

National



Haemophilia

Haemophilia Foundation Australia

www.haemophilia.org.au

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HAEMOPHILIA AWARENESS WEEK COLOURING COMPETITION



See more entries inside!

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STAFF CHANGES



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and Wednesdays.

HFA has been fortunate to have Janine Staunton join the team in the role of Development Manager. Janine is employed in the position for a year until July 2011, while Natasha Coco is on maternity leave.

Janine comes to HFA with more than 10 years of experience in fundraising, including working with charities in the UK, such as the National Autistic Society and Crimestoppers, and more recently a dynamic role with a fundraising agency helping charities in Australia with their fundraising programs.

Over the next six months Janine's focus will be to build on HFA's current fundraising activities to develop a long term and sustainable fundraising program. In particular she is working on direct mail appeals and extending the bequest and regular giving programs, two main areas for long-term growth. This is an important new direction, which aims to ensure that HFA has enough income to sustain its work into the future.

"We have a brilliant group of loyal supporters to the Foundation who have been giving for up to more than 20 years to show their support," said Janine. "It's donations from these individuals that allow us to do the work we do; we couldn't do it without them. We're hoping there are other people in the community who would consider supporting us as well to help the new generations coming along in the future."

Taking up the position at HFA has meant getting to know the bleeding disorders community, which Janine has enjoyed greatly. "I didn't know a lot about haemophilia before I started," she commented, "but the more I learn, the more I'm really impressed by people's commitment, their warmth and their friendliness. It's such a close-knit community. People know they can rely on each other for support and it's great to be a part of that."

Many of you may have had contact with Janine already. She has been liaising with state and territory Foundations for the last few months about their funding requirements and has been keeping them informed of HFA's progress with trust applications as well as working with the community on Haemophilia Awareness Week activities. **H**

TRANSITION TO A NEW SCHOOL?

Sharon Caris

You are sure to have started planning by now if you have a child with a bleeding disorder who is starting at a new school, kindergarten or crèche next year. An exciting life stage like this is likely to be a significant event for everyone in your family, and it might also be the first time the kindergarten or school has had a child with a bleeding disorder in their care. It will be important that carers have an understanding of your child's care needs and how to deal with any problems that might occur.

It may be helpful to provide general information about your child's bleeding disorder and how it is usually managed, and a specific plan for your child that carers and teachers can use for when your child is in their care. Your Haemophilia Centre health professionals can help you to plan a good transition for you and your child. HFA or your local Haemophilia Foundation can also provide printed materials that may assist.

GOING ON HOLIDAYS?

PLANNING TRAVEL AND HOLIDAYS!

If you are going interstate or overseas for holidays you need to start planning early to make sure you have arrangements in place. Don't forget to start your planning early with your Haemophilia Centre to ensure you have sufficient clotting factor and equipment, other medicines and letters from your doctor to take with you. If you are going overseas make sure you have the necessary medical, customs and quarantine documents for your treatment product and equipment, both for leaving and returning to Australia and for the countries you are visiting. Even if you are in transit through a country, remember there may be documentation requirements to carry your clotting factor, needles and other medicines through security/quarantine/customs at airports.

Make sure you select carefully where you will travel, especially if you might need medical assistance. Check whether there is expertise in the care and treatment of people with bleeding disorders in the places you are visiting, and how you would access these services. Be aware that treatment may be limited, unavailable or unaffordable in many countries. Make sure you have appropriate travel insurance and a plan in the event that you have a bleed or have an accident.

If you have been issued with additional supplies of clotting factor for your trip, make sure you take care of it when you are travelling and that you bring any remaining product home with you – you will not be issued with more product on your return if you took larger quantities than your usual supply for that period away with you.

Make sure you contact your treatment centre staff well in advance so they can help you with your travel plans – especially for ordering supplies of clotting factor and the necessary documentation required during your travel. HFA can also provide more information about your planning for overseas travel. 



THANK YOU TO EVERYONE WHO SUPPORTED HAEMOPHILIA AWARENESS WEEK IN 2010

Haemophilia Awareness Week was held this year from 10-16 October. Haemophilia Foundation Australia (HFA) and Haemophilia Foundations around the country worked together with our supporters to raise awareness about inherited bleeding disorders. The theme this year was **"Life Challenges ~ the real issues"**.

We had a fantastic response and would sincerely like to thank each and every person who helped us raise awareness of the challenges faced every day by people with a bleeding disorder and celebrate the ways that they overcome these challenges.

We had incredible support from 50 schools, hospitals and local communities across the country that held events and displayed promotional materials and information about bleeding disorders. We also had individuals taking action on Facebook and other social media sites, which raised the profile of this important cause.

We would love to hear about any activities or stories from Awareness Week so we can share them with our supporters. If you would like to share your story, please contact Janine on jstaunton@haemophilia.org.au

Haemophilia Awareness Week Newsletter

Our Haemophilia Awareness Week newsletter is still available for download on our website.

In the newsletter you can read personal stories about the challenges of being a parent or growing up with a bleeding disorder and information about haemophilia and von Willebrand disorder.

A special thank you to Donna Field and the town of Neerim South.

Donna again organized "Paint the Town Red" during Haemophilia Awareness Week with posters, balloons and promotional items around the town and ran a sausage sizzle and sold red cupcakes! Thank you to Donna, her family and everyone in the local community for their continued support and for raising a fantastic \$425 for the Foundation.

Mufti day at St Johns School in Narraweena

In Term 3 each year, St John's Catholic Primary School in Narraweena choose a health issue for their Social Justice focus and this year they selected haemophilia which affects one of their senior students, Cameron Brown.

The school held a mufti day where of the children dressed in red and white and made a gold coin donation and the Year 3 children prepared lolly bags to sell at lunchtime. A highlight of the day was an assembly presentation by Cameron and the Social Justice team explaining to the children just what haemophilia is and what it means to Cameron on a daily basis.

We would like to say a huge thank you to all the staff and students at St John's who raised \$684.70 for the Foundation - what a fantastic effort!



Top: Students at St John's School in Narraweena on their mufti day for Haemophilia Foundation Australia.

Hugo raising awareness

We were thrilled to hear from Danielle Mitchell in Brisbane about her son taking part in awareness week.

Here is an image of my son, Hugo, presenting to his class during Haemophilia Awareness Week. Hugo is in year 2 at Eagle Junction State School in Brisbane.

This is the first time that Hugo has spoken to his class about haemophilia, and he did a great job. He plans to present to the entire school next year!

Thanks so much for sending the wrist bands, tattoos and book marks. They were a great hit with the kids!

Kind regards, Danielle Mitchell



Above: Hugo presenting to his class during Haemophilia Awareness Week.

