

# The Clotting Connection

*A Newsletter for Families with Bleeding and Clotting Disorders*

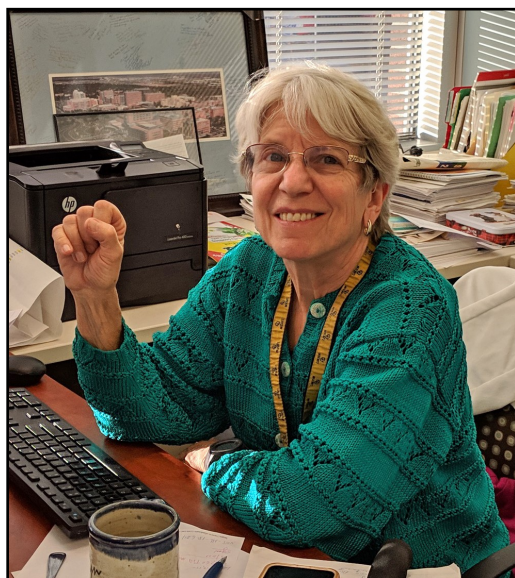
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University of Colorado  
Anschutz Medical Campus  
Hemophilia and Thrombosis Center

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

## DIRECTOR'S CORNER



Our HTC Director, Dr. Marilyn Manco-Johnson shares more insight into the research happening at our HTC.

Dr. Jorge DiPaola has studied von Willebrand Disease for many years from a genetic perspective. Dr. DiPaola has sequenced the von Willebrand factor gene in families with compatible bleeding to understand how specific genetic mutations affect the von Willebrand protein structure and function, leading to a more nuanced understanding of this molecule.

In addition, Dr. DiPaola has studied a large family of over 300 persons with von Willebrand Disease to understand why symptoms can vary among family members with the same genetic mutation. As an example, Dr. DiPaola determined that the proportion of the large von Willebrand Factor multimer that contains the mutant sequence can vary among family members causing some to show more severe bleeding symptoms than others, even though the actual genetic mutation is the same in all affected family members.

Our HTC's Dr. Chris Ng has taken on the challenge to understand why persons with von Willebrand Disease and many persons with low von Willebrand factor bleed under the stress of surgery or trauma. Dr. Ng has perfected a technique of safely removing some endothelial cells (cells that line the blood vessel) during a routine blood draw.

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Winter is half over and those of us not on the ski slopes are thinking about Spring. I would like to continue to report on more of the exciting and important research going on this winter at the HTC.

Patients with von Willebrand Disease and low von Willebrand factor have been identified as an underserved population because they frequently seek care for bleeding for several years before a diagnosis is made. Often important bleeding, such as joint bleeding, is unrecognized or overlooked. A challenge to the diagnosis of von Willebrand Disease is the imprecision of the clinical assays and the fact that many people have bleeding that looks like von Willebrand Disease, but their levels are low but not low enough to qualify for that diagnosis.



Dr. Jorge DiPaola has spent years studying von Willebrand Disease and is conducting research as a part of a program funded by the National Institutes of Health.



Did you know NHF Colorado and Backpacks & Bleeders are hosting a ski trip in March? You can attend their fun events all year. More inside!

### INSIDE THIS ISSUE

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



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Email:  
[HTC.Newsletter@ucdenver.edu](mailto:HTC.Newsletter@ucdenver.edu)

# EDUCATION DAYS IS APRIL 12-14, 2019



Registration is now open for NHF Colorado Education Days! Join us for some wonderful events, learning, and great opportunities to meet other families living with bleeding disorders.

Education Days is on April 12-14, 2019 at the Denver Marriott South at Park Meadows, located at 10345 Park Meadows Drive, Lone Tree, CO 80124. This event will start on Friday at 5 pm and run through Sunday at 3 pm.

This is one of the largest events NHF Colorado hosts throughout the year and so much is available to those who attend! The conference is FREE, and registration includes hotel accommodations, meals, daycare, a teen track, Spanish track and educational sessions!

Our Director, Dr. Marilyn Manco-Johnson will be honored as the 2019 William Hathaway Visionary Award at the Friday night opening ceremonies. We would love to have you there to help honor her years of dedicated efforts on behalf of so many patients.



