

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 Doctors & Staff Attend ASH



Natalie Smith with Dr. Brian Branchford and Dr. Marilyn Manco-Johnson attending ASH presenting research.

Early this month, several of our HTC doctors and staff were able to attend the 57th Annual American Society of Hematology (ASH) Meeting held in Orlando, Florida. This event allows professionals, doctors, researchers, and vendors educational experience and opportunities to review thousands of scientific abstracts covering a vast array of topics in hematology. Over 20,000

hematology professionals from every subspecialty attend and have a chance to connect and work with one another over the four day conference.

Our HTC's Dr. Tyler Buckner moderated one of the hemophilia clinical research oral presentation sessions with Anne Neff of the Cleveland Clinic. The presentations reported important new knowledge about the risk of cardiovascular disease in men with hemophilia, the genetics of von Willebrand disease and the possible relationship between joint disease/arthritis and high blood pressure in men with hemophilia. He also attended several presentations about new treatments for bleeding disorders, as well as recent studies investigating the new direct oral anticoagulants and how they are being used to treat blood clots. He reported there was a lot of excitement at the conference about the many new developments and potential that we will soon see as more treatment options for our patients.



Dr. Tyler Buckner

Dr. Brian Branchford reported that he attended the presentation on the randomized SIPPET study, which compared incidence of inhibitory alloantibodies in previously untreated patients with severe hemophilia A between plasma and recombinant sources of FVIII. He was involved in several meetings with national efforts to develop the first multi-center Children's Hospital-Acquired Thrombosis (CHAT) database, from which they hope to extract risk factor elements to improve our ability to predict, and prevent pediatric hospital-acquired clots. Their national group exhibited a poster summarizing their experience thus far, as did our local Children's Hospital Colorado Venous Thromboembolism Prevention Group, both of which were assisted or led by Natalie Smith, also from our HTC.

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



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Website- Go to medschool.ucdenver.edu/htc



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HTC SPOTLIGHT: SHARON FUNK, PT, DPT



Sharon Funk, Physical Therapist

The Physical Therapy School at the University of Colorado recently highlighted our own Sharon Funk on their website and newsletter. Sharon has worked for the CU Medical school system for the past 38 years and spent most of that time working with hemophilia patients, starting work with the HTC when it was created in 1978. She actually saw her first patients with hemophilia in 1977 before

the federally funded treatment centers were created! She earned her Bachelor of Physical Therapy degree at CU Boulder and received her Doctor of Physical Therapy degree from CU, Anschutz Medical Campus.

Sharon is the physical therapy coordinator at our center and has been an integral part of the team of caregivers working to help our patients manage their disorder. Those with bleeding disorders often face damage to their joints, and having physical therapists monitoring their care is vital in reducing damage and maintaining strength and joint function.

Sharon has been an international leader in the development and testing of the Hemophilia Joint Health Score (HJHS), a standardized impairment outcome measure for evaluating joint disease in hemophilia. Early versions of the HJHS were used to evaluate and measure the joints of very young boys in what has become known as Dr. Manco-Johnson's Joint Outcome Study, which found that treating very young children with preventive clotting factor decreased their frequency of joint bleeding and subsequent joint damage.

Aside from her accomplishments as a physical therapist, Sharon has raised three children here in Colorado, all three of whom attended hemophilia camp at one time or another. She is a third generation Colorado native and figure skating has been a passion of hers since she was a child. *"I really enjoyed skating on an adult women's synchronized skating team and I have done some ice dancing. While I was on the team we won the national title twice-in the Masters, or what I call the 'Old Lady', division!"* Sharon has now retired from skating, but continues to enjoy skiing and hiking. She also loves going to plays and working in the garden. She enjoys travel, exploring new countries and cultures, and has traveled extensively with her work.

She has traveled throughout the world to such diverse places as rural Mexico or Istanbul, Turkey treating patients and participating in international hemophilia meetings and seminars. Most recently, she visited Eldoret, Kenya in April, working with the Indiana Treatment Center's Twinning Program. In Africa she reported, *"It was a reminder again of how severe hemophilic joint disease can be when not treated appropriately."* There she also saw severe pseudotumors that developed due to insufficient treatment. Pseudotumors are uncommon in countries with good hemophilia care. She enjoyed working with patients in Kenya, and was able to take in a weekend safari at Nakuru National Park during her stay there.

Sharon loves working with her patients and it shows. *"I am grateful for the hemophilia community being such an important part of my life!!"* We at the HTC feel blessed to have the chance to work with Sharon and are grateful she is there to help our patients.

See the link for the PT Dept. article by viewing the digital version of this newsletter at www.medschool.ucdenver.edu/htc and find the RESOURCES tab & NEWSLETTER page.

OUTREACH CLINICS

Every year the HTC provides the opportunity for patients who live in the farther corners of our region to meet with the same doctors and specialists available in our Denver clinic at locations much closer to them. These clinics allow patients to schedule their annual comprehensive visit with our doctors, spend time managing care with our nurses, see physical therapists, social workers, and update their pharmacy needs.

