The Clotting Connection

A Newsletter for Families with Bleeding and Clotting Disorders



Hemophilia and Thrombosis Center

UNIVERSITY OF COLORADO ANSCHUTZ MEDICAL CAMPUS



NG TIPS FOR THE HOLIDA



Travel for the holidays has shifted significantly over the past year. With vastly reduced travel last year, and the introduction of vaccines this year, many are excited and ready to visit family and friends in 2021. News reports indicate that the holidays this year will be at least as busy, if not busier, than before the pandemic. However, in many areas, including Colorado, the positive COVID cases continue to rise, even as some restrictions relax. With many more people traveling both by car and by air, what steps should bleeding disorder patients take if they head out this holiday season?

Get Vaccinated, Wear a Mask, Get Tested

The biggest hurdle to visiting many locations, either foreign or domestic, is to understand the rules and restrictions in place. Some places require proof of vaccination, others do not. Many locations require proof of a negative COVID test within a certain window prior to visiting, and some require a particular kind of test. All airlines, many public transportation facilities, and some public venues require masks. Do your research and find out what you need to know well before you head out. Knowing that you will need to abide by the rules to get to where you need to go, and knowing what those rules are, can help eliminate stress and confusion. Vaccines can help keep you safer from serious infection, and regular testing as required by some locations can confirm that you are heading out without risking yourself or others. Keeping your distance and wearing masks indoors has been proven effective in helping keep you and others safe, despite vaccination status. Stay up to date with all local and destination guidelines to keep your travels as smooth as possible.

Contact your HTC

Those with bleeding disorders have extra precautions and preparations to take whether flying or driving. Our HTC is happy to provide updated travel letters with TSA travel guidelines for medications, bleeding alert cards, and luggage tags for traveling with medication. A travel letter can help you pass through security with your factor

medication, which you should always bring as a carry on. If you need extra factor for a long trip, our pharmacy can provide support in planning ahead to have enough on hand. If you are driving, you will need to make sure to keep your factor in proper and safe ways. Our nurses and pharmacists are happy to provide guidance and answer questions about traveling safely with your medication. See our holiday shipping hours to make sure that you get your factor or medical supplies without holiday disruptions.



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Avoid holiday travel turbulence by planning ahead and touching base with the HTC for support!

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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

SPOTLIGHT: JOANNA ROYBAL, PHYSICAL THERAPIST



Joanna (on the right) with her twin sister. Photo: Joanna Roybal.

Our HTC is excited to share that we have a new physical therapist that has joined our ranks! Joanna Roybal started with the HTC about three months ago and has been a wonderful asset to our PT team! She joins Laura Fox in providing much needed physical therapy support to patients. This month we connected with Joanna

to find out more about her.

Joanna has lived in Colorado most of her life. In fact, she grew up only a few miles from our HTC. She attended Regis University in Denver, where she earned a BA in Biology, and completed her Doctor of Physical Therapy right here at the University of Colorado Anschutz Medical Campus. She is excited to get to work with our patients and bring her experience to bleeding disorder care. For ten years she worked mainly in pediatrics, helping Cerebral Palsy patients. One aspect of the HTC that she looks forward to is working with patients of all ages and supporting them throughout their lives.

Joanna has jumped right in at the HTC doing all things PT. She and Laura work together providing comprehensive exams, acute evaluations, and treatment plans. Joanna enjoys providing support and education to patients, especially when it comes to gait and biomechanics. She loves helping patients understand how their bodies move and why it's important. She finds providing support to patients as they navigate challenges related to orthopedic

surgeries particularly rewarding.

Joanna has a movie loving husband, three cute kids, and a Brittney Spaniel. She has an identical twin sister and they share a special bond, including feeling one another's pain. She's a friendly, outgoing person who loves to connect with others. She loves Colorado, especially Grand Lake, and enjoys hiking, camping, backpacking and road trips. She loves to read, listen to fun podcasts, and enjoys delicious food like mac and cheese, brownies, and ice cream, and spends most of her time keeping up with her kids.

"I love the HTC team and how well we take care of our patients (and each other). Everyone is so knowledgeable and generous with that knowledge. Also-the pharmacy stashes candy and other goodies, which makes perfect sense to me. Chocolate is medicine!" - Joanna Roybal



Joanna with her husband and three kids. Photo: Joanna Roybal

Our HTC is so happy to welcome Joanna to our team. We are excited for you to get to know Joanna and we are thrilled to have her working with us. Please take the chance to say hello the next time you are in clinic.



HTC TEAM WINS PRIZE IN COLFAX MARATHON RELAY

Congratulations to our HTC Team for earning 26th place overall, and taking first place in the Colfax Marathon Relay in the Healthcare Category! They signed up last year but it was canceled, so they were excited to get a chance to try this year! Our team earned \$1250 through their win that they donated to Food Bank of the Rockies providing approximately 5000 meals to those in need!

