

The Clotting Connection

A Newsletter for Families with Bleeding and Clotting Disorders

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Hemophilia and Thrombosis Center

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ARE YOU READY FOR SCHOOL?



Summer is drawing to an end, and it's time to buy those school supplies, meet the teacher and find new classrooms. Families of kids with bleeding disorders should also consider preparing for potential problems and lay out a plan for bumps in the road ahead.

If your family is new to a school or teacher, or even if the school is well aware of your child's disorder, the beginning of the school year is the best time to address any future problems. Many teachers, schools, and caregivers may never have had a child with a bleeding disorder in their classroom or school before. Be proactive and provide information and education about your child's particular disorder upfront.

A child may or may not want to share his or her bleeding disorder with peers, but schools and teachers should be informed so they can provide the proper care. Be sure to let your teachers know whether or not your child wants other children to know about their disorder at this time.

There is a lot of information for teachers to take in at the beginning of the year, even if no one in their class has any medical issues. You can help make it easier for them to work with you and your child by providing information and a plan for them to follow if there is a problem, bleed, or injury.

If you don't know where to start, start with us. The Hemophilia and Thrombosis Center has a permanent social worker who can assist you with resources, educational materials, and training to help your child at their school. Audra LeBlanc, our social worker, regularly visits schools of our patients to provide an educational in-service for bleeding disorders. She is happy to answer any questions that you may have as a parent on how to go about advocating for your child at school. You can contact her directly by calling 303-724-6163 or emailing audra.leblanc@ucdenver.edu.

Our nurses can provide an Individual Health Plan (IHP), a document that can lay out 'what to do' for your school and teachers. You know your child best, but it can be a little daunting to explain their disorder to people who may have never heard of it before. Please call us and ask our staff for assistance if you need it.

Nearly all children with hemophilia or other bleeding disorders qualify for Section 504 of the Americans With Disabilities Act that prohibits discrimination and provides regulations requiring accommodations. Whether your child has been

Continued on page 3



INSIDE THIS ISSUE

- Back to School Tips for families with bleeding disorders
- Hemophilia Walks- Aug 27, 2016-CO
Sept 10, 2016-MT
- NHF and WFH Congress in Orlando
- Webinar available
- News

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



Go to facebook.com/ColoradoHTC



Go to twitter.com/HTCColorado



Website: Go to medschool.ucdenver.edu/htc



Email: HTC.Newsletter@ucdenver.edu

To Do

- ☐ buy school supplies
- ☐ haircuts for kids
- ☐ make lunches
- ☐ figure out bus schedule
- ☐ call HTC social worker

NHF ANNUAL MEETING & WFH CONGRESS



The exhibition hall and registration at the WFH Congress in Orlando.

The National Hemophilia Foundation's 68th Annual Meeting and the World Federation of Hemophilia World Congress 2016 were both held in Orlando, Florida at the end of July. These two major gatherings for medical providers, researchers, patients and advocates

rarely coincide as the WFH Congress is not often held in the United States. The last time both meetings were in the US was over twenty years ago, so this was a great opportunity for people from all over the world to meet, learn, and share.

Several of our doctors, nurses and staff were able to attend and participate in both the NHF and WFH events and those in attendance found the meetings to be filled with interesting research results, many new findings, and treatment options that look promising.

NHF was held first, from July 21-23, 2016. Dr. Tyler Buckner was able to participate in a roundtable discussion with patients and caregivers called "Pain in the Bleeding Disorder's Community: A Call to Action" where many could share their priorities, concerns and challenges in managing pain. He said, "There was a lot of good discussion, and we learned a great deal from the community members who attended."

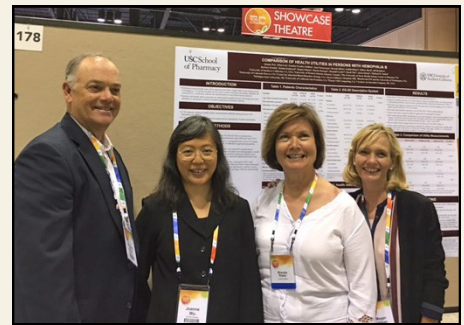
In addition, Dr. Buckner was involved in a series of presentations focused on the "My Life, Our Future" project. This is an effort to gain 5,000 participants to register and get genotyped to help advance treatments for bleeding disorders. Dr. Buckner was one of several speakers who talked about the project and how it can help advance care and provide benefits in the future. Dr. Buckner said, "The bleeding disorders research community owes a huge debt of gratitude to the

patients and family members who have contributed to the project's success."

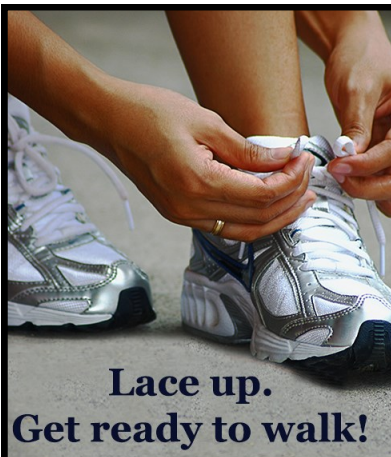
Dr. Wang attended the WFH Congress which was held immediately following the NHF meetings on July 24-28, 2016. He presented posters outlining the pivotal trial results as a late breaking presentation of PERSEPT -1, P-FIQ, and the rFVIIa phase 1b study. He reported that there was a lot of discussion about understanding inhibitor risk, use of extended half-life factor concentrates, and appropriate trough targets for prophylaxis. Dr. Wang told us, "New hemostatic agents also took center stage as the hemophilia treatment world is again preparing for a paradigm shift in treatment. This will focus attention because of improved products, on how best to use them and which outcomes are most meaningful to patients."

