

The Clotting Connection

A Newsletter for Families with Bleeding and Clotting Disorders

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University of Colorado
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A FIRST FOR HEMOPHILIA AS CHRIS BOMBARDIER SUMMITS EVEREST

Mount Everest stretches up and touches the sky at 29,029 feet, a full 14,590 feet higher than the highest peak in Colorado. For any hiker, it is an incredible feat to climb one of the more than 50 mountains that are above 14,000 feet in our state, but they all pale in comparison to Everest.

Hence, it is no surprise that during the month of May many of our HTC staff began checking Facebook often to hear the latest from Chris Bombardier as he made his way up Mount Everest. Chris grew up in Colorado, is a patient at our center, spent time working here, and is a huge part of the local NHF community—including helping start their Backpacks & Bleeders program.



Colorado mountaineer and hemophiliac Chris Bombardier on his historic climb. Photo courtesy *Bombardier Blood*.

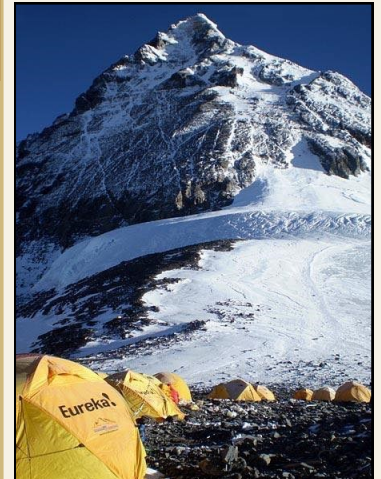
Chris has severe hemophilia B and, like many of our patients, he must infuse himself with Factor IX on a regular basis to have the right amount of clotting factor in his blood. To make such a strenuous and extended climb he had to bring his factor and supplies, make a special effort to keep his medication from freezing, and carefully plan and infuse before climbs to prevent bleeding. His public push to climb the tallest mountain in the world proved that so much can be accomplished even in the face of a difficult diagnosis such as hemophilia B.



Chris Bombardier infuses factor into his blood at base camp. Photo courtesy *Bombardier Blood*.

He has already climbed some of the highest peaks around the world, infusing along the way. Mount Everest is the sixth of seven peaks in his quest to hike the Seven Summits, the highest mountain on each continent in the world. Chris is motivated by his desire to help bring awareness and support to those with bleeding disorders around the world. During his trip to make his historic climb he met with local members of the Nepal hemophilia community and carried a flag with their names up to the top.

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Camp 4 before the summit of Mount Everest. Photo courtesy *Bombardier Blood*.

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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

UPDATES AND OPPORTUNITIES

HTC Director, Dr. Marilyn Manco-Johnson has completed her second Ride the Rockies bike tour, joining one of her patients, Kyle Haas, and the cycling team Project ReCycle. Ride the Rockies is an annual ride that allows participants a unique view of diverse and intense scenery in Colorado. This year the ride covered 447 miles, beginning in Alamosa and ending in Salida.

Marilyn first did Ride the Rockies in 2016 and was thrilled to join Kyle and the Project ReCycle Team again this year.



The First Annual Easy Brews Beer Festival was held on June 4, 2017 at the Arapahoe County Fairgrounds.

The festival was a lot of fun and we had a great turnout for a first time event! A big thank you to all the vendors and those who attended. All proceeds went to NHF Colorado to support programs like our upcoming Mile High Summer Camp.



Photos: Marilyn Manco-Johnson (RidetheRockies) and Sean Jeffrey (Easy Brews)



Our next **Self-Infusion Clinic** at the HTC will be on Wednesday, August 9, 2017 from 5 pm to 7 pm in our clinic. This is a program for our patients and families

who would like additional help with self-infusion to come and spend time with our nursing staff and practice in a one-on-one setting. You can bring your own factor to be infused, or practice with saline. We will have Spanish interpretation available at this clinic. Food and beverage provided; the event is free but you must RSVP. **Go to cohemo.org and click on the EVENTS page.**

OUTREACH CLINICS 2017

Outreach clinics allow patients to schedule their annual comprehensive visits at a location closer to their home. The clinics in Montana and Grand Junction are usually a few days once a year, while our Colorado Springs clinic is held quarterly.

