

The Clotting Connection

A Newsletter for Families with Bleeding and Clotting Disorders



Hemophilia and Thrombosis Center
UNIVERSITY OF COLORADO ANSCHUTZ MEDICAL CAMPUS



Affiliated with
Children's Hospital Colorado

HTC CLINIC UPDATE AMID COVID-19



Co-director Mike Wang shares his support for bleeding disorders with his red tie, and of course, a mask. Photo: Mike Wang

It has been more than a month since dramatic changes have taken place in our country, state, and local communities due to the COVID-19 pandemic. We applaud and thank all who have worked so hard to provide essential services in a safe manner, as well as those who are doing their part to help by staying safe at home. So many changes to our daily lives have put a strain on families, businesses, schools, and mental health. Our HTC is doing our part to provide support in the ways we can through the changes that come. As government guidelines shift and change, we will update any changes to our clinic at our website and social media pages.

As you may know, our clinic has seen drastic changes in how we operate in order to keep our staff and our patients safe. This includes our clinic and offices running on a minimal staff, and only open to acute patients with appointments. The clinic continues to see acute patients from 9 am to 1 pm Monday through Friday, and we are actively working on ways to make visits with our other patients via technology. Our nurse-of-the-day line is open and monitored from 8 am to 4:30 pm daily and much of our staff, including our physical therapy team, psychosocial team, and pharmacy are all available to provide support.

If you do have an appointment with us, please be aware that the CU Medicine building, where our clinic is located, is still locked 24/7. If you have an appointment, you will need to call us to be let into the building. Instructions are posted outside, and details are available to those making appointments. We are also screening everyone who comes into our center for fever or other symptoms. Please do not come to our clinic if you have any COVID-19 or flu-like symptoms.

While much of our HTC team is working from home, they have not been idle! Our physical therapists, psychosocial team, clinicians, and research coordinators are touching base with patients, working to manage care and follow-up research visits over the phone, and setting up tele-health methods to make it easier to treat patients.

Our psychosocial team has put together quite a few resources that can help anyone during this unprecedented time. These include ways to talk to your children about COVID-19, ways to make a mask, learning resources, online ways to get 'out' and see a zoo, park, or museum, as well as financial resources for those out of work. These are available on our website under the Resources tab. If you have any need of psychological or social work support, please reach out to our team at 303-724-0724.

The physical therapy team has gathered support materials to help patients stay physically active and work on keeping joints healthy. They made fliers on stretching, strength training, and keeping up movement while staying at home. You can find

[Continued on page 3]

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Dr. Armstrong and stroke nurse Cindy Nederveld are prepared to treat patients in clinic. Photo: Rose Drake

INSIDE THIS ISSUE

- HTC Clinic Update Amid COVID-19
- Many Resources Available Online
- Pharmacy Maintains Quality Service
- Upcoming Events

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.ucdenver.edu/htc



Email:

HTC.Newsletter@ucdenver.edu

MANY RESOURCES AVAILABLE TO SUPPORT ALL

Living through a worldwide pandemic is something that is new to most everyone. The introduction of stay-at-home orders means that kids are home from school, parents might be working from home, some have lost their jobs, or are unable to work. Others may be struggling to find childcare and dealing with the stress of working the essential jobs that could expose them to COVID-19. All of us are affected by the many changes and closures, not to mention the difficulty finding supplies that we need or want.

Luckily, we live in a time where finding information and support is easier than it ever has been. We encourage all our patients, families, friends, and co-workers to turn to the many resources available to alleviate what challenges you may be facing. Our psychosocial and physical therapy teams found some helpful resources we have made available on our website that could alleviate some issues you face. We list a few here for reference, but please head to our site to explore these helpful resources.

Financial Resources



One big problem facing many Americans is job loss, or temporary furloughs while cities and states are basically shut down. If you need to file for unemployment, need support for food, rent, internet, or finding new

employment, our resource page has several links that can help. These are major stressors that can cause significant problems. If you need some help navigating this challenge, please reach out to our social work team who can guide you to these and other resources.

