

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



Affiliated with
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PREVENTING AND TREATING NOSEBLEEDS

Winter is upon us and with that comes cold, and often dry conditions that lead to chapped hands and increased likelihood of nosebleeds. In the Denver area and other parts of the rocky mountain west, the weather has been particularly dry this fall. The conditions are right to make nosebleeds worse. Of course, nosebleeds can happen at any time of year, and are particularly common for those with bleeding disorders.

What do you know about nosebleeds and how to prevent and treat them? Nosebleeds can range from a rare, and minor inconvenience to a serious event requiring medical attention. In fact, recurring or difficult to stop nosebleeds are often a reason people may be referred to a hematologist and get a bleeding disorder diagnosis.

Some people don't have nosebleeds frequently, but others do, even without bleeding disorders. Nosebleeds can be caused by many different factors. Some of these include the obvious, like a trauma or injury to the nose, nose picking, or forceful nose blowing. But even dry air, especially in winter, or hot air like in hot tubs or saunas and steam rooms can make a nosebleed more likely. Many of our patients have nosebleeds more often because of a genetic bleeding disorder, but others can have sensitivity to it because of allergies, medications or other medical conditions.



Most nosebleeds can be managed at home, but any time you have extended period of time where the bleeding will not stop with pressure or other remedies, you may need to contact your doctor. You should call for any nosebleed lasting longer than 20 minutes, or that is shorter but happening several times a day. If you are vomiting blood, or have signs of anemia, you should also contact us at the HTC right away.

It can be scary for an adult to have a long-lasting nosebleed, but for kids it can be particularly upsetting. Whether it is a child or adult, here are a few tips to help with a nosebleed:

- Gently blow out any mucus or unstable clots through your nose
- Pinch the nostrils and lean slightly forward holding pressure for a minimum of 10 minutes, but not more than 20 minutes at a time
- Use a nose clamp to keep pressure on the nose- but only for 10 minutes at a time
- Set a timer while you are holding pressure
- Find ways to distract yourself or your child while applying pressure (watch a movie, listen to music etc.)
- Try to protect your hands, eyes, and mouth from coming in contact with blood or other body fluids
- Apply ice on the nose (using a flexible ice pack with something to protect direct contact with the skin)
- Time the nosebleed and keep track of it so you can share this with your provider
- Call your HTC and let them know about the extent of the nosebleed and for guidance

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Dealing with severe nosebleeds can be challenging and scary. Our HTC staff can help!

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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://www.facebook.com/ColoradoHTC)



Go to twitter.com/HTCColorado



Website: Go to

medschool.cuanschutz.edu/hemophilia-thrombosis



Email:

HTC.Newsletter@ucdenver.edu

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After a nosebleed, rest and take things a little easy (keep cool, no swimming or outdoor sports for a few hours). Try to avoid hot foods the day of the nosebleed. Avoid picking your nose or encourage a child who gets frequent nosebleeds not to pick their nose. Keep fingernails short to avoid scratching inside the nose too.

Some other great suggestions if you regularly are dealing with nosebleeds:

- Teach your kids to know what to do when they have a nosebleed
- Keep supplies readily available so you can easily respond
- Carry nose clamps in backpacks or the car (remember to only use a clamp for 10 minutes at a time)
- Carry a dark or red washcloth (to help disguise blood from the child)
- When traveling, bring your supplies and include, plastic bags, a dark towel, dark pillowcase, and wipes

Our clinic and pharmacy are well versed in managing nosebleeds, especially problematic or long-lasting ones. There are a number of things that they may suggest to help prevent nosebleeds. Using a cool mist humidifier can help combat the dry air and reduce nosebleeds. There are some non-prescription nasal sprays that can be helpful, but should be used under medical supervision. Over the counter antihistamine medications can alleviate allergy symptoms and help in preventing nosebleeds. Simple saline solutions as well as nose moisturizing gels can make a big difference in keeping noses healthy. Other treatments that require a prescription can be prescribed from our clinic and provide much needed relief.

In fact, our HTC pharmacy has specialized compounded

nasal preparations that we offer to patients. Our pharmacy team worked with our clinical providers and other HTC's to come up with a formula for Tranexamic Acid 5% nasal gel and amniocaproic acid 100mg/mL spray that can uniquely help bleeding disorder patients. Regis School of Pharmacy helped us to conduct stability and sterility studies on these compounds, which are available through our HTC pharmacy by prescription only. Your HTC team can help you find the right solutions to help keep nosebleeds under control.

Patients who are dealing with chronic, or occasional but long-lasting nosebleeds should [contact the HTC](#) about the frequency of these bleeds, and work with us to find ways to keep them at a minimum, whether through preventative care or treatment. If a patient is considering cauterizing the nose, our HTC staff can help provide support, treatment and recommendations. **All bleeds should be reported to the HTC** so they can be included in your medical record. This helps providers see patterns and personalize the care for each individual patient. Please reach out to our clinic or pharmacy if you have questions about nosebleeds and how we can help!

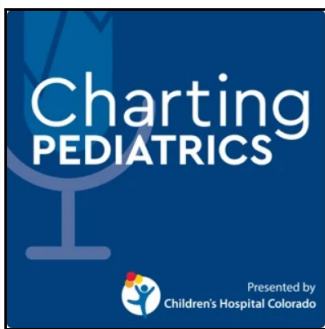


Above, Paul Limberis, our Pharmacy Director, compounding nasal preparations for a patient.



Right, our pharmacy's specialized nasal preparations. Contact us if you need support for frequent nosebleeds.

