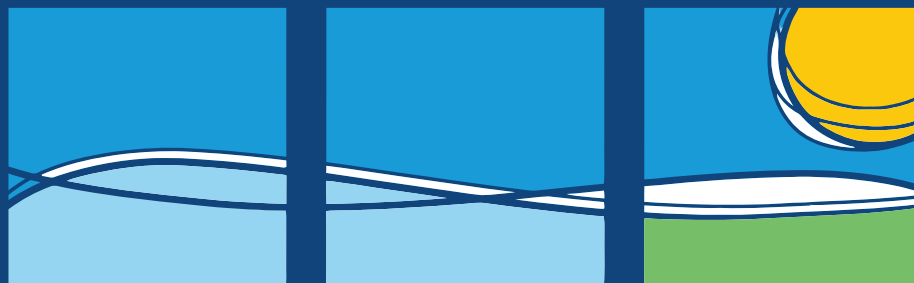


17TH Australian & New Zealand Conference
on haemophilia & related bleeding disorders
Facing the Future Together



1 - 3 OCTOBER 2015 • GOLD COAST

Conference Handbook
and **Information**

WELCOME

We welcome you to the 17th Australian & New Zealand Conference on Haemophilia & Related Bleeding Disorders.

After the very successful 2014 WFH World Congress in Melbourne last year we look forward to a stimulating and exciting Conference where we can discuss and debate issues and follow up on some of those new ideas and connections made.

People with bleeding disorders and their families and carers, health professionals, policy makers, industry and many other stakeholders will have an opportunity to share information and knowledge about the current and emerging issues for treatment and care.

We sincerely thank the Program Committee for working so hard over recent months to bring what we hope will be a very exciting meeting to you. The hard work and personal and professional commitment of all those who have participated is greatly appreciated.

We hope you enjoy the conference, and find it a stimulating and informative meeting.

Gavin Finkelstein President

Haemophilia Foundation Australia

Deon York President

Haemophilia Foundation
of New Zealand

Dr Simon McRae Chair,

Conference Program Committee

Program Committee

Dr Simon McRae (Chair)	Australian Haemophilia Centre Directors' Organisation (AHCDO)
Dr Simon Brown	Australian Haemophilia Centre Directors' Organisation (AHCDO)
Sharon Caris	Executive Director, Haemophilia Foundation Australia
Richard Chambers	Executive Officer, Haemophilia Foundation of New Zealand
Leonie Mudge	Australia/NZ Haemophilia Social Workers' & Counsellors' Group
Joanna McCosker	Australian Haemophilia Nurses' Group
Claire McGregor	Australian Haemophilia Nurses' Group
Suzanne O'Callaghan	Policy Research and Education Manager, Haemophilia Foundation Australia
Hannah Opeskin	Health Promotion Officer, Haemophilia Foundation Australia
Abi Polus	Australian and NZ Physiotherapy Haemophilia Group
Wendy Poulsen	Australian and NZ Physiotherapy Haemophilia Group
Marg Ross	Australian Haemophilia Centre Directors' Organisation (AHCDO)
Delphine Schwartzmann	Programme Coordinator, Haemophilia Foundatino NSW
Maureen Spilsbury	Australia/NZ Haemophilia Social Workers' & Counsellors' Group
Beryl Zeissink	Australian Haemophilia Nurses' Group

GENERAL INFORMATION

Conference Organisers

Haemophilia Foundation Australia
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E: hfaust@haemophilia.org.au

W: www.haemophilia.org.au

Venue

QT Hotel Gold Coast

7 Staghorn Avenue

Surfers Paradise

www.qtgoldcoast.com.au

Disclaimer

All information in the Conference Program and Abstracts is correct at the time of printing. The organisers may alter the Conference Program in the event of unforeseen circumstances. Some abstracts may not have been available at the time of print. Daily program changes will be notified during the Conference.

Mobile Phones/Pagers

As a courtesy to delegates and speakers, please switch off, or set your mobile phones and pagers to silent during all sessions. If you need to take a call please do not answer your mobile until you have left the room.

Name Tags

Entrance to the Exhibition area and Conference sessions will be limited to name tag holders only. If you misplace your name tag, please advise HFA staff at the Registration and Information Desk.

Internet

Wireless internet is available for all conference delegates

QTEVENT / Password: QTEvents

Registration and Information Desk

All enquiries should be directed to the Registration and Information Desk located in the main foyer (see attached venue map), which will be open at the times listed below:

Thursday 4 October

17:00-19:30

Friday 5 October

07:30-17:00

Saturday 6 October

07:30-14:00

Hospital

For any emergencies go to the Gold Coast University Hospital.