BELOW IS A COPY OF THE FANTASTIC SPEECH WHICH HUGO GAVE TO HIS CLASSMATES:

Good morning 2CK.

It's Haemophilia Awareness Week this week, so I wanted to tell you a few things about haemophilia that you may not know.

Haemophilia is a bleeding disorder where the blood doesn't clot properly. There is no cure for haemophilia which means that if you have it like me, it will never go away.

Haemophilia is a genetic condition which means it can be passed down from one person in a family to another, such as a mother to a son like in our family. Usually only boys get haemophilia so my sister doesn't have it which is good.

The main problem people with haemophilia experience is bleeding into their muscles and joints. This can happen because of a knock or a fall or for no reason at all. This is why you sometimes see me on crutches or with my arm in a sling.

The only way to treat haemophilia is to put back into the blood the factor 8 that is missing. This is done using a needle into a port in your chest, or into a vein in your arm.

Mostly haemophilia makes me feel sad. It hurts when I get a bleed and I hate getting needles all the time. I also can't play AFL which I love.

But it's lucky I still get to do most of the things I love most of the time!

Thank you.

Thank you so much to Danielle for sharing this story with us, and a big thank you to Hugo for doing such a fantastic job of raising awareness about haemophilia.

Would you like to share your story with the bleeding disorders community? Please contact Janine on 03 9885 1800 or email jstaunton@haemophilia.org.au



COLOURING-IN COMPETITION

Thank you to everyone who entered our colouring-in competition. All entries were fantastic and were received from children from the age of 4 up to 11. Congratulations to Emily, aged 5, who was our lucky winner!

Left: Emily's Winning Entry.
Below: Other Outstanding Entries



HOW CAN YOU STAY INVOLVED?

You can still make a difference by giving your ongoing support to HFA and the bleeding disorders community:

- Learn more about bleeding disorders by visiting our website (www.haemophilia.org.au)
- Share this journal or our newsletter with others
- Register for our email newsletter or become a fan on our Facebook page to stay in touch with the latest activities
- Make a donation and support our programs and services including peer support, camps, workshops and education activities.

For more information about supporting the bleeding disorders community through Haemophilia Foundation Australia, please contact Janine on 03 9885 7800 or email jstaunton@haemophilia.org.au

Next year, HAW will be celebrated from 9-15 October 2011. H



HFA FACEBOOK PAGE

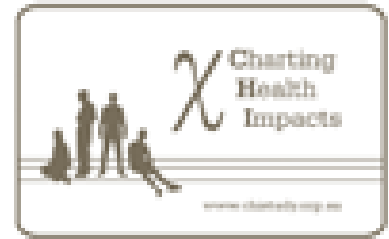
With more than 680 fans at last count, HFA's Facebook page has become a valuable communication tool to reach a wide group of people with bleeding disorders and HFA supporters.

HFA posts regular messages about current events and activities, updates on new issues of *National Haemophilia*, *Youth News* and new publications, like the von Willebrand disorder booklet and other news of interest to the bleeding disorders community. It's a place for people to connect with each other and with HFA and to give and receive support.

Some interesting facts:

- 25% of HFA Facebook fans are 13-24 years old
- 36% are 25-34 years old
- During Haemophilia Awareness Week 2010 the number of fans increased from 254 to 523 thanks to the efforts of a few dedicated supporters
- The page averages 345 visits per week. H

You can find the HFA Facebook page by searching for Haemophilia Foundation Australia in the Facebook search box – www.facebook.com



CHARTING HEALTH IMPACTS

The CHI (Charting Health Impacts) Study is about how hepatitis C affects peoples' lives and how people respond to hepatitis C. It is a national internet-based research study conducted by the Australian Research Centre in Sex, Health and Society (ARCSHS) at La Trobe University in Melbourne.

Why is this study so unique?

Unlike most research studies, which are really a snapshot of a situation at a specific time, the CHI study contacts a group of people over time, giving them a chance to share many of their experiences, good and bad, while they are happening.

Circumstances change for all of us. Because many people with chronic hepatitis C live with the virus for many years it is very likely that their lives will change. There may also be many changes to how people are able to deal with the virus from year to year. New information might become available, new treatments may be offered, new friends and supportive environments might form or they might break up. People who have lived with the virus for many years may feel very different about having hepatitis C than someone recently diagnosed. Someone who has just decided to go on treatment will probably be experiencing not only a range of new feelings but also have more interaction with the medical profession due to treatment demands. For people with bleeding disorders, there might also be complications from their bleeding disorder that impact on their hepatitis C or vice versa.

Having hepatitis C means different things for different people and it affects people in different ways. ARCSHS hopes the study will tell us about many experiences which have never before been documented. The study is an opportunity to talk about many experiences, which includes a range of health issues, but also broader social aspects of life. It is not a study just about health; it is a study about people who have hepatitis C. And it is an opportunity for people with bleeding disorders who have ever been diagnosed with hepatitis C to explain that unique experience and have that story documented in a national research study.

The study outcomes will help community organisations, the medical profession and governments when they plan for or deliver services and when decisions are made about funding. It will help these organisations and service providers to gain a better understanding of what it is like to live with hepatitis C.

Joining the Study

The study is all online. Joining the study involves taking an anonymous survey online. The researchers then contact people who have completed the survey three to six months later so that the person can explain how things have changed over that time.

If you have ever been told that you have hepatitis C and you want to find out more about CHI, you can access the website at www.chistudy.org.au

Let your experiences count – tell it how it is for you and have a voice in decisions that might be made for you in the future. **H**



AUSTRALIAN HAEMOPHILIA CENTRE DIRECTORS' ORGANISATION (AHCDO) UPDATE

Dr Megan Sarson

Education and publications

AHCDO held its Annual General Meeting and Education Day in mid November in Melbourne. This year's Education Day had speakers from WA, Queensland and local Melbournians discussing the medical management of problem joints and the presentations stimulated much discussion.

The AHCDO Chair, Dr Chris Barnes, from the Royal Children's Hospital, Melbourne, presented his annual report to members and noted the achievements of the past 12 months and the challenges which lay ahead. Achievements included the successful Education Day held in 2009, which brought together dental clinicians from around the country, in collaboration with AHCDO, resulting in the development of a consensus statement on the dental treatment of patients with inherited bleeding disorders. This statement has now been accepted for publication in the Dental Journal of Australia.

A variety of other clinical practice guidelines have been reviewed over the past year and when finalized, these too will contribute to the improved management of patients with bleeding disorders.

Achievements included the successful Education Day held in 2009, which brought together dental clinicians from around the country, in collaboration with AHCDO, resulting in the development of a consensus statement on the dental treatment of patients with inherited bleeding disorders.

