

National



Haemophilia

Haemophilia Foundation Australia

www.haemophilia.org.au

No. 175, September 2011

CELEBRATE

HAEMOPHILIA AWARENESS WEEK 2011

9-15 OCTOBER 2011

**HEALTH AND
WELLBEING INTO
THE FUTURE -
THE DECADE AHEAD**

CONTENTS

| | | | |
|----|--|----|---------------------------------|
| 2 | Haemophilia Foundation South Australia | 12 | The importance of good footwear |
| | Corporate partnerships | 15 | Report from Dubai |
| | Vale Peter Mathews | 17 | HIV futures 7 |
| 3 | From the President | 18 | Making changes |
| 4 | Haemophilia Awareness Week 2011 | 19 | World Hepatitis Day |
| 5 | All In The Family – WWD interview | | |
| 7 | Haemophilia Conference | | |
| 8 | Haemophilia Conference Program | | |
| 10 | Youth Project Officer | | |
| 11 | Beyond Prophylaxis youth project | | |

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HAEMOPHILIA FOUNDATION SOUTH AUSTRALIA

We have previously reported that HFSA has been operating with small committee member numbers to the point where it has become unviable. HFA will continue to support activities in South Australia and to keep a watching brief on the needs of the bleeding disorders community. We plan to report activities to keep in touch and will work closely with health professionals at Haemophilia Centres to have access to information about things that might affect community members. HFA newsletters will be distributed by Haemophilia Centre staff and HFA will make sure issues affecting people in South Australia are communicated in different ways so people can keep in touch.

We are delighted that funding from HFSA reserves and education grants from Pfizer and Novo Nordisk with support from HFA meant it was possible to run a Parents Empowering Parents program (PEP) in Adelaide recently. We thank Anne Jackson, clinical nurse consultant at the Women's & Children's Hospital, and Sharon Hawkins, Haemophilia Counsellor from Western Australia, for running this program for the South Australian parents who attended. ■

CORPORATE PARTNERSHIPS

Haemophilia Foundation Australia (HFA) is committed to working with governments, industry and other stakeholders to support the quality use of medicines and to improve the education of consumers about the medicines and treatments they use.

An important aspect of this education work is supported by the HFA Corporate Partnership Program which provides valuable sponsorship of some of its education activities for people with bleeding disorders.

We sincerely thank Baxter Healthcare for their participation in the HFA Corporate Partnership Program since 1998. We welcome Bayer back to the program and look forward to the work we will do as part of this valuable partnership. ■

VALE PETER MATHEWS

The HFA Council and Board acknowledges the passing of Peter Mathews on 5 September 2011. Peter served as a respected Council member representing Haemophilia Foundation New South Wales (HFNSW) for many years and held the office of HFA Vice President from 2003-2009. Peter was also employed as the Executive Officer of HFNSW for more than 10 years. Peter was loved and respected by everyone in the bleeding disorders community and everyone at HFA expresses their sympathy to Peter's family. ■

NOTES FROM THE PRESIDENT

Gavin Finkelstein

Over 32 years ago in 1979 the Haemophilia Societies of Victoria, New South Wales and South Australia came together to form the Australian Federation of Haemophilia Societies.

Our state/territory Haemophilia Foundations and HFA were not always here – they grew from parents realizing they wanted to be connected with others who shared similar experiences, so they could support each other and because they recognized advocacy was needed to get health services they required and address gaps as services were emerging, and as treatments became available, to try and increase access to them. A key driver for HFA was to meet the needs of people affected by blood borne virus infections through unsafe blood and blood products when HIV and hepatitis C came through the blood supply. The advocacy skills of many of our volunteers were needed to improve care and treatment and develop models of support and education for people with bleeding disorders and their families, and to secure supplies of clotting factor.

HFA emerged as a strong organisation in the early 1980s and it has continued to respond to issues, support people with bleeding disorders, and advocate for a supply of safe treatment products. I am pleased HFA is able to respond to issues as they arise. For example, while we are addressing the needs of youth in our community, we are also keeping our eye on the issues that are emerging for our older members and looking at ways we can help.

Our state/territory Foundations continue to offer a range of services and activities to their members. Not only do they advocate with governments at a state level to make

sure care and treatment is up to date and well organised, but they keep their fingers on the pulse of local services and activities that may be relevant to people with bleeding disorders in their state/territory. They also provide many benefits to members – some offer subsidies for good footwear, ambulance cover and medic alert subscriptions for example. These are tangible, practical ways to make a difference for individuals and families who are faced by many expenses as they get on with their daily lives. Local Foundations encourage peer support activities for different parts of our communities, run camps and workshops and collaborate with HFA to make sure we are all aware of emerging issues and take action.

HFA provides support to local Foundations in different ways through the development of education materials, information kits and templates for addressing common issues. This is an important time of the year, as the delegates of our member Foundations are preparing to attend the HFA Council meeting and Annual General Meeting after the conference in Sydney where we will be addressing many issues together and making plans for the future. Our Foundations, including HFA, operate with lean budgets and we do a lot with very little by sharing information and ideas and making information available and accessible at different levels. I look forward to seeing you all at the upcoming Conference and to reporting on our achievements at the Council meeting.

The topics selected by the Program Committee for the Sydney Conference are wide ranging and include personal stories from people living with bleeding

disorders as well as information about how to look after yourself better if you have a bleeding disorder. There will be sessions to help parents with young children with bleeding disorders and sessions for youth and adults. In addition to information about the care and treatment of bleeding disorders and practical living tips there will also be challenging sessions about best practice policy for haemophilia services and how decisions should be made. A crucial issue for discussion will also be how we, as a community, are responding to the escalating cost of clotting factor treatment and how we are playing our part in ensuring governments get value for their expenditure on our treatment and care.

We are pleased to be welcoming representatives from the National Hemophilia Foundation of Thailand and Thai Patients' Club to the Conference and our upcoming Council meeting.

See you in Sydney! ❖



**Health and wellbeing
into the future**
– the decade ahead

Haemophilia Awareness Week • 9-15 October 2011

HAEMOPHILIA AWARENESS WEEK 2011

WHAT IS HAEMOPHILIA AWARENESS WEEK?

Haemophilia Foundation Australia and Haemophilia Foundations around the country work together to raise awareness in the wider community, community organisations and governments about inherited bleeding disorders. The theme this year is “Health and wellbeing into the future – the decade ahead”.

WHEN IS HAEMOPHILIA AWARENESS WEEK?

During the week of 9-15 October 2011 a number of local events will take place across Australia including promotion across schools, hospitals, doctors’ clinics and workplaces. HFA will also have information and resources on its web page and Facebook page.

HOW CAN YOU HELP?

There are many ways you can help raise awareness of bleeding disorders during Haemophilia Awareness Week.

Here are some ideas:

- set up a stand in your workplace, school, hospital or library
- organize a colouring in competition at your or your child’s primary school or kindergarten
- hand out promotional items in your local area
- organise a casual clothes day at your workplace or school
- organise a luncheon, sausage sizzle or morning/afternoon tea
- pass on information about Haemophilia Awareness Week to your family and friends.

ARE THERE RESOURCES AVAILABLE TO HELP RAISE AWARENESS?

If you decide to organise a local event or want to promote Haemophilia Awareness Week at your school, workplace or community centre, there are a number of promotional items available.

