Adult Bleeding Disorders Program of BC

Hi everyone,

This is our fifth enewsletter from the St. Paul's Team. We hope you are finding them informative and useful, we would welcome any feedback you may have.

Gene Therapy Update

If you are interested in participating in the Gene Therapy Study for Hemophilia A, through the St. Paul's Adult Bleeding Disorders Program please contact us as soon as possible. We have just opened the observational study which is a mandatory prerequisite to the upcoming Multicentre Phase 3 FVIII Gene Therapy Study that will open at St. Paul's Hospital later this year. Read more about the observational study

As there may be limited time that both studies are open, if you have severe or moderately severe hemophilia A with no history of inhibitors, and are considering a Gene Therapy study please get in touch with the program and the study team can provide more information

Meet Stacey Cave

We are very excited to announce that Stacey Cave has joined the Adult Bleeding Disorders Team

in the role of Physiotherapist effective February 25, 2019. Stacey has been working for PHC since the fall of 2012 in a variety of areas including Acute, Rehab, Residential and Outpatient care. She came to us from the Complex Pain Outpatient team where she spent the last several years developing a self-management program with her coworkers as well as treating a variety of different pain diagnoses. She graduated from the University of British Columbia's Master of Physical Therapy program in 2012 and has a background in orthopaedics and sport. She was a varsity soccer athlete through her undergraduate studies and has always been interested in the musculoskeletal side of things. Please join us as we welcome Stacey to our team!

Calling all Hemophilia A and B Carriers

Did you know?

- Carriers can have factor VIII/IX levels varying from low (example 5%) to normal range (example 50-150%).
- In carriers of hemophilia, factor levels do not always correlate with bleeding symptoms. This means that a carrier may have a normal factor level but still bleed heavily.
- Just like a male with hemophilia, carriers may require:
    - Treatment for bleeding episodes
    - Treatment for invasive procedures
    - Management at the time of labor/delivery and postpartum

If know someone who is a carrier of the Hemophilia A or B gene who is not being followed by our

program please invite them to make a 1hr appointment by calling 604-806-8855 extn 2.

New Program Name

In order to be more inclusive of the population we serve/service we have changed our program name to **The Adult Bleeding Disorders Program of BC**. In addition to seeing patients with hemophilia A and B our program also serves patients with von Willebrand disease, rare bleeding disorders, and platelet function disorders. Our contact information remains the same. The **best** way to contact any one of us is **by phone at 604-806-8855 extn 2 or e-mail at H&HClinics@providencehealth.bc.ca**

Hemophilia Today Magazine

Hemophilia Today Magazine from the Canadian Hemophilia Society includes information to help inform the hemophilia and bleeding disorder community about current news and relevant issues. **Click here to read it**

Thanks for reading, and Happy Spring from all of us at Adult Bleeding Disorders Program of BC at St. Paul's Hospital!

1081 Burrard Street, Rm 491 Burrard Building, Vancouver , BC. | Tel. 604-806-8855 |

H&HClinics@providencehealth.bc.ca

http://hemophilia.providencehealthcare.org/