Brenda Riske, who has just recently retired from our HTC, was able to attend and be a part of a poster presented on research she was involved with investigating the health and comorbidities of those with hemophilia B. The data her group compiled studied the levels of care and the progress being made for long term problems for those with bleeding disorders.

The NHF and WFH gatherings provided many forums and opportunities for physicians, caregivers, patients, and researchers to connect and learn. The next NHF Annual meeting will be held in Chicago in August of 2017, and the next WFH Congress will be in 2018 and held in Glasgow, United Kingdom.



Brenda Riske (second from right) joined others at the WFH Congress to present their findings.



Walk for Hemophilia

Sat., Aug 27, 2016 ♦ 8 am Registration ♦ 9 am Walk
Sloan's Lake Park ♦ 17th Ave & Sheridan Blvd. Denver

Sat., Sept 10, 2016 ♦ 9 am Registration ♦ 10 am Walk
Zoo Montana ♦ 2100 S. Shiloh Rd., Billings, MT

More info go to www.cohemo.org and
www.rmhbda.org.



qualified as covered by Section 504 or not, all kids can benefit from having emergency protocols outlined for their school. Be up front and clear with your teacher and school about

what your child may need to accommodate their disorder. Sometimes it's just keeping a teacher informed if a child has a bleed so they will know extra time may be needed to go between classes.

There are many resources available to help educate teachers and schools and help them learn the best way to manage your child's unique needs. The NHF and the HFA both have many resources dedicated to helping families with everything from heading back to school or heading off to college. Take advantage of these and the local HTC resources our staff can provide and make this a great year!

To find NHF and HFA resources go to: **stepsforliving.hemophilia.org/** and **hemophiliafed.org/resource-library/toolkits/**

Save the Date!

The CDC is sponsoring a
Free Webinar
September 22, 2016 12 noon MST
Voices of 5,000+ Patients

Guest Presenters Judith Baker, Brenda Riske and Rick Shearer will discuss the HTC Patient Satisfaction Survey, how they worked together with others throughout the country to gather information to help all HTCs improve their care.

Registration is required, and space is limited. Webinar is recommended for health professionals, clinicians and researchers, but others who are interested are welcome to register.

Go here: **<http://ow.ly/6qD3303wg40>** for details and to register.

COME WALK WITH US!

The National Hemophilia Foundation (NHF) works throughout the country to support those with bleeding disorders. They have been advocating, supporting research and education since 1948 through chapters all over the country where members can find support and community.

Since 2006 the NHF has assisted local chapters in setting up walks throughout the country to fund raise and generate support for those with bleeding disorders. Millions of dollars have been raised nationwide for educational programs that empower those with bleeding disorders to be able to manage their care.

The NHF Colorado Chapter and the Rocky Mountain Hemophilia & Bleeding Disorders Association both provide camp opportunities to kids and their families, a supportive bleeding disorders community, and educational programs throughout the year. The funding from these walks directly provide chapters the ability to bring these programs to families with bleeding disorders in their area.



Denver is hosting their Walk for Hemophilia on **August 27th starting at 8 am at Sloan's Lake Park**. Our HTC staff is pleased to be able to a part of this great opportunity to both raise funds for the NHF Colorado chapter and be with our patients, their families and friends who support them. We encourage our staff, friends, and those around us to join us, donate, and participate in the walk.

If you don't live in the Denver area and are closer to Billings, Montana, consider joining the **RMHBDA with their Walk for Hemophilia on September 10th**. Their chapter also provides wonderful support for families with bleeding disorders in Wyoming and Montana. Please join them at Zoo Montana, make a donation, or participate in a 'virtual walk'.

Find out more information for both of these great opportunities to share and support here at their websites: NHF Colorado Chapter at **www.cohemo.org**, and Rocky Mountain Hemophilia & Bleeding Disorders Association at **www.rmhbda.org**.

Thank you for your support!



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.

Vonvendi Available to Treat von Willebrand Disease

Recalls Issued for Multiple Lots of Kogenate FS and Helixate FS

Bruising Uncommon in Very Young Children with Blood Disorders

Biogen Announces Hemophilia Spin-off Company as Bioverativ

UniQure Shares Updated Clinical Data for Gene Therapy Trial

Patient Elijah Warren Highlighted in Aurora Sentinel

UPCOMING EVENTS

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 16: Outreach Clinic-Colorado Springs, CO

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

Sep 30-Oct 1: RMHBDA Men's Retreat- Chico Hot Springs, MT

Nov 4-6: RMHBDA Women's Retreat- Chico Hot Springs, MT

Nov 24-25: Clinic and Admin closed for Thanksgiving Holiday

Dec 23 & 26: Clinic and Admin closed for Christmas Holiday

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

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