

# 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

## SIGN UP FOR MILE HIGH SUMMER CAMP



For over forty years, hundreds of kids with bleeding disorders and many of their siblings have attended Mile High Summer Camp. This opportunity allowed children who have rare bleeding disorders to connect, have fun, learn, and grow with others who experience similar circumstances. It was a hard choice in the past two years to shift camp to mostly virtual events, but NHF Colorado and the HTC are very excited to share that Mile High Summer Camp will be an in-person event in 2022!

This decision came after careful review of data and guidance from the CDC and other sources, as well as evaluating the current local restrictions and levels of COVID spread. At the moment, plans are in place to move forward with an in-person camp with a few adjustments and some health requirements.

To keep everyone as safe as we can, camp this year will have capacity restrictions, giving priority to participants diagnosed with a bleeding disorder. As the capacity allows, siblings could be admitted to camp as well.

The teen leadership weekend will be on **July 15-17, 2022 for teens** ages 15-17 only. Teen campers will not be attending at the Rocky Mountain Village location. Campers must be 15 on the first day of camp, and campers turning 18 during camp will not be permitted to attend. The teen weekend will be managed by Breckenridge Outdoor Education Center (BOEC) and COVID-19 vaccination is required.

The main Mile High Summer camp will be on **July 17-21, 2022** and will be limited to campers ages 7-14 years old. Campers must be at least age 7 by the first day of camp. This will be held at Easterseals Rocky Mountain Village and COVID-19 vaccination is also required to attend.

Our HTC staff will be attending, supporting, and teaching at both camps and are looking forward to seeing many of our patients enjoy this incredible opportunity. Cost of camp is provided by NHF Colorado and supported by the HTC. Campers are asked to pay a \$25 non-refundable registration fee.

[Registration is open](#) and the deadline is **June 13, 2022**. There are limitations on space, so sign up ASAP! Please review the registration checklist for details of all requirements before signing up, as you will need to upload multiple documents. There are no exceptions to the vaccination requirements for 2022 camp. For questions about camp, check out the [NHF Colorado camp page](#) or contact Hanna Beary at [hbeary@hemophilia.org](mailto:hbeary@hemophilia.org).



Mile High Camp is in person again! Our campers learn skills like self-infusing, enjoy fun adventures, and spend time having fun with friends. Details at [cohemo.org](http://cohemo.org). Pictures: NHF Colorado and HTC Staff 2019.

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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.cuanschutz.edu/hemophilia-thrombosis](https://medschool.cuanschutz.edu/hemophilia-thrombosis)



Email:

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

# GENETIC COUNSELING: AN INCREDIBLE RESOURCE



How do your genetics impact your family tree? Our genetic counselor can help!

Bleeding disorders such as hemophilia, von Willebrand disease, as well as other blood disorders can often be the result of a genetic condition.

Have you ever wondered:

- Is my blood disorder hereditary?
- How do I talk to my family about my condition?
- Should my family members be tested for my disorder?
- Will my kids be affected?
- How can genetic testing be useful?
- Are there resources available to families with my genetic condition?

These are just a few questions people with inherited bleeding disorders may ask. Our HTC provides genetic counseling as a part of our comprehensive care. Whether you are an established patient or new to our HTC, our genetic counseling team would like to meet with you for a virtual appointment as a part of your care.

Genetic counseling sessions are currently offered **only via telehealth** and last about 45-60 minutes. This gives you an opportunity to chat with your genetic counselor in the comfort of your own home or a private space.

During each session your genetic counselor will review your personal history, family history, and genetic details of your condition.

Genetic counseling sessions are offered at no cost to you! These consultations are included as a part of your care at the HTC. Your genetic counselor will explain any costs that could arise from various tests that may be available to you.

You can reach out to your genetic counselor as frequently as you need, though most often we'd like to meet with you when you join our HTC, and every few years to check-in.

This is an easy way for you to learn more about how genetics can impact you and your family as well as find resources to help.

