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 hematologist 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. 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.

(Continued page 3)
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.
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!
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 Thearapy 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

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