Australian Bleeding Disorders Registry National Blood Authority

AHCDO has also been active in the development of a new professional group within the haemophilia community. The Data Managers Group (DMG) was established in 2009 as a forum for ABDR data managers to network and engage in professional discussions. The DMG has now met three times in person and has held a number of teleconferences. At each meeting the data managers are able to strengthen their ability to develop the ABDR as an important clinical tool for health professionals in HTC's.

AHCDO receives its funding from the National Blood Authority (NBA) and in turn offers advice to the NBA on a range of bleeding disorder issues, which this year have included FVIII demand forecasting, the anticipated change in usage associated with new and revised guidelines, the currency of NBA guidelines, the availability of rare bleeding products and also the overseas supply of blood product.

It has indeed been a busy year! **H**

AHCDO Membership

AHCDO itself underwent an important change at the end of 2009. HTC directors agreed to change the Constitution to allow for a broader membership base and as a result any Australian clinician who is actively involved in the treatment of bleeding disorders may apply to be an associate AHCDO member. The increased membership has allowed a more inclusive approach and has facilitated communication between clinicians. There are now 15 associate members.

AUSTRALIA AND NEW ZEALAND HAEMOPHILIA SOCIAL WORKERS' AND COUNSELLORS' GROUP MEETS IN MELBOURNE

Sharon Hawkins

Every year the members of the Australia and New Zealand Haemophilia Social Worker's and Counsellors' group (ANZHSWCG) have the opportunity to meet face to face to discuss and share information about the work we've done over the last year, psychosocial needs and issues that have arisen for people with inherited bleeding disorders and their families and provide support for each other in the roles we fill in our Haemophilia Treatment Centres and Haemophilia Foundations. We met this year for two days on Thursday, 9th September and Friday, 10th September at the Haemophilia Foundation Australia (HFA) office in Melbourne.

Communication between members of the group during the year is by email and occasionally by telephoning each other. Likewise communication with HFA is via telecommunication. Therefore the meeting was also an opportunity to advise and consult with HFA face-to-face on the psychosocial needs of people with inherited bleeding disorders and their families. We are very grateful to HFA for providing us with the opportunity to meet and would like to thank the staff for their outstanding organisation of our meeting.

This year we welcomed a number of new members to our group so it was very beneficial for all of us to have the chance to gather as a group and to also meet the staff at HFA.

Our meeting began with each member providing an outline of their preceding year's work, the issues that are arising in the area in which they work and what is planned for future activities. Each of the members of ANZHSWCG has different scope within their role to engage with people with inherited bleeding disorders. Hearing the individual worker's reports can provide others with ideas and strategies for providing support.

Many members of our group assist their local Haemophilia Foundation, to varying degrees, some organising and co-ordinating activities and others assisting by facilitating the peer support activities. The members shared their experiences of being directly involved in many group activities and education sessions either through their Foundation or in their individual role, including:

- New Family Meetings and camps
- Young family support groups
- Transition Day
- Parent carer groups
- Partner of people with HIV and Haemophilia groups
- Women with inherited bleeding disorders groups
- Rural outreach
- Venous access and self infusion workshop
- School staff education
- HTC and hospital staff education
- Wellness Weekend
- Girls Day Out
- Parents Empowering Parents
- Children's workshops
- Grandparents Day
- Youth Camp

Some of the other issues on our agenda for further discussion included:

- Current HIV and hepatitis C issues including treatment updates
- Medications and driving
- Sexuality and sexual health for people with inherited bleeding disorders and specific issues around gay community members
- The impact of aging and the complexity of medical issues together with an inherited bleeding disorder.

- Access to aged care services and the role of the psychosocial worker in providing education and information to community services.
- Sharing of information about disability and immigration for people with inherited bleeding disorders wishing to migrate to Australia and New Zealand.
- Feedback from Alex Coombs who was assisted by HFA to attend World Congress
- Planning for psychosocial input in the 2011 National Haemophilia Conference and the 2014 World Congress.

On Thursday, Sharon Caris (HFA Executive Director) and Suzanne O'Callaghan (HFA Policy Officer) attended our meeting to update us on HFA projects, HIV and hepatitis C strategies, progress of hepatitis C recompense, resources, availability of Fibroscan, new hepatitis C treatments, HFA Wellness Weekend, travel for people with inherited bleeding disorders, product supply and research amongst many other issues. ANZHSWCG gave feedback to Sharon and Suzanne on emerging psychosocial issues that HFA may have some input into.

On Friday afternoon, a member of our group, Phil Ohman (ACT) presented on Critical Incident Stress Management. Phil outlined stress and responses to Critical Incident stress, identifying similar responses in a new diagnosis of an inherited bleeding disorder.

We managed to squeeze a lot of talking, listening, discussing, thinking, sharing and supporting into our two days along with the exceptionally well catered morning, lunch and afternoon tea breaks. Thank you again to HFA for providing us with the opportunity to meet. **H**



Activities at the recent Haemophilia Foundation South Australia camp

Sharon Caris is Executive Director, Haemophilia Foundation Australia

HFA'S FUNDRAISING PROGRAMS

Sharon Caris

From time to time our *National Haemophilia* readers ask where HFA's income is generated and how we set our priorities. HFA's directions are set by its governing Council. HFA staff and volunteers develop and run the programs and activities. We are reliant on government grants and donations from our corporate partners which account for just over half of our income.

The remainder is sourced from donations from individuals, service clubs, grants from charitable foundations and fundraising events.

The grants we receive from the Department of Health and Ageing are extremely important to HFA as they fund recurrent costs for specific activities including our secretariat, Council meetings, newsletters and website, and health professionals' meetings which we undertake on a regular basis. Our remaining education and policy work is funded by donations.

HFA employs a Development Manager to undertake fundraising towards our national education and policy work and for camps and workshops run by state/territory Foundations. A letter has been enclosed with this issue of *National Haemophilia* asking for support for these camps and workshops.

For the last 8 -10 years HFA has guaranteed significant financial support to State/Territory foundations for camps and workshops run locally for their members. To fund these important activities, HFA has sought specific donations from private trusts and charitable foundations. However, a decrease in revenue from this source has forced us to raise increased amounts of general income from donations to meet this commitment.

Camps and workshops have always been an important way for people with a bleeding disorder to connect with others who have shared similar experiences and to learn how to manage their condition. From recent feedback, the camps are as relevant now as they were many years ago. I hope that you will consider supporting our camps and workshops by reading the letter enclosed and making a donation.