Gold Coast University Hospital

1 Hospital Boulevard, Southport QLD 4215

Phone 1300 74 4284

Present to the emergency department - Hollows Way, Southport

Childcare

Childcare is not available at the Conference and children are not permitted in Conference sessions.

SOCIAL PROGRAM

Thursday 1 October

Welcome & Exhibition Opening

18:30-19:30

QT Ballroom

Come to see the exhibition and meet people before the conference. Free for all registered delegates.

Youth Meet and Greet

19:30 til late

The Lawn (Outside Stringray)

Youth are invited to meet others and connect before the conference program starts. Free to all registered youth delegates.

Friday 2 October

Remembrance Service

18:15-18:45

Malibu

The Remembrance Service is a time to remember friends and family, and the people we have cared for. The service is non-religious and everyone is welcome.

Conference Dinner

19:00 til 21:30

QT Ballroom - Tickets are \$35 (covers food and beverages)

Come and join your fellow delegates for dinner onsite at the Conference venue. This will be a social dinner giving people an opportunity to talk, share and meet others.

Dinner tickets must have been purchased in advance - no tickets will be available during the conference or on the night. The dinner will be free seating.

Saturday 3 October

Men's Breakfast

07:00 - 08:20

Sunset 1 - Tickets are \$25 (Full breakfast provided)

Women's Breakfast

07:00 - 08:20

Sunset 2 - Tickets are \$25 (Full breakfast provided)

Tickets to both the Men's and Women's breakfast must have been pre-purchased, no tickets are available during the conference.

Concurrent Options

RSVP and bookings required

Workshop 1

1515-1615

Mindfulness ~
Dr Ira Van der
Steenstraten
Room: Sunset 1

Catch up
and chill out
afternoon tea

1500-1630

Room: Sunset
Lounge

Viewing of AFL
Grand Final

1500-1800

Room: Stringray

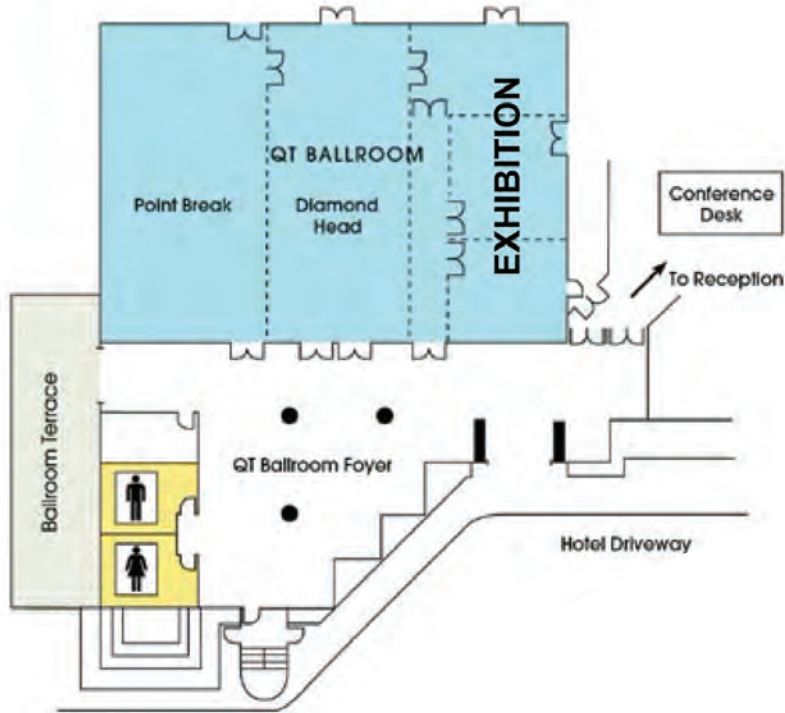
My ABDR (Private
closed group, not
for public)