These include wrist bands, tattoos, posters, balloons, pens and colouring-in sheets. To place an order for items (free of charge):

- download an order form at www.haemophilia.org.au
- call Joanne at HFA on 1800 807 173
- email jluciani@haemophilia.org.au

WHO TO CONTACT FOR MORE INFORMATION?

If you would like any information about Haemophilia Awareness Week please call Natashia on 1800 807 173 or email ncoco@haemophilia.org.au #

ALL IN THE FAMILY – GROWING UP WITH VON WILLEBRAND DISORDER

“Lyn” (not her real name) is mother to several children with von Willebrand disorder.

She was interviewed by Suzanne O'Callaghan

It was the late night telephone call every parent dreads. Lyn's son had been involved in an accident and was being rushed to hospital. But in his case there were complications – Lyn's son has severe von Willebrand disorder (VWD) and needs careful management for his bleeding disorder.

The call came from her son's girlfriend. Fortunately she had been at the scene of the accident, had taken his VWD emergency card out of his wallet and shown it to the ambulance officers, who wrote down the details and called ahead to the hospital where he was being taken. By another stroke of luck, the hospital was also where his Haemophilia Centre was located. By the time he arrived, his medical history had been retrieved and the Emergency Unit was ready for him.

“My husband and I arrived at the hospital at around 1am when our son was on his way to Intensive Care. I didn't know where to start, but in the end I left them to it,” said Lyn. “They were all trained professionals and knew about his VWD, and there was really nothing more I could do. They had already done blood tests to check his factor levels. It was interesting – they were normal. When he had the trauma his protein levels increased, so they didn't need to give him factor VIII when he arrived.”

It was a challenging time for both her son and the family. He spent three weeks in hospital, during which time he had surgery to repair his wounds. The Haemophilia Centre team were involved in his care and monitored the surgical procedures, advising the surgical team when he needed further blood testing for factor levels and treating his dropping haemoglobin levels. “The teams worked well together,” commented Lyn.

Her son was discharged to his parents' home and had another few months there recovering slowly. Lyn took several weeks off work to look after him, but in the family's usual style his care was fairly low key and he stayed in charge of what was happening. His friends brought him movies to watch and his friends and family fetched and carried what he wanted until he was able to manage for himself. He is now back finishing his studies.

It may seem that Lyn's son had luck on his side, but in many ways his hospital experience and his recovery were the result of many years of careful education and parenting that encouraged him to live his life and know how to deal with the unexpected.

OUT OF THE BLUE

Discovering that several family members had VWD came as a complete surprise to Lyn and her husband. “We had no idea,” said Lyn. “No one had ever been tested until our son was two.”

After testing they found that several members of the family had VWD

and some had the severe form while others had the mild form. When they looked at the family history, they could actually track the VWD back for a couple of generations through problems with severe blood noses.

“They were aware that they had bleeding problems and knew that it was being passed down through the generations, but didn't know there was a name for it,” said Lyn. “It could be a bit of an issue at times – sometimes people lost so much blood from their blood noses that they ended up unconscious on the floor with bowls of blood beside them – but they all survived and thought it was just them.”

GROWING UP ACTIVELY

Over the years Lyn has learned to deal with the challenges of bringing up an energetic family with VWD by learning more about it and being prepared for all eventualities. She has encouraged the children to lead active lives, in spite of their different issues, but to know their limits.

“It's always in the back of their mind, but we don't make it a big part so they live a reasonably normal life. They haven't been wrapped up in cotton wool. They've had some long nights with blood noses where they lost two to three hours sleep, but still got up in the morning and went to school. Now the older kids are going to university.”

Family holidays have been an opportunity to explore the outdoors, but also show some solidarity if

one has some bleeding problems. "Because everyone is reasonably stable, we don't need to organise factor VIII," explained Lyn. "I always take a bottle of tranexamic acid with me in case anyone has a bleed and I'm always aware where the hospitals are, although I don't touch base with them."

"The kids are fairly active and they will do anything and everything they can possibly manage – bike riding, horse riding. With most of those activities, we'd just assess at the end of the day to see if there are any bruises. If there are any injuries, we do the RICE (Rest Ice Compress and Elevate) procedure. If it's looking nasty, the whole family stops in support and does something different. They're all in it together and realise how it hurts if you have a reasonable size bruise or haematoma."

If someone has had an injury, it's a good excuse to go to the cinema or do some shopping. "Overall we don't have a lot of issues because the kids have always done these things. They can pace themselves and they know what causes their bruises and their bleeds. If it's going to hurt them, they just don't do it. I've never actually stopped them from doing anything. But they wear protective gear, like helmets, and if they ride horses, will ride a quiet horse."

DEVELOPING A PLAN

A growing family can bring many challenges. Bruises, and severe blood noses in the middle of the night, and occasionally broken arms and collarbones have all been part of the hurdles of parenting for Lyn and her husband.

Getting to the nearest medical centre is a 15 to 20 minute trip, so Lyn is aware of the need to make an early decision about whether to get treatment or not, preferably during business hours when the medical centre is fully operational, if possible. "I give myself a time limit, say 30 minutes, and try to deal with the situation but if that doesn't work, I will go and seek help rather than leave it. I keep my contact numbers on the fridge – they're easy to find there in an emergency!"

Another of Lyn's strategies is to keep a journal about the children. She documents their injuries and the treatment, and can look back later to see how they handled the situation and what worked and what didn't.

GROWING GIRLS

While there have been injuries and blood noses to deal with, one of the most difficult problems for Lyn was managing her daughter's bleeding problems when she began to menstruate. Her daughter has severe VWD. As an adolescent with her second menstrual period, the blood loss from her continued bleeding caused her haemoglobin levels to drop very low. With reservations, Lyn took her to the local hospital. They did not know much about VWD and thought they could manage it, but within the week she had been referred to the Children's Hospital and was on different medication.

"I knew that something was going to happen, but there's not a lot you can do at the local level when your local GP just doesn't fully understand," commented Lyn. "It was quite a challenge at the local hospital to say, 'we've got a problem here; we need to do something'. They would say they had it all under control, but by the end of the week they were more than happy to put us in an ambulance and send us off to the Children's Hospital."

Several years later Lyn's daughter is relatively stable and takes hormonal medication every day, but her medical team is still working with her on her medication to get control of her bleeding problems. "She's a 'work in progress'", said Lyn.

HANDLING EMERGENCIES

Encountering so many of these episodes over the years means that Lyn has made sure she has a plan for how to manage them. Their GP now knows something about family members and their history and the local hospital knows they are in the area. Family members have cards at the local hospital so that if they arrive at the hospital the staff know how to deal with them, what type of VWD they have and what treatment to order for them. "It's always worth

contacting the Haemophilia Centre, because they will organise to get you the appropriate care, and even find you a bed in the hospital if need be," added Lyn.

Her children have also been taught how to deal with emergencies. "Now that the children are older they have grown out of their blood noses, but they keep their mobile phones on them so that if they have any problems they can contact their parents or someone to help them. They have bracelets, and while they prefer not to wear them, they could be convinced to wear them when they were going on school trips. They are young adults now and carry emergency cards in their wallets instead. Friends are important too – their friends all know what to do and where they keep their emergency card and have taken them to hospital in the past."

Although her children have learned to know their limits, their exploration of their limits can cause Lyn some concern at times, for example when one son went snow-skiing. "But what can you do?" remarked Lyn. "They have good first aid at snow resorts. You just have to go with it sometimes, and he came home without even a bruise."

