

The Clotting Connection

A Newsletter for Families with Bleeding and Clotting Disorders

June 2020

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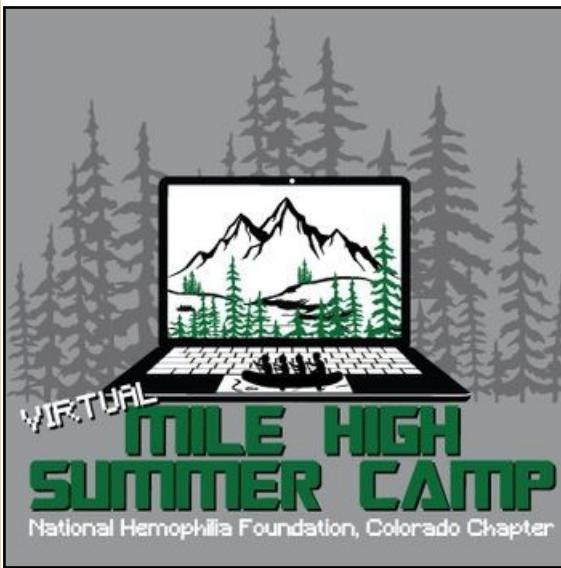


Hemophilia and Thrombosis Center
UNIVERSITY OF COLORADO ANSCHUTZ MEDICAL CAMPUS



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VIRTUAL MILE HIGH CAMP IN JULY DESPITE COVID-19



2020 has been full of unexpected changes and cancellations, and those have been tough on nearly everyone. Unfortunately, many of the things we've looked forward to year after year have been canceled this year, including fun things like camp.

Mile High Summer Camp has been hosting children with bleeding disorders for decades, so it was with great disappointment that NHF Colorado and the HTC had to make the decision that camp could not be held in person this year.

However, the great thing about 2020 is that we have a lot more technology that makes it possible for us to do VIRTUAL

Mile High Summer Camp instead! NHF Colorado spends much of the year planning for camp, so this year they had to shift their focus quickly to get Mile High Summer Camp into an all virtual format. Plans are falling into place along with some incredible help and support from previous campers, HTC staff members, the NHF Colorado team, and GutMonkey-a national support organization dedicated to supporting chronic conditions through camps, training, and programs.

This year's camp will clearly be different, but it will also be a lot of fun! Instead of a week on location, camp will be held each of the five Wednesdays in July online from 9:15 am to noon. Each day will have activities, learning, and a lot of fun. Each camper will receive a camp in a box experience that includes a camp tee-shirt and camp activities. Mark your calendar but more importantly, register now!

The registration fees for camp this year are waived, but you must register to participate in any of the dates. You do not have to be able to participate every Wednesday to attend, but of course we would love to see your faces each week you are able!

Registration deadline is **June 29th, 2020 by 5 pm**. To secure your spot in this brand new adventure, please go to www.cohemo.org, find their Program and Events Calendar and find their registration link.



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



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Website: Go to medschool.ucdenver.edu/htc



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HTC.Newsletter@ucdenver.edu

DR. BRIAN BRANCHFORD LEAVES HTC FOR WISCONSIN

After ten years with the HTC, Dr. Brian Branchford has left Colorado and started a new position in Wisconsin. With the severe restrictions due to the COVID-19 pandemic, our HTC held an online zoom farewell party for him before he left. While we wish we could have been together in person, our staff shared fun things about Brian, farewell videos, and how he has impacted each of us. We have all witnessed how he made a difference in the lives of our patients and their families, and we will miss his dynamic personality in our clinic. Best of luck Brian!

Brian shared the following:

While the absence of the Rocky Mountains is the most noticeable aspect of my new surroundings, it is the absence of the friends, colleagues, mentors, patients, and families from the University of Colorado HTC that I will miss the most in the long run.

I have returned to my native Wisconsin to work at the Versiti Blood Research Institute and Children's Wisconsin, but I will always treasure my time at the HTC and Children's Hospital Colorado. It feels good to be back home and close to family, but it is somewhat of a bittersweet transition because I truly miss everyone in Colorado who influenced and impacted my career, as well as my life. I am honored to have had the chance to work alongside such amazing people to care for such wonderful patients at such a fantastic institution and will always sincerely appreciate what I learned from you all.



