

Adult Bleeding Disorders Program Newsletter



WHAT'S NEW AT ABDP: PROGRAM UPDATE

Hello ABDP Community,

As we move into the Fall and Winter of 2024, we are excited to bring you the latest news and updates from the Adult Bleeding Disorders Program (ABDP). Since the re-launch of our patient newsletter earlier this year, we have received valuable feedback, including your thoughts, ideas, and suggestions. Our program is committed to being responsive to your input, and in this edition, we will address some of those topics along with sharing important program updates.

Are you using Factor or Hemlibra at home?

Our clinicians would like to remind you of the importance of keeping your information up to date in iCHIP, the platform we use to manage your care within the Adult Bleeding Disorders Program.

Accurate information in iCHIP allows us to provide you with the best possible care by ensuring we have the correct records. This is essential for coordinating your treatments, and maintaining seamless communication between you and your clinicians.

We understand that some patients have experienced access issues, so we have provided detailed instructions below to help you manage your account.

Tips: How to Set Your Password to '**Never Expire**':

- Log in to the desktop version of iCHIP at www.ichip.ca.
- Go to "Personal Info" and select "Change Password."
- Set "Days until Password Expires" to **Never** to avoid periodic resets.

PERSONAL INFO

Profile
Contacts
Password

Email:

* Password Recovery Question:

* Password Recovery Answer:

Enter Old Password to Change Password:

New Password:

Confirm New Password:

Two Factor Authentication

Two Factor Authentication (2FA) helps protect your privacy and the confidentiality of your personal information by verifying your account with something you know (your password) and something you have (your phone).

You may choose to opt out of the 2FA. By opting out of 2FA, you may be putting your information at risk if someone discovers your password. We recommend that you always have the 2FA enabled.

Enable Two Factor Authentication: Yes (recommended) ←

No

Days until password expires: 90

Never ←

Save
Cancel

Note. You do not need to change your password during this process – simply leave the password fields blank. paragraph text

Winter Safety Tips for Patients with Bleeding Disorders

As the colder months approach, we encourage everyone to take extra precautions to stay safe and healthy!

Here are some key tips to keep in mind this winter:

1. Stay Warm and Layer Up: Cold weather can impact circulation, making it harder for your body to manage bleeding. Dress in layers to keep warm and protect vulnerable joints from the cold.
2. Avoid Slips and Falls: Snow and ice can increase the risk of falls, which can lead to joint/muscle bleeds or injuries. Wear sturdy shoes with good traction, use handrails when available, and avoid icy areas whenever possible.

3. Stay Active: While outdoor activities may be limited, it's important to keep moving to maintain joint flexibility and strength. Continue to engage in safe, low-impact exercises!

4. Keep Your Factor Supply Ready: Ensure you have an adequate supply of clotting factor on hand in case of a bleed or emergency, especially during times when travel might be delayed due to weather conditions.

5. Communicate with Your Care Team: If you experience any joint pain, swelling, or signs of a bleed, contact your ABDP team right away. Early intervention can prevent complications.

Expert Insight: Understanding Bleeding Disorder of Unknown Cause (BDUC)

In this edition, we feature an insightful article by Dr. Vignesh Murthy on Bleeding Disorder of Unknown Cause (BDUC). This topic is crucial for patients who, despite not having a definitive diagnosis, continue to experience troubling symptoms. We hope that Dr. Murthy's insights offer clarity and reassurance for those facing this condition.



Did you know? Up to 30% of individuals with a genuine history of abnormal bleeding, referred to a bleeding disorders program, are diagnosed with Bleeding Disorder of Unknown Cause (BDUC). These individuals experience significant bleeding symptoms, yet their blood clotting tests show no abnormalities.

What is BDUC? BDUC is diagnosed after an extensive panel of blood clotting investigations. Although other centres have even conducted genetic testing, no common genes have been identified to explain this condition.

Symptoms of BDUC include: Nosebleeds; Easy bruising; Heavy menstrual bleeding; Excessive bleeding after childbirth or surgeries.

*Symptoms vary from mild to severe, with some needing emergency care.

What causes BDUC? The exact cause remains unclear. While many clotting proteins are known, others are undiscovered or difficult to test. Ongoing research may reveal the genetic or biochemical causes.

