

The Clotting Connection

A Newsletter for Families with Bleeding and Clotting Disorders

September 2018
Volume 8, Issue 9



University of Colorado
Anschutz Medical Campus
Hemophilia and Thrombosis Center

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

SPORTS AND BLEEDING DISORDERS

With the arrival of fall, many families are enjoying fall sports like football or soccer, or cheering on their favorite baseball teams as they advance toward the World Series. Sports can be a fun way to get exercise, bond with teammates, and learn life lessons. Many kids are eager to join various team sports; others prefer individual sports like swimming, biking, or climbing. All can be beneficial but to those with a bleeding disorder, many sports may feel off limits.

Families new to bleeding disorders may want to protect their child from harm and prevent all sports to keep bleeds and potential injuries at bay. However, physical activity that comes with sports can provide huge benefits to children and teens and helps them develop into active, healthy adults. Exercise and a healthy diet can reduce major risk factors later in life, such as diabetes, heart disease, stroke and some types of cancer. For those with bleeding disorders physical activity can help develop strong muscles and bones and help stabilize joints and prevent injuries and bleeds.¹

Obesity in the United States is rising for both adults and children, and recent studies have shown that obesity for those with bleeding disorders has risen right along with the general population. Unfortunately, the rate of overweight and obese children in the bleeding disorder community is higher than that of the general population. The latest data from a National Health and Nutrition Examination Survey shows that childhood



Hiking can be a great activity! Get started and learn safe hiking methods & how to bring factor with Backpacks + Bleeders. Learn more at www.cohemo.org.

obesity rates for children ages 2-19 is 18.5%,² whereas a different study by Obesity Reviews showed that patients of the same age with hemophilia in the United States was 26%.³ This significant difference reflects the trend of patients with a bleeding disorder to avoid physical activities in an effort to stay healthy.

Parents should not be afraid to allow kids with bleeding disorders to try out reasonable sports and activities. Many kids with bleeding disorders have become accomplished athletes, working with their HTC to manage bleeds and customize their medications to keep their factor levels safe for various sports.



Start young with safe riding skills! Cycling can be a great way to reduce joint problems and get exercise.

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Swimming is a great choice for those with bleeding disorders.

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



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Website: Go to medschool.ucdenver.edu/htc



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HTC.Newsletter@ucdenver.edu

2018 UNITE FOR BLEEDING DISORDERS WALK



Dr. Marilyn Manco-Johnson at the walk with her dog Bella.

Last month many from our HTC joined with patients, friends and families to support the Colorado Chapter of the National Hemophilia Foundation at the annual Unite for Bleeding Disorders Walk. This event is a fundraiser to provide amazing programs to kids and families who have bleeding disorders.

This year we had over 184 new walk participants and many groups met or exceeded their personal fundraising goals.

Most who walked have deeply personal stories about why they walk. Siblings, children, grandchildren or friends who have a bleeding disorder are an inspiration. NHF Colorado shared many of these stories on their Facebook page, which can be found at www.facebook.com/NHFColorado.



Walkers, including some of our Pharmacy staff, head off on the Unite for Bleeding Disorders Walk on August 25, 2018.

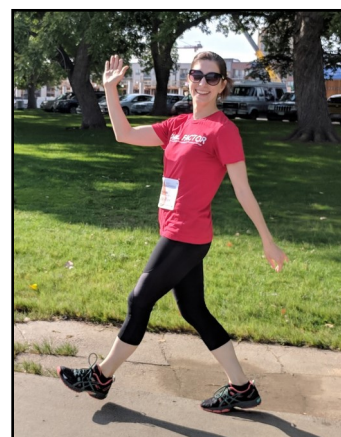
This is the main fundraiser for NHF Colorado and supports such programs as our Mile High Summer Camp. These funds make it possible for kids with bleeding disorders to experience the adventure and joy of camping and spending time outdoors with others their age and doing so in a safe way, with medical staff on hand. This camp would be financially out of reach for most in this community but for the generous support of NHF Colorado and donors.

In addition to camp, NHF Colorado has ongoing programs all year to help educate and bring a sense of community to families with bleeding disorders. Education Days is held in the spring and provides great opportunities for families to learn about bleeding disorders, new medications, research, and many other



Each of these team leaders were honored for beating their fundraising goals.

issues. NHF Social Factor events are regular meetings at various fun locations allowing families to meet socially, learn together, and get to know one another. Backpacks + Bleeders is a program that offers new ways to get out and try new things! Hiking, climbing, even paddle boarding events are planned regularly to give families a chance to try sports and hike together.



Physical Therapist Laura Fox.

NHF Colorado still needs help to reach their goal and be able to provide these incredible programs to those with bleeding disorders. Please consider donating to help NHF Colorado meet their goal. Find the link for the walk to donate at www.cohemo.org.

Your contribution adds up and makes a difference. Thank you for your support!

