

The Clotting Connection

A Newsletter for Families with Bleeding and Clotting Disorders



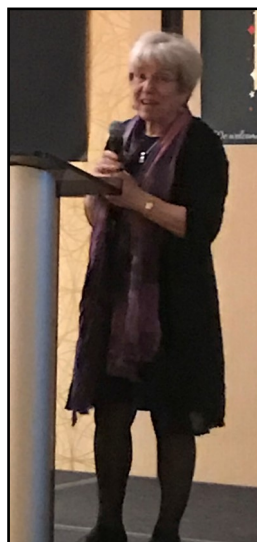
University of Colorado
Anschutz Medical Campus
Hemophilia and Thrombosis Center

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

EDUCATION DAYS!

In April, community members, families, HTC staff and NHF Colorado staff all gathered for the 2019 Education Empowerment Days weekend. The 3-day event was held at the Denver Marriott South at Park Meadows in Lone Tree, and was well attended by many in the bleeding disorder community.

The weekend began on Friday evening with a delicious dinner and presentation of the William Hathaway Visionary Award to Dr. Marilyn Manco-Johnson, our HTC Director. Dawn Rotellini, NHF Sr. Vice President of Program Development presented the award along with a touching tribute to Dr. Manco-Johnson. Members of the bleeding disorders community whole-heartedly joined in thanking and celebrating Dr. Manco-Johnson for her contributions and the many years of exceptional service to patients and families!



Dr. Marilyn Manco-Johnson at Education Days.
Photo: Dawn Rotellini.



One of our nurses, Kim Hurdstrom, helping at our self-infusion clinic during Education Days. Photo: Bryn Dunham.

panels were offered throughout the weekend, and giving families and patients the opportunity to learn and connect with staff and experts in a variety of topics.

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Saturday began early with a HTC directed self-infusion clinic led by our nursing and psychosocial staff. These self-infusion clinics are always a beneficial opportunity for our families who appreciate the opportunity to gather more tips and tricks.

At breakfast, we had the pleasure of hearing from Jeanne White-Ginder, a fantastic advocate for hemophilia patients and those living with AIDS and HIV throughout the world. Her son, Ryan White passed away in 1990 after contracting AIDS through transfusions of contaminated blood.

Multiple talks, classes, and



Jeanne White-Ginder speaking at Education Days. Photo: Debbie de la Riva.



It was great to see so many families at Education Days! Photo: Debbie de la Riva.

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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



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From left: Kim Hurdstrom, RN; Rachel Horton PT; Whitney Tedeschi, MSW; Marilyn Manco-Johnson, MD; Nancy Spomer, RN; and Mike Wang, MD lead a panel discussion at Education Days. Photo: Bryn Dunham.

Several breakout sessions were offered including “Ask the Experts” with our HTC staff as well as a teen session with our HTC Psychologist Emily Wheat. Other sessions addressed advocacy, ways to get involved, mental health, and pain and addiction.

Later that day, all groups reconvened to hear from Lieutenant Governor Dianne Primavera and learn about advocacy in our community.

On Sunday, Dr. Mike Wang, our HTC Clinical Director, gave a fascinating presentation on new drug therapies and medical advancements in the bleeding disorders field. He was followed by Michelle Witkop from NHF

who led an educational session on medical marijuana.

We would like to thank NHF Colorado for their efforts to plan and host another wonderful Education Days weekend. A special thanks to all who attended, volunteered and presented.

For more information on NHF Colorado and the resources they offer to patients please go to www.cohemo.org.



Psychologist Emily Wheat leads a discussion with teens at Education Days. Photo: Bryn Dunham



Did you know that the Hemophilia Federation of America and the Smithsonian Institute's National Museum of American History in Washington D.C. are working together to collect historical artifacts related to the history of hemophilia?

The project is collecting historical items, personal journals, articles, newsletters, other documents, photographs, oral histories (including those from HTC physicians and staff members) to preserve the history of bleeding disorders.

Their project is in its first phase of collecting these items, as well as asking for financial contributions to support the effort to share the history of the bleeding disorders community and preserve it for future generations.

You can learn more about this project at hemophiliated.org and look for the 2019 History Exhibit page under their “Understanding Bleeding Disorders” tab. There they have a link to contribute items for their exhibit.

You can also participate financially to support this project by donating at give.onecause.com/hfa.

**Pediatric
Stroke Parent
Support Group
Tuesday
May 14, 2019
6:00-7:30 pm**

Our next Pediatric Stroke Parent Support Group will be on Tuesday, May 14, 2019 from 6–7:30 pm here at the HTC.

This 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.

Please RSVP by May 10, 2019 to strokesupport@childrenscolorado.org or 303-724-6163 so we know how many to plan for.

See more details at our website at www.medschool.ucdenver.edu/htc under the COMMUNITY tab.

RETURN YOUR PACKING SLIPS!

Our Pharmacy is required to have records on file about medications and supplies they send out to our patients. When you receive factor or other items from our HTC Pharmacy, please remember to return the delivery receipt stamped in **red ink**. Instructions are included in the packaging.

These slips must be signed, dated and mailed to us. There is a self-addressed and stamped envelope provided.

