National Haemophilia

Haemophilia Foundation Australia
www.haemophilia.org.au
No. 200, December 2017

2017 Conference

CONTENTS

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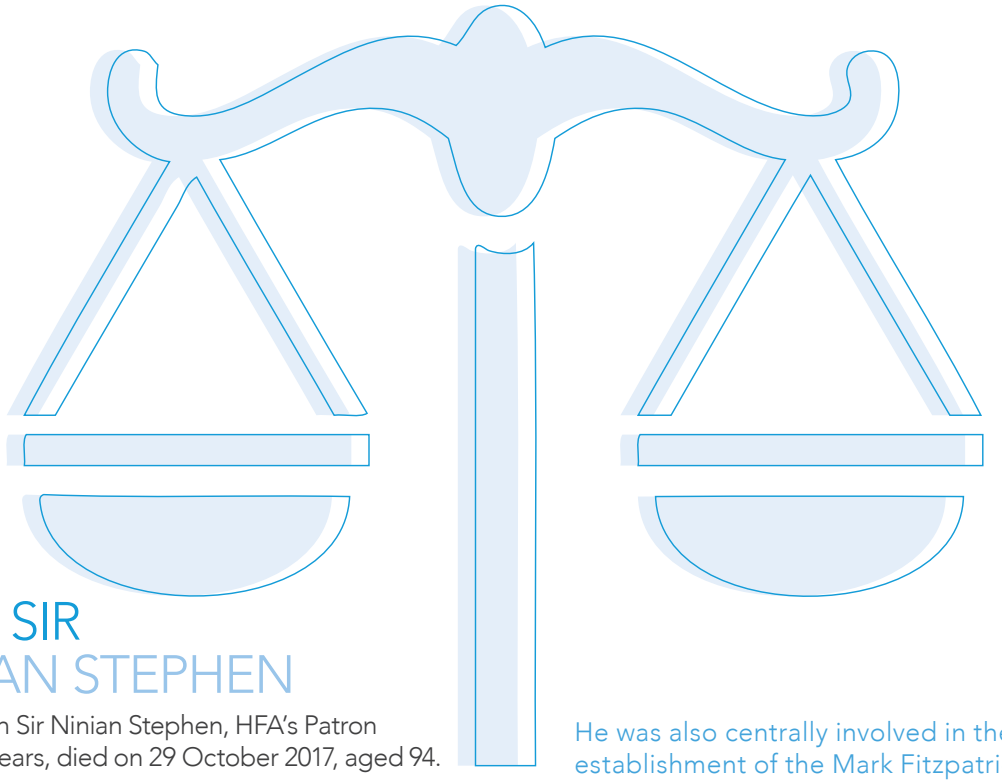
SA

SOUTH AUSTRALIA NEWS

We are working towards having an education workshop and social get together for South Australians affected by bleeding disorders in early 2018. As we may need to contact you by email with details, please advise HFA (hfaust@haemophilia.org.au) if your email address has changed.



VALE SIR NINIAN STEPHEN

The Rt Hon Sir Ninian Stephen, HFA's Patron for many years, died on 29 October 2017, aged 94.

Sir Ninian Stephen was a supportive and loyal friend to HFA over many years.

Sir Ninian had been a High Court judge and was Governor General of Australia in the 1970s and 1980s. He chaired the Review of the Australian Blood Banking and Plasma Product Sector in 2001 which gave rise to the National Blood Agreement and the establishment of the National Blood Authority.

He was also centrally involved in the establishment of the Mark Fitzpatrick Trust, which was set up by the Australian Government to provide special financial assistance to people with medically acquired HIV and their dependents and named for a young Tasmanian boy with haemophilia who died of AIDS when he was 10 years old.

Well known for the "gentle dignity" he brought to his roles and his respectful approach to all he met, Sir Ninian Stephen will be sadly missed.

Gavin Finkelstein is President, Haemophilia Foundation Australia

FROM THE PRESIDENT

Gavin Finkelstein

I was very much looking forward to the 2017 Conference in Melbourne, but unfortunately a leg injury which required surgery prevented me from travelling to Melbourne. We always think an accident like I had is stupid and avoidable, but "stuff happens", as they say. I had just been getting into the deep end of the pool using the bars for leverage and fell in, leaving my left leg behind and thus fracturing badly. It was quite an embarrassing production for me to get out of the pool. I knew instantly something bad had happened. I am grateful to the health professionals, especially the nurses, who have looked after me from the surgery through to my rehabilitation.

If there is one thing I have learned during this experience, it is that things that impact significantly on your life happen when you least expect them to, and it makes you realise how fragile we are and how much we need to adhere to all our treatment regimens. As a person with severe haemophilia, I was fortunate to have treated just before going to the pool - if I hadn't, things could have been much worse.

NEW TREATMENT PRODUCTS

I have been at each of the Australia/New Zealand conferences over the last 20 years, and as well as always getting something out of the sessions on the program, I have really enjoyed meeting up and talking with others at the conferences. It's always good to share experiences, build friendships and relationships and in recent years since Australians have had more access to clinical trials, it has been great to hear of the experiences of those on trials or from doctors who have been involved in these trials. We are in a time when more and more treatment products are emerging from "the pipeline".

The feedback I have received about the 2017 Conference has been positive. You will see reports of the various sessions in this publication, and I hope you agree that the spread of topics covered everyone in our community.

I heard there was great interest in the extended half-life (EHL) factor products now available in several other countries, but are not yet funded in Australia. Published reports show improved outcomes for both haemophilia A and B patients on trials and extension studies. We have received calls from people who have been on completed clinical trials but had continued access to the products by the grace of the manufacturers, but are now worried that they might be forced to switch back to a standard half-life product if their product is not funded by Australian governments.

HFA was disappointed there was no tender for EHLs and other new products before the current contracts for standard half-life products were extended. However, the National Blood Authority has started a process for health technology assessment for these "new" products by the Medical Services Advisory Committee, and while this process will take time, we are pleased that some very limited arrangements for access to specific EHLs are being considered for the interim (for further information go to https://www.blood.gov.au/closed-public-consultations). HFA will work proactively with governments and the Australian Haemophilia Centre Director's Organisation towards funded access as soon as possible. We want to be sure a range of products are available, including both standard half-life and EHLs and other new products so that people in our community and their clinicians can select the most appropriate treatment product for their needs.

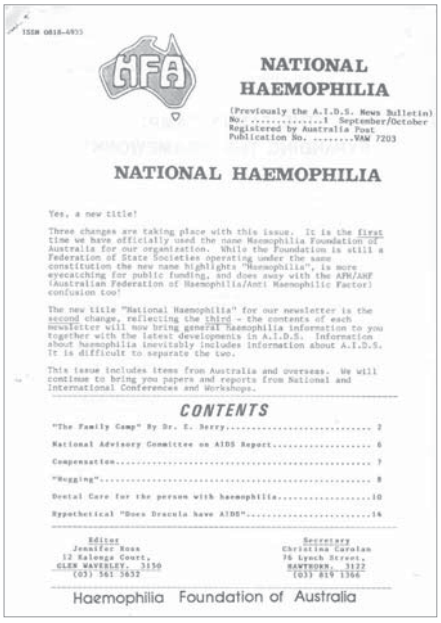
Sharon Caris, our Executive Director, recently attended the WFH Global Forum in Montreal, and will report to Council on this soon, but her immediate comments to me were about the encouraging treatment outcomes where EHLs have been available in other countries and the importance of individualising treatment to a persons' bleeding patterns to eliminate bleeds. There is great excitement globally about the benefits of EHLs and other new therapies such as Roche's emicizumab which was approved in the USA for people with haemophilia A with inhibitors in November, and there are others in the pipeline. Gene therapy is doing very well, with trials likely to ramp up. Although it will still be some time before gene therapies will be fully evaluated as safe and effective, and for them to be scaled up and affordable, we are closer than ever. These new treatments present a new paradigm for doctors and their patients and for government payers. Their costs and benefits may need to be measured differently to understand their full impact and funding processes may need to adapt to accommodate them.

We are in exciting times for treatment of people with bleeding disorders and we want to work with governments towards access to the products people will benefit most from.

200 ISSUES

NATIONAL HAEMOPHILIA

This is issue 200 of *National Haemophilia*. We thought we would take the opportunity to look back over the previous 200 issues and see how they reflect the concerns and achievements of the times – from the black and white first issue that had evolved from the A.I.D.S. News Bulletin and was now presenting information on haemophilia generally as well, to the current full colour edition which covers the gamut of issues relating to bleeding disorders in Australia.


NATIONAL HAEMOPHILIA

(Previously the A.I.D.S. News Bulletin)

NATIONAL HAEMOPHILIA

Yes, a new title!

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Haemophilia Foundation of Australia


NATIONAL HAEMOPHILIA

TEN YEARS ON

CONTENTS

HAEMOPHILIA FOUNDATION OF AUSTRALIA INC.


NATIONAL HAEMOPHILIA

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No 148 OCTOBER 2004

RECOMBINANT FACTOR VIII AND IX FOR HAEMOPHILIA – SUCCESS AT LAST, DISCRIMINATION TO END

Ann Roberts

NOW is the time to contact your Haemophilia Centre to access recombinant products.

In This Issue...

Health Minister's Media Release
Draft Hep C & HIV Strategies
A Personal Story
Interferon-Based Therapy
The Olympic Challenge
... and more


National Haemophilia

Haemophilia Foundation Australia

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No. 188, July 2014

WFH 2014 WORLD CONGRESS, MELBOURNE!


National Haemophilia

Haemophilia Foundation Australia

www.haemophilia.org.au

No. 197, March 2017

WORLD HEMOPHILIA DAY 2017 | APRIL 17

HEAR THEIR VOICES

On World Hemophilia Day let's come together to show our support for the millions of women and girls affected by bleeding disorders.

BLEEDING DISORDERS AWARENESS WEEK AND RED CAKE DAY 2017

Bleeding Disorders Awareness Week and Red Cake Day was held this year from 8-14 October 2017. Haemophilia Foundation Australia and Haemophilia Foundations around the country worked together to raise awareness about bleeding disorders.

There was great interest in the week and we had many supporters to help us fundraise and raise awareness over the week. Bendigo Bank branches across Australia joined in partnership once again to raise awareness and funds; and schools, hospitals, libraries, families and local communities around the country received promotional materials to help them run their own activities.

