

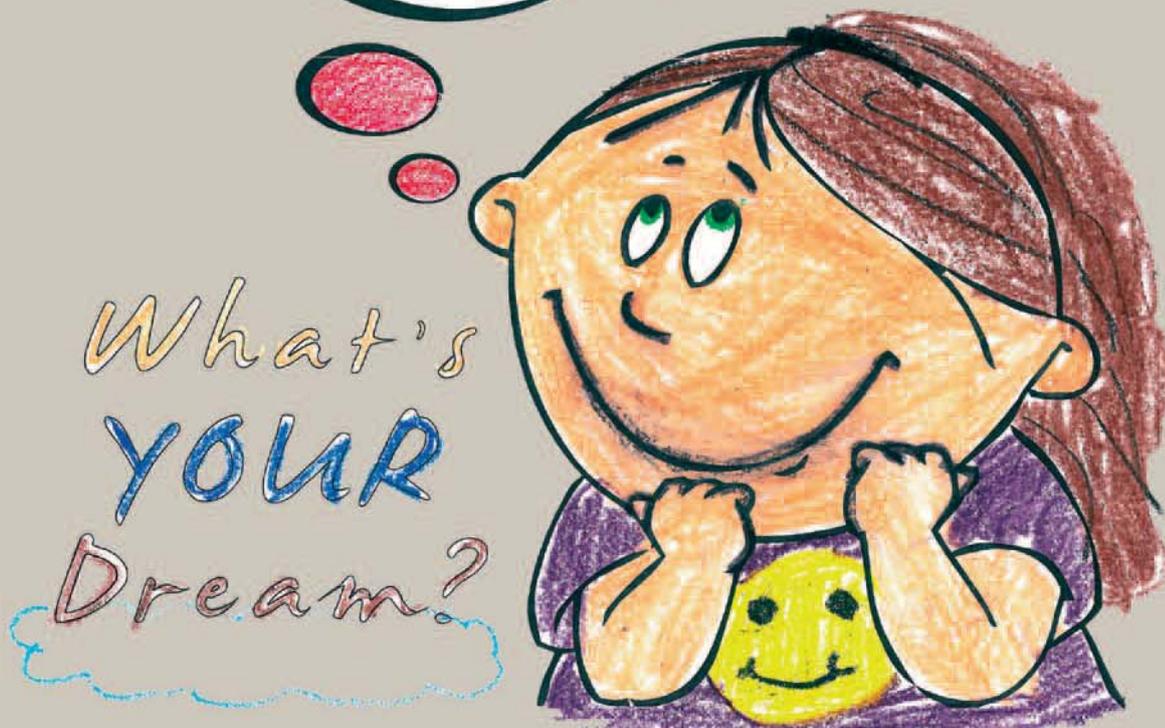
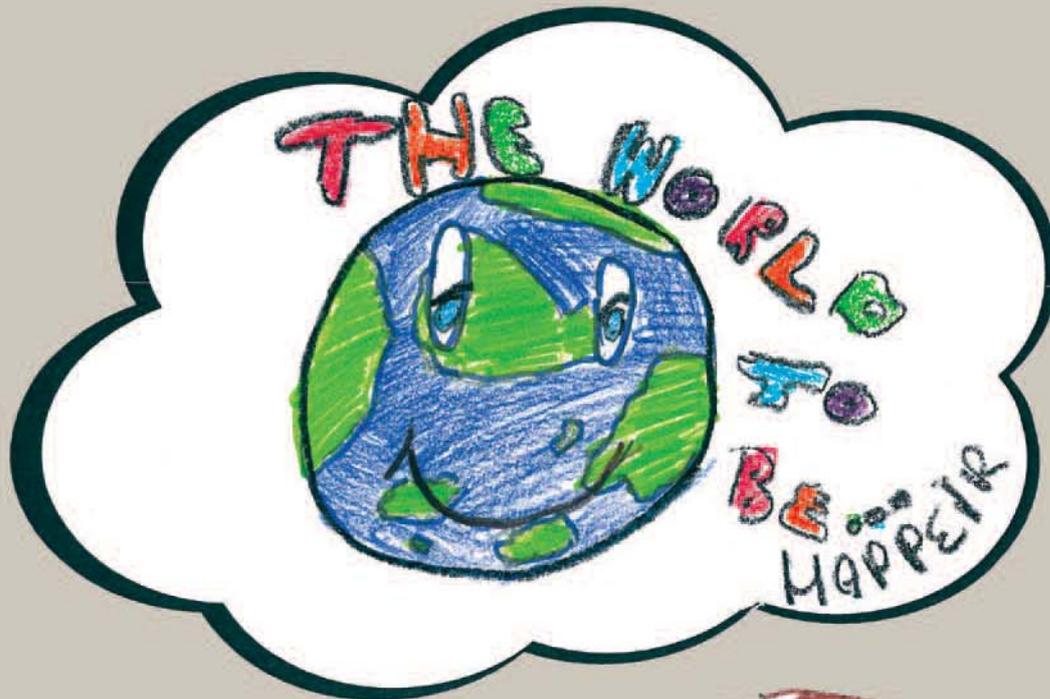
National Haemophilia

Haemophilia Foundation Australia

www.haemophilia.org.au

No. 180, December 2012

*Achieving
your dream*



HAEMOPHILIA AWARENESS WEEK

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MILD HAEMOPHILIA FACT SHEET

Although people with mild haemophilia may not have bleeding problems as often as others with moderate or severe haemophilia, this means that bleeding problems can be unfamiliar and people can be unsure about them.

How do you know what a "bleed" looks like? What do you do when you have an injury or bleeding?

What does your GP or dentist or surgeon or obstetrics team need to know? What else do you need to know?

HFA has developed a short fact sheet on mild haemophilia to answer these questions. The fact sheet includes tips on managing mild haemophilia from people with mild haemophilia, women who carry the haemophilia gene and Haemophilia Centres.

The fact sheet has been developed and reviewed by two volunteer groups, one including people with mild haemophilia or women who carry the haemophilia gene, the other including expert haematologists and haemophilia nurses, social workers and counsellors and physiotherapists.

Our thanks to the volunteer review groups who made a major contribution to the development of the fact sheet.

Print copies of the fact sheet can be ordered from HFA by emailing hfaust@haemophilia.org.au or calling 1800 807 173.

The fact sheet can also be downloaded from the HFA web site www.haemophilia.org.au/publications/mild-haemophilia

MILD HAEMOPHILIA FACT SHEET

If you have mild haemophilia it may have little impact on your life so long as you know what to do, how to manage it, and what you should tell the professionals who provide your health care.

Haemophilia is a rare genetic health condition, often inherited, where a person's body has problems forming blood clots. It results from not having enough clotting factor in the blood. A clotting factor is a protein in blood that helps control bleeding.

If a person with haemophilia has an injury causing bleeding, they may bleed for longer or their blood will clot more slowly than other people.

What type of haemophilia?

If you or your child has haemophilia, it is important to know what type of haemophilia it is.

There are two types of inherited haemophilia. Each type needs a different clotting factor treatment. Both have the same symptoms.

- Haemophilia A: lower than normal levels of clotting factor VIII (F)
- Haemophilia B: lower than normal levels of clotting factor IX (F)

Obtain the multi-sized treatment card from your Haemophilia Centre. This has:

- Brief details about your or your child's diagnosis and type of haemophilia
- Recommended treatment
- Who to contact in an emergency.

Keep this card on you and show it to doctors, nurses, ambulance officers and other health professionals who provide you or your child's care.

What is mild haemophilia?

In Australia about half of all people with haemophilia are the mild form. They people with mild haemophilia rarely have bleeding problems.

People with mild haemophilia generally have between 5% and 40% of clotting factor VIII or IX in their blood. This is usually enough to protect against bruising and minor injury. The level in a 'normal' person (without haemophilia) is usually between 50 and 100%.

People with mild haemophilia may only have bleeding problems requiring treatment when they have a serious injury or wound – for example, after an accident, surgery or dental extraction. If they have not had any injuries or operations, people might not be diagnosed with mild haemophilia until they are older.

Who has haemophilia?

The haemophilia gene is sex-linked and nearly all people who have haemophilia are male. Haemophilia does occur in females, but is very rare. However, some women and girls who carry the haemophilia gene also have bleeding problems. If females with bleeding symptoms have low levels of clotting factor in their blood, with levels in the range for mild haemophilia, they are sometimes described as having mild haemophilia or as being "symptomatic carriers".

