

# The Clotting Connection

*A Newsletter for Families with Bleeding and Clotting Disorders*

January 2018  
Volume 8, Issue 1



University of Colorado  
Anschutz Medical Campus  
Hemophilia and Thrombosis Center

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

## DIRECTOR'S CORNER



We at the HTC are excited to welcome in 2018 and a great year ahead. Things have been busy here on the Anschutz campus and I would like to provide an update on changes we've seen this past year and major changes that we expect in the next year. We are still in the same building, but the University has taken ownership and so it is no longer called the UPI building, but is the CU Medicine building. The location has been very helpful for us and we've continued to work to improve the resources available to patients here in Aurora.

We were very happy last year to welcome Angela Blue as our HTC Program Director. She comes to us from both the adult and pediatric treatment centers in Minnesota where she worked for several years. Many of the clinic staff previously worked with Angela on a Maternal and Child Health Bureau initiative to promote autonomy in young hemophilia patients. We feel very lucky to have convinced Angela to come work with us and look forward to seeing her grow and help our HTC as it develops ways to serve the bleeding disorder community. Angela is a very friendly person. She is the main HTC person for programming including outreach clinics, camps and retreats, education days, and patient support. Please feel free to contact her about any programmatic ideas or needs that you have.

Last year we also gained Steve Powell who runs our finances. We had not previously had a person in Steve's position and so didn't know exactly what to expect. Steve surprised us by the many talents he brings from the banking and investment world. In addition to helping oversee our accounting processes, Steve has become an expert in the health care laws and 340B regulations that govern our program. Steve is able to help us accomplish our goals within the federal rules and guidelines and is a positively amazing person.

Our HTC continues to benefit from the strength of some incredible medical staff. We have six pediatric hematologists, two adult hematologists, two child stroke neurologists, one adult stroke neurologist, four pharmacists and two gynecologists. Two advanced fellows from pediatric and adult hematology may be coming to our HTC clinics soon. Our clinics are running four to five days a week and nearly always at capacity. The support by our nursing and clinical staff is phenomenal. Over the past year we've had a few departures from our clinic and research staff, and we've appreciated all their hard work.

We especially want to thank Amber Casey who was a fantastic nurse with incredible dedication to our program. Amber needed to make a position change based on her family needs; we miss her already and hope to welcome her back when the time is right for her. Sarah Zellmer has taken Amber's position. Sarah had been helping us as a float nurse and showed a great ability to reach out and relate to our patients, so we were excited that she was able to move right into a full time position. Marian Hufford transitioned to clinical rotations needed for her nurse practitioner certification. She will still help us when she is available. Research has continued to grow and work with our patients to improve the outcomes of patients based on strong science. We welcome two new Clinical Research Assistants, Jillian Welker and Jason Thomas. Jillian joined us from ImmunoE Health Center and Jason came from Bozeman, MT. We gave our

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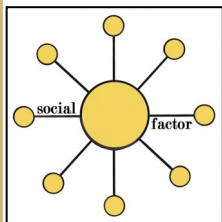


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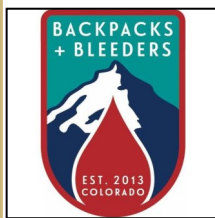
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# UPCOMING OPPORTUNITIES



**NHF Colorado's Social Factor: Denver** will be Saturday, February 3, 2018 from 4pm to 6 pm. This is a program that strives to provide education and strong support networks among the Colorado bleeding disorder community. It is a fun way to connect with friends in the community. Join us for an evening of socializing, bowling and food at AMF Monaco Lanes. 6767 Leetsdale Dr. Denver, CO 80224. More details and to RSVP, please go to [cohemo.org](http://cohemo.org) and click on their Program & Event Calendar.

Our next Self-Infusion Clinic at the HTC will be on Tuesday, February 6, 2018 from 5:30 pm to 7:30 pm. We host this opportunity for our patients, their spouses, parents and other family members to practice or learn self-infusion skills. Working with our nurses, this program is open to all our bleeding diagnoses at any severity. Please register by going to [cohemo.org](http://cohemo.org) and find details under the Program & Event Calendar.



