

The Clotting Connection

A Newsletter for Families with Bleeding and Clotting Disorders

December 2018
Volume 8, Issue 12



University of Colorado
Anschutz Medical Campus
Hemophilia and Thrombosis Center

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

HTC DOCTORS PRESENT AT ASH



Dr. Beth Warren and Dr. Marilyn Manco-Johnson at ASH. Photo courtesy Dr. Marilyn Manco-Johnson.

In early December, several of our faculty attended the American Society of Hematology's (ASH) Annual Meeting in San Diego, CA. ASH is the world's largest professional society of scientists and physicians who are involved in research to cure blood diseases. ASH has been meeting and discussing blood and blood diseases for 60 years. Their annual meeting is an educational and scientific event. Presentations on research and medical trials, along with posters and publications share the latest in the developments around the world in treating blood disorders and diseases.

Our medical staff were very involved in the events taking place at ASH. Dr. Brian Branchford gave a presentation about hospital-acquired thrombosis and how it can be better predicted. Dr. Chris Ng had two presentations; both were related to better understanding von Willebrand Disease by looking at the RNA expression

patterns in endothelial cells. One of his presentations was highlighted at the "Best of Hemostasis/Thrombosis" at the meeting. Congratulations to Dr. Ng!

Dr. Beth Warren presented results on the Joint Outcome Study Continuation (JOS-C). This was the follow up study to the Joint Outcome Study (JOS), the randomized, controlled trial which showed that prophylactic factor starting before age 2 1/2 years is better for your joints at age 6 than on-demand treatment with factor for bleeding. Dr. Marilyn Manco-Johnson spearheaded, developed and led both the JOS and JOS-C. The JOS-C followed participants of the JOS up until age 18. Those who started prophylaxis before age 2 1/2 ('early-prophylaxis' treatment group) had lower rates of bone and cartilage damage on MRI than those in the study who started prophylaxis after age six. Many study participants on early prophylaxis still had joint damage on MRI by age 18, so we need to continue efforts to improve treatments. It will be important to compare these results to future studies of new treatments such as Hemlibra (emicizumab) and gene therapy. Congratulations to Dr. Warren and Dr. Manco-Johnson for all their hard work on this study.



Dr. Chris Ng presenting on von Willebrand Disease related research at ASH. Photo courtesy Dr. Marilyn-Manco Johnson.



Dr. Brian Branchford presenting at ASH. Photo courtesy Dr. Marilyn Manco-Johnson.

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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



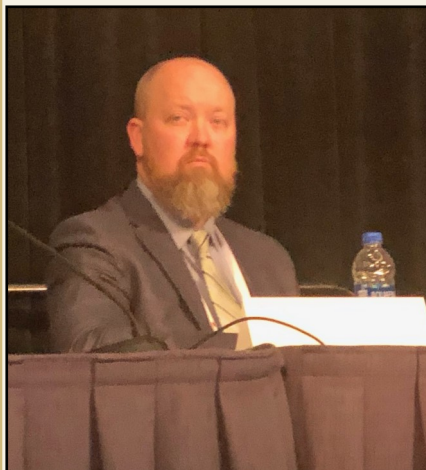
Website: Go to medschool.ucdenver.edu/htc



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Dr. Buckner in the role of moderator at a session on clinical and laboratory research in hemophilia. Photo courtesy Dr. Marilyn Manco-Johnson.

Dr. Tyler Buckner moderated a session on clinical and laboratory research in hemophilia. This also happened to include the session where Dr. Warren presented on the Joint Outcome Study Continuation!

Dr. Mike Wang spent much of the event in a wide variety of meetings, where he conferred with many dozens of people about various clinical trials for patients with hemophilia.

The time and effort our medical faculty and staff put into research provides powerful information to help families with bleeding disorders. Much of the knowledge our staff shares or gleans from worldwide meetings, such as ASH, can provide direct improvements to the care of our patients.

A special thanks to all in the bleeding & clotting community who are able to participate in studies that provide this information for future generations. Research opportunities provide much needed evidence of ways to make positive change. Thanks to our doctors and research staff for their hard work.



Happy Holidays from the HTC!

This is a busy time of year, so take care of yourself and your family members and enjoy the season.

Be aware that our clinic, pharmacy, and administrative offices have several closures coming up. We will be closed Monday and Tuesday, December 24-25, 2018 for the Christmas holiday. We will also be closed January 1, 2019 for New Year's Day, and January 21, 2019 for Martin Luther King Jr. Day.

Please keep these dates in mind if you need medical assistance or need to order more factor medication from our pharmacy. Last day to ship medications before Christmas is December 20th, and last day to ship before New Year's Day is December 27th.

If you need to contact our pharmacy or clinic when we are closed, please see our after-hours information at our website at www.medschool.ucdenver.edu/htc and click on the clinic tab.

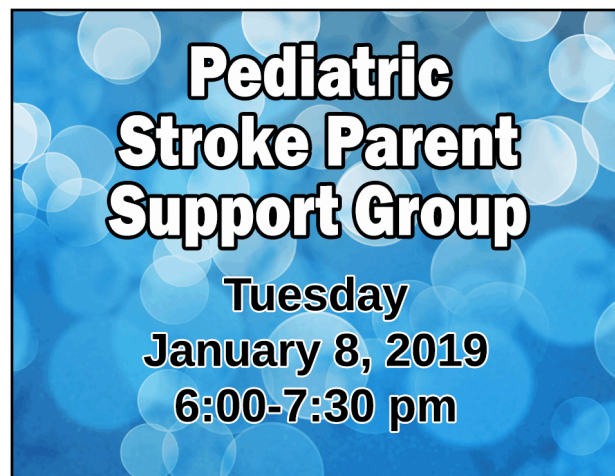
PEDIATRIC STROKE PARENT SUPPORT GROUP

After a several month hiatus, our Pediatric Stroke Parent Support Group is starting up again in January. 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.

