

# The Clotting Connection

*A Newsletter for Families with Bleeding and Clotting Disorders*

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University of Colorado  
Anschutz Medical Campus  
Hemophilia and Thrombosis Center

Affiliated with  
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## Summer Camps Change Lives

Every summer families all over the country look for activities to do to keep kids entertained and active during their vacation from school. It can be difficult for those with bleeding disorders such as hemophilia or Von Willebrand Disease to participate in activities like other children if they're worried about complications from their disorder. Since 1969, when the first summer camp for hemophilia was started in Michigan, specialty camps for kids with bleeding disorders provide an opportunity to have a fun, rewarding, and learning experience at camp in a safe environment.

Most camps for those with hemophilia teach children to self-infuse, a mile-stone that gives kids a large step to independence. During camp kids can try out new activities, stay safe, and learn about their disorder and how to take ownership of their health. Another advantage of hemophilia camp is giving kids the chance to make friends with others who are going through similar challenges. The HTC has sponsored Mile High Summer Camp for those with bleeding disorders for the past 37 years, giving kids the opportunity to learn and grow, mentor other kids and have fun.

The Denver Hemophilia & Thrombosis Center works in conjunction with NHF Colorado and the Easter Seals camp staff to provide camp activities, medical care, and a unique learning experience for kids from the entire Rocky Mountain region. Mile High Summer Camp this year is July 12-17 at Rocky Mountain Village in Empire, Colorado. Leadership camp begins on July 10 for high school aged campers. Details can be found at [cohemo.org](http://cohemo.org).

The Hemophilia Foundation of America has a great video explaining some of the benefits of attending camp at their website along with an interactive map showing the many fantastic camps available throughout the country. Those can be accessed through [hemophiliafed.org](http://hemophiliafed.org). Look under the bleeding disorders tab for camps.

**Please share your stories**--why do you attend camp? We'd love to hear your memories of camp, why you went, how you (or your child) grew or benefited from camp, and of course, funny stories and pictures are welcome! Send us an email, include pictures, or mail us a note. We'd love to share your experiences with our other families.

Our email is [HTC.Newsletter@ucdenver.edu](mailto:HTC.Newsletter@ucdenver.edu), and our mailing address is: 13199 E. Montview Blvd., Suite 100 Aurora, CO 80045.

**Please note, by sending emails/photos you give permission for us to use those on our website, social media and newsletter to share with our bleeding disorder community.**



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



Go to [facebook.com/ColoradoHTC](https://facebook.com/ColoradoHTC)



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Website- Go to [medschool.ucdenver.edu/htc](https://medschool.ucdenver.edu/htc)



Email:  
[HTC.Newsletter@ucdenver.edu](mailto:HTC.Newsletter@ucdenver.edu)

# SUMMER FUN, SUMMER SAFETY



Summer is here, and there are more opportunities for the entire family to get outdoors and play. The CDC recommends kids get at least 60 minutes of physical activity every day and children with bleeding disorders need to

exercise too. Some of the best summer activities also can have inherent risks. Here's a few ideas to stay safe this summer

**Sunburn-** With any outdoor activity, being outdoors for hours can expose skin to too much of a good thing. UV rays can cause sunburn, damage to eyes, wrinkles, premature aging, and skin cancers. In high altitude areas the sun can burn skin at a much faster rate and reflective surfaces such as water, snow and ice can also increase the chance of sunburn. Be sure to apply sunscreen early and often when playing outdoors. For good resources on sunburn go to [www.webmd.com](http://www.webmd.com) or [www.cancer.org](http://www.cancer.org).

**Dehydration-** When the temperature rises, kids get hot and dehydrated. 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. Kids should drink 12 ounces of fluid 30 minutes before activities and take drink breaks as they play. Always have extra water and encourage them to drink every 20 minutes. Never leave kids in a car, even for a few minutes. Kids are much more likely to experience heat stroke than adults. There's some great articles on keeping kids hydrated and safe in hot weather at [www.kidshealth.org](http://www.kidshealth.org) and [www.safercar.gov](http://www.safercar.gov).

**Water safety-** Swimming is one of the best activities for those with bleeding disorders. It's low impact, uses a lot of muscle groups, and is fun and refreshing. Always have a lifeguard or adult with swimming experience watching kids play in water. Around lakes, rivers and streams, be sure to have life jackets and take precautions around high water. Be sure to check local restrictions and take the risks seriously while enjoying rivers, lakes and streams. For in depth articles on drowning and water safety, head to [www.weather.com](http://www.weather.com) and [www.cdc.gov](http://www.cdc.gov).

**Helmets-** Kids love biking, skateboarding, and other activities that may require helmets. These can be great fun, but a fall without a helmet can be life threatening. Be sure to have a properly fitted helmet, and other protective gear for various sports, such as knee pads or mouth guards. Be a good example and always wear a helmet. The Hemophilia Federation of America has a great video on biking and properly fitting helmets at their website [www.hemophiliafed.org](http://www.hemophiliafed.org).

