

The Clotting Connection

A Newsletter for Families with Bleeding and Clotting Disorders

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ARE YOU PREPARED?



Did you know September is National Preparedness Month? From the recent hurricanes in Texas and Florida, to the wildfires burning all over the western part of the United States, it isn't hard to imagine that it is important to be prepared. It doesn't 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.

In Colorado and the Mountain West, fires, flooding, and severe weather such as blizzards and hail storms can cause significant damage and may force entire areas from work or home

without warning. While these kind of disasters might be rare, it's best to be prepared. 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 care of someone with a bleeding disorder during such a crisis?

Websites and apps like those from fema.gov, redcross.org, and ready.gov can help guide your preparations, but here are some of the basics to get you started thinking about how to be prepared.

Have a Plan

The first thing to do is to sit down with your family and make a plan. What are your escape routes in the event of emergencies? 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 for each. Be sure to include pets in your plans. Plan for both emergencies that allow you to shelter in place, such as a snowstorm, and have plans in place if you needed to evacuate, such as for a wildfire or flood. Identify who would be responsible for various duties and how you would work together as a family.



Check for Potential Problems in Your Area

People living in a hurricane zone may board up windows and secure loose items before the storm. They know simple objects can become deadly at hurricane force winds. But what if you live in Colorado, Montana, or Wyoming? A hurricane is unlikely to cause trouble in the Mountain West, but a snowstorm, flood, or wildfire may be a real threat. No matter where you live, become familiar with problems and natural disasters that could occur in your community. If you live in a forested area, what can you do to make it easier for firefighters to defend your home? Do you have trouble with losing electricity? Investing in your own generator might be an option. In areas prone to snow, do you have appropriate gear, shovels, tires? Analyze the potential problems in

[Continued on page 3]



INSIDE THIS ISSUE

- National Preparedness Month
- NHF CO Walk
- PEP
- Grand Junction Outreach
- HTC Awarded *My Life, Our Future Champion of the Year Award*
- News
- Events

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



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Go to twitter.com/HTCColorado



Website: Go to medschool.ucdenver.edu/htc



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HTC.Newsletter@ucdenver.edu

COLORADO WALK FOR HEMOPHILIA A SUCCESS

At the end of August the Colorado Chapter of the National Hemophilia Foundation sponsored the annual Walk for Hemophilia at Sloan's Lake Park. Each year our HTC has a team and many members of our staff contribute and participate. This year the walk drew 429 registered walkers, 37 teams, and raised \$80,000!



Walkers showing off the new "Why I Walk" bibs (above). [Photo: NHF CO]

were "Why I Walk" bibs and team tents for our top teams. Attendees who raised money received various prizes, but the support for patients with bleeding disorders is priceless.

The NHF Colorado Chapter can still use your help to meet their goal. If you were unable to attend, consider donating to the Colorado Walk for Hemophilia by going to their donor page at www.hemophiliawalk.donordrive.com, click on Find a Walk, and locate the Denver Walk page. Plan ahead, next year's walk will be on Aug 25, 2018!

Your donation makes a huge difference. All proceeds of the walk go to amazing programs, like Mile High Summer Camp, educational and patient support programs. You are welcome to donate to any team or to the overall walk. More pictures from the walk are available on our HTC Facebook page as well as the NHF Colorado Facebook page. Thanks for your support!

Our HTC team "Chill Factor" nearly doubled our fundraising goal, helped out by a last minute anonymous donation of \$1000! We thank all who donated and participated this year, both on our team Chill Factor, and the other teams and individuals who supported the event.

New at the walk this year, NHF Colorado and several sponsors provided pastries & breakfast burritos, which were welcomed and enjoyed by many. Also new this year



Some our HTC staff attending the walk (above). Walkers supporting their teams (right) [Photos: Merilee Ashton]



Parents Empowering Parents (PEP) is a non-profit program providing support

for parents of children with bleeding disorders.

This peer-to-peer program works with professionals and other parents to train and improve skills of parents to be more effective in raising children with bleeding disorders.

PEP 2017 will be on **October 20-22, 2017** at the Double Tree Hotel in Denver.

A flier on this program is available at our website by going to www.medschool.ucdenver.edu/htc find the **COMMUNITY** tab and click on **PEP**.