1500-1630

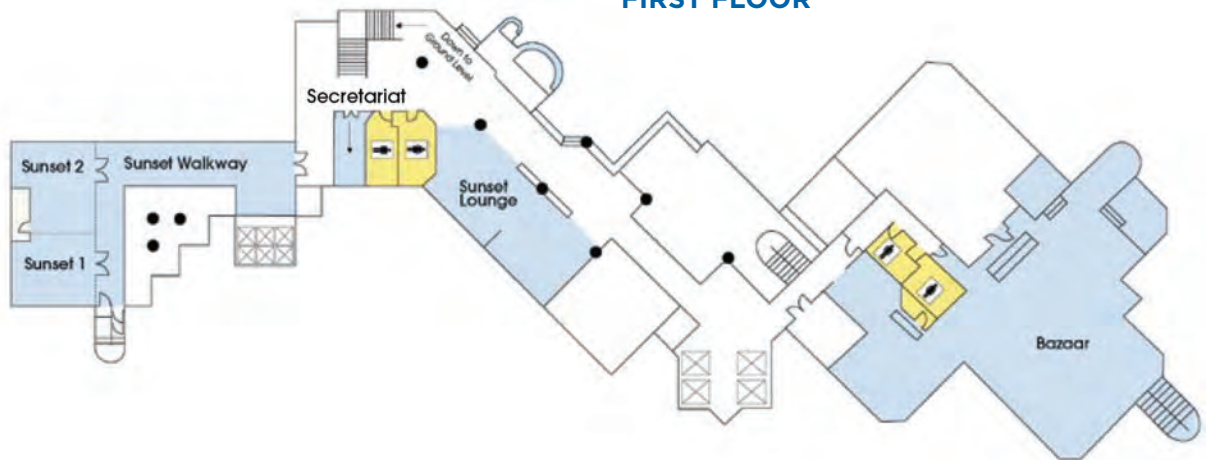
Room: Sunset 2

CONFERENCE VENUE MAP

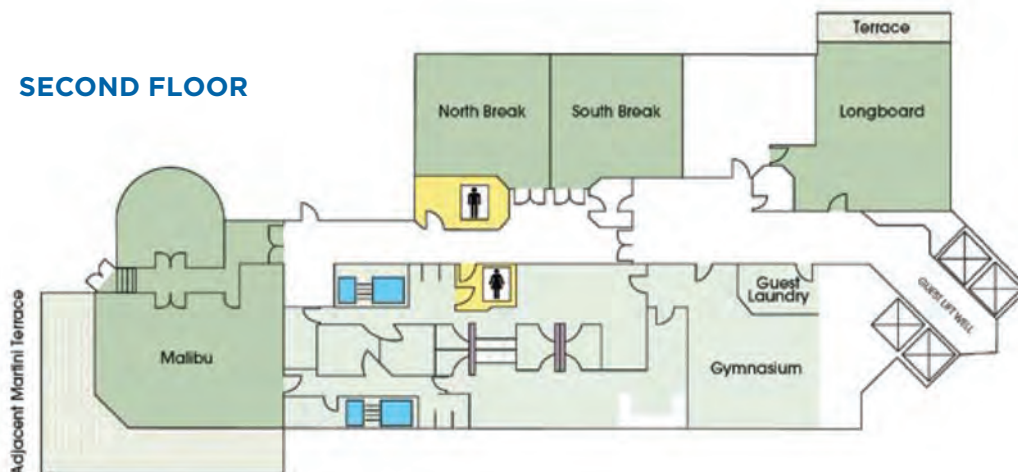
GROUND FLOOR



FIRST FLOOR



SECOND FLOOR



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POSTER ABSTRACTS

The poster display is in the main foyer area. All posters will be displayed for the duration of the conference. Poster authors will be available at their poster the following times for discussion and questions.

Friday 2 October 10:40-10:50	Friday 2 October 1510-1520
<p>POSTER 1 Andrew Atkins <i>Improving services to the Bleeding Disorder Community through collaboration between paediatric and adult Haemophilia Centres in South Australia</i></p>	<p>POSTER 8 Penny McCarthy <i>A nurse initiated men's general health screening check</i></p>
<p>POSTER 2 Dr Desdemona Chong <i>Quality of life of people who have moderate or severe haemophilia study</i></p>	<p>POSTER 9 Claire McGregor <i>Future Delivery of Haemophilia Care</i></p>
<p>POSTER 3 Dr Desdemona Chong <i>Lessons from Running a Workshop for Women who carry the Severe Haemophilia Gene: The Queensland Experience</i></p>	<p>POSTER 10 Colleen McKay <i>New Zealand Youth Training Workshop: Building the Future</i></p>
<p>POSTER 4 Julia Ekert <i>10 Years of the Haemophilia Teachers Seminar</i></p>	<p>POSTER 11 Suzanne O'Callaghan <i>MyABDR: a partnership to develop an online tool for treatment recording</i></p>
<p>POSTER 5 Janine Furmedge <i>Parent & patient survey of joint/muscle bleed management in children with haemophilia</i></p>	<p>POSTER 12 Hannah Opeskin <i>"Factoring In" youth across Australia</i></p>
<p>POSTER 6 Janine Furmedge <i>An infusaport education package - addressing the needs of parents</i></p>	<p>POSTER 13 Steven A Taylor <i>Personal Fundraising Challenge: Living With Haemophilia While Cycling Across Australia</i></p>
<p>POSTER 7 Mr Geoffrey Kershaw, Dr Liane Khoo <i>Assessment of clotting activity of recombinant factor IX Fc fusion protein (rFIXFc) in plasma samples at haemophilia treatment centres in Australia and New Zealand</i></p>	<p>POSTER 14 Beryl Zeissink and Olivia Hollingdrake <i>When to "pick" a (PICC) Peripherally Inserted Central Catheter.....A Nurse's perspective. Potentially 2nd poster - Why I "picked" a PICCA Patient's perspective</i></p>

