

# The Clotting Connection

A Newsletter for Families with Bleeding and Clotting Disorders

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Hemophilia and Thrombosis Center  
UNIVERSITY OF COLORADO ANSCHUTZ MEDICAL CAMPUS



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## NATIONAL PREPAREDNESS MONTH



Wildfires can affect both rural and urban communities. Photo: Ready.gov

September is National Preparedness Month, and a good time to ask, just how ready are you? While the Rocky Mountain West is unlikely to be affected directly by hurricanes or face massive earthquakes, there are plenty of significant disasters that can occur.

Drought and wildfires are serious issues facing our area, including metro areas. The Marshall fire in December of 2021 showed that it is not just mountain towns that face substantial threat from an out-of-control fire.

Over a thousand homes and multiple businesses were destroyed when a wind driven fire tore through Superior, Colorado, a suburb in metro Denver.

Wildfires not only destroy trees and homes, but often create burn scars that can quickly turn into mudslides and severe flooding during heavy rain. Even areas that have not been burned can experience catastrophic flood damage, such as parts of Yellowstone National Park in 2022 or the flooding in northern Colorado in 2013.

Our area faces powerful snowstorms in winter, damaging hail in spring and summer, and some areas are at risk of tornados throughout the year. It does not matter if you live in a city or a rural town; no area is immune to natural disaster, disruption of major services like electricity and water, and unexpected issues that can force you from your home. By the time a crisis occurs, it may be too late to get ready.

So, what can you do to prepare for an emergency? And do you know what to do to manage the care of someone with a bleeding disorder during such a crisis?

Websites and apps like those from [Ready.gov](https://www.ready.gov), [FEMA.gov](https://www.fema.gov) and [redcross.org](https://www.redcross.org) offer tips, guides, and resources to help prepare for natural disasters. Take some time to review the many resources at [Ready.gov](https://www.ready.gov) to help guide your preparations. Here are some of the basics to get you started thinking about how to be prepared.



Graphic: Ready.gov

### Have a Plan

The first thing to do is to sit down with your family and [make a plan](#). What are the most likely disasters you would face, and how do you respond to each one? Do you know what you would do if the power went out for an extended period of time? Do you know where to meet if cell coverage goes down and there is a major crisis? Go over scenarios and plan what you would do and make a list of things you may not already have ready to go.

[Continued on page 2]



Our area can have big snowstorms that may cause problems. Be prepared for all seasons. Check out ways to prepare at [Ready.gov](https://www.ready.gov). Photo: Ready.gov



Flooding in Colorado in 2013 caused significant damage, with more than 11,000 evacuated, and about \$2 billion in damages. Photo: State of Colorado

### INSIDE THIS ISSUE

- September is National Preparedness Month
- HTC Staff Supports CU Anschutz Block Party
- NHF Colorado Shares Fall Activity Schedule
- Upcoming Events
- News

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



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



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Website: Go to

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



Email:

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

[Continued from page 1]

Plan for emergencies that allow you to shelter in place, such as a snowstorm, or even a pandemic, and have plans in place if you needed to

evacuate, such as for a wildfire or flood. Be sure to include pets in your plans. Identify who would be responsible for various duties and how you would work together as a family. You may want to create a budget to set aside resources for emergencies.

### Know Your Area

People living in a hurricane zone will have different preparations from those far inland. The Mountain West is more likely to face snowstorms, floods, or wildfires, and should prepare accordingly. Analyze the potential problems in your area to mitigate the dangers and have firm plans in place to manage them. Check with your insurance company and find out what is covered before any disaster strikes. They may have suggestions for your local area to keep your property safer in emergencies, or may make recommendations to change your coverage.



Graphic: Ready.gov

### Have an Emergency Supply Kit

When facing a natural disaster, there may be only minutes before you need to leave. Having an emergency supply kit ready for every member of your family can make a huge difference in navigating a crisis.

**Emergency supply kits** should have at least a 3 day supply of basic items as it may take several days for emergency responders to begin bringing in supplies. An emergency supply kit doesn't have to be an expensive and overwhelming chore. It may feel like a lot to gather at once, especially with inflation, but you can build a kit slowly, starting with one thing at a time until you have collected all the items you need. Set a reminder on your phone or pick a date every six months to go through your supply kits and update the items that need replacing.

#### A basic list of items to include are:

- Water (one gallon per person per day for several days, for drinking and sanitation)
- Food (at least several days' supply of non-perishable food)
- Battery powered or hand crank radio
- Flashlight
- First aid kit
- Extra batteries
- Whistle (to signal for help if needed)



Graphic: Ready.gov

- Dust mask (for filtering contaminated air)
- Plastic sheeting and duct tape (for emergency shelter)
- Moist towelettes, hand sanitizer, garbage bags and plastic ties for personal sanitation
- Wrench or pliers (to turn off utilities if needed)
- Local maps
- Cell phone with extra chargers and back up battery/charging supplies or solar chargers

*These should be supplemented with important things you need, such as:*

- Medications, both prescription and non-prescription (such as pain relievers)
- Prescription eyeglasses/contact lens solution
- Infant formula, bottles, diapers, wipes, diaper rash ointment etc.
- Pet food and water for pets
- Cash (keep extra in a safe place and bring with you in the event of evacuation/emergency)
- Important documents, such as copies of insurance policies, identification, bank account records, saved electronically or in a waterproof container.
- Sleeping bags/blankets for each person
- Complete change of clothing, extra socks, sturdy shoes
- Feminine supplies and personal hygiene items (toothbrush, toothpaste, comb, toilet paper etc.)



