

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

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and University of Colorado Hospital

WHAT'S NEW: SELF-INFUSION CLINICS



Our Nursing Manager, Christine Mashburn, assists a patient at practicing self-infusion at our February Self-Infusion Clinic.

Learning to self-infuse factor for a bleeding disorder can take a lot of time and patience, and a lot of practice! Many bleeding disorder patients learn how to administer their factor as young kids attending hemophilia camp. Even experienced, severe hemophilia patients will admit that it isn't the easiest skill to master, or their favorite chore, but learning self-care and how to treat a chronic condition, such as a bleeding disorder can be an empowering experience. Having the knowledge and skills to manage your own care is a big step to independence.

The HTC and the Colorado Chapter of the National Hemophilia Foundation have teamed up to start a new program for our patients and their families.

We held our first Self-Infusion Clinic on February 15th here at our HTC. This

program is free and designed for any of our patients who may want to practice and have extra assistance with self-infusion or infusing their child/family member. Our staff provides the medical support and experience to teach one-on-one with our patients to give them a chance to practice. A patient can bring their own dose of factor to infuse, or practice with a saline solution.

This program is specifically tailored to provide special assistance for those who do not have to self-infuse often, such as mild hemophilia patients or those with von Willebrand disease. But all who would like extra help, particularly those who are newly diagnosed, are welcome to attend these clinics.

The Colorado NHF chapter helps our HTC by setting up the logistics of these sessions and providing support and treats. They set up an RSVP process so we can keep the clinic numbers comfortable and provide enough staff for those attending. Our nurses and social worker were able to attend our first self-infusion clinic and were delighted at the opportunity to assist families in this way.

Our next Self-infusion clinic is scheduled for Saturday, May 6, 2017 here at our HTC from 9 am to 11 am. To RSVP for this program, please see the registration information at cohemo.org, under the EVENT CALENDAR section of their website.

If you have additional questions about this event, please feel free to send an email to Sean Jeffrey of the NHF CO Chapter at sjeffrey@hemophilia.org.



Nurse Nancy lends her expertise at our first Self-Infusion Clinic.



Social Worker Audra LeBlanc offers up her arm as practice at our Self-Infusion Clinic.

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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

SPOTLIGHT: AUDRA LEBLANC-SOCIAL WORKER



If you have visited the HTC or participated in some of our events, you may have had the opportunity to bump into Audra LeBlanc, our Licensed Clinical Social Worker. We thought our families would like to learn a little more about her and the unique skills she brings to our center.

Audra is an active part of our clinic and regularly interacts with and supports our patients

in a variety of needs. She has worked at our HTC for five years and is a wonderful patient resource. She loves to work with our patients and is always willing to provide support in any way she can. As Audra will tell you, they are the reason she is here.

Audra grew up in Maine, graduated from the University of Vermont in Burlington, and received her Masters in Social Work from the University of Maryland in Baltimore. She has one older brother and is adventurous—riding her bike cross country when she graduated from college. Audra also had the opportunity during her college years to study abroad in Bali, Indonesia. She loves to hike and be outdoors, traveling, and being active. She enjoys adventurous vacations but also loves visiting tropical beaches. Audra is married and has two furry, four-legged kids (her cute dogs Brisby & Marina) and enjoys challenging home improvement projects.

Audra has always been interested in helping people, even in high school. She planned on earning a degree in psychology, but when she learned about social work she fell in love with it, choosing that path with passion.

She told us, “I like the philosophy of creating change and social justice. I sort of fell into social work in a health care setting and found that to be my niche.”

She meets with our patients in clinic and works to find out how they are coping with their unique health conditions. Audra is able to speak with families about managing insurance and learning about the assistance programs they may benefit from. She has helped patients with many issues, from billing to therapeutic support, in person and on the phone. She helps our patients manage the emotions that can come with dealing with their medical condition.

As our only social worker, she is very busy planning programs and working on quality improvement initiatives within our HTC. She regularly provides bleeding disorder education for schools and daycares and is happy to help our patients as they navigate the struggles that face families. If you have a need to help your child’s school understand their bleeding disorder, she can provide resources and expertise.

She loves to interact with our patients and finds ways to make our HTC more helpful, and improves the services we provide. Currently she is working on ways to help our newest patients feel less overwhelmed as they face living with a chronic bleeding disorder. Her influence is felt in support groups for parents, and our efforts to help our patients learn to become independent as they transition from children to young adults.



Audra's dogs, Brisby (left) and Marina (right).

We at the HTC are grateful for her incredible talents and hard work. She plays a huge role in our team effort to assist our families. If you need some additional support or have questions that she can assist with, do not hesitate to give her a call or send an email.