POSTER 1

Name: **Andrew Atkins**

Co-authors: **Anne Jackson**

Institution/Organisation: **Royal Adelaide Hospital; Women's and Children's Hospital**

Title: **Improving services to the Bleeding Disorder Community through collaboration between paediatric and adult Haemophilia Centres in South Australia**

The paediatric and adult Haemophilia Treatment Centres (HTC) in SA both provide a state-wide service for the provision of care in haemophilia and other bleeding disorders. This is provided through multi-disciplinary teams including medical, laboratory, nursing, physiotherapy, and social work departments at each site. In South Australia, the two HTC's meet together three times per year where there is opportunity for discussion surrounding treatment, complications, joint projects and future planning.

While communication between the Centres necessarily occurs surrounding the transition period, since 2011 the two HTC's have combined the final paediatric clinic review to give an introductory 'ice-breaker' to the adult services and staff. The review takes place at the paediatric site as usual, with the adult HTC staff present, giving both patient and staff the opportunity to meet each other.

The demographic spread of families and ages of affected siblings, coupled with the opportunity for professional education provided the background for choosing to combine an Outreach Clinic to Mt Gambier between the two HTC's in 2003. Since 2013 the clinics have been conducted together on an annual basis, either in the lower South-east region, or the northern areas of Port Augusta and Port Pirie.

This poster presentation outlines the advantages in South Australia of combining paediatric and adult programs, and looks at some of the issues in providing these services.

POSTER 2

Name: **Dr Desdemona Chong**

Co-authors: **Maureen Spilsbury, Dr John Rowell, Dr Rachel Bushing**

Institution/Organisation: **Queensland Haemophilia Centre**

Title: **Quality of life of people who have moderate or severe haemophilia study**

The current poster describes an exploratory study conducted in 2011, examining the quality of life of people who have moderate or severe haemophilia. The study was funded by the Haemophilia Foundation Australia.

The Poster will discuss:

- Aims of study
- Method
- Participant pool
- Main results (by demographics and type of quality of life issues)
- Discussion of findings
- Recommendations

The study is an exploratory study which gave good but limited insights in the psychosocial issues faced by the community. A more comprehensive study is being planned and will be rolled out in the upcoming months.

POSTER 3

Name: **Dr Desdemona Chong**

Co-authors: **Maureen Spilsbury**

Institution/Organisation: **Queensland Haemophilia Centre**

Title: **Lessons from Running a Workshop for Women who carry the Severe Haemophilia Gene: The Queensland Experience**

The current poster describes the Queensland Haemophilia Centre experience in running a workshop for women who carry the severe haemophilia gene (women carriers). This long-awaited workshop was made possible with support from the Haemophilia Foundation Queensland (HFQ) and funding from a Changing Possibilities in Haemophilia® Grant by NovoNordisk.

The Poster will discuss:

- Reasons/ aims for organising this workshop
- Programme development
- Recruitment process
- Participant profile
- Programme specifics
- Issues raised/ lessons learnt/ Insights gained
- Recommendations

The study is an exploratory study which gave good but limited insights in the psychosocial issues faced by the community. A more comprehensive study is being planned and will be rolled out in the upcoming months.

Conclusions/outcomes: Feedback from participants was largely positive. Varying demographics meant needs of this population is diverse and poorly understood. More services/ programmes are required to address these needs. This workshop is just the stepping stone to more concerted efforts to support this segment of the bleeding disorders community.

