

# The Clotting Connection

A Newsletter for Families with Bleeding and Clotting Disorders

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Hemophilia and Thrombosis Center  
UNIVERSITY OF COLORADO ANSCHUTZ MEDICAL CAMPUS



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## HTC PHYSICAL THERAPY TEAM PROVIDES DYNAMIC SUPPORT



Our dynamic and talented PT team includes (L to R) Nikki Clark, Joanna Roybal, and Laura Singer-Fox. Photo: Joanna Roybal

Most of our patients at the HTC are familiar with the comprehensive care model that we use in our clinic. Comprehensive care allows us to treat the whole person as a cohesive team working together with patients to achieve their goals. As a part of this model, we connect patients with hematologists, nurses, social workers, pharmacists, physical therapists, and genetics specialists as well as provide the opportunity to collaborate with researchers to improve care for all.

wellness. Our physical therapists are experts at evaluating musculoskeletal health, movement patterns, and physical function. They provide education on joint and muscle bleeding and how to take care of yourself. Our HTC is one of the only centers in the country with three full-time physical therapists, and the only one in our region with this amount of PT patient support. We wanted to highlight our physical therapists this month and share some exciting updates with new treatment resources that are now available.

Our PT team is made up of three incredible people! Laura Singer-Fox, PT, DPT has been at our HTC for thirteen years and knows many of our patients very well. She leads our team which includes Joanna Roybal, PT, DPT, PCS, and Nikki Clark, PT, DPT, TPS. Joanna joined our team two and a half years ago, and Nikki started with us two years ago. All our PTs have their doctorate degrees and as a team hold licenses to practice in Colorado, Montana, South Dakota, Wyoming, and Nebraska. This allows our team to treat patients from all over our region.

In addition to providing comprehensive care as a part of our clinical team, our physical therapists provide differential diagnosis in acute situations, rehabilitation, and provide out-patient therapy and home exercise programs as indicated. They are all trained to use musculoskeletal ultrasound for bleeding disorder patients, providing a valuable tool in caring for joint and muscle health.



Nikki Clark helps a patient on the stairs in the new PT gym. Ask our PT team about how this new space can improve care. Photo: Merilee Ashton



Laura Singer-Fox demonstrates the angle on one of the large treadmills in the new PT gym and Motion Analysis Lab. Photo: Merilee Ashton

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# NEW PT GYM AND MOTION ANALYSIS LAB OPENS AT HTC

Over the past year you may have noticed that our HTC has done quite a lot of construction. The area that used to house our administrative staff has been completely transformed. All our offices have now been moved upstairs to the second floor, and the years of planning and construction are mostly coming to an end!

On December 7, 2023, our HTC opened a part of this new area and unveiled **The Funk Manco-Johnson Physical Therapy and Motion Analysis Laboratory!** The lab was named after one of the HTC's longtime Physical Therapists, Sharon Funk, who retired in 2018 after 41 years working at the HTC, and our former HTC director Dr.

Marilyn Manco-Johnson, who continues to work at our center. Sharon and Marilyn worked together on groundbreaking research proving the impact of prophylactic treatment on joint damage over time in people with hemophilia.

This is an area with dedicated equipment and space to support physical therapy at our clinic that is integrated with a modern motion analysis portion devoted to research. The space has banks of cameras set up to measure movement in study patients with strategically placed reflective markers. It also includes a Plantar Pressure mat to measure foot pressure during activities and a lot of physical therapy equipment to treat PT patients.



Physical Therapists Laura Singer-Fox and Sharon Funk pose with Dr. Beth Warren and Dr. Marilyn Manco-Johnson at the unveiling of the new name for the PT Gym and Motion Analysis Lab. Photo: Merilee Ashton

Several studies will be ongoing in this lab. One is a study using the Plantar Pressure mat, looking at pressure distribution on the feet during various movements to see if subtle differences could predict re-bleeding after an injury. There will be significant research with the POBBOY study (Prevention of Bleeding with Biomechanics and Optimization of prophYlaxis), an effort being led by Dr. Beth Warren.