AND FOR THE FUTURE?

What is in store for Lyn and her husband? As parents, their next step is to handle their children's growing independence as they leave home and find their way in the world. What does the future hold for their children?

"Will my children be able to have the employment they want? If it's in remote areas, they will probably need to check out the requirements. They haven't thought of this yet, but I have."

But Lyn is resolute about her role as a parent. "We always encourage our kids to be independent. They have to be in control of their lives and we as their parents are just back-up." And for Lyn and her family, it is a strategy that has proven results. ■



HAEMOPHILIA CONFERENCE

The 16th Australian & New Zealand Haemophilia Conference will be held in Sydney, 20-22 October 2011. The theme for the conference is *"Health and wellbeing – the decade ahead"*.

The Conference is at the Novotel Sydney Olympic Park, Olympic Boulevard, Sydney. There is good access in and around the venue and on the conference floor and it is suitable for wheelchairs.

OTHER FUNCTIONS AND ACTIVITIES ASSOCIATED WITH THE CONFERENCE

Health Professionals Meetings

Annual meetings of the Meetings of Australian Haemophilia Centre Directors' Organisation, Australian Haemophilia Nurses' Group, Australian Haemophilia Social Workers' and Counsellors' Group, Australian & New Zealand Physiotherapy Haemophilia Group and the ABRD Data Managers Group will be held on Thursday 20 October 2011 - members of the groups will receive further details soon.

1st Australian & New Zealand Inhibitor Workshop 22-24 October 2011

This is our first specialised inhibitors workshop. Inhibitor development and treatment will be included in the Conference program as a session topic, but the workshop will be more focused to the needs of individuals living with inhibitors and their carers. HFA is working with Haemophilia Foundation of New Zealand (HFNZ) to develop this workshop. There will be a limited number of subsidised places to attend the workshop, including travel expenses. You must be attending the Conference to also attend the workshop. The inhibitors workshop will run after the Conference from Saturday night until Monday. Participants will be nominated by local Haemophilia Foundations on the recommendation of haemophilia counsellors. For more information and registrations contact HFA on 1800 807 173 or HFNZ on 03 371 7477.

It's not too late to register for the conference – register online at www.haemophilia.org.au/registration or download a registration form at www.haemophilia.org.au/conferences

Youth Social Function

After the Welcome & Exhibition Opening on Thursday 20 October, young people are invited to a "meet and greet" social function. This will be onsite and will be free of charge. It is a chance for young people to meet others and connect before the Conference program starts. Topics of interest to young people will be integrated throughout the Conference program. Further details for young people will be available to registered delegates at a later date.

Remembrance Service

The Remembrance Service is a very special time held during our Conferences to remember friends and family and the people we have cared for in our community who have died. The service will be non-religious and everyone is welcome. It will be held on Friday 21 October before the Conference Dinner.

Conference Dinner ~ Novotel Sydney Olympic Park

Join your fellow delegates for the Conference Dinner onsite on the Friday evening. There will be no speeches or presentations, it will simply be a dinner where you can talk, share and meet with others at the Conference.

A Men's Breakfast and Women's Breakfast will be held on Saturday 22 October. Come along to hear an interesting speaker and share your ideas and experiences with other men or women! For more information, check the HFA conference website at www.haemophilia.org.au/conferences

PROGRAM

Following is the program – for current updates visit www.haemophilia.org.au/conferences

THURSDAY 20 OCTOBER 2011

| | |
|-----------------|--|
| 1830-1930 | Welcome and Exhibition Opening @ The Novotel – Freshwater Room 1 |
| 1930 until late | Youth Meet and Greet @ The Novotel - Boulevard Bar |

FRIDAY 21 OCTOBER 2011

| | | | |
|----------------|--|--|--|
| 0900 | Official Welcome Gavin Finkelstein, HFA President and Deon York, HFNZ President <i>Room: Freshwater Room 2&3</i> | | |
| 0910- 1030 | Plenary 1 Work/Life balance - managing stress, looking after your back – Anna Louise Bouvier <i>Room: Freshwater Room 2&3</i> | | |
| 10.30-11.00 | MORNING TEA | | |
| 11.00-12.30 | Concurrent 1 Keeping the body in tune – children <i>Room: Freshwater 2</i> | Concurrent 2 Staying on your feet – a session for adults of all ages <i>Room: Freshwater 3</i> | Concurrent 3 Von Willebrand Disorder <i>Room: Parklands</i> |
| | Chair: Wendy Poulsen Managing diet – Dealing with fussy eaters – Dr Jacqui Dalby-Payne Exercise and sport – Dr Carolyn Broderick Personal Experience – Chris Gordon | Chair: Dr Huyen Tran Ankle fusion vs replacement – Dr Sanjeev Gupta Can we preserve joints from damage? – A/Prof Prue Manners & Dr Ann Powell How to keep going: exercise/falls/balance – a practical approach – Emma Paterson | Chair: Dr Susan Russell A personal story of a family affected by VWD – Manal Awad VWD – clinical update on treatment and care – Dr Mandy Davis Diagnosis and classification of VWD – Prof Emmanuel Favalaro |
| 12.30-13.30 | LUNCH | | |
| 13.30-15.00 | Concurrent 1 Keeping the mind and body in tune - adults <i>Room: Freshwater 2</i> | Concurrent 2 Women’s health and reproduction <i>Room: Freshwater 3</i> | Concurrent 3 Transitions: becoming an adult <i>Room: Parklands</i> |
| | Chair: Andrew Atkins Obesity/weight management: clinical issues – TBC Personal experiences: Andrew Selvaggi and Zev Fishman will share their inspiring stories of overcoming some of the complications of haemophilia Mental health – TBC Discussion | Chair: Belinda Burnett Pre-genetic diagnosis – Dr Kristi Jones Managing menorrhagia – Dr Claire McLintock HFNZ Women’s Program – Lynne Campbell | Chair: Maureen Spilsbury Transition in Qld and the relationship between adults and paediatrics - some of the challenges of transitioning – Maureen Spilsbury & Dr Desdemona Chong WA Transition program Presented by Haemophilia Counsellor – Sharon Hawkins and William Oversby A panel of young people will discuss their experiences |
| 15.00-15.30 | AFTERNOON TEA | | |
| 15.30-17.00 | Plenary 2 Ageing <i>Room: Freshwater Room 2&3</i> | | |
| | Chair: Zev Fishman Haemophilia and Ageing – Dr Mike Makris Followed by multidisciplinary panel: Leonie Mudge (Social Worker), Ian d’Young (Physiotherapist), Stephen Mathews (Nurse) | | |
| 18.15-18.45 | Remembrance Service @ The Novotel - Terrace | | |
| 19.00-til late | Conference Dinner (\$30 per person, tickets must be pre-purchased) @ The Novotel – Freshwater 2 & 3 | | |

SATURDAY 22 OCTOBER 2011

| | |
|-----------|--|
| 0730-0845 | Men’s Breakfast (\$25 per person, tickets must be pre-purchased) |
| 0730-0845 | Women’s Breakfast (\$25 per person, tickets must be pre-purchased) |

