The Clotting Connection

A Newsletter for Families with Bleeding and Clotting Disorders



Affiliated with Children's Hospital Colorado and University of Colorado Hospital

Hemophilia and Thrombosis Center

SAFE SUMMER FUN



Summer is now in full swing and with it are opportunities to get outdoors, go on vacation, and play. With all recreational activities, family trips, or long summer days off, planning ahead can help avoid trouble. Whether you are heading to the pool, the park, or taking a long awaited family trip, take a few precautions and have a great time!

Sunscreen and Shade

Summertime brings a lot of opportunity to spend time in the sun, but a sunburn can quickly make a trip to the beach or riverbank a big pain. Find sunscreen that works for you and use it. If you will be swimming a lot, remember to re-apply; no sunscreen is completely waterproof. Seek shade, or bring a large umbrella if you will be outdoors when the sun is the most intense—between 10 am and 2 pm.

Remember that water reflects the sun and even your eyes can

get sunburned. Wear sunglasses and keep shoes or flip-flops with you to protect your feet from hot sand, broken glass, or other sharp objects.

Water Safety

Swimming is a fun and refreshing summer activity, and a great way to get exercise in a low impact way. However, there are still dangers when having fun in the water, so keep a close eye on children as they swim, and if possible swim in places with a lifeguard on duty. Swimming in lakes, rivers, or streams have their own risks, especially during a year with a lot of runoff, making rivers especially dangerous. Check local restrictions, and wear safety gear while boating or playing around rivers, streams and lakes. A child can drown in only a few inches of water, so never get distracted when caring for children around pools or other water sources.

Stay Hydrated



It is easy for people to forget to stay hydrated while swimming, playing at a theme park, or driving long distances. Dehydration can be a big problem for anyone, including pets, so it is important to keep drinking water. Children are far more likely to experience heat stroke than adults, so know and watch for signs of dehydration. Some signs of dehydration are headache, muscle cramping, fatigue, weakness, and dizziness. At higher altitudes, dehydration is more pronounced and it can increase the chance of altitude sickness—which can include dizziness, fatigue, loss of appetite,

nausea or vomiting, rapid heart rate, and shortness of breath.

Remind kids, and yourself, to drink fluids before and after activities, and to have drink breaks as they play. Kids should take a drink break at least every 20 minutes during warm activities. Never leave kids or pets in a car, even for a few minutes. Be aware that some travel destinations may not have clean drinking water easily available. Research your route and destination and check into your options for purchasing bottled water if need be.

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Summer is a great time to get outdoors and enjoy a walk, jog, or hike. Photo: Merilee Ashton

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



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Go to twitter.com/ HTCColorado

HTC Website: Go to medschool.ucdenver.edu/htc



Email:

HTC.Newsletter@ucdenver.edu

UPCOMING EVENTS & OPPORTUNITIES



If you do not live in the Denver Metro area, one of our Outreach Clinics might be an easier option for your regular comprehensive care. Our Outreach Clinics offer care and support from our medical, nursing, physical therapy, psychosocial, and research teams. Our experts come to you!

Upcoming Outreach Clinics:

June 25-28, 2019—Billings, Montana July 31-Aug 2, 2019—Missoula, Montana Sept 25-27—Grand Junction, Colorado

See our website for updates on future clinics and more details at: www.medschool.ucdenver.edu/htc and find the Outreach Clinics page under the CLINIC tab.

Our Pediatric Stroke Parent Support Group meetings normally meet the 2nd Tuesdays of the month from 6 pm to 7:30. Please be aware that this group will have a brief summer hiatus and **will not meet in July**.

We plan on resuming meetings in August. For details, go to our website at www.medschool.ucdenver.edu/htc and find the Pediatric Stroke Parent Support Group page under the COMMUNITY tab.





Mark your calendar now to join us for the *Unite for Bleeding Disorders Walk* on **August 24, 2019 at 9 am at Sloan's Lake Park.**

This annual walk is one of NHF Colorado's largest fundraising efforts, providing important support for their incredible programs. The walk funds Mile High Summer Camp, Education Days and many other great events throughout the year that are designed to unite and support families with bleeding disorders.

Sign up, form or join a team, invite your friends and family and walk side-by-side to make a difference! Watch for more info at <u>cohemo.org</u>.

INSURANCE ALERT: WATCH FOR LAB COVERAGE CHANGES



Every year insurance companies make changes to their plans and sometimes those changes can catch patients off guard. It is important to pay close attention to your plan and what it covers, especially if you have significant healthcare needs.

July 1st is the start of a new insurance plan year for many people, and now is a good time to review what is covered, and the locations that are considered in-network for your plan.

We have been made aware of a change that may affect some of our patients. For those in the UnitedHealthcare Network, including those plans administered by UnitedHealthcare's Third Party Administrator UMR, please be aware that our recommended labs through UCHealth or Children's Hospital **may not be covered** on your plan. Their Preferred Lab Network excludes some of the locations we have used in the past for lab work and you must verify coverage before any lab work is performed. These changes to their in-network labs will begin on **July 1, 2019.**

In addition, sometimes lab work can still be performed at a different location than their preferred labs, but exceptions to have lab work done at an out-of-network

lab will need a referral, and may incur additional costs.

