

The Clotting Connection

A Newsletter for Families with Bleeding and Clotting Disorders

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SAFETY IN THE SUMMER HEAT

Every summer things heat up and most of the time people find ways to enjoy the warm weather and have fun in the sun. However, extreme heat can arrive in a heat wave—something much hotter and/or humid than what is average for an area—and it can be uncomfortable and even dangerous. The US has already experienced several summer heat waves and are likely to see several more before the fall and in years to come.

According to the CDC, [extreme heat causes approximately 1,200 deaths a year](#) in the United States, and nearly all of them are preventable. One of the easiest ways to avoid problems when planning your summer activities is to pay attention to the weather, watch or listen to news outlets, or check an app on your phone. The CDC has a [HeatRisk website](#) you can search for your area's risk. Just knowing if extreme heat is on the way can help you make adjustments such as spending shorter periods in the sun, having more water available, or wearing clothing appropriate for an event.

Not everyone will be as affected by a heat wave, especially those who have regular access to air conditioning at home, work in an air-conditioned office, and are fairly healthy. However, people who work outside or may have an outdoor activity during a heat wave should be prepared for extreme heat. Others, like the elderly, infants and children, athletes, and those with disabilities or chronic health conditions may be at higher risk of heat illnesses when exposed to very warm temperatures, and simple precautions should be taken.

Heat Related Illnesses

There are three significant heat illnesses to keep an eye out for. [More details at redcross.org.](#)

Heat Cramps: These are muscle spasms that occur when there is a large loss of salt and water in the body. It usually occurs when someone is doing a lot of exercise or exertion during hot temperatures. The primary symptoms are heavy sweating and muscle pain or spasms.

Heat Exhaustion: This is more severe and may require emergency treatment. Heat exhaustion symptoms like heavy sweating, cold, pale, and clammy skin, a fast, weak pulse, tiredness, headache, dizziness, or nausea are serious, and action should be taken to cool down right away.

Heat Stroke: This is a potentially deadly condition and requires immediate medical attention. Symptoms of heat stroke are a high body temperature (103F or above), dry, red, hot skin with little to no sweat, fast, strong pulse, headache, nausea, and confusion. With any of these more severe symptoms, call 9-1-1 and take immediate action to cool the person down. See graphic above.

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During warm days, be prepared with extra water, wear light colored clothing, and find shade to keep from overheating.

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Website: Go to

medschool.cuanschutz.edu/hemophilia-thrombosis



Email:

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Prevention

Avoiding heat illnesses is much better than trying to manage them. Here are a few ideas to help keep things cool during a heat wave.

- Exercise or work outdoors earlier or later in the day, avoiding the hottest and sunniest times.
- Change plans to include indoor, cooler, or shaded locations during a heat wave. Find or bring shade if you must be outdoors, such as sitting under a tree or setting up an umbrella or shade tent.
- Keep hydrated, focusing on non-alcoholic and decaffeinated drinks. Both alcohol and caffeine can make things worse. Drink water at regular intervals, even if you aren't feeling thirsty.
- Wear cool and non-restrictive clothing. Lighter colors reflect light and darker colors absorb it making you warmer. Wearing a hat and sunscreen can help protect you from both extra heat and the additional problem of sunburn, which reduces your ability to dissipate heat.
- If you don't have AC at home, visit somewhere that does during the hottest times of the day. Places like the library, shopping malls, grocery stores, movie theaters, and restaurants often have air conditioning and are options to visit. Some cities will set up "cooling centers" during a heat wave, seek these out when needed.
- If you know a neighbor, elderly relative, or friend who is vulnerable and does not have air conditioning, consider finding ways to help them get to somewhere cool during a heat wave, or help them find ways to keep their home cool.
- Covering windows with drapes or shades can help block out the heat. You can use window reflectors or upgrade to insulated or darkened glass to reduce heat. Weatherstrip doors and windows or increase insulation if your house lets in a lot of heat through cracks or walls.

- If you don't have air conditioning, install window air if possible. If you are unable to afford cooling costs, weatherization, or energy related repairs, you can contact the [Low Income Home Energy Assistance Program](#) or other programs in your area for help.
- Be aware of infants, older, sick, or frail people and pets. Children and the elderly may not be able to regulate temperature well and may not be able to express how hot they feel. Keep anyone at risk, especially children, seniors, and anyone who is frail in the coolest available location and monitor their symptoms closely.
- Pets are also unable to easily communicate a struggle with overheating. Offer pets fresh, clean water often, and avoid walks when it is the hottest part of the day. Be careful to not let your pet walk on hot surfaces like asphalt very long as they can get overheated quickly and their paws can burn.
- Never leave children, pets, or any vulnerable adult in the car, even for a few minutes. Temperatures in the car can reach extreme conditions even when it isn't that warm outside. At only 80 degrees outside, it only takes 20 minutes to be well over 110 degrees in the car.
- If you are tired, overworked, or worried that you may forget an infant in the back seat, make it a habit to put something you cannot leave without, such as a shoe, purse, phone, or bag in the back seat so you must get it out before you leave.



Heat related illness and deaths can be avoided by taking steps to be aware of the risks and using caution and care on hot days. Enjoy the summer weather and stay safe when things get hot!

DROPS OF LOVE—A WAY TO CELEBRATE OUR TEAM



We have a new program at our HTC called "Drops of Love" to celebrate our staff.