Backpacks + Bleeders is a program that was started in Colorado and is continuing to grow. They will be hosting a Northern Colorado winter Hike on Saturday, February 10, 2018 from noon to 4 pm. This group gives our bleeding disorder community a safe way to hike and learn hiking safety as well as things like storing and carrying factor product, emergency preparedness on the trail and giving infusions along the trail. To Register and find more details go to [cohemo.org](http://cohemo.org) at the Program & Event calendar, and don't forget to check out their Backpacks + Bleeders Facebook page too.

Starting in March the HTC will offer a support group to parents of children with bleeding disorders. This group will be held once a month on the last Tuesday of every month. The agenda is up to parents and it is an opportunity for people to come together to share knowledge, experiences, frustrations, triumphs and support in a safe environment. Our first meeting is March 27, 2018 from 6 pm to 7:30 pm here at the HTC on the Administrative side. Dinner and childcare is provided. Please RSVP to Audra LeBlanc at [audra.leblanc@ucdenver.edu](mailto:audra.leblanc@ucdenver.edu) or 303-724-6163.



Registration for the 2018 Factor 7 Retreat opens on February 1, 2018. The retreat is specifically for patients who have a factor 7 deficiency and their immediate families. It is free for all eligible applicants. The retreat is Friday, April 6th through Sunday April 8th, 2018. Details can be found at <http://www.comphealthed.com/fvii/#>. Questions can be also directed to Audra LeBlanc at [audra.leblanc@ucdenver.edu](mailto:audra.leblanc@ucdenver.edu) or 303-724-6163.



## AMBER CASEY SAYS FAREWELL

To all of my patients and your families,

When I was offered this position at the Hemophilia and Thrombosis Center I truly felt as if I had finally landed my dream job. I never saw myself leaving here or having to say goodbye. With that being said, the past year has been a challenging one my family. In order to be the best mother and wife I can be to my children and husband, because they deserve nothing less, I have come to the very raw decision to resign from the HTC and take a part-time position in hemophilia homecare. During this next chapter, my goal is to create more time for my children and personal growth without completely disconnecting from the bleeding disorder community.

Writing this letter to you all today is much more difficult than I imagined it would be. Although I know I am making the best decision for our family, it doesn't come without the presence of some remorse and ambivalence. The connections I have made in this community cannot and will not be broken. To each and every one of you- THANK YOU! I have learned so much from all of you. You all have proved to be my greatest teachers. The impact the HTC family has had on me personally is indescribable. I have learned more from this community than I did from 20+ years of education. I wouldn't trade in this experience for anything. Please, if you would like to keep in touch, find me on Facebook. It would mean so much to me to stay connected.

Much love,  
Amber Casey

best wishes to Rachel Kula when she moved on to a new position. Amanda Kenny moved to Iowa when her new baby was born but still helps the Stroke Team remotely; Niesje Maccini will leave in February to have her baby and we are excited to hear the good news once he or she arrives!

Our Physical Therapy team has grown and are busy working with patients to keep joints healthy and pain levels low. Rachel Wood joined Sharon Funk and Laura Fox as our third therapist. There should be ample help for comprehensive clinic, outreaches and any acute or chronic problems that need their help. Our Social Worker, Audra LeBlanc, is now heading up both the Stroke Support Group and the brand new Bleeding Disorders Support Group. These are designed to help parents gather and give strength to one another as they parent children with these challenging diagnoses.

We are enlarging the team to help with social and emotional adjustment. Kayla Kemfer is a certified Child Life specialist. She will help children with any issues, but is focusing on needle phobia and adjustment to new therapeutic regimens. We know that adults are all kids at heart so any adult is welcome to ask for Kayla kind, warm help. We are also recruiting a clinical psychologist. This psychologist will first serve children and teens who face major life change with a new onset stroke. But this person will be available to address any individual or group issues affecting the bleeding and clotting community.

The pharmacy accomplished a huge goal this year by gaining full URAC Specialty Pharmacy accreditation in 2017. They have brought our pharmacy to be fully adhering to all industry standards. The services and care they provide are a valuable resource for our patients. The pharmacy is continually striving to build on these standards to improve efficiency and support for patients.

