NHF Colorado hosted their annual Education Empowerment Days over three Saturdays in October this year. Because of the COVID-19 pandemic, the sessions were all held virtually and gave many families the opportunity to connect from all over our region. This was a different format than any of us are used to, but NHF, the HTC, and all who participated did a wonderful job with the circumstances we currently face.

Many of the sessions allowed members to listen and learn, ask questions of experts, and even earn prizes. Twenty-one sessions were provided during the three Saturdays, along with various opportunities to connect, ask questions, view resources, and even enjoy a free screening of the documentary *Bombardier Blood*.

Several sessions were provided for Spanish-speakers, and other special sessions were provided for teen programming. NHF Colorado sent over 100 event boxes to families as part of their participation in Education Days. These boxes contained various items, including masks and hand sanitizer. Participants attending several sessions were also provided with complimentary Grub Hub cards, as normally attendees would enjoy several meals together.

Dr. Mike Wang presented on Gene Therapy during an afternoon session sharing what we know, where we are in the process, and the many challenges yet before us. His presentation was very helpful to understand the pros and cons of gene therapy, how many researchers are approaching the problems and issues, and what other resources are also heading our way.

[continued on page 3]
About 1 in 5 people with hemophilia A, and about 3 in every 100 people with hemophilia B will develop an inhibitor during their lifetime according to the CDC. Inhibitors develop when your body reacts to factor replacement therapy as if it is a foreign substance. Instead of the factor product helping stop a bleeding episode, the body stops accepting it as normal and starts attacking it. Inhibitors prevent treatment from working properly in these patients.

Managing hemophilia A or B with an inhibitor can be challenging and many patients may need additional support. The National Hemophilia Foundation (NHF) usually hosts multiple Inhibitor Summits throughout the United States, however, due to the COVID-19 pandemic, this year there is one Inhibitor Summit, and it will be held online. Dr. Tyler Buckner from our HTC, is co-chair of the steering committee and is very involved in the programming of this year’s summit, which occurs from Oct 29th to Nov 1st, 2020.

The Inhibitor Summit 2020 is four days of educational sessions that are led by experts in their fields, including hematology, mental health, orthopedics, insurance, and more. The Inhibitor Summit is free, but registration is required to attend any of the virtual sessions. The summit is open to any with hemophilia A or B with an active inhibitor or an inhibitor that has been tolerized. Their families and those who are involved in their day to day care are also welcome to attend.

Dr. Tyler Buckner will be speaking twice during the program, and our HTC’s Psychologist, Dr. Emily Wheat, will also be presenting.

If you are affected by an inhibitor, take the opportunity to sign up and learn from the experts. You can find out more information by going to the NHF Inhibitor Summit 2020 website, and registration is available here.

---

**PEDIATRIC STROKE SUPPORT GROUP**

Our Pediatric Stroke Parent Support Group is now meeting online! We’ve missed visiting with our pediatric stroke families in person, but to stay safe we’ll be meeting online for a while longer.

Please join us for our next online meeting on **Tuesday, November 10th from 6:30-7:30 pm on Zoom**.

This group meeting welcomes everyone in the family to join. Your child does not need to be treated at our center to attend.

To join, please RSVP by contacting us at strokesupport@ucdenver.edu or (303) 724-8520. We’ll send a calendar reminder with the zoom link to all who RSVP. Follow us on Facebook for the latest on our meetings at [www.facebook.com/Colopedsstroke](http://www.facebook.com/Colopedsstroke). We hope to ‘see’ you on November 10th!!
Dr. Marilyn Manco-Johnson was awarded the 2020 ATHN Lusher-Shapiro Award this year at the 2020 ATHN Data Summit. ATHN stands for American Thrombosis & Hemostasis Network, and is a coalition exclusively created to support managing data, research, and measure outcomes to improve care for patients.

The Data Summit is held annually and highlights the importance of research and data in finding answers to help those with bleeding disorders. The award is given to a physician or investigator whose leadership has made a substantial impact on the direction of ATHN. The award was named after Dr. Jeanne M. Lusher and Dr. Amy Shapiro, who were co-founders of ATHN and personal mentors to Marilyn.

This year the summit was held virtually, and Dr. Manco-Johnson shared her acceptance of the award by video. We published her acceptance on our Facebook page and congratulate Marilyn on this well-deserved achievement. Her knowledge, research, and experience with bleeding disorder patients over decades has impacted so many and made huge differences in the quality of life of patients all over the globe. Congratulations Dr. Marilyn Manco-Johnson! We are thrilled you received this honor!

Members of our HTC were happy to serve on a panel session discussing HTC updates, including how our center is operating during COVID-19, staff updates, and what to expect in the near future with the upcoming use of the MyChart Vidyo platform. Our staff enjoyed chatting with our HTC families in both panel discussions and virtual booths that were available during these sessions.

Networking sessions provided families with the ability to connect with one another in a facilitated space. Nearly 250 logons occurred across all sessions, with the average session attendance of 15-20 families, representing approximately 55 individual patients.

Some other highlights included a session on kinesthetic taping, sessions focused on dealing with bullying, self-care for children with bleeding disorders, women with bleeding disorders, and interactive exhibit hours offering self-serve viewing of new and important research and information.

Many members of the bleeding disorder community also participated in the “Walk Across Colorado” challenge. They logged in over 3,550 miles from September 1st through October 23rd. Congratulations to all who took the challenge and got in some incredible numbers as we walked together virtually!

We thank all who participated in making NHF Colorado’s Education Empowerment Days a success, despite the hurdles that have come with the restrictions we all face. Our HTC staff was thrilled to connect with everyone and we are grateful to NHF Colorado for hosting this powerful event.

Keep up to date with NHF Colorado and their upcoming events at cohemo.org.

“I believe everyone who is somehow involved in the bleeding community should attempt to attend the Education days at some point. My family has attended every year since my son was diagnosed and we always learn something new. It’s a great way to see other families in the same situations as us. Families who are not affected by a bleeding disorder don’t always understand, so when we get to communicate with others who do, well we just love it!! Thank you all for hosting even though we couldn’t get together like normal! Hopefully next year!” -Jolene A
These are a few of the headlines that we’ve recently featured on our Newsroom page or on Social Media.

Data Shows Hemlibra Improves Quality of Life for Children With Hemophilia A
Study Finds Good Long-term Outcomes After Knee Replacements for Hemophilia Patients
NIH Awards $1.5 M Grant to DNA Medicine Institute to Develop Rapid Test
First Participant Dosed in Phase 3 Study for Pfizer and Sangamo’s Gene Therapy
CSL Behring States Stimate Will Not Be Resupplied Until 2022

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.

Mark Your Calendars:
Please note. These dates may be tentative and subject to change due to the COVID-19 pandemic and restrictions. Please check appropriate websites for confirmation of events.

Oct 27-30: THSNA 2020 Summit—VIRTUAL

Oct 29-Nov 1: NHF Inhibitor Education Summit—VIRTUAL

Nov 6-8: RMHBDA Women’s Retreat—Chico Hot Springs, Pray, MT

Nov 10: Pediatric Stroke Parent Support Group—VIRTUAL

Nov 26-27: HTC Clinic, Pharmacy, and Admin Offices Closed for Thanksgiving Holiday

Dec 24-25: HTC Clinic, Pharmacy, and Admin Offices Closed for Christmas Holiday

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