Her contact information is:

Audra.leblanc@ucdenver.edu or 303-724-6163



HTC/CCBD BROOM BALL TEAM

Need proof that Audra loves adventure? She joined with a few of our HTC staff and a few more brave souls from the CCBD to form a Broom Ball team that participated in the Annual Children’s Hospital Broom Ball Tourney. This fun activity pits different departments at Children’s Hospital against one another and this year the proceeds went to the Parade of Lights.

Broom Ball involves teams playing broom hockey on ice—competitive and a little rough! The HTC/CCBD team did great—winning one, but losing the second. The team was excited to make it into the second round for the first time and gave a spirited effort!

From left, Dr. Tyler Buckner, Tim Schardt, Tom Smith, Jason Child. In front, Audra LeBlanc and Amber Casey.

SCHOLARSHIPS



If you are a graduating High School Senior, or already in college, and are looking for financial assistance, it is time to think about scholarships. This time of life can be scary and full of change; it can also cost a chunk of change. We list several available scholarships on our website to provide an easy way for students and parents of teens to access these resources.

Because our HTC serves those with bleeding disorders and pediatric stroke patients, this year we have added several scholarships for those who have disabilities related to stroke. If your child has a bleeding disorder, or experienced stroke and is not yet old enough for college, be sure to keep an eye on these options as he or she grows.

Finding and applying for qualifying scholarships can be tough. Many scholarship websites have outdated information and it seems like the details you need can be buried. We have tried to screen scholarships to include those that would be the most useful to the bleeding disorder and pediatric stroke communities and directly link to the source. We have found that the NHF, HFA, pharmaceutical companies, government support programs, and various memorial scholarships offer amounts from \$150 to \$10,000 toward gaining a college, vocational or technical degree.

We hope that by hosting this list of scholarships it might be a little less frustrating to search for what you need. At our website we have posted our most recent list of scholarships by due dates and basic requirements. Each scholarship is different but we tried to link to the website page with the best information. While qualifications for these scholarships vary, if your child is a patient at our center these scholarship offerings may be an option.

Most of the scholarships we have listed are for those with a bleeding disorder but several are also for family members of those with bleeding disorders, and some are for those with disabilities that some of our pediatric stroke patients may qualify for. Be sure to check requirements carefully and watch the deadlines; they come up quickly.

We strive to maintain our website's accuracy, so if a link is broken or inaccurate, we apologize and welcome your feedback to improve this as a resource. We try and post reminders about upcoming deadlines; we encourage you to like our Facebook page and follow us on Twitter for updates.

To find our list of scholarships go to www.medschool.ucdenver.edu/htc and find the **RESOURCES** tab-then locate the **Children & Teens page**; the scholarship list is listed there (scroll down).

Questions or feedback please email: HTC.Newsletter@ucdenver.edu.



NHF Colorado invites you to take it easy at a new and exciting fundraising event coming this summer. The Easy Brews Beer Festival will be held on Sunday, June 4th from 1 pm- 6 pm at the Arapahoe County Fairgrounds, with all proceeds going to support the NHF Colorado Chapter.

The event will host local and regional craft beers, food trucks of all types, live entertainment and a view of the beautiful Rocky Mountains. General Admission and VIP tickets include a souvenir tasting glass and unlimited one ounce beer tastings with participating breweries, as well as the great entertainment. This festival is for all ages, but as you must be 21 or over to consume alcohol-and only those ticket holders will be allowed to sample the beer-be sure to bring your ID!

Non-drinkers' tickets include complimentary soda, and kids under 10 get in free! Learn more and RSVP by heading to cohemo.org and see their **EVENTS** page.

Tickets go on sale on February 23rd!

RECENT HEADLINES

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

Plant Based Hemophilia Therapy Shows Promise to Reduce Inhibitors

New Drugs to Treat Hepatitis C Under Priority Review at FDA

Dimension Therapeutics Announces Results from Phase 1/2 Trial for DTX101-AAV

uniQure's AMT-060 Gains Breakthrough Designation from FDA for 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:

Feb 28: Rare Disease Day

March is Bleeding Disorders Awareness Month

Mar 8-10: NHF Washington DC Days

Mar 26-27: NHF CO Colorado Statehouse Day

Apr 15-16: Education Dayz-Lone Tree, CO

Apr 18: RMHBDA Montana Advocacy Day

May 6: Self-Infusion Clinic Series at the HTC

May 29: Clinic and Admin offices closed for Memorial Day

Jun 16-18: NHF CO Family Camp

June 16-18: RMHBDA Family Camp

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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