

# 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

## WALK WITH US—VIRTUALLY!



We may not be able to walk like last year but all of us can still UNITE to support those with bleeding disorders.

Every year, NHF Colorado hosts a walk to raise funds to support their programs. They provide support to bleeding disorder families throughout the year via events that educate, advocate, connect and empower. The Unite for Bleeding Disorder Walk is a powerful, unifying event that brings together patients, families, friends, and all who share a desire to improve the lives of those with bleeding disorders. Unfortunately, this year the COVID-19 pandemic has forced a shift to a 'virtual' version.

You may ask, "how does one virtually walk?" While we won't be gathering in person to keep everyone safe, we will be gathering in spirit and online for a celebration and joint effort to provide support. You can walk that day and you can join us online for a fun way to connect with others! This "virtual walk" includes the chance to reach out and ask for support from family, friends, and co-workers as we join in teams to meet fundraising goals. The virtual experience hosted by NHF Colorado will begin on Zoom on Saturday, August 22, 2020 starting at 8:50 am. To join this event, sign up at [uniteforbleedingdisorders.com](http://uniteforbleedingdisorders.com) at the [Denver, CO page](#) and the zoom link is on the main page.

Walking is something we can all do to bring awareness and support to those with bleeding disorders, not to mention stay in shape. Find creative ways to get out walking (away from others) and share your steps online to spread awareness to those you know. Join a team, start your own, or simply make a donation by going to: [www.uniteforbleedingdisorders.com](http://www.uniteforbleedingdisorders.com).

Participants who donate \$25 or more are eligible for a walk tee-shirt and will make a difference to many lives! What else can you do?

- Walk! Find ways to get out and enjoy the sunshine as you walk unitedly with others supporting the cause— even if you're far apart.
- Invite! Tell your friends and family why you support those with bleeding disorders and ask them to donate.
- Share! Jump on social media and talk about this event and the opportunity to support those with bleeding disorders. You can share at [NHF Colorado's Facebook page](#), the HTC Facebook or Twitter accounts, or in your own way how you are making a difference as you Unite for Bleeding Disorders this year!

Take a step and make a difference despite all 2020 has thrown at us! For more information about this event, go to [cohemo.org](http://cohemo.org).

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Keep calm and walk with us!

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



Go to [facebook.com/ColoradoHTC](https://facebook.com/ColoradoHTC)



Go to [twitter.com/HTCColorado](https://twitter.com/HTCColorado)



Website: Go to

[medschool.cuanschutz.edu/hemophilia-thrombosis](http://medschool.cuanschutz.edu/hemophilia-thrombosis)



Email:

[HTC.Newsletter@ucdenver.edu](mailto:HTC.Newsletter@ucdenver.edu)

# 'PEP' BECOMES EEMPACT PARENTING PROGRAM



For many years, our bleeding disorder families have had the opportunity to meet with

other parents to learn, provide support to other parents, and grow as parents of kids with bleeding disorders. The Parents Empowering Parents (PEP) program was a powerful tool to help parents feel the support they need from others going through similar experiences. Over the past few years this program has shifted and adjusted to the growing changes in our world.

We would like to introduce the new 'PEP'! The EEMpact Parenting Program is designed to make it easier for parents of kids with bleeding disorders to connect and overcome some of the issues preventing them from attending. With COVID-19 pushing so much online, this course has also shifted to an online format for easier, as well as safer access. Rather than a one weekend event, this is now a 10-week program that is held online weekly for parents of kids under age 12 who have a bleeding disorder.

Though they may not meet face-to-face, each attendee will be sent materials via mail to provide support for the class. The program asks participants to attend zoom meetings and generally requires about 2 hours a week. The course is free, and sponsored by Bayer Pharmaceuticals, but registration is required. Participants will receive a certificate at the completion of the course.

Dr. Emily Wheat, will be the facilitator for our HTC clinical team. Dr. Wheat is our psychologist on staff at the HTC and her clinical focus is on providing evidence-based interventions for behavioral health concerns. Parent facilitator Lupe Torres will help administer this powerful program.

