

The Clotting Connection

A Newsletter for Families with Bleeding and Clotting Disorders

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BACK TO SCHOOL 2018



Summer is nearly over and all the “Back to School” sales have begun. Soon families will meet teachers, find new classrooms, and pack lunches. Families of kids with bleeding disorders may also be gearing up to find ways to explain to their teacher and school what they need to know to help their child.

If your family is new to a school or teacher, or even if the school is aware of your child's bleeding disorder, the beginning of the school year is the best time to set up plans and address potential problems. A child may or may not want to share his or her bleeding disorder with

peers, but schools and teachers should be informed so they can provide appropriate care and accommodations.

Nearly all schools have forms that need to be filled out that address medical needs, especially medication that might be needed. Most forms will need signatures from nurses and input from medical providers. Our nursing staff is ready to help families get those forms ready for school. In addition, many parents may want support in talking with the school about what needs may arise. Depending on the severity of your child's bleeding disorder and health, and whether or not they know how to self-infuse, schools will need to be up to speed on what to expect. Our nursing staff is happy to help explain these needs. They can lend their expertise to help school staff understand your child's disorder and describe potential accommodations that might be needed for your child. This could be anything from extra time to get to class when they have a bleed to flexibility when they need to stay home. Give our nursing staff a call at 303-724-0364 to discuss any support you may need.

It's not just K-12 kids that need support in school. Young adults heading to college should be aware of the resources they may need to use and how to prepare to live away from home. Most colleges have a disability resource officer or office on campus that they should connect with before arrival. College campuses can be painfully huge for those on crutches or having a bleed. Most colleges provide quicker ways across campus, or provide other help for those with medical needs. Find out beforehand what those resources are and how college students can access them.

College kids who infuse also need to make sure they have access to a proper and safe way to store their factor medication, and who to call in case of a problem. They will need to know how and where they can access supplies and medication, and where they

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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

2018 UNITE FOR BLEEDING DISORDERS WALK



The 2018 Unite for Bleeding Disorders Walk is nearly here. The walk, which was previously called NHF Walk for Hemophilia, has changed its name to include all bleeding disorders that NHF Chapters around the country support. This fundraiser supports programs throughout the year to provide education, connection, and activities for families facing challenges of bleeding disorders. This is the main fundraiser for NHF Colorado and is the primary means for supporting Mile High Summer Camp.

The walk will be held at Sloan's Lake Park on August 25th, with check in starting at 8 am and the walk beginning at 9 am. There will be a camp reunion booth with Voodoo donuts, as well as other tents with food and other giveaways from sponsors. For details, to sign up, or to donate, please go to www.cohemo.org, or you can go directly to the Unite for Bleeding Disorders Walk Page at www.uniteforbleedingdisorders.org and find the Denver event. You can join or donate to our team from the HTC (we're called Chill Factor), join another team, or start your own. Can't attend? Virtually walk by simply donating. It all makes a difference. We asked a few of our staff who are attending the walk: Why do you walk? This is what they said!



It's my first time attending in person so I'm excited to bring my kids. I'm inspired by family members who have bleeding disorders & our amazing patients. I love going to camp and seeing the kids outside of the clinic! **Dr. Beth Warren**



I walk to support our NHF Colorado family! I am looking forward to seeing old and new friends in our bleeding disorder community on Saturday. **Dr. Marilyn Manco-Johnson**



Our nurses, clinic, and research staff love the opportunity to come to the walk and meet with patients outside of clinic. Nurse Kim Hurdstrom and Researcher Kristi Norton want you to come say hi!



I walk to honor our patients and families, and I love having the chance to spend time with them and our team outside the clinic. **Dr. Tyler Buckner**



Our pharmacy staff, Paul Limberis, Kara Taylor, Desi Hill and Trish Tucker are all attending the walk this year. They talk with many of you on the phone on a regular basis and love meeting you in person. The pharmacy is happy to support NHF Colorado and all they do for our patients.

[continued from page 1] can go locally for appropriate medical care. Our nurses and pharmacy staff are prepared to answer questions about both of these issues. Please don't hesitate to call with any questions. Nurses can be reached at their **nursing line at 303-724-0364**. For specific questions about storing or ordering factor at other locations, please contact our **pharmacy at 303-724-0168**.



When heading to school with a bleeding disorder, know your rights and how to advocate for your child or yourself. There are many resources online that are available to get the best out of the coming year.

Check out the NHF's webpage Steps for Living at <https://stepsforliving.hemophilia.org/>, or the Back to School and College Toolkits at HFA's webpage <http://www.hemophiliafed.org/for-patient-families/resources/toolkits/>. Get ahead of the game and prepare now to support kids and young adults as they head back to school and have a great school year!

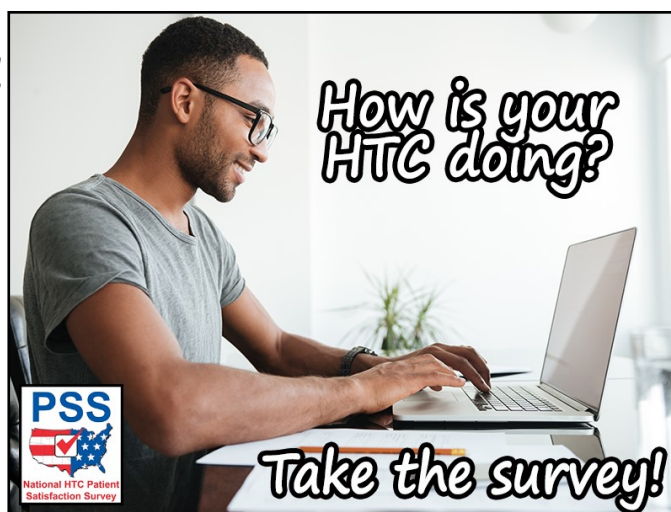


Last Chance to Share Your Voice!

The National HTC Patient Satisfaction Survey closes at the end of the month! Our HTC is participating and would love to hear from you! 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 is scheduled to close on August 31, 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!



OUTREACH CLINICS 2018

Every year our HTC schedules Outreach Clinics 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.

We have had to re-schedule several of these clinics and these are the confirmed dates. While our staff does reach out to schedule local patients, 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 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.

Updated Outreach Clinics for 2018:

Sept 7, 2018: Colorado Springs, CO

Sept 17-18, 2018: Missoula, MT

Sept 26-28, 2018: Grand Junction, CO

RECENT HEADLINES

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

Catalyst Provides Update on Phase 2/3 Trial for Hemophilia with Inhibitors

They Thought Hemophilia was a "Lifelong Thing." They May Be Wrong

Review Finds Multiple Factors Contribute to Inhibitors in Hemophilia

Spark Updates Data for Hemophilia A Gene Therapy Trial

Cost Analysis Compares Gene Therapy and Prophylaxis Care for Severe Hemophilia A

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:

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

Sept 3: Clinic, Pharmacy, and Admin closed for Labor Day

Sept 7: Outreach Clinic-Colorado Springs, CO

Sept 17-18: Outreach Clinic-Missoula, MT

Sept 25: NHF CO: Western Slope Social Factor

Sept 26: NHF CO: Western Slope Outreach Program-Microbleeds

Sept 26-28: Outreach Clinic-Grand Junction, CO

Oct 11-13: NHF 70th Annual Meeting & Conference

Oct 21: NHF CO Spanish Social Factor-Northglenn, CO

Oct 28: NHF CO Easy Brews Beer Festival & Trick-or-Treat Street-Arapahoe County Fairgrounds

Oct 31-Nov 2: Outreach Clinic-Billings, MT

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

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