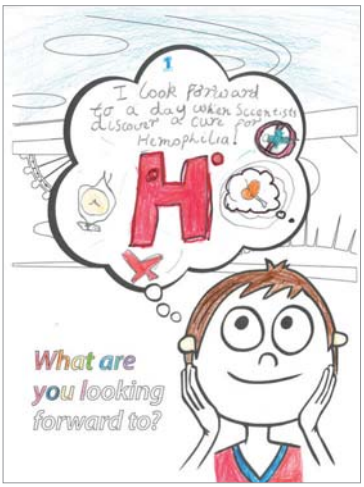
THANK YOU NEWSLETTER

A newsletter highlighting all the events held during the week will be distributed to participants soon and will be available on the HFA web site. If you wish to receive a copy please email Natashia at ncoco@haemophilia.org.au

Thank you to everyone who participated in Bleeding Disorders Awareness Week and Red Cake Day activities!

COLOURING-IN COMPETITION 2017

CONGRATULATIONS TO THE WINNERS!



CATEGORY 5-8 YEARS
UTANO, CLAYTON VIC

CATEGORY 9-11 YEARS
JACK, LISAROW NSW

18TH AUSTRALIAN & NEW ZEALAND CONFERENCE ON HAEMOPHILIA & RARE BLEEDING DISORDERS

LOOKING FORWARD TO CHANGE

Melbourne • 12-14 October **2017**

2017 Conference

The 18th Australian & New Zealand Conference on Haemophilia & Rare Bleeding Disorders held in October in Melbourne went very well. It was attended by people with bleeding disorders, their families and carers, health professionals, policy makers, industry representatives and other stakeholders who came together to meet, share information and learn from each other.

The diverse program was developed by a multidisciplinary committee chaired by Dr Huyen Tran and covered a range of interesting and challenging topics. We thank all the speakers and session chairs who contributed to our meeting.

CATCH UP ON THE PRESENTATIONS

Presentations and the abstract book are available to download from the HFA website - www.haemophilia.org.au/conferences.

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Thank you to our conference sponsors and supporters.

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REFLECTIONS ON THE CONFERENCE

WHAT DID THE DELEGATES SAY?

Delivered on the theme of *'Looking forward to change'.*

It is very hard to target broad audience and I think you do that well.

Justin was brilliant. We all have families at different levels and all the information was very relatable and achievable.

My conference highlight was meeting other haemophiliacs.

Everything is new to me so I would say that I learned so much. A lot of the presentations were helpful for those of us who don't know much.

Opportunity to network and realise from parents that what we do does make such a difference.

Interaction between all stakeholders and excellent speakers.

How far gene therapy has advanced and catching up with old friends.

Ability to have positive contact with other health care professionals working within bleeding disorders and hearing presentations from both [health professionals and patients].

HAEMOPHILIA HEALTH PROFESSIONALS AND COMMUNITY MEMBERS REFLECTED ON THEIR EXPERIENCES AT THE CONFERENCE:

I attended the Australian and New Zealand Conference for the first time this year. I was honoured to be in such an eclectic array of individuals for the Conference. All members of the multidisciplinary team were represented alongside representatives from the National Blood Authority, Department of Health and pharmaceutical companies, and patients and relatives.

The agenda was varied and encompassed sessions led by national and international experts on bleeding disorders. Most of the sessions I was able to attend included some patient presenters who brought the focus back to patient care and patient experiences, allowing more insight into how it feels to live with bleeding disorders and the associated problems.

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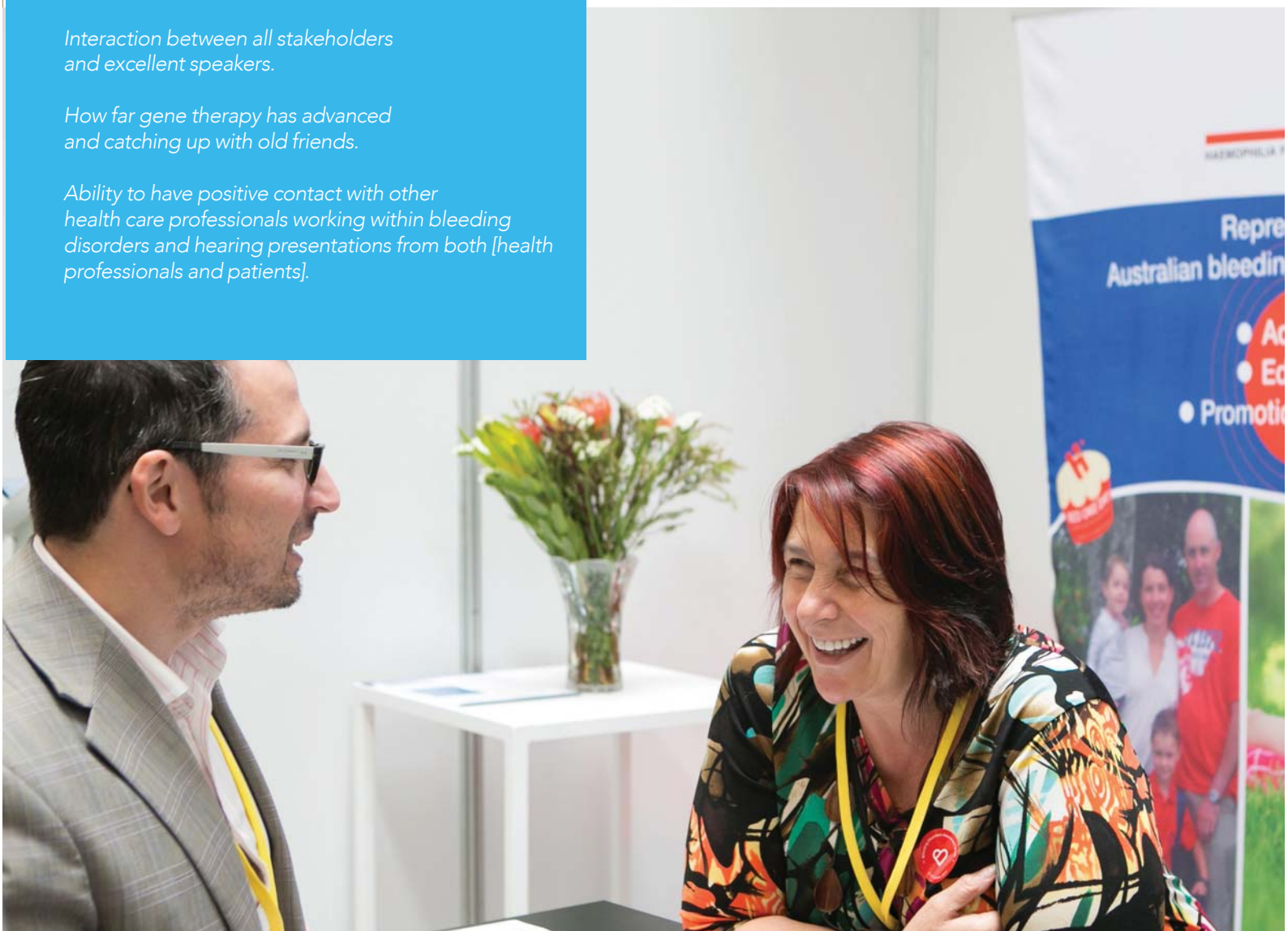


It was a real nice and cosy conference, and it was good to meet with other people with haemophilia, and hear their stories.

The opportunity to talk to patients and hear about their experience was also possible through the questions post session, at breaks in the sessions and at the evening meal. During the Conference I had the privilege of conversing with several families and patients from around Australia who have learned to live with the problems they face on a daily basis; they discussed struggles they have worked through or are still working through such as whether to have prophylaxis or not, bad experiences of hospital admissions, and positives such as the great support and expertise offered by their treatment centres, and their pleasure in their growing families.

Sue Webzell, Haematology Nurse,
Hollywood Haemophilia Treatment Centre, Perth

This was my first visit to a local conference as previously I've only been to the World Federation of Hemophilia conference that was held in Melbourne in 2014, which was very large with something like 5000 people attending from all over the world. However, the local one only had a few hundred people attend. So it was a real nice and cosy conference, and it was good to meet with other people with haemophilia, and hear their stories.

When the conference finished on Saturday it was sad to leave, but I'm hoping to go to the next Australia/New Zealand Conference in 2019.

Stephen, community member

I was very happy to be given the opportunity to attend the 18th Australia and New Zealand Conference.

Come Saturday afternoon at the finish, I realised that I had sat through two days of presentations and learnt more about haemophilia and more importantly met other haemophiliacs who have had inhibitors, major bleeds, joint replacements and mental issues. Seeing others who have conquered life with haemophilia has encouraged me to look after my body better and to exercise more.

Roll on Sydney 2019!

Phillip, community member

THE 2017 CONFERENCE:
A FOUNDATION PERSPECTIVE

DANIEL CREDAZZI

JOHN RASKO

Prof John Rasko presenting on gene therapy

Daniel Credazzi is Vice-President, Haemophilia Foundation Australia and President, Haemophilia Foundation New South Wales

Dan Credazzi spoke with Suzanne O'Callaghan from HFA about his experiences at the Conference

Suzanne: What was your overall impression of the conference?

Dan: It was one of the best I have attended. It was small enough to talk to people and catch up with a lot of people, but I also gained a lot more new information than at previous conferences.

Suzanne: What sessions stood out for you?

Dan: I was very interested in the presentations from Dr Paula James from Canada on women and bleeding disorders. This was where I learned the most new information: the numbers of women who are actually affected but undiagnosed, and her experiences in her own clinics and the relevance of the personal stories she related. For me it identified a whole under-engaged population.

Also I was very impressed by Professor John Rasko's presentation on gene therapy. It was the first time I had heard at one of our conferences that a cure was within reach. As a parent of a teenager with haemophilia, I have been waiting for 13 years to meet someone like Prof Rasko. It was quite significant to hear about the success of his trials in Sydney – and invigorating because this is a step-change in the progress of treatment development in haemophilia.

Suzanne: What was the most memorable aspect?

Dan: I really liked the Men's Breakfast and the stories from the panelists, David, Paul and Tim. David's positive attitude was absolutely inspiring: his perseverance through pain and bleeds and no treatment and being rural, and his physical stamina over decades of his life. It was refreshing also to hear from the young men and see their positive approach to life.

Suzanne: What was your take home message from the conference?

Dan: Once again it brought home to me that this is a Conference that is really worth attending. It was like everything came together – even the blood cell design on the carpet at the hotel! It was such a co-incidence and I thought it made for a perfect bleeding disorders conference venue.

But I came away being aware that there are many more unidentified females with bleeding disorders and that this is something where foundations will need to continue to develop focused support.

Paul is an Australian community member with haemophilia B

NEW HAEMOPHILIA TREATMENTS - A PERSONAL STORY

Paul

This is a transcript of Paul's presentation at the 2017 Conference

I have severe haemophilia B – less than 1%. Until I went on a clinical trial with an extended half life product 5 years ago I would treat on demand - after I had a bleed, which was once or twice a month.

