

The Clotting Connection

A Newsletter for Families with Bleeding and Clotting Disorders

April 2021
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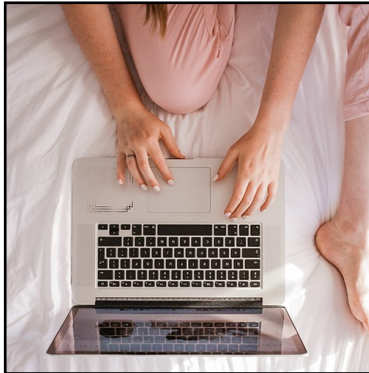


Hemophilia and Thrombosis Center
UNIVERSITY OF COLORADO ANSCHUTZ MEDICAL CAMPUS



Affiliated with
Children's Hospital Colorado

HTC CLINIC UPDATE—SPRING 2021



Now that Spring has arrived and the vaccines are starting to be distributed, we are seeing signs of improvement. The spread of COVID-19 has eased, and restrictions are slowly beginning to loosen in Colorado and surrounding states. We at the HTC work under the CU School of Medicine and abide by the practices of care and safety that they recommend to all their clinics, faculty, and staff. We are continuing to work with many patients through virtual tele-health options to reduce exposure to both our patients and staff.

As of April 2021, our facility at the CU Medicine building is still locked 24 hours a day. In-person access requires:

- Patients have an appointment.
- Patients must call when they arrive to enter the building.
- All visitors will be health screened upon entry.
- If necessary, patients can have one person with them.

Our building is regularly cleaned and sanitized and is using all precautions suggested by our CU Medicine leadership.

Many of our patients have been able to schedule planned surgeries now, so we encourage them to contact us as they schedule those so we can help support the needed preparations. Our phone volumes remain high, so we apologize if any are struggling to get through to us. In addition, we experienced some intermittent phone interruptions earlier this month. It appears to have been a problem unrelated to our HTC but the outage did impact our clinic. We believe all the issues have been resolved and apologize for any delays or frustration this may have caused our patients.

We have fully transitioned to using MyChart as our resource for tele-health. We hope that those of you who have been able to access tele-health via MyChart have so far been able to navigate the process. Our front desk staff is always happy to help and provide support to patients with problems getting access. Our HTC is interested in gathering feedback about your tele-health experience. We are currently working on a questionnaire asking for your input on how this tool has worked for you.



We are looking forward to having a joint HTC and NHF Colorado Town Hall on May 12th at 6 pm. This will be a virtual event and will be focused on COVID-19. This is an opportunity for you to hear how the HTC and NHF Colorado have dealt with the pandemic and what our future plans are. NHF Colorado will supply a free \$50 Grubhub gift card for those who stay for the entire session. We would love to see you there and hope to answer some of your questions through this event. To register, go to cohemo.org.

We hope that the future brings us together this year, and that we can return to a more normal way of operating as things improve. We thank all our patients and our staff for their patience as we navigate this intense time and work together to get to a better place for all.



It's been more than a year since the pandemic began. We've made progress, are using new tools and are continuing to abide by health protocols.

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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://www.facebook.com/ColoradoHTC)



Go to twitter.com/HTCColorado



Website: Go to

medschool.cuanschutz.edu/hemophilia-thrombosis



Email:

HTC.Newsletter@ucdenver.edu

HTC SPOTLIGHT: DR. PAVEL DAVIZON-CASTILLO



Our HTC team has many incredible people who make a difference each day. Dr. Pavel Davizon-Castillo has worked with our HTC for seven years, starting as a fellow in 2014 and working his way up to becoming one of our faculty. He works primarily with managing our laboratory doing research. You may see Dr. Davizon-Castillo in clinic, but most of the time he is in the research lab working on

some of the projects being done at our center.

