

The Clotting Connection

A Newsletter for Families with Bleeding and Clotting Disorders

June 2024
Volume 14, Issue 6



Hemophilia and Thrombosis Center
UNIVERSITY OF COLORADO ANSCHUTZ MEDICAL CAMPUS



Affiliated with
Children's Hospital Colorado

HTC HELPS HOST PT CONFERENCE



Physical therapists, members of the Hemophilia Alliance, and HTC staff met May 15-17, 2024 for the First Annual Hemophilia Alliance Physical Therapy CE Conference. The group gathered at the Brown Palace for a meet and greet during the conference. Photo: Kiet Huynh, Hemophilia Alliance

In May, The Hemophilia Alliance, in collaboration with our HTC, hosted their First Annual Physical Therapy CE Conference. This was a gathering of over forty physical therapists from HTCs around the country to learn and connect with others who treat bleeding disorder patients. In fact, we had HTC physical therapists from every region of the United States in attendance. CE stands for Continuing Education, which means this was a conference that allowed physical therapists to gain credit for their learning. The two-day conference was held in downtown Denver at the Brown Palace the first day, and at our center the second day. It was an opportunity to learn from experts as they presented the latest innovations in physical therapy for the bleeding disorder community.

Laura Singer-Fox, our senior physical therapist, was on the planning committee that organized the conference and helped with logistics along with several other members of our staff. Our location was ideal for the conference because of our new PT lab/gym and flexible space options at our building on the CU Anschutz Medical Campus.

The speakers were chosen from physical therapists around the country, including our own former lead PT, Sharon Funk. She taught on the Hemophilia Joint Health Score (HJHS), which is a measurement of joint health that Sharon helped develop. Other topics covered were grants, orthotics, acute bleed management, and MSKUS (musculoskeletal ultrasound), including a demonstration and practice session. Laura Singer-Fox was a lab instructor on the HJHS course and the MSKUS course. Nikki Clark, another of our PTs, was an excellent group leader during the practice sessions of both the HJHS and MSKUS courses.



Sharon Funk, who ran our PT program at the HTC for many years, came to speak and teach at the PT Conference. Photo: Kiet Huynh, Hemophilia Alliance

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Physical therapists met and learned at the recent PT Conference held at the Brown Palace in Denver and at our HTC. Photo: Kiet Huynh, Hemophilia Alliance

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Website: Go to

medschool.cuanschutz.edu/hemophilia-thrombosis



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HTC.Newsletter@ucdenver.edu

SPOTLIGHT: ANNA CHESHIRE, NBDF PROGRAM MANAGER



Meet Anna Cheshire, the new Chapter Program Manager at the Colorado NBDF Chapter. Photo: Anna Cheshire

You may have noticed that there have been some changes at the Colorado Chapter of the National Bleeding Disorders Foundation (NBDF). We are excited to get to work with their new Chapter Program Manager, Anna Cheshire, who has recently started with Colorado NBDF, coming from a skiing and snowboarding non-profit. We asked Anna a few questions so our readers could get to know her a little right before she heads up to help run Mile High Summer Camp!

Anna graduated from the University of Tulsa with a B.S. in Anthropology in May 2022, and moved to Denver soon thereafter. She grew up in Albuquerque, New Mexico, and is the middle child of three sisters in her family. She became interested in working with non-profit organizations after volunteering on a week-long service trip hosted by teachers in her school.

She had the chance in high school to do an internship with a cultural resource management firm which helped spark her interest in anthropology. She also has always liked learning about history. When she headed to college, she studied anthropology with minors in history, biology, and education.

Anna is already a part of the bleeding disorder community, as her family are hemophilia B carriers. Her maternal grandfather had hemophilia B and her mother and aunt were obligate carriers, and she found out she was a carrier when she was 20 years old. She began learning more about the bleeding disorder community and becoming involved. Her background working with non-profits, education, and event planning brings her well suited to provide leadership and support to the Colorado Chapter of the NBDF.

While she has only been working for the Colorado Chapter for a few months, she is excited to be involved



Anna at the top of her first Colorado 14er with one of her friends. Photo: Anna Cheshire

in the planning of events and programs that many of our patients benefit from. She was at Family Camp in early June and is in the middle of managing registrations, answering questions, and coordinating with educators, our HTC staff, and volunteers who will be working at Mile High Summer Camp in July!

She shared, ***“Working at NBDF has put me back in my favorite kind of work which is doing something that delivers tangible experiences to people and helps them to thrive. I have really been loving getting to know the community. Working with the HTC team has also helped me to see more sides of bleeding disorders.”***

Anna loves to read, and particularly enjoys Jane Austen—she even took an entire class just on Austen’s works in college. She also enjoys a good psychological mystery and shared that other favorite authors are Sally Hepworth and Liane Moriarty. She also loves playing volleyball and is on a local recreational volleyball team. Anna loves to take walks and go hiking. She did her first Colorado 14er last year and is hoping to get another one in this summer. She has friends all over the country and loves to visit them and explore to learn about where they live.