To learn more about the EEMpact Parent Program, and to sign up, go to our event page here: [https://eeminds.teachable.com/p/eempactparenting\\_uofc\\_fall](https://eeminds.teachable.com/p/eempactparenting_uofc_fall)

Space for this course is limited and will take applicants on a first come, first served basis.

The course this year will begin on

**September 14, 2020.** Please register by August 28, 2020.

If you have more questions about this program, you can contact Dr. Emily Wheat at [Emily.Wheat@cuanschultz.edu](mailto:Emily.Wheat@cuanschultz.edu) or 303-724-7900.

## HTC PT MARY O'CONNELL LEAVES FOR OREGON

Many of you may have come to know our Physical Therapist Mary O'Connell through regular visits in office or working through problems with joint or muscle pain. This month we bid Mary a fond farewell as she heads off to new opportunities in Oregon. Though we wish her the best, we will miss her delightful spirit, hard work, and generous nature with both staff and patients alike. Our HTC had a virtual coffee zoom and a very socially distanced ice cream party to wish Mary well and say goodbye. Our HTC knows that those in Oregon who get to work with her are so lucky! Best wishes Mary! Thank you for your work with our patients and staff!

Mary shared:

*As we follow our hearts and head out to Bend, Oregon, I want to extend a HUGE thank you to the HTC team, the patients, and families for warmly welcoming me into your community. I have been so fortunate to have learned something from everyone, that I will carry with me onward. You've all left a lasting mark! Your compassion, commitment to service and innovation are second to none, and will inspire everyone you work with! Best wishes to the entire community-* **Mary O'Connell**

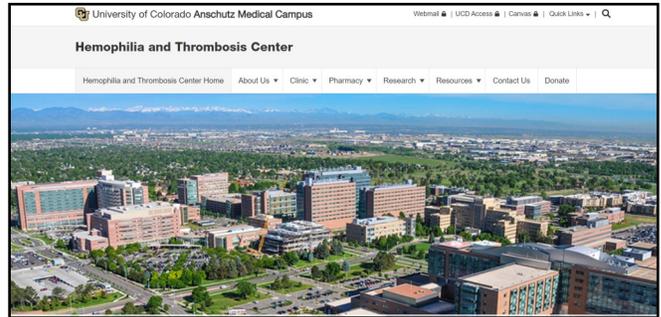


Mary O'Connell, one of our Physical Therapists, and her cute dog are heading to Bend, Oregon. Photo: Mary O'Connell.

# HTC LAUNCHES UPDATED WEBSITE

The University of Colorado Anschutz Medical Campus and the School of Medicine have been transitioning their websites from older web software and domain names to new ones over the past year or so. This process has taken a lot of time and effort but has resulted in new websites that are easier to use, easier to update, and include a more user-friendly layout.

The Hemophilia and Thrombosis Center falls under the School of Medicine and we too have transitioned our website during this process. This involved a lot of hard work behind the scenes from several of our staff, including input from the various departments at our center. We successfully moved to our new website at: [medschool.cuanschutz.edu/hemophilia-thrombosis](https://medschool.cuanschutz.edu/hemophilia-thrombosis) early this month and are very happy to have the pages up and working.



A screen shot from the home page of our new website.

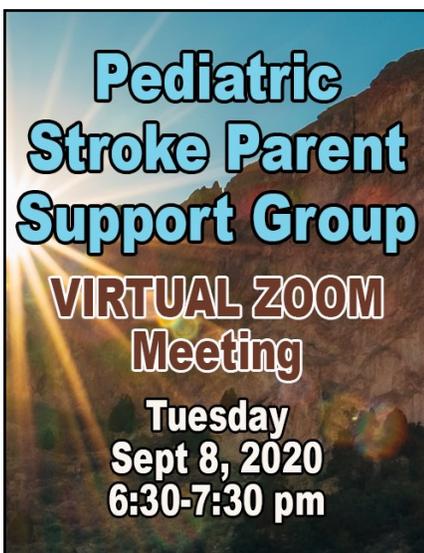
The old website links (with a ucdenver.edu address) will forward directly to our new site. Much of the information from the old site moved over to our new one, but several pages have been significantly updated or added. We realize there are some areas that still need improvement but as a whole we are thrilled to have a new site to move forward with as an updated resource for patients! Please bear with us as we work through any glitches that we may find.