Our staff reach out to local patients, but if these clinics are more convenient to your location and you would like to know more, please contact Pat Casias at 303-724-1325, Audra LeBlanc at 303-724-6163, or speak with our front desk schedulers at 888-297-0724 or

303-724-0724.

Details, forms and maps to these locations are available on our website at: www.medschool.ucdenver.edu/htc Click on the CLINIC tab and find the OUTREACH CLINICS page.

Upcoming clinics:

TBD August: Colorado Springs, Colorado

Sept 27-29, 2017: Grand Junction, Colorado

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Chris Bombardier climbing the steep Lhotse Face during his historic climb up Mount Everest. Photo courtesy *Bombardier Blood*.

On May 22, 2017 at 9:59am, Chris Bombardier became the first person with hemophilia to summit Mount Everest. He dedicated his journey and shared his victory by declaring:

“For every child who has been told no due to their bleeding disorder. For every patient wondering when his next dose of life-saving clotting factor will be. For every family who has plans derailed by hemophilia. For every parent who goes to bed in agony not understanding how to treat their child’s disorder. For every hemophiliac athlete who waits in quiet hesitation out of fear of injury. For all of us overcoming the impossible. This mountain is for you.”



Chris Bombardier at Camp 2. Photo courtesy *Bombardier Blood*.

It is with relief and joy that we at the HTC wish him the warmest congratulations at his incredible accomplishment. He told us, "I have to thank the HTC for being so supportive of this crazy endeavor. They easily could've said no but they are always working with patients to help them achieve their dreams!"

We could not be more thrilled that Chris was able to make his dream a

reality and hope that he and others can continue to blaze a path and help others in the bleeding disorder community achieve dreams of their own. Having examples such as Chris, proving what can be done with proper care and careful effort, can make a world of difference to families who are just learning of a new diagnosis and are unsure what kind of life is ahead.

You can follow Chris and learn more about his adventures on his Facebook page at www.facebook.com/AdventuresOfAHemophiliac, on his blog at www.adventuresofahemophiliac.com, and a website dedicated to a production on his climb at www.bombardierblood.com. To learn about the Backpacks & Bleeders program or NHF Colorado go to www.cohemo.org.



Chris Bombardier holding a flag of support for Save One Life that was signed by locals at the Nepal Hemophilia Society. Photo courtesy *Bombardier Blood*.

The historic climb was documented by Believe Limited, a production company and digital content agency led by fellow hemophiliac Patrick James Lynch. Production is underway for a documentary, as well as smaller series of episodes that will highlight the climb, and the involvement Chris and fellow climbers had in supporting those with hemophilia in Nepal and other places around the world.

Watch for more information on the documentary *Bombardier Blood* and other productions about the climb at www.bombardierblood.com.

To learn more about Save One Life and how you can help families with hemophilia around the world, go to www.saveonelife.net.

Thank you Chris for your huge spirit, for climbing mountains, and sharing your adventures!

RECENT HEADLINES

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

FDA Accepts Investigational New Drug Application for Hemophilia A Treatment

Man with Severe Hemophilia Talks about Climbing Mount Everest

Iowa Teen's \$1 Million-per-month Illness No Longer a Secret

Sangamo Receives Fast Track Designation from FDA for SB-525 Gene Therapy

FDA Approves Novo Nordisk's Rebinyn to Treat Hemophilia B

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, & Admin offices closed for Independence Day

July 11: Pediatric Stroke Parent Support Group meeting

July 14-15: Mile High Summer Camp-Leadership Retreat

July 16-21: Mile High Summer Camp

Aug 9: Self-Infusion Clinic at the HTC clinic

Aug 26: NHF Colorado 2017 Walk for Hemophilia—Sloan's Lake Park

Aug 27: Pediatric Stroke Parent Support Group Summer Picnic—Sloan's Lake Park

Sept 4: Clinic, Pharmacy, & Admin offices closed for Labor Day

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

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