# **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

## DR. MICHAEL WANG NAMED HTC DIRECTOR



Dr. Mike Wang is now our new HTC Director.

Our HTC is pleased to announce that Dr. Michael Wang has been named as the new Director of our Hemophilia and Thrombosis Center. Dr. Marilyn Manco-Johnson, who has been our HTC Director for many years and was Co-Director with Mike for the past two years, is stepping down from this leadership role but is continuing to work with us at the HTC. We are thrilled to have Mike step up to Director and rely on his steady guidance at our center.

Dr. Wang has worked as our Clinical Director from 2009 to 2020, when he stepped in as Co-Director less than a month before the pandemic began. He was a critical voice of leadership and reason in a very uncertain time and has helped our HTC navigate all the changes and issues that have arisen with pandemic protocols, as well as managing the daily care of patients with our staff.

Many of you have worked with Mike over the years and know he is a focused, organized, and talented leader. He earned his undergraduate degree in Biology from Colorado College in Colorado Springs and spent a year studying at Waseda University in Tokyo as an undergraduate. He also spent a year as an apprentice with Kodo, an exclusive traditional drumming group, on Sado Island, Japan through a Thomas J. Watson Foundation Fellowship. This experience added a unique richness and dedication to all the things he does. He earned his medical degree at the University of Rochester in Rochester, New York, and completed his residency in pediatrics at the University of Utah School of Medicine. He did his pediatric hematology/oncology/BMT fellowship here at the University of Colorado School of Medicine, where he worked with Dr. Marilyn Manco-Johnson on his first clinical project in coagulation.

The University of Colorado made the change of directors official in June of 2022, and Dr. Wang has already done much to guide our HTC. The mission and goals of our

center remain the same, and we are all committed as a team to continue to provide outstanding clinical care, run clinical trials to support the most up-to date therapies for our patients, and keep our strong research program working to advance those new therapies for patients.

Dr. Marilyn Manco-Johnson has been our director here at the HTC since 1989, so she has been a huge part of everything we have done here at the center for decades. Her impact can not be overstated, and we are thrilled she will be staying on to continue

Our HTC moved into the CU Medicine building in 2011 and has expanded our space there in recent years. Dr. Marilyn Manco-Johnson led us through this transition after years at the campus on Colorado Boulevard and earlier space in the Fitzsimons building on the CU Anschutz campus.



Dr. Mike Wang teaching kids at Mile High Summer Camp. More pictures from camp inside and coming soon to our website. Photo: Angela Blue.

#### **INSIDE THIS ISSUE**

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



Go to <u>facebook.com/</u> <u>ColoradoHTC</u>



Go to <u>twitter.com/</u> <u>HTCColorado</u>



Website: Go to

medschool.cuanschutz.edu/ hemophilia-thrombosis



Email:

HTC.Newsletter@ucdenver.edu

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mentoring our staff and providing significant research leadership for our center. We are so grateful for Marilyn and all she has done for so many, both patients and staff. This HTC would not be the place it is without her leadership, and we are pleased that Mike will continue to work to improve and build our center with much of her vision and support.

Important research that is used throughout the world.

As we move into this new era with Dr. Wang as Director, we are grateful for the support and involvement from our patients and staff. There is so much that makes our HTC a special place, not just a clinic. This includes many years of community involvement, dedication to teaching, and the

The University of Colorado Anschutz School of Medicine has been an integral part of this transition, and much of the support to grow our center is provided through the University. Since 1973, our HTC has gone from a small staff scrambling to find ways to get factor and treatment to our patients, to a well-known and respected clinic and

pharmacy, providing excellent care, leadership, and important research that is used throughout the world.

As we move into this new era with Dr. Wang as Director, we are grateful for the support and involvement from our patients and staff. There is so much that makes our HTC a special place, not just a clinic. This includes many years of community involvement, dedication to teaching, and the passionate people who work to improve the health of those with bleeding disorders. We look forward to new and exciting changes as we begin this new phase in the history of our HTC. We express our congratulations to Dr. Wang and our gratitude and appreciation for Dr. Marilyn Manco-Johnson for her years of dedicated service to our HTC.

### JOIN US FOR THE 2022 UNITE FOR BLEEDING DISORDERS WALK



The Denver Unite for Bleeding Disorder Walk will be held on **Saturday, August 13, 2022** at Sloan's Lake Park starting at 9 am.

Check in begins at 8 am, on the northeast side of the park, also called the North Central Area, near 22nd and Stuart Street. This is the same location as in 2021. Parking info and a map can be found at the <a href="MHF website">NHF website</a>. This year we are walking in person, but virtual walking is also an option.