Jeanne White Ginder will speak at the NHF CO Education Days.

On Saturday, Sharon Funk and Sue Geraghty will facilitate a remembrance ceremony to honor members of our community who have passed away. That same day, Jeanne White Ginder will be speaking and sharing her story. Many in our community know how her son Ryan White was diagnosed with AIDS through a blood transfusion to treat his hemophilia. After Ryan passed away in 1990, Jeanne remained a huge influence worldwide as an activist dispelling the stigma from the HIV/AIDS diagnosis so many have faced. This is a great opportunity to hear from a powerful witness to the history of our community.



Dr. Marilyn Manco-Johnson will be honored as the 2019 William Hathaway Visionary Award.

There will also be a blood drive this year for participants to support our community who need blood products more than most, and of course, there is a list of specific sessions providing education and information.

This event is free but you **MUST register!** Please go to **cohemo.org**, find the **WHAT WE DO** tab, click on we **EDUCATE**, and find **Education Empowerment Days** for more details and to register. Contact Kelly Ryan at NHF Colorado at [kryan@hemophilia.org](mailto:kryan@hemophilia.org) or 646-499-0684 for further information.

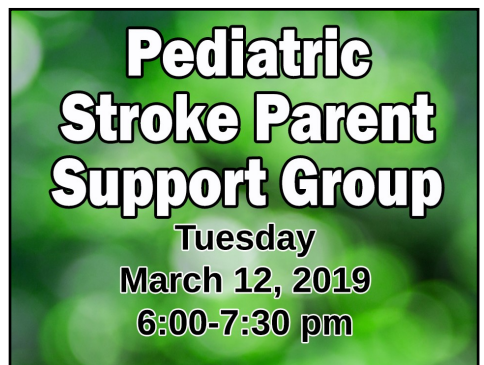
## PEDIATRIC STROKE PARENT SUPPORT GROUP

Our next Pediatric Stroke Parent Support Group will be on Tuesday, March 12, 2019 from 6–7:30 pm here at the HTC. We will be focusing on “Caring for the Caregiver” at this meeting, so join us for understanding the importance of self-care.

This support group is a wonderful opportunity for parents who have had a child experience stroke to meet with HTC staff and with other families who are in similar circumstances. The support group is open to families of children of all ages and of all types of pediatric stroke. Stroke patients do not need to be patients at our stroke clinic to join these free meetings. Dinner and childcare are provided at each meeting.

We will meet in the Lilly Marks boardroom across from our offices on the first floor of the CU Medicine building at 13199 E Montview Blvd. Suite 100 in Aurora. Parking is available in the garage just to the east of our building.

Please RSVP by March 8th with the number of parents & children to [strokesupport@childrenscolorado.org](mailto:strokesupport@childrenscolorado.org) or 303-724-6163 so we know how many to plan for. If you are unable to attend in person but would like to participate via skype or phone call, please let us know so we can arrange for technical support.





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Then, Dr. Ng uses a person's own endothelial cells to determine the amount and function of von Willebrand factor that is released from endothelial cells. Dr. Ng found that persons with "low von Willebrand factor" often release less von Willebrand protein under stress or stimulation, so that they are not able to mount an adequate response to prevent or stop bleeding. Dr. Ng hopes that this work will help to better understand how individuals with von Willebrand Disease or low VWF levels bleed and could provide a more personalized approach to each patient's treatments.

This work could lead in the future to a clinical test to predict the risk of bleeding more accurately than our current clinical assays.

Dr. DiPaola and Dr. Ng's research are conducted as part of a larger NIH-funded program project which seeks to advance basic understanding, diagnosis and treatment of von Willebrand Disease.



Dr. Ng is studying von Willebrand Disease and how stressors affect bleeding.

Dr. DiPaola is additionally involved in research to understand the genetic mutations that cause decreases in the number or function of small clotting cells called platelets, which are critical to normal blood clotting.

A new faculty member in the HTC research group is Dr. Keith Neeves. Dr. Neeves has a PhD in Chemical Engineering and works on fluid dynamics of blood clotting in what is called a microfluidic assay where blood is studied while it flows over physiologic activators, such as collagen and tissue factor. Dr. Neeves career is focused modeling the dynamics of blood clotting under flow and modeling the effects of clotting factor levels on bleeding and clotting. Dr. Neeves comes to us from the Colorado School of Mines. He will not only contribute as a basic scientist in blood clotting but will also be a fantastic resource in training young doctors and scientists in laboratory research of blood clotting.