The HTC PT Team and the HTC Biometrics team are joined by Sharon Funk, PT (middle), Dr. Marilyn Manco-Johnson (third from right), and Dr. Jim Carollo from Children's Hospital (left end), at the opening of the **Funk Manco-Johnson Physical Therapy and Motion Analysis Laboratory**. The space will serve physical therapy patients & research. Photo: Merilee Ashton

The POBBOY study involves performing simulated sports tasks while using reflective markers and cameras to track movement, then tracking bleeds on a specialized app. The Laser Labyrinth Proprioception Training (LL-PT) study allows PTs and researchers to look at how joint damage in ankles can lead to issues with the disconnect of the perception a patient may have with how their ankles move. These are just a few of the research projects that this lab will make possible in improving care of patients with bleeding disorders.

Having a lab with equipment for our patients to use with physical therapists, as well as equipment to analyze the movement and forces on a patient's body can lead to a better understanding of what impacts bleeding can have on muscles, joints, and pain.

Patients who have bleeding disorders and qualify can get involved in one or more of these research projects that are now enrolling, and many of our patients who work with our physical therapists will soon be using the equipment for PT support. If you are in our clinic, ask our PTs and researchers about these new resources.

Congratulations to all involved in creating this significant new area for our HTC!



Dr. Beth Warren got covered in reflective markers to show how the motion capture system works in the new lab area. Photo: Merilee Ashton



[Continued from page 1] Laura, Joanna, and Nikki are all involved with our bleeding disorder community in the many events provided through NBDF Colorado and RMHBDA in Montana. They provide support at Mile High Summer Camp, camp leadership weekends, family camp, and outreach clinics. They participate and teach at Education Days, and love attending Backpacks + Bleeders activities, fundraising walks, and other community educational events. Each of our physical therapists has provided presentations to bleeding disorder colleagues regionally, nationally, and internationally.

Each of our PT team members have unique skills and areas of interest which enhance the resources available to this diverse patient population.

Laura leads our PT team and has a large focus on quality improvement and education for patients. She is involved in several multi-disciplinary projects including education for transition-age patients, developing educational materials for new patients with various bleeding disorder diagnoses, and access to/standardization of care for biological females with bleeding disorders. She is working to identify other subgroups of patients who may benefit from increased access to physical therapy services.

Joanna is a certified pediatric specialist and has a strong background in orthopedics and gait analysis. She is an expert at developmental biomechanics and orthotic prescription. Joanna and Dr. Beth Warren are working on a new project supported by a grant from the Hemophilia Alliance. The grant supports a project investigating the impact of a novel physical therapy intervention on ankle joint proprioception, or the body's ability to sense joint position.

Nikki specializes in physical therapy for complex pain symptoms, which is a common issue with many of our patients. She is the HTC Pain Clinic coordinator, which is a new specialty clinic within the HTC supporting patients with bleeding and clotting disorders and chronic pain. The

HTC Pain Clinic team includes Nikki, Bryn Dunham, LCSW, and Dr. Tyler Buckner, MD. They meet with patients to discuss options for optimizing function while decreasing the impact of chronic pain on daily life. Reach out to Nikki if you have questions about chronic pain management at the HTC.

Last month our HTC completed a new physical therapy gym and lab space that allows our PT team to engage with patients with the space and equipment to support health and analysis of a patient's issues.

The new physical therapy gym space is a resource for our patients to work with our PT team to achieve goals such as decreasing pain, improving range of motion and strength after a joint or muscle bleed, and increasing overall health and wellness. Our PT team is excited to incorporate this new gym space into the support and care of patients at our center. The motion analysis laboratory has also been completed and is currently being utilized for research but will have clinical applications in the future. (see page 2)



Laura shows how some of the new PT gym equipment is designed to help patients. Photo: Merilee Ashton

We congratulate our physical therapy team on the new gym for patient care and thank them for their ongoing efforts to improve the quality of life and physical well-being of our patients. We encourage patients to reach out to our PT line at 303-724-0369 with questions regarding physical therapy indications and safety during exercise and sports.

