

# The Clotting Connection

A Newsletter for Families with Bleeding and Clotting Disorders

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University of Colorado  
Anschutz Medical Campus  
Hemophilia and Thrombosis Center

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



is BLEEDING DISORDERS  
awareness month

THE  
2017  
**RED TIE  
CHALLENGE**  
NHF | REDTIECHALLENGE.ORG



In 1986 President Ronald Reagan designated March as Hemophilia Awareness Month. In 1989 the first World Hemophilia Day was observed in April, starting a worldwide effort to spread awareness of the rare disorder. Since then, organizations such as the National Hemophilia Foundation, The Hemophilia Federation of America, and local efforts by bleeding disorder families have helped spread the word. Last year the US Department of Health and Human Services officially broadened this month of awareness to fully include those with all bleeding disorders, such as von Willebrand Disease and other rare clotting deficiencies.

With constant changes in insurance, and uncertainty about the amount of coverage that may or may not be available in coming years, many families have reached out to their congresspersons to let them know the important role insurance can play in the lives of those with bleeding disorders. Advocacy at both the national and local levels allows those who help provide funding for treatment of bleeding disorders to know of the deep impact insurance coverage can have in the lives of families with bleeding disorders.

The NHF last year began a “Red Tie Challenge” to encourage awareness. This campaign has been growing in the past year and many who visit and share on social media now include a red tie to indicate their support for those with bleeding disorders. We have a poster in our clinic and encourage families to snap and share a photo to help bring awareness to bleeding disorders.

Recent years have seen many changes in treatment—including problems like inhibitors, hopeful news in genetic research, and new medications—that it might be easy to forget the past. The HFA website has a wonderful timeline that shows the history of hemophilia and bleeding disorders, the ups and downs, achievements and problems that have been ongoing. We encourage you to help bring awareness by using the Red Tie Challenge, or sharing other media, such as information from the HFA, the NHF, your local chapter, or your own unique ideas to let others know about bleeding disorders. It is the efforts of many united people that make the difference.

## INTERACTIVE TIMELINE

*Honoring Our Past,  
Building Our Future.*

A historical journey of the bleeding disorders  
community over the last 60 years.



The HFA has a helpful timeline showing the history of bleeding disorders on their website.



NHF CO's Amy Board and Chris Bombardier talk bleeding disorder awareness, Easy Brews, Backpacks and Bleeders & Chris' trip to hike Mt. Everest on “Colorado and Company,” a local news show on NBC 9 News. Photo courtesy KUSA.

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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](https://medschool.ucdenver.edu/htc)



Email:

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

# OUTREACH CLINICS 2017



Pikes Peak from Garden of the Gods, Colorado Springs.  
Photo: Floyd O'Neil Photography, Manitou Springs, CO

Our HTC staff regularly visits areas in our region to allow patients to schedule their annual comprehensive visits at a closer location to their homes. These outreach clinics offer the hands on expertise of our doctors, nurses, physical therapists, researchers, pharmacists, and social worker to those who live in or near such places as Grand Junction and Colorado Springs, Colorado, and Billings, Montana.

The clinics in Montana and Grand Junction are usually a few days once a year, while our Colorado Springs clinic is held quarterly.

Our staff reach out to local patients, but if these clinics are more convenient to your location and you would like to know more, please contact Pat Casias or Audra LeBlanc, 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.

## Confirmed upcoming clinics:

**April 14, 2017: Colorado Springs, Colorado**

**June 19-21, 2017: Billings, Montana**

**Sept 27-29, 2017: Grand Junction, Colorado**

# UPCOMING OPPORTUNITIES



## Camp is coming! Save the dates for Mile High Summer Camp!

Our Leadership Pre-Camp Retreat (for ages 14-18) is on July 14-16, and the main camp (for ages 7-13, plus leadership kids) will be from July 16-21, 2017. More details are available online at [cohemo.org](http://cohemo.org).

Registration for summer camp will open soon, and registration forms will be available at Education Days! Check with NHF Colorado on their website at [cohemo.org](http://cohemo.org), or contact Sean Jeffrey, (720) 545-0755, [sjeffrey@hemophilia.org](mailto:sjeffrey@hemophilia.org).

