

# The Clotting Connection

*A Newsletter for Families with Bleeding and Clotting Disorders*

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University of Colorado  
Anschutz Medical Campus  
Hemophilia and Thrombosis Center

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

## DIRECTOR'S CORNER

This month I am wrapping up a three part series on the incredible research that is underway here at our HTC.



Dr. Brian Branchford heads research on blood clots in kids.

One of our pediatric hematology assistant professors, Dr. Brian Branchford, has focused his research on the effects of inflammation on the tendency to form excessive blood clots. His work to develop safe and effective thromboprophylaxis strategies has put him as the physician leader for the Children's Hospital Solutions for Patients Safety, a network of over 100 Children's hospitals nationwide. His research with our center has two parts. The first, based at Children's Hospital Colorado, is studying children who develop thrombosis while hospitalized to characterize risk factors for thrombosis, including inflammation. The second part is based in the laboratory and studies molecules that may be increased during inflammation that would activate platelets to promote blood clots. Both the clinical and laboratory research will converge in the overall goal to predict which hospitalized children are at greatest risk of blood clots and develop safe and effective prevention strategies.

The HTC research hemostasis laboratory is working to develop global assays that can be used to test for too little or too much blood clotting. Our three hemostasis technicians are Linda Jacobson, Katherine Ruegg, and Chrissy Baird. One of the global assays about which we are most excited is the computerized automated thrombogram, or CAT. This measures the final enzyme critical in blood clotting called thrombin. The CAT measures both the rate as well as the quantity of thrombin generated. Recently we found that the CAT detected too much thrombin generation in children who carry a mutation causing a decrease in antithrombin, a protein that regulates thrombin. We are now looking to see if the CAT can detect children with other mutations that cause increase clotting. The goal of this work is to predict who needs preventive anticoagulation and when is the right time to start. The CAT is also being used in samples from patients with hemophilia who are using various treatments for prophylaxis such as standard recombinant proteins, extended half-life products or Hemlibra. The goal of this study is to try to compare the amount of hemostasis gained with different therapies and ultimately to predict which activities can be reasonably performed without risk of bleeding.

Dr. Genevieve (Jenna) Moyer is focusing her research on women with bleeding disorders. She is using thromboelastography (TEG) and CAT to predict which women with menorrhagia have a blood coagulation disorder as opposed to a local gynecologic issue. She hopes to use the information from these investigations to build tools that will help to individualize therapies and reduce complications during invasive procedures.



Dr. Genevieve (Jenna) Moyer is researching bleeding disorders in women.

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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](https://medschool.ucdenver.edu/htc)



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

# COLORADO STATEHOUSE DAY

An enthusiastic group of sixteen community members went to the Colorado State Capitol on Friday, March 22, 2019 to raise awareness and educate our lawmakers about bleeding disorders. This group included patient families, HTC staff, and NHF Colorado Chapter Staff. The annual event encourages members of the bleeding disorder community to connect with state legislators to help them understand the daunting challenges that they face in getting or providing care. A similar effort on a national level also happens in Washington DC during the last week of March.

NHF Colorado invited state senators and representatives to a light breakfast to introduce our group and provide a casual environment to talk with elected officials about bleeding disorders. After the Senate session began, Senator Joann Ginal recognized the NHF group and read a declaration announcing that March is Bleeding Disorders Awareness Month in the State of Colorado.

After a very meaningful tribute, group members attempted to speak with the senator or representative



Advocates for those with bleeding disorders on the steps of the Colorado State Capitol on March 22, 2019. Photo: Briana Reinking.



Advocates in red ties working with Senator Joann Ginal to bring awareness to the needs of those with bleeding disorders in Colorado. Photo: Briana Reinking.

from their district. This can be a difficult task when navigating all the topics debated on the Senate and House floor. Our members had some success talking to legislators and for those we could not meet with, we left information with their offices and aides.

The ability to advocate for the important issues bleeding disorder patients and families encounter every day led to an empowering experience and fulfilling day at the Capitol. Those who attended felt that local Senators and Representatives they met with gained an awareness of the challenges faced by bleeding disorder patients, and that connection made it a great day!

Thank you to all who advocate for those with bleeding disorders! Your voice makes a difference.



Young advocates for bleeding disorders sitting in the senators' seats. We thank them for their energy! Photo: Briana Reinking.



## Pediatric Stroke Parent Support Group

Tuesday  
April 9, 2019  
6:00-7:30 pm

Our next Pediatric Stroke Parent Support Group will be on Tuesday, April 9, 2019 from 6–7:30 pm here at the HTC.

This group is open to families of children of all ages and of all types of pediatric

stroke. Stroke patients do not need to be patients at our stroke clinic to join these free meetings. Dinner and childcare are provided at each meeting.

Please RSVP by April 5, 2019 to [strokesupport@childrenscolorado.org](mailto:strokesupport@childrenscolorado.org) or 303-724-6163 so we know how many to plan for.

See more details at our website at [www.medschool.ucdenver.edu/htc](http://www.medschool.ucdenver.edu/htc) under the COMMUNITY tab.

