March is Bleeding Disorders Awareness Month

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.

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.

The Pharmacy wants you to take the challenge!

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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.

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.

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

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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.

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See more about the challenge at redtiechallenge.org.

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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.

**RECENT HEADLINES**

**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