

The Clotting Connection

A Newsletter for Families with Bleeding and Clotting Disorders

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University of Colorado
Anschutz Medical Campus
Hemophilia and Thrombosis Center

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

HTC STAFF ATTEND ATHN SUMMIT

In the early part of October, several of our staff members were able to attend the American Thrombosis and Hemostasis Network (ATHN) Data Summit that was held in Chicago, Illinois. The gathering is sponsored by ATHN, which is a nonprofit organization committed to advancing and improving care for people with bleeding and thrombotic disorders.

The data conference provides an opportunity for researchers, doctors, HTC personnel, and data analysts to meet and share information. They could attend presentations on ongoing research, review posters outlining results, and meet with their colleagues to exchange ideas and information.

Our director, Dr. Marilyn Manco-Johnson spoke in sessions at the summit about inhibitors and discussed many of the issues surrounding this complication for those with bleeding disorders. She shared updated data about those with hemophilia who have developed an inhibitor, as well as the latest research about the impact inhibitors make on the lives of those with bleeding disorders.

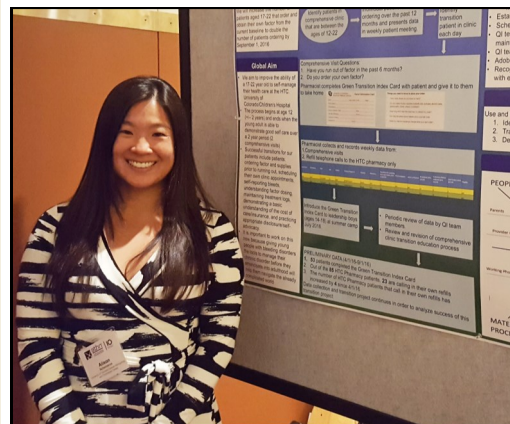
Dr. Tyler Buckner gave a presentation reporting progress on research being conducted as a part of a HTRS/ATHN DREAM Award grant he was awarded a year ago. This study is examining the use of orthopedic surgical interventions for persons with hemophilia. Its main focus is to reduce chronic pain for those with bleeding disorders.



Dr. Marilyn Manco-Johnson speaking at the ATHN Data Summit. [Photo courtesy of ATHN]

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Ali Schomerus of our Pharmacy presented a poster on a program designed to help adolescents gain confidence to manage their care as they grow. [Photo: Ali Schomerus]

Much of the summit focused on ways to improve the quality of life and how quality improvement programs can help patients. During one of the sessions, Dr. Mike Wang was able to address more details on the ongoing issue of quality improvement for patients and how the HTCs can assist in these efforts.

Our HTC was excited to present a poster about the Transitions Quality Improvement (QI) pilot program we have been working on. This Transitions program is designed to help HTC patients as they grow from adolescence to adulthood. The aim is to develop a seamless and comfortable environment for patients to become independent and claim ownership of their hemophilia as they age. The HTC has focused on providing education and discussion during

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Go to facebook.com/ColoradoHTC



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Website: Go to medschool.ucdenver.edu/htc



Email: HTC.Newsletter@ucdenver.edu

OCTOBER IS AMERICAN PHARMACISTS MONTH

We celebrate our HTC Pharmacy during October for American Pharmacists Month, and Pharmacy Week (Oct 16-22, 2016). The HTC Pharmacy is designated as a 340B Pharmacy, which means it receives federal grants to allow the pharmacy to purchase medication at a lower cost. This allows us to serve our patients at lower costs than regular pharmacies. Our Pharmacy is located just across from our clinic and earnestly strives to maintain the supplies needed for our patients.



Our Pharmacy staff, from left: Kara Taylor, Desi Hill, Trish Tucker, Paul Limberis, Ali Schomerus, and Candice Murchison.

communications between patient and pharmacy. We updated our telephone answering service in the past year so now the same number patients call during the work day is automatically forwarded to our after-hours service. This eliminates the need for different numbers when it is not office hours.



Paul and Desi review medication charts.

The HTC Pharmacy works closely with our clinical care team to quickly and efficiently provide access to needed products. Our pharmacists understand our patients' unique situations and are often able to fulfill their needs immediately.

Many times a pharmacy is seen as that last part of a visit to the doctor, the final phase of taking care of a problem. Our pharmacy staff works behind the scenes to make sure that our patients have a positive and uncomplicated experience in getting the supplies and medication they need, whether in person or via mail.

This year we are in the middle of working on a new and improved pharmacy web page to provide more access and tools for our patients, as well as easier



Kara prepares medication for an order.



