

The Clotting Connection

A Newsletter for Families with Bleeding and Clotting Disorders

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BACK TO SCHOOL 2017



It's the beginning of the new school year and most families are busy collecting school supplies, meeting the teachers, and packing lunches. If you have a child with a bleeding disorder or unique medical needs, you may also be looking for ways to tell the school what they need to know to best help your child.

Many children with hemophilia and other bleeding disorders qualify for Section 504 of the Americans with Disabilities Act, and others may need an Individualized Educational Program (IEP) through their school to get the accommodations they need. Either an IEP or being a part of Section 504 will allow children the adaptations through the school year to deal with bleeds and medical problems. This can include anything from extra time to get to class for someone on crutches to allowing a child recovering at home that extra help from the school to keep up with their peers. Our HTC also regularly provide Individualized Health Plans (IHP) for our patients, outlining what the school may need to know to treat a specific student in the case of a bleed or other injury. If you need help setting up an IHP or understanding what kinds of accommodations may work best for your child, our social worker, Audra Leblanc, is happy to speak with parents and offer her expertise.



Sometimes schools may be fine with a plan in place for your child, but often the teachers and staff need more information to fully understand a bleeding disorder or other medical condition. The HTC is happy to help provide support to our parents as they try and explain these needs. Setting up a meeting with teachers, or providing a special presentation at your school might be an option. Our HTC staff is well versed and able to help by giving a presentation to educators, or guiding you in ways to advocate for your child.

Schools should be a safe and comfortable environment for children, including those with bleeding disorders. We invite you to contact our social worker, Audra LeBlanc and discuss questions and needs that may arise in working with your child's school to have a great year ahead. Audra can be reached at 303-724-6163 or at audra.leblanc@ucdenver.edu.



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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

UPDATES AND OPPORTUNITIES

Hemophilia Walk 2017

August 26, 2017 at Sloan's Lake Park
8 am check in - 9 am walk - support all year

Participate • Volunteer • Donate



All proceeds go to NHF Colorado, funding programs for the bleeding disorder community.

Walk With Us!

Join us for the NHF Colorado Hemophilia Walk! This is a fundraiser to provide support for amazing programs for those with bleeding disorders—such as Mile High Camp!

The walk will be held at Sloan's Lake Park on August 26, 2017. Check in is at 8 am and we begin walking at 9. This year NHF Colorado has new fundraising perks! Details can be found at cohemo.org or by going to the registration page at hemophiliawalk.donordrive.com and finding the Denver walk and a local team.

The HTC team is CHILL FACTOR and we'd love to have you join us! If you miss it, or can't attend, please consider donating. It's easy and your support is needed and appreciated! We would love to see you there but all forms of support are welcome! Thank you for your donations, time and efforts supporting these programs!



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 (PEP) is a non-profit program providing support for parents of children with bleeding disorders.

This peer-to-peer program works with professionals and other parents to train and improve skills of parents to be more effective in raising children with bleeding disorders.

PEP 2017 will be on **October 20-22, 2017** at the Double Tree Hotel in Denver. **Please note, this is a change of date!** A flier on this program is available at our website by going to www.medschool.ucdenver.edu/htc find the **COMMUNITY tab and click on PEP.**

This program is free to attend, including hotel stay, meals, and day care, so spaces fill up quickly. To RSVP or for more information, please contact Audra LeBlanc 303-724-6163 or audra.leblanc@ucdenver.edu.

OUTREACH CLINICS 2017

Outreach clinics allow patients to schedule their annual comprehensive visits at a location closer to their home. The clinics in Montana and Grand Junction are usually a few days once a year, while our Colorado Springs clinic is held quarterly.

Our staff reach out to local patients but if these clinics are more convenient to your location and you would like to know more, please contact Pat Casias at 303-724-1325, Audra LeBlanc at 303-724-6163, or speak with our front desk schedulers at 888-297-0724 or

303-724-0724.

Details, forms and maps to these locations are available on our website at: www.medschool.ucdenver.edu/htc Click on the CLINIC tab and find the OUTREACH CLINICS page.