POSTER 4

Name: **Julia Ekert**

Co-authors: **Janine Furmedge, Nicola Hamilton, Chris Barnes**

Institution/Organisation: **Royal Children's Hospital Melbourne**

Title: **10 Years of the Haemophilia Teachers Seminar**

The Royal Children's Hospital in Melbourne has held annual haemophilia teachers seminars with the support of Haemophilia Foundation Victoria since 2006. The goal of the seminar was to address a perceived lack of information available to schools in assisting families dealing with the stress of a child with a bleeding disorder starting pre school or school. In addition there remains significant uncertainty amongst educators regarding haemophilia management and expectations of having to deal with a child with life threatening bleeding disorder. Formal evaluation of the seminars has occurred since 2009 using a standard qualitative questionnaire and open questions regarding value of the seminar and areas for improvement. Tailoring of the seminars based on the feedback has resulted in a program designed to meet the needs of educators in providing information about children with bleeding disorders. The program includes a formal series of lectures with 3 health professionals, consultant, nurse and physiotherapist presenting for 1/2 hour on their specialty. After this we ask some boys with haemophilia to come along and talk about their experience of having haemophilia in the school environment. We try to get a good spread of primary and secondary school age children. The boys doing their presentation has proved to be the most popular part of the presentation. Feedback from the participants has been overwhelmingly positive. The current abstract presents the objectives and outcomes of the teachers' seminars and highlights the potential for these types of seminars to be incorporated into a comprehensive haemophilia treatment center.

POSTER 5

Name: **Janine Furmedge**

Co-authors: **Arjun Haria, Reem Omarit, Emily Sim, Eshika Shrestha, Julia Ekert, Chris Barnes, Nicola Hamilton**

Institution/Organisation: **Royal Children's Hospital, Melbourne**

Title: **Parent & patient survey of joint/muscle bleed management in children with haemophilia**

Back ground: Haemophilia, is a bleeding disorder typified by bleeding into joints and muscles. Recurrent joint and muscle bleeding can lead to pain and deformity resulting in permanent impact on developing joints of children and young people. Joint and muscle bleeds can be managed through the administration of clotting factors as well as adjunct therapy such as rest, ice, compression and elevation (RICE). However, few studies have been conducted on how adjunct therapy is used in bleed management.

Aim: To investigate how children with haemophilia and/or their parents experience and manage joint and muscle bleeds in the home.

Research Method: A survey was sent out to young people with haemophilia (under 18 years) and parents of children with haemophilia who had experienced at least one joint/muscle bleed as identified by the Royal Children's Hospital, Melbourne bleeding disorder registry. Data analysis was conducted using descriptive statistics.

Results: 36 completed parent surveys were returned. RICE was used by the participants in managing bleeds where 80% indicated resting was very helpful/helpful, 81% suggested that ice was very helpful/helpful and 70% suggested compression was very helpful/helpful. However, the duration of each component of RICE varied from recommended guidelines. Interestingly, parents used pain as a marker for bleed recovery but in fact, swelling is a better indicator for when to resume normal activity. Conclusion: This study indicated parents would benefit from more information on using RICE in the management of joint and muscle bleeds at home.

POSTER 6

Name: **Janine Furmedge**

Co-authors: **Paul Monagle, Chris Barnes, Fiona Newall**

Institution/Organisation: **Royal Children's Hospital, Melbourne**

Title: **An infusaport education package - addressing the needs of parents**

Haemophilia is a potentially life threatening bleeding disorder for which treatment is administered intravenously. Infusaports are commonly used to establish reliable intravenous access in young children and most families learn to access their child's infusaport to give treatment at home. Provision of education is critical to ensure families can safely carry out infusaport care. However, few studies have explored how best to teach parents to perform this complex and often confronting procedure on their child. The purpose of this project was to develop and evaluate an infusaport education package based on the needs of parents as identified by a previous study at our centre. A draft teaching package was evaluated by four 'expert' parents who had previously learnt how to administer treatment to their child via infusaport. The suggestions of expert parents were incorporated and the package was then piloted by four 'new' parents undertaking infusaport education for the first time. Evaluation was via questionnaire. As an adjunct to written information, new parents were offered the opportunity to have an individualized DVD produced of them performing infusaport access on a model. All eight parents agreed or strongly agreed the written package was easy to read and understand. Overall package content was rated as extremely useful and length of the booklet was considered 'about right' (likert scale value) by all eight parents. General comments were invited and were very positive. Surprisingly all four new parents declined production of an individualized DVD describing that they learnt best by 'doing' rather than watching a DVD. The exploration of parents' learning needs and the involvement of parents in the development and evaluation stages has led to the production of an infusaport education guide we believe will meet the needs of parents learning to access their child's infusaport to administer clotting factor at home.

POSTER 7

Name: **Mr Geoffrey Kershaw, Dr Liane Khoo**

Co-authors: **Dr Ali Sadeghi-Khomami, Dr F. Jon Geske**

Institution/Organisation: **Royal Prince Alfred Hospital**

I wish to declare the following potential conflicts of interest: This study was funded by Biogen.

Title: **Assessment of clotting activity of recombinant factor IX Fc fusion protein (rFIXFc) in plasma samples at haemophilia treatment centres in Australia and New Zealand**

Background: Factor IX (FIX) activity in patient plasma samples is generally monitored by a one-stage clotting assay using the activated partial thromboplastin time (aPTT) test. Testing of factor activity levels in haemophilia B patients on FIX replacement therapies requires accuracy in order to deliver optimal care, and new therapies such as a recombinant FIX Fc fusion protein (rFIXFc) necessitate an understanding of assay variability in monitoring patients on these drugs.