**Hiking-** Living in the Rocky Mountains means access to some of the best trails in the country. Hiking can be a great activity for kids and can build confidence and burn energy. Be prepared and know the trail, have a plan in case anyone is separated, bring a cell phone and include extra food and water in case you are delayed or lost as you hike. It is important to apply sunscreen, drink plenty of water and keep insect repellent on hand to help prevent injuries, sunburn and bites. We found a helpful article on hiking at [www.thecohiker.com](http://www.thecohiker.com) with hiking tips. Consider joining the NHF Colorado Chapter on one of their Backpacks & Bleeders outings, such as Geocaching in late June and hiking a 14er in July. You can find details at their site [www.cohemo.org](http://www.cohemo.org) or at their Facebook page.

Stay active and stay safe this summer. For more ideas and direct links to these articles, head to our website [www.medschool.ucdenver.edu/htc](http://www.medschool.ucdenver.edu/htc) and find the digital newsletter under RESOURCES.

## SCHOLARSHIP INFORMATION

Several scholarships are available to students with bleeding or clotting disorders, and their family members. Application dates vary, but several are coming up and some have passed already.

For a list of scholarships with links, please see our website at [www.medschool.ucdenver.edu/htc](http://www.medschool.ucdenver.edu/htc) and look under the RESOURCES tab for the Children & Teens section.



## OUTREACH CLINICS SCHEDULED

Every year the HTC provides the opportunity for patients who live in the farther corners of our region to meet with the same doctors and specialists available in our Denver clinic at locations much closer to them. We already held a successful clinic in Billings, Montana at the beginning of June and have two more scheduled for 2015, one in Missoula, Montana and another in Grand Junction.

These clinics allow patients to schedule their annual comprehensive visit with our doctors, spend time managing care with our nurses, see physical therapists, social workers, and update their pharmacy needs. We

send out sign up information to our patients in each area, but if you have moved, have changed details or need information, please do not hesitate to contact us directly about these clinics and how they can help. Please contact Pat Casias or Audra LeBlanc at 888-297-0724 (toll free), or 303-724-0724. You can find more details, access forms and other info on location at our Outreach Clinic page at our website.

### Upcoming Outreach Clinics-

**July 27-29 Missoula, MT**

**Sept 23-25 Grand Junction, CO**

## NEWSLETTER INFO



If you received the newsletter in your email box it is because you signed up to receive our online newsletters. If you signed up and did not receive one, please check your spam or filtered folders and contact us if you are unable to locate it. Please feel free to forward it to family and friends who might be interested in the content.

Direct access to the subscription page can be found via our website. Just go to [medschool.ucdenver.edu/htc](http://medschool.ucdenver.edu/htc) and click on the resources tab for the Newsletter page. If at any time you wish to unsubscribe, there is a link at the bottom of the email.

We will have a few paper copies of this content available in the clinic and a link to the digital version at our website. If you have questions, corrections, or feedback, please contact us at [HTC.Newsletter@ucdenver.edu](mailto:HTC.Newsletter@ucdenver.edu).

## HOLIDAY CLOSURES

Any time our offices and clinic are closed for a holiday we can be contacted in an emergency via our after hours service. Find our after hours details on our website at the **Contact Us** page.

All of the upcoming holidays are available on our website by going to: [www.medschool.ucdenver.edu/htc](http://www.medschool.ucdenver.edu/htc) and clicking on the main **Clinic** tab (on the top bar of the main page).





## RECENT HEADLINES

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

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 head to: [www.medschool.ucdenver.edu/htc](http://www.medschool.ucdenver.edu/htc) then find the RESOURCES tab, and go to the NEWSROOM tab.

**CSL Behring Presents Phase 3 Data for rIX-FP at ISTH**

**Phase 3 Data for Novo Nordisk's Zonovate Presented at ISTH**

**Quick Action Saves Teen from Stroke**

**Apitope's Inhibitor Drug Candidate ATX-F8-117 Granted FDA Orphan Drug Status**

**Mountaineer and Hemophiliac Chris Bombardier to Conquer Seven Summits**

## UPCOMING EVENTS

**June 27:** Backpacks & Bleeders-Geocaching

**July 1:** Pediatric Stroke Survivors Teen Retreat (ages 13-19) Bear Creek State Park

**July 3:** **HTC Closed for Independence Day**

**July 9-12:** NHF Inhibitor Education Summit, Denver, CO

**July 10-12:** Mile High Summer Camp Leadership Pre-Camp Retreat

**July 12-17:** Mile High Summer Camp

**July 21:** Pediatric Stroke Parent Support Group meeting at BIAC

**July 27-28:** Backpacks & Bleeders

**July 27-29:** Outreach Clinic in Missoula, MT

**Aug 13-15:** NHF Annual Meeting, Dallas, TX

**Aug 22:** NHF Colorado-Walk for Hemophilia

**Aug 30:** Pediatric Stroke Parent Support Group Summer Picnic

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