting fit or playing sport. It is very important that you talk to your physiotherapist and rehabilitate the bleed properly before starting a new sport or exercise. Remember, doing too much too early can lead to another bleed.

You will need to start at a gentle level of exercise and gradually increase this as your body recovers after a bleeding episode. Exercise is very important, but it needs to be the right sort of exercise. Forget the idea 'no pain no gain'! It's 'NO GAIN WITH PAIN', so remember to tell your physiotherapist if an exercise is painful or if you are becoming tired or sore.

It is also important that when you start a new sport or exercise program you choose your day wisely. If you take regular prophylaxis, it is sensible to start a new exercise program on the days that you have your factor.

>>

Generally it is a good idea to administer factor an hour before you start your new program. Remember that taking factor the night before you exercise does not give you any protection!

If you have mild or moderate haemophilia and take factor 'on-demand' (i.e. only when you need it), then you may not need to take factor beforehand because your exercises will be gentle to start with and should not lead to any bleeding. Check with your Haemophilia Centre. Your physiotherapist can help to develop a sensible exercise program that is safe and suits you. It is important that you start gently, with the supervision of your therapist who can make sure that you are doing the exercises correctly.

WARMING UP

Before you start your exercise program it is very important that you prepare your muscles and joints. This helps to reduce the risk of injuries and will help you to perform your exercises better. Start by warming up your muscles and joints with a little 'cardio'. If you are exercising in a gym, use the treadmill, cross trainer, bike or rowing machine for around ten minutes. Alternatively, you can mix things up a bit and try a little time on each machine. Start gently, and slowly increase the intensity.

You will know that you are warmed up if you are starting to sweat and puff a little bit. If you are going swimming or plan to work on your arms in the gym, make sure you use your arms in the warm-up too! A cross-trainer, rowing machine or simply swinging your arms when you walk will get your arms as well as your legs ready for exercise.

STRETCHING

Once you start to get warm and puff a little bit, you are ready for part two of your warm-up: stretching. Muscle is a little bit like chewing gum. If you stretch the gum when it is cold, it can snap. In the same way, if you stretch a muscle when it is cold, it is much easier to have an injury. This is why making sure you have warmed up well before stretching is so important in order to lessen your risk of a muscle injury.

Don't let yourself cool down too much when you are stretching. Many people feel like taking off layers of clothing after spending time on the treadmill or bike. Try to avoid this – peel off layers after stretching, not before.

When you perform a stretch, remember that you should feel a gentle pull in the muscle, but it should not hurt. If your stretches hurt you are doing them too hard and you will need to check with your physiotherapist that you are doing them correctly.

When you first start your program, hold each stretch for 10 seconds but don't overdo it - stretches as part of a warm up shouldn't take too long and in most cases three stretches for each muscle group on each side is all you need to do. Eventually you will aim to hold your stretches for 20 seconds, however you may not get to this point for some time. Remember, do not push to pain – if it hurts, ease off!

Remember that as every person is different, every exercise program will be different and will need to be tailored to your needs.

WARMING DOWN

Once you have finished your program, it is important that you warm down to prevent stiffness in your muscles. When you start a new exercise plan, it is very common to feel a little muscle stiffness the next day. Physiotherapists often call this 'DOMS' or 'delayed-onset muscle soreness'. In most cases, this feeling of soreness the day after exercise only lasts for a short time and generally only in the first week or so of starting a new program.

By warming up and down sensibly, you can help to minimise this stiffness. Warming down simply involves repeating what you did in your warm-up, but this time, because you are already warm from your exercises you can start with the stretches and then finish with around ten minutes of 'cardio' – i.e. a brisk walk, riding your bike, or using the cross trainer or treadmill in the gym (or a little of each for variety!).

HOW OFTEN SHOULD I EXERCISE?

When you are recovering from a bleeding episode you will notice that your exercise program will be different compared to when you are exercising to move better or become fitter and stronger. This may be because you will need to rest certain parts of your body while keeping up with exercises to the unaffected parts of your body. In this situation your physiotherapist will tell you how often to exercise when you are recovering from a bleed or injury.

Generally young people should be active for around 60 minutes of daily activity in order to gain the health benefits of exercise; however, this can be a mix of both low and high-intensity exercise. For example, swimming or a gym program might be considered 'high intensity exercise', while a brisk walk around the park might be considered 'low intensity'. It is a good idea to have a variety of these types of exercise in your program, which will also help to keep things from getting boring.

