

Women and girls with bleeding disorders

Plenary - Women and girls with bleeding disorders

Chair ~ *Dr Meredith Wiggins*

Personal perspectives on the challenges and issues of living with a bleeding disorder

~ *Shauna*

~ *Cheryl*

Medical perspectives on diagnosis, assessment, treatment and care

~ *Gynaecologist: Prof Sonia Grover*

~ *Haematologist: Dr Briony Cutts*

Suzanne O'Callaghan

The challenges and issues for women and girls with bleeding disorders were highlighted in the plenary, which explored both the personal experience and the complexities of clinical management.

Shauna and Cheryl gave compelling accounts of what it has been like for them to live with a bleeding disorder, the complications they have had to deal with and what they hope for in the future. Shauna's story is published in this issue of *National Haemophilia*.

Although there have been advances in medical management in recent years, both Professor Sonia Grover and Dr Briony Cutts commented on the high level of under-diagnosis in women and girls and the value of Bleeding Assessment Tools (BATs) as a support to taking a bleeding history, along with checking the family history for abnormal bleeding. While a general practitioner could undertake initial laboratory testing, it was important that a specialist laboratory should process the testing and the woman or girl should be referred to a specialist to interpret the results.

Anaemia or iron deficiency is a common complication of a bleeding disorder in females and Briony Cutts noted that it is a significant outcome that can impact

on cognitive as well as other physical functioning.

Individual data is vital to understanding the impact of bleeding disorders in women and girls as well as managing their bleeding disorder over their lifetime. Briony Cutts recommended that women and girls be registered with their Haemophilia Treatment Centre and with the Australian Bleeding Disorders Registry (ABDR).

Alex Klever

Professor Sonia Grover spoke about her experiences - suspecting that women and girls were being underdiagnosed and trying to find more effective ways to identify those who had bleeding disorders. Early in her career the basic teaching was to consider a bleeding disorder in teenagers with heavy menstrual bleeding but then no further questions were being asked. She herself started doing blood clotting time testing such as APPT and PT but these tests did not find anyone with a bleeding disorder. But she changed tack and then started performing specific von Willebrand testing. She undertook some audits at her adult women's hospital and found that a lot more women with heavy menstrual bleeding qualified for bleeding disorder testing than were being tested and that a large number who were tested had abnormal results and some were even diagnosed with an inherited bleeding disorder.

A gynaecologists perspective....

- After starting at RCH – and seeing girls with heavy menses
- Order skin bleeding time, PT, APTT
.....I never found anyone

Then (after talking with some of the haematologists)
- I dropped the skin bleeding time
- started doing vW tests

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Sonia highlighted:

- gynaecologist and GPs should be asking more questions about heavy menstrual bleeding and ovulation pain
- consider the use of the Bleeding Assessment Tool www.letstalkperiods.ca
- not to test when women/girls are stressed as results are not accurate
- suppress periods and ovulation though the use of oral contraception
- use tranexamic acid
- Mirena IUDs (intrauterine devices) can be used even in young teenagers.

Dr Briony Cutts spoke as well about the use of the Bleeding Assessment Tool (BAT) developed by the International Society on Thrombosis and Haemostasis (ISTH) - <https://tinyurl.com/ISTH-BAT> This tool is easy to use and, with the combination of taking a clinical history, can be useful in diagnosing bleeding disorders or to establish if bleeding disorders are normal or abnormal.

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