

The Clotting Connection

A Newsletter for Families with Bleeding and Clotting Disorders

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Hemophilia and Thrombosis Center
UNIVERSITY OF COLORADO ANSCHUTZ MEDICAL CAMPUS



Affiliated with
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HTC RESEARCH TEAM MAKES A DIFFERENCE



Joy He and Hana Durkee are part of our incredible research team working with bleeding disorder patients.
Photo: Kristi Norton

If you have attended appointments at the Hemophilia and Thrombosis Center, then you may have had a member of the HTC research team come and talk to you about opportunities to enroll in research studies. You might see someone different each time you attend an appointment, so we thought it might be nice to introduce you to them and give some insight into what they are working on.

The Clinical Research Program is managed by longtime HTC researchers Julie Smith and Kristi Norton. Julie has been at the HTC since 2011 and Kristi has been at the HTC since 2012. Kristi's specialization is in pharmaceutical drug studies and Julie's specialization is in helping prepare, submit, and execute research that is funded by the NIH or other grant providers. Julie and Kristi were promoted to manage the department in 2018 and have found a particular passion for helping research coordinators grow and develop in their careers.

We have a truly excellent team of researchers working under Kristi and Julie's leadership. If you attend the stroke clinic, you will surely meet Lia Thompson, who has been with our stroke program for almost four years. Lia recently graduated from the University of Colorado School of Public Health with her Master's Degree. She works on all our center's projects related to pediatric stroke, including some exciting new research on seizures in stroke, treatments for Focal Cerebral Arteriopathy, and genetic testing in stroke patients. Lia is *the* expert on all things related to stroke research, so feel free to reach out if you would like to hear more about stroke research opportunities.

The rest of our team works on bleeding and clotting research, and you might already know some of them from your interactions with them in clinic.

Jason Thomas has been with our center for five years. He got married in 2022 to his lovely wife, Mackenzie, and they moved to



Researchers Lia Thompson, who does research with our stroke patients, and Hana Durkee, who specializes in bleeding disorders research. Photo: Kristi Norton



Julie Smith and Kristi Norton are the Research Managers at our HTC. They've both been working at our center for more than a decade and are the energy behind our team!
Photo: Kristi Norton

INSIDE THIS ISSUE

- HTC Research Team Makes a Difference
- HTC Staff Present Research Results at GCMAS
- Upcoming Events
- Event Calendar
- News & More

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



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Website: Go to

medschool.cuanschutz.edu/hemophilia-thrombosis



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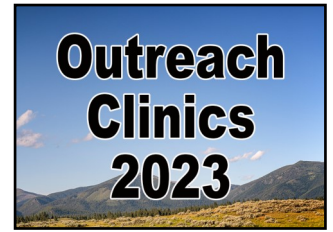
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[Continued on page 3]

MARK YOUR CALENDAR: UPCOMING EVENTS

Aug 8-10, 2023: Outreach Clinic— Missoula, MT

For our patients in and around Missoula, MT we will be holding an outreach clinic in Missoula in August. Letters should have been sent to our local patients, but give us a call if you didn't receive one or would like to make an appointment for this clinic. Front desk: 1-888-297-0724 or 303-724-0724. See more details at our outreach page at: medschool.cuanschutz.edu/hemophilia-thrombosis/clinic/clinics/bleeding-disorders/outreach



August 26, 2023: NHF CO Walk—Sloan's Lake Park, Denver, CO

Sept 9, 2023: RMHBDA Walk—Zoo Montana, Billings, MT

For details and to sign up for either walk go to uniteforbleedingdisorders.org.

NHF Colorado and RMHBDA are signing walkers up now for their annual Unite for Bleeding Disorders Walks for 2023! This is the only major fundraiser for both organizations to raise funds and awareness. Both NHF Colorado and RMHBDA provide much needed learning and community opportunities for those with bleeding disorders throughout the year, including events like Mile High Summer Camp, Family Camp, and Education Days.

Join our HTC as we walk and support these organizations and connect with other members of the bleeding disorder community. Sign up for the [NHF CO walk on Aug 26, 2023 at Sloans Lake Park, Denver, CO](https://uniteforbleedingdisorders.org) or the [RMHBDA walk on Sept 9, 2023 at Zoo Montana, Billings, MT](https://uniteforbleedingdisorders.org) by going to uniteforbleedingdisorders.org.