If you are interested in learning more about our development and fundraising program please contact either myself or Janine Staunton, Development Manager at HFA on 03 9885 7800 or email jstaunton@haemophilia.org.au . **H**

These gifts contribute to a stable financial grounding for HFA's long term programs and help ensure these outcomes for people with bleeding disorders are achieved. Even the smallest gift can make a difference.

BEQUESTS: A LASTING GIFT TO HELP FUTURE GENERATIONS OF PEOPLE WITH BLEEDING DISORDERS.

Gifts left to Haemophilia Foundation Australia by people through their wills have a major role in helping HFA to improve our programs and services and funding research that could one day lead to a cure for haemophilia and other bleeding disorders.

In recent years HFA has been fortunate to have received a number of gifts left by people through their wills. Their legacy has contributed to the future viability of our work.

The income we receive from bequests is used to support HFA's long term programs which focus on improving the lives of people living with bleeding disorders through better treatment and care, relevant support services and carefully funded research.

The bleeding disorders community has covered a great deal of ground over the last 50 years. Since the first haemophilia society was formed in Victoria in 1954, the support of donors has helped to achieve:

- A united voice for the haemophilia community throughout Australia with the formation of a strong national organisation in 1979
- Improved treatment centres and counselling services
- Education, support and advocacy for people affected by HIV and hepatitis C, and their families
- Ensuring sufficient supplies of safe treatment products for children and adults with bleeding disorders.

These are very substantial achievements.

However, there is still much more to be done. Over the next 5 years the Foundation needs to make sure health services can meet changing community needs. People with bleeding disorders need to be confident there will always be safe and secure supplies of treatment products to enable them to live well as they grow older. One of HFA's key roles in advocacy is to make sure everyone has access to high quality specialist care and treatment to ensure they have the best quality of life possible. All this can only be achieved with long term support.

Bequests, or gifts left to us by people through their wills, play an important part in this. These gifts contribute to a stable financial grounding for HFA's long term programs and help ensure these outcomes for people with bleeding disorders are achieved. Even the smallest gift can make a difference.

Leaving a gift in your will to a cause you care about is obviously a personal and important decision.

If you are interested in receiving more information about leaving a gift in your will, please contact Sharon Caris or Janine Staunton on 03 9885 7800 or email jstaunton@haemophilia.org.au

HAVE YOU SEEN A PHYSIOTHERAPIST RECENTLY??

Wendy Poulsen

- Joint and soft tissue bleeding episodes experienced by individuals with bleeding disorders have the potential to result in chronic musculoskeletal sequelae and movement dysfunction.
- Due to the physiotherapist's specialized training in evaluation and treatment of movement dysfunction they are a valuable part of a comprehensive team. At routine clinic visits they can identify any new musculo-skeletal issues and make appropriate recommendations.
- The physiotherapist is able to instruct the patient and their family in a comprehensive home care program to address individual needs, particularly following a bleed or injury. They can advise on early detection of a bleed; provide knowledge on how to treat a bleed following factor replacement and instruction on immobilization or splinting. Physiotherapists can also provide progression of exercises without the risk of causing further bleeding, as well as specific exercises for the individual problem areas.

The major role in the treatment of haemophilia is to maintain, or restore muscle and joint status, thus minimising the potentially disastrous effects that result from repeated bleeds.

Physiotherapists can:

- Improve muscle strength and co-ordination.
- Reduce pain.
- Prevent or reduce complications from bleeds.
- Assist in early resolution of a bleed.
- Offer advice in the prevention of further injury to susceptible joints /muscles.

- Promote safe involvement in fitness and sports participation
- Educate and stimulate people with haemophilia their families and friends to take an active role in their care.
- Provide advice for their chronic disease management.
- Assist with management of normal musculoskeletal issues.
- Provide of splinting, orthotics and assistive devices for optimal function.

So – if you haven't seen a physiotherapist recently; or perhaps you have had some problems with bleeding – call your physiotherapist at your Haemophilia Treatment Centre! **H**

Are you having a bleed...??

STEPS	<input checked="" type="checkbox"/> Factor Now <input checked="" type="checkbox"/> Start R.I.C.E Regime <input checked="" type="checkbox"/> Report Bleed
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FACTOR ALONE DOES NOT EQUAL TREATMENT
Physiotherapy means a speedy recovery & a safe return to activities

TO RECOVER QUICKLY FROM *bleeds* OR JUST SPRAINS OR STRAINS

R.I.C.E

Rest

Ice

Compression

Elevation

Factor in Physiotherapy
 Factor in a PHONE CALL

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TAKING ON THE FUTURE...

Suzanne O'Callaghan

From the time she was a small child Jodie Stephenson has wanted to become a doctor. Jodie has mild haemophilia. Some of her family members have other medical problems as well. Because of this, Jodie spent a lot of her time as a child and teenager in hospitals, learning about different types of medicine and developing a deep appreciation of what it means to be a doctor.

Her determination to achieve her life goal has meant that every choice she has made has been directed towards becoming a doctor. Hard work and commitment to study have been a big part of this. Jodie completed an undergraduate degree in radiography. Her studies and the work that followed it have given her an insight into the life of a doctor from the point of view of an allied health professional and have been invaluable in teaching her about how a health care team works. Combined with her knowledge of radiographic techniques, she has a head start on her chosen career.

Jodie's next step is to sit the Graduate Medical School Admissions Test (GAMSAT). Although the GAMSAT itself is held on a single day, the test measures the skills and knowledge a candidate has developed over time, as well as their ability to reason, make logical deductions and form judgments. Preparation for the GAMSAT is a training exercise for the test itself.

"When you are studying for the GAMSAT, the important factor to consider is time," says Jodie. "All study and practice questions need to be done under pressure to prepare you for the mental challenges of the Test – and

for practicing medicine itself. For example, in GAMSAT you need to write two essays in one hour, which with all the complex ideas you need to convey, is harder than it sounds. To coach myself, I am revising all areas of science and timing my practice questions. But this is what life is like as a doctor – making sound decisions quickly under pressure – so it's actually a great grounding for the future."

Winning a Vision and Leadership Award has meant that Jodie can pay for the costs of preparing for and sitting the GAMSAT in March 2011. If she is successful, she will be able to apply for admission to a university degree in medicine. And when she has completed her medical degree? In the future Jodie hopes to be able to use her medical training to be able to make a difference for the bleeding disorders community – helping with education programs and acting as an advocate for her community.