My main issue with bleeding over the years was that my left ankle became a target joint and deteriorated and needed to be fused.

When the clinical trial was suggested I saw it as an opportunity to be involved in helping with the advancement of haemophilia treatment. Also the idea of prophylaxis once a week appealed to me.

Being on prophylaxis for the first time was new for me. I found treating once a week was easy to comply with and get into a routine. Thursday was and still is the day I have my treatment and it's just a 10 to 15 minute process.

In the 5 years that I have been using the extended half life product I haven't had to treat a bleed. And my dosage has reduced from 6000 units to 4000 units per treatment.

I have peace of mind in my ability to do things without having a bleed.

I am better able to plan and enjoy life – there is less disruption to my life due to bleeds; also travel has become easier as I don't need to travel with as much product.

My mindset towards haemophilia has changed. I have a feeling of what it might be like to be normal - so little time is now spent having treatment, or dealing with bleeds. I have my dose once a week, it takes 10 -15 minutes, and I know I am covered for the week.

It all adds up to a better quality of life.

Team.Factor

For the sixth year a group of cyclists led by Dr Simon McRae and Andrew Atkins will ride as Team.Factor to take on the BUPA Challenge Tour in South Australia on Friday 19 January 2018. The 2018 Bupa Challenge Tour will be from Norwood to Uraidla, just over 137.40kms.

Their chosen charity is Haemophilia Foundation Australia.

You can support Team.Factor on the day at the check points or you can make a donation at - https://give.everydayhero.com/au/team-factor-bupa-challenge-tour-2018

21 DAYS TO A HAPPIER FAMILY

Plenary: Dr Justin Coulson

The Conference opened with a plenary session on family relationships from Dr Justin Coulson, who is a leading Australian parenting expert, author, researcher and former radio personality. Feedback was immensely positive, with delegates describing the session as "fabulous" and "excellent". Coulson used simple principles to explain how to reduce stress in family relationships and increase the sense of positive connection. While this was a session with general appeal, Coulson had prepared for the session by seeking advice on the types of issues that come up for families with bleeding disorders and used this knowledge adeptly to focus on the touch points for families: treatments, getting away from home on time, ways to find special time together when life can seem a bit rough.

The first session, *21 days to a Happier Family* by Dr Justin Coulson, was excellent (he has six children!). He made a tricky subject funny and very interesting. He spoke about having a family plan, how LOVE is spelled TIME, about limits for children and the importance of laughter in family relationships.
Stephen, community member

21 days to a happier family, a session looking at how to increase happiness within any family with some simple steps. Using 3 principles of love, limits and laughter to enhance relationships and increase positive encounters within the family. Investing time can lead to great gains.
Sue Webzell, Haematology Nurse, Hollywood Haemophilia Treatment Centre, Perth

Justin gave a very engaging and enlightening presentation, using a lot of his own life experiences (as a father of 6 daughters!) to humorously illustrate his points. Whilst not specific to haemophilia and other bleeding disorders, his talk made us all reflect on our families, our relationships, and how to make the best out of every moment, no matter what life has thrown at us. His three underlying principles of showing love and care, agreeing on limits, and finding fun and laughter in everyday events are widely applicable to all of life's interactions - be that the morning negotiation to have factor before heading off to school, having discussions around physical activity and participation with your haemophilia team, dealing with a bleed or an injury, or any other of the myriad of situations we all find ourselves in. Justin gave us a very thought-provoking start to the conference which really set the tone of family and positive relationships with loved ones and important people in your life… including the members of your haemophilia team!
Johanna Newsom, Deputy Head of Physiotherapy, the Children's Hospital at Westmead, Sydney

Coulson provided practical strategy and backed it up with science and personal experience. "Love, Limits and Laughter" were the three elements that he felt were essential in successful parenting. Coulson talked about finding ways to show the love: touch and doing things together, making family rituals and spending time together regularly were some of his ideas.

There was no shying away from having rules, and limits are an essential part of parenting. Interestingly the idea of punishment was really explored. The reality is that although on some occasions it is necessary, most of the time discipline becomes unnecessarily punitive and punishing, and this doesn't help kids learn how to do the right thing, they just become embarrassed, annoyed, and determined not to get caught the next time. Teaching them through listening, showing them, and helping them to do the right thing are more powerful and have much better results. Although in the moment it may feel that there is not time to explore a problem, give the child an opportunity or teach them, in actual fact, it will often be more effective and save time and distress. The simple example of a toddler wanting to turn off a light switch before leaving the house was given. The parent had shut the door and wanted to get into the car, so refused to go back into the house and allow the child to turn the switch. However, the child then had a tantrum, became very distressed and there was a fight to get into the car seat, there were more tears and distress, and the rest of the outing was negatively impacted by all of this. The alternate option was posed, what if the parent had unlocked the door, gone into the house and allowed the toddler to switch off the light. Of course there would have been none of the distress.

Laughter gets families through many hard times, and finding ways to laugh is vital, and powerful. It doesn't have to be big stuff to get families laughing. Through laughter difficulties and conflict can be navigated, families can forgive, and be more willing to accommodate each other, and work harder to understand.

Coulson suggested that making a written family plan is a powerful way of ensuring that families attend to the important matters and address the difficulties. He challenged the audience to go home and put pen to paper.
Jane Portnoy, Social Worker – Haemophilia, The Alfred hospital, Melbourne

Sue Webzell is Haematology Nurse at the Hollywood Haemophilia Treatment Centre, Hollywood Private Hospital, Perth

A NURSING PERSPECTIVE

Sue Webzell

NURSES GROUP MEETING

Pre-conference the Australian Haemophilia Nurses' Group met and had time to reflect on changes within the Haemophilia Treatment Centres and in the bleeding disorders community. The nurses who had been to various other international and national conferences shared information and education with the rest of the Group. As a relatively new member of the Nurse's Group, I saw that the time spent together in this way clarified management of patients and allowed for good relationships between Centres. The Group is always very supportive; discussion throughout the year via email is common especially around best practice.

HEP C AND HIV

Chair: Suzanne O'Callaghan
A personal story of hep C treatment ~ Simon
Hepatitis C update - A/Prof Joe Sasadeusz
HIV clinical update - A/Prof Edwina Wright
A personal story about living with HIV - Anthony

Historically hepatitis C and HIV has caused significant problems within the bleeding disorders community due to transmission via blood products prior to the 1990s. This session discussed these health concerns and offered a very encouraging future for patients who have been affected. It used both health professionals and patients to give a greater overview of the problems, the new treatments and a personal experience of living with these viruses.

A/Prof Joe Sasadeusz explained that hepatitis C is now a curable disease: a 95% response rate has been seen with the new treatments. These new treatments have been rolled out across Australia and can be prescribed by general practitioners as well as specialists, side effects are minimal and they can be used to treat a wide range of patients. Over 30,000 prescriptions have been dispensed in Australia in 2017.

A patient gave a personal experience which looked at his feelings of 'a strange sense of shame, worry and wondering what might happen into the future' after contracting hepatitis C from blood products taken for a couple of tooth extractions. He discussed previous interferon-based treatments and the significant side effects he suffered and the short lived response. He then talked of his experience with the newer much more tolerable treatments with which he had no side effects and achieved a cure.

A/Prof Edwina Wright spoke about the latest directions in HIV and treatment as prevention. WHO (World Health Organisation) is aiming to end transmission of HIV by 2030; Australia is striving for the same by 2020. This can be achieved by the offer of PrEP (Pre-Exposure Prophylaxis) treatment for all at risk people, education, and the use of HIV anti-retroviral treatments in people living with HIV.

HIV anti-retroviral treatments can reduce the viral load to undetectable and reduce transmission potential to virtually nil; and pre-treatment of non-affected partners or treatment within 72 hours after a potential exposure stops the virus's ability to attach to the individual so infection does not take place. Using these medications to stop the transmission of the virus to the non-affected partner or the child has enabled people living with HIV to have children safely and given them the opportunity to create a family naturally.

Another patient who had been affected by HIV and hepatitis C gave an inspiring personal account of how he has lived with his diagnosis, the treatments and the support he has had from his family and friends.

VON WILLEBRAND DISORDER

Chair: Dr Mandy Davis
VWD - diagnosis, treatment and care - Dr Paula James
Living with VWD – my personal story – Brendan

Canadian haematologist Dr Paula James presented information on the current understanding of von Willebrand disorder (VWD). VWD is the most

> Levels of VWF can be significantly affected by stress, exercise, pregnancy, hormones, bleeding, infection and age, so repeat testing may be required and timing is important.

common bleeding disorder. It affects males and females equally but more women are diagnosed as their symptoms such as menorrhagia and post-partum haemorrhage are more likely to lead to investigation. 1 in 1000 people are thought to have VWD, but many are undiagnosed. VWD can cause excessive bleeding especially of the mucous membranes. Von Willebrand factor (VWF) is normally present in adequate quantities in the bloodstream. VWF is essential for blood clotting; it sticks platelets down in vascular injury and carries factor VIII. In VWD there is either a reduction in the amount of VWF in the bloodstream or it doesn't function properly. For example, in type 1 there is not enough VWF (70-80% of patients), in type 2 VWF does not work properly (15-30% of patients), and in type 3 VWF is absent (rare).

Levels of VWF can be significantly affected by stress, exercise, pregnancy, hormones, bleeding, infection and age, so repeat testing may be required and timing is important. Day 1 of a period is a good time to test as levels are often lower during menstruation and more indicative of VWD. There are numerous treatment options for intermittent or long term control such as birth control medications, Mirena Coil, DDAVP (desmopressin), tranexamic acid, factor replacement with VWF and FVIII (at present plasma derived but recombinant product should be available in the future) or in some women surgical options such as endometrial ablation or hysterectomy may be used.

Even patients with mild VWD will likely require some treatments if undergoing any surgery or dental work. Trials to assess the effectiveness of treatments such as DDAVP are required pre-operatively; the responses can vary significantly between different people.

Dr Paula James also discussed her website 'Let's Talk Period' (https://letstalkperiod.ca) that has a self-directed bleeding score tool to assist women to determine if they need to get further testing for a bleeding disorder . The intention is that some of the currently undiagnosed women will be able to do a basic self-assessment and then seek further assistance in diagnosis and treatment if appropriate.

