

- Importance of a multidisciplinary approach, with haematologist, gynaecologist and patient to manage both the bleeding disorder and gynaecological complications, which may or may not be related to VWD.
- Include assessment and treatment of iron deficiency and anaemia.

For people with mild and moderate VWD, what are the ‘moments that matter’, the triggers to get in contact with their Haemophilia Treatment Centre (HTC)?

- If they are planning any surgery or invasive medical procedures, they should connect with their HTC.
- Managing any bleeding, particularly heavy menstrual bleeding in women.
- Need to plan in advance for pregnancy.

RESEARCH PRIORITIES

Both Simon McRae and Nathan Connell pointed to a real need for evidence-based research to answer a range of questions about VWD, for example:

- Bleeding risk as people with VWD age
- Are there predictors for who will bleed and who will not, particularly those in the 30-50% VWF range

- Evaluating different bleeding assessment tools in males and children
- Research into hormonal contraceptive therapies for women
- Large randomised controlled trials on prophylaxis for VWD
- Use of plasma-derived vs recombinant VWF concentrate for prophylaxis.

We were grateful to all the presenters for sharing their expertise and their personal stories. The expert presentations from Simon McRae and Nathan Connell were immensely valuable and gave a concise and accessible overview of priority issues in VWD diagnosis and treatment. Having the personal perspectives of Susie, Perry and Simoni alongside their presentations grounded the discussion about the guidelines in real-life experience – and highlighted just why the process of developing international guidelines has been so important.

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Suzanne O’Callaghan is HFA Policy Research and Education Manager

Women and girls

Jaime Chase

Women and Girls

Chair, introduction and personal story
 ~ Sharron Inglis

Understanding, recording and reporting bleeding symptoms in girls and women
 ~ Jaime Chase, Joanna McCosker

New clinical approaches in managing women and girls with bleeding disorders across the lifespan
 ~ Dr Mandy Davis

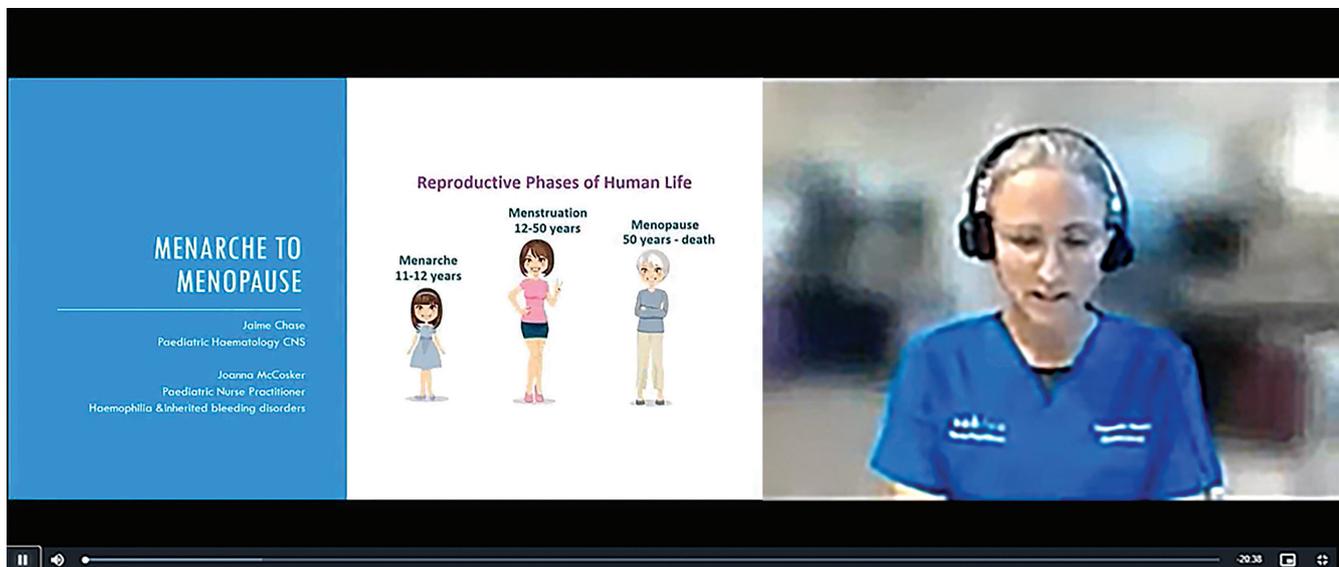
Gynaecological issues for women and girls with bleeding disorders ~ Dr Angela Dunford

Sport and exercise for girls and women
 ~ Hayley Coulson

The session regarding women and girls commenced with a personal story by Sharron Inglis, an Australian community leader, and raised some interesting questions about society’s perspective on women with bleeding disorders. Advocacy, support and education were highlighted as her most important messages.

Heavy periods can negatively impact on physical, emotional and social quality of life and reduce work capacity - so how can we fix this?

Joanna McCosker and Jaime Chase discussed the importance of normalising the conversation around periods as they commence and as a woman moves through her lifespan to menopause.



The session included:

- Define the words you use around periods - be open and honest when you talk to young women.
- What is a normal menstrual cycle and how to identify if you have heavy menstrual bleeding (HMB) - Remember 7, 2, and 1
 - 7 – Over 7 days is too long for a period to last
 - 2 – Soaking a pad or tampon in 2 hours or less is not normal
 - 1 – Passing clots the size of a \$1 coin is not normal
- What is a bleeding assessment tool and where to find one
- How to report symptoms and when to seek help
- Period tracking apps and how to prepare for the first period
- Identifying symptoms of menopause.

Further information is located at:

- HFA (Hemophilia Federation of America) Blood Sisterhood App - <https://www.sisterhoodapp.com>
- Let's talk period - <https://letstalkperiod.ca>
- Factored In > Girls - <https://www.factoredin.org.au/info/girls>

Dr Mandy Davis discussed new clinical approaches in managing women and girls with bleeding disorders across the life span, concentrating on the available treatments for bleeding issues, how to treat low iron and diagnostic difficulties that women may face.

Dr Angela Dunford discussed how challenging menarche can be for a young woman with a bleeding disorder. The causes of abnormal menstrual bleeding can differ greatly across the lifespan and this must be taken into consideration before treating. Hormonal treatments for young women are evolving and there are options available to help control the issue of heavy periods or heavy menstrual bleeding.

Finally, Hayley Coulson discussed the importance of sport and exercise for young women and how to do this safely and in a controlled way. Importantly, she discussed what to do with an injury and when to seek further help.

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Jaime Chase is the Haematology Clinical Nurse Specialist at the Children's Cancer & Haematology Service, John Hunter Children's Hospital, Newcastle NSW