The opportunity provided by the Award means a great deal to Jodie and she is proud to be part of a community which enables young people to pursue their goals. Jodie recently married (she is now Jodie Caris), another life-altering event which caused her to reconsider her values and her future and confirm her commitment to her career path. It's a commitment not only to her own future but to the bleeding disorders community as well – and Jodie says, quoting Gordon Brown, the former British Prime Minister, "you don't win your future by retreating from the world, but by engaging with it." **H**

The Vision & Leadership Awards were developed by HFA with generous sponsorship support from Wyeth (Pfizer) in 2007. Since then 19 Awards have been given to people affected by a bleeding disorder around Australia.



WORLD AIDS DAY – DECEMBER 1

People around the world observe World AIDS Day on 1 December to raise awareness about HIV and remember those who have died of AIDS. In 2010 the theme for World AIDS Day is *"Take action. No discrimination"*. HIV is still with us in our community. However, HIV-related stigma and discrimination continues to exist and it's time to take action about it and challenge it.

In Australia the HIV antibody test was introduced in 1985. It was a great shock to the bleeding disorders community to find that quite a number of adults and children with bleeding disorders had acquired HIV from their blood clotting treatment products. At the time many experienced stigma and discrimination in an Australian community that was afraid and uneducated about HIV. In 2010, 25 years later, in spite of widely available information and education, stigma and discrimination are still big issues for Australians living with HIV, and HIV positive people with bleeding disorders experience this as well as others in the community. At a time when treatments have improved so much that many Australians with bleeding disorders and HIV have better health than they have had for many years, stigma and discrimination can still mar their quality of life.

Strategies for dealing with stigma

The National Association of People Living With HIV/AIDS (NAPWA) has marked World AIDS Day by launching a new Stigma Audit web site – a survey for people with HIV to describe their experiences of stigma, how stigma affects their quality of life and mental health, and to give examples of strategies they use to overcome or manage stigma and /or discrimination. The survey is at www.hivstigma.net.au. The aim is to turn this research into practice – to use the ideas given by people who respond 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."

A time of remembrance

On World AIDS Day we have the opportunity to pause and acknowledge the people with bleeding disorders and their partners and families in Australia and around the world who have been affected by the HIV/AIDS epidemic and remember those who have died. Since then haemophilia treatment product safety has improved greatly. The risk of new infections from using human blood products is now thought to be extremely low – Australian plasma-derived clotting factor treatment products are now tested and inactivated for HIV and hepatitis C and most people with bleeding disorders use recombinant treatment products, which are genetically engineered and contain little or no human material.

Showing support

On World AIDS Day many people around the world wear a red ribbon as a symbol of sympathy, support and hope for a day without AIDS. In 2010 Australians were also asked to wear the red ribbon as a symbol of their commitment to challenge the stigma and prejudice surrounding HIV.

What can you do to show support?

- Wear a red ribbon on World AIDS Day to show solidarity and support
- If you have HIV, consider completing the Stigma Audit to share your experiences and strategies with others – www.hivstigma.net.au
- Find out more about HIV and World AIDS Day and tell others – family, friends and colleagues – www.worldaidsday.org.au 



NEW VON WILLEBRAND DISORDER BOOKLET

What do people with von Willebrand disorder (VWD) need to know to live well? This was a question the review panels for the new HFA booklet on VWD challenged themselves to answer. Two volunteer groups, one a panel of people with VWD or parents of children with VWD, the other a panel of expert health professionals, worked with HFA to develop key messages and topics to cover and make sure the information was accurate, relevant to Australians and right up-to-date with the very latest research information.

The new booklet, *A guide for people living with von Willebrand disorder*, covers a range of topics - an explanation about VWD, what it is, symptoms, diagrams on how inheritance works, diagnosis, treatment, and special issues for women and girls. It also includes a large section on living well with VWD, with information on sport, travel, school, first aid, work, bringing up your child and telling others. Throughout the booklet there are quotes and tips on managing VWD from people or parents of children with VWD.

Our thanks to the review panels who made a massive contribution to the booklet while it was being developed over the last 18 months.

Print copies of the booklet can be ordered from HFA by emailing hfaust@haemophilia.org.au or calling 1800 807 173. The booklet can also be downloaded from the HFA web site – www.haemophilia.org.au >Publications. 

AIDS 2010: A POSITIVE LIGHT?

This article is abridged from an article published in *poslink*, October 2010, the magazine of People Living with HIV/AIDS Victoria Inc, and is reprinted with permission.

David Menadue

There were many speakers at this year's World AIDS Conference who were trying to see things in a positive light. Opening Plenary speaker Professor Sharon Lewin from the Alfred Hospital in Melbourne took a proactive look at the strategies researchers needed to take to find a cure for AIDS. Former US President Bill Clinton ended his up-beat speech on better ways to fund HIV with the observation that scientists had found in the creation of matter that there were "slightly more positive ions than negative ones". In an address which spoke of the success of circumcision roll-out in many African countries and some improvement in the use of antivirals to prevent transmission from mother-to-baby, Bill Gates suggested that "if we did everything that we have now, we could reduce infections by 90% in many countries".

In a conference with few treatment surprises, Professor Lewin laid out potential strategies for a cure. These included "the sterilising cure" or traditional model, which sought to eliminate HIV-infected cells. There were difficulties with current antiviral approaches that could not eliminate the latently infected cells which hide in reservoirs in the body. She saw potential for the use of new T-cell activation inhibitors, gene activation and genetic therapy to make T-cells resistant to HIV. New research was proceeding funded by the National Institutes of Health (NIH) in America which might lead to new treatment approaches in a few years' time.

The most excitement around treatments came from the announcement of the results of the CAPRISA microbicide trial in South Africa. The trial showed a 50% reduction in infections in women who used the vaginal gel (containing Tenofovir) after twelve months and 39% after 30 months. While this is not a huge breakthrough, it does show a benefit in microbicides that will mean there is value in further developing them. There are suggestions there may be a microbicide for women on the market by 2014 and possibly an anal microbicide by 2018—admittedly a long time away.

There was also an interesting panel session on when to start antiviral therapy. Professor Steven Deeks from the University of California (San Francisco) commented on the recent US Guidelines which have been changed to recommend starting treatment at 500 CD4s. The UNAIDS endorses a start at 350 (also the current Australian guidelines). Deeks said people needed to weigh up the benefits: maybe starting at 500 may only give you an extra few years' life expectancy (say 40 instead of 37) but the new information about inflammation and ageing in PLHIV was suggesting that stopping viral replication earlier may have real advantages to future quality of life considerations.