Brian on our zoom farewell party. We had many from the HTC attend virtually to say farewell!

—Brian Branchford

NEED HELP CONNECTING TO CAMP?



If you have need of support in having the right technology and tools to go online to participate, please reach out to your local chapter for assistance. NHF Colorado has some financial and tech support options for those who are without these tools.

Hanna Beary from NHF Colorado can help answer your questions. Reach out at hbeary@hemophilia.org or 646-499-0684.

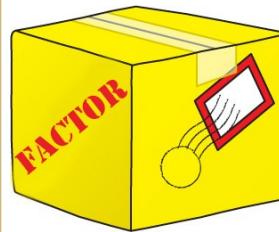
HTC PUBLISHES JOS-C RESULTS

After 26 years of intense work, our HTC research team, including Dr. Beth Warren, Dr. Marilyn Manco-Johnson, Statistician Dianne Thornhill, Physical Therapist Sharon Funk, and researcher Kristi Norton among others, published their findings on their Joint Outcome Continuation Study. Findings included outcomes for patients based on their age when starting prophylaxis care, and damage to joints despite regular infusions. **Congratulations** to our incredible research team for their patience and diligence in bringing these results to light! You can view the study results here: <http://ow.ly/ByAj50zY6oH> or on our website newsroom.



PHARMACY & CLINIC UPDATE

Our Pharmacy continues to work every day to maintain safety and provide quality care to our patients. In addition to our stringent precautions and screenings, our delivery services now include contactless delivery. This means that you should no longer need to sign when your factor products are delivered.



We know that this is a challenging time for many. If you are faced with a change in or loss of employment or insurance, please let us know immediately. There are emergency programs available to help minimize disruptions in taking your hemophilia medication.

In addition, our HTC clinic schedule has returned to our normal hours with restrictions and strict screenings. Our staff is available both in clinic and virtually to provide support. Our doctors, nurses, physical therapists, social workers and psychologist as well as our pharmacy staff are available Monday through Friday during our regular hours.

Contact us if we can help in any way.

Clinic: 303-724-0724 or Pharmacy: 303-724-0168

NHF COLORADO HOSTS VIRTUAL FAMILY CAMPFIRE

By Kim Richfield

This year's Family Camp may have looked a little different due to Covid-19 restrictions, but that didn't stop the 10 families who attended virtually from having a great time! Each family received a campfire box filled with materials and goodies to use throughout the event. The evening contained lots of camp songs and some cheesy dance moves.

Families also raced around their home searching for various items as part of the color team challenge, which required a tie breaker. At the end of the night, everyone gathered around the virtual campfire to munch on s'mores, reflect on their experiences, and wrap up with a classic camp song. This event was facilitated by NHF Colorado Staff, Bleedership leaders, GutMonkey, and HTC staff and allowed bleeding disorder families from across the state to connect and share in camp traditions.

We thank all who participated to make this fun! Enjoy a few screenshots from our Virtual Family Campfire.



RECENT HEADLINES

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

Early Treatment Linked to Reduced Joint Damage in Young Adults with Severe Hemophilia A

HTC Adjusts Hours for More In-Person Visits with Restrictions Starting June 1

NHF Switches Annual Conference to Online Virtual Resource

BioMarin's Gene Therapy for Hemophilia A Remains on Track for US Approval

Study Finds Prophylaxis is Better than On-Demand Treatment for Adults with 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:

Please note. These dates may be tentative and subject to change due to the outbreak of COVID-19. Please check appropriate websites for confirmation of events.

Jul 3: Clinic, Pharmacy, and Admin closed for Independence Day

July: VIRTUAL Mile High Summer Camp Activities each Wednesday from 9:15 am-noon ([must register online at cohemo.org](#))

July 27-31: Missoula, MT Outreach Clinic—Tele-health

Aug 1-8: NHF Annual Conference—A fully VIRTUAL Conference

Aug 21-23: RMHBDA Family Camp ([registration deadline July 10](#))

Aug 22: NHF CO Unite for Bleeding Disorders Walk (see cohemo.org for updates)

Aug 24-29: HFA Symposium— Virtual Conference

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

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Web page:
<http://medschool.ucdenver.edu/htc>

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