Self-Infusion Clinic October 23, 2018 5:30 pm-7:30 pm

NHF Colorado also supports activities like our **Self-Infusion Clinics** which we host here at the HTC.

This program is for patients and families who would like additional help with self-infusion. Come and spend time with our nursing staff and practice in a one-on-one setting. You can bring your own factor to be infused or practice with saline. The event is free but you must RSVP.

Go to cohemo.org and click on the EVENTS page for details and to RSVP to this event.

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Of course, some sports are naturally a lot harder on athletes than others. The National Hemophilia Foundation has created a chart categorizing various sports that have lower and higher risk of injury and would more likely cause bleeds and problems. We've listed just a few of the lowest and highest risk activities here. You can view or download the whole chart at www.hemophilia.org. Just enter "Playing it Safe" in the search box and you should be able to find their poster and brochure with the chart to view or download. The NHF's Playing it Safe chart⁴ gives parents an idea of the best sports to try first, and some that might need to be avoided. Our doctors and nurses are happy to discuss the needs of each patient and help them find a great option.

Patients with bleeding disorders should look carefully at the many options that are lower risk and then talk with their doctor about the best options for them. Patients may find they love a team sport like baseball or soccer, but switch to cycling or swimming to reduce problems. Depending on the child, their bleeding disorder severity and health, many more activities may be open to a child than parents might think. Over the past 41 years our patients have been involved in many sports, even the dangerous ones. Anyone with bleeding disorders or not should carefully choose which sports are best for their health. Our HTC staff work closely with our patients and can provide support or suggestions when it comes to any kind of physical activity. We've had hikers and bikers, swimmers and walkers who perform at incredibly high levels of fitness. They may need some extra factor at times, or some help from our physical therapy staff, but they manage to work sports into their lives because it is their passion.

A bleeding disorder does not mean the end of a fit and healthy life. Talk with us about ways you or someone you love with a bleeding disorder can take charge of health and enjoy a sport. We are happy to help all of our patients find ways to stay active and healthy for a lifetime.

1. <https://stepsforliving.hemophilia.org/first-step/maintaining-a-healthy-body/physical-activity>
2. <https://stateofobesity.org/childhood-obesity-trends/>
3. <https://onlinelibrary.wiley.com/doi/full/10.1111/obr.12746>
4. https://www.hemophilia.org/sites/default/files/document/files/Playing-It-Safe_o.pdf

Lowest Risk Activities

Aquatics
Archery
Frisbee
Golf
Hiking
Snorkeling
Swimming
Tai Chi
Walking

Highest Risk Activities

BMX Racing
Bounce Houses
Boxing
Football
Lacrosse
Motocross
Rodeo
Soccer
Wrestling



SHARON FUNK RETIRING AFTER 41 YEARS



Sharon Funk, Physical Therapist at our HTC since 1977.

After 41 years of service as a physical therapist here at the HTC, Sharon Funk is retiring. We know she has made a huge impact on the health and pain management of many of our patients and we will miss her skill and wonderful personality.

We would love our patients to join us in celebrating her retirement at a celebration in her honor on **October 19, 2018 from 3-6 pm** here at the HTC: 13199 E. Montview Blvd., Aurora, CO 80045 in the break room and patio, located on the east side of the building on the main floor. Light refreshments will be served and there will be a small, informal presentation from staff, family, and friends.

As a special gift for Sharon, we are asking patients and families to write a letter or note, and/or send pictures to celebrate her amazing work. Please submit notes or pictures by October 10th to Kristi.Norton@ucdenver.edu or mail to:

Kristi Norton 13199 E. Montview Blvd. #100, Aurora, CO 80045

We look forward to celebrating Sharon with you on October 19th. Additional questions can be directed to hemophilia@ucdenver.edu.

RECENT HEADLINES

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

Many Watching FDA for Ruling on Subcutaneous Formulation of Hemlibra

Liver Transplant Highly Benefits But May Not Fully Cure Hemophilia

Study Finds More Hemophilia Patients are Overweight and Obese than Previous Years

Genentech Shares Positive Phase III Results for Hemlibra in NEJM

FDA Approves Jivi-New Treatment for Hemophilia A

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:

Sept 26-28: Outreach Clinic-Grand Junction, CO

Oct 11-13: NHF 70th Annual Meeting & Conference

Oct 23: Self-Infusion Clinic at the HTC

Oct 31-Nov 2: Outreach Clinic-Billings, MT

Nov 2-4: Women's Retreat - Chico Hot Springs, MT

Nov 4: NHF CO Denver Social Factor, Spanish Program—Northglenn, CO

Nov 22-23: Clinic, Pharmacy & Admin closed for Thanksgiving Holiday

Dec 24-25: Clinic, Pharmacy & Admin closed for Christmas Holiday

Jan 1: Clinic, Pharmacy & Admin closed for New Year's Day.

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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