WHAT'S HERE NOW AND ON THE HORIZON - NEW TREATMENT THERAPIES CHAIR: CLAUDE DAMIANI

My experience with an extended half-life product - Paul
Supply and purchasing, new treatments, cost effectiveness assessment/funding pathways to new medicines - John Cahill
Extended half-life factors and other new therapies - Dr Huyen Tran
Gene therapy - Prof John Rasko

These speakers presented on a range of the new therapies for haemophilia that may be available soon for some patient groups. One type of new treatment is extended half-life products, which decrease the frequency of factor replacement infusions as there is a higher amount of factor present in the body for longer periods. Monoclonal antibodies with easier delivery methods such via a subcutaneous route continue being investigated within trial patients. Genetic therapies for a potential 'cure' are also being trialled and showing promising results. These have shown the potential to change the face of haemophilia significantly; however, there are many hurdles to be overcome and questions to be answered before these treatments can be used widely within the bleeding disorder population.

SATELLITE SESSIONS

For the health professionals there were also industry-sponsored breakfast, lunch and evening sessions with expert speakers showing new techniques such as ultrasound and recent research results of upcoming treatments, research case studies including videos of participants' experience of participation, and information on best practice techniques, all making for a very full, very interesting but tiring few days.

Simon is an Australian community member with haemophilia who has been cured of hepatitis C. He is an architect, the co-director of an architecture design practice and a senior lecturer at a university where he is also doing his PhD.

HEP C TREATMENT – A PERSONAL EXPERIENCE

Simon

This is a transcript of Simon's presentation at the 2017 Conference

Preparing this presentation began with me wondering what it was that I could bring to the Conference regarding my experience with hep C and its treatment. I mean, a guy in his mid-40s takes a pill with no side effects for three months and is cured of a disease without any residual issues is hardly compelling listening. In conversation with Suzanne from HFA though, my jaw dropped when she told me that some people had not taken up treatment. I couldn't believe that anyone would refuse the opportunity to finally rid themselves of that bomb ticking away inside them.

So I thought, well then, this is going to be about me giving reasons and experiences that you can relate to patients you encounter. Patients that may have reasons to avoiding or delaying taking up this quite amazing treatment. So I thought I'd imagine what those could be.

1. For those who are perhaps suspicious

As I, or I should say my mother and I, were in the early 80s when all of a sudden treatment became dangerous. It was about 1984, a year or so after I had already contracted hep C from blood products taken for a couple of tooth extractions. Never mind the opportunity to contract HIV had probably already come and gone, the fact was that trust in treatment had evaporated.

So what to do? As a mild haemophiliac I had the option, for the most part, of just waiting out the slow healing of my joint trauma injuries. And my mum, keen to find some way to ease my pain and bleeding from injuries to my joints looked into alternative medicines. Safe medicines, and as it turned out quite useless ones.

I recall lying on my couch strapping cotton wool soaked in arnica to my knee, or ankle, or elbow – tinctures - for years, of unnecessary pain and lost days suffered. It still makes me very angry to think someone, an adult, advised a haemophiliac child and their mother to undertake such nonsense.

So for those who are suspicious, I've tried things that don't work too, and I also had good reasons. This treatment we are talking about isn't that.

2. For those who have already lost time

I avoided any form of treatment for hep C following my ultimately unsuccessful interferon treatment in my early 20s. I had cleared the virus after the 6-month treatment. It was quite heartbreaking to discover it had returned in the 6th month following the end of treatment, and contributed to a period where I lost about a year of my studies – or of much of anything really - to that vague funk that accompanies interferon treatment, along with the distress of the unsuccessful aftermath that I found hard to take and the source of quite crippling anxiety.

Any description of the treatments I've been offered over the years since involved lengthy commitments

33 years...

of carrying this disease with all the strange sense of shame, worry and wondering what might happen into the future evaporated like it never happened.

of up to 12 months, the possibility of side effects and unsatisfying cure rates, particularly for my genotype. I had already lost time and was not keen to lose more, to give up time that could be spent on my post-grad studies, or later the projects I was working on such as Federation Square, later the time for my business I was building; it just didn't seem worth it. I was yet to have a result from biopsy or ultrasound that showed the disease was doing any damage, so I waited. And I am now glad I did for the total time lost to this treatment, the one that worked, would be three trips to the pharmacy and two to the hepatitis clinic.

3. For those who are avoiding it

That said, waiting was not so easy. It's a time spent wondering why I couldn't feel comfortable to tell people that I have this disease, and that's why I hide my toothbrushes away from accidental use by others.

The awkward explanations to new partners, when you aren't exactly sure how much risk you are asking them to take.

The mornings after too many drinks the night before when you wonder if this really was the time that you'd finally done it to yourself, that the next fibroscan would come with bad news.

And so, like most people faced with the fear of bad news, I tried the avoiding it, missing scans and not chasing referrals, hoping my fears away. Finding out that I no longer have anything to avoid, no longer need to worry about some future where my luck runs out really was such a release.

4. The last reason…

The last reason I'll give is not really a specific argument against why a person might refuse to take treatment. It's really just to say that the moment when the specialist looked at my results and turned casually saying, yep, you're cured – there was a tone he had like there was never any other possibility – that was one of the most incredible moments of my life. Thirty-three years of carrying this disease with all the strange sense of shame, worry and wondering what might happen into the future evaporated like it never happened. And that's a feeling you really do want.

On reflection it's the lack of drama in this story that's the real point. After so many years the end was so easy and ordinary.

Anth is an Australian community member with haemophilia and HIV

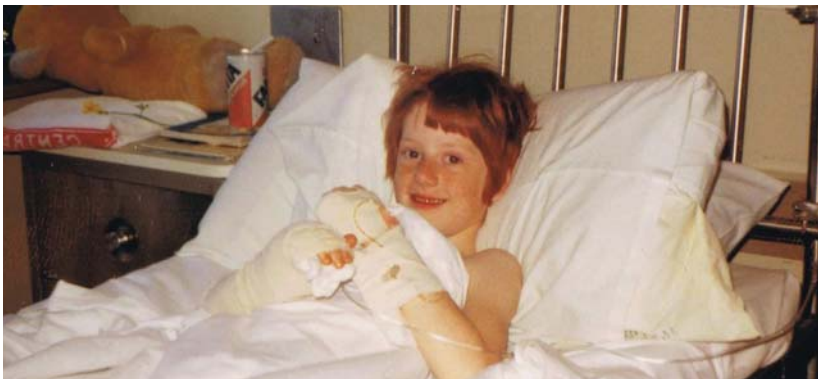
LOOKING FORWARD TO CHANGE WITH HIV

Anth

This is a transcript of Anth's presentation at the 2017 Conference.

It's great to be here with you, looking forward to change. I am a person living with a bleeding disorder and HIV. I've been asked to share some of my experiences of disclosure, survivorship and some of the financial issues of living with haemophilia, HIV and hep C.

Last year, on World AIDS day, December 1, I used social media to publicly disclose my status as a person living with HIV. For a long time I could not have contemplated doing such a thing. I felt compelled to hide what I thought was a weakness. It took me over 30 years to learn that it was in fact a strength and that I have something to offer by sharing it.



Treatment for bleeds at the children's hospital

I was born with severe haemophilia A. By the mid-80s I'd acquired HIV and hep C from factor replacement made from human blood donations. My parents and I thought I was going to die from AIDS, and we were scared and bewildered. Our situation was repeated in many families and the majority of those of us who medically acquired HIV are gone. I want to acknowledge that the pain and grief continues right up to today. You can imagine how fortunate I feel to have survived through to this era where antiviral medicines are so advanced and effective.

It was frightening and confusing to be a child living with HIV with such a high level of fear in the community. People poorly understood how it was passed on. I heard the idea that God sent AIDS to punish certain behaviours. My parents and I heard the jokes and derogatory references. I feared bullying if my secret got out. To an extent, I began to internalise those negative messages about people living with HIV.

With another student on crutches at school

I missed a lot of school due to bleeds and I absolutely hated going on crutches. It meant revealing that I had something wrong with me. Haemophilia wasn't easy to explain and it was now associated with HIV. In the photo of me at school on this occasion there just happened to be another kid on crutches.

My parents and I quickly worked out that my connection to HIV was something to hide. Secrecy felt like a pathway to survival. We feared being ostracised and we isolated ourselves from support by not telling a single other person.

It was really tough for Mum and Dad, but they did amazingly well with what they had. We could barely talk about HIV, even to each other, but I never questioned their love. They provided me with a safe place where I could be myself and where I felt valued. I had a happy childhood despite the bombshell of HIV. I believe they provided the best possible foundation from which to build resilience.

Graduating from Year 12

By the time I was graduating from Year 12, I'd made the conscious decision to be optimistic, and to fight HIV, and live the best life I could. But I was beginning to feel very lonely in my struggle, and desperate to take some control over the isolation.

I decided to tell my siblings about what I had been dealing with. It was honestly one of the hardest things I've ever had to do. I remember my palms sweating and voice shaking. I had to say "I have HIV" aloud.

I realise now what an important breakthrough that was. It enabled me to begin a slow careful process of disclosing to others close to me. It was always difficult, but it was incredibly rewarding. I found that revealing that I had HIV allowed me to feel more connected to the special people who would love and support me regardless of HIV.

My partner Jennifer

One of those people was Jennifer. I disclosed to her when she was my friend and house mate, before we formed a relationship. Jennifer is a unique, wise and wonderful person. She is just one of many non-HIV positive partners of people living with HIV. Love overcomes HIV.

Me, Jennifer and the kids in 2016

So why did I feel the need to publicly disclose? The best way to answer is to read some of what I had to say;

Dear friends, family, strangers, world,

Today is #WorldAIDSday and to celebrate I'm coming out of the viral closet. I am proud and grateful to be a long term survivor of HIV. I have been living with this virus for over 30 years and I'm in remarkably good shape. Now that is something to celebrate!

Until now I have concealed my status in fear of the judgement and stigma that comes with it. HIV stigma is complex, insidious and toxic, and it undermines the welfare of people living with HIV in many ways. But it does more than that. HIV stigma interferes with HIV prevention. It is a threat to the whole community, not just those living with HIV.

So, I have decided to own being HIV positive and to strike back at stigma. I'm sick of allowing others to feel more comfortable by hiding HIV. I have nothing to be ashamed of. I no longer feel vulnerable to judgement or shame. Whenever I have confided in a friend, I have been rewarded by the kindness they show. In my experience, most people on the planet are like that.

Please remember that people living with HIV feel the threat of stigma acutely, and often choose not to disclose. You just never know who might be silently living with HIV - I'm proof that not everyone with HIV fits the stereotypes. So please take care how you think and speak about HIV. Your words can be hurtful, and they can be healing.

