

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
Children's Hospital Colorado

HTC PHARMACY CELEBRATES 25 YEARS OF SERVICE

The University of Colorado Hemophilia and Thrombosis Center is the largest HTC in the region and serves people with bleeding disorders throughout Colorado, Wyoming, Montana, and several other surrounding states. This not only involves regular annual visit care, physical therapy, psychosocial support, genetic counseling, and research, but stellar support from a fully accredited, specialized HTC pharmacy. Our HTC pharmacy began as an idea of Dr. Marilyn Manco-Johnson and former Pharmacy Manager Judy



Desi Hill, Clinical Pharmacist

Primeaux. It launched on a loan and from a small office 25 years ago and has become a national leader. In fact, our HTC pharmacy is viewed as the gold standard, with innovations that have been replicated in other HTCs and directly and indirectly improved pharmacy services and care all over the country.

When the earliest start of an HTC in Colorado began in 1973, the products used by patients to treat hemophilia or other bleeding disorders were mostly fresh frozen plasma or freeze-dried powder formulas of factor. These factor concentrates were distributed jointly from the University of Colorado Hospital and Belle Bonfils Blood Centers. This arrangement worked for some time, but in 1990 this system was discontinued, and for several years patients had to find factor infusion through home infusion pharmacies. While those pharmacies provided the needed care, the increasing

cost of factor became an issue for many patients.

As newer and more efficient products began to become more available, and treating patients prophylactically became more common, it was clear that the price of these lifesaving factor replacement therapies would become excessive. Having a rare condition and a specialized treatment could price families out of the care they needed.

In 1995, the University of Colorado HTC signed on with a new federally funded program, called 340B, that allowed a specialized pharmacy to open in conjunction with an HTC that provided clinical care. The 340B program began a system that has changed the state of the HTC and care for patients with bleeding disorders throughout the United States. The program allows the pharmacy to purchase and dispense factor products to patients at a lower cost. This helps the patients in many ways. The profit generated by these factor sales supports the continued services of the HTC and care for our patients. The careful management of this non-profit program has allowed both lower costs to patients and improved comprehensive care needed for those with a bleeding disorder.



Olivia Rapacchietta, Clinical Pharmacist

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Paul Limberis, Pharmacy Manager

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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

THANK YOU TO OUR HTC STAFF



Our busy nursing staff wish you a warm holiday and a safe new year! Pictured: Kim Hurdstrom, Nancy Spomer, Kate Hoeft and Deborah Parrott. Photo by Kevin Anthony.

This year has been a challenge for most people, and we are grateful that we are still able to serve most of our patients in some capacity. As we approach the end of 2020 and look forward to what we all hope will be little bit less challenging 2021, we would like to acknowledge the hard work and dedication of our staff at the HTC.

From mid-March, when we shifted to a bare minimum capacity, to the summer when we opened with restrictions, our staff has been flexible and optimistic in serving our patients. We have learned to navigate new technologies, found new ways to communicate and connect with patients, and found ways to adapt to make things work. Many hours of Zoom meetings where we discussed patient needs, problems with technology, and what to do about all the things that were just not normal this year led to a different kind of unity within our staff. New and veteran staff members went above and beyond to provide the support and care needed this year. Each week has brought us new hurdles, but it has been powerful to see everyone working together.

We express our thanks to all those in the healthcare industry who have done so much to improve the lives of others. It has been a challenging year, and we especially thank all our staff for all they have done and thank our patients who walked the path with us this year. Have a safe holiday season and a healthy new year!

THIRD PATIENT SATISFACTION SURVEY TO ARRIVE IN 2021



In 2015 and in 2018, HTCs across the country sent out a National Patient Satisfaction Survey (PSS). This survey was sent to patients with bleeding disorders who sought care at HTCs asking how their experience was. The first two surveys helped local and national leaders gauge the things that were and were not working for HTCs across the United States.

Each survey was anonymous but was attached to the HTC where the patient received their care. This allowed each center to look at the responses and hear honest feedback from patients. The third version of this survey will be sent out in the spring of 2021 and offers patients a great opportunity to again help HTCs evaluate their care.

Nearly all HTCs had to make major adjustments in 2020 due to the COVID-19 pandemic, so questions have been added asking patients for feedback on tele-health as well as in-person care. The PSS team [recently published a paper](#) that reviewed the first survey, and multiple posters and articles have been written showing what has been learned so far.

Please watch for more information on how to participate in the next survey, which is slated to begin in March 2021. The survey is brief and will be available in both English and Spanish. You are encouraged to fill out the survey online, but paper surveys will be mailed out to families as well. For questions, or to learn more about the earlier surveys, please go to htcsurvey.com.

**Pediatric
Stroke Parent
Support Group**
**VIRTUAL ZOOM
Meeting**
**Tuesday
Jan 12, 2021
6:30-7:30 pm**

PEDIATRIC STROKE SUPPORT GROUP

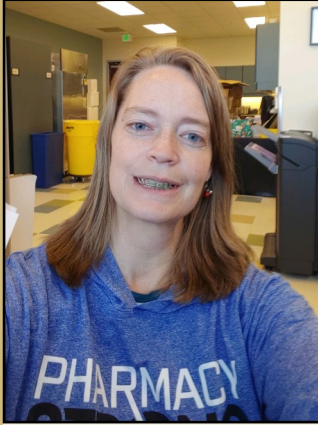
Our Pediatric Stroke Parent Support Group has been meeting online now for several months. While we miss visiting in person with our pediatric stroke families, we will continue meeting online a while longer to keep everyone safe.

