# **The Clotting Connection**

A Newsletter for Families with Bleeding and Clotting Disorders



Hemophilia and Thrombosis Center

UNIVERSITY OF COLORADO ANSCHUTZ MEDICAL CAMPUS





The holidays are upon us, and that can mean travel to visit family or friends. Whether you plan a short trip in the car or have a vacation in a distant country, traveling with a bleeding disorder can make things complicated. Extra preparation before any travel can make a huge difference in comfort and convenience.

Our HTC clinic and pharmacy staff are prepared to provide support to our patients and families in preparing for their travels, whether near or far. Even if you have no plans to travel over the holidays, being prepared for winter weather and holiday

closures when access to medical or pharmaceutical care may be limited can make a big difference.

#### **Meet With Your HTC**

Our team at the HTC is able to provide an updated travel letter with TSA travel guidelines for medications, bleeding alert cards, and luggage tags for travel. A travel letter allows you to pass through security with your factor medication, which you should always take as a carry-on. If you need extra factor for a longer trip, our pharmacy can provide support to plan ahead. If you are going to be traveling, please feel free to call us with any questions. Our nurses and pharmacy members are happy to offer guidance and answer travel questions.

#### **Know Your Options**

If you are traveling outside of the United States or even just one state away, it is important to know what your resources are once you arrive. If your factor needs to be kept in a refrigerator, does the place you are staying have one available to you? If you need infusing help, or need to get medication while vou are away, do you know where to find the closest HTC? You can find a directory of HTCs in the United States



by going to the CDC's website: at www.cdc.gov and enter "Hemophilia Treatment **Centers**" into their search bar. If you are traveling internationally, find details on the closest treatment center and other international travel tips at www.wfh.org and click on the Resources tab, and then the "Find a Treatment Centre" page.

#### **Check Your Insurance Coverage**

Insurance can be challenging when you are being treated at your local HTC, but while traveling it is important to know what benefits are available outside of your home state. Contact your health insurance company directly and talk to them about your travel plans and how to find resources that are covered by your plan. It is important to check if you are covered at all in another state or country, and what insurance information you might need if you need to seek care.

# **Happy**

As we approach the holidays, be aware of our clinic and pharmacy closures. See holiday hours online at medschool.ucdenver.edu/htc.

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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



**HTC** Website: Go to medschool.ucdenver.edu/htc



Email:

HTC.Newsletter@ucdenver.edu

#### HTC SPOTLIGHT: NURSE KIMBERLY HURDSTROM



This month we spotlight nurse Kim Hurdstrom who started working at the HTC six years ago. If you have been in our clinic, you have probably had a chance to meet her. She regularly sees patients and their families, doing infusions, handling phone triage, assisting with prescription refills, prior authorizations, or providing care in the case of a bleed. Kim works to educate families about

their diagnosis and teaches how to use their medications properly. Kim coordinates surgical care management, visits patients in the hospital, and is a wonderful asset to our HTC.

Kim manages the Colorado Springs Outreach clinic that allows patients near the Springs to receive their regular care closer to home. She also often attends our Grand Junction clinic and Mile High Summer Camp. Kim also has been team captain for our "Unite for Bleeding Disorders Walk" team, Chill Factor. She shared a few things with us to let our patients get to know her better.

Kim and her husband both grew up in Arvada, but never met until they both moved 700 miles away to Las Vegas, Nevada! She wanted to be a photographer growing up, and pursued that passion as a creative outlet in her life. She has a few photos that she has entered into various art shows and enjoys the challenge of finding the right shot. She has three children who keep her very busy, and who are regular subjects of her photos. She and her husband enjoy finding and collecting unique coins. Kim shared that she loves to be near the ocean where she can snorkel, put her feet in the sand, or swim.

She attended the College of Southern Nevada, Las Vegas where she got her Associated Degree in Nursing. She

followed that up with a Bachelor of Science in Nursing at Walden University. Kim enjoys working with a multi-disciplinary team that helps care for patients and their families in the unique environment here at the HTC.

She says, "It has always been important to me to work with a community where I can form connections with the patient and family and feel like I really make a difference in their lives. I found that working with this community."

Kim enjoys having regular interactions with patients and families by phone, in clinic, or at other groups and events. Kim works in our HTC as a part of the Effective Clinical Management (ECM) groups for women with bleeding disorders, new patients, and patients with inhibitors. She has also been involved in supporting the Parents Empowering Parents (PEP) program that provides support to parents of children with bleeding disorders.

Recently, Kim passed the Care Coordinator and Transition Management Certification (CCCTM) exam. This nationally recognized certification endorses her work as a top-level, highly experienced nurse care coordinator. This is a huge accomplishment, and she is the first nursing team member at our HTC to become certified. In addition, Kim was chosen as the Mountain States Hemophilia Network representative to the Nurse Working Group. This means she will help plan the annual NHF national meeting, and help shape policies and procedures for nurses who care for bleeding disorder patients nationally. She will act as a nursing representative in various multi-disciplinary committees across the nation that define and influence treatment of bleeding disorders.