Focus on Human Rights

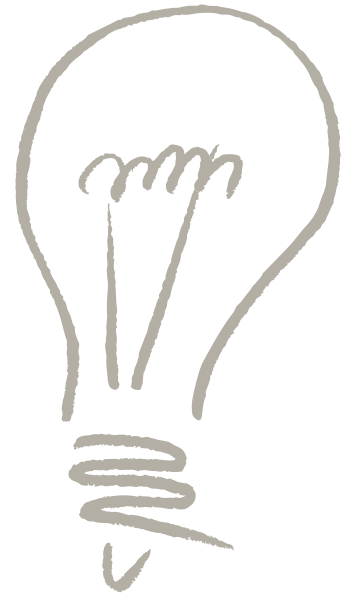
In an epidemic though where 7400 people are infected and some 3000 die every day, no one could put much

of a positive spin on the ongoing global crisis HIV will be for many years to come. President of the International AIDS Society (IAS) Julio Montaner was scathing of the G8 and G20 countries' decisions to reduce new funding for the Global Fund, saying that when banks needed bailing out in the financial crisis, money was found but "for global health, the purse is always empty." Montaner gave a special emphasis to the fastest growing epidemic in the world, in Eastern Europe where only 23% of the HIV-positive population receive antivirals and every fourth person with HIV is in prison.

Long Term Complications of ART

My main interest in attending this conference was to find out the latest on ageing with HIV. In a session on the long term complications of ART (anti-retroviral therapy), Dr Paddy Mallon from Ireland said that there was evidence of lower bone mineral density in about half the HIV positive people studied in cohorts to date, leading to a greater risk of osteoporosis and osteopenia. This contributed to a higher prevalence of fractures in HIV-positive people occurring at an earlier age (50s and 60s) than their HIV-negative peers (where it usually occurs from the 70s). Nearly all ARV regimens contribute to the bone loss experienced. Dr Mallon said it was uncertain whether Vitamin D supplements will help to solve the problem although they were beneficial to general health.

Another presentation in this session looked at PLHIV and the increased



cardiovascular risk. Dr George Behrens from Germany said that while the DAD study showed cardiovascular disease only contributed to 10% of deaths, clinicians needed to look at risk factors in positive people at a younger age and where possible, change therapy to reduce the risk. We now know that HIV infection itself interferes with systemic inflammation in the body and that some drugs contribute to this as well. Protease inhibitors such as Indinavir and Lopinavir added to the risk but the research was still unclear about the role of Abacavir. Diet modification to reduce lipids, giving up smoking and managing diabetes and blood pressure abnormalities were important interventions.

In the sensitive subject of HIV in the brain, Dr Victor Balfour from UCSF in the US said that cognitive impairment was the "silent epidemic" of HIV. It is an active disease, immunologically based, with some cohorts such as ACTG showing up to 39% of the positive population has some impairment when commencing treatment.

The good news is that HIV-associated dementia is rare, affecting only 1-2% of the population. HIV-Associated Neurological Disorder (HAND) was more prevalent, with, for instance, some patients finding multi-tasking difficult. A job that might take someone with no problems 8 hours to do may take someone with HAND 10 hours. Contrary to some perceptions there are things people can do to improve brain function: stopping smoking, getting regular exercise, staying at work or getting involved with thinking tasks can help.

HIV and Ageing is becoming a major topic of discussion here in Australia with a recent NAPWA (National Association of People Living with HIV/AIDS) forum on the subject looking at ways to prepare for these issues here. Hopefully the topic will achieve more coverage at AIDS 2012 in Washington than the couple of sessions which were allocated to it at this conference. Let's hope there is more news on a cure as well! **H**



HFA NATIONAL SURVEY 2010

Our thanks to those of you who completed the HFA National Survey. The Survey closed on 30 November 2010. We were pleased to receive more than 200 responses with helpful comments and feedback, which will be very valuable for HFA's planning now and for the future. Results will now be analysed and summarised in National Haemophilia in 2011.

*Prizes will be drawn for the Survey Prize Draw on 14 December and winners announced on the HFA web site – www.haemophilia.org.au. **H***

NATIONAL HAEMOPHILIA FOUNDATION RAFFLE

The raffle was drawn Friday 29th October 2010 at 1624 High Street, Glen Iris VIC at 4pm (AEDST). All winners have been notified.

1st PRIZE ~ SONY Bloggie RRP \$299.00

Kindly donated by Midland Retravision

Winner: Ticket No 2469 – J Garlinge

2nd PRIZE ~ Buffalo External USB Hard Drive RRP \$199.00

Kindly donated by Midland Retravision

Winner: Ticket No 2142 – M & L Goncalves

3rd PRIZE ~ Natio Skincare Hamper RRP \$150.00

Kindly donated by Natio

Winner: Ticket No 1940 – S Slavin

4th PRIZE ~ iSUBSCRIBE! voucher RRP \$50.00

Kindly donated by iSUBSCRIBE!

Winner: Ticket No 2239 – E Cunningham

*Thank you to all supporters. **H***

FOOD FOR THOUGHT: HIV/HEPATITIS C CO-INFECTION AND NUTRITION – PART 1

Lia Purnomo

Given the efficacy of highly active antiretroviral therapy (HAART), Australians with HIV are living longer. However, lifestyle related co-morbidities are now becoming increasingly evident among HIV/hepatitis C co-infected patients. The co-morbidities are attributable to a range of factors, some of which can be addressed by dietary changes.

Alcohol

Heavy alcohol intake is associated with an increased risk of liver damage. Research also shows that alcohol adds extra kilojoules to the diet and may increase energy intake further by increasing appetite,¹ which may affect an individual's tendency to gain weight.² High alcohol consumption and being overweight are two factors that might lead to a poorer health outcome in people co-infected with HIV and hepatitis C.³

Current guidelines recommend that generally, both men and women should not drink more than two standard drinks per day (20g/day) – a standard drink being one schooner of light beer, one middy of full strength beer, one standard glass of wine or one nip of spirit.

These guidelines are not suitable for people living with HCV, who should consider avoiding alcohol altogether – particularly people with hepatitis C who have evidence of liver damage.⁴

Body weight

The incidence of being overweight and obesity is increasing in people living with HIV, both in Australia and internationally. This means that the incidence of obesity-related disorders, such as cardiovascular disease and diabetes are also on the rise among people living with HIV. The transition appears to be a result of effective anti-retroviral treatment, poor eating choices and low levels of physical activity^{5,6} – similar trends to those in the general population.

In chronic hepatitis C infection, obesity is associated with: inflammation, insulin resistance, fatty liver, progression of fibrosis, and non-response to treatment with interferon or peginterferon alpha and ribavirin.⁷ Modest weight loss

increases the chance of better response to treatment and improves liver enzymes and serum insulin levels.⁸

Maintaining a normal weight by monitoring food intake and physical activity is important in people with HIV/hepatitis C co-infection. Successful weight management requires establishing a life-long commitment to a healthy lifestyle.