Some of the newer features our patients and families may benefit from include a format that is much easier to navigate on a cell phone, a resource page for our insurance and billing, new pages for our Physical Therapy and Psychosocial teams, an updated Research section, along with continued access to a Newsroom, Newsletter, Events, Bleeding and Clotting Resource pages, and a COVID-19 Resources page. Our Pediatric Stroke page in the resources section has expanded and now includes the current brochures we provide to patients in clinic. Our Pharmacy section has also grown and includes helpful information and resources, including factor comparison charts.

We invite you to check out our new site and see what it has to offer. We hope you find it helpful and easy to navigate. While you're there, [don't forget to subscribe to this newsletter!](#) Currently, our newsletter is completely digital to avoid in-person contact. We know things can feel disconnected right now, but we at the HTC are hoping to stay in touch in any way we can, including the new website.

If you have questions or feedback on our new website, we'd love to hear from you. Please send us a note at [HTC.Newsletter@ucdenver.edu](mailto:HTC.Newsletter@ucdenver.edu).

## PEDIATRIC STROKE PARENT SUPPORT GROUP



For many months, our Pediatric Stroke Parent Support Group has been put on hold! We've missed visiting with our pediatric stroke families and finding ways to provide support and uplift to one another!

While we still can't yet meet in person, we are

excited to announce that our Pediatric Stroke Parent Support Group will resume on **September 8<sup>th</sup>, 2020** virtually! You can join us on a zoom call from 6:30 pm to 7:30 pm where we can re-connect in a safe way.

This group meeting welcomes everyone in the family to join and we will not be splitting out into any age groups this month. Your child does not need to be treated at our center to attend. We will have time to talk about our recent experiences, share stories, and hear about the journey of a stroke survivor!

To join, please RSVP by contacting us at [strokesupport@ucdenver.edu](mailto:strokesupport@ucdenver.edu) or (303) 724-8520. We'll send a calendar reminder with the zoom link to all who RSVP. We hope to 'see' you in September!

## RECENT HEADLINES

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

### **CSL Behring and Ferring Issue Recall of Stimate**

### **Data from Biopsy Study of BioMarin's Gene Therapy Shows Positive Results**

### **Gene Therapy from BioMarin Could Be Most Expensive US Drug Ever**

### **Phase 1/2 Trial of Gene Therapy for Hemophilia B Shows Promise**

### **Data Shows Hemlibra Continues to Maintain a Favorable Safety Profile**

### **Roche Posts Update on Hemophilia A Gene Therapy Data**

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. Go to [medschool.cuanschutz.edu/hemophilia-thrombosis/resources/newsroom](https://medschool.cuanschutz.edu/hemophilia-thrombosis/resources/newsroom) to read more. We also share news on our [Facebook](#) and [Twitter](#) accounts.

## 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.**

**Aug 20:** NHF CO Joint for Health Webinar

**Aug 21-23:** RMHBDA Family Camp

**Aug 22:** NHF CO Unite for Bleeding Disorders VIRTUAL Walk (see [cohemmo.org](https://cohemmo.org) for updates)

**Aug 24-29:** HFA Symposium— Virtual Conference

**Sept 7:** Clinic, Pharmacy, and Admin Closed for Labor Day

**Oct 10:** RMHBDA Unite for Bleeding Disorders VIRTUAL Walk (see [rmhda.org](https://rmhda.org) for updates)

**Oct 26-28:** Outreach Clinic—Billings, MT

**Oct 27-30:** THSNA 2020 Summit—VIRTUAL

**Nov 6-8:** RMHBDA Women's Retreat—Chico Hot Springs, Pray, MT

**See more at our Events Page on our website:** [medschool.cuanschutz.edu/hemophilia-thrombosis/resources/events-calendar](https://medschool.cuanschutz.edu/hemophilia-thrombosis/resources/events-calendar)

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Web page:

[medschool.cuanschutz.edu/  
hemophilia-thrombosis](https://medschool.cuanschutz.edu/hemophilia-thrombosis)

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