

The Clotting Connection

A Newsletter for Families with Bleeding and Clotting Disorders

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University of Colorado
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Hemophilia and Thrombosis Center

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

CLINICAL RESEARCH AT THE HTC



Our Research Team. Top row: Amanda Kenny, Naghmeh Kamyab Hesari, Chloe Ries, Rachel Kula, Dianne Thornhill, Niesje Maccini. Seated: Dr. Jennifer Armstrong, Kristi Norton, Molly Brown, Julie Smith. [Photo: Merilee Ashton]

You may already have met our most experienced HTC Research Coordinators, Kristi Norton and Julie Smith. Combined, these two researchers have almost 16 years of experience and provide leadership and knowledge to our research program. They manage projects focused on bleeding and clotting disorders including hemophilia, von Willebrand disease, inhibitors, thrombophilia and thrombosis.

Our newest research coordinators are Molly Brown, Niesje Maccini, Rachel Kula, Chloe Ries, and Naghmeh Kamyab Hesari. A large team of coordinators, combined with the addition of our new statistician Dianne Thornhill, creates a well-rounded and complete Clinical Research team that is focused on excellence in research from start to finish. Our team strives to provide opportunities to be at the forefront of care and new treatments, as well as collecting important data that could change the way we approach and care for patients with bleeding and clotting disorders.

The research team has recently added a "Clinical Research Hotline" phone number and email address that are specifically designed to allow patients to reach the research team directly rather than going through the nursing staff or the front desk. With these new ways of contacting the Clinical Research team you can ask about research results, a specific study, or check on the studies we have available. The Clinical Research Hotline is 303-724-0306 and the email address is CRCalendar@ucdenver.edu.

Our Clinical Research team has grown in the past few months and they are busy working to improve the lives of those with bleeding disorders, clotting disorders, and stroke. Director of our Clinical Research group is Dr. Jennifer Armstrong. She manages the many aspects of care that come with pediatric stroke and works closely with Dr. Tim Bernard, the Director of our Stroke Program.

They both work with our Pediatric Stroke Parent Support Group Coordinator, Amanda Kenny, providing care, expertise, and support to families of children who have experienced stroke. Their ongoing research projects focus on learning more about pediatric stroke—just one aspect of our research department here at the HTC.



Senior Researchers Kristi Norton, Julie Smith, and Amanda Kenny. [Photo Naghmeh Kamyab Hesari]



Photo from Chris Bombardier at Base Camp 1 as he attempts to climb Mt. Everest. Follow his adventure on Facebook—search for Adventures of a Hemophiliac Chris Bombardier.

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- Education Days Update
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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

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UPDATES & UPCOMING OPPORTUNITIES



Registration for Mile High Camp is OPEN!

Our Leadership Pre-Camp Retreat (for ages 14-18) is on July 14-16, and the main camp (for ages 7-13, plus leadership kids) will be from July 16-21, 2017. Registration for summer camp is now open and can now be done online! Go to cohemo.org to find the link to start registration, or contact Sean Jeffrey, (720) 545-0755, sjeffrey@hemophilia.org with questions or if you need paper forms or don't have internet access. Make sure you sign up now. Camp registration closes on June 1st!

Our next **Self-Infusion Clinic** at the HTC will be on

Saturday, May 6, 2017 from 9 am to 11 am. This is a new program where we invite our patients and families who would like additional help with self-infusion to come and spend time with our nursing staff and practice self infusion 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 EVENT CALENDAR.



NHF CO Family Camp and the **RMHBDA Family Camp** will be June 16-18, 2017. This is an opportunity for families affected by bleeding disorders to have their own special camp to bond with other families going through similar circumstances. It is sponsored by NHF Colorado and the Rocky Mountain Hemophilia & Bleeding Disorders Association in Montana, and is for all ages, parents included! Registration is now open at cohemo.org and at rmhbda.org.

Leading X is a week long back-country adventure offered free to any adult in the bleeding disorders community. It's camp for adults! No experience necessary. Go to gutmonkey.com for information and to apply for one of four upcoming 2017 expeditions!

Updates from **Adventures of a Hemophiliac: Chris Bombardier** as he attempts to climb Mount Everest are available at his Facebook page @AdventuresOfAHemophiliac, with more information at www.saveonelife.net, the hemophilia support organization he is bringing to light. He has been providing updates and photos as he attempts this climb. He also is being documented on this journey; more information on his climb and this adventure is up at bombardierblood.com. We wish him the best!