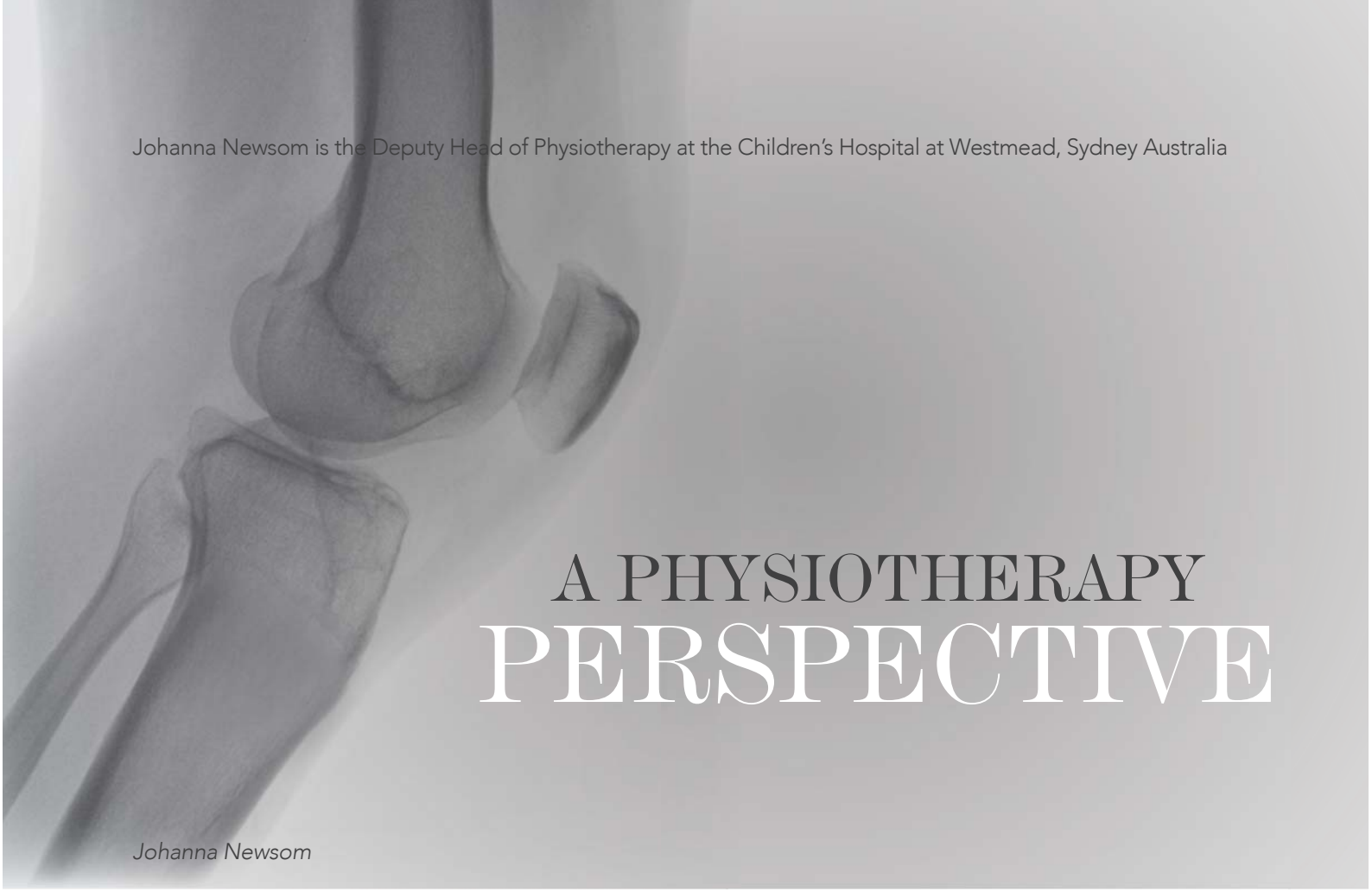
Hitting post that day is one of the most satisfying things I've ever done. After years of fearing that others would disclose for me, I chose the time and means to make a strong statement. It felt great to celebrate in that way, and to free all those people who had kept the secret for me.

I was overwhelmed by the supportive and affirming comments that my post received. I still need to disclose from time to time, but life is easier now. It takes a lot of energy to hide a secret.

In 2013, I was very fortunate to clear hep C. I can't tell you how joyful that felt. To get rid of a virus, rather than take one on. My co-speakers today, Dr Edwina Wright and Dr Joe Sasadeusz collaborated with me on that project for many years including three rounds of treatment.

Haemophilia, HIV and hep C would normally cause financial hardship. Thankfully, that is not my story. I received a financial settlement for damages in 1991, and because I resented it for the way it came to me, I refused to spend it, and it was invested for me by Mum and Dad. Wow, am I thankful for that now. Jennifer and I own our home outright. I have never been able to sustain full time work but I'm eligible to claim the disability support pension while working part time.

I put my survival down to the kindness and compassion shown to me in difficult times. As we look forward to change; while we hear about all the medical advancements, fresh new thinking and the role of technology at this conference, let's just acknowledge that underpinning our efforts is our ethos of kindness and compassion. It's a powerful thing. Days like this, and gatherings of people like you, who I know work from a base of kindness and compassion fill me with hope for a bright future.



Johanna Newsom is the Deputy Head of Physiotherapy at the Children's Hospital at Westmead, Sydney Australia

A PHYSIOTHERAPY PERSPECTIVE

Johanna Newsom

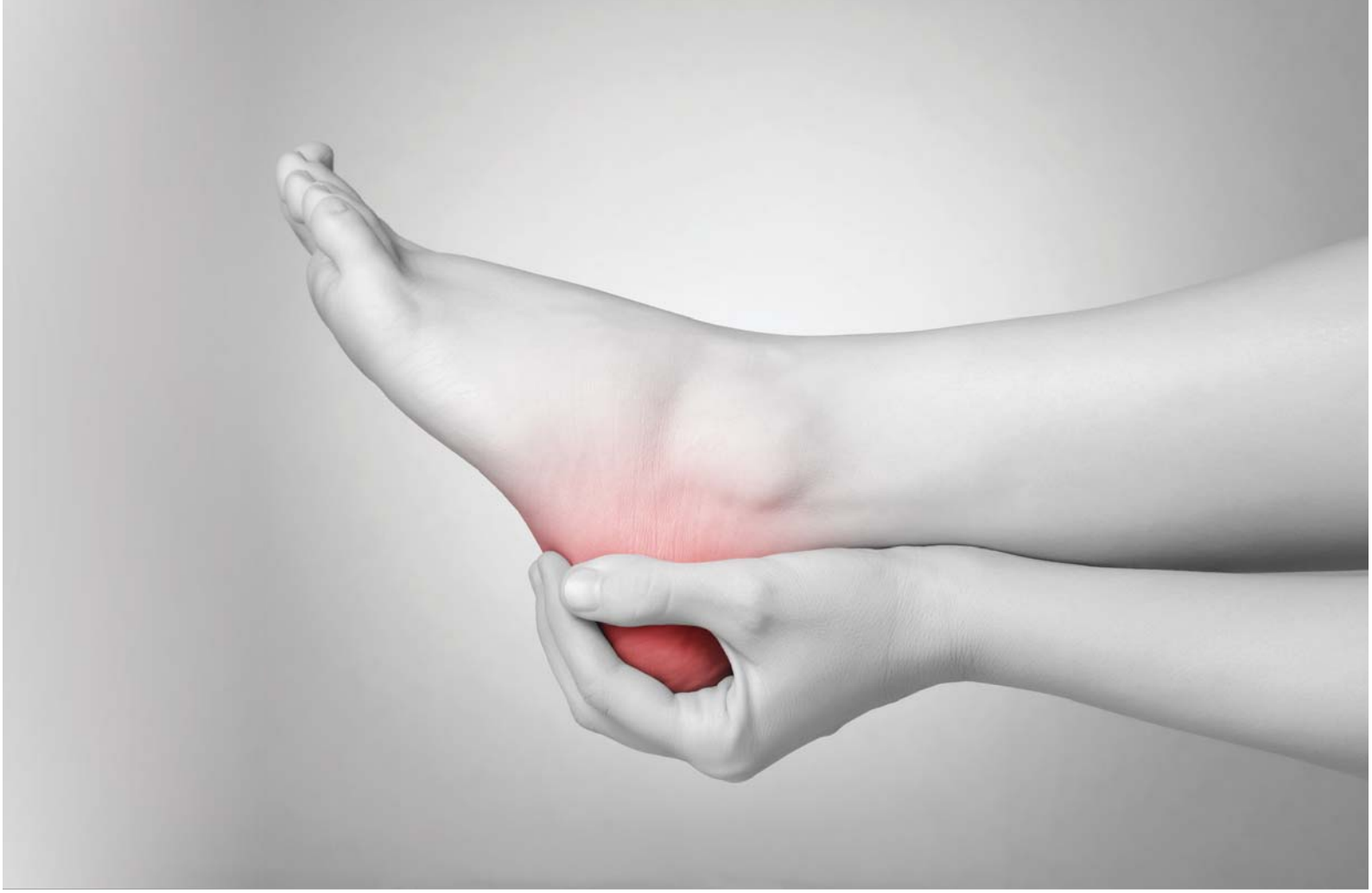
PAIN MANAGEMENT

Chair: Cameron Cramey
Understanding pain… in 20 minutes – Martina Egan-Moog
Evolving concepts in pain management – A/Prof Carolyn Arnold
Clinical application of modern pain sciences for People with Bleeding Disorders (PWBD), an 'active approach' – Catherine Pollard

Pain is always a topic of interest and debate in the bleeding disorder community, and it was good to see it featuring again on this year's conference program. With up to 50% of the bleeding disorder population reporting chronic pain, this informative session was well-attended by both people with bleeding disorders and health professionals. Martina Egan-Moog gave us the rapid-fire version of the current understanding of pain - huge amounts of recent research into the area of pain is suggesting that our bodies send potential "danger signals" to our brains, and our brains "turn up" or "turn down" these messages depending on what else is happening for us. Things that can turn up these messages include stress, fatigue, or bad memories. But the messages can be turned down by positive things such as happiness, trusting relationships, and comprehending how pain works. Thus we learnt that it is really important to know how pain is interpreted by our brains, and we all need to understand that many things (happening inside and outside our bodies) will contribute to pain for each person. Most importantly, we can influence our experience of pain by acknowledging and managing things like stress and fatigue, and by looking for more positive factors that will help to turn down those danger messages!

Carolyn Arnold then talked more specifically about pain in people with bleeding disorders, and reiterated what we have all heard before – that pain does not always mean active bleeding. We all know that synovitis (inflammation of the lining of the joint) and haemarthropathy (disease of or damage to a joint as a result of blood in the joint space) cause significant pain, and it is important to see your treatment team to help you determine what is going on for you. A team approach to controlling this pain is imperative - medications play a small role, but it is just as important to maintain a normal body weight and a healthy lifestyle, improve joint and muscle function, increase positivity and enjoyment, and decrease stress.