Please join us for our next online meeting on **Tuesday, January 12th from 6:30-7:30 pm on Zoom.**

This group meeting welcomes everyone in the family to join. Your child does not need to be treated at our center to attend.

To join, please RSVP by contacting us at strokesupport@ucdenver.edu or (303) 724-8520. Follow us on Facebook for the latest on our meetings at www.facebook.com/Colopedsstroke. We hope you can join us and start off 2021 with our first meeting of the year!

[continued from page 1] In May of 1995, with a loan from the University of Colorado, the HTC Pharmacy first opened its doors and treated its first seven patients. From that point, the pharmacy began to work with more and more patients and went from one pharmacist to a fully staffed pharmacy team. Lynn Magnuson started doing accounting work for our pharmacy in 1997 and has



Kara Taylor, Pharmacy Technician

worked with the HTC pharmacy and clinic ever since. Though the pharmacy was not located at the same place as those who treated patients in clinic, the pharmacy continued to thrive and support a growing HTC.

The pharmacy, research grants, and support from the University of Colorado allowed the HTC to flourish and develop into one of the premier research centers for those with bleeding disorders.

In 1999 the clinic and pharmacy moved to the Fitzsimons building while Anschutz Medical Campus was just beginning construction. This allowed the pharmacy and clinic to work more easily together, providing the support and supplies our patients needed.



Trish Tucker, Pharmacy Assistant

In 2011, the University of Colorado provided a combined space in the then brand-new University Physician's Building, now called the CU Medicine building, located on Montview. Since that time, the clinic and pharmacy have grown to occupy most of the first floor as well as offices upstairs. This massive growth wasn't without struggles, but in 2020, now 25 years after the pharmacy first opened, the pharmacy staff operates an efficient, quality, accredited specialty pharmacy program dedicated to our patients.



Jonathan Truong, Pharmacy Intern

In the past several years the pharmacy has updated many of their systems, processes, and procedures and has been fully accredited as a Specialty Pharmacy with the Utilization Review Accreditation Commission (URAC) since December 2017. The pharmacy is in the process of obtaining a second accreditation in 2021.

From only seven patients in that first month of May 1995, to now serving hundreds, our pharmacy continues to work to improve services each year. With upgraded mailing processes, including temperature monitoring, expedited shipping and tracking, and recycling efforts to reduce our impact on the environment, our patients can count on their medications being delivered promptly and under safe conditions.



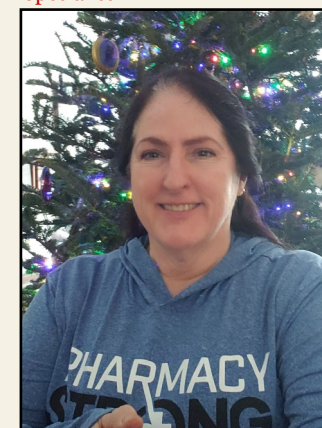
Candice Murchison, Insurance Specialist

Our pharmacy staff laid out plans in early 2020 to work in the pharmacy in two teams to make sure that there will always be enough staff on hand, despite the pandemic sweeping the nation. Each team alternated being in the pharmacy to minimize any impact if any team member was exposed to the virus. In addition, extra sanitary precautions were put into place, including all staff wearing masks, shields, gloves, and disinfecting the pharmacy daily. This has allowed the pharmacy to continue to dispense factor and serve our patients without interruption.



Yevette Portillo-Corral, Pharmacy Prior Authorization Specialist

Congratulations to the HTC Pharmacy on their 25 years of high-quality care and service to our bleeding disorder patients! We honor and thank you for your continued efforts to improve the lives of people with bleeding disorders!



Rae Gerold-Smith, Business Operations Coordinator

RECENT HEADLINES

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

Updated Phase 1/2 Hemophilia Gene Therapy Study Data Presented at ASH

MarzAA for Hemophilia A or B with Inhibitors Given Fast Track Status from FDA

UniQure Shares Positive Data from AMT-061 Gene Therapy Trial for Hemophilia B

Study Finds Passive Stretching, Manual Therapy Helps Joints of Hemophilia Patients

Results Published from Patient Satisfaction Survey Show Positive Reviews of HTCs Nationwide

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 due to the COVID-19 pandemic and restrictions. Please check appropriate websites for confirmation of events.

Dec 24-25: HTC Clinic, Pharmacy, and Admin Offices Closed for Christmas Holiday

2021

Jan 1: HTC Clinic, Pharmacy, and Admin Offices Closed for New Years Day.

Jan 12: Pediatric Stroke Parent Support Group Meeting-VIRTUAL

Jan 18: HTC Clinic, Pharmacy, and Admin Offices Closed for Martin Luther King Jr. Day

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

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Web page:

[medschool.cuanschutz.edu/
hemophilia-thrombosis](https://medschool.cuanschutz.edu/hemophilia-thrombosis)

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