

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. MARILYN MANCO-JOHNSON HONORED WITH NHF LIFETIME ACHIEVEMENT AWARD



By Merilee Ashton and Beth Warren, MD

Dr. Marilyn Manco-Johnson, current co-director at our HTC, was honored last month at the National Hemophilia Foundation's Annual Bleeding Disorders Conference with the NHF Lifetime Achievement Award. Our staff and many of our patients know that this is a well-deserved honor that speaks to the years of dedicated care, service, and research done on behalf of thousands of bleeding and clotting disorder patients.

Dr. Manco-Johnson has been working with bleeding disorder patients for more than forty years and became the HTC director of our center in 1989. She is committed to the health and well-being of her patients

and has used her intelligence and passion through significant changes in treatments, developing knowledge of bleeding and clotting disorders, and massive health issues impacting those in her care.

Early in her career, Dr. Manco-Johnson diagnosed one of the first cases of pneumocystis pneumonia in a patient with hemophilia, contributing initial data to the AIDS epidemic. Her research focus switched from basic science questions in sheep to HIV/AIDS and the related needs of people with hemophilia. Her career has revolutionized care for those with bleeding disorders, including establishing prophylaxis for hemophilia as the standard of care based on the Joint Outcome Study, which she led. She has worked closely with a multidisciplinary team to better establish measurements of hemophilic arthropathy by physical exams and MRI. In addition, she has focused on keeping quality of life and a need for physical activity in kids and families with bleeding disorders as a high priority. She has also led and contributed to groundbreaking care improvements in patients with afibrinogenemia and dysfibrinogenemia, and protein C deficiency.

Her patients know her as a compassionate and energetic caregiver who has continued to seek improvements in treatments through research and hands on involvement. She is known less as a doctor and more as a friend to hundreds of life-long patients and spends much of her



Dr. Marilyn Manco-Johnson on a camp adventure helping one of her patients. Photo: NHF Colorado

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Thanks to all who participated in the 2021 Unite for Bleeding Disorders Walks! Photo: RMHBDA

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



Go to facebook.com/ColoradoHTC



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Website: Go to

medschool.cuanschutz.edu/hemophilia-thrombosis



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SPOTLIGHT: ERICA RHEIN PHARMACIST



Erica Rhein with her dog enjoying the great outdoors. Photo: Erica Rhein.

Our HTC Pharmacy has added some new members to their team in recent months, including two new pharmacists. One of our new pharmacists is Erica Rhein. She has been working at our pharmacy for the past four months and has fit right in with the outstanding pharmacy team. When you or a loved one fill your medications at our HTC Pharmacy, you are likely to get a phone call from Erica. We hope you can get to know her a little more through this spotlight.

Erica attended Oakland University in Rochester Michigan and earned her Doctor of Pharmacy at East Tennessee State University. She completed her two years of residency training in two different states. Her first was at Providence St. Patrick hospital in Missoula, Montana, and her second year oncology and hematology training was at St. Luke's hospital in Boise, Idaho.



Erica loves to spend time fly fishing. Photo: Erica Rhein.

She became interested in treating hemophilia and bleeding disorders patients when she was in residency. Erica was inspired by how pharmacists can make a difference in the lives of their patients through helping them better understand their medications. Erica currently helps patients coordinate their medication refills to make sure they always have the medication they need.

Erica loves to spend time outdoors and enjoys living here in Colorado. Rock climbing, and fly fishing are two of her favorite hobbies. Erica has really enjoyed getting to know pharmacy patients in the past several months and looks forward to learning more about our patients and their families. We are excited to have Erica working on our pharmacy team and are grateful to welcome her to our HTC family!

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time focused on supporting and encouraging them to follow their dreams. She's been hiking and camping with many patients, personally carrying medical gear to make sure they were prepared in the event of a bleed. She even rode alongside a patient for Colorado's Ride the Rockies in 2016. She loves to bike but was also there to lend her support on the 400 miles of intense, high-country exercise.

Everywhere she goes, Dr. Manco-Johnson is surrounded by others wanting to learn from her incredible experience and deep knowledge of bleeding disorders and the impact on patients. She's been called upon as an expert to speak at countless national and international symposiums and regularly helps educate patients, pharmaceutical companies, and medical trainees as she shares her research and knowledge. Dr. Manco-Johnson has been a mentor to many and is passionate about continuing research and finding ways to improve the health of everyone around her.

She has been a significant part of building up the HTC at CU Anschutz Medical campus from a small clinic to one of the largest bleeding disorder treatment centers in the country. She has a wicked sense of humor, an arsenal of fantastic stories, including sometimes dramatically saving patients' lives, and encouraging their efforts to push through hard times for better outcomes. She has a deep compassion for others, a strong fortitude, even stubbornness, but those who know her can appreciate both her genius and her friendship.