SATURDAY 22 OCTOBER 2011 (CONTINUED)

| | | | |
|-------------|---|--|--|
| 09.00-10.30 | <p>Plenary 3 Treatment challenges Room: Freshwater Room 2&3</p> <p>Chair: Dr Scott Dunkley</p> <p>Safety of current products used to treat inherited bleeding disorders – Dr Mike Makris Current and emerging challenges, risk factors for inhibitor development – Dr Julie Curtin Update from the AHCDO Tolerisation Advisory Committee – Dr Chris Barnes Inhibitors in mild haemophilia – Dr Simon McRae A personal experience of tolerisation – Hamish Robinson</p> | | |
| 10.30-11.00 | MORNING TEA | | |
| 11.00-12.30 | <p>Concurrent 1 Men's Business Room: Freshwater 2</p> <p>Chair: Sharon Hawkins Facilitator: Dr Ronald McCoy</p> <p>What's normal? – across the lifespan – Dr Ronald McCoy Roadblocks; physical problems; solutions – TBC Panel – Q&A Haemophilia physiotherapist – Cameron Cramey Haemophilia nurse – Clare Waite Haemophilia Counsellor – Sharon Hawkins BBVs and body image – Dr Roger Garsia</p> | <p>Concurrent 2 The challenges of prophylaxis Room: Freshwater 3</p> <p>Chair: Ian d'Young</p> <p>Clinical update on prophylaxis – Dr Alessandro Gringeri Prophylaxis: the challenges of venous access and ports – Dr Susan Russell & Robyn Shoemark When prophylaxis isn't the only answer: joint health for children and adolescents – Ian d'Young</p> | <p>Concurrent 3 The rarer bleeding disorders Room: Parklands</p> <p>Chair: Grainne Dunn</p> <p>A personal story by a mother of a child with severe factor XI deficiency – Nadine Penn Nursing perspectives – 3 nurses will present snapshots of their experiences of looking after patients with rare bleeding disorders and the nursing issues that arise: Acquired haemophilia – Andrew Atkins Afibrinogenaemia – Olivia Hollingdrake Glanzmann's – Penny McCarthy Rare bleeding disorders – factor X deficiency – Dr James Price Platelet function disorders – Dr Tim Brighton Discussion</p> |
| 12.30-13.30 | LUNCH | | |
| 13.30-15.00 | <p>Concurrent 1 Living with hepatitis C and/or HIV co-infection Room: Freshwater 2</p> <p>Chair: Megan Walsh</p> <p>From a patient's perspective – TBC Medical update on HIV co-infection including reproduction for HIV discordant couples – Dr Roger Garsia Update on hepatitis C and treatment – A/Prof Simone Strasser Managing symptoms and liver health – Frances Tenison</p> | <p>Concurrent 2 Caring for parents and carers Room: Freshwater 3</p> <p>Chair: Dr Desdemona Chong</p> <p>An overview: parenting – managing stress, caring for young children, work/life balance, managing chronic conditions – Dr Desdemona Chong Empowering Parents! PEP in Australia – Anne Jackson PEP in New Zealand – Colleen McKay The benefits from a Mother's perspective – Lynley Scott The benefits from a Father's perspective – Richard Scott Caring for Carers across the spectrum – Elena Katrakis</p> | <p>Concurrent 3 Communication and Social Media Room: Parklands</p> <p>Chair: Jonathan Spencer</p> <p>Social networking – community perspectives and issues to consider for community organisations – Suzanne O'Callaghan Ethics & impact of social networking for health professionals/doctors – TBC Cyber issues: bullying, stalking, identity theft, managing your privacy – Melissa Sevil Panel discussion</p> |
| 15.00-15.30 | AFTERNOON TEA | | |
| 15.30-16.50 | <p>Plenary 4 Treatment and care – now and the future Room: Freshwater Room 2&3</p> <p>Chair: Geoff Simon</p> <p>What are some of the issues? – Geoff Simon Expectations from a community perspective – Deon York Managing demand and supply of clotting factor - Health Technology Assessment, assessing new products for funding; ensuring an effective health care system – Stephanie Gunn The future of haemophilia care – a personal view - Dr Mike Makris Discussion</p> | | |
| 16.50-17.00 | <p>Closing Gavin Finkelstein, HFA President and Deon York, HFNZ President</p> | | |

YOUTH PROJECT OFFICER



“I’m hoping to work with young people on some amazing resources and together create a way for young people with bleeding disorders to communicate with each other easily”

Kate Walton joined the HFA team in August 2011 in the role of Youth Project Officer. Over the next 12 months she will consult with the community and health professionals about the unmet needs of young people affected by bleeding disorders and will work with young people on ways to communicate nationally and create a strategy for developing life skills. Together they will also put together a plan to sustain this into the future.

Coming from a background in youth work, Kate brings a wealth of knowledge and experience in dealing with the many issues confronting young people as they mature and become independent, especially for those without the support of a stable home or family. She has worked in youth education and employment, helping young people get a job or continue their studies at school or at TAFE or university. Most recently, she specialised in youth homelessness as a case manager, working with young people to help them find long-term stable accommodation and assisting them with other issues, such as mental health, drug and alcohol problems, literacy and numeracy skills, struggling with financial problems or having a history of abuse.

She also teaches Youth Work and subjects in the Victorian Certificate of Applied Learning (VCAL), a hands-on alternative to the Victorian Certificate of Education (VCE) for Year 11 and 12 students.

Kate is a fan of taking a more creative approach. One of her favourite projects was a street art project that she developed in conjunction with local government. “It was a great way to give young people the opportunity to turn their illegal graffiti into legal artwork – by getting permission from the owner, the young person was allowed to produce legal ‘street art’ on the local football club wall.”

Kate’s diverse skills and interests will be a great asset to the HFA team. As a teenager, she wanted to be a journalist and had a monthly column in the local newspaper, with some articles published in *The Age* and other major newspapers.

She also brings an insiders’ knowledge about the sporting industry: a Calisthenics coach to people of all

ages, Kate has done Calisthenics since she was three.

She is a member of the Victorian Institute of Sport and participates regularly in forums, seminars and competitions to maintain her coaching status. Apart from all the usual gymnastics, including splits and cartwheels, she numbers among her specialities the backward shoulder roll and changing splits from one leg to another – feats most of us would find impossible!

Like most young people, Kate is well versed in social media, such as Facebook, Twitter, and developing and maintaining web sites.

Kate believes social media has a strong role to play in communication and education for young people today. “Social media reaches a wider range of young people” she commented. “This is the way young people are learning and communicating these days and it is important to provide them with information the way they are getting it. It can be really colourful and interactive and the volume of information people can find on the internet is really helpful. It is also a means of support, connecting people with each other in a way that they wouldn’t have the opportunity to do if the internet didn’t exist – interstate, worldwide, and it can be in real time. It’s pretty amazing if you think about it.”

For Kate, the *Beyond Prophylaxis* project is a stimulating new challenge. “It hit me as a very exciting project – it’s quite different. I have never worked with a young person with a bleeding disorder before and it will be a big learning curve which I really look forward to. I’m hoping to work with young people on some amazing resources and together create a way for young people with bleeding disorders to communicate with each other easily. I expect to learn a lot!” ■

If you are between 13 and 25 years of age, have a bleeding disorder, carry the gene or are a sibling or parent, and are interested in working with Kate on this project, you can contact Kate on:

T: 1800 807 173

E: kw Walton@haemophilia.org.au

Kate works on Mondays, Tuesdays, Thursdays and Fridays

BEYOND PROPHYLAXIS YOUTH PROJECT

Kate Walton

The *Beyond Prophylaxis* project started in August 2011. This project will address the lack of information and understanding about the unmet needs of young Australians with bleeding disorders and the lack of resources to respond to these needs.