Unfortunately, failure to return signed packing slips could result in a delay in receiving your next factor order or possibly being held financially responsible for the order.

Thank you for your help! Returning packing slips is a requirement and we thank you for helping us comply with regulations.

Contact our Pharmacy if you have questions at 303-724-0168 or at hemophilia@ucdenver.edu.

PRESCRIPTION COVERAGE ALERT

Our staff wanted to give our bleeding disorder patients a heads up to be sure to double check your insurance prescription coverage for 2019. If you use Express Scripts as your prescription provider, please note that some significant changes have been made to some of their excluded medications.

If you are currently on Elocate, Recombinate, Xyntha, or Xyntha Solofuse, you may have issues and need alternative medications. **Please check with your insurance company to find out what is covered and with your doctor at our HTC to make sure you are able to access the right medication for you.**

Changes to coverage of medications often come during a renewal period, and these Express Scripts changes take effect July 1, 2019. Contact your healthplan to verify coverage of your prescriptions and if you need help please feel free to contact us to make sure you're covered.

Our Pharmacy and insurance counselor are happy to help confirm any changes. Contact us at 303-724-0724.

UPCOMING OPPORTUNITIES



Mile High Summer Camp is **July 14-19, 2019** with our Leadership Camp starting on **July 12-13, 2019**. Camp is once again at Rocky Mountain Village Easterseals Camp near Empire, Colorado.

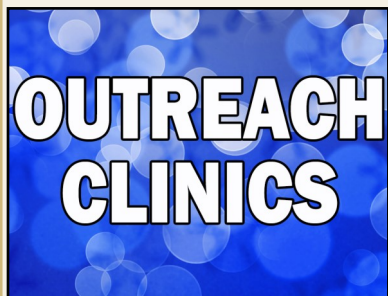
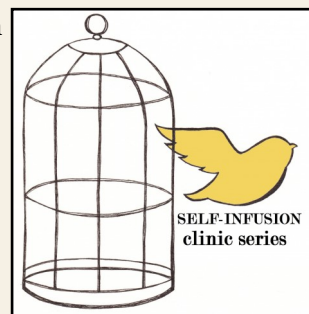
This is a great opportunity for kids with bleeding disorders to grow and have tons of fun. Campers can attend starting at age 7 and are divided by age group. The 12-13 year olds can attend an adventurous wilderness program. Our 14-17 year olds are eligible for our leadership program. Graduated campers can even apply to be a "Bleedership Counselor" when they are 18.

Our nursing, physical therapy, social work, pharmacy and clinical staff are on hand throughout camp to help teach and provide support. Registration is open until **May 1, 2019** and spots are filling fast. Please go to cohemo.org to register and for more information.

Our next Self-Infusion Clinic will be held on **Saturday, June 8, 2019** here at our HTC from 9 am to 11 am. At each clinic our nursing staff is on hand to provide support, experience, and guidance as we help patients practice infusing. You can practice with saline or bring your own factor to infuse that day.

This infusion clinic is open to families and caregivers as well as patients of all ages. While we don't have separate childcare at this clinic, you are welcome to bring your children to this clinic with you.

While NHF Colorado normally handles registration for this clinic, they are currently undergoing staff changes. For this Self-Infusion clinic, please direct questions and RSVP directly to us at the HTC by email at hemophilia@ucdenver.edu or contact Christine Mashburn at 303-724-0724.



If you do not live in the Denver Metro area, one of our Outreach Clinics might be an easier option for your regular comprehensive care. Our Outreach Clinics offer care and support from our medical, nursing, physical therapy, psychosocial, and research teams. Our experts come to you!

Upcoming Outreach Clinics:

May 24, 2019—Colorado Springs, CO

June 25-28, 2019—Billings, Montana

July 31-Aug 2, 2019—Missoula, Montana

See our website for more details at medschool.ucdenver.edu/htc

RECENT HEADLINES

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

**Accumulator Program Update:
Washington Tells Insurers "Not So Fast"**

**Believe Limited Releases "Hemophilia:
The Musical" Soundtrack and Launches
Musical Theater Programs Nationwide**

**Catalyst Biosciences Enrolling for Phase
2b Trial for Hemophilia B Treatment**

**NHF Joins PAN to Offer More Support
for Bleeding Disorder Patients**

**New Interim Data from Sangamo &
Pfizer on Gene Therapy for Hemophilia 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. 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:

May 4-5: NHF CO Family Camp

May 24: Outreach Clinic—Colorado Springs, CO

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

June 8: Self-Infusion Clinic at the HTC

June 14-16: RMHBDA Family Camp—Anaconda, MT

June 25-28: Outreach Clinic—Billings, MT

July 4: Clinic, Pharmacy & Admin closed for Independence Day

July 12-13: Leadership Training at Mile High Summer Camp

July 14-19: Mile High Summer Camp

Aug 24: NHF CO Unite for Bleeding Disorders Walk-Denver, CO

Sept 2: Clinic, Pharmacy & Admin closed for Labor Day

See more at our Events Page on our website:

www.medschool.ucdenver.edu/htc find **RESOURCES** tab, go to **EVENTS**

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Pharmacy Main: 303-724-0168

or toll free at 888-724-7427

Web page:

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

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