We congratulate Kim on her accomplishments and are grateful she works with us at our center. Her caring heart allows her to work with many patients regularly, and these connections give her great satisfaction and are a huge benefit to our HTC and patients. Thank you Kim!

## NHF Colorado - Upcoming Events

Backpacks & Bleeders Indoor Rock Climbing: Dec 9: Springs Climbing Center, Colorado Springs Dec 11: Movement Climbing & Fitness, Boulder Dec 14: Earth Treks, Englewood

Dec 15: NHF Colorado Holiday Party 3-7 pm Perl Mack Community Center-Denver

Details-go to: www.cohemo.org

#### **Keep Tabs on Your Health**

It is easy to forget to infuse or neglect regular physical care when traveling. If you are out of town, be sure to track your bleeds, the factor you use, and any complications you may have. Keeping proper records can help pharmacy staff or clinicians in assessing needs should you have any problems during or after your trip.

#### **Travel Tips**

No matter if you are traveling or staying home for the holidays, be aware of how much factor you have. With several holiday closures coming up, take the time to contact our pharmacy well in advance if you will need factor. Winter



weather and busy delivery routes can cause delays, so be sure to check when you need to place an order for the delivery to get to you on time.

- Our pharmacy deadlines for shipping can be found at our website. Go to www.medschool.ucdenver.edu/ htc. Find the Pharmacy tab and click on Shipping Information.
- When flying, ALWAYS bring factor as a carry-on. Airlines may limit you to one carry on or one personal item, but this DOES NOT apply to medical supplies. Check with your airline about their specific policies to avoid problems. At the TSA or security checkpoints, notify the security officer that you have a bleeding disorder and that you are carrying your

- medication and supplies with you.
- Always bring a travel letter explaining your medical condition and your medications. If you are traveling to a foreign country, bring the letter in 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. Bring all your infusion supplies and make sure they are labeled. Pack a travel sharps container for needle disposal. Never leave your factor in a hot or freezing car.
- Wear medical identification. While it is important to bring paper documentation, having some kind of medical ID bracelet can be critical in the case of an emergency.
- Know your resources. Whether it is booking a hotel with a fridge to keep your factor, requesting special seating or wheel chair assistance at the airport, or knowing where the closest HTC is, check into your options before you go.

Other great tips on traveling can be found online at these websites:

- At <u>www.hemophiliafed.org</u>, find the For Patients tab, click on Additional Resources and look under "Away We Go!"
- Type in <u>www.hemaware.org/life/traveling-medication</u>
- Go to www.wfh.org and under the Resources tab and click on Find a Treatment Centre.

Enjoy the holidays, and be prepared! Contact us if you need any assistance with your travel plans.

# Shipping Deadlines

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

- Thurs & Fri, Nov 28-29, 2019 for Thanksgiving
- Tue & Wed, Dec 24-25, 2019 for Christmas
- Wed, Jan 1, 2020 for New Year's Day

Please plan ahead and order any factor or other supplies you may need in time for these closures. Shipping dates and deadlines, closure information, and after hours contact information can be found at our website at:

www.medschool.ucdenver.edu/htc and click on the CONTACT US page.

# Pediatric Stroke Parent Support Group Holiday Celebration

Our Pediatric Stroke Parent Support Group will have a fun holiday party including food, games, and other festive activities as we close out the year. Fun for the whole family as we look forward to 2020!

Please RSVP via email with the number of parents and children by December 6th to:

strokesupport@ucdenver.edu or call us at 303-724-6163.

The HTC will provide the main dishes and we would love you to bring potluck items to share. Please see our website or Facebook pages for the direct link for the signup or give us a call.

#### RECENT HEADLINES

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

FDA Approves Octapharma's Wilate for Hemophilia A in Adult and Adolescent Patients

Genentech Issues Statement on Hemlibra Particles; MASAC Responds

Freeline's Gene Therapy for Hemophilia B Shows Promising Phase 1/2 Results

Hemlibra Given with Immune Tolerance Induction Safely Treats Children

FDA Grants Orphan Drug Designation to SIG-001 for Hemophilia A

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:**

**Nov 28-29:** Clinic, Pharmacy, and Administrative Offices closed for Thanksgiving Holiday

**Dec 9:** Backpacks + Bleeders Indoor Rock Climbing: Colorado Springs, CO

**Dec 10:** Pediatric Stroke Parent Support Group Holiday Party

**Dec 11:** Backpacks + Bleeders Indoor Rock Climbing: Boulder, CO

**Dec 14:** Backpacks + Bleeders Indoor Rock Climbing: Denver Metro

Dec 15: NHF CO Holiday Party-Denver, CO

**Dec 24-25:** Clinic, Pharmacy, and Administrative Offices closed for Christmas Holiday

**Jan 1:** Clinic, Pharmacy, and Administrative Offices closed for New Year's Day

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

# Hemophilia & Thrombosis Center

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Web page:

http://medschool.ucdenver.edu/htc

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