WOMEN AND BLEEDING DISORDERS SHARED IN PODCAST



Women with bleeding disorders face significant issues that are often overlooked but can impact their daily lives. Dr. Jenna Moyer from our HTC helps lead the "Spots and Dots" clinic along with Dr. Huguélet from Children's Hospital. Others on our HTC staff also support and treat women through this clinic and find ways to help them better manage their health.

Dr. Moyer and Dr. Huguélet were recently featured on the podcast "Charting Pediatrics" to share with providers what they do to support women who face significant bleeding. While targeted at providers, the podcast is packed with helpful and

hopeful information. They discuss causes and treatments for heavy menstrual bleeding, and how a provider or a patient can get help. It's worth a listen.

Check it out at [Apple Podcasts](#), [Spotify](#), or wherever you get podcasts. Look for: Charting Pediatrics, Season 5: Episode 13.

Congratulations to Dr. Moyer and Dr. Huguélet for sharing this important information!



Dr. Jenna Moyer was featured during a recent podcast discussing women's bleeding.

HTC CHILL FACTOR TEAM EARNS TOP SPOT IN THE US

Market Group 1: Los Angeles, Ortho Walkers : Team Captain, Doris Quon, Orthopaedic Institute for Children Hemophilia Program
Market Group 2: Colorado Chapter, Chill Factor: Team Captain, Kimberly Hurdstrom, University of Colorado Hemophilia & Thrombosis Center
Market Group 3: Indiana Chapter, Indiana Hemophilia & Thrombosis Center: Team Captain, Chris Roberson, Indiana Hemophilia & Thrombosis Center
Market Group 4: Tri-State Bleeding Disorders Chapter, Team Hemophilia Treatment Center: Team Captain, Lisa Littner, Cincinnati Children's Hospital
Market Group 5: North Dakota Chapter, Team Sanford's Stop the Bleed Team: Team Captain, Kim Rasmussen, North Dakota Hemostasis and Thrombosis Treatment Center

**2021 Top
HTC
Fundraising
TEAMS**



Congratulations to our HTC Team “Chill Factor” who earned not only the top fundraiser for our area, but the top HTC fundraising team in the country! Our HTC team loves to connect with patients and the Unite for Bleeding Disorders Walk is a fun way to support the bleeding disorders community. Kim Hurdstrom was our team leader and did a fabulous job coordinating our group! Our team was able to raise over \$4000 to support bleeding disorders in Colorado!

Our Chill Factor team was honored in an online Unite Rally Awards ceremony in early December and awarded a \$1000 scholarship to help send a staff member to the 2022

Bleeding Disorders Conference. More importantly, the money earned by our team can help support our patients directly through the NHF Colorado chapter and their educational and community events. We are thrilled that we were able to work together to get this done, and for the good it does for our patients.

Congratulations to all who participated and supported our Chill Factor team! Thank you for your donations, no matter which team you contributed to! We look forward to 2022 with a hope for future events that can provide connection and learning for our patients through these great programs.

PEDIATRIC STROKE PARENT SUPPORT GROUP

**Pediatric
Stroke Parent
Support Group**
**VIRTUAL ZOOM
Meeting**
**Monday
Jan 10, 2022
6:30-7:30 pm**

Our Pediatric Stroke Parent Support Group will be on **Monday, January 10, 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. We hope you can join us to start off the new year!

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 have changed the date of our meetings to 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.

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

HOLIDAY CLOSURES & SHIPPING DEADLINES

Our HTC clinic, pharmacy, and administrative offices will be closed for several upcoming holidays. Please be aware of the following closure dates and shipping dates to make sure you are able to get your factor or other medical care when needed.



Clinic, Pharmacy, and Offices Closed on the following dates:

Thurs-Fri Dec. 23-24, 2021
Friday Dec. 31, 2021
Monday Jan. 17, 2022

Christmas Holiday
New Year's Eve
Martin Luther King Jr. Day

Last Date to ship before holidays:

Before Christmas
Before New Year's
Before MLK Day

Tues. Dec. 21, 2021
Wed. Dec. 29, 2021
Thurs. Jan. 13, 2022

If you need to contact our clinic or pharmacy during any holiday, [please see our contact page for details](#).

To obtain emergency factor from the pharmacy, contact the pharmacy directly at 303-724-0168.

RECENT HEADLINES

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

Update for Hemophilia B Gene Therapy Trial from uniQure and CSL Behring

Hemophilia A Patient Develops Complications in SIG-001 Clinical Trial

Data Analysis Sheds Light on Bleeding Patterns of Young VWD Patients

Data Finds Fitusiran Reduced Bleeds in Patients with Hemophilia A and B

FDA Puts Hold on Gene Therapy SB-525 Phase 3 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 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.

Dec 23-24: Clinic, Pharmacy, and Admin offices closed for Christmas Holiday

Dec 31: Clinic, Pharmacy, and Admin offices closed for New Year's Eve.

Jan 10: Pediatric Stroke Parent Support Group

Jan 16: Backpacks + Bleeders: Indoor Rock Climbing at Ubergripping– Denver.

Jan 17: Clinic, Pharmacy, and Admin offices closed for Martin Luther King Jr. Day

Jan 22: NHF CO Teen Leadership at Family Sports Center at South Suburban in Littleton

See more at our Events Page on our website: medschool.cuanschutz.edu/hemophilia-thrombosis/resources/events-calendar

Hemophilia & Thrombosis Center

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

Web page:
medschool.cuanschutz.edu/hemophilia-thrombosis

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