

The Clotting Connection

A Newsletter for Families with Bleeding and Clotting Disorders



Hemophilia and Thrombosis Center
UNIVERSITY OF COLORADO ANSCHUTZ MEDICAL CAMPUS



Affiliated with
Children's Hospital Colorado

EDUCATIONAL OPPORTUNITIES AHEAD

“Education is the most powerful weapon which you can use to change the world.”

These words by Nelson Mandela are inspiring and hopeful for many people all around the world facing challenges big and small. In the world of bleeding disorders, knowing about and understanding a diagnosis can not only help you face the challenges associated with it, but can be a powerful source of change.

Every year, new people are diagnosed with a bleeding disorder. This can be something expected, as in a family with a history of bleeding disorders, or it can come as a shock and surprise.

Hemophilia, von Willebrand Disease, and other bleeding disorders can bring significant physical, financial, and emotional challenges. Becoming educated on a medical diagnosis can empower a patient to be able to face their challenges with confidence. People with bleeding disorders and their families have many opportunities throughout the year to learn about treatments, research, genetics, therapies, and options to manage their diagnosis.

Locally, the Colorado chapter of the National Hemophilia Foundation (NHF), and the Rocky Mountain Hemophilia and Bleeding Disorders Association (RMHBDA) based in Montana, both provide an annual education weekend. These provide opportunities to learn and meet others locally who face similar challenges.

RMHBDA (for Montana and Wyoming bleeding disorder patients) has its Education Weekend and Annual Meeting **February 21-23, 2020** in Bozeman, MT. Learn more about their programs at rmhbda.org.



Backpacks + Bleeders learning snowshoeing in mid February 2020. Photo: NHF CO.

NHF Colorado (for patients in Colorado) will host their Education Days this year on **April 17-19, 2020** at the Denver Marriott South in Lone Tree, CO. They will also be hosting an advocacy opportunity at their Colorado Statehouse Day on **April 17th** as a part of World Hemophilia Day, followed by the beginning of their Education Weekend. Registration for these events are open now at cohemo.org.

Both NHF Colorado and RMHBDA offer various events throughout the year that can benefit families and teach new skills. Some are as simple as a gathering with a speaker sharing insights on a new treatment. Backpacks + Bleeders (sponsored by NHF CO) provides a chance to try new physical activities like hiking, kayaking, rock climbing, skiing, or even snowshoeing. Self-infusion clinics offered with support of our HTC staff can help families learn and practice infusions.

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Families participate at NHF Colorado's Education Days. Photo: NHF CO.

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HTC SPOTLIGHT: MIKE WANG, HTC CO-DIRECTOR



Dr. Mike Wang has been named as Co-Director of the HTC.

Many of our patients and families know Dr. Michael Wang, who has been treating patients at the HTC clinic for the past eleven years. Mike has agreed to take on the role of Co-Director here at the HTC, partnering with Director Dr. Marilyn Manco-Johnson. This month we spotlight Mike to let our readers learn a little more about him.

Dr. Wang has been working as our HTC Clinical Director since 2009, and is deeply

involved in the details of trying to improve the care delivered to people with coagulation disorders. Mike is a Colorado native, graduating from Arvada West High School with a strong interest in music performance. However, he chose a more traditional, liberal arts education, eventually finding medicine as the best way to use his strengths and interests in a profession that helps people. Outside of work, Mike enjoys skiing, cycling, running, hiking, reading (mostly non-fiction), and cooking. He also loves to travel and explore new cities.

Mike attended Colorado College in Colorado Springs for his undergraduate degree in Biology. He also spent a year at Waseda University in Tokyo as an undergraduate. He then completed a Thomas J. Watson Foundation Fellowship as an apprentice with Kodo (an exclusive traditional drumming group), on Sado Island, Japan. With Kodo, he lived and learned traditional Japanese drumming and dance. He then matriculated at the University of Rochester School of Medicine and Dentistry in Rochester, NY.

While in medical school, he pursued research in tumor immunology as a Howard Hughes Medical Institute Research Scholar at the National Cancer Institute. He completed his pediatrics residency at the University of Utah School of Medicine and his pediatric hematology/oncology/BMT fellowship here at the University of Colorado School of Medicine. He worked with Dr. Marilyn Manco-Johnson on his first clinical project in coagulation as a fellow reporting a dose-finding for TPA in pediatric patients.

Mike's first interest in coagulation disorders occurred as a resident when he was caring for a teenage patient with a massive pulmonary embolism. It seemed at that time that there was just so much we did not know about

thrombosis in children. When he became a fellow, he became more interested in patients with hemostatic disorders and caring for people across their entire lifespan. Along this journey, Mike has seen many new medications become available. He soon realized that many tools to improve patient lives were underutilized. This insight, that we can improve care for patients through a systematic process of quality improvement, has shaped the last seven years of Mike's clinical career.

Every week Mike sees patients and clinical trial research subjects. He is involved with a good deal of administrative work that he sees as vital to ensure the maintenance and advancement of the HTC. This includes advocacy for both patients and colleagues. Mike tries to find a balance with his busy schedule through brief meditation, and by reading something personally and professionally meaningful each day. He also exercises every day, even when traveling, as he finds that consistent, *mildly* strenuous physical activity helps him live a more balanced life.

Mike loves the team of people here at the HTC. He enjoys working with all of the different personalities and learning from their diverse experiences and strengths. He admires how everyone, from the doctors to volunteers, seem to have a selfless drive to support the bleeding disorders community and each other.

