

The Clotting Connection

A Newsletter for Families with Bleeding and Clotting Disorders



Hemophilia and Thrombosis Center
UNIVERSITY OF COLORADO ANSCHUTZ MEDICAL CAMPUS



Affiliated with
Children's Hospital Colorado

GROWING INTO A NEW DECADE

It's already 2020 and as we head into a new decade we thought we would reflect on the changes in the past 10 years. Our HTC has been in operation in some form since 1973 and has seen more than four decades of patients, treatments, and locations. Many of our patients and families have been with us even before that! We are grateful for the positive changes we have seen over the years. What has happened over the past decade? Quite a lot!

Location, location, location

In 2010, the Hemophilia and Thrombosis Center was located in the Fitzsimons Building, which was known then as Building 500. Many other buildings on Anschutz Medical Campus had recently opened, including the UC Health University of Colorado Hospital and Children's Hospital Colorado in 2007. Some buildings on campus were still under construction including our current building, the CU Medicine building.

The property on which CU Anschutz Medical Campus now stands used to be Fitzsimons Army Medical Center, which had a rich history of caring for veterans for many years. Building 500 opened in 1941, just days before the attack on Pearl Harbor; it was called Building 500 because it was 500 feet from the center of the campus. It is also well known for treating President Eisenhower for a heart condition on three occasions during his presidency. It is the only significant, historical building to be incorporated into the new Anschutz campus



The Fitzsimons Building (aka Building 500) where our HTC was housed from 1999 to 2011.



Our current location, the CU Medicine Building, where the HTC has been operating since 2011.

layout. Our staff was housed in Building 500 on the first floor for twelve years. However, we knew that our HTC was growing. Our patient population base was expanding, and we were becoming larger, so we needed more space. In 2011, we moved into our current location at the CU Medicine Building (formerly called the UPI Building). We have office space, clinical space, and our pharmacy on the first floor, and our lab is located in one of the research facilities on campus. In the fall of 2019 we expanded our office space further to include a portion of the second floor to make room for added employees and services.

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



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When we moved to our current location, we saw many changes in how we run our clinic, owing to our collaboration with Children's Hospital Colorado. These changes mirrored shifts occurring throughout medical care, such as using electronic medical records, incorporating advanced practice providers as well as medical doctors for visits, and bringing on more staff in nursing, physical therapy, social work and pharmacy. This now includes a Child Life specialist, a psychologist, a geneticist and additional support staff. Our clinic also expanded more services to include a stroke clinic that specializes in pediatric patients, and one that provides services for women with bleeding disorders.

Treatments

In 2010, patients were regularly learning self-infusions and following stricter prophylactic infusion plans to prevent bleeds and joint disease. In the past decade, research and pharmaceuticals have produced more than a dozen new products for patients that have made improvements to quality of life. Subcutaneously administered products arrived on the scene, and



Dr. Marilyn Manco-Johnson at camp in 2010. We have shifted much of the management of camp to NHF Colorado, but many of our staff attend camp each year to provide education and support.

research is ongoing for gene therapy products that promise huge changes for bleeding disorder patients. Better monitoring of factor levels and joint disease, and point of care ultrasound were new diagnostic tools that improved management of care at our center in the past decade.

Although we

continue to have good access to quality orthopedic care, we do not need to refer as many patients! Why? Our proactive infusion protocols have prevented much of the joint disease we used to deal with. Instead, we now refer patients to orthopedic care for more sports and activity-related injuries, showing that our patients are becoming more active in higher-risk activities and are experiencing many of the same injuries of people in the general population.

Research

Our director, Dr. Marilyn Manco-Johnson, has seen hundreds of patients over the years and has been deeply involved in research since she began working in hematology. Her landmark, ten-year Joint Outcome

Study was completed in 2005 and changed the face of hemophilia and how we treat it. It proved that prophylactic treatment of hemophilia patients protected their joints from damage. By 2020, our HTC had an active team of research doctors and staff that allows our patients to be involved in studies, as well as benefit from the findings. Since 2010, our HTC has been a part of hundreds of studies and program grants, some ongoing, some completed. These research projects make it possible for future advancements in care for those with bleeding disorders.

Staff

In 2010, there were about 35 people on our staff, including part-time support, our administrative team, research staff, pharmacy staff, and those working in our labs. The Mountain States region we cover has greatly increased in population in the past decade and the number of those we treat continues to rise. The need for our staff to expand became apparent.



About a third of our staff dressed up as characters in Harry Potter for Halloween in 2019. The HTC has a long tradition of finding the fun as a team-dressing up for Halloween is a favorite staff event.

About 13 members of the staff who were with us in 2010 are still included in our larger staff of about 70 people in 2020. We've expanded our physical therapy team, grown our social work group to a fully staffed psychosocial team, seen our nursing staff increase, added new doctors to allow them to focus on specific patients, and more than doubled our research staff. Our admin team has grown with the need for more providers help to keep the center going, and our pharmacy has expanded to provide their essential services with efficiency.

In the past ten years, the management of most community activities, such as camps or education days were shifted over to the Colorado Chapter of the National Hemophilia Foundation (NHF CO) or the Rocky Mountain Hemophilia and Bleeding Disorders Association (RMHBDA), located in Montana and also covering patients in Wyoming. We regularly have outreach clinics in Montana, Grand Junction, and Colorado Springs to see our patients who live far from our treatment center in the Denver metro area.