Congratulations to Dr. Marilyn Manco-Johnson for receiving the much-deserved Lifetime Achievement Award in 2021!



Dr. Marilyn Manco-Johnson leading the pack on a long climb by Horsetooth Reservoir in 2016 while on Ride the Rockies. Photo: Merilee Ashton

2021 SATISFACTION SURVEY COMPLETE



The Third National Patient Satisfaction Survey (PSS) has closed and the numbers are all being combined. We know we had over 5,300 surveys turned in from around the United States representing patient voices from over 92% of all HTCs. The data will be sorted and the information will be sent to each region and each HTC, allowing them to learn from the feedback you helped to share.

The National PSS committee thanks you for taking the time to let us know about your care and treatment last year. This valuable information can make a difference at your HTC, letting them know the strengths and weaknesses they may have. The impact of COVID-19 on our treatment centers was significant, and we know many of you provided feedback on how well we adjusted. Watch for future articles sharing what we found from the survey in coming months.

To learn more about this year's survey or the other two previous surveys and what we found, please go to htcsurvey.com.



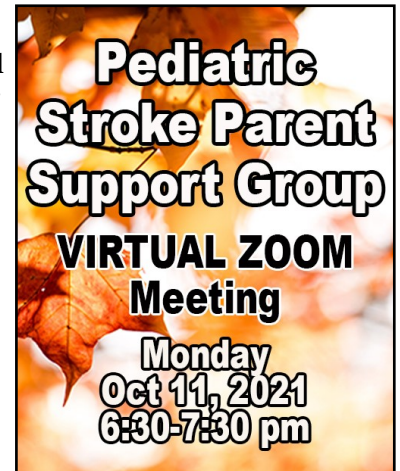
PEDIATRIC STROKE PARENT SUPPORT GROUP

Our Pediatric Stroke Parent Support Group will be on **Monday, October 11, 2021 at 6:30 pm** on Zoom. This group invites parents of children who survived a stroke to meet with one another and our stroke team each month.

This month our topic will be 'Coloring and Connection', and how coloring can help reduce stress and improve focus! Normally we meet in person, but with the COVID-19 pandemic restrictions we are continuing to have these meetings on Zoom until things improve.

We have changed the date of our meetings to the second Monday of the month from 6:30 to 7:30 pm. Meetings are open to families of children of all ages and all types of stroke. Your child does not need to be seen at our stroke clinic to join our meetings.

For more details, see our [website here](#), or [follow us on Facebook](#). To join our September meeting, please RSVP to strokesupport@ucdenver.edu or call 303-724-8520.



THANK YOU FOR WALKING WITH NHF CO AND RMHBDA



A few photos of families who attended the RMHBDA Unite for Bleeding Disorders Walk in Billings, MT. Photos: RMHBDA.



In the last month, both NHF Colorado and RMHBDA held Unite for Bleeding Disorders Walks, the main fundraisers for both organizations to provide support for those with bleeding disorders in their areas. The walk in Colorado was on August 28th and the Montana walk was on Sept 11th.

Both organizations were supported by a great turnout and generous donations, helping them reach their fundraising goals. The Colorado chapter was excited to host over 130 people in person, and RMHBDA were thrilled to have more than 100 in attendance at their event.

Thank you to all who donated, walked, or participated in any way. Both NHF CO and RMHBDA are grateful for those who attended virtually and the support from those who donated to allow them to continue to offer their much-needed, year round, educational and community events. Check out their websites for future events at cohemo.org and rmhbda.org.

Unite
for Bleeding Disorders

RECENT HEADLINES

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

FDA Restores BeneFIX as Prophylactic for Children with Hemophilia B

SerpinPC Prevents Bleeds in Hemophilia A and B Patients in Phase 2a Trial

NHF and HFA Partner to Create "Together Project"

Emicizumab (Hemlibra) May Improve Outcomes for Acquired Hemophilia A

Phase 2 Study Shows Monoclonal Antibody Marstacimab Appears Safe and Effective

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.

UPCOMING EVENTS

Mark Your Calendars:

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

Oct 11: Pediatric Stroke Parent Support Group

Oct 24: NHF CO Men's Connection Group– Top Golf in Thornton, CO

Oct 28-29: ATHN Data Summit

Nov 5-7: RMHBDA Women's Retreat-Chico Hot Springs, Pray, MT

Nov 25-26: Clinic, Pharmacy, and Admin offices closed for Thanksgiving Holiday

Nov 30: NHF CO Denver Zoo Lights

See more at our Events Page on our website: medschool.cuanschutz.edu/hemophilia-thrombosis/resources/events-calendar

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[medschool.cuanschutz.edu/
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