Great Links for Families

Our psychosocial team has listed multiple resources to help parents explain the crisis that is going on right now. Sometimes it is overwhelming to find the right words to say to make sense of a pandemic, and these resources might be helpful to parents.

In addition, many families are home with their kids and trying to navigate learning online. Your local school district likely has many supports in place to help parents guide their children through this new online learning process. Most districts also offer lunches or food to families, regardless of need. Do not hesitate to contact your school for support, they have many wonderful people working to help make things easier for kids and their parents.

Being cooped up inside and unable to visit our favorite parks, theaters, zoos, or other venues can seem confining. However, there are many, including some you

may not normally ever get to go to, that are sharing virtual tours, visits, and performances. Our web page has a good number of these listed; however, we know there are many more out there. We hope you take advantage of some of these incredible offers that are free during this challenging time.

We also found some great websites with some fun ideas to keep kids entertained with crafts and activities that we encourage you to check out. It can be challenging, but your family can make fun memories amidst this difficult time. And these ideas and links are not just for kids. There are many fascinating options that can be enjoyed by young and old alike.

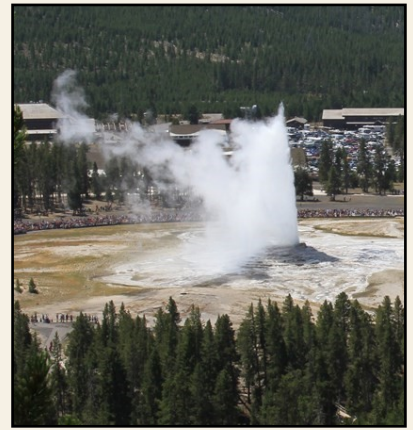
Keeping Fit

Our physical therapy team is encouraging our patients to stay on top of their physical exercise as much as possible. It can be hard on everyone when we are out of our

normal physical routines. If you usually go to the gym, or the recreation you choose is currently inaccessible, our PT team hopes you make the effort to maintain your physical health. They have created a new guide called *"How to Keep Moving While Staying at Home"* as well as three guides specifically outlining helpful stretches.

These are just guidelines, but if you have specific questions or concerns our PT team asks you to reach out to them directly for help.

Our psychosocial team and physical therapy team are happy to provide support, and our clinical staff are monitoring the nursing line to answer questions about your clinical care. Please reach out and allow us to help! Our psychosocial team and physical therapists can be reached through our main line at 303-724-0724 and our nursing line is 303-724-0364. Stay safe and we look forward to seeing you again!



Everything from art museums to national parks have free resources online; even live webcams of Old Faithful in Yellowstone National Park. Photo: NPS



[continued from page 1]



Like many of you, our teams meet often on Zoom calls. Our research staff touch base regularly to continue their work from home. Photo: Kristi Norton

these materials on our website under the Resources tab. If you have questions or need to talk with one of our physical therapists, they are working with patients from home. Please contact us at 303-724-0724 if you need PT support!

Our pharmacy team remains working at full capacity while maintaining social distancing and using strict cleaning methods to keep medications delivering as usual throughout this crisis. There has been no interruption in medication, and we recommend continuing to keep your factor medication schedule as normal. Please contact our pharmacy if you have questions about maintaining your supply of medication.

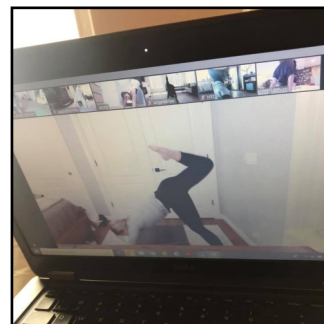
Our plans for Outreach Clinics, camps, and other activities are tentative and shifting daily with what is recommended. For those who would normally attend our Grand Junction clinic in May, we are working to handle those clinic visits via tele-health. You should be

contacted by our HTC about the options and times available. If you haven't heard from us or have questions about this clinic, please call our main clinic line.