HTC STAFF PRESENT RESEARCH RESULTS AT GCMAS



Joseph Mah presenting at GCMAS in June. Photo: Beth Warren

In June, several members of our HTC attended the Gait and Clinical Motion Analysis Society (GCMAS) Annual Conference that was held at High Point University in High Point, North Carolina. The conference was all about gait and motion, and finding ways to help improve function for people with a wide variety of conditions that may affect walking or normal movement. Their goal was to study how people move and measure it using cameras, force plates, and other tools so they can improve patient care.

Our HTC sent hematologist Beth Warren, MD, biomechanics researchers Caden Robertson, MS, Joseph Mah, BS, Niamh Mah, BS, and physical therapist Joanna Roybal, DPT to the conference. Our team was excited to participate and learn from others who study gait and motion as our HTC is undergoing construction that will include an HTC motion lab that should be completed in the next few months. The hope in attending was to learn and make sure that our center will have an accurate motion lab and get ideas on ways to make this a powerful tool for patients.

Two of our biomechanics researchers, Joseph Mah and Caden Robertson, presented at podium talks. Joseph discussed research we have done with Dr. Brecca Gaffney at UC Denver to model muscle forces in persons with hemophilia and controls (persons who do not have hemophilia) while they did squats in a motion lab. Caden addressed the normalized symmetry index when simulating sports movements in the lab with both persons with hemophilia and with controls.

Some of the HTC's early findings from this study showed that for things like walking, people with hemophilia look very similar to those who do not have hemophilia. However, there appears to be more differences in people with hemophilia with higher impact tasks (like jumping) and in tasks where you use both legs at the same time (like squatting). The research is ongoing, but the current thought is that the hemophilia group may contract the muscles that flex the knee more in the leg that has more joint damage, possibly to stabilize and protect knees that had bleeds in the past. The research, and potentially our new HTC motion lab, could help us guide our patients to find new ways to keep them healthy and with properly functioning muscles as they manage their bleeding disorder.

Congratulations to Caden and Joseph and the rest of our HTC biomechanics research team for their presentations. We look forward to seeing the impact of the new things our team has learned and how we can help patients in the future.



Caden Robertson presenting at GCMAS in June. Photo: Beth Warren

[Continued from page 1]

Montana during the pandemic. From Montana, Jason helps plan all of our outreach clinics, including attending them to perform research duties. In addition, Jason works diligently every day on many of our projects that report on the populations we serve and the metrics we need to meet for our center's grant funding. He helps keep our operation in compliance with his hard work. He also manages some data-only research projects that use only medical records, and he is the lead coordinator at our center for the CDC Community Counts Bleeding Disorders Registry. In his personal time, Jason is an adventurer. He loves mountain biking, camping, hiking, and anything outdoors with friends.

Hana Durkee has been with our center for four years. She is an avid skier and hiker, as well as a yoga instructor. If you participated in a study we called ATHN 7, you probably know Hana very well. She has worked closely with a cohort of patients using emicizumab, known as the brand name Hemlibra, and also works on trials studying Hemlibra in previously untreated patients (PUPs). Hana also works very closely with Dr. Beth Warren on her Biomechanics studies, which we refer to as the POBOY projects (both the app project and the biomechanics studies). In addition to being a meticulously detailed research coordinator, Hana brings humor and happiness to work every day. If you haven't met her yet, we hope you will get the chance to meet her in clinic soon.



Jason Thomas enjoying the outdoors of Montana. Jason works remotely but manages many research projects for our HTC. Photo: Jason Thomas



Julie and Joy enjoying some time together at the office. Joy works with women with bleeding disorders. Photo: Kristi Norton

Joy He has been with our center for almost two years. Joy came to us as a graduate of CU Boulder, and we are so thankful to have her. She has fortuitously slid into a specialty focused on women with bleeding disorders and attends all our Spots and Dots clinics with Dr. Huguelet and Dr. Moyer. She connects with women with bleeding disorders to enroll them in research, as they are a population that has not been studied enough. Joy works closely with Dr. Keith Neeves to study the effects of oral contraception on the clotting system. Joy loves hard work and is happiest when she has many tasks ongoing at one time. She loves seeing patients in clinic and hopes to be a physician one day. Joy loves attending outreach, so you might see her there as well. Joy loves to learn and is a voracious student. She loves dogs and spending time with friends, especially playing tennis. If you haven't met Joy, she is a delight, and we hope you will get to meet her soon.

