

# The Clotting Connection

*A Newsletter for Families with Bleeding and Clotting Disorders*



University of Colorado  
Anschutz Medical Campus  
Hemophilia and Thrombosis Center

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

## MILE HIGH SUMMER CAMP 2018



Once again Mile High Summer Camp was a huge success and created some great new memories for kids and staff alike. Camp was held at the Easter Seals Camp in Empire, CO. Our leadership retreat for youth leaders ages 14-18 was on July 13-14 with the rest of the campers joining them July 15-20<sup>th</sup>.

This annual camp is designed for children ages 7-18 with bleeding disorders and gives them an opportunity to have fun, get to know others who face similar challenges, learn and play all within a safe environment. Many of our HTC staff are in attendance and are available for teaching and medical care.

Our campers were able to participate in a wide variety of fun activities, including kayaking, rock climbing, swimming, fishing, hiking, horseback riding, crafting and more! Our staff taught classes on everything from learning components of blood (and made "blood soup!") to self-infusion.

Over 80 kids participated and for many this is an opportunity to step outside their comfort zone, make new friends, and gain confidence. Camp is funded through NHF Colorado and our HTC, but it would not be possible without the support of donations to their program.



One of the favorite activities at camp is swimming. Photo: NHF Colorado



Spending time with friends in the shade. Photo: NHF Colorado

We encourage everyone to get involved to help support this amazing camp by participating in the Unite for Bleeding Disorders Walk on August 25<sup>th</sup> at Sloan's Lake Park. You can help by joining us, donating to a team of walkers, or donating directly to NHF Colorado. You can learn about the walk and NHF Colorado at [www.cohemo.org](http://www.cohemo.org).

We are excited to share pictures from camp and have included a few in our newsletter here and on page 3, but we have many more. You can find a slideshow of photos on our website as well as a link to the video that was shared at camp. To find them go to our website at: [www.medschool.ucdenver.edu/htc](http://www.medschool.ucdenver.edu/htc) and find the COMMUNITY tab at the top and click on CAMP. The slideshow is at the bottom of the page.

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Infusing at camp! (top) Kayaking (left) Photos: NHF Colorado

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



Go to [facebook.com/ColoradoHTC](https://facebook.com/ColoradoHTC)



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



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



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

# Walk With Us!

Sign up today for the **2018 Unite for Bleeding Disorders Walk!** Formerly called the NHF Walk for Hemophilia, the name change is designed 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 the 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 begins at 9 am. NHF Colorado will have a camp reunion booth with donuts, booths with food and giveaways, and more.

For details on the walk and to sign up or donate, go to [www.cohemo.org](http://www.cohemo.org), or you can go directly to the Unite for Bleeding Disorders Walk page at [www.uniteforbleedingdisorders.org](http://www.uniteforbleedingdisorders.org) and find the Denver Event. You can join our team from the HTC, start your own, or join friends by searching at the website. Our HTC team is CHILL FACTOR, and we'd love to see you there. Thank you for your generous support for those with bleeding disorders!



## Last Chance to Share Your Voice!

Our HTC is participating in the National HTC Patient Satisfaction Survey! We want to know how we're doing and if we need to find ways to improve care. 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](http://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](http://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 now have updated dates to share with our patients. 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](http://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**

**Oct 31-Nov 2, 2018: Billings, MT**







## RECENT HEADLINES

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

### **Pfizer Initiates Phase 3 Study for Hemophilia B Gene Therapy**

### **FDA Issues New Guidance for Advancing Gene Therapy**

### **Study Finds Hemophilia Patients Still at Risk for Cardiovascular Disease**

### **NHF Collaborating with ASH, ISTH, and WFH to Create Guidelines on VWD Care**

### **UniQure Enrolls First Patient in Phase 3 HOPE-B Study of AMT-061**

### **Catalyst Biosciences Shares Update on CB 2679 Program 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](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:**

**July 29:** NHF CO Denver Social Factor: Pool Party

**Aug 5:** NHF CO: VWD Education Program - Englewood, CO

**Aug 10-12:** RMHBDA Family Camp-Rollins, MT

**Aug 18:** Backpacks + Bleeders: ADA Compliant Hike

**Aug 20-21:** Backpacks + Bleeders: Annual 14er -Mt. Quandary

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

**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**

### **Hemophilia & Thrombosis Center**

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Pharmacy Main: 303-724-0168  
or toll free at 888-724-7427

Web page:  
<http://medschool.ucdenver.edu/htc>

PLEASE  
PLACE  
STAMP  
HERE