The Clotting Connection

A Newsletter for Families with Bleeding and Clotting Disorders

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University of Colorado
Anschutz Medical Campus
Hemophilia and Thrombosis Center

Affiliated with
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and University of Colorado Hospital

March is Bleeding Disorders Awareness Month

We challenge you to take the Red Tie Challenge! Rock the tie!

We challenge you to take the Red Tie Challenge! What is this Red Tie Challenge you ask? For the past 30 years March has been designated "Hemophilia Awareness Month" but this year the US Department of Health and Human Services (HHS) officially broadened this month of awareness to fully include all of those with bleeding disorders, such as von Willebrand disease or other rare clotting factor deficiencies. March is now not just for "Hemophilia Awareness", but has been changed to "**Bleeding Disorders Awareness Month**."

As a part of that change, the National Hemophilia Foundation started a fun campaign called the Red Tie Challenge to help bring awareness during Bleeding Disorders Awareness Month. This challenge asks people to share their own creative way of wearing a red tie and encourage others to get involved. The red tie is to express the blood ties we have in a community facing bleeding disorders. All are encouraged to challenge friends and family to also take the challenge to spread the word. Including the hashtag #RedTieChallenge on social channels such as Facebook or Twitter can help spread the word. Take the opportunity to bring awareness and remind those around us to consider a donation to support the bleeding disorders community.

The Pharmacy wants you to take the challenge!

Our staff has been donning red ties all over the office and we would love to see you in red ties too. It only takes a few seconds to grab a red tie, snap a picture or video and share it on Facebook, Twitter or other social media.

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Our research lab looks great in red!

INSIDE THIS ISSUE

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

OVER 5000 RESPOND TO NATIONAL SURVEY OF US HEMOPHILIA TREATMENT CENTERS

PSS
National HTC Patient Satisfaction Survey

What do people with bleeding disorders really think about their Hemophilia Treatment Center (HTC)? How satisfied are they with their care? Are there groups of patients that have specific problems with getting the HTC services they need? These are some of the questions that over 5,000 people with bleeding disorders answered in the first national survey of HTC patient satisfaction.

What is the National HTC Patient Satisfaction Survey?

In early 2015, HTCs in the United States sent out a survey to their patients, called the Patient Satisfaction Survey (PSS). The two-page PSS was designed using questions similar to other national surveys using input from the ten HTC Regional Coordinators. The intent was to measure the level of satisfaction with care that people received at their local HTC during 2014. Each center mailed paper copies to their patients or provided an online option. While all surveys were anonymous, the form indicated the name of the center where the patient received care. Patients returned completed surveys to the HTC at the University of Colorado, which compiled and shared the results with each region and center.

Why was the Survey Conducted?

While many centers have conducted their own satisfaction surveys in the past, this was the first survey of how HTCs nationwide are doing. The surveys were sent from 133 centers to over 28,000 patients or their caregivers, representing over 95% of all HTCs in the US. The feedback is valuable to centers and delivers a snapshot of national, regional and local views of success and areas for improvement. Patients responding included those with bleeding disorders such as hemophilia A, hemophilia B, and von Willebrand Disease. The survey was in both Spanish and English, asked about severity, age, race and ethnicity, and allowed people to rank the level of satisfaction with care received. Questions included the option to write in comments on what their center was doing well or how it could improve.

> "The only thing I can think of would be to have the hemophilia clinics closer to my home."
>
> 54 year old man with severe hemophilia from West Virginia

> "The care and caring there is far beyond anything I have experienced elsewhere!"
>
> 37 year old woman with von Willebrand Disease, Illinois

What will be done with the results?

The PSS responses describe satisfaction with HTC care throughout the country. While most surveys showed a high level of satisfaction, some responses were not as positive. The results showed that patients have different challenges with their care around the country, including insurance access, language barriers and communication with staff. Patients described what worked well and what did not at their center, providing details to the HTC that may not have been received as openly from patients in person. This vital patient feedback helps all centers focus on what services need to improve at the local, regional, and national levels.

The results of the 2014-2015 Patient Satisfaction Survey led national leaders to agree that surveys should be sent out every two years to see if positive change is occurring at centers over time and to help identify trends in patient satisfaction. The hope is that an increased number of patients will participate, growing the feedback regarding satisfaction, which is an important measure of quality of care. The next survey is tentatively scheduled to be sent out in 2017. Regional HTC leadership thank all patients and caregivers who participated and the HTCs for their collaboration.