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Finally, our Children's Stroke Program is gearing up a new research study. Our Children's Stroke Team is part of the International Pediatric Stroke Network. In collaboration with their colleagues in Toronto, Dr. Tim Bernard and the Stroke Team are using new approaches to brain imaging in order to lay a foundation for research on pediatric stroke and better understand the mechanism of injury and recovery. Another important focus of the stroke program is the role of seizures in the outcome of children who suffer a stroke.

We are happy this research is moving forward here at our center and hope that the findings will lead to increased understanding and better care for all patients.



Dr. Tim Bernard leads our team researching pediatric stroke

*Marilyn J. Manco-Johnson MD*

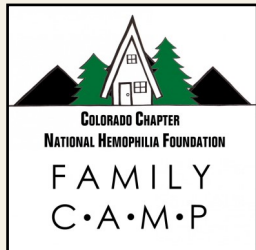
Marilyn Manco-Johnson, M.D., Director

## UPCOMING OPPORTUNITIES



Education Days is on April 12-14, 2019 at the Denver Marriott South at Park Meadows, located at 10345 Park Meadows Drive, Lone Tree, CO 80124. This event will start on Friday at 5 pm and run through Sunday at 3 pm.

This is one of the largest events NHF Colorado hosts throughout the year and so much is available to those who attend! We hope to see you there! Details can be found at [cohemo.org](http://cohemo.org) under the WHAT WE DO tab, click EDUCATE.



NHF Colorado invites the whole family to come up to Rocky Mountain Village and enjoy a family camping experience! NHF Colorado especially encourages families with siblings who have always wanted to attend the experience at camp.

Family Camp will be May 4-5, 2019 and registration is still open! Don't miss this opportunity to enjoy camp together! For more information or registration questions, please contact Kelly Ryan at [kryan@hemophilia.org](mailto:kryan@hemophilia.org), phone is 646-499-0684 and go to [cohemo.org](http://cohemo.org).



Mile High Summer Camp is July 14-19, 2019 with our Leadership Camp starting on July 12-13, 2019. Camp is once again at Rocky Mountain Village Easterseals Camp near Empire, Colorado.

This is a great opportunity for kids with bleeding disorders to grow and have tons of fun. Campers can attend starting at age 7 and are divided by age group. A wilderness program for our 12-13 year olds is an option that can be a great adventure, and our leadership program is for kids ages 14-17. Graduated campers can even apply to be a "Bleedership Counselor" when they are 18.

Our nursing, physical therapy, social work, pharmacy and clinical staff are on hand throughout camp to help teach and provide support. Registration is open until May 1, 2019 at [cohemo.org](http://cohemo.org).

If you are not living in the Denver Metro area, one of our Outreach Clinics might be an easier option for your regular comprehensive care. Most of our 2019 Outreach Clinic dates have been set with just a few still pending.

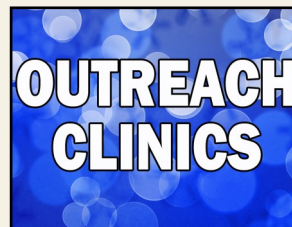
### Upcoming Clinics:

April 26, 2019 and May 24, 2019—Colorado Springs, CO

June 25-28, 2019—Billings, Montana

July 31-Aug 2, 2019—Missoula, Montana

See our website for more details at [medschool.ucdenver.edu/htc](http://medschool.ucdenver.edu/htc)



## RECENT HEADLINES

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

**Study Finds Benefit From Extended Half-Life Products for Hemophilia A Patients**

**Pharmacokinetic Dosing May Benefit Hemophilia A Patients, Study Finds**

**Precision BioLogic's Inhibitor Screening Kit Cleared by FDA for Sale in US**

**Roche to Buy Spark Therapeutics for \$4.3 Billion**

**FDA Approves Novo Nordisk's Esperoct for 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](http://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/](http://www.facebook.com/ColoradoHTC/)

## UPCOMING EVENTS

### Mark Your Calendars:

**April 4-7:** HFA Symposium, San Diego, CA  
**April 9:** Pediatric Stroke Parent Support Group  
**Apr 12-14:** NHF CO Education Days—Lone Tree, CO  
**Apr 17:** World Hemophilia Day  
**Apr 26:** Outreach Clinic—Colorado Springs, CO

**May 4-5:** NHF CO Family Camp  
**May 24:** Outreach Clinic—Colorado Springs, CO  
**May 27:** Clinic, Pharmacy & Admin closed for Memorial Day

**June 8:** Self-Infusion Clinic at the HTC  
**June 14-16:** RMHBDA Family Camp—Anaconda, MT  
**June 25-28:** Outreach Clinic—Billings, MT

**July 4:** Clinic, Pharmacy & Admin closed for Independence Day  
**July 12-13:** Leadership Training at Mile High Summer Camp  
**July 14-19:** Mile High Summer Camp

See more at our Events Page on our website: [www.medschool.ucdenver.edu/htc](http://www.medschool.ucdenver.edu/htc) find **RESOURCES** tab, go to **EVENTS**

### Hemophilia & Thrombosis Center

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or toll free at 888-724-7427

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

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