Common physical signs of mild haemophilia in males and females

- Bruising easily
- More painful swelling and bruising than you would expect after an injury, eg falling off a bike, car accident, football injury
- Bleeding for an unusually long time with wounds or after surgery, dental extractions or medical procedures that cut or scrape any part of the body.

And also for girls and women

- Heavy and/or long menstrual periods
- Heavy bleeding for an unusually long time in the weeks after childbirth.

Treatment

Haemophilia treatment helps the blood to clot normally and stop the bleeding. If internal bleeding is not stopped quickly with treatment, it will result in pain and swelling. Without treatment, any continued bruising and swelling may cause further problems. Treatment can include the drug desmopressin (DDAVP) for haemophilia A, or factor VIII (F) or IX (F) concentrates. You or your child might need testing beforehand with DDAVP to determine the optimal treatment. Not all hospitals have these products, so you might have to wait for treatment or go to a larger hospital. If you have any concerns, ask the doctor to contact the Haemophilia Centre or a Clinical Haematologist directly. Treatment can also include other ways of treating symptoms, rest or physiotherapy.

Where to go for help with mild haemophilia

Register with your local Haemophilia Centre and let them know if your contact details change. Stay in touch regularly for a treatment plan specific to you or your child's needs and can teach you how to manage you or your child's mild haemophilia. There is at least one Centre in every Australian state or territory located in a major public hospital. Haemophilia Centres have a team of health professionals who specialise in haemophilia care and treatment, including doctors (haematologists), nurses, social workers, physiotherapists and laboratory services. See www.haemophilia.org.au or phone 1800 807 173 for details.

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TEAM.FACTOR

2013 BUPA CHALLENGE TOUR ADELAIDE FRIDAY 25 JANUARY

Cycling enthusiasts from around Australia and the world are now registering to participate in the 2013 BUPA challenge tour on Friday 25 January. Cyclists will have the opportunity to ride the same route as competitors in the 2013 Santos Tour Down Under.

The route from Modbury, just north of Adelaide, to Tanunda in the beautiful Barossa will give cyclists the opportunity to challenge themselves just hours before the professionals take to the same route. The full route from Modbury to Tanunda is 127 kilometres, while the second start from Kersbrook is a 92 kilometre ride.

The third start from Mt Pleasant is 46.5 kilometres from the finish line at Tanunda.

For all you cyclist enthusiasts out there, join TEAM.FACTOR and participate in this amazing race. The team will be headed by Dr Simon McRae and will support Haemophilia Foundation Australia.

For registration and information visit www.tourdownunder.com.au/event-details.htm

When registering ensure you answer yes to being part of the team and the team code is BCT285

Will you be entering as part of a team? YES NO

What is the team code? BCT285

For more information contact Dr Simon McRae simon.mcrae@imvs.sa.gov.au or phone 08 8222 6840

FROM THE PRESIDENT

Gavin Finkelstein

As we have almost come to the end of 2012, Haemophilia Foundation Australia (HFA) has been reviewing activities and outputs for the year and confirming plans for 2013. It has been a busy year – amongst other things we have developed several new education resources for different parts of our community, launched our new youth web site www.factoredin.org.au, and commenced work with World Federation of Hemophilia in preparation for the upcoming WFH 2014 World Congress to be held for the first time in Australia. This is the major medical and scientific congress on bleeding disorders and we are encouraging as many Australians as possible to take up the wonderful opportunity of having the Congress on our doorstep in Melbourne in May 2014.

HFA FUTURE DIRECTIONS

The HFA Council met in October and considered a range of issues, including new education resources to be developed in the next year and possible peer support programs, as well as making a decision to review the governance of our organisation and how to more proactively include our member Foundations in communications about policy development and decision making. We will be consulting with community members who are experiencing special problems such as those who are ageing, women and girls with bleeding disorders, and seeking assistance for men and women whose health is deteriorating because of hepatitis C. We will again seek a meeting with Tanya Plibersek, the Federal Minister for Health, to discuss the needs of this part of our community.

We also look forward to collaboration with Australian Haemophilia Centre Director's Organisation, Haemophilia Centres and the National Blood Authority to further develop the Australian Bleeding Disorders Registry (ABDR) to include a recording tool for people with bleeding disorders to document details of their bleeds and clotting factor use to enhance their clinical care and for supply planning. We believe this is a critical step for the ABDR and I am proud that this was a key recommendation from our 2011 Council meeting which is moving forward.

HOLIDAYS AND TRAVEL

As the holiday season approaches I remind everyone to think of their treatment needs if they are travelling or going on holidays. This might require liaison with your Haemophilia Centre about your clotting factor supply arrangements, making sure you have enough product to take with you and temporary arrangements in place for any necessary changes to your home delivery plan. If you are planning an overseas holiday you should plan early and carefully to ensure you have travel insurance, sufficient treatment supplies with you, and all the appropriate documentation to enable you to take your clotting factor, medicines and other supplies in and out of other countries. If you need information about travel please feel free to contact the HFA office and most importantly contact your Haemophilia Centre for advice about carrying and storing your clotting factor during your travels and the documentation you might require.



Remember that many regular holiday travel destinations may not have well developed health services for people with bleeding disorders and may not have supplies of any clotting factor, let alone the specific product you use now, so you will need to make a careful plan for your trip. If you need information about treatment services in another country you could visit the WFH website on www.wfh.org and click on FIND A TREATMENT CENTRE.

NEW BEGINNINGS

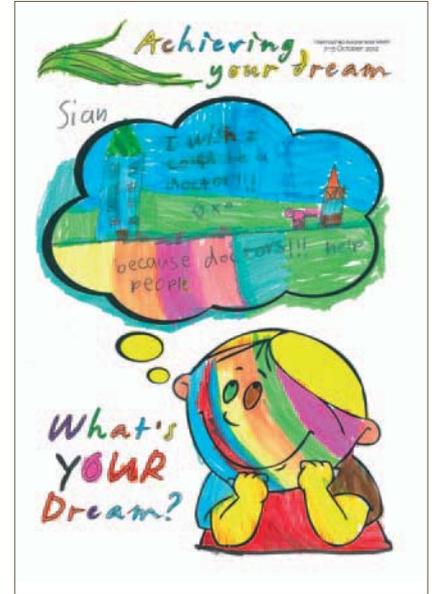
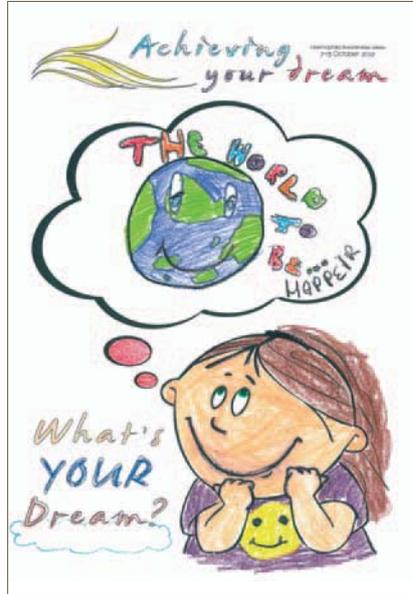
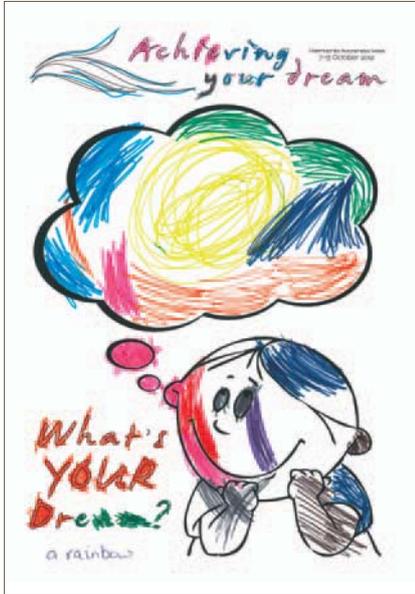
For some of our younger community members with bleeding disorders 2013 might mark new beginnings at kindergarten, primary or secondary school or university or transitioning from school to work. Times like this require some thought and planning so the relevant people know what they need about providing care and support. Haemophilia Centre staff can help develop plans with this and I urge you to make early contact for discussion to make sure these transitions work as smoothly as possible. You will also find relevant education resources on the HFA website to download at www.haemophilia.org.au or if you prefer hard copy feel free to contact the HFA office on 1800 807 173.