Candice and Ali in the Pharmacy reviewing insurance issues.

In the coming year our pharmacists hope you connect with them if you have needs for factor, supplies, or have pharmaceutical questions they can assist you with.

Please feel free to contact our pharmacy for your needs, or to let them know they are appreciated. Our center would not be the same without their hard work and our entire HTC is grateful for their dedication to our patients.

Happy Pharmacy month and thanks to all pharmacists for all they do to make our lives better.



Trish prepares an order for shipment.

Pharmacy:
303-724-0168

Photos: Merilee Ashton

comprehensive visits, and over the past 9 months has seen a slight uptick in empowering behaviors for young adults (ages 17-22). This program is ongoing as we work to help transition these young patients into adulthood and gain confidence in managing their own care.



Dr. Tyler Buckner at ATHN reporting on research he has been working on. [Photo courtesy of ATHN]

In addition, our HTC was a part of a Breakfast Breakout presentation at the summit where one of our researchers, Kristi Norton, presented on our center's involvement in a program designed to look into the genotyping of hemophilia patients and families. Our center has reported positive responses, growing involvement, and increased participation by genetic carriers-not just patients. This engagement has led to a deeper connection between our HTC staff and these families, resulting in proactive behaviors and increased awareness of the community benefit of genetic research.

Our nursing staff learned more about a specific certification now available to credential them as Hemostasis Nursing Board Certified. This would give our staff an additional level of expertise in treating our bleeding disorder patients.

The opportunities for our staff to connect with other HTC staff, learn about data being collected and qualifications for studies were of particular interest to those who attended. Our staff was thrilled to learn more about other studies, the way data is being collected, and requirements that qualify patients for specific studies.

The ATHN summit was a great opportunity for all of our HTC staff members who were able to attend. Our hope is to continue to be involved, share and learn from research, and apply the advances in medicine to help our patients.



Dr. Mike Wang discussing quality improvement programs at ATHN. [Photo courtesy of ATHN]

Please join us as we support and celebrate with NHF Colorado in their annual Black and Blue Gala "Boots + Brews" on November 17th, 2016.

Purchase tickets online: bit.ly/nhfcogala2016

the National Hemophilia Foundation
Colorado Chapter presents

BOOTS + BREWS

2016 Annual Black & Blue Gala

Thursday, November 17th, 2016
doors open at 6:30 p.m.
silent auction closes at 8:30 p.m.

Howl at the Moon
Dueling Piano Bar
1735 19th Street
Denver, Colorado 80202

\$550 group of 10 tickets
\$110 per couple
\$65 per individual

COWBOY UP!
dress in your finest western wear

RETURN YOUR PACKING SLIPS

Our Pharmacy is required to have records on file about the medications and supplies they send out. 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 packing slips must be signed, dated and mailed to us. There is a self-addressed and stamped envelope provided to make returning the delivery receipt easy and painless.

Returning this packing slip is a requirement for us to comply with regulations. We appreciate your help! October is American Pharmacists Month-show your appreciation by just popping that packing slip in the mail!

Unfortunately, failure to return the signed packing list verifying that you received the medications 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! Please contact us if you have questions. Our main pharmacy line is 303-724-0168 or toll free at 888-724-7427 and our email is: hemophilia@ucdenver.edu.

RECENT HEADLINES

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

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 head 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/

BloodStreamPod Interviews Jeanne White-Ginder, Mother of Ryan White

FDA Warns of Risk of Hepatitis B Reactivating in Some Patients Treated for Hepatitis C

Virtual Reality Games Make Infusions Easier on Young Patients

NHF and 31 Apparel Team up to Fight Bleeding Disorders

National Youth Leadership Institute Applications Due Oct 31st

UPCOMING EVENTS

Oct 21-23: NHF CO Parents Empowering Parents (PEP) program

Oct 25: NHF CO Food and Factor Program

Oct 29: World Stroke Day

Nov 4-6: RMHBDA Women's Retreat— Chico Hot Springs, MT

Nov 17: NHF CO 2016 Annual Black and Blue Gala: "Boots + Brews" at Howl at the Moon Dueling Piano Bar

Nov 24-25: Clinic and Admin closed for Thanksgiving Holiday

Dec 2-4: RMHBDA Men's Retreat— Pray, MT

Dec 23 & 26: Clinic and Admin closed for Christmas Holiday

See more at our **Events Page** on our website: www.medschool.ucdenver.edu/htc find **RESOURCES** tab, go to **EVENTS**

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or toll free at 888-724-7427

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

PLEASE
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