

The Clotting Connection

A Newsletter for Families with Bleeding and Clotting Disorders

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Take in the Colors



Photo: Maroon Bells by Ali Schomerus

Autumn is upon us and it's a great time to plan a hike, walk, or drive to see the fall colors. Hiking and walking can be low impact and the movement is good for joints and muscles. Our NHF Chapter in Colorado regularly hosts hikes to inspire and challenge through their Backpacks and Bleeders program. We're lucky to live in a region where there are many opportunities to see this colorful change of season in all its glory. Whether it's a walk in your neighborhood or a road trip to take in the views, grab your shoes and sunscreen and enjoy the colors before they fade. We asked around at the HTC and came up with a list of our favorite family-friendly hikes to enjoy at this lovely time of year. Be sure to check in advance for trail conditions, weather, and prepare for emergencies.

Rocky Mountain National Park

The park has been celebrating its 100th anniversary and the opportunity to see fall colors and wildlife in the area are abundant. Take advantage of the 355 miles of hiking trails in the park, the amazing views along Trail Ridge Road, or plan a picnic. The park is accessible from the scenic towns of Estes Park or Grand Lake. To get to Estes Park take either Hwy 34 from Loveland, or Hwy 36 from Denver/Boulder. To access via Grand Lake, take I-70 and take Exit 232 to Granby, follow through Granby and turn on Hwy 34. Be aware that Trail Ridge Road generally closes mid-October through late-May.

Golden Gate Canyon State Park

This beautiful wilderness area has 12,000 acres of forest, mountain trails, and meadows to explore and is located only 13 miles west of Golden. There are many hikes with varying levels of difficulty, available camping, scenic views and picnic areas available. From Golden, take Hwy 93 to Golden Gate Canyon Rd., turn left and continue for 13 miles to Crawford Gulch Rd. Turn right and travel 200 yards to park entrance.

Maroon Bells

The iconic view of Maroon Bells in White River national Forest near Aspen is one of the most beautiful sites to visit in the state. Many popular trails in the area



Photo: South of Fairplay by Merilee Ashton

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NHF ANNUAL MEETING UPDATE

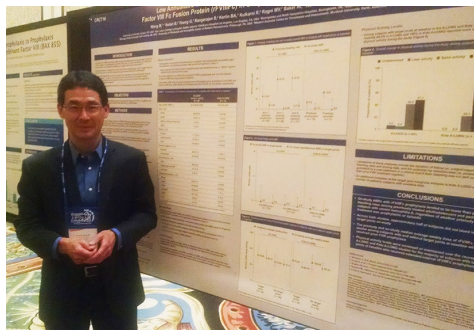


Photo: Mike Wang presenting Posters by Brenda Riske

Members of our HTC were pleased to be able to attend the National Hemophilia Foundation's 67th Annual

and treatments. Our Center's Tyler Buckner, Mike Wang, Sharon Funk and Laura Fox all spoke during some of the conference sessions. During the Friday session they each, along with Brenda Riske, presented poster abstracts, highlighting research being done at our Center.

The NHF Annual meeting is a wonderful opportunity for both providers and patients to learn and connect. If you were unable to attend and are interested in learning more about the sessions taught this year, the NHF offers downloadable files of the recording of their sessions at their website.

Meeting that was held in Dallas, Texas on August 13-15, 2015. This gathering is intended to bring providers together with patients and their families to directly address the many aspects of living with and overcoming the issues that may arise with bleeding disorders. Family-friendly, and offering a wide variety of topics addressed in their sessions, the annual meeting is a great opportunity for learning, interaction, and socialization with those around the country.

The next annual meeting is scheduled for July 21-23, 2016 in Orlando, Florida. It will directly precede the World Federation of Hemophilia (WFH) meeting that will also be held in Orlando. The NHF website and WFH website will provide updates on registration as well as the options available. We also will post updates on our social media accounts as they are updated and made available.

Several of our doctors, nurses, physical therapists and staffers were able to attend as well as some of our patient families and representatives from the NHF Colorado Chapter and Rocky Mountain Hemophilia & Bleeding Disorders Association (RMHBDA). Lisa Maxwell, one of the RMHBDA Board Members, was the co-chair for the entire meeting. She hosted the awards luncheon and represented the western states very well.

Nearly 3,000 people attended the three day conference that provided more than 95 sessions, roundtables for families, and updates on research, clinical trials,

PHARMACY ALERT: RETURN YOUR SIGNED PACKING SLIPS!

Included in every factor or medication order that you receive from the HTC Pharmacy is a delivery receipt showing what medication and supplies are included in the box. One copy is to keep for your records and a second copy is **stamped in red ink for you to sign, date, and return**. A self-addressed and stamped envelope is provided to make returning the delivery receipt easy and painless.

Why do you need to sign and return this receipt? ***It's the law--healthcare and insurance regulations require it!*** Pharmacies are required to obtain and provide proof that a patient received the medications for which they are billing. A pharmacy in New York was recently fined \$2.55 million dollars for failure to obtain patient signatures as proof that the medications were received.

Failure to return the signed packing list verifying that you received the medications could result in a delay in receiving your next factor order or possibly being held financially responsible for the order.

If you have questions about our pharmacy or healthcare regulations, please give us a call or send us an email. Our main pharmacy line is 303-724-0168 or toll free at 888-724-7427 and our email is: hemophilia@ucdenver.edu. Thanks for doing your part to help us be in compliance!

NEWSLETTERS

We are now digitally sending and sharing our newsletters. Please sign up and receive a notification with access to our digital version as soon as it becomes available. You can subscribe by going to our website:

www.medschool.ucdenver.edu/htc and click on the **RESOURCES** tab for the **NEWSLETTER** page.

