

The Clotting Connection

A Newsletter for Families with Bleeding and Clotting Disorders

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University of Colorado
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and University of Colorado Hospital

MILE HIGH SUMMER CAMP 2019



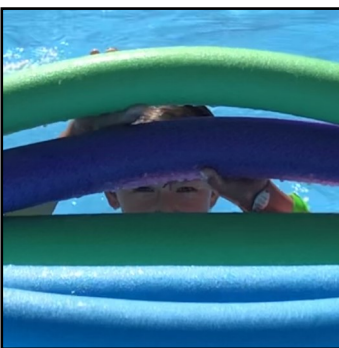
Mile High Summer Camp was held July 14-19, 2019 up at the Easterseals Rocky Mountain Village near Empire, Colorado. We had a great group of campers and a wonderful week of fun activities, learning, and connecting.

This annual camp is designed for children ages 7-18 with bleeding disorders, and gives them the chance to have fun and get to know others who have similar challenges all in a safe and beautiful location. Many of our HTC staff were up at camp the entire week providing medical care and education. Easterseals provided the camp counselors to work with the kids in each age group to help things run smoothly. We saw a lot of successes with younger kids learning from older kids how to administer their medications, a fun rafting trip for our older campers (with few injuries despite very high water!), and a really lovely week of good weather in the high country.



Campers had many activities they could try, including archery. Photo: Kim Richfield

During the week the campers can choose from many fun activities, including swimming, fishing, hiking, archery, horseback riding, crafting, zip-line, and more. They get to be silly with skits, and learn to be serious and supportive during self-infusion sessions.



Campers love to swim and relax in the pool. Photo: Kim Richfield

Over 80 campers joined us this year, and for many, it was a great chance to make new friends, gain confidence, learn leadership skills and independence, and enjoy nature. Camp is funded through NHF Colorado and our HTC, but it would not be possible without support of donations.

We encourage everyone to get involved to help support this amazing camp by participating in the Unite for Bleeding Disorders Walk on August 24, 2019 at Sloan's Lake Park. You can help by joining us, donating to a team of walkers, spreading awareness, and donating directly to NHF Colorado. Learn about the walk and how you can help support camp at www.cohemo.org.

In coming weeks we will be posting more pictures at our website. Please follow us at facebook.com/ColoradoHTC for regular updates or go to our website at medschool.ucdenver.edu/htc.



One of the most powerful things at camp is to see our older campers help younger kids with infusing. Photo: Chris Mashburn

INSIDE THIS ISSUE

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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

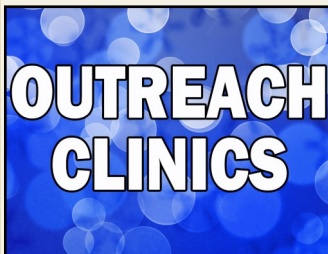


Website: Go to medschool.ucdenver.edu/htc



Email: HTC.Newsletter@ucdenver.edu

UPCOMING EVENTS & OPPORTUNITIES



If you do not live in the Denver Metro area, one of our Outreach Clinics might be an easier option for your regular comprehensive care. Our Outreach Clinics offer care and support from our medical, nursing, physical therapy, psychosocial, and research teams. Our experts come to you!

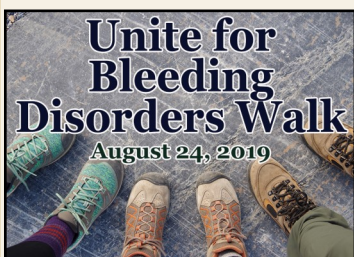
Upcoming Outreach Clinics:
July 31-Aug 2, 2019—Missoula, Montana
Sept 25-27—Grand Junction, Colorado

See our website for updates on future clinics and more details at: www.medschool.ucdenver.edu/htc and find the Outreach Clinic page under the CLINIC tab.

Our Pediatric Stroke Parent Support Group is starting up again in August! Please join us on Tuesday, August 13, 2019 from 6-7:30 pm here at the HTC. Meetings are once a month on the 2nd Tuesday of the month. Dinner and childcare are provided and you do not need to be a patient with us to attend.

To RSVP or for other questions, please go to our website at www.medschool.ucdenver.edu/htc and find the Pediatric Stroke Parent Support Group page under the COMMUNITY tab.

**Pediatric
Stroke Parent
Support Group**
Tuesday
August 13, 2019
6:00-7:30 pm



Mark your calendar now to join us for the **Unite for Bleeding Disorders Walk** on **August 24, 2019 at 9 am at Sloan's Lake Park.**

This annual walk is one of NHF Colorado's largest fundraising efforts, providing important support for their incredible programs. The walk funds Mile High Summer Camp, Education Days and many other great events throughout the year that are designed to unite and support families with bleeding disorders.

Sign up, form or join a team, invite your friends and family and walk side-by-side to make a difference! Watch for more info at cohem.org.

LEADERSHIP CAMP 2019

Every year Mile High Summer Camp begins with a two-day leadership outing for our oldest campers. These campers then go on to support younger campers throughout the rest of the week. Many of these older campers know exactly the fears and challenges facing the new, young campers. This year the leadership group went rafting and gave these teens a wonderful opportunity to bond and create lasting relationships.



Campers infusing together before their river rafting adventures. Photo: Whitney Tedeschi

It was a unique experience to watch these older campers prepare for their day, all calmly chatting as they infused at the picnic table. It was both

heartwarming and uplifting to see them get to bond over this commonality they are used to performing alone.

The Breckenridge Outdoor Education Center (BOEC) counselors did a fantastic job of guiding and educating our group on and off the river, as well as challenging us with riddles to solve throughout the weekend. Overall, we witnessed admirable leadership skills that then carried over into Easterseals camp. Several of our leadership group successfully helped teach younger campers infusing tips and provided guidance as they learned to self-infuse.

We are grateful for our leadership campers and all their efforts in supporting camp despite their own struggles with bleeding disorders. Camp is a great opportunity for these teens to learn leadership and build a strong and supportive community of peers.



One of our campers demonstrating safety at Leadership Camp. Photo: Whitney Tedeschi



Photos: Chris Mashburn, Whitney Tedeschi, and Kim Richfield.

RECENT HEADLINES

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

Positive Data from Multiple Studies Shared about Hemlibra at ISTH Congress

New Results Presented on Catalyst's MarzAA for Hemophilia A or B

BioMarin Plans to Submit to FDA for Gene Therapy Marketing Authorization

Bioverativ Presents Positive Data from Completed Phase 1/2 EXTEN-A Study

Takeda Shares New Data from PROPEL Study

Sangamo and Pfizer Announce Updated Results for Gene Therapy

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:

July 28: Chapter Staff Meet and Greet, Greenwood Village, CO

July 31-Aug 2: Outreach Clinic—Missoula, MT

Aug 24: NHF CO Unite for Bleeding Disorders Walk-Denver, CO

Sept 2: Clinic, Pharmacy, & Admin closed for Labor Day

Sept 7: RMHBDA Unite for Bleeding Disorders Walk—Billings, MT

Sept 14: RMHBDA United for Bleeding Disorders Walk—Kalispell, MT

Sept 25-27: Outreach Clinic—Grand Junction, CO

Oct 3-5: National Hemophilia Foundation Annual Conference—Anaheim, CA

Oct 13: Women's Wellness Retreat

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>

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