Aims: To assess FIX activity assays in haemophilia treatment centres (HTCs) in Australia and New Zealand by distributing uniformly prepared frozen plasma samples containing various levels of rFIXFc.

Methods: Sample kits contained FIX-immunodepleted plasma spiked with rFIXFc at three levels (0.80, 0.20, and 0.05 IU/mL) based on the manufacturer's labelled potency. Twenty HTC's across Australia and New Zealand participated and each centre tested the sample kits using their own one-stage aPTT-based assay and calibrator.

Results: Twenty-five sets of results were received from twenty different participating HTC's (four labs returned more than one set of results). In total, seven commercial aPTT reagents were used between the labs with eleven different reagent/instrument combinations, and results varied for each sample tested. For the 0.80 IU/mL sample, results ranged from 0.61 to 1.04 (mean = 0.78; CV = 16.5%). Results for the 0.20 IU/mL sample ranged from 0.15 to 0.30 (mean = 0.23; CV = 16.8%), and the 0.05 IU/mL sample returned results from 0.04 to 0.11 (mean = 0.07; CV = 24.9%). When only aPTT reagents were considered, Actin FS/FSL aPTTs generally resulted in slightly higher observed activities compared to other aPTT reagents used in this study.

Conclusions: There is variability between HTC's in the measurement of rFIXFc in the plasma samples. Sources of variability include aPTT reagent, diluent, FIX deficient plasma, calibrator, and instrument used. Ultimately, local HTC's need to be aware of this variability and understand its clinical significance.

POSTER 8

Name: **Penny McCarthy**

Co-authors: **Megan Walsh**

Institution/Organisation: **Ronald Sawers Haemophilia Centre, The Alfred.**

Title: **A nurse initiated men's general health screening check**

In Australia with adequate replacement therapy and specialised haemophilia care, the life expectancy of people with haemophilia (PWH) is now approaching that of the general male population.

As PWHs develop more and more age-related clinical conditions never experienced before, they often present not only with the comorbidities typically associated with haemophilia but also with common age-related illnesses.

In Australia it is well recognised that men are reticent to seek timely health care often delaying visiting a doctor until symptoms' are present and generally don't practise or recognise the need for preventative health care.

Although haemophilia centres are funded to care for PWH, the service frequently cannot extend to monitoring the ongoing demands of providing preventative men's health care across all age groups of PWH managed in haemophilia centres.

Adopting healthy behaviours may minimise the effects of illness and are helpful in coping with chronic medical problems.

Men attending the haemophilia centre often expect that all their health care needs will be met during a routine visit and thus do not see the need to have a GP involved in their ongoing health management.

However, despite the many benefits of adopting lifestyle changes, PWH often overlook recommendations for routine screenings because other health-related issues, such as joint bleeds or other complications of haemophilia or past treatment, dominating their lives.

The aim of this project is to improve health outcomes for PWH by introducing a nurse initiated, general health screening check including BMI, blood pressure, cholesterol glucose and smoking.

The patients were given immediate feedback on their results as a 'traffic light' coloured printout identifying their risks. The results and suggested actions were discussed at the time of consultation, as well as information and advice on suggested actions such as visiting a GP, for further tests and diagnosis and ongoing preventative health management.

The results to date demonstrate that many of the screened patients identified various risk factors that required follow-up with a GP.

The equipment for this for this project was generously funded by through NovoNordisk Changing Possibilities grant 2013.

POSTER 9

Name: **Claire McGregor**

Co-authors: **Gavin Finkelstein**

Institution/Organisation: **Fiona Stanley Hospital**

Title: **Future Delivery of Haemophilia Care**

I wish to declare the following potential conflicts of interest: (last 2 years) honorarium – Pfizer, Biogen

Background: The current standard of care for haemophilia is comprehensive care delivered at a Haemophilia Treatment Centre. The question will be, “Can HTC’s survive in the current economic scrutiny of health care whilst providing appropriate care for people with bleeding disorders?”.

Aims: With haemophilia treatment largely home based or conducted through outpatient care, it may be important for HTC’s to consider extending the services provided to both meet the future needs of people with haemophilia, as well as ensuring their economic survival.

Methods: A discussion was held between nursing and patient representatives to identify what services are paramount and what needs to change.