Our patients benefit so much from physical therapy, and our HTC is grateful for the PT Team, their leadership, and their expertise in supporting patients.

## GRATEFUL TO SHARE HOLIDAY CHEER



Our HTC was thrilled to sponsor our third annual holiday project last month. This was a well-supported and heartwarming time as our staff came together to support families who needed a little extra help during the holiday season. Gifts as well as gift cards were donated, wrapped, and packed up.

We watched two versions of "A Miracle on 34<sup>th</sup> Street) while wrapping presents and we finished with a record time of 4 hours! We thank our HTC staff for going above and beyond to help deliver a little extra joy during the season, and we hope 2024 is filled with peace and prosperity for all our HTC families!

## MARK YOUR CALENDAR: 2024 EVENTS!

January is the time of year where goals are set and we pencil in plans for the months ahead. NBDF Colorado & RMHBDA have shared some dates for 2024 that you may want to mark down and set aside. We keep an online calendar on website—go to [Resources>Events Calendar](#). Confirm dates and info at [cohemmo.org](http://cohemmo.org) and [rmhbda.org](http://rmhbda.org).



- Mar 2:** Bleeders on the Slopes (NBDF CO)—Granby, CO
- Mar 22-24:** NBDF CO Education Empowerment Days—Denver, CO
- Apr 19-21:** RMHBDA Education Weekend & Meeting—Pray, MT
- June 7-9:** NBDF CO Family Camp—Allenspark, CO
- July 12-14:** Teen Leadership Weekend—Empire, CO
- July 14-18:** Mile High Summer Camp—Empire, CO
- Aug 8-9:** RMHBDA Teen Retreat—Seeley Lake, MT
- Aug 9-11:** RMHBDA Big Sky Family Camp—Seeley Lake, MT
- Aug 24:** NBDF CO Unite for Bleeding Disorders Walk—Denver, CO
- Sep 7:** RMHBDA Unite for Bleeding Disorders Walk—Billings, MT
- Oct 4-6:** NBDF Women's Wellness Retreat—Denver, CO
- Nov 1-3:** RMHBDA Women's Retreat—Pray, MT

## RECENT HEADLINES

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

**Jivi Safe, Effective for Hemophilia A in Long-term Study**

**First US Patient Treated with Hemophilia A Gene Therapy Outside a Clinical Trial**

**Three Year Study Shows SerpinPC is Safe and Reduces Bleeds in Hemophilia A & B**

**Gene Therapy Hemgenix Lowers Bleeding Rates and Rate of Replacement Therapy**

**Dosing Begins in Phase 1/2a Trial of Optimized Gene Therapy for Hemophilia A**

**FDA Grants Dual Designations for Investigational Hemophilia A Therapy**

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](https://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](http://eepurl.com/bnszoz) or scan the QR code and fill out the form!



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## UPCOMING EVENTS

### Mark Your Calendars:

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

**Feb 8:** Pediatric Stroke Support Group Virtual Meeting

**Feb 10:** Backpacks + Bleeders Hike Rocky Mountain Arsenal

**Feb 18:** NBDF CO Women's Teatime Event

**Feb 19:** Clinic, Pharmacy, and Admin offices closed for Presidents Day

**Feb 29:** Rare Disease Day

**Mar 2:** NBDF CO Bleeders on the Slopes—Granby, CO

**Mar 6-8:** NBDF Washington Days—Washington, DC

**Mar 22-24:** NBDF CO Education Empowerment Days—Denver, CO

**See more at our Events Page on our website:**  
[medschool.cuanschutz.edu/hemophilia-thrombosis/resources/events-calendar](https://medschool.cuanschutz.edu/hemophilia-thrombosis/resources/events-calendar)

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