

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
Children's Hospital Colorado

CELEBRATING OUR HTC FRONT DESK TEAM



Our new reception area is located to the left when you walk in the door of our clinic.

We continue to have construction work in the area where we used to house our administrative staff and offices. Our admin and office areas are now located on the 2nd floor, allowing us to develop the first floor space for use by our laboratory, physical therapy and research teams, and other services for patients. This area is set to open later this fall—more information on that to come!

With some administrative changes, we have some new team members managing our front desk, and we'd love to introduce them to you! Yvette Portillo-Corral is our Practice Business Supervisor. She manages our front desk team and works by their side for much of the day. She has been with the HTC for almost 5 years and spends much of her time working with consents and waivers, allowing patients to better understand their out-of-pocket costs, and where any charges may be coming from.

She also helps patients check in, get scheduled, get authorization for urgent needs, and works to support our HTC clinic team to make things work more smoothly. Yvette is a delightful and efficient worker, who cares deeply about making a visit to our clinic the best it can be for our patients.

She is a native Coloradan, who enjoys sports, Mexican food, hiking, and taking long walks. She was drawn to our HTC and the Anschutz campus by the ongoing collaboration with research and clinical medicine, including innovation into new methods of care, and the healthy diversity on campus. She speaks both English and Spanish fluently and is generous with her kindness and support for others.

Working with Yvette are two newer employees who have brought their experience and have quickly fit in to our HTC team. Stephanie Maney and Noé Calva Vargas are Patient Services Representatives, who help us manage the busy front desk, handling scheduling and phone calls from patients and providers. When visiting our clinic, it is likely you will have a chance to meet each of them, as they are often found helping our patients get checked in.

If you've visited our HTC clinic recently, you may have noticed some of the changes we have been making to the layout of our reception area and adjustments to some of our exam rooms. These changes are just a part of the construction happening at our HTC. The reception area has been changed by moving the front desk to the left, where there used to be a children's area. This allowed us to expand clinic space into the area where our front desk team used to be situated.

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Meet our Front Desk Team! Yvette Portillo-Corral (left), Noé Clava Vargas (middle), and Stephanie Maney (right). Photos: Merilee Ashton



In August our Pediatric Stroke Parent Support Group met at a park in Aurora for a fun morning of play and connection. Photo: DeEtta Barnhardt

INSIDE THIS ISSUE

- Celebrating our Front Desk Team
- Updates from our Pediatric Stroke Parent Support Group
- Back to School Ideas to Help Families Thrive
- Event Calendar
- News & More

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



Go to facebook.com/ColoradoHTC



Go to twitter.com/HTCColorado



Website: Go to

medschool.cuanschutz.edu/hemophilia-thrombosis



Email:

HTC.Newsletter@ucdenver.edu

[Continued on page 3]

BACK TO SCHOOL IDEAS TO HELP FAMILIES THRIVE

School has already begun and after three years of a wide variety of restrictions at many schools, most are starting to feel more like normal. Change of any kind can cause kids to struggle, and most people need some structure. Sometimes the change to back to school schedules can throw the whole family off. If you're off your routine, now is a good time to review if you need to make any adjustments. Here are a few ideas to think about:

Set aside some time to talk about schedules with your family. This could be a weekly discussion over dinner, or a set-aside planning session. Depending on the ages of your kids, and their activities, simply touching base can help make sure no major conflicts are coming on the calendar. Such a family gathering is a great time to get a feel for how everyone is doing with their schedules, to-do lists, if some activities may need to be dialed back, or if other family members can pitch in to help. Planning logistics for everyone's schedule can help kids and parents keep track of the items they need to attend to. See some tips on schedules for families at [verywellfamily.com](https://www.verywellfamily.com).

Find a good bedtime routine.

It doesn't matter if you are dealing with teenagers, young kids, or adults, sleep is something we all need! Set a bedtime and create a



regular pattern that allows your kids time to wind down and get enough rest. This could include things like a bath, or a story for the littles, or could be some chat time or space to do relaxation for older kids. Try to not have other activities running into your bedtime routine to keep things on track. If you feel like this time is chaotic, find one thing to adjust to your routine at a time. See a few great ideas at [sleepfoundation.org](https://www.sleepfoundation.org).



Plan to have family meals with healthy choices.

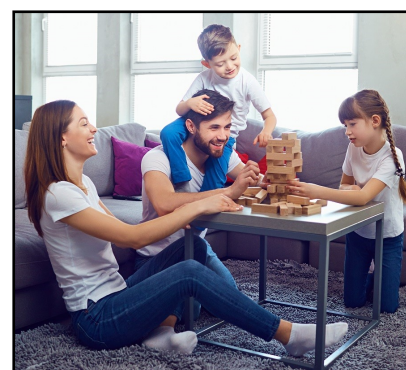
Many studies show the benefits of sharing a meal with your family, but it's also not the easiest thing to do! When planning your

weekly schedule, you could also incorporate your plans for meals. If you are able to have a regular dinner time, even if it's a few times a week, include the kids in planning and cooking healthy meals. Family meals can not only help with filling bellies, but they've been shown to encourage healthier eating habits, improve communication skills, and support mental health of kids and adults alike. Life with kids can be

very busy, so don't feel bad if every meal isn't a perfectly balanced gourmet spread! Cook what you and your kids will eat and enjoy the time connecting over dinner when you can. See some benefits from family meals at [parents.com](https://www.parents.com).

Reduce technology and screen time.