If you are starting a new exercise program to improve strength, flexibility, balance or your cardiovascular fitness when you have not had a recent bleed or injury, then aim to repeat the program three times per week initially. Try riding a bike, having a swim or going for a brisk walk on the alternate days to add a little variety.

If you take regular prophylaxis, then do your exercises around an hour after you had had your factor initially. As you get fitter and stronger, you can gradually increase the number of times you do your program from three to five times per week and from there to every day. This doesn't mean you need to go to the gym every day, but repeating your exercise program 'little and often' can be a very useful way of making sure your body is in top shape.

WHAT ABOUT REPETITIONS?

The number of 'reps' you do for each exercise will depend on your own situation. Often this number will be determined by what is felt to be safe by your physiotherapist and by listening to your body.

If you start to feel discomfort this is normally a sign that you have done enough for the moment. Remember, when you are recovering from a bleed you may only be able to do a small number of reps.

Start slowly and gradually build up your program – it is much safer to build up an exercise program over two or three months than to start too hard and find you've had a muscle strain or another joint bleed.

One of the best ways to start is to use gravity or the resistance of your own body weight in very simple, practical exercises. You do not need to use expensive equipment, and generally the simple exercises are the safest. Don't be fooled though – simple exercises can also be very effective, as well as being easy to do at home.

LISTEN TO YOUR BODY

Be sensible and listen to your body. If your body is telling you that an exercise is hurting you or starting a bleed, listen! Never keep exercising through the pain – remember, it's NO GAIN WITH PAIN!

Every person is different and every person may react differently to a type of sport or exercise, so it is important that you listen to your body. If you notice a bleed or sustain an injury every time you ride your bike or go for a run, your body is telling you that this is not the right type of exercise for you. Talk to your physiotherapist about alternative sports or activities.

GOVERNMENT TO SUBSIDISE NEW HEPATITIS C TREATMENTS

Two new hepatitis C treatments will made available on the Pharmaceutical Benefits Scheme (PBS) by the Federal Government.

The Federal Minister for Health, Ms Tanya Plibersek, announced on 19 February 2013 that boceprevir (Victrelis®) and telaprevir (Incivo®) will be subsidised by the government for adults with hepatitis C genotype 1. This will make the treatment more affordable. If they were not available through the PBS, these medicines could cost individuals up to $78,000 a year.

"These breakthrough medicines represent new hope for patients with hepatitis C," said Ms Plibersek.

When combined with the current standard hepatitis C treatment of ribavirin and pegylated interferon, boceprevir and telaprevir can increase the cure rate for people with hepatitis C genotype 1 from around 40% to around 75%. The length of treatment can also be shortened to around 6 months for some people.

Even people with genotype 1 who have had unsuccessful treatment in the past see some improvements in success rates, ranging from around 30% for people who previously had a "null response" to around 75-85% for those who relapsed after treatment. However, there is also the potential for additional side-effects such as rash and anaemia and the new treatments require careful monitoring and management by the treating specialist.[1]

Haemophilia Foundation Australia (HFA) welcomes the announcement by the Minister for Health.

"These treatments are an important development for the bleeding disorders community and we have made a number of representations and submissions to the Government about them," said Gavin Finkelstein, HFA President.

"We are very pleased to hear that they will be available on the PBS. This will give some further treatment options to some members of our community who have been living with long-term hepatitis C infection and advancing liver disease. Many people with bleeding disorders who have hepatitis C genotype 1 have previously had unsuccessful treatment or have delayed treatment until more promising treatment options came along."

For more information about hepatitis C treatment, contact your local hepatitis or liver clinic or speak to your Haemophilia Centre.

REFERENCES

1.Dore DJ. The changing therapeutic landscape for hepatitis C. MJA 2012;196:629-632.

Desdemona Chong is Advanced Psychologist – Haemophilia at the Royal Brisbane & Women's Hospital

MINDFULNESS

Desdemona Chong

WHAT IS MINDFULNESS?

'Mindfulness' is currently a very popular concept in psychology in countries like Australia. It is simply becoming aware of your here-and-now experience in an attitude of openness, interest and receptiveness. Consistent use of mindfulness exercises has been shown to lead to positive outcomes such as reduction in stress, increased self-awareness and better emotional regulation. It has also been shown to reduce the impact and influence of stressful/painful thoughts and feelings on the individual.