**Leading X** is a week long back-country adventure offered for free to any adult in the bleeding disorders community. Learn canoeing, camping, and leadership skills; make great friends and connect with others in the bleeding disorders community. It's camp for adults! No experience necessary. Go to [gutmonkey.com](http://gutmonkey.com) for information and to apply for one of four upcoming expeditions in 2017!



## Stories Project 2!

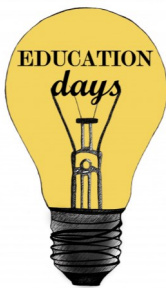
Do you want to share your story? Boys, men, fathers, and brothers who would like to share their journey about living with a bleeding disorder could be included in a new Stories Project. Males of all ages who have experiences with a bleeding disorder are invited to share their story in 1,000 words or less. You don't have to be a strong writer to share your story-this project comes with editors! For more information on how to participate in this opportunity, please contact our social worker, Audra LeBlanc at 303-724-0724.





## EDUCATION DAYS IS APRIL 14-15, 2017

Education Days is an annual program sponsored by NHF Colorado and our HTC to educate and inform our local community about various topics that affect the bleeding disorders community.



Education Days will be on April 14-15th, 2017 and held at the Denver Marriot South at Park Meadows, located at **10345 Park Meadows Dr, Lone Tree, CO 80124.**

Education Days is aimed at helping our patients and families navigate the wide variety of issues that can be challenging while living with a bleeding disorder. Experts from the HTC participate to help our families get up to speed on everything from healthcare, insurance, treatment options, and how to sign up for summer camp, to keeping joints healthy. Talk with our nurses about infusion, discuss inhibitors and healthcare with our staff, and get to know others in the community.

Some of the topics that will be covered at this year's Education Days are:

- Healthcare and Insurance Updates
- von Willebrand Disease
- How to identify bleeds and injuries
- Physician panel on upcoming treatment options
- How to keep joints healthy
- and much more!

Plus, you can sign up for our upcoming Summer Camp as well as the Hemophilia Walk.

**Registration is required**, with a small fee per person or per family. Find out more, register and join us at this helpful event by going to the NHF Colorado website here: **cohemo.org** then click on the **NEWS & EVENTS** tab and select the **PROGRAM & EVENTS CALENDAR**. We hope to see you there!



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/Designated Driver tickets include complimentary soda, and kids under 10 get in free! **Learn more and RSVP by heading to [cohemo.org](http://cohemo.org) and see their EVENTS page.**

**Tickets are on sale now!**

## Colorado Pediatric Stroke Program

**April 4, 2017  
6-7:30 pm**

**Brain Injury Alliance of Colorado  
1325 S. Colorado Blvd., Building B, Suite 300  
Dinner Provided  
RSVP by April 3**

## JOIN US! APRIL 4, 2017

Our Pediatric Stroke Parent Support Group meeting in April will be at the Brain Injury Alliance of Colorado on April 4, 2017 at 6 pm.

We will have guest speakers from Naropa University to discuss a teen wilderness experience for our patients. Dinner is provided but no childcare.

**RSVP by April 3rd** to Amanda Kenny at [strokesupport@childrenscolorado.org](mailto:strokesupport@childrenscolorado.org), or at 303-724-2677.

More info: [www.pedsstrokesupport.ucdenver.edu](http://www.pedsstrokesupport.ucdenver.edu)

## RECENT HEADLINES

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

**Aptevo Therapeutics Announces New IXINITY Supply Available May 2017**

**Record Number Attend Washington Days to Advocate for those with Bleeding Disorders**

**"My Life, Our Future" Repository Opens Data to Researchers**

**Data from Long Term Study of Alprolix to Treat Hemophilia B Published**

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:

**Apr 14:** Outreach Clinic-Colorado Springs, CO

**Apr 14-15:** Education Days-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

**June 16-18:** NHF CO Family Camp

**June 16-18:** RMHBDA Family Camp

**June 19-21:** Outreach Clinic-Billings, MT

**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](http://www.medschool.ucdenver.edu/htc) find **RESOURCES** tab, go to **EVENTS**

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Web page:

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

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