There is plenty of research showing that TV, computers, phones, games, and other screens and tech devices have been proven to stimulate the brain so it's hard to settle down and can make it hard to focus on the task at hand. The saturation of digital tools and toys is impacting everything from development of language skills, social interactions, sleep, physical health, self-esteem, and mental health. Talk with your kids honestly and in an age appropriate way about the use of technology and screens, what they can be good for, but also their drawbacks. As the parent, you can set rules about screentime, but adults and kids alike struggle with spending too much time on screens and tech. Work together as a family to set your own limits and encourage other ways to spend time together, such as playing outside or learning a skill—that isn't on a screen. If your kids are struggling with controlling impulses with tech, set a time when these items are off limits, such as during dinner, or as part of a bedtime routine. For some insights on how screen time can affect us, check out [discovery mood.com](https://www.discovery mood.com).



Look for opportunities to do simple play and have family fun.

No matter what age your kids are, spending time together doesn't have to be a large event to be meaningful. Small activities over time create a safe space at home and opportunities

to connect and build healthy relationships. Schedule a regular family board game night or go on a walk or bike ride together.

Life can be chaotic and busy, but you can take steps to help smooth things out. If you feel overwhelmed and like you need to change all the things, just pick one that seems reasonable and do your best. All families are unique, and healthy routines and planning family time can make a big difference. See a few more great ideas on routines and fun family activities at [raisingchildren.net.au](https://www.raisingchildren.net.au) and at [parents.com](https://www.parents.com). All photos Adobe Stock.

[Continued from page 1] Stephanie Maney has been working with the HTC since April of 2023, and is delighted to be able to work with so many of our families. She has always been interested in medicine and helping families, particularly babies and kids, but had not been able to work in a clinic until recently. Stephanie grew up in Oklahoma but has lived in Colorado for 11 years. She works to check in patients, manages scheduling, and helps with insurance authorization, referrals, and coordinating care.

Stephanie has a happy personality and brings enthusiasm and kindness to our clinic. She has a green thumb, but her garden is mostly indoor houseplants! She enjoys reading, and loves listening to podcasts, especially about True Crime, Politics, Science, and Technology. She is a HAM radio enthusiast and has spent many years connecting to others in this unique way. She is constantly impressed and grateful to see the strength of the patients and families who visit our clinic.

Noé also joined our HTC team about six months ago and is full of energy and good humor. He grew up in Aurora, and still lives nearby, which is one of the reasons he loves working here! He loves to learn and has enjoyed learning a lot about hemophilia and other bleeding disorders through helping patients with their appointments. Day-to-day, he works with Stephanie doing scheduling, clinic check ins,

and coordinating care. He also speaks fluent Spanish, which is a great help for our team.

He enjoys working with our HTC and gets great satisfaction from helping our patients find the treatment they need. Noé likes to play and coach soccer, hike in the mountains and taking road trips to New Mexico with his family. His favorite foods are Italian, Mexican, and Asian, and if you look closely when you are next in clinic, you'll see that Noé loves to wear fun and interesting socks!

We are so grateful for our incredible front desk team, who are genuinely happy to help our patients have a good experience at the HTC. They each bring something unique and dynamic to our front desk and provide a great deal of care and compassion to our patients.



Our Front Desk Team, Stephanie, Noé, and Yvette. Photo: Merilee Ashton

PEDIATRIC STROKE SUPPORT GROUP UPDATE-SAVE THE DATES

In early August our Pediatric Stroke Parent Support Group held a fun event for patients and families at the park. This was our 1st Annual Day at the Park, meaning we hope to be able to repeat this event in the future! A few of our stroke families were able to join us on August 5th at Red Tailed Hawk Park in Aurora for a lively time. The day was perfect for playing in the park's inclusive splash pad, and the kiddos had a great time.

Our HTC would like to invite our pediatric stroke families to "Save the Dates" for some upcoming stroke support opportunities.

Tuesday, Oct 3, 2023 from 6:30-7:30 pm: Virtual support group meeting that will focus on self-esteem and self-advocacy.

Wednesday, Dec 6, 2023, from 6:00-7:30 pm: In-person party to celebrate the holidays with other patients and families, including a discussion with Dr. Tim Bernard about stroke research and news.

Thursday, Feb 8, 2024, from 6:30-7:30 pm: Virtual support group meeting focused on coping and managing difficult emotions.

Saturday, Apr 20, 2024, Time TBD: A half-day in-person educational event for the entire family at the HTC.

Our team will send most of the invite information via email, so if you are not yet signed up, please reach out to our stroke team to get added to our email list at strokesupport@ucdenver.edu or contact DeEtta Barnhardt at 303-724-6163. See our [website](#) and follow our [Facebook page](#) for more pictures and updated events and information.

A few pictures from our day at the park. Photos: DeEtta Barnhardt



RECENT HEADLINES

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

Colorado Man Shares Positive Results from Gene Therapy Treatment

Analysis Shows Preventative Treatment with Extended Half-Life Products Improve Outcomes Over On-Demand Care

NHF Changes Name to NBDF to Include All Bleeding Disorders

Small Number of Young Patients Experience Severe Bleeds on Hemlibra

Gene Therapy Roctavian Likely to Arrive in US in August 2023

Roche's Gene Therapy Trial of SPK-8011 Moves Forward to Phase 3

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.

Oct 3: Pediatric Stroke Parent Support Group-Virtual Meeting

Oct 6-8: NHF Colorado Women's Wellness Retreat, Glenwood Hot Springs, Colorado

Nov 3-5: RMHBDA Women's Retreat—Chico Hot Springs, Pray, MT

Nov 5: Daylight Saving Time Ends

Nov 11: Veterans Day

Nov 23-24: Clinic, Pharmacy, and Admin offices closed for Thanksgiving Holiday

Dec 6: Pediatric Stroke Parent Support Group In-Person Holiday Party

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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