A few printed copies will be available at our clinic. If at any time you wish to unsubscribe, there is a link at the bottom of the email. Questions, corrections, or problems please contact us at HTC.Newsletter@ucdenver.edu.

COLORS (FROM PAGE 1)



Photo: On Boreas Pass by Merilee Ashton

Maroon Bells continued:

Favorite trails: Maroon Lake Scenic Trail, Crater Lake Trail and Maroon Creek Trail. From Aspen, take the shuttle bus from Ruby Park Transit Center to trailheads.

Guanella Pass-Colorado Scenic Byway

This scenic drive is accessible from I-70 at Georgetown or from the town of Grant along Hwy 285. This pass is twenty-two miles and hosts many scenic vistas. The drive provides access to the Mt. Bierstadt (14,060 foot peak) trailhead, multiple campgrounds and picnic areas.

Mount Galbraith Park

This smaller park is a hiker-only destination providing beautiful views of Golden, the plains and the mountains. It is a great location that is not far from town but affords beautiful views during the fall. To access, take Hwy 93 from Golden, turn at Golden Gate Canyon Road and travel only 1.4 miles to the trailhead.

Nederland

Two of our favorites in this area are Lost Lake Trail and Diamond Lake Trail; both a 30 minute drive West of Boulder. These hikes are very popular and provide mountain views, wildflowers, and forested areas. To access, follow Boulder Canyon Rd (Hwy 119) through Boulder and West to Nederland. Shuttle bus is available from Nederland RTD to the Hessie Trailhead (Lost Lake Trail). Note that the road to the Fourth of July Trailhead (Diamond Lake Trail) is rough and parking is very limited.

Boreas Pass

This pass between Breckenridge and Como is lined with gorgeous fall color and views of the Breckenridge and South Park Valleys. Several short hikes begin at or near the top of the pass, where parking is available by the historic railroad buildings and an old train car. Access from I-70: take the Frisco exit, pass through Breckenridge and turn left at Boreas Pass Rd (at the light by the Conoco). Access from Hwy 285: turn at CR 33, the Como exit, and follow through the town to the hairpin turn for the Boreas Pass road (also CR 33). Our favorites: Black Powder Pass Trail, Trail to Hoosier Ridge (behind the train car to the top of the ridge), and Gold Dust Trail (just south of the pass).

Kenosha Pass

Located only about 50 miles from Denver on Hwy 285, this pass is loaded with aspens and connects to several trails, including the Colorado Trail. Easy access and ample parking make it a wonderful day trip from Denver to spend with friends and family.

Be sure to be prepared, even if planning a short trip. Always bring water, snacks, sunscreen, an emergency kit, and be ready for any kind of weather. Enjoy the views and let us know, what are your favorites?

For direct links to information on these locations, please visit our website at ww.medschool.ucdenver.edu/htc and find the Newsletter page under our RESOURCES tab.

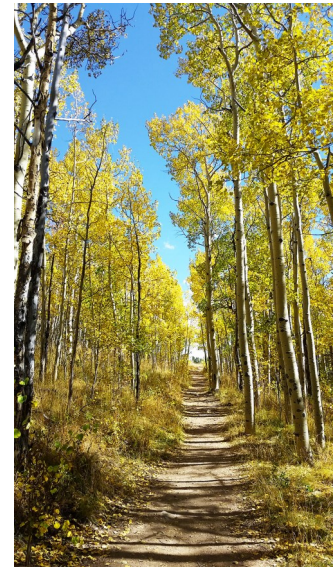


Photo: Kenosha Pass by Merilee Ashton

OUTREACH CLINICS

Outreach Clinics provide the opportunity for our patients who do not live near our Center in the Denver area to see our staff nearer their own homes and get services for their annual comprehensive visits.

Our next Outreach Clinic is scheduled for September 23-25, 2015 in Grand Junction, CO. Those staff attending this clinic are: Marilyn Manco-Johnson, Tyler Buckner (our new adult hematologist), Nancy Spomer, Sharon Funk, Amber Casey, and Audra LeBlanc, as well as two clinical research team members offering research studies and helping with laboratory blood draws.

Paperwork has been mailed out to those patients in the area but if you have questions, haven't received yours, or need to reprint any paperwork, we have details and those forms available on our website here.

Our next clinic in Billings, MT will be a follow-up clinic on **November 9th**. Dr. Marilyn Manco-Johnson and Nancy Spomer will be attending that clinic and providing interim visits for patients that need follow-up from earlier visits.

Save the date: The next full staff clinic visit to Billings, MT is already scheduled and will be held June 6-8, 2016.

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 then find the **RESOURCES** tab, and go to the **NEWSROOM** tab.

FDA Approves Octapharma's NUWIQ to treat Hemophilia A

FDA Grants Breakthrough Therapy Designation to Genentech's ACE910 to treat Hemophilia A with Factor VIII Inhibitors

World Leaders Meet at First World Hepatitis Summit to Discuss Prevention

Recombinant FVIII with Extended Half-Life Shown Safe, Effective for Hemophilia A

CSL Behring Enrolling for Study of rVIIa-FP for Hemophilia Patients with Inhibitors

UPCOMING EVENTS

Oct 2: Clinic and Admin closed at 1 pm for Staff Appreciation

Oct 2-4: Neurologic Disorders Family Camp at Roundup River Ranch

Oct 13: World Thrombosis Day.

Nov 6-8: RMHBDA Women's Retreat- Chico Hot Springs, MT

Nov 19: NHF Colorado-Black and Blue Gala-- Denver

Nov 26-27: Clinic and Admin offices closed for Thanksgiving Holiday

Dec 5: NHF Colorado-Holiday Party-Grand Junction, CO

Dec 12: NHF Colorado-Holiday Party-Denver

Dec 24-25: Clinic and Admin offices closed for Christmas Holiday

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