For individuals living with an inherited bleeding disorder, this could be a very helpful tool for you to manage the added challenges that comes along with the condition.

WHY MINDFULNESS?

As an evidence-based tool, mindfulness training has shown benefits in common health issues like chronic pain, substance use, anxiety and depression. In fact, there is recent research showing that with as little as 20 minutes of daily mindfulness practice, the brain structure actually changes. Specifically, brain imaging studies indicate that the portion of the brain that sends messages of anxiety and distress slows down while the portion of the brain responsible for sending messages of calmness and comfort to the body actually becomes more active.

HOW TO DO IT?

Mindfulness exercises do not need to be done only in times of distress; they can be incorporated into your everyday routines, such as mindful walking or eating. By making a conscious decision to incorporate mindfulness in as many aspects of your everyday life as possible, you will begin to increase your ability to focus on everyday activities and increase your sense of control and choice over your life. There are countless mindfulness exercises available online and in audio formats. Check out a few today and see what suits you. Like any new skill, they need to be practiced and it is best to practice them BEFORE you really need them so that they are familiar to you.

FINDING OUT MORE

Information for this article was taken from the following web sites. Please also visit the web sites for more information about mindfulness and actual guided exercises to help you start on this journey.

ABC1. Making Australia happy: Mindfulness
www.makingaustraliahappy.abc.net.au/mindfulness.php

Harris, Russ. The happiness trap: Mindfulness
www.thehappinesstrap.com/mindfulness

Living Well. Tips for living well: What is mindfulness
www.livingwell.org.au/Tipsforlivingwell/Whatismindfulness.aspx

ONE MINDFUL EXERCISE

Source: Living Well.
5. Breathing mindfulness

<www.livingwell.org.au/Tipsforlivingwell/Mindfulness exercises/5BreathingMindfulness.aspx>

Exercise reprinted with permission from Living Well, www.livingwell.org.au.

BREATHING MINDFULLY

Background: The purpose of this exercise is to simply notice, accept and be aware of your breath – it is not about relaxation or stress reduction, although this may well occur. Breathing is something we all do – if you have a pulse then you breathe. Your body knows how to do this; it has done it since birth. This is simply about breathing mindfully. Breathing is something you carry with you everywhere; you are just not usually aware of it.

Sit quietly in a chair with both feet on the ground and your hands on your lap. Allow yourself to feel centred in the chair. Bring all of your attention to the physical act of breathing. Start to notice the breath as it enters your body through your nose and travels to your lungs. Notice with curiosity whether the inward and outward breaths are cool or warm, and notice where the breath travels as it enters and departs.

Also notice the breath as your lungs relax and you inhale through your nose. Don't try to do anything with your breathing – simply notice it, pay attention to it and be aware of it.

It doesn't matter if your breathing is slow or fast, deep or shallow; it just is what it is. Allow your body to do what it does naturally.

You will start to notice that each time you breathe in, your diaphragm or stomach will expand… and each time you breathe out your diaphragm or stomach will relax. Again, don't try to do anything – just be aware of the physical sensations of breathing in and breathing out. If you find that thoughts intrude, this is okay. Don't worry, just notice the thoughts, allow them to be, and gently bring your awareness back to your breath.

Start this exercise initially for 5 minutes, building up daily. You can also do this exercise lying down in bed if you have difficulty sleeping. It is simply a way of allowing you to have more mindful and conscious awareness of your body and its surroundings, its breathing and its capacity to relax. When our breathing relaxes our muscles relax.

Kate Walton is Haemophilia Foundation Australia Youth Project Officer

YOUTH PROJECT UPDATE

Kate Walton

FACTORED IN WEB SITE

Factoredin.org.au is proving to be a great way for young people affected by bleeding disorders to keep in touch with other young people in their community. Users are encouraged to tell their story and comment on other people's story, which enables them to make a connection with each other, regardless of which State or Territory they live in. Users can also ask questions, read the latest resources available to them and find out what's going on in their local area.

Competitions are a new initiative on Factored In and have been running on the web site since November 2012. Competitions are used as an instrument to attract young people to the website and encourage them to stay involved with Factored In. Featuring competitions on the web site was a suggestion from the Youth Working Group (YWG). They thought it was a way to have fun and at the same time help to build a strong youth presence in the bleeding disorder community.

