

The Clotting Connection

A Newsletter for Families with Bleeding and Clotting Disorders

April 2018
Volume 8, Issue 4



University of Colorado
Anschutz Medical Campus
Hemophilia and Thrombosis Center

Affiliated with
Children's Hospital Colorado
and University of Colorado Hospital

EDUCATION DAYS A SUCCESS



Backpacks + Bleeders participants at Education Days showing off their backpacks. Photo: NHF CO.

Last month our HTC participated in NHF Colorado Chapter's Annual Education Days weekend. This event provides an opportunity for families in the bleeding disorder community to learn and connect with others facing similar challenges. Education Days 2018 was very well attended and was one of the larger groups that NHF Colorado has seen in several years.



James Patrick Lynch hosted "Powering Through" with guests Lacey Jai Henderson, Cathy Bombardier and Seth Rohjani. Photo: NHF CO.

Education Days provides opportunities for adults and teens to learn, and has activities and childcare for children as well. A track of sessions was available in Spanish to help those in our community who may need the education and support in that language. Many of the staff from our HTC attend, teach, and provide support throughout the weekend. We also staffed a table to share some of the important news and information about our center with those who were able to attend.

Dr. Mike Wang led a session about gene therapy. This session had a lot of interest and was a great opportunity for Dr. Wang to answer questions about the progress of research and trials.

There were two keynote events and both were very well received. The first was speaker Dawn Rotellini from the National Hemophilia Foundation. She talked about taking control of your own treatment and care. The second keynote event was a "Powering Through" panel hosted by Patrick James Lynch. Panelists shared their story and journey in the bleeding disorder community. The panel included Cathy Bombardier, Seth Rohjani, and Lacey Jai Henderson. Their stories were inspiring and hopeful.

One session, hosted by Backpacks + Bleeders, gave attendees the chance to make a backpack out of tee-shirts. The session allowed discussion about preparing for hiking and the extra precautions that might be needed for those with a bleeding disorder.

We would like to thank NHF Colorado and all who participated and attended to make this event a success!



Claire DiCola from Breckenridge Outdoor Education Center was awarded the Dr. William Hathaway Visionary of the Year Award. Photo: NHF CO.

INSIDE THIS ISSUE

- Education Days
- Patient Satisfaction Survey: Voices of Adolescents
- Upcoming Opportunities
- News
- Events

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



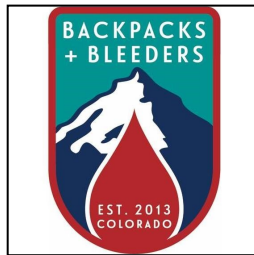
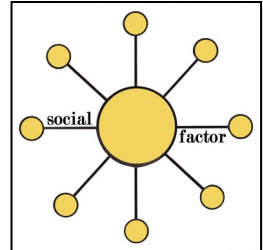
Email:
HTC.Newsletter@ucdenver.edu

UPCOMING OPPORTUNITIES

Bleeding Disorder Parent Support Group

The Bleeding Disorder Parent Support Group will next meet on **May 29, 2018** at our HTC in the administrative side of our clinic from 6 pm to 7:30 pm. This group is open to parents of children with bleeding disorders; both childcare and dinner are provided. We will meet once a month on the last Tuesday of every month. The agenda is up to parents and it is an opportunity for people to come together to share knowledge, experiences, frustrations, triumphs and support in a safe environment. Please RSVP to Angela Blue at angela.blue@ucdenver.edu or 303-724-0167.

NHF Colorado's Social Factor is hosting a Guys Night on Friday, **April 27, 2018** from 5-8 pm at Chopper's Sports Grill. This is an opportunity for some guy time with others in the Colorado bleeding disorder community. Join us to watch the Rockies game, eat some food, and have healthy conversation with other guys in our community. Whether you are a patient with a bleeding disorder, a dad, or another male relative, you're invited! Please RSVP through the NHF Colorado website at cohemo.org under their Program & Events Calendar.



Backpacks + Bleeders is currently planning their next hike, tentatively set for **May 12, 2018**. Please watch the NHF Colorado website cohemo.org, or the Backpacks + Bleeders Facebook page for updated information. We will share their updated information on our social media once the location and time are confirmed. This program is a great opportunity to exercise, learn self-care and make friends enjoying the outdoors. RSVP and learn more about this fun opportunity at cohemo.org under their Program & Events Calendar.

Our next Self-Infusion Clinic will be on **May 12, 2018** from 9 am to 11 am here at the HTC. This is an opportunity for our patients, their spouses, parents and other family members to practice or learn self-infusion skills from HTC nurses. This program is open to all patients with bleeding diagnoses at any severity. You can bring your own factor to self infuse, or practice with saline. It's a great way to practice with confidence knowing a nurse is right your side. Food is provided. Please register by going to cohemo.org and find details under the Program & Event Calendar.



Registration will close soon for both Family Camp and Mile High Summer Camp! Family camp will be on **June 8-10, 2018** and provides a great opportunity for families with bleeding disorders to bond with families and peers. Mile High Summer Camp will be held on **July 15-20, 2018**, with the Leadership Retreat for older teens from **July 13-15th**. Registration is open now and closes for both these amazing camps on **MAY 1st!**

For a list of upcoming events please go to our website at www.medschool.ucdenver.edu/htc and click on the RESOURCES Tab, and find the EVENTS page.



Let Your Voice Be Heard! Take the National HTC Patient Satisfaction Survey Today!



Our HTC is participating in the National HTC Patient Satisfaction Survey! If you, or someone you care for, had contact with us in 2017, we need to hear from you! You can take the survey online at www.htcsurvey.com, or fill out the paper survey you should have received from us in the mail. **All surveys must be completed by June 30, 2018.**

This survey is a follow up to the survey done in 2015. The input from our patients helped our center identify areas of strength and where we need to improve. Your voice now can help our HTC know how we are doing.

