

The Clotting Connection

A Newsletter for Families with Bleeding and Clotting Disorders



University of Colorado
Anschutz Medical Campus
Hemophilia and Thrombosis Center

Affiliated with
Children's Hospital Colorado
and University of Colorado Hospital

WE CLIMB MOUNTAINS



Backpacks + Bleeders out on a hiking adventure. Photo: Backpacks + Bleeders.

Summer is here and with it is the chance to get outdoors for fun activities. For those in the bleeding disorder community, it may seem daunting or out of reach to hike or try new activities. If you've ever wondered if you could hike a 14er (14,000+ foot mountain) or just wanted to hike more but weren't sure how to get started with a bleeding disorder, look no further than Backpacks + Bleeders.

This unique program was created by severe hemophiliac and local Coloradan Chris Bombardier. You may have heard of Chris from his accomplishment of hiking the seven summits, the tallest mountain on each continent, including Mount Everest in 2017. He was the first hemophiliac to climb Everest and to complete the seven summits. While on his journey to achieve these climbs he was inspired by his experience and wanted everyone to be able to have the chance to feel the beauty, serenity, and personal accomplishment of reaching their goals. He also knows that anyone with a bleeding disorder has extra preparation and planning to safely hike and do most physical activities.

With his help, the Colorado Chapter of the National Hemophilia Foundation began Backpacks + Bleeders in 2013. They started with hiking and have expanded their activities to include indoor rock climbing, snowshoeing, paddle boarding, geocaching, rafting, and even summiting a 14er. Their activities are designed to be family friendly, and Backpacks + Bleeders offers events that vary from beginner to advanced. With each activity, they provide an opportunity to allow those with bleeding disorders to experience the accomplishment and beauty of an adventure with support from experts and with specific care for those facing their unique challenges.

The best part is that no experience is needed to get started! Backpacks + Bleeders teach skills starting from the very basics, such as what to bring, how to dress, what to expect, and still have freedom for those who are more experienced.

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Hiking a 14er. Photo: Backpacks + Bleeders.



Infusing on an activity. Photo: Backpacks + Bleeders.

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Find us on Facebook, Twitter, and our website for frequent updates on news and events.



Go to facebook.com/ColoradoHTC



Go to twitter.com/HTCColorado



Website: Go to medschool.ucdenver.edu/htc



Email:
HTC.Newsletter@ucdenver.edu



Stand up Paddle Boarding activity last year. Photo: Backpacks + Bleeders.

They welcome ALL physical ability levels, including those using crutches and wheelchairs, and all ages are welcome. The group advocates prophylaxis adherence and consistent, direct communication with the HTC to prepare and stay healthy while enjoying fun activities.

Each adventure Backpacks + Bleeders plans is different, but it's a great option to try out new things and make friends. Learn a new trail, discover new activities without feeling alone, and get familiar with gear without the costs. The program covers the price of equipment and rentals and those attending just need to bring the basics, like water, snacks and wear good shoes. The only requirement is to RSVP and that is done with a simple click or two through NHF CO's website www.cohemo.org or a phone call.

teach you how to pack, store and access it during activities. They usually have several community members infuse while on a trail during hikes. Their goal is to help share how those with bleeding disorders can still be healthy and be active and independent.

If you are interested in taking a step to enjoying a new adventure, follow Backpacks + Bleeders on their Facebook page or Instagram where they regularly share upcoming activities. You can also see details of what's next at www.cohemo.org under their Program & Event Calendar tab.

Already this year they've hosted hikes in various parts of Colorado and just hosted stand up paddle boarding in Colorado Springs. Coming up is a family hike outside Fort Collins on July 7th, their ADA/Wheelchair accessible hike at Garden of the Gods on August 11th, and their annual 14er hike on August 21st. This year they're hosting their first ever overnight father/son camping trip in September and are working to get a firm date for their fishing trip. Backpacks + Bleeders loves sharing moments of accomplishment with so many of our community. Seeing family members crest the top of a difficult hike or teaching people with fused joints how to do something they never thought possible is a joy. Please don't let a bleeding disorder stop you from doing some of these great activities. Backpacks + Bleeders is here to help! Their mission statement and social media hashtags say it all: ***Cultivating adaptable independence one meaningful adventure at a time.*** #WeClimbMountains #getoutside #playitsmart #adventure



Indoor rock climbing activity. Photo: Backpacks + Bleeders.

For more information or to contact Backpacks + Bleeders, see their Facebook page, Instagram, or www.cohemo.org.

DR. MICHAEL MANCO-JOHNSON PASSES AWAY



It is with our deepest sympathies that we announce the passing of Dr. Michael Manco-Johnson, husband of our director, Dr. Marilyn Manco-Johnson.

Many of our patients and staff have been privileged to meet and know Michael and knew he was a wonderful husband, father, grandfather, brother, son, and a friend to all.

Michael passed from this life on June 18, 2018 and a memorial mass was held to celebrate his life on June 26, 2018. Michael and Marilyn have five children and ten grandchildren.

A full obituary is available at www.horancares.com. In lieu of flowers, the family requests donations in honor of Michael Manco-Johnson to be made to the Krugman Award Endowment (a scholarship fund for the University of Colorado School of Medicine) using this link: <https://giving.cu.edu/fund/write-fund>.

HTC STAFF ATTEND WFH WORLD CONGRESS

In May four of our staff members were able to attend the World Federation of Hemophilia's World Congress in Glasgow, Scotland. This event brings together doctors, allied health professionals, researchers, and specialists from around the world to discuss the many aspects of



Dr. Tyler Buckner speaking at the WFH World Congress. Photo: Sharon Funk.

bleeding disorders. Posters sharing results of years of data research are on display, and attendees hear the latest from experts in talks, panels and symposia which are spread out

over the course of five days.

