

The Clotting Connection

A Newsletter for Families with Bleeding and Clotting Disorders

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RIDE THE ROCKIES

If you've ever wondered what our doctors get up to in their free time, you just may be exhausted when you find out. Our director, Dr. Marilyn Manco-Johnson, is well known for being full of energy but this month she brought that vigor to a new level. She joined one of her patients, Kyle Haas, with Team Project ReCycle and rode Ride the Rockies.

Ride the Rockies is a bicycle ride that for the past 31 years has brought cyclists over the high roads of Colorado, traversing about 400 miles through various towns and cities. The routes change every year and test the endurance of cyclists as they rise over multiple mountain passes and ride on roads where even lifelong residents of the state might be nervous about driving a car. This year the course began in Carbondale, wound from Aspen to Copper Mountain, past Grand Lake, through Rocky Mountain National Park, and ended in Fort Collins. They climbed Independence Pass, Fremont Pass, Tennessee Pass, Ute Pass and even Trail Ridge Road for a total elevation gain of 29,311 feet—that's higher than Mt. Everest!

Though Marilyn has been biking for many years, this is the first year she has been a part of Ride the Rockies. During the week of Ride the Rockies, she and Kyle checked in with the HTC a few times and let us know they were well and enjoying the beautiful route across the state. While it was tough, both Marilyn and Kyle were able to complete each day. Kyle even reported he didn't have a single flat tire.

The cyclists had mornings with ice on their tents and rides with temperatures in the 90s but both Marilyn and Kyle reported one of the most intense challenges was facing 50 mph headwinds as they ascended Trail Ridge Road. These were followed by powerful crosswinds at the top, requiring riders to cluster together to keep from being blown off the road. A bear crossed their path one of the days but overall cyclists were thrilled to be enjoying the



Marilyn waving as she climbed Horsetooth Reservoir. Photo: Merilee Ashton

incredible views and energy that comes from such an adventure.

Kyle, who has hemophilia, was able to keep all his medications and supplies safely stowed with the Ride the Rockies medical staff. He and Marilyn both expressed appreciation to all in the Ride the Rockies support and medical staff that were so vigilant in keeping all the participants healthy during such a challenging ride.

We at the HTC are both impressed and relieved that Marilyn and Kyle made it through without any problems and congratulate them on completing Ride the Rockies 2016!



Kyle Haas and Dr. Marilyn Manco-Johnson at the finish of Ride the Rockies in Fort Collins. Photo: Kyle Haas



Marilyn cresting Horsetooth Reservoir. Photo: Merilee Ashton

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SUMMER TRAVEL TIPS



Summer is finally here, and with the rising temperatures and longer days many are looking to take a few days off on vacation to spend with friends and family.

No one wants to get sick or have trouble on vacation. While some problems can't be prevented, there are many things that travelers can do to make the trip go smoothly. Those with bleeding disorders know that preparation can make the difference between a minor and major problem on the road. Here are a few travel tips to remind vacationers to prepare for a problem free vacation:

Knowledge is Power

Whether it is learning or reviewing emergency techniques like CPR or double checking your first-aid kit, preparation is the key. When an emergency occurs, knowing how to treat injuries and illness can be life saving, especially for those with bleeding disorders. Teach family members how to respond if bleeds occur and how to inform medical personnel about treatment. Keep emergency documents with you or wear medical ID bands to make it easier to be treated in a crisis.

Prevention Avoids Pain

Basics like wearing sunscreen and bringing appropriate shoes and clothing for your activities can be the difference between a great vacation and a terrible one. Find sunscreen that works for you and use it. If you'll be swimming a lot, remember to re-apply and seek shade when the sun is most intense. If you're hiking, break those shoes in before you leave; if you're going to be surfing, be prepared with rash guards or wet suits. Small details like wearing comfortable socks, wrapping a sensitive toe to prevent blisters, or wearing a hat can make that tour much more comfortable and enjoyable.



Up to Date

While it sounds more like something to do before school, keeping up on vaccinations is a big deal for travelers. Many diseases that are rare in the US can be much more prevalent in other countries. If there's a vaccine available, it's worth it to get updated before you leave. Know when your last tetanus shot was, just in case. If you're going to countries where diseases such as Zika virus are spreading, be aware of the options

available to you. In some cases, such as Zika, there is not yet a vaccine, but there are precautions you can take to avoid infection. Check out resources like www.cdc.gov for updates on diseases and reducing the risks at your destination.

Pack Right

For those with bleeding disorders and anyone requiring medications, make it a priority to pack your medications and supplies carefully, safely, and conveniently. Being able to access medication quickly can be helpful for unexpected bleeds and having all the supplies you need at hand is worth the prep time it may take. Our HTC pharmacy regularly works with patients to plan and supply enough factor or other materials for those attending camps and going on trips. Be prepared with information on where to go if you need more medication on your trip by researching your options. The CDC has an HTC Directory on their website that can help you prepare. Keep contact information for your doctor and HTC handy if you need help finding medications on the road.

