

Women with Bleeding Disorders Committee Report - AHCDC AGM 2019

Mission:

To promote the multidisciplinary care of women with inherited bleeding disorders through education, public awareness, clinical experience/expertise, and research.

Membership:

Dr. V. Price (Chair), Dr. R. Winikoff (Co-Chair), Dr. C. Demers, Dr. B. Garvey, Dr. S. Israels, Dr. S. Robinson, Dr. P. James, Dr. E. Saidenberg, Dr. M. Sholzberg, Dr. N. Laferriere, Dr. E. Rimmer, Dr T Dumont, Ms C Thibeault (RN).

Activities for 2018-2019 – submitted by individual members of the committee:

a. Education:

1. CODErouge: 1 June 2018, Quebec City, co-chairs : **Dr Rochelle Winikoff and Pam Wilton** in partnership with CHS. This was the second national symposium dedicated to the care of women with bleeding disorders.

b. Research Initiatives:

1. Health-related quality of life in Canadian women with bleeding disorders
P. Manuel, GH. Tang, G. Floros, J. Baker, R. Martin, F. Meffe, **Michelle Sholzberg**
Will be presented at AHCDC 2019 as a poster presentation.
2. The CHIC Study: The Canadian Hemophilia Carriers Study – **PI Dr Paula James.**
3. Understanding involvement in obstetric and neonatal decision making: a qualitative study to explore the experiences, preferences and needs of parents of infants at risk or affected by moderate or severe hemophilia A or B. **HOPPE Study – PI Dr Anthony Chan.**
4. Are there inequities in access to care and quality of life amongst certain groups of patients with inherited bleeding disorders? - **PI Dr Michelle Sholzberg.**
5. Postpartum Hemorrhage in Women with Inherited Bleeding Disorders: Knowledge-Translation and Exchange Project –**PI Dr Michelle Sholzberg.**
6. Do carriers of hemophilia over-report bleeding symptoms? **SISTERS Study - Dr Paula James and Dr Michelle Sholzberg.**
7. Pregnancy loss in von Willebrand disease: A multi-centre cohort study –**Dr Leslie Skeith.**
8. Take Control. Period. – Evaluating the effect of a website designed to enhance utilization of tranexamic acid and iron supplementation in women with heavy menstrual bleeding – **Dr Michelle Sholzberg.**
9. The use of an objective structured clinical examination to assess obstetrics and gynecology residents' knowledge of investigation and management of women and girls with bleeding disorders – **Dr Eliana Saidenberg.**
10. CHiMPS – Canadian Hemophilia Management in the Perinatal Setting **PI: Dr Paul Moorehead.**
11. The Validation of the Heavy Menstrual Bleeding Questionnaire in Adolescent Girls **PI: Dr Victoria Price.**

c. **Publications:**

1. Dalia Karol, Philip Tsang, Gaeun Rhee, Daniel Weiss, Karima Khamisa, **Elianna Saidenberg**. Development of competencies related to diagnosis and management of bleeding disorders in women and girls for use in residency training. *Haemophilia* 2019; 25(2):103-105.
2. H. VanderMeulen & **M. Sholzberg**. Iron deficiency and anemia in patients with inherited bleeding disorders. *Transfusion and Apheresis Science*. 2018 Nov.
3. Candy V, Whitworth H, Grabell J, Thibeault L, Harpell L, Bowman M, Good D, Hopman WM, Sidonio Jr. RF, **James P**. A Decreased and Less Sustained Desmopressin Response in Hemophilia A Carriers Contributes to Bleeding. *Blood Adv*. 2018 Oct 23;2(20):2629-2636.
4. Lavin M, Aguila S, Dalton N, Nolan M, Byrne M, Ryan K, White B, O'Connell NM, O'Sullivan J, di Paola J, **James PD**, O'Donnell JS. Significant Gynaecological Bleeding in Women with low von Willebrand Factor Levels. *Blood Adv*. 2018 Jul 24;2(14):1784-1791.
5. Parker JW, **James P**, Haley S. Spinal Anesthesia in Two Consecutive Caesarean Deliveries in a Parturient with Type 3 von Willebrand Disease: A Case Report. *A A Pract*. 2018 Jul 25.
6. Thorne JG, **James PD**, Reid RL. Heavy Menstrual Bleeding: is Tranexamic Acid a Safe Adjunct to Combined Hormonal Contraception? *Contraception*. 2018 Mar 23.
7. Moorehead, PC, Chan AKC, Lemyre B, **Winikoff R**, Scott H, Hawes SA, Shroff M, Thomas A, **Price VE**. A Practical Guide to the Management of the Fetus and Newborn with Hemophilia. *Clin Appl Thromb Hemost*. 2018 Oct 29.

d. **Book Editorship:**

1. *Inherited Bleeding Disorders in Women*, second edition. Wiley-Blackwell 2018. Co-editors Kadir R, Lee CA, **James P**.

e. **Book Chapters:**

1. **James P**, O'Brien S. Bleeding Assessment Tools. Chapter in *Inherited Bleeding Disorders in Women*, second edition. Wiley-Blackwell 2018.

f. **Public Awareness/Advocacy/Education:**

1. Let's talk Period: a community outreach and knowledge translation project utilizing social media. Developed and maintained by **Dr Paula James**.

g. **Clinical:**

1. CHS 5th New Team Workshop, Toronto 2018 – **Drs Winikoff and James** spoke on issues pertaining to women with bleeding disorders.

h. **Committee Meetings:**

1. Our last meeting was held at the AHCDC AGM in 2018. There have been no teleconferences this year.

Respectfully submitted by Victoria Price.