Catherine Pollard finished this session with a presentation about the "active approach" to managing pain in people with bleeding disorders. She presented research about exercising and training for people who experience chronic or persistent pain, and how best to approach this. It is well known that maintaining strength, flexibility, normal body weight, and activity levels is important for people with bleeding disorders to minimise bleeds, but these things are also very good for assisting with pain management. Your physiotherapist can help you



devise a graduated exercise program that aims to avoid flaring up your pain, whilst still getting you the results you are after!

HEALTHY JOINTS FOR LIFE

Chair: Nicola Hamilton
Bleed, Arthritis or Something Else – Alison Morris and Abi Polus
Decision Making in Sport & Physical Activity – Not Everyone Wants to Swim! – Alison Morris

In what was a whirlwind tour of common aches and pains, injuries and conditions for the normal population, Alison Morris and Abi Polus managed to succinctly present the role of the physiotherapist in the haemophilia team. Having a diagnosis of haemophilia or another bleeding disorder obviously does not prevent any other injury or musculoskeletal condition occurring, and frequently the physiotherapist is in the best position to help work out exactly what is going on and make sure the appropriate treatment is undertaken. Alison started proceedings with a summary of common musculoskeletal conditions seen in childhood and adolescence, explaining how they appear, how they are diagnosed, and what can be done to treat them. Abi then followed on by telling us all that we have 10 good years (between about 20 and 30 years old), and then upsettingly it is all downhill in terms of musculoskeletal deterioration. An examination of common injuries and presentations seen in adulthood, complete with diagnosis and possible treatments, helped us all to better appreciate that we are ageing human bodies prone to accidents and mishaps, and this is no less true in the bleeding disorder population. A good reminder that a bleeding disorder is only one part of the puzzle when it comes to assessing joint and muscular health!

Alison Morris finished this session with a mindset-challenging presentation about decision making for participation in sport. Gone are the days of recommending swimming and other non-contact sports to everyone! Alison described the contradictions that exist in the literature around the suitability of various sports and activities for people with bleeding disorders, and the issues with trying to categorise sports as "safe" or "dangerous", or somewhere in between. The take home message was that decisions about inclusion in a new physical activity needed to be a made from a considered and researched basis – what is the training and playing schedule like? What are the risks of the activity? Do they outweigh the benefits? What is the agreed level of acceptable risk? Can it be modified with treatment (factor), strengthening or stretching, bracing or other protective gear? These are just some of the questions, and the team at your haemophilia treatment centre can help to answer these and more as needed.

I would like to thank everyone at HFA and the many other people involved for all their work in putting together such a great conference program, and for the inclusion of the poster display, the trade areas, and the social events.

Jane Portnoy is Social Worker – Haemophilia at The Alfred hospital, Melbourne

A PSYCHOSOCIAL PERSPECTIVE

Jane Portnoy

YOUTH MYTH BUSTING

Chair: Moana Harlen

Youth Myth Busting was the most exciting session that I attended. I really enjoyed the energy and involvement from the audience.

The session involved three teams: a youth team, and adult team, and a health professional team. There were a series of 'myths' and the question was posed whether each myth was **true** or **false**. The audience voted, true or false, and then the teams were given a chance to answer and support their response. Finally the audience was asked if they had changed their views. There was a chance for comments and more questions, and we were really lucky to hear from so many members of the community about their own experience.

We were lulled into a sense of false security with a couple of easy 'myths' where there was a general consensus; these included 'prophylaxis means that there are no more bleeding problems' and 'tattoos are perfectly safe for people with bleeding disorders'. However, the myths became more controversial, and there was a broad range of different views. The answers were rarely straightforward. *Yes … but*, or *No … maybe*, or *perhaps!* Or *… but if you put it that way …* seemed to be very common.

The most interesting thing for me was the stories that were told to support or to demonstrate a particular point. Talking about telling your boss about your bleeding disorder was one area where there were many examples on both sides. Generally it seems that being proactive and taking responsibility for yourself was really positive and successful way of approaching this area. However, we did hear of one young woman who was fired after she informed her manager of her haemophilia. She went to the union and was supported to approach her employer. She got her job back and the offending manager was dismissed.

Another interesting debate was 'it is inappropriate to discuss sex and bleeds with your treating team'. Of course, this seemed obvious to me, but then one of the young people said it was really uncomfortable as he had known his treating team his whole life, and it felt a bit like talking to your auntie about sex … YUK! It seems that whilst the professionals are in agreement that this it is appropriate and reasonable to talk sex and bleeds, usually they don't bring these things up. So it's left to the patients. One of the great strategies we heard about was the session at the 'blood brothers camp' where anonymous questions are able to be put to either one of the haematologists or the nurses. Usually a great conversation follows; of course everyone wants to know about the same things.

Thanks to Hannah, who worked hard to put this session together before she left HFA for a new job.

EVOLVING CONCEPTS IN PAIN MANAGEMENT

Chair: Cameron Cramey
Understanding pain … in 20 minutes!!
- Martina Egan-Moog
Evolving concepts in pain management
- A/Prof Carolyn Arnold
Clinical application of modern pain sciences for People with Bleeding Disorders (PWBD), an 'active approach'
- Catherine Pollard

I found the Pain Management session to be really helpful. Of course there are many tried and tested strategies of pain management, and for many people these work well.

It is always beneficial to listen to pain specialists speak about how they work with pain, what is helpful, and what are some of the challenges. Dr Arnold was, as always, insightful about how to manage pain. She emphasized that whilst medication is a part of the story, other strategies are also very important. Some other strategies were then talked about by the speakers who followed.

Catherine Pollard, haemophilia physiotherapist in Auckland, spoke about using the gradual physiotherapy approach, making sure to avoid the boom and bust cycle, which does lead to reduced functionality. Catherine described a very gradual increase in exercise with close supervision of a physiotherapist which enabled a person with a bleeding disorder to return to their previous level of functioning; whilst a too fast approach led to further injury and slowed down the recovery process.

Have you heard of DIMs and SIMs? Martina Egan-Moog presented a really useful idea. Martina talked about how our body has danger and safety receptors not pain receptors. The more our sense of safety is the lesser our need for a protective pain response. DIMS stands for Danger in me: anything that is dangerous to your body tissues, life, lifestyle, job, happiness, your day to day function. Essentially anything that is a threat to who you are as a person. SIMS are Safety in Me: anything that that makes you stronger, better, healthier, more confident, more sure and certain within and about yourself.

The diagram below explains how these both can modulate our pain experience.

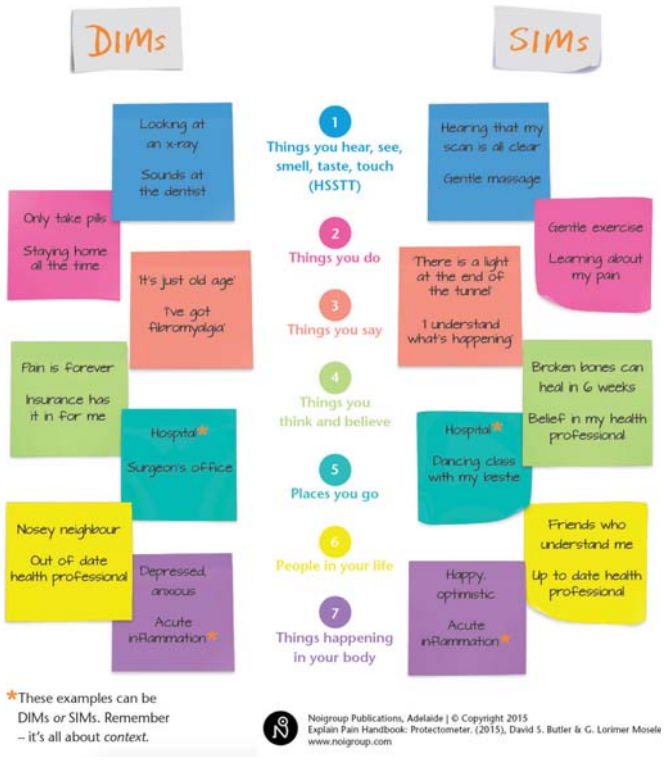


Diagram reproduced with permission from Noigroup Publications

> "Interestingly she spoke about how stress levels can affect your factor VIII levels. In extreme circumstances they can double or even triple them."

WOMEN & BLEEDING DISORDERS

Chair: Dr Jenny Curnow
Let's Talk Period: Women and bleeding disorders - Dr Paula James
Panel Discussion: Dr Jenny Curnow, Dr Chris Barnes, Dr Paula James, Dr Dominic Pepperell

Dr James spoke about women and bleeding disorders and how often bleeding disorders in women can go undiagnosed. Her Self-BAT (self-administered bleeding assessment tool), which is on her Let's Talk Period website (letstalkperiod.ca), was developed to help concerned women to better understand whether their bleeding episodes are normal or abnormal.

Interestingly she spoke about how stress levels can affect your factor VIII levels. In extreme circumstances they can double or even triple them. This can lead to difficulties in VWD testing and discrepant results. In the panel discussion, the haematologists spoke about the reluctance from the medical field to label a person with a specific disorder if doctors are uncertain of the diagnosis, but they also acknowledged that this doesn't diminish the person's bleeding experience and that these women still require treatment to manage their bleeding.

IMPROVING CARE THROUGH MYABDR

Chair: Dan Credazzi
Why do we use MyABDR? - Dr Chris Barnes
Working with the community - Suzanne O'Callaghan. A HTC Royal Children's Melbourne experience - Julia Ekert
MyABDR in the clinic and at home:
Paediatric - Dr Chris Barnes and Karan
Adult - Andrew Atkins and Michael
Moving Forward with MyABDR - Dr Chris Barnes

I thought that the session on why to use MYABDR was greatly enhanced by the patient and family stories of how they had used this method of reporting bleeds and treatments. They described frustrations and system limitations; however, MYABDR has improved greatly and most of the glitches are gone. When they do have a problem the MyABDR Support team is really helpful. One thing that was only briefly touched on was the desire of the young adult to rebel and with a chronic illness such as a bleeding disorder the rebellion can have lifelong effects. I think that talking about this system is incredibly important and hearing about the frustrations is equally vital.

Suzanne O'Callaghan is HFA Policy Research and Education Manager

A FORWARD PERSPECTIVE

Suzanne O'Callaghan

The Conference theme of *Looking forward to change* gave a very positive direction for many of the sessions and raised important questions. What issues are we facing now and into the future? How can we address them in a constructive way and to the benefit of the bleeding disorders community? Presenters, panels and delegates looked at these questions and discussed the strategies that might work best.