There is little information about the impact of bleeding disorders on young people in Australia. In preparatory consultation, community organisations and haemophilia health professionals have reported that young people may need assistance with their decision-making skills regarding their lifestyle and life choices, to ensure they have the best outcomes for their health and wellbeing. This would help young people to understand how having a bleeding disorder could affect their way of life such as recreation and sport, travel, career, relationships, or having children.

The consultation highlighted that young people with bleeding disorders may face a range of issues in growing up. It might relate to managing their treatment as they become independent or preparing for emergency situations, or for travel, or for work and planning a career. Bullying and discrimination at school due to their bleeding symptoms may be another issue, especially among girls. Further investigation is required to understand the issues fully.

In previous times planning for the future was a part of growing up. Many young people in earlier generations grew up without adequate clotting factor treatment due to limited availability of treatment product and developed arthritis and joint problems at an early age. Asking yourself questions like "How long can I work for?" and "Do I need to put a plan in place if I need to stop working?" was a common practice. In Leah Lonsdale's history of Haemophilia Foundation Victoria, *Achieving the Extraordinary*¹, a passage about employment in the 1960s notes, "Several other questions had to be considered. What physical limitations and immobility issues did he have to contend with? Would the preferred career provoke bleeds? Could he sit behind a desk when his troublesome knee had yet another bleed? Could a job be held given the number of days usually spent in hospital?"

Achieving the Extraordinary also describes the questions people with bleeding disorders considered regarding travel during the 1970s. "What would they do in an emergency? Who could they contact for treatment? What if they were too far from the patient's regular hospital?" The state Foundation newsletters of the time offered suggestions regarding travel such as taking your identify card away with you, having letters from doctors and knowing where services are located for your travel destination.

The aim of the Beyond Prophylaxis project is to enable young people to make positive and informed choices about their lifestyle, like the option of travelling and other life choices, and to increase the understanding of issues and unmet needs of young Australians with bleeding disorders.

The Youth Project Officer will discuss the issues and needs of young people affected by bleeding disorders with the young people themselves and consult with Council, state/territory Foundations and current HFA committees, including the Youth Committee, along with parents and other stakeholders.

The plan is to develop a strategy to equip young people to manage the realities of living with a bleeding disorder. This will involve developing an accessible and attractive tool as a communication platform. Young people will have an active role in deciding what the communication tool will look like and what information it will provide. The tool will enable young people to connect, share experiences and obtain information about relevant life and lifestyle choices, including work, travel, sport, recreation, relationships and socialising. There will also be work on a strategy to help develop the life skills of young people, whilst building the youth leadership capacity of HFA. ■

Reference

1. Lonsdale L. *Achieving the extraordinary: Haemophilia Foundation Victoria, 1954-2004*. Melbourne: HFV, 2004.

This article is adapted from an article published in *Bloodline*, volume 39 number 1, March 2011, the magazine of Haemophilia Foundation New Zealand, and is reprinted with permission. Ian d'Young is National Clinical Lead, Haemophilia Physiotherapy, New Zealand and Co-Chair of the Australian and New Zealand Physiotherapy Haemophilia Group.

THE IMPORTANCE OF GOOD FOOTWEAR

FOR PEOPLE WITH HAEMOPHILIA

Ian d'Young

Good supportive footwear is hugely important for people with haemophilia and related bleeding disorders. It is an essential part of both minimising the risk of joint bleeds at the knees and ankles and managing any joint damage that may already exist because of a history of bleeding.

In order to understand why appropriate footwear is important, it is important to understand the nature of walking and the forces acting on the joints and muscles of the legs during this activity.

WALKING: A COMPLEX TASK

Normal walking (or 'gait') refers to the mechanical process by which the body achieves locomotion using the limbs in a series of joint movements and muscle forces that move the body in a desired direction while all the time maintaining a stable posture.

Most people achieve a 'normal' adult pattern of walking from around seven years of age, and this pattern is maintained (in the absence of lower limb joint damage) until around 60 years of age, where subtle age-related changes start to occur.¹ This 'normal' walking is referred to as a 'heel-toe' pattern: ie. the heel hits the ground first and the toes push off to propel the body forwards.

During walking, the limb must absorb the shock arising from the transfer of weight on to the leg, while maintaining a stable position and allowing forward momentum. The leg must dissipate compressive, shear and twisting forces, adapt to changes in the ground surface and provide a rigid lever for propulsion in order to maintain this smooth, even pattern of movement.²

The symmetry and smooth reciprocal nature of walking, and the dissipation of the forces acting on the leg when it makes contact with the ground is dependent on coordinated joint

movement, muscle activity, and joint position sense.³ This means that each joint and muscle group in the leg is dependent on the next during walking, and this is termed 'coupling'. What is amazing is that all of this occurs without you having to think about it!

Consider then that normal walking is like a 'chain' of coordinated joint movements and muscle forces. We call this chain 'gait biomechanics', and where there is a disruption to one link in the chain, bleeds are more likely to occur and joints that are affected by arthritis are more likely to be painful.

This is because a deviation from the normal motion, alignment and strength at a joint or muscle during walking (the 'heel-toe pattern'), exposes the joint to greater stress and load.

This leads to damage to the membrane that lines the joint (the 'synovium') and therefore bleeding and joint damage.⁴

This leads us to the key concept of gait in people with joints affected by haemophilia: because muscle activity and joint movement is 'coupled' at the whole limb, changes in strength or movement at one link in 'the chain' affects the rest of the whole limb: ie, something else has to compensate. This can often lead to a vicious cycle of bleeding related to these ineffective compensatory mechanisms.

For example, if the ankle is stiff, then there is, amongst other things, a decrease in the force generated by the calf required to propel the body forwards. This means that joints and muscles around the knee and hip, or joints on the other side of the body must work harder to compensate for the affected ankle joint. This places extra load on the knee joint in particular, and in turn makes it more likely to be the site of a joint bleed.



POOR BIOMECHANICS AND JOINT BLEEDING

The majority of all bleeding within the musculoskeletal system, up to 85% of all adverse haemostatic episodes, occur within the knee, ankle and elbow.⁵

These joints are terms 'synovial hinge joints', because they are lined with an important membrane called the 'synovium'. This membrane produces the nourishing, lubricating fluid inside the joints.

Joint bleeds occur as a result of damage to the synovium. This membrane has lots of tiny blood vessels and when they are trapped and torn, blood fills the joint. This is what we call a *haemarthrosis*.

Blood contains iron, and the release of this into the joints damages the cartilage that protects the weight-bearing surfaces of joints, and makes the synovium more susceptible to further damage, and therefore further bleeding.

When there is a normal 'heel to toe' pattern of walking, the synovium is at a relatively low risk of damage and subsequent bleeding. When there is a disruption in the normal biomechanics of walking (for example where the heel is not well aligned or the knee remains bent when the foot makes contact with the ground), then the synovium is at a much greater risk of damage.

THE ANKLE: AN AT-RISK JOINT

Damage to the synovium that lines the ankle joint is particularly common. This is because the ankle is actually two hinge joints, one on top of the other, that have to propel the entire weight of the body and absorb the forces of walking.