We know that often our HTC team members do a great job but may not know that their efforts were appreciated. We would love your help!

This is an opportunity for any patient, family member, caregiver or visitor to our HTC to recognize anyone at our center who went above and beyond when you visited!

Just scan the QR code (left) to send a "drop of love" to our staff members and let us know how they made a difference in their service to you! Thank you for sharing your feedback with us!

POKE COMFORT KITS DESIGNED TO HELP



Does your child show signs of fear and anxiety around getting “poked” at medical appointments, including the HTC? Our staff knows that this is a challenge for many of our pediatric patients. Getting lab

draws, infusions, and other needle sticks is not fun, and we feel our patients deserve as much of a pain-free experience as possible when receiving “pokes.”

DeEtta Barnhardt, one of our social workers, was awarded a grant through the Hemophilia Alliance to build “Poke Comfort Kits.” The kits are provided to all patients between the ages of 3 and 18 who come to the HTC for a diagnosed bleeding disorder and those undergoing a work-up for a suspected bleeding disorder. The kits are designed for three age groups: 3-6 year olds, 7-12 year olds, and 13-18 year olds. Because of the grant requirements, we are not able to provide the Poke Comfort Kit to our Thrombosis or clotting patients.

The Poke Comfort Kits include various items to help enhance each child’s sense of control, provide them with distractions to utilize during a “poke,” and offer items to support and sooth them during lab draws and needle sticks. It also provides suggestions on ways to provide comfort to a child who will be receiving a “poke” including different ways to practice deep breathing and different holds caregivers

can use when supporting a younger child. The Poke Comfort Kits are tools that can be used at the HTC but also in any other clinic where a child may receive a “poke.”

Our HTC team will meet with each patient who meets criteria for a Poke Comfort Kit, even if they are not receiving a “poke” during their scheduled visit. The team member will explain the kit and answer any questions. Not every patient will feel like they want or need the Poke Comfort Kit. It is ok to turn it down! The staff at the HTC began providing Poke Comfort Kits to patients in June and plan to hand deliver five hundred kits to patients both at the Aurora HTC and during our outreach clinics in Billings, Missoula, and Grand Junction.

There is a QR code survey in the Poke Comfort Kit for caregivers and for

teenagers to complete. This survey will help the social work team determine if the Poke Comfort Kits were beneficial as well as what items were most worthwhile for patients. We are very excited to be able to offer this important resource to our patients and caregivers. If you have questions, please reach out to our Social Work Team.



Some of the Poke Comfort Kits divided by age, ready to go to provide comfort to kids attending our clinics. Photo: DeEtta Barnhardt.

UPCOMING OPPORTUNITIES—MARK YOUR CALENDARS



for Bleeding Disorders

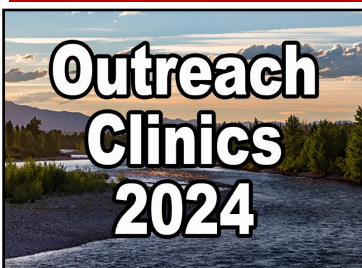
Join us at the Unite for Bleeding Disorders Walks in 2024. These fundraisers support the Colorado Chapter of the NBDF and the Rocky Mountain Hemophilia & Bleeding Disorders Association in Montana. Each of these organizations spend the entire year providing support, community events, educational opportunities, fun activities, and camps for those with bleeding disorders. The Annual Unite for Bleeding Disorders Walks are the main way funds are raised to provide these incredible services to patients and families for free or at minimal cost. Please join us at one of the following walks and make a difference to families with bleeding disorders! We’ll see you there!

Colorado NBDF Unite Walk

August 24, 2024—Sloan’s Lake Park, Denver, CO

RMHBDA Unite Walk

September 7, 2024—Zoo Montana, Billings, MT



Our HTC visits locations in our region to offer comprehensive care to patients who live in more distant cities from our main clinic. If you live closer to one of these clinics and would like to be seen there instead of at our location in Aurora, CO, please contact our front desk and ask about scheduling. 303-724-0724 or toll free at 1-888-297-0724

July 30-Aug 1, 2024—Billings, MT
Sept 17-19, 2024—Billings, MT

Aug 27-29, 2024—Missoula, MT
Oct 8-10—Grand Junction, CO

RECENT HEADLINES

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

Small Study Shows Extended Half-life Using Experimental Treatment for Hemophilia with Inhibitors

Study Shows Hemlibra Safe, Effective in Older Patients

FDA Grants Orphan Drug Status to Biopharma's B-cell Treatment for Hemophilia B

Phase 3 Trial Shows Mim8 Better at Reducing Bleeds for Hemophilia A Patients than Standard Treatments

New Study Shows Long Term Benefits of Gene Therapy for Severe Hemophilia A

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.

Aug 8-9: RMHBDA Teen Retreat—Camp Paxon, Seeley Lake, MT

Aug 9-11: RMHBDA Big Sky Family Camp—Camp Paxon, Seeley Lake, MT

Aug 24: NBDF Colorado Unite for Bleeding Disorders Walk—Sloan's Lake, CO

Aug 27-29: HTC Outreach Clinic—Missoula, MT

Sep 2: Clinic, Pharmacy, and Admin offices closed for Labor Day

Sep 6: RMHBDA Golf Clinic & Dinner-Billings, MT

Sep 7: RMHBDA Unite for Bleeding Disorders Walk-Billings, MT

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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