

The Clotting Connection

A Newsletter for Families with Bleeding and Clotting Disorders

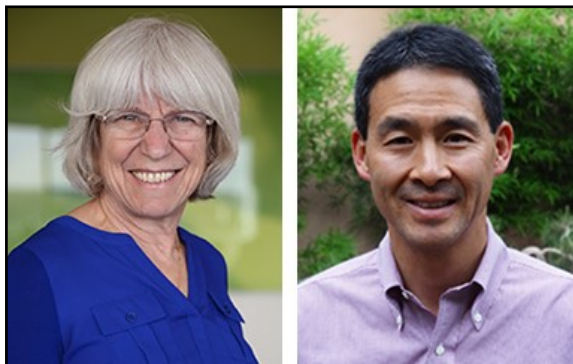


Hemophilia and Thrombosis Center
UNIVERSITY OF COLORADO ANSCHUTZ MEDICAL CAMPUS



Affiliated with
Children's Hospital Colorado

DIRECTOR'S CORNER—HTC 2021 UPDATE



Dr. Marilyn Manco-Johnson and Dr. Mike Wang are Co-Directors of the HTC.

We write you with guarded but genuine optimism for 2021. For the HTC, we started the pandemic odyssey on March 13, 2020 with a decision to move our clinical program to a virtual space. The labs were forced to close temporarily. Little did we know at that time that 10 months later, we would be in that same “space”, but much wiser.

Like so many, we struggled with new schedules and home demands, work inconsistency and disruption, and social unrest. 2020 brought all

of us challenges, many of which we never dreamed we would face. For many of us, we faced these challenges alone, or at least separated from our usual support structures. We eagerly said good-bye to 2020, but what does 2021 have in store for us?

Science was showcased in 2020, and we will harvest the fruits of multiple advances. We rapidly learned how to care for SARS-Covi-2 patients, and a number of medication trials showed promising results. Rapid execution of vaccine development thru clinical trial and FDA approval may be one of the key components of a successful resolution of the pandemic. The science of hand washing, isolation when ill, masks, and social distancing repeatedly showed its effectiveness, and sadly, ineffectiveness when not used. Influenza may serve as a guide for us: diagnosis of influenza decreased 98% this year locally, and this cannot be explained by anything else but wide-spread vaccination and proper attention to “COVID-19 pandemic hygiene” as detailed previously.

We have reflected throughout the year about the last infectious crises, HIV & hepatitis B and C, that devastatingly affected our patients, and still affect many today. We must constantly learn from the lives that touch us. We will emerge from COVID-19 fundamentally changed; our aspiration is that we have done this together, in the best ways that we could, for the greater good.

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	HIV Infection	COVID-19
Number of U.S. cases	1.9 million	17.5 million
Number of U.S. deaths	700,000	314,000
Number of Global Cases	75 million	76 million
Number of Global Deaths	32 million	1.7 million
Duration of Pandemic	40 years	12 months

For both pandemics, the number of undiagnosed infections is great.
For HIV, the number of life-years lost is greater.

Data taken from David Schwartz, MD, and Steven Johnson, MD.



Photo: Dawid Zawila Unsplash

INSIDE THIS ISSUE

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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.cuanschutz.edu/hemophilia-thrombosis



Email:

HTC.Newsletter@ucdenver.edu

HTC STAFF DONATES TO LOCAL CRISIS CENTER

During December, our incredible staff engaged in a special HTC Holiday Project. One of our nurses, Nancy Spomer, suggested we gather items to donate to the local [Comitis Crisis Center](#), which is located just across the street, east of our HTC. The Comitis Crisis Center serves people experiencing homelessness every day of the year, including families, veterans, and people struggling with addictions, trauma, and mental health issues. The center offers emergency shelter for adults, transitional family shelter, emergency family shelter, a transitional VA shelter, as well as a cold weather activation support for those homeless during extreme weather.

The center is always in need of donations and support, and our staff responded to this opportunity with enthusiasm. During the few weeks before Christmas, our staff was able to provide donations that resulted in the purchase of over 50 blankets, 30 sets of sheets, more than 150 toiletry kits, over 200 personal care items, multiple handmade knit hats, and gloves. Laura Fox, our Physical Therapist, worked with Nancy to gather these items and shared,

"It was very heartening to see people, while going through their own struggles, embrace gratitude and kindness to help their neighbors."

This stream of personal donations from our staff made a big difference to those housing at Comitis, and they warmly welcomed our support.



One of our staff member's car stuffed with items to help at the Comitis Crisis Center.

Our HTC was thankful for this opportunity to serve those nearby in need, and we hope to continue to have opportunities such as this in the future. The effort lifted the spirits of many of our staff who felt gratitude and joy for the opportunity to help. We especially thank Nancy Spomer and Laura Fox for their leadership and efforts in making this a successful event that touched so many lives.

PEDIATRIC STROKE SUPPORT GROUP

**Pediatric
Stroke Parent
Support Group**
**VIRTUAL ZOOM
Meeting**
**Tuesday
Feb 9, 2021
6:30-7:30 pm**

Our Pediatric Stroke Parent Support Group has been meeting online now for several months. While we miss visiting in person with our pediatric stroke families, we will continue meeting online a while longer to keep everyone safe.