Results:

Patient Future Needs:

- Maintain the status quo, whilst extending the service to include “holistic” services
- Ongoing service guarantee
- Feel supported in living independently across the life-span
- Service extension into ageing (such as conducting mens health screening)
- Involvement with other services such as cardiology (given the complexity of anticoagulation and bleeding disorder)
- Services closer to home including telehealth services.

Health Professional Future Needs:

- Continue to support patients with bleeding disorders and have a guarantee of ongoing services, including appropriate clinical areas to manage urgent drop-in cases.
- Establish trust, both between individuals/community and HTC, which is vital to improve patient interactions
- Time and facilities maintain accurate record keeping.

Conclusion: Efficient and good comprehensive care can have an economic impact by decreasing the volume of clotting factor concentrate used, decreased haemophilia related co-morbidities and decreased haemophilia related surgery, leading to a decreased overall cost over a life time. With advances in haemophilia treatment on the horizon, there will be an increasing need for patients to re-engage with their HTC to access these treatments and develop more tailored treatment plans. A discussion surrounding the future of haemophilia care is needed to ensure all needs are met in this changing environment.

POSTER 10

Name: **Colleen McKay**

Institution/Organisation: **Haemophilia Foundation of New Zealand**

Title: **New Zealand Youth Training Workshop: Building the Future**

The Haemophilia Foundation of New Zealand Inc. (HFNZ) held its first ever Youth Leadership Training Weekend in Christchurch from 8th – 10th August. Although there have always been opportunities for youth to step up within HFNZ – traditionally as Youth Leaders at Camps / Workshops, on local HFNZ MRG (Branch) Committees and as Youth Representative on HFNZ National Council, many of these roles / activities have not been youth initiated or youth-led.

During the workshop, 18 future community leaders tapped into their leadership potential, their skills and interests, and how they can contribute to the future of HFNZ. Participants were aged 17-30 years and included youth with a bleeding disorder (haemophilia or von Willebrand Disorder) and siblings. The goals of the workshop included expanding and refining personal leadership skills and developing opportunities to become part of youth leadership within HFNZ.

The programme was carefully developed to start and end with the youth themselves. The first day focused on identifying leadership qualities, the second on opportunities and expectations to represent HFNZ, and the last on building for the future. Each participant developed an individual or small group plan for a project for ‘stepping up’ within HFNZ. A Social Work student followed up with the youth on progress of plans for the remainder of her placement and HFNZ Outreach Workers continue to follow-up projects.

Outcomes of the workshop included an increased sense of involvement within the Foundation, further development of youth peer network and 7 youth-initiated projects. The projects ranged from stepping up within existing Camp / Workshop Programmes, making plans for a children’s area on the HFNZ Website, through to planning a workshop targeted at young women or von Willebrands. The impact of these projects on the community is ongoing.

POSTER 11

Name: **Suzanne O’Callaghan**

Co-authors: **Rebecca Heland; John Rowell**

Institution/Organisation: **Haemophilia Foundation Australia; National Blood Authority; Australian Haemophilia Centre Directors’ Organisation**

Title: **MyABDR: a partnership to develop an online tool for treatment recording**

Widespread home therapy and individualised treatment plans for people with bleeding disorders (PWBD) in Australia has meant that increased communication between PWBD and their haemophilia treatment centre (HTC) has become crucial to best practice clinical care. The MyABDR app and web site have been developed to address this by enabling PWBD to record bleeds and home treatments and manage their inventory of treatment product, all of which flows directly into the Australian Bleeding Disorders Registry (ABDR). The ABDR is the national system used by HTCs for the clinical care of their patients. De-identified data is also provided to government to plan for treatment purchase and supply. MyABDR is a collaboration between Haemophilia Foundation Australia (HFA), the Australian Haemophilia Centre Directors’ Organisation (AHCDO) and the National Blood Authority (NBA) on behalf of Australian governments.

While strict security protocols ensure that identifiable data is kept private, this collaboration enables integration across a range of systems that manage treatment and supply. This includes full integration into the ABDR clinical record, drawing on product data from suppliers via the NBA system for the inventory, and statistics to feed into national supply planning. This collaboration has also facilitated ongoing consultation with PWBD and health professionals to assist with tailoring functionality.

Results: By June 2015 there were 520 registered users of MyABDR. Consultation with PWBD and health professionals has led to several new developments: improved functionality, such as faster synchronization, and new features, including photo upload. It also highlighted the need for shared definitions and understanding of how to communicate with the HTC. This has been built into the online prompts and education plan.

Conclusions/outcomes: The MyABDR collaboration has provided an opportunity to engage PWBD and health professionals in tailoring the MyABDR shared online clinical tool and integrating with existing information systems for best practice clinical care.

