

# The Clotting Connection

*A Newsletter for Families with Bleeding and Clotting Disorders*

November 2016  
Volume 6, Issue 11



University of Colorado  
Anschutz Medical Campus  
Hemophilia and Thrombosis Center

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

## TRAVEL TIPS FOR THE HOLIDAYS



Traveling for the holidays? Whether you are headed on a short road trip or flying to a different country, traveling with a bleeding disorder can require extra preparation to make things go smoothly.

Many of the problems that might come up can be avoided or at least made easier by knowing your options and planning ahead. Our HTC clinic and

pharmacy staff are prepared to help you make travel plans with a bleeding disorder easier. Even if you're staying in town, planning ahead can help you minimize holiday complications.

### Meet With Your HTC

At every comprehensive visit we provide an updated travel letter with TSA travel guidelines for medications, bleeding alert cards, and luggage tags for travel. If you need any of these between your comprehensive visits, please contact Ali in our pharmacy and we will be happy to provide new ones. Contact us if you have questions or need help with a treatment plan that works best for your trip. Our staff can offer guidance to know how much medication you should bring, or when you should take factor before you head out. Set up a visit or give us a call. We can help answer your questions about dosing, your prophylaxis schedule or how to pack and store medications you may need to bring.

### Know Your Options

Are you traveling to a different country, a different state? What are your resources and needs once you arrive or on the way? If you need help infusing, or need to get factor while at your destination, it is worth finding the closest HTC and working with our pharmacy and clinic to make sure you have the care you need. Going for an extended period of time? Speak to our pharmacy about the option of shipping to your location. Depending on your destination, it may be easier for us to ship your supplies to you rather than you trying to bring it all on a plane.



### Ensure Your Insurance

If you're traveling to a foreign country, or even another state, you may need to check directly with your health insurance company to find out what benefits are available outside your area, and check details like what the definition of an emergency is. Some policies may have specific restrictions on where you can seek care.

Continued on page 3



### INSIDE THIS ISSUE

- Travel Tips for the Holidays
- HTC Attends Regional Meeting
- Return your packing slips
- News
- Events

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)

## HTC ATTENDS REGIONAL MEETING



HTC Staff from L to R: Molly Brown, Jorge DiPaola, Kim Hurdstrom, Beth Warren, Rick Shearer, Paul Limberis, Sharon Funk, Nancy Spomer, Tyler Buckner, Marilyn Manco-Johnson, Brian Branchford, Donna Oscepiniski, Kristi Norton. [Photo Courtesy, Kristi Norton]

Early in November, many of our HTC staff attended the annual Regional Meeting in Portland, Oregon. This meeting includes eleven HTCs in our region, the Mountain States Hemophilia Network. It is a chance for our physicians, nurses, physical therapists, social workers, pharmacy staff, and researchers to gather with others in our region. These regional meetings also invite members of the regional NHF chapters to attend. It is an invaluable opportunity for all who attend to connect, provide education, share information and work together to improve outcomes of our patients.

The meeting included larger groups for all attendees and small breakout sessions and workshops designed to focus on specific topics related to the various duties of HTC and chapter personnel. Those who attended found these small sessions to be helpful. They appreciated the chance to directly visit and discuss clinical care, research opportunities, and quality improvement initiatives that are going on in different states.

Our HTC's Dr. Tyler Buckner shared, "One of the topics I was involved in most was how we can improve the way we assess and manage pain in individuals with hemophilia. The meeting provided a great opportunity for face-to-face discussion among physical therapists, nurses, physicians, social workers and other providers about how we can approach this challenging issue as healthcare providers."

One panel discussion focused on pediatric stroke, and was led by Dr. Catherine Lefond from Seattle, a world expert in the subject. Dr. Brian Branchford, also of our HTC, was able to participate in that panel and represent our HTC. In addition, there was a session on the SIPPET trial and helpful dialogue about the results and how those results will affect patient care.

Our HTC members also attended a "Research Slam", which was a presentation on what each center was working on in research. Dr. Beth Warren shared her research on preventing breakthrough bleeding on prophylaxis and welcomed the feedback and suggestions from other HTCs. This was exciting and informative method of learning enjoyed by all who attended.

Many from our HTC mentioned that they appreciated the regional meeting for the sense of community it fosters among HTCs and building relationships with others in our region doing the same or similar positions. It was also beneficial to learn more about projects going on in other centers, and learn and share what challenges we have in common.

Our HTC expresses gratitude to the Mountain States Hemophilia Network and all their efforts to make this gathering such a success.