Stay tuned next month when I will discuss more of the incredible research being done by our outstanding staff.

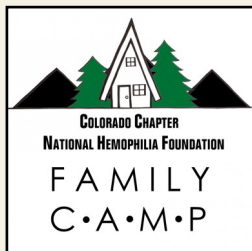
Marilyn Manco-Johnson, M.D., Director

## UPCOMING OPPORTUNITIES



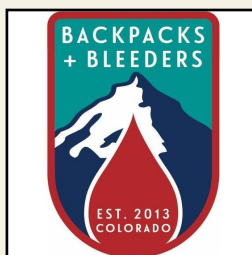
Our next Self-Infusion Clinic will be held on March 19, 2019 from 5:30-7:30 pm here at our HTC clinic. At each clinic our nursing staff is on hand to provide support, experience, and guidance as we walk patients and families through infusions. You can practice with saline or bring your own factor to infuse that day.

At this Self-Infusion Clinic we will be focusing on helping our adult patients, so we ask that only those 18 and up attend. There will be no childcare available at this clinic. For questions and to RSVP please contact Kelly Ryan of NHF Colorado at [kryan@hemophilia.org](mailto:kryan@hemophilia.org) or 646-499-0684 or see details at [cohemo.org](http://cohemo.org)



NHF Colorado invites the whole family to come up to Rocky Mountain Village and enjoy a family camping experience! NHF Colorado especially encourages families with siblings who have always wanted to attend the experience at camp.

Family Camp will be May 4-5, 2019 and registration is now open! Don't miss this opportunity to enjoy camp together! For more information or registration questions, please contact Kelly Ryan at [kryan@hemophilia.org](mailto:kryan@hemophilia.org), phone is 646-499-0684 and go to [cohemo.org](http://cohemo.org).



Did you know that Backpacks & Bleeders doesn't just host hikes? This group, designed to encourage those with bleeding disorders to safely learn to enjoy outdoor experiences, has great opportunities throughout the year. They hike, but they also have done paddle boarding, rock climbing and skiing trips! In fact, their trip to Loveland this March is already full, which means everyone agrees, it's a great opportunity to do fun things!

Stay up to speed and learn more about all their upcoming events by going to their Facebook page at <https://www.facebook.com/backpacksandbleeders/>.

## RECENT HEADLINES

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

### **Roche to Buy Spark Therapeutics for \$4.3 Billion**

### **FDA Approves Novo Nordisk's Esperoct for Hemophilia A**

### **Pool More than a Safeguard for Sun Devil Swimmer Elijah Warren**

### **Study Finds Bleeding Assessment Tool from ISTH is Useful in Assessing Severity of Hemophilia Patients**

### **Physical Therapists Rank Risks of Activities for Hemophilia Patients**

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](http://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/](http://www.facebook.com/ColoradoHTC/)

## UPCOMING EVENTS

### **Mark Your Calendars:**

### **March is Bleeding Disorders Awareness Month**

**Mar 8:** RMHBDA MT State Advocacy Day

**Mar 9:** Backpacks & Bleeders Ski Trip

**Mar 12:** Pediatric Stroke Parent Support Group

**Mar 19:** Self-Infusion Clinic at the HTC for Adults

**Mar 22:** NHF CO State Advocacy Day

**Mar 27-29:** NHF Washington DC Days

**April 9:** Pediatric Stroke Parent Support Group

**Apr 12-14:** NHF CO Education Days—Lone Tree, CO

**Apr 17:** World Hemophilia Day

**May 4-5:** NHF CO Family Camp

**May 27:** Clinic, Pharmacy & Admin closed for Memorial Day

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

### **Hemophilia & Thrombosis Center**

13199 E. Montview Blvd., Suite 100  
Aurora, CO 80045

Clinic Main: 303-724-0724

or toll free at 888-297-0724

Pharmacy Main: 303-724-0168

or toll free at 888-724-7427

Web page:

<http://medschool.ucdenver.edu/htc>

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