The ankle must also work in concert with a complex system of joints in the foot, as well as adapt to changes in the ground surface. This means that the ankle is a relatively unstable joint, and where ankle mechanics are poor, the synovium that lines the joint is more susceptible to damage, and subsequent bleeding into the joint cavity. Let's look at one or two examples you may recognise. People who 'over pronate' the forefoot tend to be at a higher risk of ankle bleeding. Pronation is a normal movement at the foot during walking, however when this is excessive (often recognised in patients by the appearance of a flat foot or low 'medial' arch), it forces other structures at the ankle joint to compensate, making the synovium more susceptible to damage.

People who have flat feet, wear thongs a lot, or alternatively women who wear high heels, tend to 'over pronate' the forefoot. It is important that if you recognise some of these issues in your own feet that you select a pair of footwear that helps to support and correct this 'over pronation', in conjunction with advice from your physiotherapist.

THE VICIOUS CYCLE

Let's look at another example. When a bleed occurs at the ankle, the joint fills with blood and it is painful to walk on. Because of the extra fluid inside the joint, and the pain associated with this, the body quickly adapts the pattern of movement at the whole leg to compensate for this painful joint: ie, you limp or cannot put weight on the limb.

In response to this altered pattern of movement, muscle strength and joint movement change at the whole limb. If the bleed is not rehabilitated and the strength/movement do not return to normal, then many of these subtle changes persist, even after the bleed appears to be settled. When these changes persist, the synovium is exposed to more stress and is damaged more easily, leading to further bleeding and accelerated joint damage.



FOOTWEAR

“Good shoes that fit well can be found in most shops and do not need to be manufactured individually”⁶

So what is the best footwear for a person with haemophilia? This can be a very difficult question to answer as every person is different and will have their own unique set of requirements, however here are some ‘top tips’.

- A good shock-absorbing pad, especially under the heel, is important. Most types of sports shoes will have this built in
- A support for the medial arch – many sports shoes will also have this built in, however you will need to check that this is at an appropriate height and you may need to consider putting an extra ‘insole’ into the shoe to support this part of your foot
- A good, firm supportive upper around the heel that comes up to the bony points on either side of your ankle (the ‘malleoli’). This needs to be firm and well fitting to keep the heel in the correct position when your foot makes contact with the ground
- A firm sole that keeps the foot stable but has some spring in it – most modern sports shoes have this type of sole
- The shoe needs to fit your foot correctly – not too tight, but also not too loose – if the shoe is too loose then it does not give support
- Your shoes should have laces – Use them! If your laces are not

tied firmly then your shoe will not provide you with any protection

- Many men with existing ankle joint damage find a ‘sports walking boot’ very comfortable: these tend to combine the arch support/shock-absorbing heel pad of a sports shoe with an upper that comes over the ankle like a boot and provides good side-to-side support for the ankle
- Many sports shoe retailers now offer an assessment of your walking pattern to help you find the right type of shoe. These assessments can often be useful
- Remember, shoes wear out! A pair of shoes that is several years old and is looking a bit tatty is unlikely to be giving you any significant support
- You may need an assessment by your physiotherapist to help you select the correct footwear. Your physiotherapist can also make a referral for orthotics to be made that suit the contours of your foot and can be inserted into your shoes if extra support is required
- Remember, if you are used to walking in a certain way, it can often take a while to get used to new shoes or insoles. Be patient, but remember to report any problems you are having. Most people need to wear new footwear for at least two weeks to get used to them.

AND A FEW FINAL POINTS...

- Your state or territory Haemophilia Foundation may

offer financial support to people with bleeding disorders for supportive footwear – contact them for more information

- If you have a history of bleeding into a knee or ankle joint, or joint damage because of previous bleeding, it is advisable to avoid wearing thongs (or high heels for that matter!)
- Remember to adapt your footwear to suit the terrain: if you are going for a walk in the bush on an uneven track do not wear thin canvas tennis shoes!
- There are many ‘fads’ in children’s footwear (in particular). Avoid the current trend for ‘heelies’. These are children’s shoes that have a wheel inserted into the heel, and are very destabilising for the ankle. ❗

References

1. Prince F, Corriveau H, Hebert R, Winter DA. Gait in the elderly. *Gait and Posture* 1997; 5: 128-135.
2. Whittle M. *Gait analysis: an introduction*. Oxford: Elsevier Health Sciences, 2002.
3. Perry J. *Gait analysis: normal and pathological function*. Oxford: SLACK, 1992.
4. Stephensen D. Biomechanics of the lower limb in haemophilia. In: *Physiotherapy management of haemophilia*. Buzzard B, Beeton K, eds. Oxford: Blackwell Science, 2000.
5. Roosendaal G, Van Den Berg HM, Lefeber FPJG, Bijlsma JWJ. Blood-induced joint damage: an overview of musculoskeletal research in haemophilia. In: *Rodriguez-Merchan EC, Goddard NJ, Lee CA, eds. Musculoskeletal aspects of haemophilia*. Oxford: Blackwell Sciences, 2000.
6. Heijnen L, Heim M, In Der Maur H. Manufactured shoes and orthopaedic shoes. *Haemophilia* 2000;6 (suppl 1):4-6.

REPORT FROM DUBAI

THE INTERNATIONAL MUSCULOSKELETAL CONGRESS

Auburn McIntyre



The World Federation of Hemophilia 12th International Musculoskeletal Congress was held in Dubai UAE from March 31 to April 2, 2011. I was fortunate to be the physiotherapist that the Haemophilia Foundation of Australia supported to attend this Congress. My thanks to all involved.

Attendance at this conference allowed me see and explore the "forest" of people working in the field of haemophilia. Until then I had been working at the "tree" level at the Women's and Children's Hospital in Adelaide. I guess you would say that a few exploratory branches of the "tree" have made their way, via questions, to resource physiotherapists, Wendy Poulsen in Brisbane and Ian d'Young in New Zealand, but the haemophilia "forest" in Dubai was extensive.

Most of the presenters were specialists in their fields. The way the conference was organized meant I didn't have to choose between alternative sessions, but could listen to all speakers. Unlike most physiotherapy-specific conferences, doctors, orthopaedic specialists, haematologists, radiologists, and rheumatologists

attended and presented, as well as physiotherapists. Topics covered included musculoskeletal issues, primary prophylaxis, radiosynovectomies, scoring joint damage progression on MRIs and X-rays, cartilage, synovitis and bone effects of haemophilia, not to mention a focus on knee and ankle joints. Posters were displayed concurrently.

Many physiotherapists spoke, which naturally, was of particular interest to me. Their topics included ankle bracing, physiotherapy assessment tools and exercises, adolescence and managing surgical patients.

I had left Australia with plenty of unanswered questions. Sharon Caris, from Haemophilia Foundation Australia, had put me in touch with a Kiwi physiotherapist, Katie, who was also attending the congress alone. We had tried to meet in Melbourne and Dubai airports but finally managed in the lobby prior to registration. It was great to have a friendly face in a foreign country. Not having co-workers was actually an advantage: Katie and I got to know each other and compare our respective paediatric Haemophilia Centres.



By the afternoon session of day 1, we had answered each other's questions and were advancing on the "forest"! We spotted a group of 5 to 6 friendly English-speaking physios. We put many questions to them to compare notes on "what do you do for...?", "when do you do...?" Everyone was extremely helpful.

Since the conference I have spoken to Katie again, as well as a physiotherapist in Canada and emailed physiotherapists I met from the UK and Ireland (as well as the ever helpful Wendy and Ian). I look forward to meeting many again at the 2014 Melbourne conference.

