

The Clotting Connection

A Newsletter for Families with Bleeding and Clotting Disorders



University of Colorado
Anschutz Medical Campus
Hemophilia and Thrombosis Center

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

MARCH IS BLEEDING DISORDERS AWARENESS MONTH



Patients, family members, and others gathered at the Colorado State Capitol to educate legislators on the needs of those with bleeding disorders. Photo courtesy NHF Colorado.

Groups and individuals advocating for those with bleeding disorders wear red ties as they visit their local and national leaders to spread the word about their unique needs. Many in both Washington and at state capitols now recognize these grass roots groups wearing their red ties as they discuss the very significant health needs of those with hemophilia, von Willebrand disease and other bleeding disorders.

On Friday, March 16th, 2018, NHF Colorado held its second annual Statehouse Day at the Colorado State Capitol to raise awareness and educate Colorado legislators on the issues that are important to the bleeding disorders community. This year the focus was HTC education and the need for access to the treatment center. They were hosted by Rep. Joann Ginal (Ft. Collins) and a tribute to Bleeding Disorders Awareness Month was read on the House floor.

Others throughout the country have taken the opportunity to visit Washington D.C. to bring similar awareness and understanding to national legislators. In nearly all of these visits to those serving in these leadership roles, members of the bleeding disorder community have worn red ties to stand out and be remembered.

March is Bleeding Disorders Awareness Month, which means it's time to get out the red ties! For the past couple of years the National Hemophilia Foundation has encouraged members of the bleeding disorder community to spread awareness by sharing photos of themselves with red ties. The red tie symbolizes the blood ties that bind these community members together and they have left an impression both locally and nationally. The campaign has led to shared information and awareness and has encouraged donations and support.



NHF Colorado members advocating at the State Capitol. Photo courtesy NHF Colorado.



HTC Program Director Angela Blue and HTC Social Worker Audra LeBlanc meet with Senator Kevin Priola (R) who represents the district where our HTC is located. Photo courtesy NHF Colorado.

INSIDE THIS ISSUE

- Bleeding Disorders Awareness Month
- Upcoming Opportunities
- Long Time Employees of CU Medicine honored
- HTC Staff Attends THSNA
- News
- Events

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



Go to facebook.com/ColoradoHTC



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Website: Go to medschool.ucdenver.edu/htc

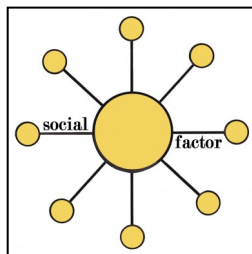


Email:

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[Continued on page 2]

UPCOMING OPPORTUNITIES

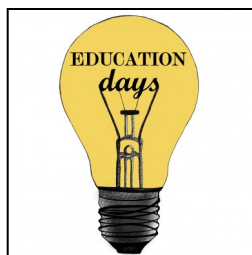


NHF Colorado's Social Factor/Backpacks + Bleeders Mashup will be Saturday, **March 24, 2018** from 12 pm to 3 pm. This event will be an indoor, educational, "Do it yourself" workshop that will teach you the 10 wilderness essentials when playing outdoors. You will even have chance to put together a DIY backpack that you can take home after the program! For more details and to RSVP, please go to cohemo.org and click on their Program & Event Calendar.

Our first Bleeding Disorder Parent Support Group will meet on **March 27, 2018** at our HTC in the administrative side of our clinic from 6 pm to 7:30 pm. This group is open to parents

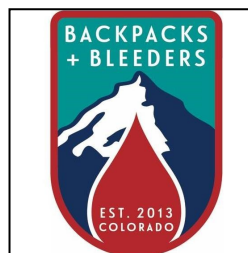
of children with bleeding disorders and both childcare and dinner is provided. We will meet once a month on the last Tuesday of every month. The agenda is up to parents and it is an opportunity for people to come together to share knowledge, experiences, frustrations, triumphs and support in a safe environment. Please RSVP to Audra LeBlanc at audra.leblanc@ucdenver.edu or 303-724-6163.

Bleeding Disorder Parent Support Group



Education Days is rapidly approaching! Don't miss this great opportunity to learn and connect with others in the bleeding disorder community! This is a great weekend of fun and education aimed at families and individuals who want to learn about bleeding disorders, making healthy choices, and get to know others with similar issues. Kids even have their own special activities so adults can concentrate, and there is a separate track for teens. Education Days will be on **April 6-8, 2018** at the Denver Marriot South at Park Meadows location: 10345 Park Meadows Dr., Lone Tree, CO 80124. Don't forget that the registration deadline for Education Days is **March 30th!**

Backpacks + Bleeders is hosting their next hike on Mount Falcon Castle Trail on Saturday, **April 14th, 2018**. The hike is considered moderate and is a 7.9 mile out and back, heavily trafficked trail near Morrison, Colorado. Enjoy beautiful views, great friends, and get outside! Dogs are welcome on this trail but must be kept on leash. RSVP and learn more about this fun opportunity at cohemo.org under their Program & Events Calendar.



Our next Self-Infusion Clinic will be on **Saturday, 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. Working with our nurses, this program is open to all our 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.



