

# The Clotting Connection

A Newsletter for Families with Bleeding and Clotting Disorders

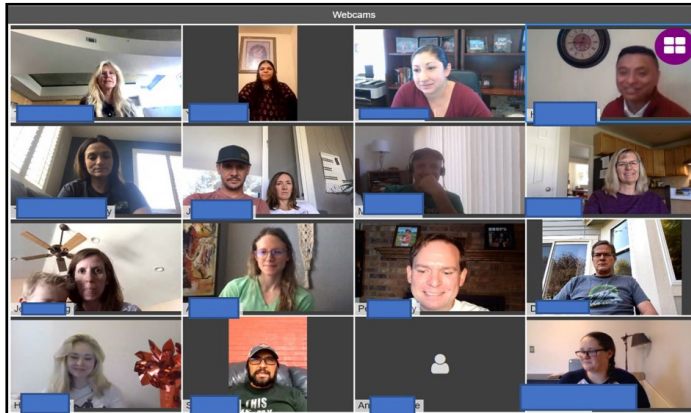


Hemophilia and Thrombosis Center  
UNIVERSITY OF COLORADO ANSCHUTZ MEDICAL CAMPUS



Affiliated with  
Children's Hospital Colorado

## EDUCATION DAYS CONNECTS!



Members of the bleeding disorder community came together via technology for the NHF Colorado Virtual Education Empowerment Days, held on Oct 10th, 17th, and 24th, 2020.

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.

2020 GT Preparedness\_Wang\_vCONHF17Oct2020 (26 / 27)

Overview of licensed and investigational (italics) therapies to treat hemophilia A or B with or without inhibitors: 2020

Factor replacement therapies (green), Gene or Cellular therapies (red), substitutive therapies (purple), rebalancing therapies (blue)

**Factor replacement therapies (green):**

- VIII or FIX concentrates
  - Standard half-life (SHL)
  - Extended half-life (EHL)
  - ADPT190 (Sandoz)
  - OCFT410 (Octapharma)
  - ADPT190 (Sandoz)
  - OCFT410 (Octapharma)
- Gene transfer
  - AA1-FIT1
  - AA1-FIT2
- Gene editing
  - SP-FIX (Sangamo Therapeutics)
- Cellular therapy
  - SG-011 (Sangamo Therapeutics)
  - Levo-FIT2 (Medical College Wisconsin)

**Substitutive therapies (purple):**

- Bispecific antibodies, FVIII mimetic
  - Emicizumab (Genentech)
  - Mand (Novo Nordisk)

**Rebalancing therapies (blue):**

- VWD Type 3
  - APC inhibition
    - Serpins PC (Accion XL Ltd)

**Rare Bleeding Disorders:**

- FYIIa concentrates
  - Novoseven (Novo Nordisk)
  - SevenFact (LFB SA, HEMA Biological)
  - Macroprecip (Alliance BioPharma)
  - MOD-301 (COPKO Health)
- TFPI
  - TFPI antibodies, anti-Xa only
    - Emicizumab (Novo Nordisk)
    - Macroprecip (Alliance BioPharma)
    - MG111 (Green Cross)
- AT knockdowns
  - Fitusiran (Sandoz)

Other terms: Contact activators: XIa, IXa, XI, XII; Tissue factor: VIIa, VIIIa, IXa, X, XI, XII; APC inhibition: Serpins PC (Accion XL Ltd); AT knockdowns: Fitusiran (Sandoz); Emicizumab (Novo Nordisk); Macroprecip (Alliance BioPharma); MOD-301 (COPKO Health); TFPI antibodies, anti-Xa only: Emicizumab (Novo Nordisk); Macroprecip (Alliance BioPharma); MG111 (Green Cross).