HEP C AND HIV

Chair: Suzanne O'Callaghan
A personal story of hep C treatment - Simon
Hepatitis C update - A/Prof Joe Sasadeusz
HIV clinical update - A/Prof Edwina Wright
A personal story about living with HIV - Anthony

In the hepatitis C and HIV session the clinical experts had simple but powerful messages.

A/Prof Joe Sasadeusz described the enormous changes in hepatitis C treatment: it is now a curable disease and the new treatments are simple, have few if any side-effects, have high success rates across different populations, including those with cirrhosis and HIV/HCV co-infection – and are available to all on the PBS in Australia. He pointed out that there is the possibility of drug to drug interactions for people on other medications, but this is quite manageable. His key messages: the bleeding disorders community can aim to eradicate hep C; and he made a plea to all to come forward for treatment if they haven't done so yet.

HIV has turned another new and positive corner. A/Prof Edwina Wright presented the latest studies showing that with antiretroviral therapy (ART) for HIV and new PreP (pre-exposure prophylaxis) treatment HIV transmission can effectively be prevented. It was welcome news to hear the confirmation from the Centers for Disease Control that people taking ART and with an undetectable HIV viral load "have effectively no risk of sexually transmitting the virus to an HIV-negative partner". This gives a strong basis to challenge the stigma and discrimination associated with HIV in the wider community.

The legacy of blood borne viruses is felt deeply in the bleeding disorders community. Decades of pain, ill health and unsuccessful treatment; the loss of family and friends; and the worry of stigma and discrimination.

Simon's personal story acknowledged this and the concerns of some people with bleeding disorders who haven't yet accessed treatment; and that, ironically, after all the difficulties he had faced with hepatitis C, the treatment that cured his was so simple and ordinary – just taking a tablet a day with no side-effects that he was aware of. On World AIDS Day in 2016 Anth made a very significant personal decision: after nearly a lifetime of secrecy, to disclose his HIV status to the world – with the intention of overcoming HIV stigma. Simon and Anth's personal stories are published in this issue of *National Haemophilia.*

Where to next? Those attending the session made felt it was time to make a commitment as a community to support those who are considering hepatitis C treatment and having doubts, or living with HIV. Suggestions included encouraging community leaders affected by HIV or hepatitis C who are happy to disclose to speak up and be visible so that those who do not wish to disclose publicly can connect privately or know they are supported.

WOMEN AND TELLING OTHERS

Chair: Sharron Inglis & Kathryn Body
Navigating Employment and Insurance ~ Kim Shaw
Telling others – personal stories
Haemophilia – Sharron
VWD - Susie
Panel discussion and Q&A

Dr Paula James presenting on women and bleeding disorders

The Women and Bleeding Disorders session highlighted the complexities of diagnosis for women and girls with bleeding disorders. Dr Paula James from Canada had

noted that there is thought to be a substantial number of females with bleeding disorders who have not yet been diagnosed, and Australian clinicians described the careful process involved in diagnosis in females and their reluctance to make a premature diagnosis but acknowledging the need to make sure bleeding symptoms are managed.

When a woman or girl has been diagnosed, telling others is a step that follows and will be part of her decision-making. This session explored some of the issues.

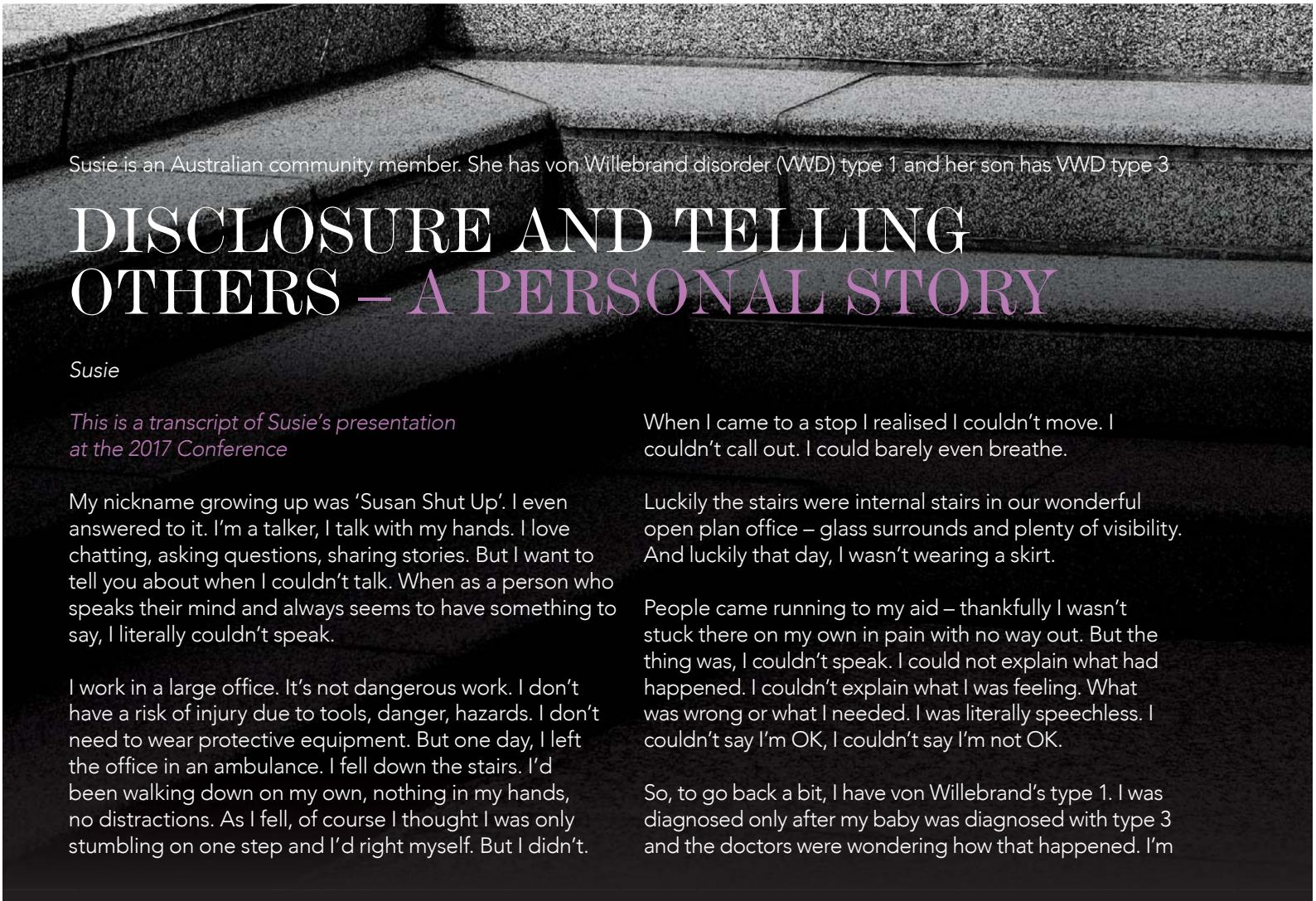
Kim Shaw from Maurice Blackburn lawyers walked through some of the law associated with disclosure to insurance companies and employers. Interestingly, while women are required to disclose their bleeding disorder to insurance companies if asked, there is no case law in Australia about whether they are required to disclose the results of genetic testing, for example, if it shows they carry the gene. There are protective anti-discrimination laws, but it would take a case of discrimination to test the law.

Personal stories from Sharron and Susie followed, exploring how they or their parents told teachers, partners (Sharron had prepared herself to disclose to her partner, only to find a friend had already told him!), and in their workplace.

The Q & A and panel discussion was an opportunity to look more closely at a range of situations. A main area of focus was the workplace and it was clear that disclosure may be different depending on the size of the organisation. In a large organisation the panel recommended looking at its policies in relation to human resources and discrimination and then choosing who it is appropriate to disclose to. In smaller organisations policies can be less obvious or non-existent; a woman may want to get to know the management and test the waters before deciding whether to disclose; alternatively it may work better to disclose before taking up employment.

The emphasis on women and bleeding disorders at this Conference also raised awareness of its importance for community delegates. It was great to see the support and real interest, and these comments by a male community delegate speak to this:

I attended the Women and Telling others session on Saturday afternoon. I wanted to get a female viewpoint on haemophilia. This was a good session for me to attend as my mother bruises very easily and almost certainly will have haemophilia. I also wanted to see haemophilia from a female point of view. This session really showed the problems that women have with haemophilia and VWD and shows quite strongly that haemophilia is not just a 'boys' sickness.



Susie is an Australian community member. She has von Willebrand disorder (VWD) type 1 and her son has VWD type 3

DISCLOSURE AND TELLING OTHERS – A PERSONAL STORY

Susie

This is a transcript of Susie's presentation at the 2017 Conference

My nickname growing up was 'Susan Shut Up'. I even answered to it. I'm a talker, I talk with my hands. I love chatting, asking questions, sharing stories. But I want to tell you about when I couldn't talk. When as a person who speaks their mind and always seems to have something to say, I literally couldn't speak.

I work in a large office. It's not dangerous work. I don't have a risk of injury due to tools, danger, hazards. I don't need to wear protective equipment. But one day, I left the office in an ambulance. I fell down the stairs. I'd been walking down on my own, nothing in my hands, no distractions. As I fell, of course I thought I was only stumbling on one step and I'd right myself. But I didn't.

When I came to a stop I realised I couldn't move. I couldn't call out. I could barely even breathe.

Luckily the stairs were internal stairs in our wonderful open plan office – glass surrounds and plenty of visibility. And luckily that day, I wasn't wearing a skirt.

People came running to my aid – thankfully I wasn't stuck there on my own in pain with no way out. But the thing was, I couldn't speak. I could not explain what had happened. I couldn't explain what I was feeling. What was wrong or what I needed. I was literally speechless. I couldn't say I'm OK, I couldn't say I'm not OK.

So, to go back a bit, I have von Willebrand's type 1. I was diagnosed only after my baby was diagnosed with type 3 and the doctors were wondering how that happened. I'm

a classic case of plenty of symptoms but no diagnosis. I know now that I have a diagnosis, that I need check with my HTC in the event of injury. But when this happened I couldn't explain this to anyone.

I spent a while on the stairs with work colleagues who came to my aid. They acted quickly and really quite confidently, assigning roles as per our Emergency Response Guidelines. They attempted to glean from me some info and were calmly checking for injuries. I could not fault the way my peers helped to work through what had happened and what I might need. As the plans progressed and it became clear that I needed medical assistance, something important happened.

My manager was there on the stairs with me and she was able to take the extra step of calling the HTC to speak with the Haemophilia Treatment Nurse to report my injuries and work out a plan. This is when disclosure helped me. And not filling out a form, tick a box. This kind of disclosure I mean is how I went about telling her. This had been a conversation that wasn't held only once. It had been a series of chats, and was varied.