The **Achieving your dream video competition** was to raise awareness for Haemophilia Awareness Week and saw young people making videos as competition entries addressing the theme.

The **Answer the question, Barry!** competition was run for five weeks between November and December 2012 and quizzed young people's knowledge about the content on the web site. All questions asked in this competition were based on information on the web site and required young people to read the resources and find the correct answer. Each correct answer received by HFA was put into a draw and 1 winner was drawn per question. The lucky winners received 2 movie tickets to a cinema in their local area. To enter both competitions you had to be a member of Factored In and this was a way to encourage young people to join the web site and read the resources available to them.

The **Question and Answer** section continues to be popular and I encourage people to use this function. Users are invited to ask questions about bleeding disorders, and they are then passed on to the relevant 'expert' to answer. Depending on the question they may be answered by a haemophilia doctor, nurse, physiotherapist, social worker or a YWG member. Factored In members can also comment on each other's questions or the answers. To date we have received questions about sport, a cure for haemophilia, vein issues and online apps for treatment diaries. There are currently also a few questions being answered by our experts.

Information on the web site has been developed to cover key topics requested by young people. New web pages include information about travel, and one on employment is almost ready for publication. The process for writing resources is thorough, and this is to ensure our readers are receiving accurate and up-to-date information.

CURRENT STATISTICS

Factored In was launched on 26 June 2012 and these statistics cover the period from 26 June 2012 to 31 January 2013.

The website currently has 62 members: 45 male/17 female

Visits to the site: 2110

Unique visits (a new user each time): 1175

Most visitors are from Australia, but the web site has also been visited by users in United States, United Kingdom, New Zealand, Ireland, France, Denmark, India, Canada, Brazil and Malaysia.

THE NEXT PHASE

The next phase of the HFA Youth Project is a leadership and mentoring program for young people based on some of the recommendations from the *Beyond Prophylaxis Needs Assessment* specifically around face-to-face contact, mentoring and developing a sustainable youth program.

The HFA leadership and mentoring program for young people has multiple aims for young people in our community but also for the bleeding disorder community at large. For young people the program's goal is to create an environment for peer support and provide them with the opportunity to have a 'voice' within their community. The program also aims to provide information and education for young people on personal development issues. At the same time, the program aims to benefit the broader community in the longer term by creating a sustainable and mutually supportive bleeding disorders community and fostering leaders for the future.

The leadership and mentoring program is well underway. Young people have been identified to join the program as leaders and mentors in most states through recommendations from State and Territory Foundations and health professionals.

The leaders and mentors will play a major role in the program by undertaking such activities as organising youth catch ups with the support of the Youth Project Officer and their State Foundation. They will also provide peer support to other young people with bleeding disorders and assist with the engagement of young people who are not yet connected with the community. Other tasks of the role include helping to sustain the Factored In website by becoming moderators, producers of content, providing online peer support and promoting youth activities in their State or Territory.

If young people are interested in being involved in the leadership and mentoring program they should keep an eye on Factored In for upcoming events and their State or Territory newsletters.

YOUTH NEWS

The "Question and Answer" section on Factored In has been popular with young people. The Youth Working Group and members of Factored In tell us why they like it and why it's beneficial for young people…

"It's really easy to use"

"We can remain anonymous for those really embarrassing questions"

"We can ask certain types of questions that our family or friends might not know!"

"We can see other people's Q & As, so we can learn things that we might not have known"

"We are able to have our questions answered"

CAN HAEMOPHILIA BE CURED

"Ask questions online in the relaxed and safe atmosphere of our homes"

IS SPORT GOOD FOR TEENAGERSWITH HAEMOPHILIA

ARE THERE ONLINE APPS FOR TREATMENT DIARIES

"The older guys on Factored In can help with experience questions"

"We cannot always go to the hospital/doctors etc. to ask these questions as some of us may be too young to drive or we don't own a vehicle."

"You can remain anonymous, I feel discreetness is needed for some medical questions."