Some tips for effective weight management include:

- Aim for slow weight loss (0.5–1kg a week)
- Focus on eating healthy foods
- Cut back on refined sugars
- Eat less takeaway and processed foods
- Reduce the size of portions for calorie reduction
- Aim for at least 60 minutes or more of moderate intensity physical activity on most, if not all, days of the week (eg. 30 minutes walking and 30 minutes lifestyle activity), and
- Forget crash diets, as the lost weight is most likely regained within years.

Insulin resistance and metabolic syndrome

Insulin resistance is the condition of decreased tissue sensitivity to the actions of insulin. It is associated with Type 2 diabetes as the pancreas cannot keep up with the body's need for insulin and excess glucose builds up in the bloodstream.

Type 2 diabetes and insulin resistance are becoming more common in people living with HIV due to the adverse metabolic effects of highly active antiretroviral therapy (HAART – particularly protease inhibitors), the effect of lipodystrophy and the impact of the obesity epidemic.⁹ The hepatitis C virus, regardless of genotype, has also been shown to induce insulin resistance.¹⁰

People with HIV/hepatitis C co-infection who are on HAART have been reported to have a higher incidence of insulin resistance,¹¹ and lower total and low density lipoprotein (LDL) cholesterol than HIV mono-infected individuals.¹² HIV and hepatitis C have been linked to



metabolic syndrome – a collection of manifestations including high body mass index, low high density lipoprotein, high triglycerides, insulin resistance and high blood pressure – as they demonstrate similar pathophysiologic pathways. Metabolic syndrome is a risk factor of cardiovascular disease. The similar risk factors for metabolic syndrome are also associated with hepatic and metabolic dysfunction leading to fatty liver and other complications.^{13,14}

There is no 'quick fix' solution that is effective for the management of metabolic abnormalities. Studies have shown that lifestyle modification focusing on healthy eating, weight management, smoking cessation, and increased physical activity is essential to reduce risk of cardiovascular disease and type 2 diabetes in high-risk populations.^{15,16,17,18} **H**

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HEP C PROPOSAL FOR FINANCIAL ASSISTANCE

Gavin Finkelstein

HFA has proposed a financial assistance scheme to governments for people with bleeding disorders who have acquired hepatitis C through their blood products.

The proposal to the Federal government and State/Territory Health Ministers results from a long consultation with HFA member foundations and people with bleeding disorders affected by hepatitis C around Australia. Many individuals have come forward to describe the difficult situation they are in due to their deteriorating health and financial circumstances. The HFA proposal includes a cumulative payment schedule according to disease progression, and additional financial benefits for people with bleeding disorders and hepatitis C and their spouses, families and dependents to cover the medical, social and economic impact on their lives:

- Financial and social assistance with out-of-pocket health care costs, treatment, disability, loss of income, managing grief and loss issues
- Universal health care card access and prioritized public housing
- Subsidised insurance and superannuation cover.

The scheme has been developed around the actual costs to the Australian bleeding disorders community of managing the additional health and wellbeing costs associated with hepatitis C over their lifetime, and are based on models developed in countries overseas with similar bleeding disorder patient populations and health systems, such as Canada, United Kingdom, New Zealand and Ireland.

The payment system would be available incrementally over a person's lifetime and would be made where costs to the individual are highest. The scheme would cost on average around \$11 million per year over 20 years or less per year over a longer period or if treatment success rates improve.

In response to the increasingly desperate situation that many affected people find themselves in, HFA put this model to the Federal Government in February 2010. There have been some discussions and correspondence since, and additional information about the overseas schemes has been provided.

The proposal is based on the model HFA put to the Senate Inquiry into Hepatitis C in the Blood Supply in 2003. In 2004 the inquiry made some recommendations about financial support for people with bleeding disorders who

acquired hepatitis C from the blood supply. So far these recommendations have not been implemented.

HFA has been encouraged by the response of State and Territory governments, as most have indicated a willingness to discuss the matter again at a national level. Meetings with the State and Territory Health Ministers have commenced HFA met with representatives from the Federal Health Minister's office and the ACT Health Minister in early November 2010. We await their response, but we will actively pursue this matter with all governments so people get the help they need.

Why is the scheme needed?

The HFA proposal recognises that hepatitis C is a difficult condition for all people who live with the condition; however, it has been developed for people living with the complexities of having a bleeding disorder and hepatitis C and in recognition of the very serious problems that result.

The ex-gratia no-fault financial assistance scheme is proposed specifically for people with bleeding disorders who acquired hepatitis C as a consequence of their treatment and it only relates to hepatitis C acquired through clotting factor treatment before hepatitis C testing and viral inactivation processes became available. People with bleeding disorders have not been eligible for the compensation schemes established by governments for medically acquired hepatitis C. The deteriorating health of community members has made this an increasingly urgent issue.

Because they have both conditions, people with bleeding disorders and hepatitis C also need much more complex care. Hepatitis C compounds the problems people already experience with haemophilia and can make health and disability problems overwhelming. Many people have to stop or reduce work by their late 30s. The conditions become more complicated and impact on each other, especially over time and as people grow older. This can have serious, sometimes life-threatening, implications for their health – for example, a person might not be aware their liver disease has escalated until they have developed liver cancer because they are trying to deal with severe fatigue and needing a joint replacement; or they may not realise they are developing a serious joint infection because of the fatigue and nausea related to their hepatitis C.

Having hepatitis C as well as haemophilia complicates many other aspects of life. A major problem is that it can exclude people from some of the financial safety nets available. Many people with haemophilia and hepatitis C are not eligible for life, travel and mortgage protection insurance; some are not eligible for superannuation.

Ironically, some people with haemophilia and hepatitis C are also excluded from financial safety nets because they try to continue working and staying self-sufficient as long as they can. As a result these people do not have a health care card or other pension benefits. It is a very stoic community: people with haemophilia are taught from the time they are children to plan a working career that accommodates their arthritis and mobility problems and to save and buy a house or flat early because they know their working life will be limited. So they try to stay working and supporting their families as long as possible – but with hepatitis C can end up being the “working poor”. They already need unpaid time off to manage their many appointments and for bleeds. The symptoms of hepatitis C – among them, severe fatigue, brain fog and nausea – can stop them working early or result in them working casually or part time in their late 30s. They cannot afford all the extra costs with treatment and care, pharmacy and GP costs, tests etc. In addition, most cannot afford to take time off work to have treatment because they are already struggling financially.