We'd talked about my son with type 3. She had supported me when I needed to take time out for appointments. When I'd needed to field calls from his teachers. We had talked in general terms about my diagnosis journey. And these conversations weren't intrusive. They were caring, based on the facts of my situation, my needs at the time and her level of responsibility for me as well as interest.

She was not only my manager but also the floor first aid officer so she had a vested interest in knowing what might be required of her in just such an event.

During these conversations, she had asked simple questions about my condition, the treatments and response plans that helped put it into context. She had never dealt with a bleeding disorder before so she was learning, busting her own myths and misconceptions. I never felt I was being judged or penalised for having a condition that might need additional requirements.

The practical things we talked about were the different types of von Willebrands. What the severities meant. What the treatment options were and why some things helped in certain situations and why others didn't. We have an active blood donation program at work and we talked about how crucial that is to my son for a normal life and when I've received product too. We talked about the advances in treatments, or the lack of them. We talked about DDAVP. We talked about how simple first aid 'stepped up a notch' is a way to approach understanding treatment. We talked about the realities of symptoms and, how they for the most part, are confidently managed and don't take over my life.

But we also talked about risks about what can go wrong and why appropriate care and trauma response is so crucial.

So what else was going on here? I had already learned that as a person with a bleeding disorder I needed to be my own best advocate, both for myself and as a parent of a person with a bleeding disorder. But crucially, sometimes you need to plan and have contingencies for others to advocate for you. By having these conversations with my manager I had thought we were talking about my world my needs. I hadn't realised that by doing this I was helping her in her world, her needs, when they intersected with mine.

Sumit Parikh is the AHCDO ABDR Senior Research Fellow

AHCDO PROPHYLAXIS STUDY

Sumit Parikh

In the June issue of *National Haemophilia*, I provided an outline of the large retrospective study conducted last year characterising current prophylaxis practice in patients with haemophilia A and haemophilia B in Australia. At the 2017 Conference I presented the results of this study and an article on the study has been peer reviewed and accepted for publication in the *Haemophilia* Journal.

PROPHYLAXIS

Chair: Dr John Rowell
Australian multicentre study of current real-world prophylaxis practice in severe and moderate haemophilia A and B - Dr Jane Mason
ABDR Data analytics - Sumit Parikh

Key Findings

Nationally a total of 718 haemophilia A (551 severe and 79 moderate) patients and 166 haemophilia B (87 severe and 79 moderate) patients were included in the full analysis of the study. Children, adolescents and adults were all represented. Overall 453 patients (82%) with severe haemophilia A were receiving regular prophylaxis, versus 42 patients (25%) with moderate haemophilia A. There were 66 patients (75%) with severe haemophilia B versus 11 patients (13%) with moderate haemophilia B receiving regular prophylaxis.

Near universal prophylaxis was achieved in the paediatric group. The percentage of patients on prophylaxis was generally seen to decline with increasing age.

The mean weekly dose of factor VIII for prophylaxis in severe haemophilia A was 84 international units per kilogram per week (IU/kg/week) versus 71 IU/kg/week of factor IX in severe haemophilia B. Overall, rates of patients with severe haemophilia on prophylaxis in Australia are generally comparable with other developed nations. However the mean weekly dose for patients receiving regular prophylaxis appear to be slightly lower than most Western European centres but still within the lower range of the high dose Malmo/ Swedish protocol. Mean annual consumption of factor VIII and factor IX for patients with severe or moderate haemophilia A and B was substantially higher for patients on prophylaxis compared to on-demand therapy. Most patients on prophylaxis were treated ≥3 times/week for haemophilia A and 2 times/week for haemophilia B.

Adherence

Non-adherence in severe haemophilia A patients peaked in the 20 - 29 year (32%) and 30 – 39 year (37%) age group, using less than 75% of the expected amount of factor concentrate. Data for severe haemophilia B demonstrated further reduction in adherence in the 20 - 29 year age group with 50% of patients using less than 75% of expected factor concentrate.

This study demonstrated that the adolescent and young adult group remain vulnerable during the transition to autonomous health care. It is uncertain whether the less than optimal adherence in this group will have any significant impact on Annual Bleed Rate and joint outcomes. On the other hand it was interesting to note that a subgroup of older individuals on regular prophylaxis used more factor than was expected for their prescribed regimen. The observation that older adults on prophylaxis were routinely prescribed a lower more "intermediate" style dose than their younger counterparts raises the possibility that the additional consumption is to be expected (bleed / surgery / hospitalisation). A very low percentage of haemophilia A and B patients recorded their bleeds on MyABDR app during the study period and as a result reliable Annual Bleed Rates were not obtained.

The evolution of autonomy in haemophilia care and successful empowerment of patients to self-administer clotting factor concentrates at home has brought with it great improvement in quality of life. A consequence of this is the challenge of balancing autonomy with the need to actively monitor bleed outcome, compliance and track product usage. Future AHCDO projects revolve around these topics hoping to provide further insight and improve our understanding to help deliver better treatment outcomes.

WORLD AIDS DAY

World AIDS Day is marked internationally on 1 December.

In 2017 the World AIDS Day national theme is HIV is still here - and it's on the move

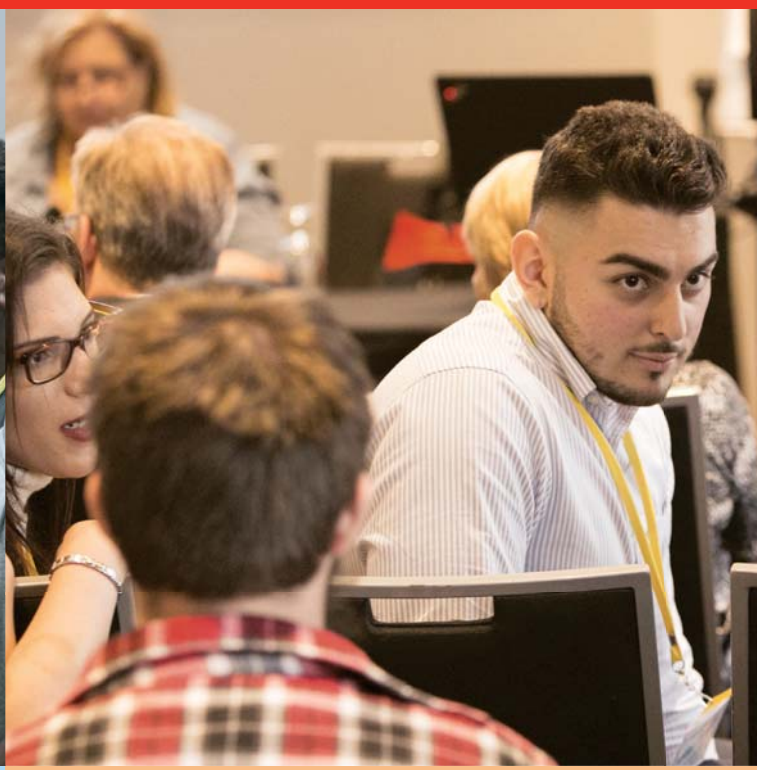
This is a time to raise awareness in the wider community about the issues surrounding HIV and AIDS. It is a day to demonstrate support for people living with HIV and to commemorate those who have died. Wearing a red ribbon is a way that you can show solidarity and raise awareness of HIV.

A TIME TO REMEMBER

This is also a time when we remember the members of the bleeding disorder community who were affected by HIV when in the mid-1980s HIV was transmitted through some batches of clotting factor treatment product.

In 2017 HIV continues to be a part of our community's experience. Some people with bleeding disorders live on with the challenges of HIV. The personal story of Anth in this issue of *National Haemophilia* reminds us how vital it is to create a supportive and stigma-free environment for our community, and to acknowledge these individuals who inspire us by their positive attitude, resilience and determination to build a better future.

YOUTH NEWS



WHAT WAS YOUR FAVOURITE SESSION IN THE CONFERENCE?

The gene therapy session because it showed that we are on our way to a lot better treatment or a kind of cure.

Dale

The youth discussion as it allowed us as a community to raise some questions and answer them from all viewpoints. This allowed us to fully understand what the youth, parents and health care professions think and know.

Alan

Evolving concepts in pain management - pain is something almost all haemophiliacs suffer. Understanding the root cause of this and the way that we perceive this was really valuable in evaluating my own situation.

Josh

WHAT DID YOU ENJOY MOST ABOUT THE CONFERENCE?

Catching up with certain people I haven't seen in a long time, being from different states I rarely get to see them.

Dale

I very much enjoyed the networking with other fellow bleeders and to get a chance to interact with the doctors and pharmaceutical companies.

Alan

Sharing stories with other people was the highlight. I haven't met another hemo since I was really young. To talk to others who understand exactly what you're going though is always nice.

Josh

CONFERENCE EXPERIENCES FROM YOUTH DELEGATES

WHAT MESSAGE WOULD YOU GIVE OTHER YOUNG PEOPLE ABOUT THE CONFERENCE?

Advice I'd give is to get behind your local foundation for the chance to see bleeding disorders on a national level at conferences. People with bleeding disorders have a lot of community support and if you're struggling, you're bound to find someone who can help you out.

Dale

I greatly encourage all the youth to get involved and make the most out of all the things the HFA do for our community. Connect with other youth and make the whole foundation grow as a whole.

Alan

Just go! If you're at all interested about learning about something that is a big part of your life, this is a great place to grow that knowledge.

Josh

WHAT DID YOU FIND MOST INTERESTING ABOUT THE YOUTH MYTH BUSTING SESSION?

What I found interesting was having the audience interact with the panel and share their thoughts and experiences.

Cara

CALENDAR

World Haemophilia Day
17 April 2018
www.wfh.org/whd

XXX111 WFH World Congress, Glasgow, Scotland
20-24 May, 2018
https://www.wfh.org/congress

Bleeding Disorders Awareness Week
7-13 October 2018
Tel: 03 9885 7800
Fax: 03 9885 1800
Email: hfaust@haemophilia.org.au
www.haemophilia.org.au

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BIOVERATIV | CSL BEHRING
NOVO NORDISK | PFIZER | ROCHE | SHIRE

The HFA Council and Staff

wish you a happy and safe festive season. Thank you for your support during 2017 and we look forward to working with you again in 2018.

The HFA office will close on **Friday 22 December 2017** and reopen on **Monday 8 January 2018**. During that time if you have any queries or need to contact HFA, please note that messages left on the answering machine will be monitored. If you have an urgent matter please contact **Sharon Caris** on **0410 419 914**.

HAEMOPHILIA FOUNDATION AUSTRALIA