Dr. Davizon-Castillo grew up in Los Mochis, Mexico, a city on the western side of Mexico near the Gulf of California. He attended university at Monterrey Tech at the Escuela de Medicina Ignacio A. Santos in Monterrey, Mexico. While he was a medical student, he found hematology fascinating and had the opportunity to participate in a summer research program at Baylor College of Medicine. There he met one of his mentors, Jose A. Lopez, and worked in his laboratory, where he became interested in coagulation, particularly platelet and megakaryocyte biology.

He became a fellow through the Pediatric Scientist Development Program and earned the specialized grant training program K99/ROO through NHLBI (National Heart, Lung and Blood Institute). This is an award that

allows young scientists to work through a mentorship program into an independent research scientist.

Currently, Dr. Davizon-Castillo works on two major projects through the HTC. He is helping to develop a clinical testing lab for platelet disorders and helping find new ways to identify the metabolic and inflammatory mechanisms for platelet hyperactivity that contributes to thrombosis. The research employs functional, transcriptional and bioenergetic approaches to find answers.

He is excited to be working with our HTC on some of these important projects, including the process of building a laboratory infrastructure with the capability to perform in-house diagnostic testing for our patients with suspected bleeding disorders.

Dr. Davizon-Castillo loves the supportive group that we have at the HTC and especially enjoys the satisfaction of working in patient care. He finds a lot of fulfillment in seeing and understanding clinical problems and needs that fuel our creativity for discovery of solutions.

When he isn't at our HTC, Dr. Davizon-Castillo enjoys photography, tasting all kinds of foods, and going on adventures with his family. He even has skills in preparing seafood-something he learned when working in a restaurant in his hometown as a youth. They enjoy visiting other family members both in the Northwest and in Mexico. Dr. Davizon-Castillo is a fabulous asset to the team here at the HTC and we are grateful to work beside him to find more ways to help our patients.

HTC & NHF CO

Town Hall

Join us for a virtual gathering
May 12, 2021 at 6 pm

Register at cohemo.org

Free Grubhub giftcard to those attending
who stay for the entire meeting.

NEW APP TO TRACK YOUR BLEEDING DISORDER

How to get started...

1. Download the app from the Apple store:



The POBOY Study
Hemophilia & Thrombosis Center

2. Let a member of our team know you are interested and we will send you an email with further information.

For more info contact:

Hana Durkee

Email: hana.durkee@cuanschutz.edu

Phone: 303-724-0422

Track bleed-
ing events,
medications,
& activities
that may have
contributed to
bleeding.

Currently
available on
iPhone or
iPad.

[Android development
is in process!]

Pediatric Stroke Parent Support Group

VIRTUAL ZOOM Meeting

**Tuesday
May 11, 2021
6:30-7:30 pm**

PEDIATRIC STROKE RESOURCES AVAILABLE

Our [Pediatric Stroke Parent Support Group](#) will be meeting online on **Tuesday, May 11, 2021 from 6:30-7:30 pm**. We will not meet in June, July or August but will resume meeting in September. Don't miss this chance to virtually gather before the summer!

This group meeting welcomes everyone in the family to join. Your child does not need to be treated at our center to attend.

To join, please RSVP by contacting us at strokesupport@ucdenver.edu or (303) 724-8520. Follow us on Facebook for the latest at www.facebook.com/Colopedsstroke.

Did you know that our pediatric stroke patients have some wonderful resources available through [Roundup River Ranch](#)? This is an amazing resource that offers a unique support system for kids with specific disorders and diagnoses, including pediatric stroke.

Normally Roundup River Ranch holds in-person camps, but due to COVID-19 restrictions they will have all camp sessions online this year. Camp is free to qualifying individuals ages 7-17, and to their families for family camp with kids ages 5-17. Learn more about the camps available at RoundupRiverRanch.org or contact their Camper Recruitment Team at 970-524-5713 or CamperRecruiter@RoundupRiverRanch.org.