NHF Colorado and RMHBDA are both shifting their plans and activities to keep their distance but provide support. Some events are postponed, others may be canceled. A lot depends on things out of their control. Please check with their websites regularly at cohemmo.org and rmhbda.org, to keep up to date.

Our HTC strives to help provide support and often shares information about their events and the changes. Please follow us on Facebook or Twitter and subscribe to our monthly newsletter to stay informed with what is happening. We will continue to endeavor to have the most up to date information available.

As we move forward, we anticipate many more changes; some things may be long-lasting, others may not. We will adjust our staffing and scheduling according to national, state, campus, and other local guidelines. We will continue to do our best to provide support and help to our patients and families. Do not hesitate to reach out to us with questions or problems that may arise. Stay healthy, stay safe, and know we at the HTC are here to help.



Hana Durkee from research has been leading many of our staff in HTC online Zoom Yoga once a week. Photo: Kristi Norton.

PHARMACY MAINTAINS QUALITY SERVICE DURING COVID-19



Our Pharmacy showing support for Bleeding Disorders Awareness last month and also practicing social distancing. Note, this was taken before masks were required, however, they always use masks when preparing your order. Photo: Kevin Anthony

Our team has been able to maintain normal levels of inventory to fill orders and are processing prescriptions without delay. Our pharmacy is strict in their social distancing but are available to answer questions over the phone and provide support. Please reach out to our pharmacy if you have questions about the medications you receive or if you need to place a new order. We always have a pharmacist on call, but our regular phone hours are Monday through Friday from 8:30 am to 4:30 pm. Keep our pharmacy number handy at 303-724-0168.

Even before the stay-at-home orders began in March, our HTC Pharmacy was working diligently to ship medications and supplies to our patients without interruption. The pharmacy remains fully operational and has put in place several measures to ensure safety to both patients and staff. The pharmacy has adjusted schedules to work with teams of one pharmacist and one pharmacy tech that rotate weekly working onsite or at home. The pharmacy manager is on site every day and our reimbursement manager is working remotely.

Every day our staff is carefully screening everyone who comes into the pharmacy with a symptom screening form, including a temperature check. Our pharmacy team wears masks and gloves while preparing and shipping orders, and all shipping containers are disinfected when they enter the pharmacy. Our counters, high touch areas, and work areas are disinfected daily as well.

RECENT HEADLINES

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

New Bloodstream Media Podcast Tackles Pain

Backpacks + Bleeders Offers "Trailblaze from Home" Challenge

NHF CO and HTC Share Updates on COVID-19 in Virtual Town Hall

FDA Approves Sevenfact for Hemophilia A and B with Inhibitors

Medexus Acquires IXINTY from Aptevo

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 then find the **RESOURCES** tab, and go to the **NEWSROOM** page. Find other stories at our Facebook page at www.facebook.com/ColoradoHTC/

UPCOMING EVENTS

Mark Your Calendars:

Please note. These dates may be tentative due to the outbreak of COVID-19. Please check appropriate websites for confirmation of events. We will update as we learn of changes or cancellations.

May 1: NHF CO Bleedership Institute Zoom Meeting

May TBD: Virtual/Tele-health Outreach Clinic—Grand Junction, CO (scheduled individually for personalized times)

May 25: Clinic, Pharmacy, and Admin closed for Memorial Day

Jun 6-7: NHF CO Family Camp

Jul 3: Clinic, Pharmacy, and Admin closed for Independence Day

July 10-11: Leadership Weekend at Mile High Summer Camp

July 12-17: Mile High Summer Camp

Aug 22: NHF CO Unite for Bleeding Disorders Walk

See more at our Events Page on our website: www.medschool.ucdenver.edu/htc find RESOURCES tab, go to EVENTS

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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:

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

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