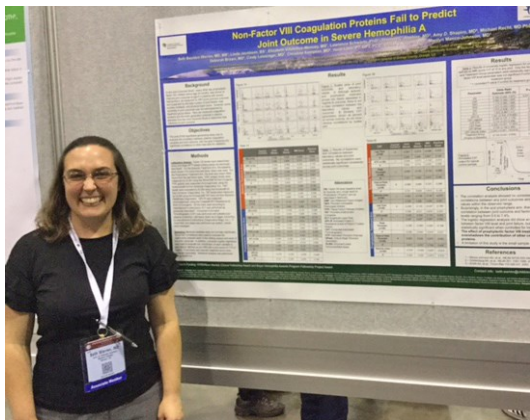
Upcoming Clinics:

We will have a follow up clinic on **February 22, 2016** in **Billings, MT** with limited staff.

The next full staff clinic visit to **Billings, MT** is already scheduled and will be held **June 6-8, 2016**.

Details about our Outreach Clinics can be found at our website at www.medschool.ucdenver.edu/htc and clicking on the **CLINIC** tab at the top of the page. Then go to the **OUTREACH CLINICS** tab.

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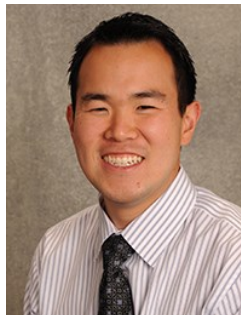
Dr. Beth Warren presenting at ASH.

Dr. Beth Warren presented her work analyzing variation in coagulation factors other than factor VIII and IX to see if they contribute to variation in joint outcomes in patients with hemophilia. She is looking at data collected as part of the Joint Outcome Study, the landmark study led by Dr. Marilyn Manco-Johnson that showed that prophylactic treatment with every other day factor VIII led to better joint outcomes (as measured by number of bleeds, physical exam, and MRI) than on-demand factor VIII treatment in patients with severe hemophilia A. Although none of the coagulation factors evaluated so far

have shown an effect on joint outcome, other conference participants were glad to hear about the study so that they could use their time wisely and not duplicate efforts.

She and our other staff also enjoyed going to many varied research and educational sessions. Highlights included the challenges in developing noninvasive genetic testing for prenatal diagnosis of hemophilia, the importance of fibrinogen and factor XIII on placental implantation in the uterus, caring for newborns with hemophilia from the obstetrician's perspective, the report on the SIPPET study, new developments in monitoring and reversing direct oral anticoagulants, and how to better incorporate and describe patient experiences and side effects in clinical trials.

Dr. Chris Ng was able to attend and presented his research on using hemostatic assay to understand different bleeding patterns with von Willebrand disease.



Dr. Chris Ng

Overall there were many investigators at the conference thinking about bleeding disorders in new and different ways to try to develop more effective and convenient treatments. There was a lot of effort from grant funding agencies to help new scientific discoveries at Universities make a smoother transition to reaching patients. The conference highlighted the large amount of research, the rapidly improving treatment options and new treatment options that have potential to assist patients in the future.



When the holidays arrive things are busy for everyone! Don't get caught in the rush of things and realize too late that our offices, clinic and pharmacy are closed when you need assistance.

Our office and clinic close during the official holidays at the Anschutz Medical Campus, as well as any additional days, like snow days, that may affect the campus. Know what to do if you need to contact us in an emergency, after hours, or on a holiday.

Prepare by ordering any medications or supplies you need in time for all those shipping deadlines. You can find all our holiday info, the shipping deadlines and after hours contact information at our website.

Some upcoming closures:

Dec 24-25, 2015

Christmas Eve/Christmas Day

Dec 31-Jan 1, 2016

New Years Eve/New Years Day

Jan 18:

Martin Luther King, Jr. Day

Feb 15: Presidents Day

May 30: Memorial Day

REMEMBER: RETURN THOSE PACKING SLIPS

When you receive factor or other medications from our HTC Pharmacy, please be sure to pay attention to the paperwork included in the packaging. There will be two copies of a packing list included. **One copy is to keep for your records and a second copy is stamped in red ink for you to sign, date, and return.** A self-addressed and stamped envelope is provided to make returning the delivery receipt easy and painless.

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.

If you have questions about our pharmacy or healthcare regulations, please give us a call or send us an email. Our main pharmacy line is 303-724-0168 or toll free at 888-724-7427 and our email is: hemophilia@ucdenver.edu.

Complying with healthcare regulations is a partnership between you and your pharmacy. Thanks for doing your part to help us be in compliance!

RECENT HEADLINES

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

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** tab.

FDA Approves Vonvendi as 1st Recombinant von Willebrand Factor Treatment

New Positive Data on Eloctate & Alprolix

Positive Data for Alnylam's Once-Monthly Fitusiran (ALN-AT3) for Hemophilia A & B

Data Presented by Sangamo BioSciences on SB-FIX, Gene Therapy for Hemophilia B

Baxalta Updates on Most Recent Trial of Adynovate

CSL Behring Presents Data on Phase III Trial for rIX-FP for Hemophilia B

UPCOMING EVENTS

Dec 24-25: Clinic & Admin offices closed for Christmas

Dec 31-Jan 1: Clinic & Admin offices closed for New Year Holiday

Jan 18: Clinic & Admin offices closed for MLK, Jr. Day

Dates to Note in 2016:

Feb 19-21: RMHBDA Education Weekend

Feb 22: Follow-up Outreach Clinic Billings, MT

Ap 8-10: NHF Colorado Education Dayz

Jul 8-10: Mile High Camp Leadership Pre-Retreat

Jul 10-15: Mile High Summer Camp -Rocky Mountain Village

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

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

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