

# The Clotting Connection

A Newsletter for Families with Bleeding and Clotting Disorders



Hemophilia and Thrombosis Center  
UNIVERSITY OF COLORADO ANSCHUTZ MEDICAL CAMPUS



Affiliated with  
Children's Hospital Colorado

## UNINSURED DOESN'T HAVE TO MEAN UNPREPARED



Our social work team is able to help with counseling, emotional, and logistical support.

There are many reasons individuals may experience a gap in insurance: a change in jobs, a move to or from another state, turning 26 and losing coverage from your parents, etc. You are not alone if you may have had, or are soon facing a gap in insurance. When you have a bleeding disorder diagnosis, however, planning ahead or taking action as soon as a gap occurs, is *of utmost importance*.

Our HTC social work team helps coordinate factor assistance applications to receive factor at no cost during your insurance gap. The important thing to know is that factor assistance programs do not have a 1-2 day turnaround; they often take 1-3 weeks to process applications and deliver factor, and only if you are eligible and approved. For this reason, it is extremely important to **notify the HTC nursing or social work team as soon as you know you will have a gap in insurance.**

Bleeding disorder diagnoses are unpredictable, and experiencing a bleed while being uninsured without factor at home is a dangerous situation. We do not recommend saving your factor and informing the HTC when you have just a few doses left. This will not help you in the event of a bleed and is extremely risky. We encourage you communicate your gap in insurance as

soon as you find out. A quick call to our social workers can help both you and our staff most effectively address your factor needs in a timely, safe, and proactive manner.



Health insurance is incredibly important, especially for those with bleeding or clotting disorders. Unfortunately, insurance can be very confusing to manage and understand, even when plans might look straightforward on paper. Significant issues arise when patients lose coverage and do not know how to take action to address their loss of insurance.

Our team has recently seen an increase in patients experiencing loss of insurance and gaps in insurance. When patients face a sudden loss or gap in insurance, it is vital to take action right away to avoid delays in treatment, care, and medications.



Once you realize you will no longer have an active insurance plan, please contact us right away for support.

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Health insurance can keep you protected, but if you lose your insurance, we can help you find emergency support.

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



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Website: Go to [medschool.ucdenver.edu/htc](https://medschool.ucdenver.edu/htc)



Email:  
[HTC.Newsletter@ucdenver.edu](mailto:HTC.Newsletter@ucdenver.edu)

## UPCOMING EVENTS & OPPORTUNITIES

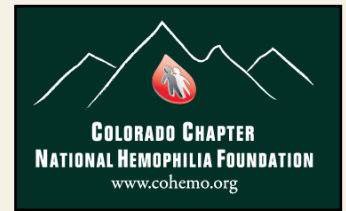
### OUTREACH CLINICS

If you do not live in the Denver Metro area, one of our Outreach Clinics might be an easier option for your regular comprehensive care. Our Outreach Clinics offer care and support from our medical, nursing, physical therapy, psychosocial, and research teams. Our experts come to you! Our next Outreach Clinic is:

**Sept 25-27 in Grand Junction, Colorado.**

NHF Colorado will host fun and interactive dinners on the 25th and 26th in conjunction with this clinic. Details and to RSVP go to [cohemo.org](http://cohemo.org).

See our website for updates on future clinics and more details at: [www.medschool.ucdenver.edu/htc](http://www.medschool.ucdenver.edu/htc) under **Outreach Clinic** in the **CLINIC** tab.



Our next Pediatric Stroke Parent Support Group will be on **October 8th** from 6-7:30 pm here at the HTC. This is a great opportunity for families of those who have experienced a pediatric stroke to meet, mingle, learn and connect with others in similar circumstances. Meetings are once a month on the 2nd Tuesday of the month. Dinner and childcare are provided and you do not need to be a patient with us to attend.

To RSVP or for other questions, please go to our website at [www.medschool.ucdenver.edu/htc](http://www.medschool.ucdenver.edu/htc) and find the Pediatric Stroke Parent Support Group page under the **COMMUNITY** tab.

**Pediatric Stroke Parent Support Group**  
Tuesday  
Oct 8, 2019  
6:00-7:30 pm



Attention all ladies! If you are affected by a bleeding disorder, are a carrier, or a caregiver, save the date for some pampering and self-care! NHF Colorado is hosting a Women's Wellness Retreat on Sunday, **October 13th, 2019** at the Washington Park Boathouse.

This opportunity only requires a \$25 registration fee per person, and you will get lunch, a special welcome gift, and a self-care option package– including a massage. Please go to [cohemo.org](http://cohemo.org) and find their News and Events calendar for more details.

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From left: Social Workers Whitney Tedeschi & Bryn Dunham, Psychologist Dr. Emily Wheat, and Child Life Specialist Kim Richfield.

Social workers Bryn Dunham and Whitney Tedeschi both joined our HTC social work team late last year and are very happy to provide support, including navigating a gap in insurance.

Whitney joined us from Children's Hospital Colorado, and has worked in pediatrics for the past 9 years. She previously worked at an HTC in Philadelphia, which prompted her interest in bleeding disorders. She continues to focus on supportive counseling throughout the lifespan, advocacy for our patient's and family's

needs, coordination of community resources, and transitions from adolescence to adulthood in the setting of chronic conditions.