I wish you and your families a safe and happy holiday season and best wishes for 2013! ❖



Achieving your dream

Haemophilia Awareness Week
7-13 October 2012



Haemophilia Awareness Week and Red Cake Day was held this year from 7 to 13 October 2012. Haemophilia Foundation Australia and Haemophilia Foundations around the country worked together with our supporters to raise awareness about inherited bleeding disorders. The theme this year was 'Achieving your Dream'.

We had a fantastic response and sincerely thank each and every person who helped us fundraise and raise awareness during the week. Red Cake Day was an overwhelming success and we aim to be bigger and better in 2013.

We had incredible support from 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 hosted Red Cake Days.

SUNLESS

Tracey Churchill from sunless.com.au hosted a Red Cake morning tea and held an online auction and raised \$764.

COLOUR-IN COMPETITION

230 children submitted entries to the colour in competition this year. Congratulations to the winners:

- 5 and under – Georgia, Sydney
- 6-9 years – Sian, Rainbow Street Public School NSW
- 10 and over – Millie, Wonthaggi Vic

EUDUNDA FAMILY HERITAGE COMMITTEE, SA

The Eudunda Family Heritage Committee held a Red Cake Day in the town centre and also ran a raffle during the week. In total \$471.55 was raised. The raffle was drawn at the Melbourne Cup Luncheon held down at the local hall and won by Lylie Gaerth.

PAINT THE TOWN RED, NEERIM SOUTH & BENDIGO BANK BRANCHES, SOUTH GIPPSLAND REGION

In its 4th year, Neerim South once again hosted 'Paint the Town Red' organized by Donna Field." The day was an overwhelming success. Together with the support of the Neerim District Community Bank®, Bendigo Bank Branches South Gippsland Region displayed posters and promotional items to raise awareness about haemophilia and undertook internal fundraising. For example, one branch held a BBQ and another held a Red Cake morning. In total Paint the Town Red and fundraising from the Neerim District Community Bank® and Bendigo Bank Branches South Gippsland Region raised \$2,294.





WHEELATHON, BRISBANE

By Howard, Danielle, Hugo and Poppy Mitchell

24 keen riders embarked on the inaugural Ride for a Cure wheelathon on Sunday. It was a great turn-out with tremendous support by many families at Eagle Junction State School as well as a few of Hugo's keen cousins, aunts, uncles and grandparents. Kids and a few dads cycled the 1.2km track at the Nundah Criterium Circuit to see how many laps they could complete in 30 minutes. The maximum achieved was 9 which was a mammoth effort on such a hot morning. Extra excitement was created by a red belly black snake that decided to scoot across the track right in front of Hugo and his cousin Portia. Not something you would expect to see on a bike track on a Sunday morning! Hugo and his friends on total raised just over \$3,000.

ST ANDREWS GRAMMAR, PERTH

Thank you to St Andrews Grammar which raised \$2,585. Sofia Papadopoulos who is in Year 6 at the school wrote about the day:

On Friday 17 August 2012 our school, St. Andrew's Grammar held a 'RED Day' in support of Haemophilia Awareness Week. This was an important event in our school as we currently have one student with haemophilia and another student starting next year. This day was held to raise awareness and an understanding of haemophilia amongst all the students and staff of our school.

The organisers of the event Mrs Dionisia Tsokos and Ms Katerina Dimopoulos arranged a huge variety of events to take place on the day. Some of these events were a colouring in competition for all primary school students, guessing how many RED frogs there were in a HUGE! Tub of lollies.

The winner got to keep the whole tub! We sold RED ribbons for everyone to wear, listened to stories and completed activities (on haemophilia) in our school library with Miss Jongeling, our teacher librarian. Our undercover area became RED Day headquarters; there were RED balloons, colouring pictures displayed, prizes for the raffle and much more.

All staff and students wore RED accessories all for gold coin donations. Our school canteen provided a special RED Day lunch deal with a variety of yummy food prepared and sold on the day. Our year 11 home economics class cooked up a storm of, trifle, fruit balls and RED cupcakes to sell. The primary school and the secondary school held a staff & student soccer game during their respective lunch times. These were so much fun as were the RED balloons our Preprimaries' released prior to the start of the games.

A special assembly was held to finish the day's events and announce winners.

As well as a lot of money being raised for the foundation we learnt a great deal about haemophilia and the challenges faced daily by people with the condition.

NEWSLETTER

A newsletter highlighting all the events held during Haemophilia awareness Week will be distributed to participants soon and will be available online. If you wish to receive a notification please email Natasha at ncoco@haemophilia.org.au 📧

DON'T FORGET THE RICE

Kevin Fisher

As a "mature age" person living with severe haemophilia (amongst other things) I have recently rediscovered the benefits from using RICE as part of treating a joint bleed.

I have been fortunate to have been on twice weekly prophylaxis for the past several years. This in itself has been quite remarkable in as much that I rarely have what we commonly called "spontaneous bleeds". Virtually all my bleeds are a direct result of trauma, although sometimes it is difficult to determine whether it is a bleed or a spike in the arthritis.

In view of these less frequent bleeds, I have become less used to the previously well-rehearsed treatment regime, but I am sure that I am not on my own when it comes to this.

Over the years, if I had a joint bleed, I had become more focussed on treating with clotting factor and not much else. However I recently had a left knee bleed as a result of trauma and treated the bleed with clotting factor and my idea of rest and ice (the RI in RICE).

After a week of several doses of factor and "RI", I didn't feel as though my knee was improving sufficiently despite the bleed having settled down. It was time to seek advice.

Abi, the haemophilia physio at the Alfred Haemophilia Centre, reminded me of RICE, ie REST, ICE, COMPRESSION, ELEVATION

I decided to spend a whole weekend at home undergoing RICE to the max. By the Sunday evening my knee felt a lot better in that the swelling had gone down considerably (this had not been the case before the weekend).

Within a few more days I no longer needed to use my walker or crutches or walking stick. Mind you, I was supported all the way during this "layoff" period by my wife Judi who never ceases to step up when I am out of action.

I strongly recommend that you "don't forget the RICE" - it speeds up the whole process of getting over a joint bleed. #

Abi Polus is Clinical Physiotherapist in Haemophilia at the Ronald Sawers Haemophilia Centre, Alfred Health, Melbourne

A RECAP ON RICE

Abi Polus

It is really nice to hear first hand that what we physios preach is actually practiced!

With the advances in factor replacement, correct rehabilitation is sometimes overlooked. RICE is vital in the management of joint and muscle bleeds.

A QUICK RECAP:

REST: is so important that rest and the TIME needed to achieve healing of the damaged tissues be factored in to your treatment regime. This helps stop re-bleeding (including small micro-bleeds that can be undetected) from occurring and also ensures that a joint is less likely to have permanent damage. There is evidence to show that walking on or using a blood filled joint can severely increase damage to cartilage.

ICE: is well established in aiding pain management, although current thinking is that factor replacement should be administered first.

COMPRESSION: can also stop the amount of swelling and blood present, which may prevent further muscle and other soft tissue damage and also how much blood that has to be reabsorbed in the joint or muscle.

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

Are you having bleeds...??

STEPS

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

FACTOR ALONE DOES NOT EQUAL TREATMENT

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

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

R.I.C.E

Rest

Ice

Compression

Elevation

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

Australian & New Zealand Physiotherapy Haemophilia Group

Haemophilia Foundation Australia www.haemophilia.org.au

ELBOWS – A PROBLEMATIC LITTLE JOINT

Claire Bell

Within Australia elbow arthropathy is becoming an increasing problem, affecting both young and older adults affected with severe haemophilia.

The elbow is not only a hinge joint, like the knee, but rotation through the joint allows us to move our lower arm and hand into positions required to undertake daily activities. Unfortunately it is one of the joints that is prone to becoming a target joint for men affected with severe haemophilia.

Think about how we rely on using our arms during our day – you need to be able to bend it, extend it and move it around so that your hands are facing up, down and all around. The elbow is a very complicated joint and surgeons around the world acknowledge this. At the recent World Hemophilia Congress it became the subject of a number of presentations.

SO WHY CAN'T WE JUST REPLACE IT?

Elbows are not like knees...Not only are elbow replacements extremely difficult to perform, they are not really suitable for men with haemophilia due to their weight bearing limitation. Elbow replacements have a weight capacity of only 5kg. 5kg may sound like a lot when you consider carrying a cup of coffee or the paper. What about picking up kids, grandkids, the dog...or when you have to use your arms for crutches because your knee or ankle has a bleed...or when you are simply using your arms to push up to stand from a sitting position. In these situations we place more than 5kg through the elbow, sometimes significantly more.