Drink up

It is easy for people to forget to stay hydrated when swimming in the ocean, playing in a theme park, or driving long distances. Sodas and sugary drinks may be the most available and tempting choice, but make an effort to drink plain water as a part of your travel choices. If your destination has unclear drinking water, use bottled water to keep hydrated and healthy. Keep extra water in the car on road trips and use it. It may mean an extra pit stop or two, but taking the time at those rest stops to walk around is better for circulation and can keep you feeling better once you arrive at your destination.



Don't get Bugged



Ticks, mosquitoes and other insects can cause pain, irritation and spread disease. Keep a supply of repellent handy when in areas where you may encounter these and avoid the itchy consequences. Be alert about the places you stay. Hotels and

motels are some of the most common places to find bed bugs. Inspect your hotel mattress, keep your clothes up off the floor, and try to check out the places you stay in advance. Often travel sites will have reviews available, and if someone encountered bed bugs, you will likely hear about it before you book.



For emergency factor after hours-
Please call our regular pharmacy number:

303-724-0168

HTC PATIENT SPOTLIGHT: KYLE HAAS



At the top of the pass. Photo: Kyle Haas

When Kyle Haas did Ride the Rockies in June of 2015, he checked off an item on his bucket list but definitely wanted to do it again. This year he not only got the chance to ride, he got to invite someone to fill an open spot on the team he was riding with, Project ReCycle. He immediately

thought of his lifelong doctor, Dr. Marilyn Manco-Johnson.

Marilyn has been seeing Kyle as her patient since as long as he could remember when he was diagnosed with severe hemophilia as an infant. She's treated him, watched him grow and, like many of her patients, became friends with him and his family along the way. When anyone mentions Kyle to the HTC staff their faces will light up with a smile. Kyle is one of those patients that faces his challenges with a great attitude and inspires everyone around him in the process.

Kyle grew up in Greeley, Colorado, graduated from CU Boulder, and now lives in Englewood working at a finance company and running a web design business called One Stop Site Shop- www.onestopsiteshop.com. His parents raised him to believe that with adequate preparation he could tackle anything a normal person could.

Like many with bleeding disorders, Kyle did have to

choose carefully the sports he was involved in to reduce the chances of serious injury. Many sports can have a negative impact on joints and cause or

worsen bleeds. Kyle is a talented golfer and played competitively in high school. However, a troublesome ankle led him to search for a sport that would put less pressure on that joint. He tried cycling after friends recommended he give it a chance. It turned out to be a perfect match.

Despite recent surgery on his ankle, cycling allows Kyle the opportunity to push hard and yet keep his sensitive joints healthy. This proved to be rather noticeable during the ride as he told us, "people kept asking me if I'd crashed. I was limping around the campground but passing them on the climbs."

He worked closely with the Ride the Rockies staff to keep factor available for him to infuse each day. The medical van even had an entire cabinet dedicated to Kyle's medications and supplies. He expressed his gratitude to the Ride the Rockies medical team by saying, "They do such a great job of keeping everyone safe and helping me to make the ride a possibility. I'm always "that rider" to the volunteer medics because the med staff does a great job filling them in on what to do if I were to have an accident."



Riding at Ute Pass. Photo: Kyle Haas



Kyle's Cabinet on the medical van, storing his supplies. Photo: Kyle Haas



Luckily he didn't have any problems and he and Marilyn made it to the finish without a scratch. The HTC followed their progress as they texted and called to share their adventure. Thanks Kyle for inspiring those around you and sharing your Ride the Rockies adventure with us!

Marilyn and Kyle with Team Project ReCycle at the start of the Ride. Photo: Kyle Haas.

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** page.

Analysis Published in *Blood Reviews* Outcomes

Drug Makers Work to Woo Kids With Hemophilia

Spark Therapeutics Releases Positive Data on Gene Therapy

uniQure Presents Data From Gene Therapy Trial for Hemophilia B

FDA Approves CSL Behring's AfstylA to Treat Hemophilia A

SIPPET Study Results Published in New England Journal of Medicine

UPCOMING EVENTS

June 26: Strike Out Stroke with the Colorado Rockies at Coors Field

June 29: NHF CO Food & Factor Program

July 4: Clinic and Admin closed for Independence Day

Jul 8-10: Mile High Camp Leadership Pre-Retreat-Rocky Mountain Village at Easter Seals, Empire, CO

Jul 10-15: Mile High Summer Camp-Rocky Mountain Village at Easter Seals, Empire, CO

July 21-23: NHF Annual Meeting-Orlando, FL

July 24-28: WFH World Congress-Orlando, FL

July 29-31: RMHBDA Family Camp-Rollins, MT

Aug 1-2: Outreach Clinic-Missoula, MT

Aug 27: NHF CO Walk for Hemophilia-Denver

Sep 5: Clinic and Admin closed for Labor Day

Sep 10: RMHBDA Walk for Hemophilia-Billings, MT

Sep 21-23: Outreach Clinic-Grand Junction, CO

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

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