Our stroke team has several new members and this is a great opportunity to come meet them and start of the new year in a supportive environment. We have two new social workers Bryn Dunham and Whitney Tedeschi as well as nurse Cindy Nederveld who sees many of our stroke patients in clinic. All three will be there and are excited to get to know our stroke families a little better.

Our January meeting is on Tuesday, January 8th from 6-7:30 pm here at our HTC. Parking is available in the garage just to the east of our building at 13199 E Montview Blvd. Suite 100 in Aurora.

Please RSVP at 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.



Nearly 4800 Patients Respond to Second National Survey of US Hemophilia Treatment Centers



In the spring and summer of 2018, nearly 4800 Hemophilia Treatment Center (HTC) patients or caregivers answered the Second National HTC Patient Satisfaction Survey. The number of people taking the survey was similar to the first survey a few years ago.

Ninety-two percent of the HTCs in the US sent surveys to patients.

What questions were asked? The survey asked how satisfied patients were with care received in 2017 from HTC team members, services, and how care was delivered. It also asked how often insurance and language were problems to getting HTC services. Patients could comment about their care at the end of the survey.

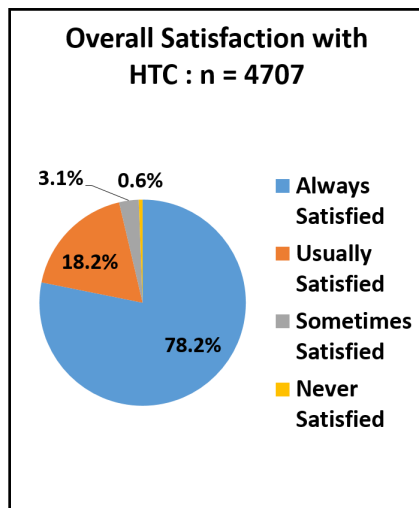
Who answered the survey? The 4767 patients answering were males and females with hemophilia A or B, von Willebrand Disease, and other rare inherited bleeding disorders. People who completed the survey were from all racial and ethnic backgrounds and all ages. Surveys were available in Spanish and English. All surveys were anonymous.

What was new in this survey? In this survey, two questions were added: satisfaction with the HTC 340B factor/pharmacy program, and whether hemophilia patients had an active inhibitor.

Results: Satisfaction is high nationally!

Overall HTC Care: In 2017, 96% reported being “always” or “usually” satisfied with their overall HTC, just like in 2014.

HTC Team: Over 85% reported that they were ‘always’ or ‘usually’



satisfied with the HTC hematologist, nurse or nurse practitioner, social worker, or physical therapist.

HTC Services and Care: Between 93% - 98% were ‘always’ or ‘usually’ satisfied with HTC services and how HTCs provided care. In addition, 96% indicated they were ‘always’ or ‘usually’ satisfied with their HTC 340B factor/pharmacy program.

Teen Transition: Over 92% of 12-17 year olds reported they were ‘always’ or ‘usually satisfied’ with how HTCs talked about how to care for and become independent in managing bleeding disorders as they grew up.

Insurance: Overall, about 13% reported that insurance was ‘always’ or ‘usually’ a problem to getting needed HTC services.

Language problems: Just under 8% reported that language was ‘always’ or ‘usually’ a problem to getting needed HTC services

How can this data be useful? What’s next?

This national data tells us that patients around the country in 2017 were generally very satisfied with HTCs, just like in 2014. That’s important because being satisfied with medical care means patients are more likely to get the care they need to stay healthy. The responses that were not as positive are helpful feedback as well. All results allow centers to focus on what services need to improve at the local, regional, and national levels.

These 2017 results were sent to each HTC and will be compared to the 2014 responses to see changes over time. Highlights of these new national results were presented at the National Hemophilia Foundation Annual Conference and the ATHN Data Summit. More will be shared in 2019.

Articles addressing various trends that we found in the data will be shared at our website over the coming year. The next survey is tentatively scheduled to be sent out in 2021.

Regional HTC leadership thank all patients and caregivers who participated and the HTCs for their collaboration.

For more information go to: www.htcsurvey.com.

RECENT HEADLINES

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

Data on Elocate and Alprolix Show Efficacy and Safety over Four Years

Spark Therapeutics Announces Updated Data for Gene Therapy SPK-8011 for Hemophilia A

Roche Shares Positive Data for Hemlibra at ASH

BioMarin Sponsors "Hemophilia: The Musical" with Teens from Around the Country

Local Carson McCabe Interviewed on 9News After Being Chosen for Musical

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:

Dec 24-25: Clinic, Pharmacy & Admin closed for Christmas Holiday

Jan 1: Clinic, Pharmacy & Admin closed for New Year's Day.

Jan 8: Pediatric Stroke Parent Support Group

Jan 12: Self-Infusion Clinic at the HTC

Jan 21: Clinic, Pharmacy & Admin closed for Martin Luther King Jr. Day

Feb 22-24: RMHBDA Education Weekend & Annual Meeting—Bozeman, MT

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

May 4-5: NHF CO Family Camp—Easter Seals, Rocky Mountain Village, Empire, CO

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

July 14-19: Mile High Summer Camp

See more at our Events Page on our website:

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

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