

The Clotting Connection

A Newsletter for Families with Bleeding and Clotting Disorders

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A SHOT OF PREVENTION

With weather pushing more people indoors, the spread of germs and illness increases. What can you do to prevent colds and flu from spreading in your family?



The most common winter ailments include the 'stomach flu', the common cold, and influenza (the flu). The '**stomach flu**' isn't actually influenza; it is usually one of many gastrointestinal viruses that cause stomach pain, nausea, vomiting, diarrhea, and sometimes a fever or other symptoms.

The **common cold** is a virus that causes a sore throat, a runny nose, and can include congestion, coughing, sneezing, headaches or body aches. Usually colds end after a week or two, so treating symptoms and waiting for it to pass is the best option.

Influenza, commonly referred to as the flu, has many symptoms of the common cold, but the influenza virus is almost always more severe. Influenza causes body aches, fever, feeling tired, coughing, sore throat, and can be accompanied by a runny nose, or congestion. While most people who get influenza can recover anywhere from a few days to two weeks, the flu can develop into serious complications.

The stomach flu, a cold, or influenza can be spread by germs on surfaces, coughing and sneezing, sharing food or utensils, so it is important to **wash hands well**, and be careful around those who are ill, avoiding contact if possible. There is no vaccine for the stomach flu or the common cold, but influenza can be prevented or made far less severe by getting a flu shot every year.

Myths abound about getting the flu vaccine, but the vaccine does not cause the flu. The virus inside is dead and cannot cause the flu. Anecdotes about becoming sick right after vaccination are likely caused by either being exposed to the flu prior to the shot, or symptoms generated as the immune response begins to work in the body. If you have questions about the flu shot, ask your doctor.

People with bleeding disorders are just as likely to get the stomach flu, colds or influenza as anyone else. We recommend getting the flu shot, as well as keeping up on all your vaccinations. Vaccines do not generally cause any additional complications for those with bleeding disorders, however following the guidelines provided by MASAC are recommended. These are available at hemophilia.org and a direct link to the guidelines is available on our digital version.

As we head into winter, make a conscious effort to wipe down those surfaces, wash your hands, and avoid contact with sick people if possible. If you do come down with an illness, stay home and take steps to prevent spreading it to others. Contact your doctor if you have any severe, persistent or unusual symptoms, or an unusually high or prolonged fever.

To access links about the flu, colds, vaccinations and prevention see the links in our digital version of this newsletter by going to www.medschool.ucdenver.edu/htc and find the RESOURCES tab. Click on the NEWSLETTER page and find the Current Digital Newsletter & Archives link and find the October 2017 Newsletter.



Our HTC building was re-named as CU Medicine and has new signage.

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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.ucdenver.edu/htc



Email:

HTC.Newsletter@ucdenver.edu

PHARMACY CHANGES AND UPDATES

October is American Pharmacists Month and we celebrate our HTC Pharmacy with the work they do each day to help our patients. Our HTC Pharmacy is not for profit and is designated as a 340B pharmacy, meaning it is able to purchase medications for our qualifying patients at a lower cost. This allows us to pass along those savings to patients and provide more services to our patients.

The HTC Pharmacy has worked diligently this past year to work with payers and benefit plans in order to improve patient access for their medications and supplies as needed.



The HTC Pharmacy Staff. Photo: Merilee Ashton, 2016.



New TagAlert Indicators to monitor factor temperature during shipping.

During this year, the HTC Pharmacy's web page went live. It provides information related to the services they provide, shipping, forms, holiday closure dates, and other helpful information. To find our pharmacy page, go to: www.medschool.ucdenver.edu/htc, and find the "Pharmacy" tab located along the top.

This past month the HTC Pharmacy has implemented a new temperature device which is placed in all factor shipments. The TagAlert system uses an updated technology to monitor the continuous temperature of factor shipments and is a part of an ongoing effort to ensure quality and safety. Instructions are included in every shipment to assist patients verify that the temperature was appropriate for their factor during shipping. If an alarm has been triggered or if patients have any question regarding the monitoring system, they should call our HTC Pharmacy at 303-724-0168. A link to the instructions can be found on our website.

Our HTC Pharmacy has worked throughout the year to encourage patients to be involved in our Pharmacy Patient Management Program. This is a process in which our pharmacists talk with patients/caregivers, to collect information that helps patients manage their own bleeding disorder therapy. The pharmacists work directly with you and your providers and nurses to monitor bleeding events, quality of life, and adherence to prescribed treatment plans.

Many of you filled out surveys this year to help provide feedback to us and help us ensure we are fulfilling the needs of patients in a timely and helpful manner. We appreciate patient feedback and encourage patients to respond to future surveys so we will have an honest gauge of how we're doing.

More plans are in the works for the coming year as the HTC Pharmacy strives to help patients receive the items they need and adhere to their treatment plans with ease. Happy Pharmacy Month and let us know how we are doing!



Our next **Self-Infusion Clinic** at the HTC will be on **Saturday, November 4, 2017 from 9 to 11 am.**

This program is for patients and families who would like additional help with self-infusion. Come and spend time with our nursing staff and practice in a one-on-one setting. You can bring your own factor to be infused or practice with saline. The event is free but you must RSVP.