We continue to have Outreach Clinics in Grand Junction, CO, Billings and Missoula, MT and are working to add Bozeman and other locations in Montana to support patients there. We began a quarterly Outreach Clinic in Colorado Springs last year and that has been very helpful for our patients in the more southern locations of our state. We strive to bring our services to our patients who are spread out in our region and hope they continue to benefit from a high level of service.

Which brings us to novel treatments in hemophilia. There has never been a time of so much change and advancement in hemophilia care. The first “nonfactor” bypassing agent for inhibitors, Hemlibra, has been FDA approved for patients 12 years and older with inhibitors. Data in hemophilia A patients without inhibitors should be presented soon, and possibly at the World Federation of Hemophilia in May, 2018. Two other non-factor bypassing agents are in clinical trials. Both seek to balance the decreased thrombin in hemophilia by decreasing natural inhibitory proteins to a balanced level. One decreases antithrombin and the other decreases the inhibitor to tissue factor. Gene therapy is in clinical trials for both factors VIII and IX and some trial results are actually qualifying as a “cure”. The extended half life factor IX products are continuing to do very well. We are still waiting for a “break-through” extended half life factor VIII product.

With so much fundamental change in hemophilia therapy, it is more important than ever that we health care providers partner with patients in the conduct of clinical trials and clinical studies to document the best use and application of new treatments. The specific diagnosis of joint and muscle bleeding and other damage has taken on an even more important role, as excessive treatment can now be dangerous. We were all raised in the era of “if you have any pain, treat it as a bleed” when extra treatment carried no extra harm and potential benefit. Now the paradigm has shifted and many of our approaches have been turned upside down! Please talk to us about any questions you have and we should address this topic in educational symposia. It has never been more important to make an accurate, immediate diagnosis of bleeding vs. no bleeding. To help with this, nine of the HTC staff traveled to the University of California San Diego to train in the use of ultrasound to image joints. We had a fantastic course with Dr. Annette Drygalski and are ready to start imaging. Our Ultrasound machine should arrive in the next week, and many of you will be invited to have a look “inside” when you come to clinic. We are all very excited to start joint imaging as an additional outcome measure with number of joint bleeding events and physical therapy joint scores.

The anticoagulant world is having a broad expansion in the use of direct oral anticoagulants (DOACs). As time and experience accumulate, these agents are continuing to show good efficacy and no increased bleeding risk. Clinical trials are ongoing with small children, so that an oral and small dose formulation should be available soon.

As the director I am blessed to witness the HTC grow from a small clinic to a large, highly efficient and capable center that provides world-class care to inspiring patients. Seeing many of you grow from infants to adulthood has been a thrill and a gift. You are the reason we are here and our goals are based on the aspirations and dreams of our patients. We hope to see as many of you as possible in clinic, at camp, at Education Days, retreats and hiking the trails! Have a great 2018 and help us improve our community throughout the year.

Sincerely,



Dr. Marilyn Manco-Johnson

## RECENT HEADLINES

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

**Chris Bombardier Completes the Seven Summits by Climbing Mt. Vinson**

**Alnylam and Sanofi Partner to Treat Rare Disorders**

**NY Times Shares Patient Voices: Hemophilia**

**Catalyst Biosciences Given Permission to Change Trial Length for CB 2679d for Hemophilia B**

**BioMarin Shares New Data on Gene Therapy 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/Save the Date:**

**Feb 3:** Social Factor: Denver—Bowling

**Feb 6:** Self-infusion Clinic at HTC

**Feb 9:** Outreach Clinic-Colorado Springs

**Feb 10:** Backpacks + Bleeders Northern CO Hike

**Feb 19:** Clinic, Pharmacy & Admin closed for Presidents' Day

**Feb 23-25:** RMHBDA Education Weekend & Annual Meeting

**Apr 6-8:** NHF CO Education Days

**Apr 26-29:** HFA's 2018 Annual Conference

**June 8-10:** NHF CO Family Camp

**June 16-21:** Camp for Kids with Neurologic Disorders at Roundup River Ranch

**June 19-21:** Outreach Clinic-Billings, MT

**July 15-20:** 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**

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

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