He says, ***"What matters to me is that I am able to partner with patients and staff to discover the best versions of ourselves."***

Mike is interested in discovering what influences decision making, both in health care professionals and patients. He shared, "It is a long journey in unraveling the mystery of how complicated people really are."

Mike is excited to be working at a time when there has been so much innovation in medicines and processes for clinical care. When he looks back at the many times in his life where he had to choose a direction in his life, he sees his choice to go into medicine as one of the most important. It has given him the opportunities to develop relationships with patients and colleagues, solve problems, investigate and innovate, celebrate, cry, and laugh. What he has learned every day from patients, families, and colleagues, motivates him to live the best life he can.

Congratulations to Mike as he takes on more responsibilities here at the HTC as our Co-Director.

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Both of these groups have members that attend Mile High Summer Camp, where kids learn valuable skills to help them manage their bleeding disorder throughout their life.

Details on the upcoming events from both of these helpful organizations can be found on their websites; RMHBDA can be found at rmhbda.org, and NHF Colorado can be found at cohemo.org.

NHF and the Hemophilia Federation of America (HFA) are both national organizations that offer several educational opportunities on a larger scale. Both NHF and HFA have robust websites with news, education, and many helpful tools to support families.

HFA is hosting this year's Annual Symposium in Baltimore, Maryland **April 23-26, 2020**. This national meeting draws members of the bleeding disorder



community from across the United States to join in a supportive learning environment. Registration for children and teens must be done online. Details can be found at

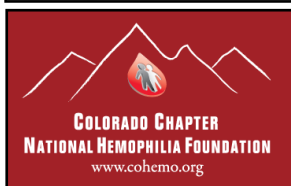
hemophiliafed.org.

NHF hosts its Annual Bleeding Disorders Conference this year in Atlanta, Georgia on **August 6-8, 2020**. This event provides education, networking opportunities, and exhibitions on research and other projects. A children and teens program is available and registration is open online.



In addition, NHF offers Inhibitor Summits on a regional level for those families with hemophilia A or B who have inhibitors. This year two Inhibitor Summits are available in Denver. The first is **May 29-31**, and the second is **Oct 16-18**. You can find details on all their events at hemophilia.org.

Globally, the World Federation of Hemophilia (WFH) offers resources and annual events that support research and connection with others facing bleeding disorders. Their website also is a great resource for bleeding disorder families worldwide. The WFH offers an international level meeting at their World Congress every



two years in a different region of the world. This meeting brings scientists, doctors, healthcare workers, bleeding disorder organizations, and people with bleeding disorders together to learn about the latest developments, share research and provide discussion. This year the WFH 2020 World Congress will be held in Kuala Lumpur, Malaysia on **June 14-17, 2020**. Details and information can be found at wfh.org.



Our HTC also provides in-house educational materials and support for patients throughout the year. Our staff attend Education Days, Camp, and other learning opportunities such as self-infusion clinics. We share details for many educational and other events for families in our newsletter, social media, website, and on our clinic bulletin board.

Keep up to date with what is going on by subscribing to our newsletter or following us on Facebook or Twitter. To subscribe to our newsletter go to: <http://eepurl.com/bnszoz> and to find us on Facebook or Twitter, go to facebook.com/ColoradoHTC or twitter.com/HTCColorado.

Families with bleeding disorders are encouraged to attend events, use the resources at each of these organizations' websites, and ask questions of their healthcare providers to have the best understanding of their particular diagnosis and treatment options.

Some great opportunities are available this year! Check out any of the websites of these great organizations for an option that works for you and make 2020 the year you invest in learning.

BOMBARDIER BLOOD

The HTC is pleased to present a free screening of the documentary *Bombardier Blood*.

Friday, March 13, 2020 at 2:30 pm
Hensel Phelps Auditorium-West.
(Research 1 North)



Seats are first come, first served and we hope you can join us. Chris Bombardier and his wife Jess will be in attendance along with many members of his HTC team who helped support his journey.

For more information contact Angela Blue at Angela.Blue@CUanschutz.edu or 303-724-0167 or go to bombardierblood.com.

RECENT HEADLINES

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

Novo Nordisk Launches Esperoct, Long-Acting Recombinant for Hemophilia A

Bloodstream Interviews Dr. Laura Fox, PT, in a Bloodstream MINI

New Study Suggests Primary Postpartum Hemorrhage Remains a Challenge for Type 3 VWD Patients

FDA Updates Guidelines for Gene Therapy Treatments

Dr. Leonard A. Valentino Chosen as the New President and CEO of NHF

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:

Feb 21-23: RMHBDA Education Weekend and Annual Meeting—Bozeman, MT

Feb 26-28: NHF Washington Days

Mar 8: Backpacks + Bleeders at Winter Park

Mar 10: Pediatric Stroke Parent Support Group

Mar 13: Free Screening of *Bombardier Blood* at CU Anschutz Campus-Hensel Phelps West

Mar 15: NHF CO Dinner Program: The Science of Connection

Apr 14: Pediatric Stroke Parent Support Group

Apr 17: World Hemophilia Day

Apr 17: Colorado Statehouse Day

Apr 17-19: NHF CO Education Days

Apr 23-26: HFA Symposium—Baltimore, MD
See more at our Events Page on our website:
www.medschool.ucdenver.edu/htc find **RESOURCES** tab, go to **EVENTS**

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