If you use UnitedHealthcare and need lab work performed, please be sure to contact them to verify coverage of the location of the lab before going.

Our HTC staff may be able to answer some questions, but we also encourage you to contact our HTC Prior Authorization Technician, Yevette Portillo-Corral, for support in verifying coverage. She can be reached at Yevette.portillo-corral@ucdenver.edu or at 303-724-7174.



Yevette Portillo-Corral is our Prior Authorization Technician, working to help you verify coverage.

HTC SPOTLIGHT: DR. MEGAN BARRY



In May we celebrated Pediatric Stroke Awareness Month and shared about our program here at the HTC. Our stroke patients and others visiting our center may encounter one of our newer doctors that treat pediatric stroke, Dr. Megan Barry.

Dr. Barry is an Assistant Professor of Pediatrics and

Neurology and has been working with our Stroke Clinic for about two years. She grew up just outside of Chicago, and still has family living there. She was a swimmer in high school and played water polo throughout high school and into college. Dr. Barry attended Michigan State University, and went to medical school at Des Moines University.

After her residencies at the University of Missouri-Columbia, and Vanderbilt University in Nashville, TN, she began a Vascular Neurology Fellowship here at the University of Colorado. Dr. Barry treats both pediatric

and young adult patients, and is at our HTC stroke clinic on Tuesdays and Fridays. She splits her time caring for patients at the hospital, treating patients at the stroke clinic, and working on pediatric stroke research.

Seeing patients recover from stroke is one of the most satisfying things Dr. Barry enjoys about her job. She is so happy to see patients outside of the hospital doing better and getting back to their normal lives. Dr. Barry also helps enroll patients into a few different pediatric stroke studies that can help us understand stroke, and how best to treat and recover from stroke.

Dr. Barry enjoys working with all the people in the stroke clinic. She says, "We have a terrific group of people across all different specialties who work together to bring the best care to our stroke patients." When Dr. Barry is not working, she enjoys skiing, hiking, and hanging out with her dog Addison. She is also planning a trip to Japan for the 2020 Summer Olympics!

Our clinic is grateful to have Dr. Barry's knowledge and experience to help our patients find the best possible care.

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Safe Hiking

If you are planning on a hike, especially in the mountains, remember that you can get sunburned much faster at high altitude, so sunscreen is still important even if it feels cool. Wear a hat and bring a jacket if you will be hiking in the mountains, and always bring a first aid kit and plenty of water and snacks. If you have new hiking shoes, break them in before you take a long hike, and wear wool or other specialized hiking socks to help prevent blisters. Hiking in the summer often brings the risk of a thunderstorm and dangerous weather like hail or lightning. Keep an eye on the weather, and plan on heading down from high peaks before noon. Research and know your hiking trail, and carry emergency supplies in case you get lost or stranded by weather. Always plan on hiking with a friend, especially in remote locations, and let others at home know your schedule and location, and when you are anticipated to be home.

Don't get Bugged



Ticks, mosquitoes, and other insects can cause pain, irritation, and spread disease. Keep insect repellent on hand in areas where you may encounter bugs, and avoid having exposed skin during their most active hours. Be alert about the places you stay, as hotels and motels are sometimes places you may be exposed to bedbugs. Inspect your hotel mattress, keep clothes off the floor and try to learn more about places you stay in advance. Travel sites will have reviews available, and if someone has encountered bedbugs, you will likely hear about it before you book.

Medication on Hand

Bleeding disorder patients should take special care in preparing to travel if they have a need to bring factor. Being able to access medication quickly can be helpful in the event of an unexpected bleed, and keeping factor at the right temperature is important. Airports may require you to have a note from medical personnel when screening liquids, such as factor, through security. Our pharmacy staff regularly work with patients to plan and supply enough factor or other materials for those attending camps and traveling. Be prepared to know the restrictions you may come across, and pack medical supplies carefully and safely.



Summer is a great chance to get out and enjoy many activities! Stay active, and stay safe this summer.

RECENT HEADLINES

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

NHF Colorado Welcomes Perry Jowsey as New Executive Director

Bayer Joins WFH to Help Hemophilia Patients in Developing Countries

BioMarin Shares Data for Gene Therapy Before FDA Submission

Six Ways for Young Adults to Make Adherence Easier

UniQure Presents Updated Data for Gene Therapy Trial for Hemophilia B

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:

June 25-28: Outreach Clinic—Billings, MT

July 4: Clinic, Pharmacy, & Admin closed for Independence Day

July 12-13: Leadership Training at Mile High Summer Camp

July 14-19: Mile High Summer Camp

July 31-Aug 2: Outreach Clinic—Missoula, MT

Aug 24: NHF CO Unite for Bleeding Disorders Walk-Denver, CO

Sept 2: Clinic, Pharmacy, & Admin closed for Labor Day

Sept 7: RMHBDA Unite for Bleeding Disorders Walk—Billings, MT

Sept 14: RMHBDA United for Bleeding Disorders Walk—Kalispell, MT

Sept 25-27: Outreach Clinic—Grand Junction, CO

Oct 3-5: National Hemophilia Foundation Annual Conference—Anaheim, CA

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

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Web page:

http://medschool.ucdenver.edu/htc

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