POSTER 12

Name: **Hannah Opeskin**

Institution/Organisation: **Haemophilia Foundation Australia**

Title: **“Factoring In” youth across Australia**

A web-based platform called “Factored In” has been developed by Haemophilia Foundation Australia to increase engagement of young people with bleeding disorders, build social connections and increase their efficacy to make healthy lifestyle choices.

In 2012, a needs assessment of young people with bleeding disorders aged 13-30 years divulged that youth oriented information and a stage on which to build social connections was lacking across Australia. It was the recommendation of the needs assessment from which the Factored In website originated. The needs assessment addressed a lack of information and understanding about the unmet needs of young Australians with bleeding disorders, and was conducted using consultation of 62 participants including young people, haemophilia health professionals at treatment centres, Haemophilia Foundations and parents across Australia. Recommendations from the needs assessment include: building a web-based platform to include a space where young people can share experiences and personal stories, access accurate information in the language of young people, and information specifically for girls with bleeding disorders.

The Factored In website has been successful with almost 100 members and several personal stories and events created by users monthly. To ensure sustainability and that the site is embedded within the bleeding disorders community, Haemophilia Foundation Australia trained 7 young people aged 18-30 years in early 2015 to moderate, develop content, lead promotion and assist in the ongoing development. Training included positive reinforcement, confidentiality and risk management. Moderators were required to create content and moderate user generated content. As a result, new content is created monthly and these young people have been central in promoting the site at camps and youth events.

Young people are notoriously hard to engage among the bleeding disorders community, however due to the creation of a youth developed and run website, engagement has increased including access to relevant comprehensive information.

POSTER 13

Name: **Steven A Taylor**

Title: **Personal Fundraising Challenge: Living With Haemophilia While Cycling Across Australia**

Outline: A person living with a bleeding disorder discussing a six month long personal challenge/fundraising project (conducted 2014-15), how it has both benefited the individual's health, and also the wider bleeding disorder community.

Content: Discussion of how undertaking a period of independent travel and exercise was achieved safely, riding nearly 6,000 kilometers across Australia completely without physical/material aid from a support crew.

Report of the planning stages/priorities. From medical consultation, to coordinating travel arrangements between relevant medical clinics throughout Australia, as well as networking between the HFA and HFV.

Explanation of the physical training and other preparation required for a Haemophiliac: home exercise regimes, targeted Pilates classes, in close consultation with Physiotherapy and Hematology specialists at the Alfred hospital that developed injury rehabilitation practices into effective athletic training, and the resultant, lasting health benefits.

Summary of the practical planning involved, from logistical/communications and emergency, mitigating potential safety risks ensuring an incident free trip.

Overview of the fundraising process, the online and media platforms used (such as Radio and local newspaper) to raise over \$4,000 for the bleeding disorder community How it progressed through the trip, and also served to promote awareness of Haemophilia in the wider Australian population.

Conclusions/outcomes

Conclusion: That people with bleeding disorders can (and should) be encouraged to undertake projects that will enhance their health and broaden the scope of opportunities presented to them, if planned and managed correctly/carefully

Outcomes: An entirely incident free and safe completion of the cycling project, exceeding the fundraising goal. Improved physical health for the individual, specifically in maintaining strengthening joints, increasing physical strength, weight loss and stamina.

Approximately \$4,500 raised and donated to Bleeding disorder treatment clinic in rural Vietnam, in conjunction with Alfred hospitals twinning program.

POSTER 14

Name: **Beryl Zeissink and Olivia Hollingdrake**

Co-authors: **Desdemona Chong and Rebecca Dalzell**

Institution/Organisation: **Queensland Haemophilia Centre, Royal Brisbane and Women's Hospital**

Title: **When to "pick" a (PICC) Peripherally Inserted Central Catheter.....A Nurse's perspective.**

Venous access remains a challenge for many haemophilia patients performing home therapy. With an ageing population, patients and health care professionals are likely to see an increase in issues in gaining frequent and reliable venous access. This poster will look at

- a. what a Peripherally Inserted Central Catheter (PICC) is,
- b. in what context it may be utilized,
- c. methods of insertion and removal,
- d. educational requirements for those that have a PICC inserted,
- e. day to day care of a PICC line,
- f. advantages and difficulties with PICC use.

The 2nd part of the poster will explore three case studies. This will examine patients' experiences of day to day life with a PICC line, why they chose a PICC in the first instance, and what they found easier or more difficult with a PICC.

Conclusion: The use of a PICC line in these circumstances had a positive outcome for those patients involved.



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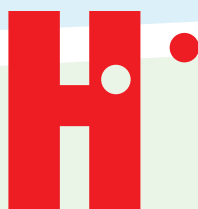
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