

# The Clotting Connection

*A Newsletter for Families with Bleeding and Clotting Disorders*



Hemophilia and Thrombosis Center  
UNIVERSITY OF COLORADO ANSCHUTZ MEDICAL CAMPUS



Affiliated with  
Children's Hospital Colorado

## BACK TO SCHOOL 2019



It is already August and the fun days of summer are winding down! Many families are collecting school supplies, visiting new teachers, or moving kids to college. Families of children with

bleeding disorders may have extra steps they need to take to keep the school and teachers informed on how to keep their child healthy and safe.

Whether your child is brand new at school, entering a new grade, or moving to college, the beginning of the school year is the best time to set clear plans and guidelines for managing their care. A child may or may not want to share his or her bleeding disorder with their friends, but teachers and administrators should be informed so they can provide support and accommodations.

Many resources are available to families to help make this transition to a new school year a smooth one. The first step is to reach out to the school and ask to talk or meet with teachers, nurses, or administrators who may need to be involved. Sometimes the most effective tool is to educate these important people on what your child's bleeding disorder is, what your child may need, what the school may need to do or provide, and when they should be calling for assistance. Accommodations may be available if your child needs extra time to get to class or will need extra days at home and the ability to turn in homework late without penalty. Our HTC team regularly provides Individualized Health Plans (IHP) for our patients that can help outline your child's specific needs.

Depending on the severity of your child's condition, you may need additional and more formal protocols in place to provide the support you need. A 504 plan or an IEP may need to be set in place to make sure your child's needs are met. If you are unsure which plan is best, or if you need a plan at all, talk with your child's school about their needs. Usually K-12 schools and colleges have counselors or staff who manage care of children who may require special accommodations and they can help explain what would work best.



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**Start the new year right! Talk with your child's school frankly about their bleeding disorder, what may be needed, and find out how we at the HTC can help!**

### INSIDE THIS ISSUE

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



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Go to [twitter.com/HTCColorado](https://twitter.com/HTCColorado)

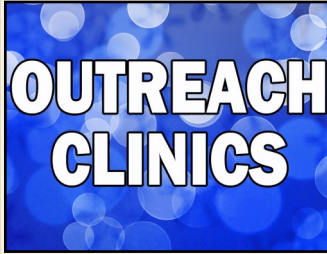


Website: Go to [medschool.ucdenver.edu/htc](https://medschool.ucdenver.edu/htc)



Email:  
[HTC.Newsletter@ucdenver.edu](mailto:HTC.Newsletter@ucdenver.edu)

## UPCOMING EVENTS & OPPORTUNITIES



If you do not live in the Denver Metro area, one of our Outreach Clinics might be an easier option for your regular comprehensive care. Our Outreach Clinics offer care and support from our medical, nursing, physical therapy, psychosocial, and research teams. Our experts come to you!

Our next Outreach Clinic is **Sept 25-27 in Grand Junction, Colorado.**

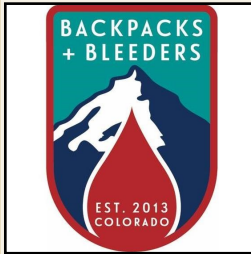
See our website for updates on future clinics and more details at: [www.medschool.ucdenver.edu/htc](http://www.medschool.ucdenver.edu/htc) and find the Outreach Clinic page under the CLINIC tab.

Our next Pediatric Stroke Parent Support Group will be on **September 10th** from 6-7:30 pm here at the HTC. This is a great opportunity for families of those who have experienced a pediatric stroke to meet, mingle, learn and connect with others in similar circumstances. Meetings are once a month on the 2nd Tuesday of the month. Dinner and childcare are provided and you do not need to be a patient with us to attend.

To RSVP or for other questions, please go to our website at [www.medschool.ucdenver.edu/htc](http://www.medschool.ucdenver.edu/htc) and find the Pediatric Stroke Parent Support Group page under the COMMUNITY tab.