Please go to www.htcsurvey.com to take the survey or to find out more information about the results from the previous survey. The survey only takes a few minutes of your time! Thank you for your valuable input!

PATIENT SATISFACTION SURVEY

Patient Satisfaction with U.S. Hemophilia Treatment Centers: Voices of Adolescents



The teen years are a time of change, moving from childhood to adulthood. Teens who have a medically complex bleeding disorder—like hemophilia or von Willebrand Disease—have added challenges growing up. These challenges include understanding and managing the disorder, how to minimize bleeds, how to infuse factor or take other medications, how and when to call the clinic, and how to make appointments. Building these skills takes a lot of help: from parents, other caregivers, and from the Hemophilia Treatment Center (HTC).

Improving the health, safety, and well-being of adolescents and young adults is a

national priority¹. Making sure teens with health issues like a bleeding disorder gain the confidence to manage their medical needs as they mature has become a focus in HTCs nationwide. One priority is increasing communication between HTC providers and teens about planning for adult health care.

What did we ask youth with bleeding disorders about their care?

“Encouraging independence.”

15 year old male with severe hemophilia from Texas

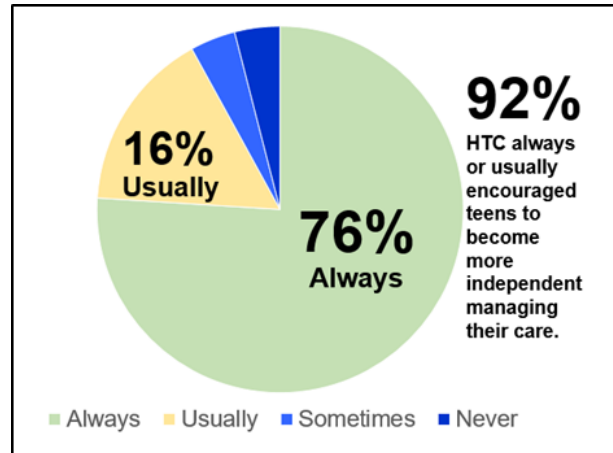
Over 800 HTC patients ages 12-17, or their caregivers, completed the First National Patient Satisfaction Survey (PSS). The survey asked this age group two specific questions about how HTCs encouraged teens to take charge of their own care. The questions asked if they were satisfied with the way the

HTC talked about how to care for their bleeding disorder as they become adults, and whether the HTC encouraged the teens to become more independent in managing their disorder. The feedback was sent back to each HTC so they could find ways to better help teens take charge of their own care.

So, how are HTCs doing? What did we find out?

Overall, 90% of the teens and caregivers reported that they were ‘always or usually’ satisfied with how the HTC

talked about how to care for the bleeding disorder as they become adults.



We also learned that 92% of the teens or caregivers were ‘always or usually’ satisfied with how the HTC encouraged the 12-17 year old to become more independent in managing their bleeding disorder. However, about 8-10% of teens were only ‘sometimes’ or ‘never’ satisfied with HTC adolescent transition discussions with their HTCs.

What’s next?

HTCs are paying extra attention to the ‘teen transition’ to adult care and finding ways to improve their services. Many HTCs are offering skill building workshops: teaching teens how to schedule appointments; how to order and manage medications; and how to work with caregivers to help them take on these responsibilities as they mature.

The second national Patient Satisfaction Survey is now open and available until **June 30, 2018**. We are again

asking teens how the HTC is meeting their needs as they adjust to adult care. By comparing answers from both surveys HTCs can see if they made progress and what work remains.

Details on the 2014 survey and a link to take the current survey are available at www.htcsurvey.com.

For any questions regarding the PSS, please contact us at HTCSurvey@ucdenver.edu.

“Now that my child is a teenager, the staff can talk to him more than they talk to me—he usually won’t talk, so they need to engage him better.”

Parent of 13 year old male with von Willebrand Disease from Ohio

¹Healthy People 2020: Adolescent Health <https://www.healthypeople.gov/2020/topics-objectives/topic/Adolescent-Health>

RECENT HEADLINES

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

FDA Grants Breakthrough Therapy Designation for Hemlibra

World Hemophilia Day Marks 28th Year of Sharing Knowledge

CSL Behring Discontinues Monoclate-P

Dr. Marilyn Manco-Johnson Talks Gene Therapy in Ask The Expert Podcast

Camp Registration is Open—Deadline is May 1st

NHF Encourages Patients to Participate in the Second National HTC Patient Satisfaction Survey

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:

Apr 26-29: HFA's 2018 Annual Conference

Apr 27: NHF Colorado Social Factor: Guys Night

May 6: Stroke Comeback Trail—Hudson Gardens

May 8: Pediatric Stroke Parent Support Group

May 12: Self-Infusion Clinic—HTC

May 28: HTC Clinic, Pharmacy & Admin closed for Memorial Day

May 29: Bleeding Disorder Parent Support Group

June 3: NHF Colorado Programa de Español: Greeley

June 8-10: NHF CO Family Camp

June 16-21: Camp for Kids with Neurologic Disorders at Roundup River Ranch

June 19-21: Outreach Clinic-Billings, MT

July 15-20: Mile High Summer Camp

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

Hemophilia & Thrombosis Center

13199 E. Montview Blvd., Suite 100
Aurora, CO 80045

Clinic Main: 303-724-0724

or toll free at 888-297-0724

Pharmacy Main: 303-724-0168

or toll free at 888-724-7427

Web page:

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

PLEASE
PLACE
STAMP
HERE