SO WHAT CAN WE DO?

Firstly, it is important to state upfront that whatever is lost in the ability to extend or straighten the arm is lost forever. Therefore prevention and protection of the joint is critical to maintain normal function. If you have a target elbow joint maintaining regular prophylaxis or undertaking a course of secondary prophylaxis may be initiated to reduce the bleeding cycle within the elbow joint. Quick and correct factor replacement to manage a bleeding event is also very important.

But for some patients a surgical option may be considered when there is a significant reduction in the ability to rotate the lower arm and hand and/or when there is significant pain. The surgery offered is called a radial head dissection or resection.

WHAT IS A RADIAL HEAD DISSECTION?

The radius is one of the bones in the lower arm. The other (larger) bone is called the ulna.

Due to repeated bleeding events and developing arthritis, the radial head becomes bigger than normal. When it gets too big it sits right against the ulna bone.

This loss of space between the two bones reduces the ability of the lower arm to rotate.

The option then is to take off the end of the radial bone, thus allowing rotation to occur.

Everyone is a bit different, so while surgeons will make an effort to remove the bone above the ligaments which hold all the bones together, making it more stable in the long term, this is not always possible.

Whilst it may seem odd that they would leave it "floating" around, the bones are well supported by muscles. Over time, however, this stability may reduce and there is then the risk of pain in the wrist.

As with any surgery there are always risks, but this surgery offers the best chance to regain some function and maintain a quality of life for men with severe elbow joints.

MORE INFORMATION

If you are concerned about the health of your elbows or would like more information please contact your local Haemophilia Centre. ■

PHYSIOTHERAPY AT THE WORLD CONGRESS

Emma Paterson

I was fortunate to be one of the four Australian Physiotherapists who attended the World Hemophilia Congress in Paris this year. As a first time attendee at the world congress, the scale of it was impressive. Over 5000 attendees from more than 100 countries met to exchange the current ideas on best practice, research updates and generally try to find ways to improve outcomes for those whose lives are affected by bleeding disorders. I was very impressed with the balance of multidisciplinary presentations by health professionals, as well as community representatives. In the musculoskeletal presentations I attended there was a clear effort to have a balanced representation of different health professionals, cohesively discussing surgical, medical and physiotherapy management options.

I have summarised some particularly interesting presentations.

AMBIDEXTERITY TRAINING PROGRAM FOR PATIENTS WITH HEMOPHILIA

Roveri R, Matta M, Silva J, Sambo A, Colella M, Ozelo M

Ambidexterity training (meaning being able to use both your right and left hand) was presented by Margareth Ozelo. This was a very interesting and practical idea. Acute bleeding episodes and chronic arthropathy in a dominant hand or arm can be a major problem for people with haemophilia. When a bleed is occurring there is frustration in trying to rest as it is very difficult to avoid using your dominant hand. It can often lead to time off school or work during recovery, or inadequate rest for recovering from a bleed. This Brazilian group taught their patients to practice using their non dominant hand for usual daily activities, writing, and other activities

requiring fine hand control such as games or painting. Another benefit of developing ambidexterity is the ability to self infuse factor with either hand. An important point to note here is that they did not recommend ambidextrous training for children aged 7 years or under. Up to this age children's developing brains need to first acquire initial fine motor control as well as language and writing skills without adding further complications.

JOINT DISTRACTION RESULTS IN CLINICAL AND STRUCTURAL IMPROVEMENT OF HEMOPHILIA ANKLE ARTHROPATHY

van Meegeren M, van Veghel K, de Kleijn P, van Roermund P, Lafeber F, Roosendaal G

An interesting discussion of surgical ankle joint distraction with external fixation (a metal frame around the ankle with pins going into the bone for about 3 months) was presented by Monique van Meegeren, a surgeon from the Netherlands. Their case studies have indicated some very promising results in clinical symptoms as well as structural improvement of ankle in a presentation of three cases of young men with haemophilia. Details of these cases were published this year in the Haemophilia journal¹.

ENDURANCE PERFORMANCE IN ADULT HEMOPHILIA PATIENTS BEFORE AND AFTER A THREE-MONTH SPORTS THERAPY PROGRAM

Czepa D, Gohler S, Stauber F, Brunner A, Kirstein J, Stephan H, Walden M, Hilberg T

Cardiovascular and endurance training for people with haemophilia was presented by Dorte Czepa from Germany. He discussed how, as life expectancy has increased, awareness of cardiovascular disease and fitness has also become



more important. In this context he discussed the challenges achieving and maintaining physical fitness for people with haemophilia, who research shows have on average lower scores for physical fitness than their counterparts without bleeding disorders. An exercise program needs to be specifically adapted to allow for joint or muscle problems as well as suit an individual's likes and preferences to have a positive influence on their endurance and performance. A take home message from this presentation is that individuals with haemophilia who are thinking about ways to try and improve their fitness would benefit from talking to their physiotherapist. This can help to minimise injury, frustration and setbacks. If both the person with haemophilia and the physiotherapist think a little creatively together they can come up with an exercise plan which is achievable, fun, varied, sociable, or just suits their lifestyle.

REFERENCE

1. Van Meegeren MER, van Veghel K, De Kleijn P, et al. Joint distraction results in clinical and structural improvement of haemophilic ankle arthropathy: a series of three cases. Haemophilia 2012;18(5):810–817

HAEMOPHILIA SOCIAL WORKERS AND COUNSELLORS GROUP ANNUAL MEETING

Leonie Mudge

On 6th and 7th September 2012 eleven representatives of the Australian/New Zealand Haemophilia Social Workers and Counsellors Group (ANZHSWCG) convened at the HFA offices for our annual meeting. Representatives from adult and paediatric Haemophilia treatment Centres in Australia, and two representatives from the New Zealand Outreach Services met to discuss the past year's progress and challenges and to share ideas about the way forward for our group and our potential contribution to the bleeding disorders community.

We shared information about Family Camps, the 2011 Inhibitor Workshop, Men's Business gatherings, 'Paddle Your own Canoe' day to encourage taking responsibility, Women's Groups and Outreach Clinics in our feedback sessions. These were just some of the activities our members were involved with since our last meeting.

Speakers included Leigh McJames and Donna Nicholls from the Australian National Blood Authority. They updated us on the redevelopment of the Australian Bleeding Disorders Registry (ABDR) and the importance of a Social Work/Counsellor presence in recording data and developing guidelines for our recording.

Kate Walton, the HFA Youth Project officer consulted with us on the Youth Project and 'Factored In', the new HFA web site for young people.

Sharon Caris, HFA Executive Director, met with us and we talked together about the following ideas:

- Ageing – a sub-committee of our group was formed to collect resources, and develop a standardised assessment tool to use in our practice.
- Parents Empowering Parents (PEP) – could we run a national workshop in 2013 to provide support and networking opportunities for young families?
- Ongoing issues regarding travelling, both domestic and international. The need to be prepared – product supply, insurance, letters of introduction.
- The process for New Zealanders coming to Australia – and what is covered by Haemophilia Centres and government instrumentalities and what is an individual responsibility.
- Step Up Reach Out (SURO), an international youth leadership program available for some of our youth (18-24 years).

- Support for our gay patients – through website and newsletter.
- The need to gather information about the availability and cost of reproductive genetics, such as Pre-implantation Genetic Diagnosis (PGD).

Individual members who had been provided the opportunity to attend the recent World Federation meeting shared their impressions and the highlights of the congress. We are keen to contribute to the 2014 WFH Congress in Melbourne. Plans were made to offer our support – in particular to help foster a friendly atmosphere with networking opportunities.

We greatly appreciated the opportunity for a face to face meeting. Thank you HFA! 🍷



'CHANGING POSSIBILITIES IN HAEMOPHILIA' GRANTS

Three new proposals to advance the care of Australians living with haemophilia are to be funded to a total of \$50,000 through the 'Changing Possibilities in Haemophilia' grant program. The grant program has been developed by Novo Nordisk to encourage innovative projects by health professionals for the benefit of their patients.

An independent professional panel, representing the range of healthcare disciplines working in haemophilia, and a Haemophilia Foundation Australia representative have been involved providing recommendations about the program and judged the applications.