This program is free to attend, including hotel stay, meals, and day care, so spaces fill up quickly.

To RSVP or for more information, please contact Audra LeBlanc 303-724-6163 or audra.leblanc@ucdenver.edu.

GRAND JUNCTION OUTREACH

Our Grand Junction Outreach Clinic will be held on **September 27-29, 2017** at the Western Colorado Pediatric Associates location. Local patients should have been contacted and scheduled, but more information is available at our website. Go to www.medschool.ucdenver.edu/htc and click on the **CLINIC** tab, and find our **OUTREACH** tab.

As a part of this clinic, NHF Colorado provides dinner along with learning and gathering opportunities for attendees.

There will be an informal dinner program on Wednesday, Sept 27th, as well as an educational dinner program on Thursday, Sept 28th.

If you are participating in these clinics, please go to cohemo.org and click on their Program & Events Calendar for details and to RSVP for these events.

If you have questions about the Grand Junction Outreach Clinic, please contact Pat Casias at 303-724-1325 or Audra LeBlanc at 303-724-6163

your area and mitigate the dangers or 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.

Have an Emergency Supply Kit

When facing a natural disaster, there are often only minutes for people to leave their homes behind. Having an emergency supply kit ready for every member of your family may make a huge difference in how you manage during the crisis. Go to websites, such as redcross.org or ready.gov and begin to collect the items you will need for at least a 3 day supply. During a crisis, it may take 3 days or more for emergency responders to begin bringing in supplies. Emergency kits should include clothes, food, water and other items like batteries that will need to be replaced on a regular basis, particularly clothing for children. Set a reminder, or choose a specific date once or twice a year where you gather as a family and replace these items. Plan now to slowly gather the supplies you might need in the event you needed to flee your home. Supply kits are essential but the costs can add up. Planning in advance to gather these items over time makes it easier to manage.

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. Having a medical wristband, medical records and insurance information, as well as emergency phone numbers to doctors and pharmacists are essential during a crisis.



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. Review the resources available to you, including alternate HTC's 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 on ways you can prepare for an emergency at. Look for "7 Ways You Can Prepare for Emergencies" under their news tab.

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, or you may be out of range. 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 this month, 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.

HTC AWARDED "MY LIFE, OUR FUTURE CHAMPION OF THE YEAR"



The University of Colorado Hemophilia and Thrombosis Center was selected for recognition as a *My Life, Our Future Champion of the Year* at the 2017 NHF Annual Meeting that was held in Chicago last month. The award recognizes our HTC as one that has been instrumental in the successful implementation of the My Life, Our Future program.

The committee issuing this recognition noted that our HTC staff is "professional and enthusiastic, taking a lead role in supporting and enrolling participants, and displaying a passion to further science and hemophilia care." We congratulate our research staff, nursing staff and medical staff for their efforts in making a difference in the support of the My Life, Our Future program. Our team would

like to express a big THANK YOU to all of our patients and families who participated. This recognition would not have been possible without your support and contribution to this project.

RECENT HEADLINES

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

New Section of Memorial Dedicated to People with Hemophilia who Died of AIDS

"How do you thank someone for saving your life?"

Alynlam's Hemophilia Program on Hold Following Patient Death

Catalyst Biosciences Announces Positive Clinical Data for Hemophilia B Trial

Bioverativ and Bicycle Join to Develop Drugs for Hemophilia

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 then find the **RESOURCES** tab, and go to the **NEWSROOM** page. Find other stories at our Facebook page at www.facebook.com/ColoradoHTC/

UPCOMING EVENTS

Mark Your Calendars:

Sept 23: RMHBDA Walk for Hemophilia—Kalispell, MT [date change]

Sept 27-29: Outreach Clinic-Grand Junction, CO

Sept 27: NHF CO Mix & Mingle Dinner—Grand Junction

Sept 28: NHF CO Educational Dinner—Grand Junction

Oct 20-22: PEP (Parents Empowering Parents) Program—Denver [date change]

Nov 3-5: RMHBDA Women's Retreat—Chico Hot Springs

Nov 4: Self-Infusion Clinic

Nov 23-24: Clinic, Pharmacy & Admin closed for Thanksgiving Holiday

Dec 2: NHF CO Western Slope Holiday Party-Grand Junction

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

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