This walk is the main fundraiser for NHF Colorado, which works the whole year to provide education, community events, and opportunities for patients and families with bleeding disorders. This includes Mile High Summer Camp, Education Days, and Backpacks + Bleeders events. This community provides much needed support for those facing the unique challenges of those with hemophilia, von Willebrand disease, and other bleeding and clotting disorders.

Our HTC team is Chill Factor, and we welcome you to join us, join another team, or create your own. If you can't

make it in person, we encourage you to support NHF Colorado by making a donation. This is a fun and engaging way to show support, as well as getting in a nice walk around the lake! To register for the walk, please go to cohemo.org, or the uniteforbleedingdisorders.org page.

If you are located in Montana or Wyoming and would like to get involved, you are welcome to join or donate to the event in Denver, or attend and support the RMHBDA Unite for Bleeding



Team Chill Factor encourages you to come join us in 2022! Photo: Kim Hurdstrom.

Disorder Walk, which is also coming up soon! The Montana walk will be on **September 10**, **2022** in Billings, Montana at the Billings Zoo. For more info, please go to <a href="mailto:rmhbda.org">rmhbda.org</a>.

### MILE HIGH SUMMER CAMP A LIVELY SUCCESS



Campers in 2022! See more pics at our website! Photo: Bryn Dunham.

After two years of mostly virtual events for our Mile High Summer Camp, we were thrilled that camp was once again held all in person! We divided our campers this year into two groups. The older kids, ages 15-17 went on a rafting and camping adventure over the weekend, and our younger kids, ages 7-14 went up to the EasterSeals camp in Empire, Colorado for their week of learning and fun.

Due to the many restrictions of COVID still impacting our patients, and the separation of these age groups, this year's camp was noticeably smaller, but also filled with many fun activities, learning opportunities and connection with new and old friends. At the main camp for our younger campers, the kids had the chance to zip line, do wall climbing, fishing, swimming, hiking, and various arts and crafts. Our staff worked with them to practice infusing, learning coping methods, taught about new treatments and future medicines, and had activities to help patients manage their care.

We have included a few pictures from camp on the next page, but we will be adding many more at our website camp page located here: <a href="https://medschool.cuanschutz.edu/hemophilia-thrombosis/resources/bleeding-disorders/camp">https://medschool.cuanschutz.edu/hemophilia-thrombosis/resources/bleeding-disorders/camp</a>

# **MILE HIGH SUMMER CAMP 2022**



## RECENT HEADLINES

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

Freeline Shares Positive Data from Gene Therapy Trial

Sanofi Shares Data from Two Phase 3 Studies

NHF Requests Risk Evaluation and Mitigation Study for Pending Gene Therapies

Elocta (Eloctate in the US) Reduced Elbow, Knee Bleeds in Severe Hemophilia A Study

**Bayer Announces Discontinuation of Kogenate FS** 

FDA Grants Breakthrough Status to efanesoctocog alfa (BIVV001) for Hem 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. Go to medschool.cuanschutz.edu/hemophilia-thrombosis/resources/newsroom to read more. We also share news on our Facebook and Twitter accounts.

Sign up to get this newsletter delivered directly to your email box each month! Just go to **eepurl.com/ bnszoz** and fill out the form!

## **UPCOMING EVENTS**

#### **Mark Your Calendars:**

Please note. These dates may be <u>tentative and subject to change</u>. Please check appropriate websites for confirmation of events.

Aug 11-12: RMHBDA Teen Retreat — Rollins, MT

**Aug 12-14:** RMHBDA Family Camp — Rollins, MT

**Aug 13:** NHF CO Unite for Bleeding Disorders Walk —

Sloan's Lake, Denver, CO

Aug 25-27: NHF Bleeding Disorders Conference,

Houston, TX

Aug 27: NHF CO Lakeside Breakfast and Goat Yoga

**Sept 5:** Clinic, Pharmacy & Admin offices closed for

Labor Day

**Sept 10:** RMHBDA Unite for Bleeding Disorders Walk —

Billings, MT

Sept 12: Pediatric Stroke Parent Support Group

**Sept 28-30:** HTC Outreach Clinic — Missoula, MT

See more at our Events Page on our website:

 $\underline{\text{medschool.cuanschutz.edu/hemophilia-thrombosis/resources/events-calendar}}$ 

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Web page:

medschool.cuanschutz.edu/ hemophilia-thrombosis PLEASE PLACE STAMP HERE