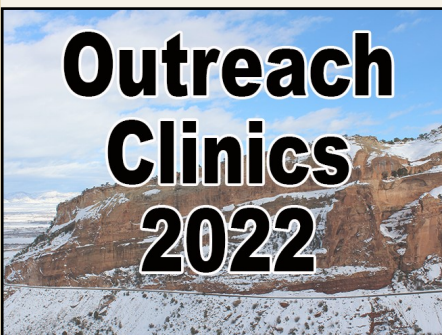
There are three ways for you get started with genetic counseling at the HTC:

1. Stop by the front desk when you are in the office to schedule an appointment.
2. Call to schedule an appointment at 303-724-0724.
3. If you are in our clinic for a yearly visit, you should receive a MyChart invite for genetic counseling after your visit. Just respond to schedule your appointment!



Our genetic counselor is Kaylee Dollerschell, MS, CGC. She is happy to help you learn more!

We have recently added a genetic counseling webpage to our main website. There you can find out more about genetic counseling and how we can help. [Click here](#) or scan this QR code to learn more:



## OUTREACH CLINICS SCHEDULED FOR 2022

Outreach Clinics are an opportunity for our patients who do not live close to our clinic in the Denver area to meet in person with our clinical staff closer to their homes.

These clinics were cancelled during the pandemic due to travel restrictions for our staff as well as safety concerns. After two years of stops and starts, the HTC has several scheduled Outreach Clinics for 2022!

Of course, these are subject to change, but we are hopeful that we will be able hold them this year. Each of our Outreach Clinics will be scheduled through our front desk, and our staff will be sending out letters to those who live in these locations as we approach each date. Some of these clinics we are not yet scheduling.

### Save the Date:

May 18-20, 2022: Grand Junction, Colorado

June 22-24, 2022: Billings, Montana

Sept 28-30, 2022: Missoula, Montana

Oct 26-27, 2022: Billings, Montana

If you have questions, please [contact our front desk](#), or see our [Outreach Clinic website page](#) for more information.

# PEDIATRIC STROKE PARENT SUPPORT GROUP

**Pediatric  
Stroke Parent  
Support Group**  
**VIRTUAL ZOOM  
Meeting**  
**Monday  
May 9, 2022  
6:30-7:30 pm**

Our May Pediatric Stroke Parent Support Group will be on **Monday, May 9, 2022 at 6:30 pm** on Zoom. This group invites parents of children who survived a stroke to meet with one another and our stroke team each month.

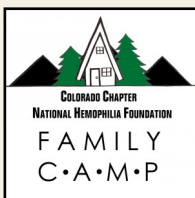
Normally we meet in person, but with the COVID-19 pandemic restrictions we are continuing to have these meetings on Zoom until things improve.

We are meeting on the second Monday of the month from 6:30 to 7:30 pm. Meetings are open to families of children of all ages and all types of stroke. Your child does not need to be seen at our stroke clinic to join our meetings. **This group will not meet during June, July, or August, so we encourage all to join us before the summer break.**

For more details, see our website, or follow us on Facebook. To join our meeting, please RSVP to [strokesupport@ucdenver.edu](mailto:strokesupport@ucdenver.edu) or call 303-724-8520.

## GREAT OPPORTUNITIES AHEAD

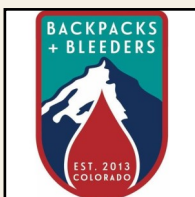
More activities are being planned as COVID restrictions ease and the numbers allow. We are excited to share some amazing opportunities coming up for our bleeding disorder patients and families. Please be aware that these are subject to change. These events likely will require abiding by COVID-19 safety protocols, so please check carefully what restrictions are in place.



### NHF Colorado Family Camp

**May 21-22, 2022 Registration Deadline: May 1, 2022**

This is designed for individuals, families, and children living with a bleeding disorder. The focus is on fun, relaxation, support, community, as well as education to help those with bleeding disorders learn to self-infuse. [Learn more at cohemo.org](http://cohemo.org) or contact Hanna Beary at [hbeary@hemophilia.org](mailto:hbeary@hemophilia.org).