Upcoming clinics:

Sept 27-29, 2017: Grand Junction, Colorado

TBA: Colorado Springs, Colorado

PATIENT SATISFACTION SURVEY

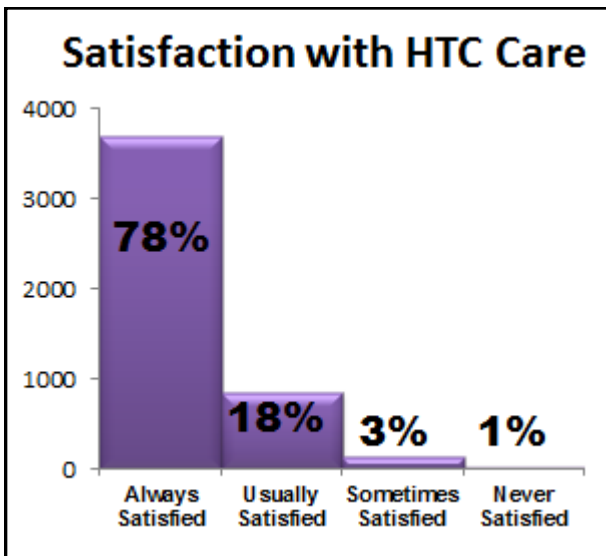
Patient Satisfaction with U.S. Hemophilia Treatment Centers: What Did We Learn?



Patient satisfaction with Hemophilia Treatment Centers (HTCs) is important. Input from patients tells us what HTCs across the country are doing well and where HTCs can improve services. Direct input from patients helps HTCs focus improvement actions to provide

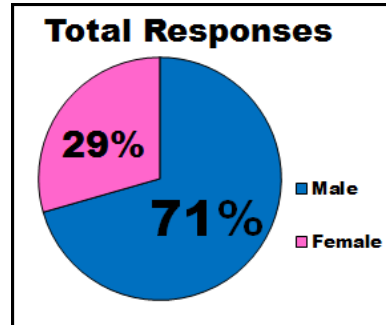
the best care.

In early 2015, over 130 HTCs around the country, including the Colorado HTC, sent out a survey to patients asking about their levels of satisfaction with their care during 2014. Over 5000 patients filled out this first-ever national Patient Satisfaction Survey (PSS). The answers are helping HTCs better understand patient views about HTC strengths and weaknesses.



What did we find out? We learned that 96% of patients were “always” or “usually” satisfied with their HTC care. But we learned much more. We found differences in patient satisfaction around the country. We learned about ways our HTCs could improve.

While surveys identified the HTC the patient used, every response was anonymous. This allowed patients to give us direct and honest feedback, including highlighting problems that may not have been specifically addressed in a question. Nearly 30% of the surveys were from female patients, reflecting the general HTC population.



While overall the results were positive, there were repeated issues all over the country that deserve attention. Each center received their own feedback and can pinpoint the most critical problems,

helping them to find ways to change for the better.

We have created a series of articles that address various trends in the responses we received. We will share these articles in the coming months with both patients and our centers. We hope these will provide valuable information and support patient care improvements around the country.

The data from our first survey provided interesting insights into how HTCs are working for different segments of the bleeding disorders community. Watch for each of these articles to appear at our site, htcsurvey.com, and in other publications in the coming months.

- **Voices of Females with von Willebrand Disease**
- **How Do HTCs Help Adolescents?**
- **Voices of Males with von Willebrand Disease**
- **Voices of Adult Men**
- **Women with Bleeding Disorders**
- **Does Location Matter in Satisfaction with HTC care?**
- **Where is Insurance a Barrier to HTC care?**
- **Does Diagnosis Play a role in HTC satisfaction?**
- **Where is Language a Barrier to HTC care?**

You can read these articles once posted, and find more information about the survey at htcsurvey.com.

More information about the upcoming 2018 Patient Satisfaction Survey will be made available toward the end of 2017.

For any questions regarding the 2015 survey, or the 2018 survey, please contact us at HTCSurvey@ucdenver.edu.

RECENT HEADLINES

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

FDA Grants Priority Review of Genentech's Emicizumab for Hemophilia A with Inhibitors

NHF, HFA, and Hemophilia of Iowa file Hemophilia Discrimination Complaint against Wellmark Blue Cross Blue Shield

Hemophilia B Pediatric, Adult Patients Benefit from Idelvion Studies Show

Regis Jesuit's Elijah Warren Eager to Get Going at Arizona State

UniQure Presents Data on Hemophilia B Gene Therapy Research

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:

Aug 26: NHF Colorado 2017 Walk for Hemophilia—Sloan's Lake Park –donate by going to cohemmo.org.

Aug 27: Pediatric Stroke Parent Support Group Summer Picnic—Sloan's Lake Park

Sept 4: Clinic, Pharmacy, & Admin offices closed for Labor Day

Sept 16: RMHBDA Walk for Hemophilia—Billings, MT

Sept 23: RMHBDA Walk for Hemophilia—Kalispell, MT [date change]

Sept 27-29: Outreach Clinic-Grand Junction, CO

Oct 20-22: PEP (Parents Empowering Parents) Program—Denver [date change]

Nov 4: Self-Infusion Clinic

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

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