Tickets are now available for the first annual **Easy Brews Beer Festival**. It will be held on Sunday, June 4, 2017 from 2 pm-6pm (VIP entry at 1 pm) at the Arapahoe County Fairgrounds. All proceeds from this event will benefit the National Hemophilia Foundation. Learn more and RSVP at the cohemo.org EVENTS page.

Want to share your story? Consider being a part of **Stories Project 2**, where males of all ages who have experiences with a bleeding disorder are invited to share their story in 1,000 words or less. For more information on how to participate in this opportunity, please contact our social worker, Audra LeBlanc at 303-724-0724.

[Research continued from page 1]

In addition to our ongoing studies, the research team is also working to provide better patient access to information about past research results. The goal, set for the end of this year, is to provide published articles in the clinic waiting room so you can read about projects you contributed to while waiting for your appointment. Another Research Team goal is to have a booklet of research advertisements/flyers available so that patients can know what studies are open and can ask their HTC doctor, nurse or research coordinator if they would like more information.

Our Clinical Research team looks forward to hearing from you either through our Clinical Research Hotline or via email at CRCalendar@ucdenver.edu. Our research coordinators work hard for those with bleeding and clotting disorders and strive to have that research make a positive difference in patient lives. We are grateful for our patients who so willingly participate in studies. We couldn't do it without you!

Find more information at our website at www.medschool.ucdenver.edu/htc

Click on the RESEARCH tab.

EDUCATION DAYS A GREAT SUCCESS

On April 14th and 15th, 2017 the Colorado Chapter of the National Hemophilia Foundation and our HTC joined forces to present our annual Education Days. The event was held at the Denver Marriott South at Park Meadows and many of our HTC staff participated. We were thrilled to learn that more than 100 attended.

Topics ranged from Keeping Joints Healthy to Updates in Healthcare and Insurance. Wonderful sessions on the Signs and Symptoms of Bleeding Disorders, von Willebrand Disease, Hispanic issues, and new Non-factor Therapies were all well attended and had great participation from patients and families.

Dr. Mike Wang and Dr. Tyler Buckner were keynote speakers; HTC Pharmacists Paul Limberis and Desi Hill led discussions about how to advocate when dealing with pharmaceutical companies, and answered questions about products. Nancy Spomer and Kim Hurdstrom from our nursing team helped with a session on infusions, both teaching and assisting families as they infused. Kristi Norton and Julie Smith from our research team provided information to patients about projects they are working on and how to touch base with our Clinical Research team.



Our Nursing team provided support during a session on infusions. [Photo: Kim Hurdstrom]

Sessions were offered on mental health services provided by Colorado Health Network, and many in the bleeding disorders community were very responsive to this topic. Our Physical Therapy team spoke on a panel and NHF Colorado awarded the Hathaway Award to one of our Physical Therapists, Sharon Funk as well as presenting other awards to those in the bleeding disorders community.



Physical Therapist Sharon Funk received the Hathaway Award at the 2017 Education Days. [Photo: NHF Colorado]

Corporate Kids provided wonderful childcare for our younger children and took our older teens for an offsite trip to the Family Sports Center where they had fun options like ice skating, mini-golf, and bumper cars to keep them entertained.



Childcare included fun activities like mini-golf. [Photo: NHF CO]

Education Days has grown so much in just the past 5 years, it has become a helpful resource and great gathering point for our community. This is only possible through the

efforts of a strong chapter, our dedicated staff, and wonderful families who are proactive in learning how to improve the lives of those with bleeding disorders every day. Thanks to all for making this a great event this year!

OUTREACH CLINICS 2017

Outreach clinics that are scheduled for 2017 are designed to 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 or 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.

Confirmed upcoming clinics:

June 19-21, 2017: Billings, Montana

June 26-27, 2017: Missoula, MT

Sept 27-29, 2017: Grand Junction, Colorado

RECENT HEADLINES

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

CDC Publishes Efforts and Progress to Prevent Inhibitors in Bleeding Disorders

Positive Results for Roche's Phase III HAVEN 2 Study for Children with Hemophilia A and Inhibitors

Catalyst Biosciences Reaches Milestone to Advance Factor IX Program to Human Trials

Ryan White's Letters to go on Display

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:

May 6: Self-Infusion Clinic Series at the HTC

May 21: Comeback Trail 5K for Stroke, Hudson Gardens, Denver

May 29: Clinic and Admin offices closed for Memorial Day

June 4: NHF CO Easy Brews Beer Festival

June 16-18: NHF CO Family Camp

June 16-18: RMHBDA Family Camp

June 19-21: Outreach Clinic-Billings, MT

June 26-27: Outreach Clinic-Missoula, MT

July 4: Clinic and Admin offices closed for Independence Day

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

July 16-21: Mile High Summer Camp

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

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