### Backpacks + Bleeders: Fly Fishing Clinic

**June 25, 2022 Registration Deadline: June 6, 2022**

Backpacks + Bleeders is offering a fly-fishing clinic designed for anyone new to the sport, those needing practice, or those who want some one-on-one time with experts. 5280 Anglers will guide our group. Space limited to 25 people; registration is \$20 per person. Info at [cohemo.org](http://cohemo.org).



### Mile High Summer Camp – [Registration is now open!](#)

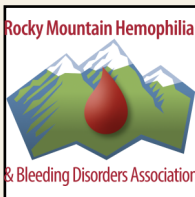
**Ages 15-17 only– Teen Leadership Weekend Registration Deadline: June 13, 2022**

**July 15-17, 2022** with Breckenridge Outdoor Education Center

**Ages 7-14 only– Mile High Summer Camp Registration Deadline: June 13, 2022**

**July 17-21, 2022** at Easterseals Rocky Mountain Village

[Learn more at cohemo.org](http://cohemo.org), or contact Hanna Beary at [hbeary@hemophilia.org](mailto:hbeary@hemophilia.org).



### RMHBDA Big Sky Family Camp—Flathead Methodist Camp, Rollins, MT

**August 12-14, 2022 Registration Deadline: July 1, 2022**

This is a camp for affected families living in Montana and Wyoming to attend a weekend of education, bonding and fun. Infusion classes will be offered by HTC staff. Learn more at [rmhbda.org](http://rmhbda.org) or contact Brad Benne at [brad@rmhbda.org](mailto:brad@rmhbda.org).



### Unite for Bleeding Disorders Walks

NHF Colorado: **August 13, 2022 at Sloan's Lake Park, Denver, CO**

RMHBDA: **September 10, 2022 at Billings Zoo, Billings, MT**

Mark your calendars now to join NHF Colorado or RMHBDA for their annual Unite for Bleeding Disorders Walks this year. This event raises funds to make events like camp, Education Days, and other activities throughout the year free to families. Learn more at [cohemo.org](http://cohemo.org) or [rmhbda.org](http://rmhbda.org) for more information and how to register.

## RECENT HEADLINES

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

**Bone Disorders More Common for Female Hemophilia Carriers and VWD Patients**

**Rebinyn Shows Positive Data in Canadian Real World Study**

**First US Patient Dosed in Freeline's Hemophilia B Gene Therapy Trial**

**Gene Therapy Roctavian Safely Raises FVIII Levels for Hemophilia A Patients in Trial**

**Sobi and Sanofi Announce Positive Data for Efanesoctocog Alfa to Treat Hemophilia A**

**Joint Damage Still Evident in Hemophilia A Patients with Milder Disease**

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. Go to [medschool.cuanschutz.edu/hemophilia-thrombosis/resources/newsroom](https://medschool.cuanschutz.edu/hemophilia-thrombosis/resources/newsroom) to read more. We also share news on our [Facebook](#) and [Twitter](#) accounts.

## UPCOMING EVENTS

### Mark Your Calendars:

**Please note. These dates may be tentative and subject to change. Please check appropriate websites for confirmation of events.**

**Apr 24-29:** NHF CO Education Empowerment Days-Spring Series—virtual and in-person

**Apr 29-May 1:** RMHBDA Education Weekend—Fairmount, MT— in-person

**May 7:** Backpacks + Bleeders: Garden of the Gods Climbing Event

**May 8-11:** WFH 2022 World Congress-Montreal, Canada

**May 9:** Pediatric Stroke Parent Support Group

**May 12:** NHF Get Cookin! A Women's Event

**May 19-22:** The Coalition for Hemophilia B Annual Symposium-Orlando, FL

**May 21-22:** NHF CO Family Camp-Allenspark, CO

**May 30:** Clinic, Pharmacy, & Admin offices closed for Memorial Day

**See more at our Events Page on our website:**

[medschool.cuanschutz.edu/hemophilia-thrombosis/resources/events-calendar](https://medschool.cuanschutz.edu/hemophilia-thrombosis/resources/events-calendar)

### Hemophilia & Thrombosis Center

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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:

[medschool.cuanschutz.edu/hemophilia-thrombosis](https://medschool.cuanschutz.edu/hemophilia-thrombosis)

PLEASE  
PLACE  
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