Originating in Perth, Melbourne and Brisbane, the three successful initiatives emerged from a competitive pool of high quality applications submitted by haemophilia health professionals around the country.

The recipients of the 2012 'Changing Possibilities in Haemophilia' grants (in alphabetical order) are:

Dr Chris Barnes - Director, Henry Ekert Haemophilia Treatment Centre, Royal Children's Hospital, Melbourne

Claire Bell - Clinical Nurse Consultant, Haemophilia and Sharon Hawkins - Haemophilia Social Worker, Royal Perth Hospital

Joanna McCosker - Clinical Nurse Consultant, Haemophilia and Bleeding Disorders, Royal Children's Hospital, Brisbane

FOCUS ON FAMILY

The adoption of family-centred care in haemophilia treatment will be the focus of research to be conducted in Melbourne by Dr Chris Barnes. His project will review the standard of care at the Royal Children's Hospital against published assessment tools with a view to ensuring this approach is being implemented across all touchpoints including medical, dental, nursing, social work and physiotherapy.



Dr Chris Barnes

'Family-centred care is something we are all aware of but it's usually adopted in an ad hoc way. We need to ensure the family knows how the multi-disciplinary team works, and that care is not compromised by the inconvenience of appointments, for example. Giving them responsibility for elements of healthcare and monitoring the patient can also improve outcomes and compliance,' said Dr Barnes.

Dr Barnes will put the funds towards employing a dedicated project officer to focus on the research and on assisting him to implement the findings where possible. Judges commented: 'While family-centred care should indeed be in place in all Haemophilia Centres, it is not the case that it is uniformly applied, and we look forward to seeing the results of Chris's project potentially being published so other Centres can learn from it.'

YOUNG WOMEN'S WEEKEND

After seven years working in direct care for people with bleeding disorders, WA haemophilia nurse Claire Bell recognised that both clinical support and non-clinical resources are mostly for affected males and their parents, while the particular needs of young women are not being met.

The grant will enable Claire to run a peer summer camp for young women



Sharon Hawkins and Claire Bell

affected by bleeding disorders, with a program of group interaction and presentations designed to convey medical information and encourage friendship connections. Working with Claire to deliver the camp program is Haemophilia Social Worker Sharon Hawkins, who also has extensive experience in working with women and children with inherited bleeding disorders.

'I am keen to develop services for women living with haemophilia since it has particular impact on their lives and their reproductive choices,' said Claire.

The judges felt the camp, which was inspired by a similar project in New Zealand, is 'a cost-effective, proven project that can be readily duplicated by other centres.'

FROM PORT TO VEIN: TRANSITION SUPPORT FOR ADOLESCENTS

Brisbane-based Clinical Nurse Consultant Joanna McCosker is 'passionate about helping young boys and adolescents with haemophilia move to independent treatment, so they can live their lives without haemophilia being a barrier.' Joanna's grant will enable her to develop a standardised, evidence-based education package for parents and health professionals teach boys how to administer their own intravenous treatment.

WORLD AIDS DAY



Joanna McCosker
Photos: Cube

'Achieving self-infusion prior to adolescence is critical to supporting compliance in this chronic disorder,' said Joanna. 'I want these young boys to see haemophilia as something they manage, not a disability. Their parents are important role models and need to be able to impart the skills and knowledge to achieve this.'

Joanna's research uncovered a lack of standardised Australian and New Zealand guidelines to assist in the teaching process, and showed that many related resources lacked evidence-based information on learning. 'In particular, non-specialist nurses in regional areas do not understand the role of prophylaxis, the importance of transition from port to vein, or the implications of long-term central venous access device (CVAD) use.'

One of the judges said: 'It will be fantastic to see a web-based resource that nurses and parents can easily access, that provides current, standardised guidance.'

MORE INFORMATION

Further details on the 2012 grant recipients and judges can be found at www.changingpossibilities.com.au.

If you would like to receive updates on the 2013 'Changing Possibilities in Haemophilia' grants program, which will open in April 2013, please email your details to the secretariat at info@cube.com.au. ■

Every year World AIDS Day is celebrated globally on 1 December. For the bleeding disorders community in Australia it is a day to remember the community members who were affected by HIV when HIV was transmitted through some batches of clotting factor treatment product in the mid 1980s. As a result of this tragic episode, some people lost partners, family members, children, patients, colleagues and friends. Some people continue to live with the challenges of HIV and some to inspire by their positive attitude, resilience and determination to build a better future.

In 2012 the World AIDS Day global campaign theme is:

GETTING TO ZERO

- Zero new HIV infections
- Zero discrimination
- Zero AIDS related deaths

In Australia, the aim is to encourage all Australians to be aware that HIV still exists in the community; to take action to prevent transmission of HIV by promoting safe sex practices; to support and understand people living with or affected by HIV; and to uphold their right to participate in the community free from stigma and discrimination.

This year World AIDS Day highlights the role of HIV positive people in strengthening community spirit. It is a reminder how important it is for people living with HIV to share their experiences and knowledge and educate others about HIV, resilience and the personal skills needed to adapt and manage hardship. This is particularly true of the bleeding disorders community where people may live with and manage multiple health conditions.

In this issue of *National Haemophilia* we hear from the national research on HIV and resilience, some personal accounts of strategies people with HIV and haemophilia use to manage disclosure and the potential for discrimination - and exciting new scientific developments at an international level. ■



TOWARDS AN HIV CURE

Suzanne O'Callaghan

There was an air of excitement at the 2012 Australasian HIV/AIDS Conference this year. The Conference was held at Melbourne Convention Centre from 17-19 October 2012 and when I spoke to the Conference organisers, they explained that – like the World Hemophilia Congress – Australia will be hosting the 2014 World AIDS Conference and that they were preparing to have around 20,000 delegates flood into Melbourne in July that year.

In preparation for the World AIDS Conference, Professor Françoise Barre-Sinoussi is working closely with the Australian Conference team to bring the latest work of leading international HIV researchers to Australia. Prof Barre-Sinoussi was awarded a Nobel Prize in 2008 with Luc Montagnier for their discovery of HIV and is now Co-chair of the International AIDS Society Working Group on HIV Cure, a think tank of more than 40 HIV research scientists who are working with key HIV and non-HIV researchers around the world. She spoke about the work of this think tank at a very memorable and exciting plenary session at the Conference.

IMPERATIVES FOR AN HIV CURE

Prof Françoise Barre-Sinoussi

Françoise Barre-Sinoussi explained that the International AIDS Society has convened the think tank of the world's leading scientific experts in HIV and related fields to undertake intensive work to develop a cure for HIV.

For the first time advances in science and medicine mean a cure now appears more achievable. People with HIV on treatment are living longer and some now have a normal life expectancy. But the cost of providing treatment to the increasing number of people around the world who are becoming HIV positive is unsustainable. Ironically it is this issue that makes finding a cure an economic imperative worldwide.

The aim is to develop a cure, or long-term remission without treatment, through a combined approach:

- Optimising treatment
- Reversing HIV latency (eg, reactivating latent infection in t-cells, HIV reservoirs)
- Stopping replication of HIV.

This will involve further research into immune-based treatment strategies and safer gene therapy. Considering that many people on treatment are now in reasonably good health, it will be important that the treatment to cure HIV does not endanger this. The cure will need to be safe, affordable and able to accommodate the growing numbers affected.

If you would like to read more about this, the reference below explains the current work of the International AIDS Society Working Group on HIV Cure.

REFERENCE

Deeks S et al. Towards an HIV cure. *Nature Reviews Immunology* 2012;12:607-614.

HIV STIGMA AUDIT

Suzanne O'Callaghan

As part of the national work to understand the issues for people living with HIV (PLHIV) in Australia, the National Association of People Living with HIV/AIDS (NAPWA) and the National Centre for HIV Social Research conducted a "Stigma Audit" during 2011. In this project they asked PLHIV for their experiences of living with discrimination and the strategies they use to overcome it. The aim was to turn this research into practice – to use the ideas given by people who responded to the survey to develop education programs so that people can learn from each other and build up their resilience.

What strategies do HIV positive people with bleeding disorders use in their daily life to overcome the challenges of stigma and discrimination? Some are very private about their status; others are more open; some choose carefully when and whom they tell.

"I have found being open about my HIV status liberating. Being able to communicate with people about living with HIV and then helping to break down attitudes is extremely rewarding. Feedback I've received has ranged from heartfelt concern to being an inspiration, how wonderful! It's a huge step to speak out but it has worked out for me and helped me enormously in coping with HIV".