The Musculoskeletal meeting was a fantastic melting pot of therapists, nurses, doctors, experiences and ideas. Many of the more experienced (older) doctors repeated the mantra to "treat the patient and not the disease".

I recognize now more than before, that each person with a bleeding disorder has their own path, as part of their uniqueness. Most of the therapists I talked to were in awe that a child who had a bleed in Canada or Ireland would stay off their feet for longer than 48 hours: we thought – a week, longer, stay inside that long? Mad... impossible... ridiculous! But do you know what? I have learned it is possible if it is needed and we give the right advice, reasons and education and follow up with support and treatment.

Back in Adelaide my skills have been enhanced and I feel much more confident being part of the Women's and Children's Hospital (WCH) Comprehensive Care team. We now have a comprehensive flow chart of possible presentations and alternate paths to follow should a person with a bleeding disorder present to Physiotherapy. I can now work at much more of a "forest" level and this benefits everyone.

If you are under 18 and live in Adelaide, watch out! The opportunity I was given by HFA will potentially result in more visits to see the happy smiling physiotherapists at WCH!! There will be more education about how to check to see if your muscles are bulky and well toned, if you are fit and if your balance is up to scratch. Hopefully I can offer more musculoskeletal education if time allows.

And what was Dubai like? It is an amazing surreal city. As we circled for half an hour, due to a much delayed midnight take off and missing our "allocated landing time", I could see sand, sand and more sand. On the ground, it was 6 lane highways in one direction and 6 in the opposite. A massive "Jetsons" like rail network and enormous space age buildings, including the largest in the world. The river was full of luxury boats. Wooden boats at the other end of the river were being loaded by hand, from small trucks, no cranes in sight. There were very few trees or vegetation and whilst it was in the 30s when I was there, it apparently reaches into the 50 degrees C in the summer, when I was told the luxury boats leave.

I was there for four nights and saw 6 or 7 shopping centres as they seem to be the most famous attractions. Some have ski slopes, others ice hotels and gold markets, and some are designed around moats, with hotels and quality restaurants. I went to one centre where people pay to scuba dive with sharks and shoppers watch it all from the mall.

The conference was at the Sheraton, in the old town. Most of the physiotherapists I met were accommodated there or the Hilton and were stunned by our 4-star accommodation. However the conference dinner, at an inn on the beach near the famous Burj Al Arab with its helipad, meant we walked through a 7-star hotel. The foyer was enough for most of us to take our cameras out! The car park, with valets and carpet, felt like we were arriving at the Oscars, rather than a smorgasbord dinner. The revolving front doors all had massive flower arrangements in them. In the hotel lobby, the pianist was playing her piano, which was sitting in the middle of a massive lake. There was an even larger swimming pool outside and the external lift went up, who knows how many floors and altered colours as it went. You could say we had open mouths and the cameras were definitely flashing. We had never seen anything like it and probably are unlikely to see it again.

Dubai is an amazing place built on sand, much of it reclaimed. It is an architect's and designer's paradise. I'm not sure if it was real or if it's sustainable but it oozed money and nice things, and when I win the lottery...! ❧

HIV FUTURES 7 MAKING POSITIVE LIVES COUNT

Coming Soon!

HIV Futures seven is the seventh national survey of Australian People Living with HIV (PLHIV) conducted by the Living with HIV program at the Australian Research Centre in Sex, Health and Society, La Trobe University, Melbourne.

HIV Futures is an anonymous survey of PLHIV. It asks people about a range of issues including their health, treatments, work and financial situation. HIV Futures surveys have been conducted every two to three years since 1997, attracting responses from around 1000 PLHIV each time, including people with bleeding disorders.

The HIV Futures survey has been developed in consultation with a variety of community groups and it is officially supported by the National Association of People Living with HIV/AIDS (NAPWA), the Australian Federation of AIDS Organisations (AFAO), the Australasian Society of HIV Medicine (ASHM) and Haemophilia Foundation Australia (HFA).

HIV Futures provides information to PLHIV, community organisations, service providers, doctors and government about the actual experience of living with HIV and the current needs of PLHIV. It is an opportunity for people with bleeding disorders and HIV to give data on their particular experience of living with a bleeding disorder, HIV and hepatitis C co-infection for a national evidence-based study.

HIV Futures Seven will be run between October 2011 and 15th January 2012. Hardcopy survey booklets will be sent out to HIV/AIDS organisations across the country and will also be available in some Haemophilia Centres and from HFA. These can be returned anonymously and free of charge via the envelope attached to the survey booklet.

The survey can also be filled out online by going to: www.hivfutures.org.au

For more information, or to request a copy of the survey booklet, contact:

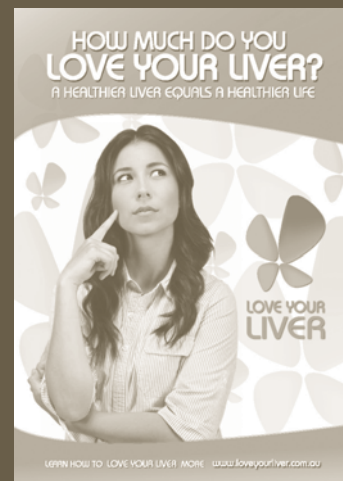
HIV Futures – Living With HIV Program
Freecall 1800 064 398 or email hivfutures@latrobe.edu.au

Haemophilia Foundation Australia
Telephone 03 9885 7800 or call 1800 807 173 (toll free).
Or speak to your Haemophilia Social Worker or Counsellor.

Make sure your experience counts. Let us know what living with a bleeding disorder and HIV is like for you. Be part of HIV Futures 7. #

WORLD HEPATITIS DAY

*World Hepatitis Day was
celebrated globally on 28 July.*



World Hepatitis Day is an opportunity for interested groups around the world to raise awareness and influence real change in disease prevention and access to testing and treatment.

This year in Australia the national campaign focussed on raising awareness about viral hepatitis in the context of good liver health. This campaign aims to create a better quality of life for people with viral hepatitis by reducing the stigma in the community. It is working towards creating an environment in Australia where people are more generally aware of their liver health and viral hepatitis is portrayed as a health condition which impacts on liver health without attaching value judgements.

The campaign included:

- Redeveloped Love Your Liver web site with new and dynamic information on good liver health, liver-friendly recipes, Love Your Liver Lunch fundraising information, videos and audio recordings
- Community page for Love Your Liver on Facebook
- O'Liver mascot for public events, the web site and Facebook
- National webinar about what your liver does and how to take care of it (www.loveyourliver.com.au)
- Poster, lapel pins, t-shirts, temporary tattoos and balloons

Around Australia, HFA and some state and territory Haemophilia Foundations supported the national Love Your Liver campaign with a range of activities:

- A Love Your Liver education workshop facilitated by the Queensland Haemophilia Centre in partnership with Haemophilia Foundation Queensland
- Promoted the campaign by wearing t-shirts and putting posters up in hospitals, the workplace and shopfront windows of Haemophilia Foundations
- Promoted information about the campaign in their newsletters.

For more information about the Love Your Liver campaign, go to the web site www.loveyourliver.com.au

If you are interested in raising awareness about the Love Your Liver campaign, it's not too late – this is an ongoing campaign. #

HIV futures seven
www.hivfutures.org.au

The following article is abridged and adapted from an article published in *Positive Living*, Summer 2010-2011, the magazine of the National Association of People Living with HIV/AIDS (NAPWA), and is reprinted with permission.

