

The Clotting Connection

A Newsletter for Families with Bleeding and Clotting Disorders

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UNIVERSITY OF COLORADO ANSCHUTZ MEDICAL CAMPUS



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HOLIDAY TRAVEL TIPS



The holiday season is upon us and with it many people are making plans to travel to visit family and friends. Over the past several years the various restrictions and adjustments to COVID made travel rules confusing at best, and downright chaotic at worst. As things begin to move back to normal, heading out on a vacation is something more and more people are feeling comfortable doing. Airports, trains, cruises, and roads all feel a whole lot busier, even if many are just now catching up to 2019 levels.

If you are planning a trip this holiday season, or any time of the year, a few tips and tricks can make travel easier. For those who are managing a bleeding disorder, our HTC has a few extra ideas to help. While we can't help with predicting the weather or avoiding a traffic jam, we are happy to provide some support for our HTC families!

What To Expect. What is New?

Most places in the United States do not have any restrictions to travel or requirements for vaccination cards or masks to travel anymore. However, you will see a few people on planes, trains, or in large public gatherings wearing masks. Many do this to help protect others if they have a cold or cough, and some may be immunocompromised or have someone in their family with a serious illness. But it is very unlikely that you will come across restrictions where a mask, or proof of vaccination is required. If you are traveling to a foreign country, you should check their rules and restrictions. Wherever you are heading, it is very likely you will face full airplanes, and busy highways for parts of your journey. If you are concerned about being around a lot of people and potential germs, consider flying on less busy days, such as Tuesdays or Wednesdays, or early in the morning as those flights (or at least the airports) are generally less crowded. Talk with your doctor about getting the flu vaccine and keeping up on any other vaccinations you may need.

If you are driving, it is likely you will find areas where traffic is quite busy, but depending on your destination, it may be the weather you have concerns about. As we head into winter, you should make sure you have appropriate tires, and be aware that some places, such as Colorado, have new traction laws requiring snow or AWD tires during the winter on certain roads. As you prepare your driving itinerary, make sure you know what the rules are so you don't get stuck, or fined in the event of a slippery crash. It is important to make sure your car is equipped for the drive, no matter what road you head out on. That may include getting a tune up, changing



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Wherever you travel for the holidays, be prepared! Our HTC pharmacy can help provide travel documents for your medications, tips on safety and much more.

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



Go to facebook.com/ColoradoHTC



Go to twitter.com/HTCColorado



Website: Go to

medschool.cuanschutz.edu/hemophilia-thrombosis



Email:

HTC.Newsletter@ucdenver.edu

RESEARCHER KRISTI NORTON SHARES A GOODBYE

For more than a decade, if you worked with our research team, you likely had the chance to meet with Kristi Norton. Kristi was one of our Research Program Managers and has been a dynamic part of our research team. Kristi has accepted a new opportunity as a site manager at a private research organization.

Kristi is creative, hard working, personable, and kind. She helped organize many of our staff parties and gatherings, found ways to support co-workers who were facing surgeries or other problems, and she loved to decorate and share joy with all around her. She will be greatly missed at our HTC, but we are excited for this new step in her life. Kristi shared a few thoughts as she left, and we are happy to be able pass that along here. Best of luck to you Kristi!

Dear HTC Staff and Patients,

I cannot believe that after 11 years here (16 total with the University of Colorado) I will be leaving the HTC! I will miss working with my team of EXTRAORDINARY researchers—some of the most brilliant minds of our future! I will also dearly miss you, our patients!

I have had the pleasure of working with some families of young ones over the years and they will always hold a special place in my heart. Words cannot describe how much watching your little ones grow up has meant to me. I have also had a chance to partner with many adults in various studies using new factor, new subcutaneous injectables, and studying pain. I have truly enjoyed getting to work with you, laughing with you, and getting to know you!

I will miss the activities of the NBDF, such as the Unite Walk and Zoo Lights. The family incorporation into the community has always been something I have loved to be involved in. It has been a very difficult decision to leave, and I hope that you all know that I have loved getting to know you. Hopefully, we shared a laugh and a smile while we were together, and I sure will miss this community!