### Pediatric Stroke Parent Support Group

Tuesday  
Sept 10, 2019  
6:00-7:30 pm



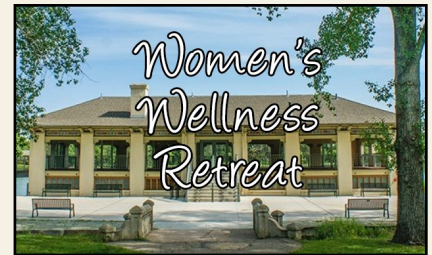
NHF Colorado's Backpacks and Bleeders program is starting up again in September!

Backpacks and Bleeders cultivates adaptable independence one meaningful adventure at a time by challenging our community to think beyond their limitations and enjoy the outdoors.

Join us for a fun, family hike on Saturday, **September 14, 2019**, and come prepared to give feedback on what kinds of adventures you'd like to see. To save your spot and find out more about this great program, please go to [cohemio.org](http://cohemio.org) and find their Backpacks and Bleeders page under the WHAT WE DO tab– and look for We Trailblaze.

Attention all ladies! If you are affected by a bleeding disorder, are a carrier, or a caregiver, save the date for some pampering and self-care! NHF Colorado is hosting a Women's Wellness Retreat on Sunday, **October 13th, 2019** at the Washington Park Boathouse.

This opportunity only requires a \$25 registration fee per person, and you will get lunch, a special welcome gift, and a self care option package– including a massage. Please go to [cohemio.org](http://cohemio.org) and find their News and Events calendar for more details.



## SET A SCHEDULE FOR LEARNING, REST, NUTRITION, & PLAY

As the new school year begins, start now to set up a schedule to help your family find a good balance. Study after study has emphasized the importance of getting enough rest, eating nutritious food, putting in the hard work for learning, and making time for play. It can be hard to find the right balance with extracurricular activities, friends, new routines, and homework. Here are a few ideas to get you started:

- Set aside some time early in the school year to talk about schedules with your family. Consider setting aside a short family meeting once a week to enjoy time together as a family and talk about the week ahead.
- Find a good bedtime routine. Whether your kids are young, teens, or approaching adulthood, find a simple routine that works and follow a pattern to allow your kids time to wind down and get enough rest.
- Plan ahead to have family meals with healthy choices. It can be easy to run out of time in a busy school year. Sit down and talk about what your family wants for meals, if you can have a set dinner time, or ways to share cooking healthy meals together.

- Reduce technology in the bedroom. TV, computers, phones, games, and most tech devices have been proven to stimulate the brain so that it is hard to settle down. Think about ways to limit screen time and talk about it with your kids. If they struggle to control their impulses with technology, set a time when these items are off limits, or turn off access.
- Cut back on being busy. It is very easy to fall into a schedule that is so busy no one has enough time for homework, play, dinner, or rest. Look at your family's activities, calendars, homework expectations, screen time and find areas where you can cut back.
- Look for opportunities for simple play, like a regular family board game night, or going on a walk or bike ride together.

Don't let a new school year bring chaos. You have the ability to control many aspects that can put stress on family members. Find more helpful resources at our online newsletter at [www.medschool.ucdenver.edu/htc](http://www.medschool.ucdenver.edu/htc). Click the RESOURCES tab and then the Digital Newsletter link and find the August 2019 link.



# COME WALK WITH US!

## Unite for Bleeding Disorders

August 24, 2019 at Sloan's Lake Park  
8 am check in - 9 am walk - support all year

**Participate ♦ Volunteer ♦ Donate**



All proceeds go to NHF Colorado, funding programs for the bleeding disorder community.

The Unite for Bleeding Disorders Walk is coming right up! This is a great opportunity to make a difference in the lives of families with bleeding disorders. The funds raised from the walk support all the incredible activities and learning opportunities NHF Colorado offers each year. This includes Education Days, Family Camp, Mile High Summer Camp, Backpacks & Bleeders, Social Factor meetings, and more!

Join us on **August 24, 2019** at 9 am at Sloan's Lake Park near the South pavilion to walk and make a difference. Registration is available online and check in begins at 8 am on the day of the walk. You can sign up at [uniteforbleedingdisorders.org](http://uniteforbleedingdisorders.org) and search for the 2019 Unite Walk Denver. If you would like to join our HTC team, just search for Chill Factor, but you are welcome to join friends or create your own team too.