Anna enjoying a hike, one of her favorite things to do. Photo: Anna Cheshire

She is excited to be working with Colorado NBDF and our HTC, and looks forward to finding ways to innovate new ideas for how best to serve the bleeding disorders community. She would love feedback and ideas from community members to help direct future activities. You can contact Anna at acheshire@bleeding.org and find more information about upcoming events and activities at the NBDF Colorado Chapter website at cohemmo.org.

Anna shared a quote that inspires her from Kirk Cousins, the Atlanta Falcon’s quarterback, who said, ***“You must strive for perfection in order to achieve excellence.”***

She thinks about this quote often, acknowledging that nothing is going to be perfect, but that pushing to be better is the only way to progress. We are grateful for Anna and her optimistic and energetic personality! We hope you get to know her when you are able to attend an upcoming NBDF event!

[Continued from page 1] Dr. Beth Warren brought in her children for the MSKUS course lecture so the instructor could demonstrate how to use a musculoskeletal ultrasound on children. The event was very well received and allowed these physical therapists the chance to discuss the unique issues that come up with their patients. This conference is one of very few dedicated to physical therapists and their continued education in advances in the care of the bleeding disorder population. It was a wonderful opportunity to build connections between these providers. We are grateful to the Hemophilia Alliance for their leadership in creating this conference and our HTC was happy to be involved.

We thank all who taught, attended, and made the conference a success to build on for future learning opportunities for physical therapists who care for bleeding disorder patients.



One of the classes during the conference focused on MSKUS, or musculoskeletal ultrasound. The MSKUS is a helpful clinical tool but it isn't a skill all PTs may have learned. The conference gave PTs hands-on experience working with this specialized equipment and in learning how to interpret the information they see. Photos: Merilee Ashton (left), Kiet Huynh, Hemophilia Alliance (right)

DROPS OF LOVE

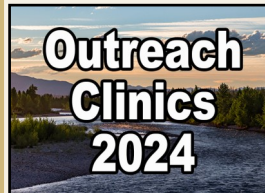


We have a new program at our HTC called “Drops of Love” to celebrate our staff.

If anyone at our center went above and beyond when you visited, we would love to hear about it!

Just scan the QR code (above) to send a “drop of love” to our staff members and let us know how they made a difference in their service to you!

UPCOMING OPPORTUNITIES



Our HTC visits locations in our region to offer comprehensive care to patients who live in more distant cities from our main clinic.

Upcoming Outreach Clinics include:

- July 30-Aug 1, 2024—Billings, MT**
- Aug 27-29, 2024—Missoula, MT**
- Sept 17-19, 2024—Billings, MT**
- Oct 8-10, 2024—Grand Junction, CO**

Join us at the Unite for Bleeding Disorders Walks in 2024. This fundraiser supports the Colorado Chapter of the NBDF and the Rocky Mountain Hemophilia & Bleeding Disorders Association in Montana.

Unite
for Bleeding Disorders

Donate, raise funds, and walk with us as we bring awareness and provide support for the educational and community events provided by these organizations.

Colorado NBDF Unite Walk

August 24, 2024—Sloan's Lake Park, Denver, CO

RMHBDA Unite Walk

September 7, 2024—Zoo Montana, Billings, MT

RECENT HEADLINES

These are a few of the headlines that we've recently featured on our Newsroom page or on Social Media:

FDA Grants Orphan Drug Status to Biopharma's B-cell Treatment for Hemophilia B

Phase 3 Trial Shows Mim8 Better at Reducing Bleeds for Hemophilia A Patients than Standard Treatments

New Study Shows Long Term Benefits of Gene Therapy for Severe Hemophilia A

FDA Approves New Hemophilia B Gene Therapy Product BEQVEZ

New Long-Term Data Shows Emicizumab Safe, Effective in Hemophilia A Patients

We maintain a newsroom page at our website with a list of news articles that may be of interest to our patients and families. Go to medschool.cuanschutz.edu/hemophilia-thrombosis/resources/newsroom to read more. We also share news on our [Facebook](#) and [Twitter](#) accounts.

Sign up to get this newsletter delivered directly to your email box each month! Just go to eepurl.com/bnszoz or scan the QR code and fill out the form!



QR Code to Subscribe!

UPCOMING EVENTS

Mark Your Calendars:

Please note. These dates may be tentative and subject to change. Please check appropriate websites for confirmation of events.

July 4: HTC Clinic, Pharmacy and Admin offices closed for Independence Day

July 12-14: Teen Leadership Weekend

July 14-18: Mile High Summer Camp

July 30-Aug 1: HTC Outreach Clinic—Billings, MT

Aug 8-9: RMHBDA Teen Retreat—Camp Paxon, Seeley Lake, MT

Aug 9-11: RMHBDA Big Sky Family Camp—Camp Paxon, Seeley Lake, MT

Aug 24: NBDF Colorado Unite for Bleeding Disorders Walk—Sloan's Lake, CO

Aug 27-29: HTC Outreach Clinic—Missoula, MT

See more at our Events Page on our website:
medschool.cuanschutz.edu/hemophilia-thrombosis/resources/events-calendar

ME-WE-HTC We create hope.

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