Bryn joined us from UCHealth Cancer Center, but worked for 10 years in pediatric oncology and hematology in Florida. Her experience focuses on adjustment to diagnosis, transitions from adolescence to adulthood with medical conditions, as well as individual counseling, and connection to resources both locally and nationally.

Our psychosocial team also includes our psychologist Dr. Emily Wheat and Certified Child Life Specialist Kim Richfield. As active members of your comprehensive care team, they provide care, services, and resources unique to your family and individual needs to assist in illness-related coping across the lifespan.

We strongly encourage you to utilize our support services available here at the HTC when navigating a loss of insurance. Our social workers will help coordinate necessary assistance applications and talk with you about your potential options for insurance coverage moving forward.

For more information or questions about being uninsured with a bleeding disorder, contact Whitney ([whitney.tedeschi@cuanschutz.edu](mailto:whitney.tedeschi@cuanschutz.edu), 303-724-6163) or Bryn ([bryn.dunham@cuanschutz.edu](mailto:bryn.dunham@cuanschutz.edu), 303-724-6159).



# High Satisfaction with Hemophilia Treatment Center 340B Pharmacy Programs Nationwide



Many Hemophilia Treatment Centers (HTC) in the U.S. participate in the 340B drug purchasing program. This allows for more comprehensive services to be provided to all patients receiving care at HTCs. How satisfied are HTC patients with their 340B programs?

In 2018, nearly 4800 U.S. HTC patients or caregivers from 128 HTCs answered the Second National Patient Satisfaction Survey (PSS) about their HTC care received in 2017. One hundred seven (84%) of all HTCs had a 340B program that year. One PSS question asked about experience with 340B.

## How Satisfied are Patients with HTC 340B Programs?

Overall 96% of 2535 HTC patients across the US who used the HTC 340B program were 'always' or 'usually' satisfied with it. Not all HTCs have a 340B program. Sometimes HTC patients use other places to get factor or other bleeding disorder drugs because of insurance restrictions or patient choice.

## How did 340B Satisfaction Differ among the HTC Patients who use it?

Satisfaction with the HTC 340B program was consistently high. Regardless of diagnosis, severity, race, gender, or age, the majority of patients reported overall positive experiences with their HTC 340B program.

In fact, 97% of PSS survey respondents with hemophilia, and 95% with Von Willebrand Disease were 'always' or 'usually' satisfied with their 340B program.

Satisfaction with this program was uniformly high in all eight HTC regions (between 94% - 99%). Even those PSS respondents who had trouble with insurance reported high levels of satisfaction with their HTC's 340B program.

## Did Satisfaction with their HTC change if the patient used the HTC 340B Program? No.

Using the HTC 340B program did not affect patient satisfaction with overall HTC care. Satisfaction with their HTC was consistently high, whether they used 340B or not. If they used the 340B program, 93% were 'always' or 'usually' satisfied with their HTC care—nearly identical to the 94% rate of satisfaction reported by those who did not use their HTC's 340B program.

"We are very happy with the program and delivering exactly what we need, when we need it."

Parent of teen with severe hemophilia  
from Oregon

**What does this tell us?** First, most HTC patients are highly satisfied with their HTC 340B programs. Second, even if patients don't use 340B, they are highly satisfied with HTC care overall. That's important because being satisfied with medical care means patients are more likely to take actions they need to stay healthy. While some people reported problems with 340B, most of those concerns mentioned other pharmacies or insurance limiting access to a 340B program.

**What is next?** Anonymous feedback from the PSS was sent to each HTC that participated. That feedback provided summarized results, allowing HTCs to compare to regional and national HTC satisfaction in order to guide areas for improvement. Though this was the second time this PSS survey was conducted, this was the first time we asked about HTC 340B programs. In the future, the 340B question will be included to help us understand if 340B programs are continuing to do well or need to improve.

"The HTC has difficulty understanding the needs I've faced with my infusions, supplies, insurance, and co-pay issues."

Adult male with moderate hemophilia  
from North Dakota

The next PSS survey is tentatively scheduled for 2021. Regional HTC leadership would like to thank all patients and caregivers who participated and the HTCs for their collaboration. You can find out more about the PSS and the results at [www.htcsurvey.com](http://www.htcsurvey.com).

## RECENT HEADLINES

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

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

**Study Shows Hemophilia 3 Times as Prevalent in Men than Originally Thought**

**BioMarin Explains Phase 3 Results for Hemophilia A Gene Therapy Trial**

**Hemlibra Given with Immune Tolerance Induction Safely Treats Children with Severe Hemophilia A**

**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](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/)

## UPCOMING EVENTS

### Mark Your Calendars:

**Sept 25-27:** Outreach Clinic—Grand Junction, CO

**Sept 25:** NHF Colorado Outreach Clinic Dinner—Grand Junction, CO

**Sept 26:** NHF Colorado Outreach Clinic Dinner—Grand Junction, CO

**Oct 3-5:** National Hemophilia Foundation Annual Conference—Anaheim, CA

**Oct 13:** Women's Wellness Retreat

**Nov 1-3:** RMHBDA Women's Retreat—Chico Hot Springs, MT

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

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

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

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STAMP  
HERE