I will be leaving the HTC (and University of Colorado) to manage a site for a private research organization. I am excited to learn a different side of research and to teach and train new and less experienced coordinators. This was a really hard decision and I hope that all of you know that you have touched my heart, and I will take you with me as I grow. Thank you for allowing me to share in one small piece of your care and research over the years. You will truly be missed!

With love,

Kristi Norton, Research Co-Manager, HTC



Kristi enjoying the great outdoors with her innate sense of adventure. Photo: Kristi Norton

UPCOMING EVENTS & HOLIDAY CLOSURES



Our clinic, pharmacy, and admin offices will be closed for several upcoming holidays. Please plan ahead and contact us if you have medical or pharmacy needs before any closures. Clinic, Pharmacy, and Admin Offices are closed on the following dates:

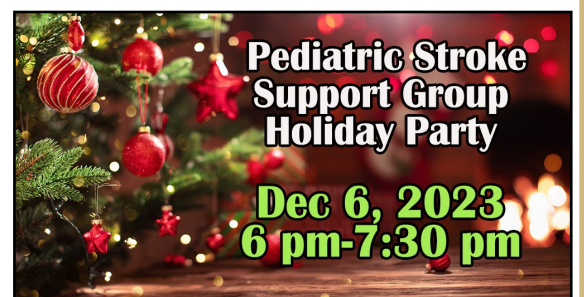
Thurs.-Fri. Nov 23-24, 2023: Thanksgiving Holiday
Mon.-Tue. Dec 25-26, 2023: Christmas Holiday
Mon. Jan 1, 2024: New Year's Day

See our [holiday closure calendar on our website contact page](#). Our clinic will be open between Dec 27-29, 2023 but with a modified schedule; availability and services may be limited. Please see our [pharmacy shipping page](#) for an updated schedule of holiday shipping deadlines.

Our [Pediatric Stroke Parent Support Group](#) will be hosting an in-person Holiday Party to celebrate the season on **December 6, 2023 at 6 pm** here at the HTC. Our staff will let families into the building.

Dinner will be from 6-6:30 pm, followed by a presentation for parents/adults by Dr. Tim Bernard from 6:30-7:30 pm. During the presentation, the kids will get to decorate cookies and play trivia games with our team.

To attend, please RSVP by Nov 30th to strokesupport@ucdenver.edu. Please let us know the number of adults and children attending, and if there are any food allergies. We look forward to celebrating with you!





your oil, topping off your windshield wiper fluid with winter grade windshield fluid, or even getting new wiper blades. Mechanic and tire shops can get very busy right before a big holiday, so try and set an appointment earlier to avoid a long wait. Pack the car up carefully, making sure you have a good window scraper, extra gloves, warm clothing,

blankets, and extra food and water, so you are ready if you end up in a long traffic jam. It's also a good idea to have detailed paper maps with you, in case you are forced to re-route or you lose access to digital maps or GPS services.

Meet with your HTC

Preparing for the journey is step one, but for those with bleeding disorders or medical conditions, the planning doesn't end there. Our team at the HTC is happy to provide support for our patients who are traveling at any time. Those with bleeding disorders will need to bring their medication with them, and whatever way you travel, you may need some guidance on how best to safely do that. We provide travel letters with TSA travel guidelines for medications, bleeding alert cards, and luggage tags for traveling with medication. The travel letter allows you to pass through security with specialized medications, which you should always take as a carry-on. Plan extra time to go through security, as each TSA location handles things slightly differently. Our pharmacy can answer any questions about how to handle issues that may come up going through security. If you need extra factor or medication for a long trip, our pharmacy can also provide support.

Know Your Options

No matter where you are heading, it is important to know what your resources are once you arrive. If you have factor or other medications that need to be refrigerated, do you know if the place you are staying has a fridge available? If you need help with infusing, have problems, or need medication while you are away, do you know how to find the closest HTC? There is a directory of HTCs in the United States at the CDC's website [cdc.gov](https://www.cdc.gov). You will need to navigate to their **search bar and enter "Hemophilia Treatment Centers"** to find the list of US HTCs.