It is time to get registered for 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.



[Continued from page 1]

The NHF is encouraging wearing your red tie, snapping a photo, sharing it on social media, and asking people to donate to support those with bleeding disorders. In addition, they are asking for members of the community to sign an online petition that emphasizes the need for quality healthcare. Their website redtiecampaign.org has various ways you can support and share information about bleeding disorders during Bleeding Disorders Awareness Month and up through World Hemophilia Day, on April 17th.

We have a poster in our clinic explaining the campaign that includes some fun ties for patients and families to use to snap a photo if they so desire. Whether it's a photo of you or your family with red ties, inviting others to join you at the local Walk for Hemophilia, sharing informational videos or resources online, or visiting your local statehouse to speak to a senator, your efforts can make a difference. We hope that you can choose one or more of the many ways to support bringing awareness to bleeding disorders during March and the rest of the year.

LONGTIME HTC STAFF HONORED



Sharon Funk was honored for her 40 years of service at CU Medicine. Photo: CU Medicine Staff

Our HTC is very happy to congratulate two of our staff for hitting major milestones with CU Medicine. Sharon Funk, one of our physical therapists, has achieved forty years of service with CU Medicine, starting with the HTC in 1977. Lynn Magnuson, our accountant, has reached fifteen years of service with CU Medicine this year. However, Lynn has been with the HTC when she started on a temporary basis, since 1997, bringing her service with us at the HTC to twenty years. Both were honored at a recent breakfast hosted by the CU Chancellor's office marking exempt professional and classified staff who had achieved years-of-service milestones in 2017. Those milestones were marked in five year increments beginning at ten years. You can read about this special event by going to our website newsroom.

Sharon was the second longest tenured staff member honored, and has worked almost exclusively with the Hemophilia and Thrombosis Center under CU Medicine. She is one of the few who have seen patients grow from infancy to adulthood and witnessed so many changes over the years. She's seen everything from new ways to manage

care, the HIV/AIDS crisis that so affected our patients, and she's moved with our clinic multiple times as the HTC has grown. Most of our patients have worked with her for many years and trust her long time experience with prevention of joint disease through good management of their bleeding disorder. Sharon works closely with our doctors and others on our physical therapy team to make sure our patients receive the care they need to maintain a healthy lifestyle.



Lynn Magnuson was honored for 15 years at CU Medicine.

Lynn began work with us exclusively through our pharmacy. Starting as a temporary employee, she helped the HTC pharmacy navigate the federal hoops to form a 340B Pharmacy. This program allows our patients to access the vital medications they need at a lower cost through a federal program. Lynn has helped to carefully manage the financial details of the HTC and has been a tremendous asset. Though she doesn't often visit with patients, her hard work helps to keep the HTC on strong ground.

These two are just examples of the fantastic staff here at the HTC that are committed to the care of patients with bleeding and clotting disorders. We are grateful for their years of service and expertise. They both have provided incredible examples to the entire HTC staff. Thank you for your hard work Sharon and Lynn!

HTC STAFF PARTICIPATES IN THSNA 2018 SUMMIT



Dr. Marilyn Manco-Johnson speaking at THSNA 2018. Photo: Angela Blue.

Several of our staff from the HTC were able to participate in the Thrombosis & Hemostasis Summit of North America that was held earlier this month in San Diego, California. The summit is an opportunity for professionals who treat or work with bleeding and clotting disorders to meet, learn, and discuss the latest in treatments and research findings.

The summit hosts more than 1,500 people who are in some way involved in the care of those with bleeding or clotting disorders. It is sponsored by fifteen leading non-profit organizations who work with either bleeding or clotting disorders. Sessions included experts and researchers speaking on topics ranging from drug interactions to gene therapy.

Both Dr. Marilyn Manco-Johnson and Dr. Jorge DiPaola spoke during panel sessions at the conference. Dr. Manco-Johnson spoke at a session addressing thrombosis in challenging patient populations and discussed "Thrombolysis and Thrombectomy in Pediatrics." Dr. DiPaola spoke on using genomics and proteomics to dissect platelet disorders in a session regarding controversies in platelet disorders. Attending THSNA is just one of the opportunities our staff takes to continue learning and teaching others about the changes and research that is ongoing in the bleeding and clotting disorder field.

RECENT HEADLINES

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

Camp Registration is Open—Deadline is May 1st

Hemophilia Gene Therapy is Effective and Safe *Blood* Reports

Miracle of Hemophilia Drugs Comes at a Steep Price

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

Bleeding Disorder Awareness Month Begins with Red Tie Campaign

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:

Mar 27: Bleeding Disorders Parent Support Group

Apr 6-8: NHF CO Education Days

Apr 11: Outreach Clinic—Colorado Springs

Apr 14: Backpacks + Bleeders—Mount Falcon Castle Trail

Apr 17: World Hemophilia Day

Apr 26-29: HFA's 2018 Annual Conference

May 1: Registration Deadline for Family Camp & Mile High Summer Camp

May 6: Stroke Comeback Trail—Hudson Gardens

May 12: Self-Infusion Clinic—HTC

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**

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

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