HAVE YOU HEARD ABOUT THE HFA LEADERSHIP AND MENTORING PROGRAM FOR YOUNG PEOPLE? TURN TO PAGE 21 FOR MORE INFO

FACTORED IN
WWW.FACTOREDIN.ORG.AU

Andrew Atkins is Clinical Practice Consultant at the Haemophilia Treatment Centre, Royal Adelaide Hospital

Dr Simon McRae is Director of the Haemophilia Treatment Centre, Royal Adelaide Hospital

TEAM.FACTOR

Andrew Atkins and Simon McRae

On a balmy Friday summer morning on 25 January 2013, a group of fearless haematology staff from Royal Adelaide Hospital comprising of Haemophilia Centre Director Dr Simon McRae, haematologist Dr Uwe Hahn, haemophilia nurse Andrew Atkins and research nurse Donna King completed a massive 127km in the BUPA Challenge Ride. The BUPA Challenge Ride is part of the Santos Tour Down Under in Adelaide, the first stop on the world cycling calendar, and gives regular cyclists the opportunity to ride during a Union Cycliste Internationale World Tour event while fundraising for their favourite cause.

The group, also known as "the Haematology Warriors", competed as Team.Factor to fundraise for Haemophilia Foundation Australia. The team rode the same route on the same day as the elite cyclists in the Stage 4 of the Santos 2013 Tour Down Under in South Australia and cycled from Modbury, just north of Adelaide, to Tanunda in the Barossa Valley. The team did the ride in a very respectable 5 hours 10 minutes, starting at 6.40am and finishing at 11.50am.

A total of $2,025 was raised – thank you to all the supporters and most of all thank you to Team.Factor.

A very happy team at the finish

ANDREW ATKINS

Before the ride I was cautiously confident. We had mapped out the course and had trialled some of the course the day before, so we knew something of what to expect. It helped to be riding in a team, and to be with several thousand other people - the challenge seemed somewhat more achievable. The day was cool, about 25°C, which we were thankful for (the day before was 36°), but the wind was up and that made parts of the ride harder than we would have liked.

There had been so much build-up to the ride that the thought of riding 126km seemed awful. During the ride, it seemed to go surprisingly quickly. When we could we got behind a pack of riders who were going past at roughly our speed and we would be pulled along in the draught… those moments were few, though. The first 40-50 kms were mostly uphill and hard going. About two-thirds of the way into the ride we stopped at one of the 'refuelling' stations, and it was pretty hard to get the legs going when we set off again. Overall, I'd say it was easier than expected.

After the race, I was pretty tired, but happy with the training we'd done. We weren't as sore as we thought we were going to be. The adrenaline had really kicked in and kept us going and feeling good even after we'd finished. A few hours later, it was a different story…

DR SIMON MCRAE

I set out on the ride with some nervousness but was also reassured that I had ridden a similar distance the week before in training and hadn't exploded. We had been training for about 3 months, doing two to three rides a week in the month before the event, and riding around 100kms per week with one long 90km ride the week before. It was great to have training partners such as Andrew and Uwe to chase up the hills to keep me motivated, also the fact that some of my waistline was disappearing was a good incentive.

On the day it was great to be part of such a large group of riders all riding for different causes. The support along the route was great with people of all ages watching and encouraging, and plenty of food and drinks stops available if needed. The fact that we had a tailwind during the middle third of the ride was a big help, and meant the legs didn't get too wobbly along the way. Getting to the end was a great experience and finishing under the same finish line that the professional riders did was a good buzz. There were plenty of cold drinks, food and some entertainment at the finish line at Tanunda to enjoy, and catching up with the stories of the other riders in the team was great.

I can highly recommend getting on the bike as a way to achieve/maintain a degree of fitness, and a great motivation to get out of bed early on a weekend. We are planning to do the same ride next year and all are welcome to participate.

CALENDAR

WORLD HAEMOPHILIA DAY
17 April 2013
www.wfh.org

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

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

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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RED CAKE DAY

Haemophilia Awareness Week
13–19 October 2013
P: 1800 807 173 W: www.haemophilia.org.au

Last year we launched the inaugural Red Cake Day with Haemophilia Awareness Week which proved an overwhelming success!

We had incredible support from over 100 schools, hospitals, libraries, families and local communities across the country.

A range of different events were held and many organisations displayed promotional materials and information about bleeding disorders as well as hosting Red Cake Days.

Our aim, of course, is for it to be bigger and better in 2013!

To be kept up to date email your contact details to ncoco@haemophilia.org.au or call Natashia Coco on 1800 807 173.

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