The Clotting Connection

A Newsletter for Families with Bleeding and Clotting Disorders



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



Every Step Counts

Do you know what you're doing on August 22nd? Why not consider spending some of your morning walking and enjoying the beautiful Colorado landscape with friends and family? The Colorado Walk for Hemophilia is a 5k walk held annually to raise funds to benefit those living with bleeding disorders in the Colorado community. This year the walk will be held on Saturday, August 22, 2015, at 9 am (registration begins at 8 am) at Sloan's Lake Park in Denver.

The proceeds from the walk will directly benefit NHF Colorado, our local chapter of the National Hemophilia Foundation which provides many valuable resources to those in the hemophilia community.

Every year NHF Colorado provides great educational programs, support, awareness and most importantly, family and summer camp! Without the funds the many programming activities simply could not be available to those living with hemophilia, Von Willebrand disease and other bleeding conditions.

Please consider joining us this year, either by walking with our HTC team "Chill Factor, joining another team, or simply donating if you are unable to attend. We hope to see you there!

Sloan's Lake Park is located on Sheridan Blvd and 17th Avenue in Denver. Parking is available throughout the park, however the closest area to the starting line is located on the south side (green arrow indicates starting location). You can park in either of the two south lots or along 17th Avenue.





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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

HTC Website- Go to medschool.ucdenver.edu/htc



Email:

HTC.Newsletter@ucdenver.edu

HTC SPOTLIGHT: DR. BETH WARREN-FELLOW



Dr. Beth Warren, a fellow who works with our research and clinical staff at our HTC, has earned two awards to in researching outcomes for hemophilia.

Beth has been working with the HTC in

conjunction with the Pediatric Hematology/ Oncology Department at the University of Colorado and Children's Hospital Colorado for the past three years in Jorge Di Paola's lab.

Beth brings both academic and personal experience to her work. She has two cousins with hemophilia who have directly benefited from advancements in hemophilia research. Beth has been working with her mentor, Dr. Marilyn Manco-Johnson, to research improved NEWSROOM page.

outcomes for hemophilia patients.

The 2015 Bayer Hemophilia Award will help allow her to continue her work and hopefully answer some of the questions in the treatment of hemophilia and thrombosis that remain unanswered. She will be working on a secondary analysis of the Joint Outcome Study and Joint Outcome Continuation Study, trying continue her work to determine how to better predict and prevent individual bleeding risk. She was awarded additional funding from the HTRS Novo Nordisk Clinical Fellowship Award. In addition to her research, Beth will continue her training to become a clinical doctor treating hemophilia and thrombosis.

> Congratulations to Beth! Our HTC staff is excited to get to work with her for the next two years at our center on these studies that will likely improve the lives of many patients in the future.

The Denver Post recently printed an article about Dr. Warren and it can be by visiting our website: www.medschool.ucdenver.edu/htc Go to the RESOURCES tab and find our

OUTREACH CLINICS

Every year our center provides care to those living in those areas in our region that are not near our center in Aurora, Colorado. Our Outreach Clinics provide the opportunity for patients to schedule their annual comprehensive visit with our teams at locations closer to them. We have an upcoming clinic on July 27-29 in Missoula, MT as well as one Sept 23-25 in Grand Junction, CO.

For more questions, please contact Pat Casias or Audra LeBlanc at 888-297-0724 (toll free), or 303-724-0724. More details are available at our website: www.medschool.ucdenver.edu/htc Go to the CLINIC tab and find our OUTREACH CLINICS page.

Upcoming Outreach Clinics:

July 27-29 Missoula, MT

Sept 23-25 Grand Junction, CO

NEWSLETTERS

If you received the newsletter in your email box it is because you signed up to receive our online newsletters. If you signed up and did not receive one, please check your spam or filtered folders and contact us if you are unable to locate it. Please feel free to forward it to family and friends who might be interested in the content.

Direct access to the subscription page can be found via our website. Just go to medschool.ucdenver.edu/htc and click on the resources tab for the Newsletter page. If at any time you wish to unsubscribe, there is a link at the bottom of the email.

We will have a few paper copies of this content available in the clinic and a link to the digital version at our website. If you have questions, corrections, or feedback, please contact us at HTC.Newsletter@ucdenver.edu.

INSIDE THE CLINIC: PHOTOS BRING SMILES & BONDS

When the HTC moved into its new location at the UPI building back in 2011, one thing we noticed right away was our huge blank walls. As we scrambled to find some appropriate adornments, we realized we had our answer in a talented mom bringing in her children to our clinic.

Kathryn Ames brought her experience dealing with her children's bleeding disorders, and talent as a photographer, to light up those hallways with smiles.



"My style as a photographer is to capture the realness of a person... What results are images of truth and love and sometimes even sadness and fear... I am so happy to have had these experiences to get to know each one of these families." —Kathryn Ames



You may recognize a few pictures as the very children and families that are patients here and a part of our bleeding disorder community. Each photo captures the joy and intimacy of the unique individuals and families facing a variety of challenges but smiling in the face of them.

Kathryn expressed her gratitude at being able to relate so closely with each family and the bond that comes through the trials of life.

You can see these beautiful photographs as you walk down our clinic hallway. Stop and smile next time you're in.

MILE HIGH CAMP PICTURES!



We just finished up Mile High Camp-our camp for kids with bleeding disorders. Camp was held up at Easter Seals-Rocky Mountain Village in Empire, Colorado and it was fantastic! We are grateful for all our nurses, staff and most especially the NHF Colorado staff and the Easter Seals-Rocky Mountain Village staff for all they did to make camp amazing!

Both NHF Colorado and our HTC staff managed to snap a few photos. We've posted or shared those on our Facebook page and you can find many posted at the NHF Colorado Facebook page as well.

Did you get any fun pictures you'd like to share? Did you have a good time-did your

child benefit from the experience? We'd love to hear from you. Send us an email, share with us your pictures and stories from camp, either from this year or years past. Our email is HTC.Newsletter@ucdenver.edu. [Note: by sending emails/photos you give permission for us to use those on our website, social media and newsletter to share with our bleeding disorder community]





RECENT HEADLINES

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

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 head to: www.medschool.ucdenver.edu/htc then find the RESOURCES tab, and go to the NEWSROOM tab.

Hepatitis Drug Overtakes \$1000-per-pill Treatment in Shifting Options for Care

CU Doctor Earns Awards to Research Improving Hemophilia Outcomes

Baxalta Launches as Spinoff of Baxter Aimed at Underserved Conditions

Bayer Files Hemophilia A Drug Marketing Application in Japan

Walgreen Settles Medicaid False Billing Case in New York

UPCOMING EVENTS

July 27-28: Backpacks & Bleeders

July 27-29: Outreach Clinic in Missoula, MT

Aug 13-15: NHF Annual Meeting, Dallas, TX

Aug 22: NHF Colorado-Walk for Hemophilia

Aug 30: Pediatric Stroke Parent Support Group Summer Picnic (please RSVP)

Sept 7: Clinic and Admin offices closed for Labor Day

Sept 12: RMHBDA Walk for Hemophilia, Billings MT



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http://medschool.ucdenver.edu/htc

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