Gather supplies for your emergency kits over time, and update them regularly. Photo: Ready.gov.

For those with bleeding disorders it is vitally important you always have emergency amounts of the medications and supplies you need on hand. Factor needs to be kept at specific temperatures. Be ready with coolers and ice packs to keep your supply safe during a crisis.

#### Additional recommendations for people with bleeding disorders:

- Wear medical alert bracelet or necklace
- Keep multiple ice packs in the freezer
- Keep as much medication and supplies on hand as your insurance will allow
- Take factor/supplies with you when you leave for an emergency
- Keep important phone numbers (HTC, local doctors, insurance) with you in your emergency kit

Our Pharmacy has emergency protocols in place to make sure we can supply our patients. In the event our HTC and pharmacy were to be compromised, we have national resources to provide these essential supplies. But if a significant disaster takes place, you must be ready to manage until things stabilize.

[continued on page 3]



## HTC HOSTS BOOTH AT CU ANSCHUTZ BLOCK PARTY

Our HTC joined NHF Colorado and dozens of other on-campus organizations on September 14, 2022 to bring awareness as well as share more information about what our center does. It was a powerful opportunity to connect with other professionals on campus as well as introduce the importance of treatment centers for bleeding disorder patients in our area. Thank you to all who participated!



Photos (left to right): Physical Therapist Nikki Clark with Program Director Angela Blue at the event. Pharmacy Tech Talia Garramone with Pharmacist Clair Kaiser running our booth. Physical Therapist Laura Singer-Fox, Hanna Beary from NHF Colorado, and Psychologist Emily Wheat sharing information about our center. All Photos: Emily Wheat.

## NHF COLORADO FALL EVENTS

NHF Colorado has several new opportunities coming up in the next few months. Go to [cohemo.org](https://cohemo.org) for details and to sign up.

**Sept 24-25: Women's Wellness Retreat– Glenwood Hot Springs**

**Oct 15: Backpacks + Bleeders: Bikes and Brews Adults Only Event**

**Nov 29: The Zoo and You! Denver Zoo Lights Party**

**Dec 8: Bleeders and Blades: A Men's Event—Axe Throwing at Primal Axe House**

[continued from page 2] Review the resources available to you, [including alternate HTCs](#) and pharmacies in different states in the event you must leave the area that supplies your medications. The NHF has recommendations featured on their website at [hemophilia.org](https://hemophilia.org) on ways you can prepare for an emergency at. Look for “[7 Ways You Can Prepare for Emergencies](#)” under their news tab or go to [stepsforliving.hemophilia.org](https://stepsforliving.hemophilia.org) and find Preparedness Tips under “[First Step \(Birth-8 years\)/Family Life/Emergency Preparedness.](#)”

### Communication is Key

Along with having a plan, preparing, and having an emergency kit, be ready to have several options to communicate during a crisis. Sometimes cell towers go down or are overburdened by demand. Have strategies in place with options for locations that could provide service, such as a friend in a nearby unaffected city, a public place like a coffee shop you know has internet or landlines, so you are able to share your location with friends and family

or contact emergency personnel. Keep important numbers in several locations in the event your phone is damaged or lost.

Take some time and review your resources and decide what you may need to do to keep your family safe in any emergency. Natural disasters, and local issues like disruptions to your local water supply or electricity could cause serious complications. Be prepared, know your options, and stay safe.



## RECENT HEADLINES

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

**FDA Grants Orphan Drug Status to SerpinPC for Hemophilia B**

**FDA Grants Priority Review of Efanesoctocog Alfa for Hemophilia A**

**Hemlibra Improves Joint Health in Younger Hemophilia A Patients in Trial**

**Recombinant von Willebrand Factor Prophylaxis May Reduce ABR for VWD Patients**

**FDA Approves Rebinyn for Routine Prophylaxis in Patients with Hemophilia B**

**Freeline Shares Positive Data from Gene Therapy Trial**

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.

Sign up to get this newsletter delivered directly to your email box each month! Just go to [eepurl.com/bnszoz](http://eepurl.com/bnszoz) and fill out the form!

## UPCOMING EVENTS

### Mark Your Calendars:

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

**Sept 24-25:** NHF CO Women's Wellness Retreat – Glenwood Hot Springs, CO

**Sept 28-30:** HTC Outreach Clinic – Missoula, MT

**Oct 15:** Backpacks + Bleeders: Bikes and Brews (Adults only event)

**Nov 4-6:** RMHBDA Women's Retreat – Chico Hot Springs, Pray, MT

**Nov 9-11:** HTC Outreach Clinic – Billings, MT **(Date Change)**

**Nov 24-25:** Clinic, Pharmacy, and Admin offices closed for Thanksgiving Holiday

**Nov 29:** The Zoo and You! Denver Zoo Lights Event

**Dec 8:** Bleeders + Blades: A Men's Event– Primal Axe House

**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

13199 E. Montview Blvd., Suite 100  
Aurora, CO 80045

Clinic Main: 303-724-0724

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)

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