How is BDUC treated? Although the mechanisms behind BDUC are not fully understood, we have safe and effective treatments available. These include:

Tranexamic acid: reduces clot breakdown; can be taken as a pill or intravenously in a hospital setting.

Desmopressin: a synthetic version of Antidiuretic Hormone; can be given subcutaneously or intravenously. It is safe and effective in treating and preventing bleeding episodes.

STAFF ANNOUNCEMENTS: RETIREMENT & MATERNITY LEAVE

A Fond Farewell

We would like to share that Michelle Bech, one of our Nurse Practitioners, will be retiring after 8 years of dedicated service to our ABDP program. Michelle has been a valued provider to many of you, and we are so grateful for her contributions to our program.



As she prepares for her next chapter, Michelle wanted to share a few words with all of you:

"I hope I've been able to make life a little easier as you navigate the challenges of living with a bleeding disorder. As I reflect on my time at the clinic, I realize how much I will miss being part of your journey—helping find answers, offering support, and advocating for better care. My greatest hope is that the work we've done will drive lasting change. As I close this chapter, I look forward with optimism to the future of bleeding disorder care and the promise of new treatments. Wishing you all the very best."

Michelle's commitment and care have made a lasting impact, and while we will miss her greatly, we wish her all the best in her well-deserved retirement.

Maternity Leave



We are thrilled to share that Stacey, one of our physiotherapists, will be starting maternity leave on November 20, 2024 as she prepares to welcome her second child! We're all excited for Stacey and her growing family, and we want to wish her the very best during this special time.

While Stacey is on leave, Jill Kipnis will be stepping up from her part-time shared role with Stacey to full coverage of the Adult Bleeding Disorders Program to ensure everything runs smoothly.

Here's a message from Stacey herself:

"I'm excited to share that my family will be growing and another boy will be added to the already chaotic mix! This is such a special time, and I truly appreciate your support and understanding as I step away to welcome our new little one. While I'm away, you're in great hands with Jill taking over the helm, and I look forward to seeing you in early 2026 when I return."

Please join us in sending warm congratulations to Stacey!

ABDP CLINICIANS' PROFESSIONAL DEVELOPMENT ADVANCING KNOWLEDGE AND EXPERTISE

Our ABDP team is dedicated to continuous learning and professional growth, ensuring we provide the highest quality care to our patients. This year, several clinicians have taken part in specialized courses and national conferences, ensuring we stay at the forefront of bleeding disorder care.



POCUS Education Initiative: We are excited to welcome Dr. Bruno Steiner from the Washington Center for Bleeding Disorders to provide POCUS (i.e., Point-of-Care Ultrasound) training to clinicians at BC Children's and St. Paul's Hospitals, improving our diagnostic capabilities.



Michelle Bech, NP: will be presenting at PBCO Education Day on "Inherited Bleeding Disorders (Adult) in Hospital Care - Developing A Provincial Guideline." You can view the emergency-specific guideline [here](#), first published in 2023. Michelle and the team has worked hard to raise awareness and develop a resource for healthcare providers, focusing on improving access to timely factor treatment for Persons with Inherited Bleeding Disorders (PWIBD) in BC/Yukon.



Karen Sims, NP: Participated in the 2024 American Association of Nurse Practitioners National Conference and the Canadian Association of Nurses in Hemophilia Care Annual General Meeting, further enhancing her ability to manage complex conditions within the ABDP program.



Stacey Cave, PT: As secretary of the Canadian Physiotherapists in Hemophilia Care (CPHC), hosted a January physiotherapy only education session in Toronto and presented on "Muscle Bleeding: Introduction to Assessment and Treatment. Stacey also hosted the CPHC AGM and attended the AHCDC education day this past May. She also led a mentorship for the primary adult physiotherapist from the Alberta Bleeding and Rare Blood Disorder Adult Clinic in Edmonton.



World Federation of Hemophilia (WFH) 2024 World Congress
We would like to congratulate our team for representing our program at the WFH 2024 World Congress in Spain. Michelle, Shannon, and Stacey were able to attend in person. Their contributions to this global forum highlight their dedication to advancing care for bleeding disorders!