In addition, Roundup River Ranch also offers a really fun perk called Joy Delivered, where campers receive a fun box with art projects, activities, games, jokes and songs four times a year. Check out this resource at RoundupRiverRanch.org/Joy.

We have fliers about these two wonderful resources [available at our website](#) and you can learn more information by contacting any of our [Psychosocial Team](#) – Dr. Emily Wheat, Bryn Dunham, Whitney Tedeschi or Cindy Nederveld.

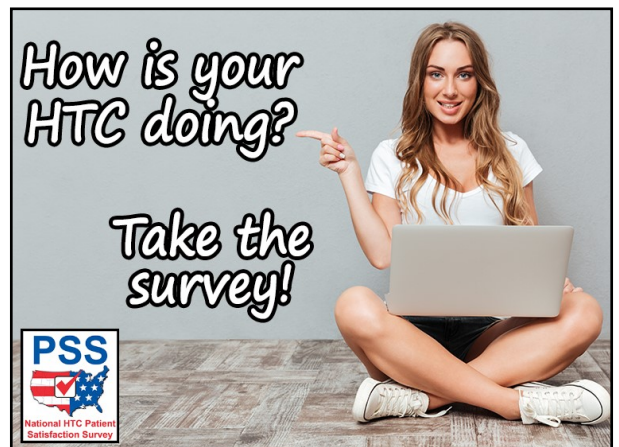
THIRD NATIONAL PATIENT SATISFACTION SURVEY NOW OPEN!

How satisfied are you with your HTC services? HTC bleeding disorder patients and caregivers throughout the US are invited to tell us by taking the Third National Patient Satisfaction Surveys (PSS). The survey is now open and available to all who were treated by an HTC during 2020 to let us know how your care was.

Our HTC sent out paper copies of this survey last month to all our bleeding disorder patients. We encourage our bleeding disorder patients to take this survey online as it is easier for processing, however we included a survey and a self-addressed, stamped envelope if sending by mail is easier for you. If you did not receive a paper copy, please just go to the website to fill out a survey at htcsurvey.com.

This survey is anonymous but both the paper survey and the online version allows a patient to identify the center at which they received care. This helps our center by allowing us to get honest feedback from patients about their care in the past year. Nearly all HTCs had to make major adjustments in 2020 due to the COVID-19 pandemic. In response, questions have been added to this survey asking patients for feedback on tele-health as well as in-person care. You can respond to this survey whether or not you were seen in person, via tele-health, or sought support over the phone, as long as you were receiving care during 2020.

The survey is brief and is available in both English and Spanish. We ask that parents of young children fill out one survey per child, and any patients who are 18 and up fill out their own survey. For questions, or to learn more about the earlier surveys, please go to htcsurvey.com.



RECENT HEADLINES

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

Study Shows Continuous Advate IV Effectively Prevented Bleeds in Surgery

Investigation Shows that Gene Therapy AMT-061 Unlikely to Have Caused Liver Tumor

Genentech Updates Hemlibra Labeling

BioMarin's Roctavian, Gene Therapy for Hemophilia A, Gets FDA Regenerative Medicine Advanced Therapy Status

Nuwiq Shows a Low Risk of Developing Inhibitors in Hemophilia A Trial

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 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 COVID-19 pandemic and restrictions. Please check appropriate websites for confirmation of events.

Apr 17: World Hemophilia Day

Apr 22: NHF CO State Advocacy Day—VIRTUAL

Apr 30: NHF CO Bleedership Institute: Camp Training

May 6: NHF CO Women's Retreat

May 11: Pediatric Stroke Parent Support Group

May 12: NHF CO and HTC Town Hall Update

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

Hemophilia & Thrombosis Center

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or toll free at 888-297-0724

Pharmacy Main: 303-724-0168

or toll free at 888-724-7427

Web page:

medschool.cuanschutz.edu/hemophilia-thrombosis

PLEASE
PLACE
STAMP
HERE