The last member of our team is certainly not the least. Ashley Weller has been with our team for less than a year, but she has already made a big impact on the HTC. She is diligent in everything that she does and has been spending her first six months at the HTC recruiting in clinic and processing samples. This fall, we hope to teach her the ins and outs of outreach clinic. She is also starting to work on the initial phases of some new studies that will look at new treatments for VWD and Hem A/B and inhibitor patients. In the past, inhibitor patients have been excluded from treatment studies, so we are excited for these upcoming studies that will expand our research relationships with new groups of patients. In her free time, Ashley loves to be active—she plays soccer and pickleball, as well as working out and working in her garden. She loves spending time with friends and family and enjoying all that Colorado has to offer. Ashley's voice is small, but her heart is big—we hope you get to meet her soon.

Historically, our research department has been involved in many exciting projects that have changed care for bleeding and clotting disorders! Before Julie and Kristi came to the HTC there was the huge impact of the Joint Outcome Study (JOS) and Continuation of the JOS, and over the past decade there have been some amazing studies our research team has been involved in. These include Long-Acting Factor VIII and IX studies—including seeing those medications get FDA approval, Hemlibra studies—which became groundbreaking new treatment for Hemophilia A and patients with FVIII inhibitors, and gene therapies for FVIII and FIX deficiency—two of which were just recently approved by the FDA. The exciting topics that the research team at the HTC has been able to work on over the years would not be possible without YOU—our wonderful patients who selflessly volunteer for these studies and trials. Even data-only projects provide valuable insights to current treatments and patterns and help guide care improvement for the future. Without your partnership, none of this would be possible and we are very grateful to you!

We are still working on the best way to get results of the studies you participate in back to you. Please stay tuned for more information on that initiative. If you have any questions about past or current research, your rights as a research participant, or if you have questions about any of the projects that have been mentioned, you can contact us at 303-724-0306 or CRCalendar@ucdenver.edu. You can reach Julie Smith at Julie.Smith@cuanschutz.edu or Kristi Norton at Kristi.Norton@cuanschutz.edu. Our HTC research team is thrilled when we see how much of an impact each volunteer in our studies can make on potential future care for bleeding and clotting disorder and stroke patients. Thank you for your willingness and we look forward to getting to work with each of you!



Julie with our newest researcher Ashley who works regularly with patients. Photo: Kristi Norton

RECENT HEADLINES

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

Recent Studies Show Fitusiran Could Treat Women's Bleeding Disorders

In Non-Severe Hemophilia A, Hemlibra is Not as Cost-Effective as Standard Care

FDA Approves First Gene Therapy for Adults with Severe Hemophilia A

FDA Will Review Ixinity for Use in Children Under 12 with Hemophilia B

Early Prophylaxis Leads to Better Outcomes for Hemophilia A Patients

Pfizer Announces Positive Results from Phase 3 BASIS Study of Marstacimab

We maintain a newsroom page at our website with a list of news articles that may be of interest to our patients and families. Go to medschool.cuanschutz.edu/hemophilia-thrombosis/resources/newsroom to read more. We also share news on our [Facebook](#) and [Twitter](#) accounts.

Sign up to get this newsletter delivered directly to your email box each month! Just go to eepurl.com/bnszoz or scan the QR code and fill out the form!



QR Code to Subscribe!

UPCOMING EVENTS

Mark Your Calendars:

Please note. These dates may be tentative and subject to change. Please check appropriate websites for confirmation of events.

Aug 4: NHF CO Inspiring Shots Golf Clinic—Men's Group

Aug 5: HTC First Annual Stroke Day at the Park—Red Tailed Hawk Park, Aurora, CO

Aug 8-10: HTC Outreach Clinic—Missoula, MT

Aug 10-11: RMHBDA Teen Retreat—Rollins, MT

Aug 11-13: RMHBDA Big Sky Family Camp—Rollins, MT

Aug 17-19: NHF National Bleeding Disorders Conference

Aug 26: Unite for Bleeding Disorders Walk—Denver CO

Sep 4: Clinic, Pharmacy, and Admin offices closed for Labor Day

Sep 9: Unite for Bleeding Disorders Walk—Billings, MT

See more at our Events Page on our website:
medschool.cuanschutz.edu/hemophilia-thrombosis/resources/events-calendar

ME-WE-HTC We create hope.

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