Their team came in at 3:37:19. Great job HTC team!

Photo—L to R: Tim Schardt, Cindy Nederveld, Jenny Bender, Hana Durkee and Mike Wang. Photo: Mike Wang.

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Know Your Options

Whether you are visiting inside or outside the country, it is helpful to know what your resources are. If your factor needs to be kept in a refrigerator, does the place you are staying have one available? If you need help infusing or need medical support while you are traveling, do you know where to find the closest HTC or hospital? In the United States, you can find a directory of HTCs by going to the CDC's website at www.cdc.gov and search "Hemophilia Treatment Centers". Internationally, you can find your closest treatment center and other international travel tips for people with bleeding disorders at the World Federation of Hemophilia website www.wfh.org at their Resources tab.

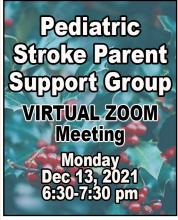
Verify Your Insurance

Every year there are many changes to insurance plans, and what you may have done before may not apply today. Be sure to double check your insurance to make sure you can be treated outside of your home state. Contact your insurance company directly to talk with them about your travel plans to make sure your resources are covered if needed.



There are many other travel resources, including support from our clinic and pharmacy, NHF chapters and national level organizations to help guide you through traveling this season. Whether you travel or stay home, we hope the holiday season finds you healthy and happy.

PEDIATRIC STROKE PARENT SUPPORT GROUP



Our Pediatric Stroke
Parent Support Group
will be on **Monday**, **December 13, 2021 at 6:30 pm** on Zoom.
This group invites
parents of children
who survived a stroke
to meet with one
another and our
stroke team each
month. In December
we will have a festive
evening filled with

holiday fun. Please join us!

Normally we meet in person, but with the COVID-19 pandemic restrictions we are continuing to have these meetings on Zoom until things improve.

We have changed the date of our meetings to the second <u>Monday</u> of the month from 6:30 to 7:30 pm. Meetings are open to families of children of all ages and all types of stroke. Your child does not need to be seen at our stroke clinic to join our meetings.

For more details, see our website here, or follow us on Facebook. To join our meeting, please RSVP to strokesupport@ucdenver.edu or call 303-724-8520.

HOLIDAY CLOSURES & SHIPPING DEADLINES

Our HTC clinic, pharmacy, and administrative offices will be closed for several upcoming holidays. Please be aware of the following closure dates and shipping dates to make sure you are able to get your factor or other medical care when needed.



Clinic, Pharmacy, and Offices Closed on the following dates:

Thurs-Fri Nov. 25-26, 2021 Thurs-Fri Dec. 23-24, 2021 Friday Dec. 31, 2021 Monday Jan. 17, 2022

Thanksgiving Holiday Christmas Holiday New Year's Eve Martin Luther King Jr. Day

Last Date to ship before holidays:

Before Thanksgiving Before Christmas Before New Year's Before MLK Day

Tues. Nov. 23, 2021 Tues. Dec. 21, 2021 Wed. Dec. 29, 2021 Thurs. Jan. 13, 2022

If you need to contact our clinic or pharmacy during any holiday, please see our contact page for details.

To obtain emergency factor from the pharmacy, contact the pharmacy directly at 303-724-0168.

RECENT HEADLINES

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

Data Finds Fitusiran Reduced Bleeds in Patients with Hemophilia A and B

FDA Puts Hold on Gene Therapy SB-525 Phase 3 Trial

Small Study Finds Extended FIX Prophylactic Therapy May Not Ease Pain

Long-Term Preventative Use of Esperoct Effective in Hemophilia A Patients

"Reverse Vaccination" May Help Prevent Immune Response

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 <u>tentative and</u> <u>subject to change</u>. Please check appropriate websites for confirmation of events.

Nov 25-26: Clinic, Pharmacy, and Admin offices closed for Thanksgiving Holiday

Nov 30: NHF CO Denver Zoo and You

Dec 11: Backpacks + Bleeders: Eldorado Canyon State Park Hike

Dec 13: Pediatric Stroke Parent Support Group **Dec 15:** NHF CO Von Willebrand Disease A-Z

Dec 23-24: Clinic, Pharmacy, and Admin offices closed for Christmas Holiday

Dec 31: Clinic, Pharmacy, and Admin offices closed for New Year's Eve.

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

Hemophilia & Thrombosis Center

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Clinic Main: 303-724-0724 or toll free at 888-297-0724 Pharmacy Main: 303-724-0168 or toll free at 888-724-7427

Web page:

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