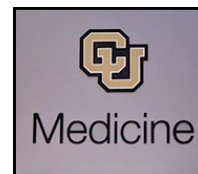
Go to cohemo.org and click on the EVENTS page.



Parents Empowering Parents, a special program

designed to educate parents about the skills they need to navigate family life and bleeding disorders, was held Oct 20-22nd.

Facilitated by our HTC social worker, parents, and healthcare professionals, this program helps support navigating the unique needs of children with bleeding disorders. If you are interested but were unable to attend please watch for upcoming dates. Contact our social worker, Audra LeBlanc about the next PEP at 303-724-6163 or at audra.leblanc@ucdenver.edu.



Recently the HTC had a few cosmetic changes. While our location and address has not changed, the

building in which we have our clinic, pharmacy and administrative staff has been re-named.

Our building was formerly called the University Physician's Inc, or UPI building. The name has been changed to CU Medicine. The logos from CU and the word signage have been changed on the building and the parking garage. We've updated our website to reflect this to be as clear as possible.

PATIENT SATISFACTION SURVEY

Patient Satisfaction with U.S. Hemophilia Treatment Centers: Voices of Females with von Willebrand Disease



Females with von Willebrand Disease (VWD) are the fastest growing population obtaining care at Hemophilia Treatment Centers (HTC) in the United States¹.

When the first National HTC Patient Satisfaction Survey (PSS) was conducted in early 2015, over 5,000 patients or caregivers from

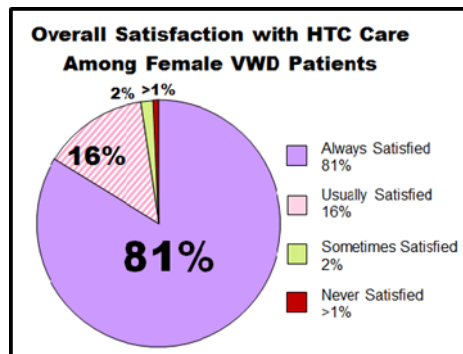
around the country reported on HTC services they received in calendar year 2014.

How many females with VWD completed the 2014 National PSS?

While men and boys make up about 70 percent of HTC patients in the U.S., many inherited bleeding disorders affect females. Twenty-nine percent who completed a survey were female. Of all the females returning a PSS, 868 persons—more than half—had a diagnosis of VWD. This translates to nearly 1 out of 5 patients at HTCs who responded to the survey.

This confirmed that significant numbers of girls and women obtain treatment for VWD at an HTC and are an important segment of the overall HTC patient population. Their feedback is valuable to discover if their needs are met.

Are females with VWD generally satisfied with HTC Care?



Yes. Women with VWD and the parents of girls with VWD reported high satisfaction with overall HTC care, matching the general PSS responses nationwide.

Nearly all female VWD survey respondents reported being either “always” or “usually” satisfied with their overall HTC care.

1. Baker et. al. *Haemophilia* 2013; 19: 21-26.

More specifically, 99 percent of women with VWD, or parents of girls with VWD, reported that HTC staff ‘always’ or ‘usually’ treated them with respect. Similarly, 95 percent reported it was ‘always’ or ‘usually’ easy to get the information they needed, and 93 percent reported that HTC clinic staff ‘always’ or ‘usually’ coordinated their care with other specialists or providers. These high positive results from patients tell us that many things at our HTCs are meeting the needs of this group.

“My daughter is in wonderful hands.”

Mother of 10 year old girl with von Willebrand Disease, Maine

What else did we learn?

The survey asked what HTCs are doing well, how HTCs could improve and invited participants to share anything else. Many did, providing helpful insights into areas that were working or needed improvement.

HTCs received many complimentary comments. The positive feedback was more than double the number of comments identifying problems. However, there were some recurring responses that shed light on challenges HTCs could improve upon.

“HTC can communicate better with patients.”

22 year old woman with von Willebrand Disease, New York

Some of the most common problems mentioned were:

- difficulty communicating with their HTC
- scheduling appointments
- long wait times
- problems with billing or insurance
- distance to the HTC
- needing bilingual assistance

What’s next?

Each HTC has the data and feedback from the anonymous responses of the patients at their center. This information is a tool to help each HTC find ways to improve their quality of care.

Regional HTC leadership thanks all patients and parents who participated, and the HTCs for their valuable input.

For more information and additional articles about the results of this survey go to: www.htcsurvey.com.

RECENT HEADLINES

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

UniQure Announces New Study for Hemophilia B Gene Therapy Program

Hemophilia A Study Shows Potential to Reduce Inhibitors

BloodStream Podcast Presents Factor Revolution: 60 Years of Hemophilia

How to Talk to Kids About Tragic Events

NHF Collects Funds to Support Puerto Rico Patients with Bleeding Disorders

Urgently Needed Hemophilia Drugs Delivered to Puerto Rico Pediatric Hospital

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:

Oct 28: NHF CO VWD Coffee Chat Series

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

Nov 4: Self-Infusion Clinic at HTC

Nov 18: NHF CO Social Factor: Enrollments & Benefits

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

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

Dec 10: NHF CO Denver/CO Springs Holiday Party-Centennial

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

Jan 1: Clinic, Pharmacy & Admin 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

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>

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