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

MAKING CHANGES

David Menadue

Every time I look in the mirror I think about ways I could improve myself. Like the rest of the human race, I guess. All I need to do is a bit more exercise, I think. And steer clear of fatty foods. So why do I find it so hard to make these changes and stick to them? Why do I find it so easy to think of a reason why I don't need to go to the gym today? Why can I never stick to a diet for longer than 24 hours? Why do so many of my positive friends have such trouble giving up smoking?

For Celia Eregizli, an occupational therapist at the Royal Prince Alfred Hospital in Sydney, one of the main reasons people find it hard to change unhealthy habits is because the directives are often coming from someone else. 'The motivation to change needs to come from you,' she says. Celia has found that if people sit and reflect on what is really important in their lives, before deciding on the changes they want to make, they are often then more receptive to the ways they can bring about these changes.

A couple of years ago she and another occupational therapist ran a workshop on how to make life changes for positive men in Sydney. Along with ACON's Women's Project, Pozhet and Positive Central, she was planning a similar workshop for positive women. 'In order to help people achieve their goals, we use an activity-based, holistic approach to facilitate the learning of techniques,' Celia says.

A good place to start is to draw a pie-chart of how you divide up your time at the moment. Include how much time you spend with friends, with family, on your personal care, spirituality, and so on. Then look at whether your chart is balanced or not. What is not working and what needs to change? How satisfied are you with your life?

After this initial life review, the group then discusses things like motivation and the strategies they can use to bring about positive change. 'This heightens people's awareness,' she says, 'expands your knowledge and gives

you the courage to develop personal goals and actually work towards achieving them.'

Interestingly, many of the positive men in the group found that often what they thought were goals changed when they put them under scrutiny. One guy thought he wanted to get a job and go back to work. On reflection, he realised that what he really wanted was to go to TAFE and train for a different career. Another thought that giving up smoking was his first priority but then realised that learning how to destress and reduce the trigger factors for smoking had to come first.

To make change more achievable, it's often a matter of altering the way you think about a problem. Celia suggests you try to remove the obstacles in your head and make your primary goals more attainable. Maybe start with smaller achievable goals, at first, and not be disheartened if you 'fall off the wagon' a few times before you see results.

It's also important to make new behaviours a part of a regular routine. If you want to start an exercise program, for example, you need to give it time in your daily routine. This reminds me of Deanna Blegg, a Melbourne woman who became a personal trainer to overcome the effects of HIV wasting and lipodystrophy.

In the AFAO/NAPWA Balance campaign we did a few years ago, she says: 'It's easy to sit at home and use the virus as an excuse not to be bothered. You can blame the virus for lots of things but if you are depressed, fatigued or lethargic, exercise can move you in the right direction. It just means making a start. Once you do, you see the changes.'

Re-visiting that quote has led me to a revelation – I need to see exercise in a different light. I need to see it not as about trying to achieve the body beautiful (against the odds at my age, anyway) but about the value of exercise in itself. About it improving my mood, limiting the damage



my diabetes can do and reducing my cholesterol and triglyceride levels. Also, if I focus on the way a good exercise workout makes me feel then maybe I'll do it more often?

A friend of mine, living in a south-east Asian country, was recently diagnosed with several AIDS-defining illnesses. 'First I came down with Kaposi's Sarcoma lesions all over my body,' he wrote. 'A week later, I was admitted to hospital with PCP (the AIDS-related pneumonia). When I was in hospital I was told I'd somehow contracted hepatitis C as well. What next is the world going to bring on for me? No matter what it is, I'm going to deal with it.'

I admire my friend's resilience in the face of adversity. Rather than buckle under the weight of misfortune, he is determined to recover and be back to full health as soon as possible. It seems to me that those of us who have lived a long time with HIV have already shown a remarkable level of resilience. When you have lived with a major threat to your mortality and survived, you are, perhaps, better placed to deal with the smaller (albeit frustrating and often debilitating) co-morbidities that HIV throws at you. Of course not everyone with HIV is going to be so resilient – nor is it a quality that is easily taught.

The Bobby Goldsmith Foundation in Sydney runs Phoenix workshops to help people with HIV deal with life-changes and learn to re-engage after periods of illness. Part of their course involves challenging negative thinking patterns that can easily develop when you are diagnosed with a stigmatising condition like HIV. Learning to see that you need not be limited by the virus and can still achieve your full potential is a part of the message that self development courses like this promote.

Rob Lake, formerly CEO of Positive Life NSW, highlighted that being diagnosed with a comorbidity related to HIV, such as cancer or diabetes, can be a time of extra strain. He believes that there is great value in having people with

HIV support each other through an experience that is, unfortunately, becoming more common these days.

- If you're in NSW and interested in the upcoming Pozhet Annual Workshop for men and women living with HIV, their partners, friends, or Pozhet's other social activities, please contact Pozhet on freecall 1800 812 404 or go to www.pozhet.org.au; for details of the next Phoenix course in NSW, contact BGF on 1800 651 011; for details on support groups run by Positive Life NSW, call (02) 9361 6011; if you're in Victoria and interested in doing a Quit course with PLWHA Vic, contact Vic Perri on (03) 9863 8733.
- HIV organisations around the country run a variety of programs aimed at helping you live better with HIV. Contact your local AIDS Council or PLHIV organisation to find out what's happening.

Thank you to Jennifer Stewart from the HIV Hepatitis and STIs Education Resource Centre at the Alfred Hospital, Melbourne for help with this article. Also thanks to Celia Erzegli, Rob Lake, Ian Walker and Vic Perri.

If you would like to explore ways to make changes in your life or get some information about your options, it may be useful to speak to your Haemophilia Social Worker or Counsellor or contact your Haemophilia Centre to be linked to other services. Keep in touch with your state or territory Haemophilia Foundation for information about their men and women's groups, where people often talk about the changes they are making in their life, and other upcoming activities. ❖

CALENDAR

Haemophilia Awareness Week

9 -15 October 2011

ph 03 9885 7800

fax 03 9885 1800

email: hfaust@haemophilia.org.au

www.haemophilia.org.au

16th Australian & New Zealand Haemophilia Conference

20 - 22 October 2011

Novotel, Sydney Olympic Park,
Sydney NSW

ph 03 9885 7800

fax 03 9885 1800

email: hfaust@haemophilia.org.au

www.haemophilia.org.au

WFH Congress 2012

8-12 July 2012 – Paris, France

World Federation of Hemophilia

Tel.: +1 (514) 875-7944

Fax: +1 (514) 874-8916

email: info2012@wfh.org

www.wfhcongress2012.org

XXXI International Congress of the World Federation of Hemophilia

Melbourne, Australia 2014

www.wfh.org

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CSL Biotherapies



ADVANCE YOUR PASSION

The Advance Your Passion Award program was developed by Baxter Healthcare and has been managed by Haemophilia Foundation Australia. The program offers awards to young people to enable them to pursue their passion – over the years Advance Your Passion has encouraged academic interests, sporting dreams and it has helped people to develop an interest or talent which has led to an emerging career.

We are grateful to Baxter Healthcare for their financial support for the Advance Your Passion 2011 Awards which were judged by an HFA Panel in June. Awards were given to young

men and women for a variety of exciting passions - to encourage music and sporting talents, support film making, take steps to establish a business and to support education activities at school and university.

Stories of some of the winners will be published in future newsletters.



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