If you are traveling internationally, do you know where the closest treatment center is? Our HTC can provide suggestions on what to do if you need medical support in a foreign country. You can also go to [wfh.org](https://www.wfh.org) and click on their **Support tab** to locate their **Find Local Support** page which has a "Find a Treatment Centre" page, as well as other international travel tips.

Know your Insurance Coverage

Insurance is challenging enough when you know you are covered at home, but while traveling it is important to know what your benefits are and what is available to you outside

your home state. We suggest contacting your insurance company directly about your travel plans and how to find resources that are covered by your plan if you need them. Many insurance plans shift and change coverages without clearly explaining some of those details. Check with your insurance provider to know where to go, and what you will need if you must seek medical care while away from home.

Other Travel Tips

Even if you aren't going very far, or staying at home for the holidays, make sure you keep tabs on how much medication you have on hand. We have several holiday closures coming up in the next few months, and winter weather can also cause delays in delivery. Be sure to check with our pharmacy if you need to place an order close to the holidays to verify you can get your medications on time.

- When flying you should ALWAYS bring factor and other medications with you as a carry-on. Airlines often limit you to one carry-on, or one personal item. But it is important to



- note that this DOES NOT apply to medical supplies. Check with your airline about their policies to avoid problems. At TSA or security checkpoints, notify a security office that you have a bleeding disorder and are carrying your medication and supplies with you.
- Always bring a travel letter explaining your condition and your medications. If you are traveling to a foreign country, it is best to bring the letter in English and translated into the language of your destination.
- Be aware of the temperature at which your medication must be stored. If it requires refrigeration, keep it in a cooler with ice packs. Make sure all your medications are labeled. Pack a travel sharps container for any needle disposal and never leave factor or liquid medications in a hot or freezing car.
- Wear medical identification. While it is important to have paper documentation, having some kind of medical ID bracelet can be critical to your care in the event of an emergency.
- Know your resources and alternate options for care. Whether it's picking a hotel that has a fridge for your medication, requesting special seating, wheelchair assistance at the airport, or knowing where the local HTC is located, being prepared can make the trip a lot easier.

Please call our pharmacy, at **303-724-0168** or toll free at **888-724-7427**, about traveling with medications and what you may need, and if you have other questions about travel, our nurses are also able to provide support and assistance.

Check out our [holiday closure schedule](#) and know how to contact us if you happen to need help during a holiday or on a weekend, and safe travels!

RECENT HEADLINES

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

Novo Nordisk and Genevant Join Forces to Develop Gene-editing Treatment for Hemophilia A

Study Looks at Therapies for Women with VWD and Heavy Menstrual Bleeding

Over Half of Hemophilia Patients Hide Symptoms & Don't Share Negative Impacts

Study Shows Hemophilia Survival Rate Disparities

FDA Grants Orphan Drug Status to Baudax Bio's TI-168 for Hemophilia A w/Inhibitors

Colorado Man Shares Positive Results from Gene Therapy Treatment

We maintain a newsroom page at our website with a list of news articles that 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.

Sign up to get this newsletter delivered directly to your email box each month! Just go to eepurl.com/bnszoz or scan the QR code and fill out the form!



QR Code to Subscribe!

UPCOMING EVENTS

Mark Your Calendars:

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

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

Nov 28: NBDF Colorado Holiday Party

Dec 6: Pediatric Stroke Parent Support Group In-Person Holiday Party

Dec 11: NBDF Colorado Annual Stakeholder Meeting

Dec 25-26: Clinic, Pharmacy, and Admin offices closed for Christmas Holiday

Jan 1, 2024: Clinic, Pharmacy, and Admin offices closed for New Year's Day

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

ME-WE-HTC We create hope.

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Pharmacy Main: 303-724-0168

or toll free at 888-724-7427

Web page:

medschool.cuanschutz.edu/hemophilia-thrombosis

PLEASE
PLACE
STAMP
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