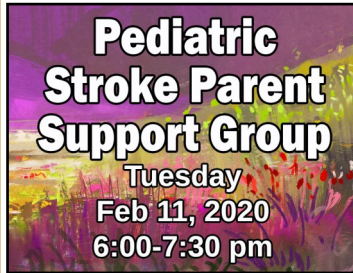
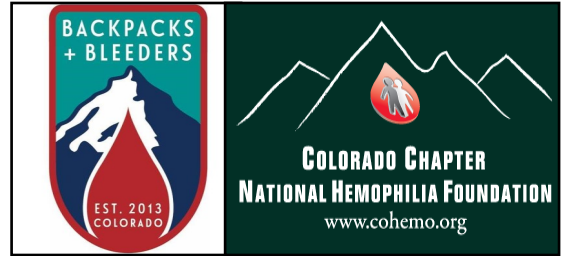
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UPCOMING OPPORTUNITIES

Backpacks + Bleeders is hosting three exciting upcoming activities!

- Jan 25, 2020— Indoor Rock Climbing in Colorado Springs, CO
- Feb 15, 2020— Snowshoeing Mayflower Gulch in Frisco, CO
- Mar 8, 2020— Skiing at Winter Park, CO

Each of these activities are free, however, you must register online to attend. To RSVP or for details on each of these go to cohemo.org and find their Program and Event Calendar.



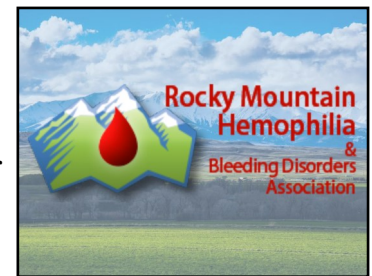
Our Pediatric Stroke Parent Support Group will meet on Tuesday, Feb 11, 2020 here at our HTC from 6-7:30 pm.

A Creative Arts Therapist will be speaking with us about using creative arts as therapy. Dinner and Childcare provided.

Please RSVP to strokesupport@ucdenver.edu or 303-724-6163 by Friday, Feb. 7, 2020, so we know how many to plan for. We hope to see you there!

The Rocky Mountain Hemophilia and Bleeding Disorders Association is hosting their 2020 Education Weekend and Annual Meeting on February 21-23, 2020 in Bozeman, Montana. This event offers informative sessions, youth programming for all ages, and an opportunity to connect with others who face similar challenges.

The event provides lodging and meals free of charge, but registration is required. For more information or to register please go to rmhbda.org. Registration deadline is **February 1, 2020**, so be sure to check it out soon!



RETURN SLIPS & RECYCLE BOXES!

Our pharmacy is required to have records on file about medications and supplies they send out to our patients. When you receive factor or other items from our HTC Pharmacy, please remember to return the delivery receipt stamped in **red ink**. Instructions are included in the packaging.



These slips must be signed, dated and mailed to us. There is a self-addressed and stamped envelope provided. Thank you for your help!



Our pharmacy also has made it easier for you to recycle your Certis, specialized shipping materials! We include recycling instructions with each of our factor shipments that explain the process to have FedEx pick up your box and return it. The pharmacy is happy to print out as many return labels as you need.

Contact our pharmacy if you have questions about this program or other questions about your medications at 303-724-0168 or at hemophilia@ucdenver.edu.

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With so much change, many of our staff and patients struggled with growing pains. We have spent much of the past decade working to find ways to continue building great relationships with patients and families, despite expanding to one of the largest HTCs in the country. We invite all our patients and their families to stay connected with us through signing up for our monthly newsletter, following us on social media, or attending the many events that are available through NHF Colorado or RMHBDA. Things may have changed in the past decade, but much of that change is positive and the outlook for healthier lives is better than ever. Our HTC aspires to have personal connections and to keep our patients and families informed, even in a more crowded, distant, and busy world.

As we begin a new decade, we have hope for more improvements to the treatment options and quality of care that patients with bleeding or clotting disorders need. Thank you for your continued connection with us, and we hope to continue working with you for many years to come.

RECENT HEADLINES

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

BioMarin Says Gene Therapy May Cost up to \$3 Million

Sangamo Transfers Development of SB-525 Gene Therapy to Pfizer

Emicizumab May Yield Improvements in Joint Health in Hemophilia Patients

UniQure and Pfizer Share Updates on Gene Therapy Trials for Hemophilia B

Takeda and Enzyre Partner to Develop Home Blood Test for Hemophilia Patients

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:

Jan 25: Backpacks + Bleeders Indoor Rock Climbing—Colorado Springs, CO)

Feb 11: Pediatric Stroke Parent Support Group 6–7:30 pm

Feb 15: Backpacks + Bleeders Snowshoeing with BOEC

Feb 17: Clinic, Pharmacy, and Administrative Offices Closed for Presidents Day

Feb 21-23: RMHBDA Education Weekend and Annual Meeting—Bozeman, MT

Feb 26-28: NHF Washington Days

Mar 8: Backpacks + Bleeders at Winter Park

Mar 10: Pediatric Stroke Parent Support Group

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

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