Attending this conference is a great opportunity for HTC staff members to interact with providers from around the world. The wide variety of healthcare environments worldwide allows us to see the differences and limitations of treatments due to variances in access, cost, and insurance. The talks and presentations allow attendees to learn new things as well as providing refresher courses. They can also help us find new insight into many areas where we still need to see improvement.

From our HTC, Dr. Mike Wang, Dr. Tyler Buckner, Dr. Beth Warren, and Physical Therapist Sharon Funk all attended and participated at the congress. Sharon Funk was a contributor to two posters on studies in Thailand and the validation of the Hemophilia Joint Health Score in adults.

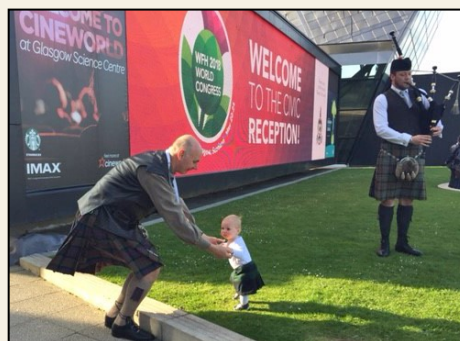
During the congress Dr. Warren presented a poster on "Influence of Prophylaxis Initiation Age on Hemophilia

Joint Health Scores in Hemophilia A", which shared data that appears to show that starting prophylaxis treatment before age three is more protective for joints than starting later.

Dr. Tyler Buckner presented a talk entitled "Increased Severity of Joint Disease in Individuals with Hemophilia A Compared to Hemophilia B as Measured by the Hemophilia Joint Health Score." In the research Dr. Buckner found that based on the HJHS, joint disease tends to be worse with people with hemophilia A, compared to hemophilia B even after accounting for age and severity.

Our HTC participants shared that there was a lot of discussion and excitement around the studies of emicizumab (Hemlibra). This is a non-factor medication that is currently approved to treat hemophilia A with inhibitors. Several studies on the medication are ongoing.

The conference also had a lot of discussion about ongoing research in gene therapy, and quite a few talks about continuing to move toward a standard set of measures to evaluate effectiveness of new therapies in ways that will be directly meaningful to patients. These topics and many more may affect our patients in the future, and it was a wonderful opportunity for our providers to learn and gain insights on best treatments available to patients now and in the future.



A shot of Scottish style at the WFH in Glasgow, Scotland. Photo: Sharon Funk.

Let Your Voice Be Heard! Take the National HTC Patient Satisfaction Survey Today!

Our HTC is participating in the National HTC Patient Satisfaction Survey! If you, or someone you care for, had contact with us in 2017, we need to hear from you!

You can take the survey online at www.htcsurvey.com, or fill out the paper survey you should have received from us in the mail. **The survey will remain open throughout the summer of 2018!**

Please go to www.htcsurvey.com to take the survey or to find out more information. The survey only takes a few minutes of your time! Thank you for your valuable input!

An advertisement featuring a smiling woman with short blonde hair, wearing a white cardigan over a white top, gesturing with her hands. To her right, the text "How is your HTC doing?" is written in a large, stylized, handwritten font. Below that, "Take the survey!" is written in a similar font. In the bottom left corner, there is a logo for the "PSS National HTC Patient Satisfaction Survey" featuring a heart and the letters "PSS".

RECENT HEADLINES

These are a few of the headlines that we've recently featured on our Newsroom page or on Facebook.

FDA Grants Priority Review to Efficizumab for Hemophilia A Without Inhibitors

Octapharma Presents Data on Nuwiq for Hemophilia A Patients

Spark and Pfizer Share Data from SPK-9001 Trial for Hemophilia B Patients

FDA to Speed Path to Approval for Some Gene Therapies-Starting with Hemophilia

Data from Hemlibra (emicizumab-kxwh) Trials Shared at WFH World Congress

Bioverativ Shares Data on BIVV001 for Hemophilia A Patients

We maintain a Newsroom page at our website with a list of the news we feel may be of interest to our patients and families. To see more go to: www.medschool.ucdenver.edu/htc then find the **RESOURCES** tab, and go to the **NEWSROOM** page. Find other stories at our Facebook page at www.facebook.com/ColoradoHTC/

UPCOMING EVENTS

Mark Your Calendars:

July 4: Clinic, Pharmacy, and Admin closed for Independence Day

July 7: Backpacks + Bleeders Fort Collins Summer Hike

July 10: Pediatric Stroke Parent Support Group

July 13-15: Mile High Summer Camp-Leadership Retreat

July 15-20: Mile High Summer Camp

July 24: Bleeding Disorder Parent Support Group

Aug 10-12: RMHBDA Family Camp-Rollins, MT

Aug 14: Pediatric Stroke Parent Support Group

Aug 25: NHF Unite for Blood Disorders-Walk at Sloan's Lake Park

Aug 28: Bleeding Disorder Parent Support Group

See more at our Events Page on our website:
www.medschool.ucdenver.edu/htc find **RESOURCES** tab, go to **EVENTS**

Hemophilia & Thrombosis Center

13199 E. Montview Blvd., Suite 100
Aurora, CO 80045

Clinic Main: 303-724-0724
or toll free at 888-297-0724
Pharmacy Main: 303-724-0168
or toll free at 888-724-7427

Web page:
<http://medschool.ucdenver.edu/htc>

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