"Living with HIV since the 1980s and seeing how HIV positive people were treated within the community and media has made me a very private person. Only a select few family members and close friends know that I am HIV positive. When I have had to disclose my status I always state that I acquired HIV through contaminated blood products that were used to treat my haemophilia; I find people seem to very understanding and compassionate about this."

"The biggest problem I've had with stigma has been the fear of the consequences of discrimination and particularly how and when to bring my HIV status up with a girl I was interested in. The easiest thing I have found is to get someone else – a friend – to tell them."

OVERVIEW OF HIV STIGMA AUDIT FINDINGS

The HIV Stigma Audit community report is now available and you can download it from the NAPWHA web site napwa.org.au.

The report makes the point that for many years the Australian national strategic response to HIV/AIDS has acknowledged the need to reduce stigma surrounding HIV.

The HIV Stigma Audit is the first national study in Australia to investigate HIV stigma. It did this by focusing on the experiences of people living with HIV (PLHIV).

EXPERIENCE OF STIGMA

The study results confirmed that PLHIV have experienced HIV stigma, but that for the participants in the study, this 'could be described as moderate rather than severe'.

- Women and heterosexual men tended to report higher levels of stigma than gay men
- Participants reported higher levels of feeling stigmatised rather than seeing stigma acted out by others.

The authors of the report wondered whether this was a result of Australia's culture of anti-discrimination, which makes discriminatory attitudes socially unacceptable. However, they also noted that the comments of participants showed how difficult it is to challenge deeply ingrained beliefs that HIV has tainted a PLHIV's identity.

MANAGING STIGMA

Findings from the study showed that people have two ways of managing the effects of stigma:

- **Controlling disclosure carefully:** people with HIV generally can choose the circumstances in which they disclose to others. The study found that those who had the most positive experience were the people who strike a balance between telling those who are supportive while keeping it confidential in their wider community. They saw HIV as a personal issue but not a secret.
- **Developing skills and characteristics to give them resilience in the face of stigma and other setbacks in life.** For example, seeking support when they needed it; reducing the importance of HIV to their identity; and "cultivating the capacity to bounce back from, or not take to heart perceived slights".

In conclusion, the authors highlighted that these strategies for managing stigma demonstrate that people with HIV do not just deal with stigma passively. 'Rather, PLHIV are overwhelmingly resilient in the face of what remains a significant life challenge'.

REFERENCE

Slavin S, Brener L, Callander D, de Wit J. 2012. The HIV Stigma Audit community report. [Sydney]: National Association of People Living With HIV/AIDS; National Centre for HIV Social Research. www.napwa.org.au ❧

The following article is abridged from an article published in *Positive Living*, September 2012, the magazine of the National Association of People with HIV Australia (NAPWA), and is reprinted with permission.

David Menadue is a journalist and HIV activist, and is currently the Associate Editor of *Positive Living*

THE POWER OF RESILIENCE

David Menadue

In this article, David Menadue comments on resilience, a trait we could probably all do with a little more of.

re-sil-ience [ri-zil-ee-uhns] noun

2. ability to recover readily from illness, depression, adversity, or the like; buoyancy.

Unlike dictionaries, psychologists vary in their definition of resilience with some saying it is less about actual recovery and more about 'the ability to establish and maintain a stable equilibrium across and over time'.¹

One thing is for sure. Positive people know about resilience . . . particularly those of us who lived through the horror years of the eighties and early nineties. Just getting through that period — when many of our friends were dying and society was reacting with fear and hostility — took a lot of resilience.

Even with much better prognoses, an HIV diagnosis today is still a big deal. There's the initial shock, followed by wondering how you will be treated and what it all means for your health. Some people find it easier to adjust, while others — battling feelings of stigma, fear of rejection and uncertainty about the future — find it extremely hard.

According to the recent NAPWA stigma audit, a significant percentage of positive people in Australia feel that living with HIV is something to feel guilty or ashamed about. Forty percent also agreed with the statements that 'most people think that a person with HIV is disgusting' and 'I have been hurt by how people have reacted to learning I have HIV'.²

Much of the stigma attached to being HIV positive occurs because we have either been treated badly in the past when the information became known or because we fear this will happen if we were to reveal it. One way to tackle this is to mount anti-stigma campaigns which expose the unfairness of it all. But it is also important to build the capacity of positive people to cope with negative comments by adopting a resilient attitude.

HELP WITH BUILDING RESILIENCE

For a number of years, the Bobby Goldsmith Foundation (BGF) in Sydney has held a range of workshops to help people with HIV build their skills in resilience.

One of these, a four-day retreat called PosQuest, has been run in partnership with Petrea King from Quest for Life. Petrea has had a lot of experience helping people with cancer and other chronic illnesses and her groups have often included people with HIV.

'Participants found some sections of the program to be quite confronting . . . because we ask people to share their stories,' reveals Peter Thoms from BGF.

'This can bring up feelings of anger and guilt related to getting HIV but also about things to do with people's upbringing, family, school and personal relationships.'

Peter believes that the way forward is to let go of the past and to change the view that 'if only this hadn't happened, my life might be OK'.



'While it may be useful to understand why you have got to where you are today, and to try to prevent repeat behaviour or negative thinking, it isn't useful to cling to the past,' he says.

The course suggests that participants live in the present as much as possible. But how people actually develop a positive frame of mind varies from person to person. Some find sharing their story or writing it down helps.

Others succeed through meditation, yoga and learning mindfulness techniques. For some, developing a more spiritual outlook on life is the key. Unfortunately, funding for the PosQuest course has been withdrawn, but people with HIV are still able to attend general Quest for Life courses (www.questforlife.com.au).

RISING FROM THE ASHES

BGF has run Phoenix courses for many years, helping positive people to identify their skills and explore how they might develop them to re-engage with the workforce or as a volunteer. They also support people to deal with depression by assisting them to attend workshops run by the Black Dog Institute.

'People might just want practical advice on how to deal with "the system",' says Peter.

'Some get very frustrated with housing agencies or Centrelink,' he says, 'because they see the bureaucracy as being stacked against them. Simple, practical tips on understanding the best path to deal with these agencies can help people feel less overwhelmed and disempowered.'

Peter has noticed that some people who have lived with HIV for a long time share a particular set of challenges. Many have left the workforce because of illness or the prospect of illness and have lost a lot of their previous skills and confidence. Some are too young to be out of the workforce, while others are dealing with the effects of early ageing and other health problems.

'Many are socially isolated,' he says. 'They live in one-bedroom public housing where sharing is not possible and feel unable to engage with former friends or go out socially because of the cost or because they don't feel accepted in those circles anymore.'

THE COUNSELLING OPTION

Groups are not everybody's preferred way of dealing with things. Some people don't want to tell their story in front of others and prefer to have one-on-one counselling to work through their issues.

Michelle Earle is an experienced HIV counsellor at the Alfred Hospital in Melbourne.

She thinks the objective of counselling should be to help people make a healthy adjustment to life.

'Everyone needs ballast to keep afloat in a storm,' she says. 'We all need something to deal with the stresses that life throws up for you.' When she starts to counsel someone, she looks to see if they possess certain key components to help them make that adjustment. Do they have a healthy self-esteem or an adequate way of coping with stressors? Are they in denial over any fundamental issues or at a loss to find ways to solve the problems they are confronting?

'These are hallmarks of how resilient people are,' she believes.

There are external factors she looks for as well, including how strong their relationships are with their partner, family and friends.

'If someone is isolated without a support network, they may have a harder time getting on top of things,' Michelle says.

She believes that people also need to be involved with some meaningful activity in their lives.

It might be a job or being a volunteer or following a passion or hobby. Michelle sees many people in her practice who have great potential but lack the vehicle to show it in their lives.

'Counselling can help awaken some of these possibilities,' she says, 'providing people are able to sort out the things that are holding them back.'

DOING IT YOUR WAY

We all have different ways of living with HIV.

Disclosing your status and discussing its implications with just a few trusted friends may be enough to give you the level of acceptance you need to be a confident individual.

Others don't care who knows . . . and this has been my approach - albeit over a number of years gradually building up the courage to let family, workmates and sex partners know.

For me, this technique has decreased any internalised stigma I have felt about having HIV and any thoughts that I was hiding a big secret. But such an approach will not work for everyone.

Michelle Earle claims that most people she sees show quite a high level of resilience in adjusting to an HIV diagnosis over time.