> "Communication needs to improve."
>
> Parent of 3 year old boy with severe hemophilia from California

For more information go to: www.htcsurvey.com.

MONTH (FROM PAGE 1)

Our research team wants you to try to tie! Take the challenge today!

If you have questions, you can check out our poster in our clinic, which we also posted on our Facebook and Twitter pages. If you don't have a red tie, you can drop by our clinic and borrow one of our cute 'prop' ties to snap a quick photo. Don't forget to use the hashtag #RedTieChallenge, and we'd love it if you tagged us so we can see your pictures. Use @ColoradoHTC for Facebook and @HTCColorado on Twitter.

See more about the challenge at redtiechallenge.org.

NHF | MARCH IS BLEEDING DISORDERS AWARENESS MONTH

RED TIE CHALLENGE™

REDTIECHALLENGE.ORG

STUDY OF HEMOPHILIA CARE REVEALS PROGRESS, ONGOING HEALTH NEEDS

Brenda Riske, Regional Coordinator for the Mountain States Hemophilia Region and Program Director at the University of Colorado HTC, co-authored with Drs. Mazepa, Monahan, Baker, and Soucie, an article published this month in ***Blood***.

"Men with severe hemophilia in the United States: birth cohort analysis of a large national database" is an analysis of data for 7,486 men with hemophilia collected prospectively by the CDC and 130 federally supported Hemophilia Treatment Centers (HTC) between 1998 and 2011, which represents the largest database of men living with hemophilia.

Complications of hemophilia and treatment were reviewed and separated by age groups. The study found that though care and new medications have continued to improve, frequent bleeding persisted in one third to one half of men studied regardless of age. While younger groups show improving access to standard of care therapy that reduced bleeding frequency, bleeds continued to regularly cause complications at all ages.

The study shows evidence of improving treatments but demonstrated a need for continued effort to improve care. The analysis revealed that the disability gap between severe and mild hemophilia did not grow smaller despite advancements in care.

The full article can be accessed via our website at www.medschool.ucdenver.edu/htc; go to the **RESOURCES** tab; find the **NEWSROOM** tab for the link to the article.

REGISTRATION OPEN FOR EDUCATION DAYZ, APR 8-10

Registration is now open for Education Dayz, to be held on April 8-10, 2016 at the Sheraton Denver Tech Center Hotel in Greenwood Village. Education Dayz is a two-day conference co-hosted by NHF Colorado and the University of Colorado HTC specifically designed for those with bleeding disorders and their families.

This conference will have sessions with experts, including Dr. Tyler Buckner, Dr. Mike Wang, Laura Fox, D.P.T., and nurses Nancy Spomer and Kim Hurdstrom from our HTC.

Sign up now for the opportunity to learn and socialize with other families in the community.

Special sessions are available for young adults, new families, vWD patients, and Latino families. Childcare and teen programs are available. To register and for more details please visit cohemo.org.

RECENT HEADLINES

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

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 head to: **www.medschool.ucdenver.edu/htc** then find the **RESOURCES** tab, and go to the **NEWSROOM** page.

FDA Approves Idelvion to Treat Hemophilia B

BioMarin Receives Orphan Drug Status from FDA for First AAV-Factor Gene Therapy to Treat Hemophilia A

Baxalta Submits sBLA for Adynovate to Treat Pediatric Hemophilia A Patients

Dr. Kohrt, Hemophiliac Who Made Condition a Crusade, Dies at 38

NHF Issues Red Tie Challenge to Support Bleeding Disorders Awareness Month

UPCOMING EVENTS

March is Bleeding Disorders Awareness Month

Apr 8-10: NHF Colorado Education Dayz

Apr 17: World Hemophilia Day

May 27-29: NHF CO Family Camp–Allenspark, CO

May 30: Clinic and Admin closed for Memorial Day

June 6-8: Outreach Clinic–Billings, MT

Jul 8-10: Mile High Camp Leadership Pre-Retreat-Rocky Mountain Village

Jul 10-15: Mile High Summer Camp-Rocky Mountain Village

July 21-23: NHF Annual Meeting-Orlando, FL

July 24-28: WFH World Congress-Orlando, FL

Aug 1-2: Outreach Clinic-Missoula, MT

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

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