We hope you can join us for our next online meeting on

Tuesday, February 9, 2021 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. Follow us on Facebook for the latest on our meetings at www.facebook.com/Colopedsstroke.

LOVE IS IN THE AIR

COUPLE'S VIRTUAL BRUNCH

FEBRUARY 13, 2021
10 AM- 12 PM PST | 12 PM- 2 PM CST

We invite you and your partner to join us for a brunch program where we will teach you how to make a delicious brunch in real time followed by a discussion on Love Languages and translating it into advocacy for your marriage, a bleeding disorder and beyond by Dr. Emily Wheat, Colorado HTC psychologist.

Registration includes Love Language book, recipe card and Valentine's goodies. Gift card reimbursements will be sent after event for cost of food for brunch.

Register on your local chapter's website by February 1, 2021. *Event for members of host chapters only*



Pacific Northwest
Bleeding Disorders



BDAND
Bleeding Disorders Alliance of North Dakota

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It's a new year! We may have mountains to climb in 2021, but we hope we can walk the path together and help one another as we do.

For patients with bleeding and clotting disorders many new medications became available, and clinical trials were kept open safely. 2021 will bring approval of additional novel therapeutics, and for hemophilia, the discussion around gene therapy will become more intense.

For the foreseeable future, the HTC will be a “hybrid” clinic of in-person and virtual visits. This depends on social distancing requirements, community spread of COVID-19, and available staff to see and care for patients. This will fluctuate. We have seen distinct advantages for each type of visit. Long range preparation includes the following:

- Telehealth visits will be preferentially scheduled in Epic MyChart. If you do not have a [MyChart](#) account, we will help you open one. This also allows you to message the clinical staff directly,

and see notes and lab/radiology reports. We have also seen that it is a much more seamless way of doing a virtual visit.

- We are committed to outreach once we are able to travel. We do not know when that will be possible. Please reach out to us for an appointment if we have not seen you in the last year, or if you need to be seen sooner. Please do not wait for us to come to you. We want to see you, and provide the care you want and need.
- Licensure of providers in multiple states surrounding Colorado and beyond.
- Re-building of clinical space to accommodate more space and different patient flow, development of clinical lab services in the clinic, physical therapy space that will allow for more therapy, and an infusion center.

Reflecting on a year repeatedly punctuated with loss has been difficult. However, our narratives will be about service, sacrifice, compassion, growth, adaptability, resilience, innovation, purpose, kindness, and joy. Never have you, our community, meant more to us. We thank you for your abundance of patience and support. The numerous kindnesses afforded to us are all appreciated.

We wish for and hope for the best for everyone in 2021.

Our best,

Marilyn and Mike

THIRD NATIONAL PATIENT SATISFACTION SURVEY TO LAUNCH IN SPRING 2021



How satisfied are you with your HTC services? HTC patients and caregivers throughout the US are invited to tell us this Spring. In 2015 and in 2018, HTCs across the country sent out the first and second National Patient Satisfaction Surveys (PSS). This survey was sent to patients with bleeding disorders who received care at HTCs asking how their experience was. The first two surveys helped local HTCs understand where care could be improved and helped national leaders gauge the things that were and were not working at HTCs across the United States.

Each survey was anonymous but was linked to the HTC where the patient received their care. This allowed each center to look at the responses and hear honest, anonymous feedback from patients. The third national survey will be sent out in the spring of 2021. It offers patients a great opportunity to again help HTCs evaluate their care.

Nearly all HTCs had to make major adjustments in 2020 due to the COVID-19 pandemic. In response, questions have been added asking patients for feedback on tele-health as well as in-person care. The PSS team [recently published a paper](#) that reviewed results from the first survey, and many [posters and one page articles](#) have been written showing what has been learned so far.

Please watch for more information on how to participate in the next survey, which is slated to begin this spring. The survey is brief and will be available in both English and Spanish. Those who received care from their HTC in 2020 are encouraged to fill out the survey online once it goes live. Paper surveys will be mailed out to families as well. For questions, or to learn more about the earlier surveys, please go to htcsurvey.com.

RECENT HEADLINES

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

Study Suggests Eloctate Induces Faster Immune Tolerance than other Regimens

Phase 3 Trial Shows Sustained Drop in Bleeding Rates for Roctavian, Gene Therapy for Hemophilia A

NHF Shares Information about COVID-19 Vaccines

FDA Puts Clinical Hold on uniQure's Hope B Trial

Updated Phase 1/2 Hemophilia Gene Therapy Study Data Presented at ASH

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 due to the COVID-19 pandemic and restrictions. Please check appropriate websites for confirmation of events.

Feb 9: Pediatric Stroke Parent Support Group—Virtual

Feb 13: NHF CO Couples Brunch—Virtual

Feb 13: RMHBDA Women's Retreat—Virtual

Feb 15: Clinic, Pharmacy, and Admin offices closed for Presidents Day

Mar 1-5: NHF Washington Days—Virtual

Mar 9: Pediatric Stroke Parent Support Group—Virtual

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

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Web page:

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

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