'People discover their own comfort level around disclosure,' she says, given that there are some forums where it might still be problematic — such as the workplace or in certain family situations.

'People tend to find a level of self-acceptance about their diagnosis that lets them get on with life.'

If you would like some help to deal with the various stresses related to living with HIV (as well as other things), some of the approaches mentioned above might help you build your own capacity for resilience.

MORE INFORMATION FOR PEOPLE DEALING WITH HIV AND AGEING

Ahead of Time is a comprehensive booklet available from HIV agencies or online on the NAPWA web site – www.napwa.org.au

REFERENCES

1. Cichetti D and Garnezy N (1993). Prospects and promises in the study of resilience, *Development and Psychopathology* 5 (04):497-502
2. NAPWA Stigma Audit 2011. The sample was of 697 HIV positive people in Australia. Thirty-six percent agreed with "I feel guilty because I have HIV"; 35% disagreed with "I never feel ashamed of having HIV". See www.napwa.org.au ■

INTERESTED IN FOLLOWING UP?

If you would like to explore strategies to deal with stigma or discrimination or other challenges in your life, you may find it useful to speak to your Haemophilia Social Worker or Counsellor or contact your Haemophilia Centre to be linked to other services.

HIV organisations around the country also run a variety of programs to provide individuals with support and help PLHIV develop their personal skills. Contact your local AIDS Council or PLHIV organisation to find out what's available.

STIGMA AND SEXUAL IDENTITY - HETEROSEXUAL MEN WITH HIV

Suzanne O'Callaghan

Most of us don't talk about ourselves very often in terms of our sexuality or find ourselves in a situation where we feel we have to declare to others 'I am heterosexual' or 'I am gay'. However, for Australian heterosexual men who are HIV positive, the experience can be quite different. Asha Persson is a researcher with the National Centre for HIV Social Research and works in collaboration with Pozhet, an HIV health promotion service for heterosexuals living with HIV. In her work with HIV positive heterosexual men she has become very aware of the impact of the history of the HIV epidemic in Australia on them and the way they describe themselves to others. In a recent article in the journal *Men and Masculinities* Asha reflected on sexual identity and the challenges for heterosexual men with HIV that have been highlighted in her research.

Unlike most other countries, in Australia historically most people who have HIV are gay men. As you would expect, this has resulted in a larger number of HIV prevention campaigns in the media and HIV support programs aimed at gay men. The unintended impact of this has been that many people in the wider community in Australia assume that if you are HIV positive and a male, you must be homosexual.

Asha points out that it is the norm to assume that males in the wider community are heterosexual unless told or shown otherwise.

So HIV positive heterosexual males are caught in an unusual situation where they feel forced into an 'identity corner', and find that if they are explaining their HIV status, they need to declare they are heterosexual to counter other people's assumptions about them – which feels very awkward. They go through a type of heterosexual 'coming out' experience. Some men she interviewed said it gave them real sympathy for gay men and the stigma they live with related to their sexuality.

For these men the situation is also complicated by the common association in Australia of 'masculinity' not only with heterosexuality, but with physical strength and being a provider for the family. However, these men were often unwell and unable to take the lead providing role in their family and felt this was another blow to their sense of being a 'real man'. Asha's research highlights the work individuals need to do to overcome the stigma they experience with being HIV positive and to confirm to themselves their own sense of worth. It also points to the need for understanding and support in their community to make this work less personally demanding.

Putting together the interviews for this research meant covering some very personal topics and would have taken a very skilled approach. We asked Asha Persson how she went about interviewing for the project.

'The first thing to emphasise is that all research interviews are confidential,' said Asha. 'The information that you give to the researcher is kept private and secure, and all personal details that could potentially identify you are removed from the interview transcript. When I interview people for research, I always make sure the interview is done in a place that is private and where people feel safe and comfortable. This can include their own home. The interview itself is more like a free-flowing conversation and research participants are given lots of space to tell their story in their own way. They don't have to answer any questions they don't want to. It is very important that the interview is done in a non-judgmental and respectful way. We all have our stories and we are all human.'

If you are interested in reading the full article, contact Asha Persson at a.persson@unsw.edu.au.

REFERENCE

Persson A. The undoing and doing of sexual identity among heterosexual men with HIV in Australia. *Men and Masculinities* 2012;15(3):311-328. ■

Sharon Caris is Haemophilia Foundation Australia Executive Director

HAEMOPHILIA RESEARCH

Sharon Caris

A special fundraising campaign was commenced by Haemophilia Foundation Australia (HFA) in 1990 to raise funds for Australian based research to benefit the bleeding disorders community. This led to the establishment of the Haemophilia Foundation Research Fund and since the first grant in 1994 more than \$570,000 has been distributed for scientific, clinical or psychosocial research. The funds available enable small grants for local research which might not otherwise be funded. The HFA Board determines the grants each year and last year decided to allocate an annual amount of \$20,000 towards these research grants.

The Fund is administered by HFA and the Haemophilia Foundation Research Fund Committee makes recommendations for grants each year. The Haemophilia Foundation Research Fund Committee includes representatives of the Australian Haemophilia Centre Directors' Organisation Research Sub-Committee, Australian Haemophilia Nurses' Group, Australian Haemophilia Counsellors' and Social Workers' Group, the Australian and New Zealand Physiotherapy Haemophilia Group, and a representative of HFA Council, usually the President.

The Committee has recently met and two research proposals have been approved for funding.

Dr Liane Khoo, Royal Prince Alfred Hospital, has been awarded \$5200 for a small study to monitor factor levels in recombinant FVIII concentrates: Xyntha and Kogenate Factor VIII.

Dr Joe Sasadeusz, Monash University, was awarded \$20,000 for an open-label study to evaluate the safety of boceprevir or telaprevir in addition to pegylated interferon and ribavirin for the treatment of chronic hepatitis C in patients who have bleeding disorders and are co-infected with HIV. ■

YOUTH PROJECT UPDATE

Kate Walton



NEEDS ASSESSMENT

The final HFA Youth Needs Assessment Report was completed in July 2012 and is now available on the HFA web site and in print. Many members of the community and health professionals contributed to the needs assessment. I would like to convey my thanks to all who took part for their valuable input.

A small number of additional copies are available from Haemophilia Foundation Australia by phoning 1800 807 173, faxing 03 9885 1800 or sending an email to hfaust@haemophilia.org.au.

The full Report is also available on the HFA web site in PDF format at www.haemophilia.org.au. Report summaries are also available in the September 2012 edition of *National Haemophilia*, the HFA web site under 'Kids & Youth' and the Factored In web site www.factoredin.org.au under 'Get involved in stuff'.

HFA welcomes your feedback and comments on the Report. You can do this by using the contact details above or make your comments through your State or Territory Haemophilia Foundation.

FACTORED IN WEB SITE

Competitions will now be running on the web site regularly. The 'Achieving your dreams video competition' was launched in October to run in conjunction with Haemophilia Awareness Week. The competition closes on 31st December 2012.

The aim of the competition is to raise awareness for Haemophilia Awareness Week and also further engage with young people and make new resources for the web site.

Smaller competitions will also be run throughout the year quizzing young people's knowledge about the content on the website. 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 encourage young people to stay involved with the Factored In web site community, and that this would help to build a strong youth presence in the bleeding disorder community.

There are already some great resources available on the web site including material on sport and medical information. There are many personal stories written by young people with bleedings disorders, young women who carry the gene or siblings who are willing to share their stories. The next resources being produced include employment and travel and I hope to have them up on the website shortly.

The Question and Answer section on the website has been quite popular. 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. As you don't have to be a member of Factored In to ask a question, anyone is able to use this function.

When utilising this part of the web site, users are asked to provide their email address and a nickname. They are also asked if they want their question answered on the web site or if they want a personal answer via email. Both of these options have been utilised by users. Responses can take up to 2-4 weeks depending on the complexity of the question and the availability of the experts.

CURRENT STATISTICS

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

The website currently has 56 members: 41 male/15 female

Visits to the site: 1526

Unique visits (a new user each time): 742

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, Finland, Italy and United Arab Emirates

THE NEXT PHASE

I have been scoping the leadership program for a few months, based on recommendations from the needs assessment. I have researched program models from Australia and around the world and explored ways for young people to communicate and provide support to each other.

I have consulted with community members and YWG members, as well as health professionals and Foundations.