Typically there are many hidden out-of-pocket costs with managing their health and wellbeing for people with haemophilia and hepatitis C, whether they receive government benefits or not – it’s a double whammy. Each condition complicates the other and means they need to deal with an increasing number of health complications, which means more over-the-counter medications to manage pain and other symptoms, more visits to the hospital and the GP with associated travel costs, more need for other therapies, home help and other care not covered under the public health system. The Senate Inquiry also recognised this was an issue when it recommended financial assistance, stating that “these costs can be substantial and impose financial hardship on hepatitis C sufferers and their families”.

HFA believes it is essential and urgent for a scheme to be established to deal with these very serious financial and health issues and provide the support necessary for people with bleeding disorders affected by hepatitis C. HFA will continue to pursue this actively. **H**

The HFA proposal includes a cumulative payment schedule according to disease progression, and additional financial benefits for people with bleeding disorders and hepatitis C and their spouses, families and dependents to cover the medical, social and economic impact on their lives...

SLEEP RIGHT, SLEEP TIGHT



Our sleep patterns change as we get older. Developing good sleep habits is a more effective way of solving sleep problems than resorting to medicines. Sleeping tablets usually make sleep problems worse, not better, in the long term. They can also cause side effects, even those bought without a prescription. If you don't sleep well, some of these strategies might help.

Reset your body clock

We all have an internal 'body clock' that controls our daily cycle of becoming sleepy in the evening, sleeping through the night, and waking up in the morning. Being 'in sync' with your body clock makes it easier to sleep.

You can help to set your body clock by consistently going to bed and getting up at the same time every day, regardless of how well you slept the previous night. If you can't get to sleep within 20 minutes, get up and do something relaxing in another room until you feel sleepy again. Persist with this routine until you develop a regular sleep pattern. It will also help your body to associate going to bed with sleep rather than sleeplessness and frustration, which, in turn, will help you to sleep better.

Sunlight also helps to set your body clock, so try to get outside in the sun for a while every day.

Some people can sleep well despite having a short nap in the afternoon. However, if you're having trouble sleeping at night, avoid having a nap during the day. If you do nap, keep it to only 20 minutes before 3pm.

Have a bedtime routine

Doing the same things each night in the last half hour or so before going to bed helps to remind your body that it's time to go to sleep.

Your bedtime routine might include things like having a light bedtime snack or glass of warm milk, having a warm bath, reading, or listening to music, the radio or a talking book. Avoid computers.

Be comfortable

Keep the bedroom dark while you sleep. Even dim lights, such as those from a television or computer screen, can disturb the body clock and result in poor sleep.

Try to keep your bedroom and bed at a comfortable temperature. Being too warm or cold is a common reason for waking up frequently in the night.

Relax your mind

You can't sleep well if your mind is not relaxed, so try not to take your day-time stress, anger or work to bed with you. Also, avoid work and activities involving concentration, such as working on the computer, late in the evening.

If you can't relax because of chronic worrying, stress or anger, consider learning some relaxation techniques to help you 'switch off', or seek help from a GP or counsellor.

Avoid stimulants

Avoid caffeine drinks, such as tea, coffee, energy drinks and cola, close to bedtime and maybe even from early afternoon. Milk contains tryptophan, which has been shown to enhance sleep, so consider a warm milk drink instead.

Alcohol before bedtime may help you to dose off. However, it also disturbs the normal sleep rhythm, so you won't tend to sleep as well.

Get regular exercise

Being physically active during the day makes it easier to fall asleep and improves how well you sleep. However, the timing is important. Exercise too late in the day stimulates the body and raises body temperature, making it harder to sleep. Exercise in the morning or afternoon gives your body time to wind down and cool down.

Getting back to sleep

If you wake up during the night, relax and try not to get stressed. Try some relaxation techniques or a repetitive, non-stimulating activity like counting sheep. Remind yourself that although it's not as good as sleeping, resting in bed can still refresh your body. If you've been awake for more than 20 minutes, try getting out of bed and doing a quiet activity in dim light until you feel sleepy again.




Tackle underlying problems

Poor sleep can be a side effect of some medications and some chronic conditions, including depression, anxiety and sleep apnoea. In these situations, treating the underlying problem often alleviates the sleep problem.

If you have sleep problems, talk to your doctor or pharmacist, and tell them about any other symptoms you may be experiencing. If their suggestions don't help, consider asking for a referral to a sleep specialist or sleep clinic, so your sleep problem can be investigated.

Get NPS resources

NPS has some resources to help you get a good night's sleep. They can be ordered from the NPS website.

- The *Sleep right, sleep tight* fact sheet has advice about sleep, sleep problems and things you can do to improve your sleep.
- If you're having trouble sleeping, use the Sleep diary to help you work out what might be affecting your sleep. Take it to your doctor to use as basis for discussing your sleep problems. 

ANZ HAEMOPHILIA CONFERENCE IN SYDNEY IN 2011

The 2011 Australia and New Zealand Haemophilia Conference will be held at the Novotel, Sydney Olympic Park in Sydney, 20 - 22 October 2011.

HFA is currently establishing committees to plan for the conference. Conference sessions will cover clinical and psychosocial aspects of living with bleeding disorders and treating and care for bleeding disorders. As usual there will be sessions which feature current issues and debates of interest to patients and their families, health professionals, government officials and industry.

In a new joint initiative with Haemophilia Foundation of New Zealand we are also planning an Inhibitors Workshop for people affected by inhibitors to be held after the conference. This will be for patients with inhibitors and their families who wish to learn more about up to date treatment and care and improving quality of life. Some funding will be available for people to attend the workshop.

For inquiries about the conference contact Sharon Caris at HFA on 03 9885 7800 or email hfaust@haemophilia.org.au

For conference updates visit:
www.haemophilia.org.au 

CALENDAR

Haemophilia Awareness Week

9 -15 October 2011

Phone: 03 9885 7800

Fax: 03 9885 1800

Email: hfaust@haemophilia.org.au

www.haemophilia.org.au

2011 Haemophilia Conference, Sydney

20 - 22 October 2011

Novotel, Sydney Olympic Park,
Sydney NSW

Phone: 03 9885 7800

Fax: 03 9885 1800

Email: hfaust@haemophilia.org.au

www.haemophilia.org.au

XXX International Congress of the World Federation of Hemophilia

Paris, France 2012

www.wfh.org

XXXI International Congress of the World Federation of Hemophilia

Melbourne, Australia 2014

www.wfh.org

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SEASON'S GREETINGS!

The Council and Staff of Haemophilia Foundation Australia wish you a safe and happy festive season. Thank you for your support during the year and we look forward to working with you again in 2011.

The HFA office will close on Thursday 23 December 2010 and will reopen on Monday 3 January 2011. If you have any queries or need to contact HFA, please leave a message on the answering machine. However, if the matter is urgent, please contact Sharon Caris on 0410419914. **H**



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