The Clotting Connection

A Newsletter for Families with Bleeding and Clotting Disorders



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



Mile High Summer Camp 2017 was a tremendous success! Camp was once again at Easter Seals Camp in Empire, Colorado and held on July 16-21, 2017 with a leadership retreat held on the 14th-15th.

This annual camp for youth with bleeding disorders provided round the clock care for campers by our amazing clinical team. More than 20 of our HTC staff went up and provided support, training, and care to our campers. The kids participated in everything from swimming and fishing to face painting and infusing. Camp started with the theme of Disney Princesses and transformed into Zombies!





More than 80 campers participated this year and for many it is a huge step toward independence and learning self-care. Campers are safely able to participate in many activities, have fun, become friends with others who have similar challenges, and even learn to infuse for the first time. Camp is funded through NHF Colorado, and would not be possible without the support of donations.

Join us at Hemophilia Walk Colorado on August 26, 2017 at Sloan's Lake, or donate to

NHF Colorado to continue to fund programs like camp.

We are excited to share our photos from camp and are collecting them from the HTC and NHF staff for our campers and their families to enjoy. We have a few included here and on page 3, but we've created a slideshow online for this year's camp and will be adding to it as more photos come in. To find them, go to our website at: www.medschool.ucdenver.edu/htc find the COMMUNITY tab at the top and click on CAMP. The slideshow will be at the bottom of the page.

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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



HTC.Newsletter@ucdenver.edu

UPDATES AND OPPORTUNITIES

Hemophilia Walk 2017

August 26, 2017 at Sloan's Lake Park 8 am check in - 9 am walk - support all year

Participate • Volunteer • Donate



Il proceeds go to NHF Colorado, funding programs for the bleeding disorder community

Walk With Us!

Mark your calendar and sign up today for the 2017 NHF Colorado Hemophilia Walk! This is a fundraiser to provide support for amazing programs for those with bleeding disorders—such as Mile High Camp!

The walk will be held at Sloan's Lake Park on August 26, 2017 with check in at 8 am, and the walk begins at 9. This year NHF Colorado has new fundraising perks! Details can be found at **cohemo.org** or by going to the registration page at hemophiliawalk.donordrive.com and finding the Denver walk and a local team.

The HTC team is CHILL FACTOR and we'd love to have you join us, or simply donate! Join our team, form your own, or pick a friend to

walk with-but remember to register and support these amazing programs!





PARENTS
Parents Empowering Parents
(PEP) is a non-profit program to
provide support for parents of
children with bleeding disorders.

This peer-to-peer program works with professionals and other parents to train and improve skills of parents to be more effective in raising children with bleeding disorders.

PEP 2017 will be on September 8-10, 2017 at the Double Tree Hotel in Denver. A flier on this program is available at our website by going to www.medschool.ucdenver.edu/htc find the COMMUNITY tab and click on PEP.

This program is free to attend, including hotel stay, meals, and day care, so spaces fill up quickly. **To RSVP or for more information**, **please contact Audra LeBlanc 303-724-6163 or audra.leblanc@ucdenver.edu.**



Our next **Self-Infusion Clinic** at the HTC will be on Wednesday, August 9, 2017 from 5 pm to 7 pm in our clinic. This is a program for our patients and families

who would like additional help with self-infusion to come and spend time with our nursing staff and practice in a one-on-one setting. You can bring your own factor to be infused, or practice with saline. We will have Spanish interpretation available at this clinic. Food and beverage provided; the event is free but you must RSVP. Go to cohemo.org and click on the EVENTS page.

OUTREACH CLINICS 2017

Outreach clinics allow patients to schedule their annual comprehensive visits at a location closer to their home. The clinics in Montana and Grand Junction are usually a few days once a year, while our Colorado Springs clinic is held quarterly.

Our staff reach out to local patients, but if these clinics are more convenient to your location and you would like to know more, please contact Pat Casias at 303-724-1325, Audra LeBlanc at 303-724-6163, or speak with our front desk schedulers at 888-297-0724 or

303-724-0724.

Details, forms and maps to these locations are available on our website at: www.medschool.ucdenver.edu/htc Click on the CLINIC tab and find the OUTREACH CLINICS page.

Upcoming clinics:

August 8, 2017: Colorado Springs, Colorado

Sept 27-29, 2017: Grand Junction, Colorado



RECENT HEADLINES

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

BioMarin Announces Results of Phase 1/2 Study to Treat Hemophilia A

Alnylam and Sanofi Report Strong Results for Novel Hemophilia Drug

Update on Emicizumab Prophylaxis in Hemophilia A with Inhibitors Published in New England Journal of Medicine

FDA Approves Bevyxxa to Prevent VTE in At Risk Patients

Shire Submits Application to FDA for Gene Therapy to Treat Hemophilia A

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:

Aug 8: Outreach Clinic—Colorado Springs

Aug 9: Self-Infusion Clinic at the HTC clinic

Aug 26: NHF Colorado 2017 Walk for Hemophilia—Sloan's Lake Park

Aug 27: Pediatric Stroke Parent Support Group Summer Picnic—Sloan's Lake Park

Sept 4: Clinic, Pharmacy, & Admin offices closed for Labor Day

Sept 8-10: PEP (Parents Empowering Parents) Program—Denver

Sept 9: RMHBDA Walk for Hemophilia—Kalispell, MT

Sept 16: RMHBDA Walk for Hemophilia—Billings, MT

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

Hemophilia & Thrombosis Center

13199 E. Montview Blvd., Suite 100 Aurora, CO 80045

Clinic Main: 303-724-0724 or toll free at 888-297-0724 Pharmacy Main: 303-724-0168 or toll free at 888-724-7427

Web page:

http://medschool.ucdenver.edu/htc

PLEASE PLACE STAMP HERE