The findings of the needs assessment led to the concept of "youth catch ups," as compared to camps, as a model for the mentoring program. I am now looking at how to develop the concept of "catch ups". They might be more informal and take place in a central, relaxed environment (like a park or café) and organised by a young person with the assistance of myself and the Foundation. I would look at ways to develop skills in young people as 'mentors' and provide training to the young person who would run the "catch ups". The aim of this model is for young people to have contact with each other more often, while not asking them to commit to too much time in the hope that friendships form naturally where young people exchange phone numbers, email, or become facebook friends. This model will be trialed in a few states over the coming months.

I'm looking forward to developing the mentor program further and putting the recommendations from the Needs Assessment into action. H



Kristine Robertson is Haemophilia Foundation Australia Fundraising Manager

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

Andrew Selvaggi is a Victorian community member with severe haemophilia A and inhibitors and a member of the HFA Youth Working Group

MAKING YOUR OWN FUTURE

Kristine Robertson and Suzanne O'Callaghan

Taking control of your health and life can be a big ask for anyone, but for a person with severe haemophilia and inhibitors it can be a great challenge.

In the past five years 25 year old Andrew Selvaggi has turned his life around so that it is almost unrecognisable from his childhood years. He talked with Kristine Robertson from HFA about his 'moment of truth' and his determination to make his life the way he wanted it to be.

Andrew Selvaggi was diagnosed with severe haemophilia A at 15 months old when, on top of always bruising very easily, he cut his upper lip on a bottle and it wouldn't stop bleeding.

There was no family history of bleeding disorders in Andrew's family. Like around 30 per cent of all people with haemophilia, his condition was the result of a genetic mutation.

Andrew developed inhibitors, which are a complication where treatment with factor VIII is not effective. He says he spent "around five years collectively" as a hospital inpatient by the time he was 11 years old.

'From age 0-11 there was not a treatment for me that worked properly, so I'd get a bleed and I'd pretty much have to sit there and ride it out until it went away, which without treatment can pretty much be weeks or months.'

'Most of my young childhood memories are of spending time in hospital with bleeds and being in a wheel chair constantly. I missed out on a lot of school and other things because of bleeds.'

'Once treatment that worked with my inhibitors became available when I was 11, it opened up a few more doors for me. I could do things like go to school more often, go on camps, do things I hadn't really been able to do before.'

GROWING UP AND SPORT

It was at this time Andrew became more involved with Haemophilia Foundation youth camps and peer support gatherings, which he remembers as being "great". But for Andrew, there were still so many things he wanted to do but just couldn't.

'I come from a very sport-orientated family. My father played football for 20 years and still plays, but I couldn't play any sports, especially contact sports. Growing up through school and seeing all the kids do Auskick, or even really basic things like playing four square, I couldn't do it. I would have given anything to be able to do all those things. I'd go and watch my father play football and think to myself I wish I could do that. It was very hard and it affected me a lot both physically and mentally.'

Because of the severity of damage to Andrew's joints, he was in a wheelchair 'nearly 100 per cent' of the time, and needed a full knee reconstruction by the age of 19.

'Any time I got out of a wheelchair I'd bleed into my knee, if I went on crutches, I'd get an elbow bleed and I'd be back into the wheelchair. That was pretty much my life.'

TURNING HIS LIFE AROUND

Due to his immobility Andrew put on a lot of weight, becoming clinically obese. This in turn put tremendous stress on his body and joints and had a devastating effect on his self-esteem.

'To be honest I was in a pretty bad place mentally. Physically I was in an even worse place. I think they go hand in hand actually. The lower your mind, the lower your body gets. It affected me quite a lot but in all honesty it made me mature quite a lot more as well. It gave me a different perspective on things.'

It may have been this different perspective that eventually caused Andrew to not only make the decision to work with his Haemophilia Centre to turn his life around, but to also persevere with the changes when obstacles appeared in his way.

'As cheesy as it sounds I took a look at myself in the mirror. One day I'd had a shower and I looked at myself in the mirror and thought, something needs to change. It's not working for me. Life isn't working for me the way I thought it should be. I could have either lived with it or changed it. I decided to change it.'



Andrew as a boy



Andrew now



Photos: Andrew Selvaggi

'Pretty much I walked out of the bathroom, put on a singlet and a pair of shorts, went out to the exercise bike, blew off the dust and hopped on it. First day I jumped on the bike I did five minutes. The next day I did six minutes. The day after that I did seven minutes....All the way up to an hour. Once I did that, I started doing it twice a day. Then, three times a day.'

OVERCOMING DEPENDENCE

For Andrew, it wasn't just about starting an exercise regime that worked for him and a healthy eating plan and losing weight. He also wanted to break what he describes as a 'dependence' on the pain relief medication he had taken all of his life to deal with bleeds.

'I was very strongly dependent on opioid pain relief. I needed it to function. I'd been on it for so long that to not take it you'd go through withdrawals and that sort of thing.'

Even though the Haemophilia Centre team recommended that Andrew slowly wean himself off the medication, he felt that, for him, the only way to overcome his dependence was to go 'cold turkey'.

'That was the hardest part, but it's how I wanted to do it. I didn't want to taper off or anything like that. For me it was the only way to go.'

MAKING THE CHANGES

He admits it wasn't easy, but Andrew kept going, bringing about tremendous changes in almost every area of his life. He lost 30 kilograms in weight and went from having three bleeds a week to having one

bleed a month. His bleed recovery times were almost halved. If he had setbacks, he worked around them.

'I definitely, without a doubt, had ups and downs. The nature of haemophilia is that it doesn't go away, it's always there and every now and then it does come back and bite you. I remember, about two weeks in, I had a major elbow bleed. The doctors said don't do anything upper body. So I thought to myself, I can still do lower body stuff and I kept going.'

'I'm naturally a very stubborn person and when the Haemophilia Centre team told me to take it easy with this or, take it easy with that I wouldn't and something would happen. I think by making those mistakes, it helped me grow.'

Andrew quit his job as a sales representative at a major internet company and gained a qualification as a health and fitness personal trainer; something unthinkable just a few years before. He now works for both himself and large companies as a personal trainer with hundreds of clients, including young men with haemophilia.

THE FUTURE

Andrew's aim now is to help others with bleeding disorders improve their health and fitness and turn their lives around.

'If someone like myself can step up, kick dependence not once, but twice, get out of a wheelchair, lose weight, get fit and work as a personal trainer, nearly anyone in the community can do the same.'

Andrew joined the HFA Youth Working Group and contributed a great deal to the development of the new Factored In youth web site and the ongoing work in the HFA youth project.

Today Andrew is philosophical about haemophilia and the impact it has had on his life.

'I see it more as I got a different experience in life and everyone gets their own experience in life growing up. You're only dealt one card and all you can do is play it.'

Andrew has advice for other young people with haemophilia.

'Live life. Don't let anything hold you back. If haemophilia is at the forefront of your mind in everything that you do, it will stop you doing things. You are not a kid with haemophilia. You are a person. Haemophilia is not who you are. Never let it get in the way of achieving your dreams and being the person you want to be.' H

YOUTH NEWS

Did you know Factored In will have competitions running throughout the year? Why competitions? Ask the YWG...



"Competitions help us attract all different sorts of young people, with a little incentive"

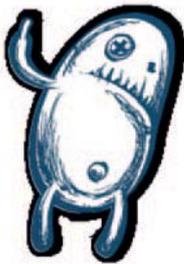


Cast vote

"Competitions renew interest in the website"

To have some fun

"Competitions are useful as it's a way for people to showcase their creative talents"



"I think competitions on the website are great because they keep it fresh"

You can win great prizes!

COMPETITION TIPS

To encourage more young people to join the web site

It is your chance to get involved with the community



You get to interact with the website

Post comments

You can share your experiences with others





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

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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

XXXI INTERNATIONAL CONGRESS OF THE WORLD FEDERATION OF HEMOPHILIA

11-15 May 2014

Melbourne, Australia

www.wfh.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.



CSL Biotherapies



Season's Greetings

On behalf of the Council and Staff of Haemophilia Foundation Australia, wishing you and your loved ones all the very best for a wonderful, safe and happy festive season.

Thank you for your invaluable support during the year. We look forward to continuing our partnership working to support people affected by bleeding disorders again in 2013.

The HFA office will be closed from Friday 21st December. The office will reopen fully on Monday 7th January 2013. During that time if you have any queries or need to contact HFA, please note that messages left on the answering machine will be monitored. If you have an urgent matter please contact Sharon Caris on 0410419914.



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