## NHF Colorado - Upcoming Events

**Nov 29: Prepare for the Holidays Program**

**Dec 3: Holiday Party - Grand Junction**

**Dec 4: Holiday Party - Denver Metro Area**

**Dec 11: Holiday Party - Colorado Springs**

**Details-go to: [www.cohemo.org](http://www.cohemo.org)**



## Monitor your Health

While out of town, be sure to carefully track any bleeds, the factor you use, and any other complications. Keeping proper infusion records can assist both pharmaceutical staff and clinicians in assessing needs should you have any problems during or after your trip.

### • Top Tips:

Whether traveling or staying home, always check to see if you have enough factor on hand to treat a bleed through a holiday closure or long weekend.

- Our pharmacy will be closed for several upcoming holiday dates. Coordinate with our pharmacy to get shipments of factor on time. Our schedule is posted on our website if you have any question about when orders should arrive around the holidays.
- When flying, ALWAYS bring factor as a carry on. Airline limits of one carry on and one personal item do not apply to medical supplies, but check with your airline for details.
- Always bring a travel letter explaining your medical condition and your medications. If traveling to a



foreign country, bring the letter in both English and translated into the language of your destination country.

- Be aware of the temperature at which your factor must be stored. If it requires refrigeration, keep it in a cooler with ice packs.
- Wear medical identification. While it's important to bring paper documentation, having some kind of medical ID bracelet can be critical in case of emergency.
- Know your resources. Whether it's booking a hotel with a fridge to keep factor, or requesting special seating or wheel chair assistance at the airport, look into your options and take care of your health.

Families with bleeding disorders know sometimes a bleed can put a damper on things; make your plans flexible enough to adjust if needed but go knowing whatever happens, you can work around any problems to enjoy yourself. We hope you enjoy the upcoming holidays and have fun on any trips you may take.

For additional travel resources please see our digital edition of this newsletter at our website:

[www.medschool.ucdenver.edu/htc](http://www.medschool.ucdenver.edu/htc)

**Find the RESOURCES tab and click on the NEWSLETTER tab. Click on the Digital Newsletter & Archives and find the November 2016 Newsletter.**



Be aware that our offices, clinic and pharmacy will be closed on the following dates:

**Thurs & Fri, Nov. 24-25, 2016 for Thanksgiving**

**Fri & Mon, Dec. 23 & 26, 2016 for Christmas**

**Fri & Mon, Dec. 30 & Jan 2, 2017 for New Years**

Please plan ahead and order any factor or other supplies you may need in time for these closures.

Shipping deadlines, closure dates and after hours information can be found on our website at:

**[www.medschool.ucdenver.edu/htc](http://www.medschool.ucdenver.edu/htc) and click on the CONTACT US Page**

## RETURN YOUR PACKING SLIPS

Our Pharmacy is required to have records on file about the medications and supplies they send out. When you receive factor or other items from our HTC Pharmacy, please remember to return the delivery receipt **stamped in red ink**. Instructions are included in the packaging.

These packing slips must be signed, dated and mailed to us. There is a self-addressed and stamped envelope provided to make returning the delivery receipt easy and painless.

Unfortunately, failure to return the signed packing list verifying that you received the medications could result in a delay in receiving your next factor order or possibly being held financially responsible for the order.

**THANK YOU** for your help! Returning this packing slip is a requirement for us to comply with regulations.

Please contact us if you have questions. Our main pharmacy line is 303-724-0168 or toll free at 888-724-7427 and our email is: [hemophilia@ucdenver.edu](mailto:hemophilia@ucdenver.edu).

**Pharmacy:  
303-724-0168**

## RECENT HEADLINES

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

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 head 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/)

**HFA Produces New Podcast for Young Adults with Hemophilia**

**Roche Updates on Problems with ACE910 During Clinical Trials**

**To Treat One Rare Blood Disorder, Scientists Exploit Another**

**Voices of 5000+ Patients: First National HTC Survey Experience**

**Prescription Benefit Program Changes for Recombinant Clotting Factor Product**

## UPCOMING EVENTS

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

**Nov 29:** NHF CO Prepare for Holidays Program

**Dec 2-4:** RMHBDA Men's Retreat– Pray, MT

**Dec 3:** NHF CO Holiday Party: Grand Junction

**Dec 4:** NHF CO Holiday Party: Denver

**Dec 11:** NHF CO Holiday Party: Colorado Springs

**Dec 15:** Strike Out Stroke with the Denver Nuggets

**Dec 23 & 26:** Clinic and Admin closed for Christmas Holiday

**Dec 30 & Jan 2:** Clinic and Admin offices closed for New Year's Holiday

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**

### 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:

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

PLEASE  
PLACE  
STAMP  
HERE