If you can't walk on the 24th you can still make a difference! Consider donating online and sharing the website with others who could help support NHF Colorado as well. Go to [cohem.org](http://cohem.org) for more info.

NHF Colorado is providing breakfast treats, lawn games, and a Camper Reunion area for campers to reconnect, hang out and enjoy donuts. There are team and individual fundraising incentives, and you can even become a volunteer at this event.

If you don't live in the Denver area and are closer to Billings or Kalispell, Montana, consider joining the RMHBDA Unite Walks on September 7th and Sept 14th. You can find information

about their walks and how to contribute at [rmhbda.org](http://rmhbda.org). We hope you can join us, donate, and help make a difference in the lives of those with bleeding disorders.

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Our team at the HTC can also provide help and be there to guide you as you work with your child's school and get

the proper plans in place. Please touch base with our social work team or our nursing staff if you have questions or need some guidance.

If for any reason your child needs infusion in a different environment than home or a clinic, special care must be taken to keep medication at the proper temperature. A young adult heading to college will need to make sure there is a place set aside to properly keep their medication and supplies at their dorm or apartment.

College students also need to be aware of the resources available to them in case of a medical need. They should know where to find a clinic that can offer care, how and

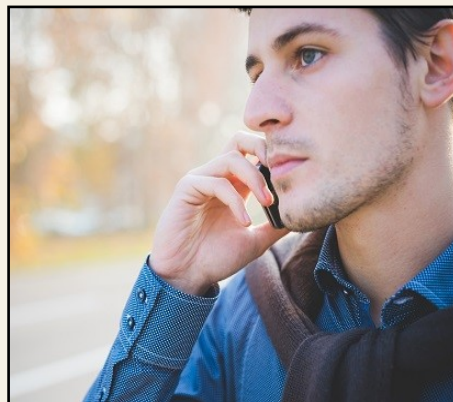
where to get medication, and numbers to call if they have a bleed. If your college student is not already regularly handling their own calls to the HTC for support, now is a good time to help them understand the importance of this responsibility. High schoolers should begin this process to prepare them for living away from home as well.

The start of school is an exciting and busy time. Make the new school year smoother by proactively managing and planning for issues that could arise with their bleeding disorders, and know that the HTC is here to help.

Our social workers Bryn Dunham and Whitney Tedeschi, our psychologist Emily Wheat, and our nursing staff can provide support and help answer questions.

Reach out if you need some support, at 303-724-0364. If you have questions on medications, safe storage, or supplies, you can also chat with our pharmacy at 303-724-0168.

Have a great school year!



## RECENT HEADLINES

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

**Study Finds Jivi May Protect Hemophilia A Patients Longer than Eloctate**

**UniQure Announces Positive Follow Up Data from Gene Therapy Studies**

**Bioverativ Presents Positive Data from Completed Phase 1/2 EXTEN-A Study**

**New Results Presented on Catalyst's MarZAA for Hemophilia A or B**

**Sangamo and Pfizer Announce Updated Results for Gene Therapy**

**Positive Data from Multiple Studies Shared about Hemlibra at ISTH Congress**

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](http://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/](http://www.facebook.com/ColoradoHTC/)

## UPCOMING EVENTS

### Mark Your Calendars:

**Aug 24:** NHF CO Unite for Bleeding Disorders Walk-Denver, CO

**Sept 2:** Clinic, Pharmacy, & Admin closed for Labor Day

**Sept 7:** RMHBDA Unite for Bleeding Disorders Walk—Billings, MT

**Sept 10:** Pediatric Stroke Parent Support Group

**Sept 14:** Backpacks & Bleeders Family Friendly Hike

**Sept 14:** RMHBDA United for Bleeding Disorders Walk—Kalispell, MT

**Sept 25-27:** Outreach Clinic—Grand Junction, CO

**Oct 3-5:** National Hemophilia Foundation Annual Conference—Anaheim, CA

**Oct 13:** Women's Wellness Retreat

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

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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>

PLEASE  
PLACE  
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HERE