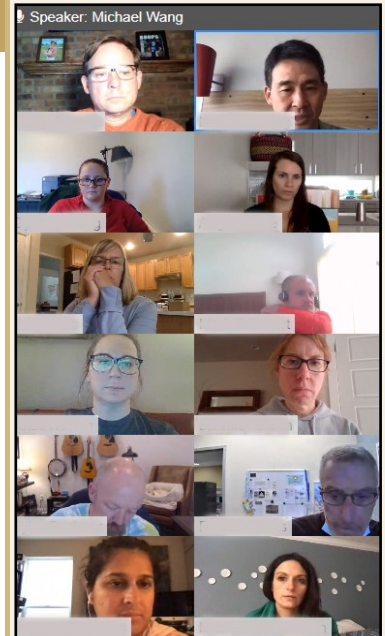
Source: Crook, Wang & Wheeler. AJH (in press)

Dr. Mike Wang presenting on Gene Therapy and many of the current and upcoming therapeutics available.

problems and issues, and what other resources are also heading our way.

[continued on page 3]

October 2020  
Volume 10, Issue 10



Dr. Mike Wang presented on Gene Therapy during an Ed Days session.

### INSIDE THIS ISSUE

- Education Days Connects!
- HTC Staff to Present at NHF Inhibitor Summit
- Dr. Marilyn Manco-Johnson Receives ATHN Award
- Pediatric Stroke Parent Support Group
- Upcoming Events
- News

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



Go to [facebook.com/ColoradoHTC](https://facebook.com/ColoradoHTC)



Go to [twitter.com/HTCColorado](https://twitter.com/HTCColorado)



Website: Go to

[medschool.cuanschutz.edu/hemophilia-thrombosis](https://medschool.cuanschutz.edu/hemophilia-thrombosis)



Email:

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

# HTC STAFF TO PRESENT AT 2020 INHIBITOR SUMMIT

**Inhibitor** EDUCATION  
SUMMITS

NATIONAL HEMOPHILIA FOUNDATION

October 29th - November 1st, 2020



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



Dr. Tyler Buckner is the co-chair of the steering committee for the Inhibitor Summit and will speak at two sessions.

summit, which occurs from Oct 29<sup>th</sup> to Nov 1<sup>st</sup>, 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](#).



Dr. Emily Wheat, our HTC Psychologist, will present at this year's Inhibitor Summit.

**Pediatric  
Stroke Parent  
Support Group**  
**VIRTUAL ZOOM  
Meeting**  
**Tuesday  
Nov 10, 2020  
6:30-7:30 pm**

## PEDIATRIC STROKE SUPPORT GROUP

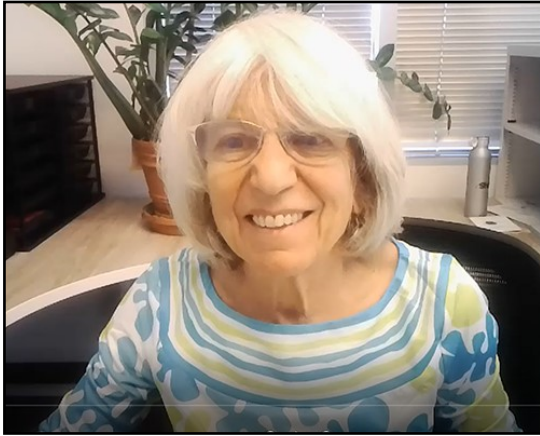
Our Pediatric Stroke Parent Support Group is now meeting online! We've missed visiting with our pediatric stroke families in person, but to stay safe we'll be meeting online for a while longer.

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](mailto: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](https://www.facebook.com/Colopedsstroke). We hope to 'see' you on November 10th!!

# DR. MARILYN MANCO-JOHNSON GIVEN ATHN AWARD



Dr. Marilyn Manco-Johnson accepting her award via video at the 2020 ATHN Data Summit.

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!

## [Education Days, continued from page 1]

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



A session on kinesthetic taping offered by NHF CO at Ed Days.

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!



A few of the Challenge stats from NHF CO.

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](http://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**

## RECENT HEADLINES

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 Stimute 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](https://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 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](https://medschool.cuanschutz.edu/hemophilia-thrombosis/resources/events-calendar)

### 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:

[medschool.cuanschutz.edu/hemophilia-thrombosis](https://medschool.cuanschutz.edu/hemophilia-thrombosis)

PLEASE  
PLACE  
STAMP  
HERE