

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

SHARON FUNK RETIRES



Dr. Marilyn Manco-Johnson presents Sharon Funk with a gift to thank her for her years of service at the HTC.

Sharon Funk, who has worked as a physical therapist for 41 years for the University of Colorado—40 years with our HTC—retired on October 5, 2018. A few weeks later, friends, family, patients, and co-workers all joined to celebrate her years of dedicated service and the wonderful impact she has made on so many lives.

Sharon began at CU Medicine on July 7, 1977 and joined our staff when the HTC opened in 1978. She has watched many of our patients grow up and wept with families when patients have died. She has seen patients through injuries and surgeries, supported families when patients have struggled, helped encourage physical fitness and helped patients overcome sports injuries. Sharon witnessed firsthand the terrible toll of HIV and Hepatitis C on the bleeding disorder community. She has led research studies to improve the health

and care of patients with bleeding disorders, mentored many in various fields of healthcare, and has shown kindness and generosity to all.

During her time as the physical therapist at the HTC, Sharon earned a doctorate in physical therapy. She worked for many years on the development and testing of the Hemophilia Joint Health Score (HJHS) a standard to measure impairment to evaluate joint disease. This tool allows medical professionals to measure joint scores to compare care and joint damage universally. The standard



NHF CO Director, Amy Board, hugs Sharon after speaking about her great impact on so many.



Sharon Funk reacts as Researcher Kristi Norton shares thoughts about her impact upon both staff and patients.

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Sharon visits with patients she has treated over the years.

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Website: Go to medschool.ucdenver.edu/htc



Email: HTC.Newsletter@ucdenver.edu

NHF CO PLANS SCREENING OF BOMBARDIER BLOOD



BOMBARDIER BLOOD

JOIN US FOR THE COLORADO PREMIERE SCREENING

SATURDAY DECEMBER 1ST

DOORS OPEN: 2PM
FILM STARTS: 2:30PM

UA COLORADO CENTER
STADIUM 9 AND IMAX
2000 SOUTH COLORADO BLVD
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COLORADO CHAPTER
NATIONAL HEMOPHILIA FOUNDATION
cohem.org

NHF Colorado will host the Colorado Premiere of “Bombardier Blood” on December 1, 2018. This documentary follows the progress of local Chris Bombardier as he climbed the tallest mountain in the world, Mount Everest. Everest was one of the one of the “seven summits”, the highest peaks on each continent, which he was working toward climbing over several years.

Chris grew up in Colorado and has been treated by our HTC staff for many years. His goal of climbing these summits was both lofty and inspiring. He joined with Believe Limited to film his historic journey to Nepal to climb Mount Everest and on the way provided support for Save One Life, a charitable organization that provides much needed assistance to families living with bleeding disorders in developing countries.

NHF Colorado is providing tickets to this screening free of charge, but seats are limited. Any who would like to attend must register in advance. To register and for more information please go to cohem.org or directly to the registration site at <http://bit.ly/BombBlood> (case sensitive). We hope to see you there!

OCTOBER IS AMERICAN PHARMACISTS MONTH

In October we celebrate our HTC Pharmacy during American Pharmacists Month. Our HTC pharmacy is not for profit and is designated as a 340B pharmacy. This means they are able to purchase medications for our qualifying patients at lower costs. This allows us to pass those savings on to patients and provide more services.

During this past year, our Pharmacy has worked hard to make improvements and changes that can help patients and continued to provide incredible service. A few new changes this past year include:

- The pharmacy purchased a ventilated compounding cabinet for use by staff for compounding non-sterile preparations for treating nosebleeds.
- Following their first accreditation with URAC last year, the pharmacy is now working on a second specialty pharmacy accreditation with ACHC.
- Patients may have noticed that the pharmacy shipping containers and processes are now much more robust in order to stay in compliance with specialty pharmacy standards.



Pharmacy staff (left to right) Kara Taylor, Trish Tucker, Desi Hill, Janine Johnson, Paul Limberis, Ali Schomerus and Anup Shrestha.

As we move toward 2019, our pharmacy staff continue to strive for the highest quality standards and efficiency. Contact our pharmacy if you have medication needs or questions about your medications. Our pharmacy is open Monday through Friday 8 am to 4:30 pm, and can also be reached after hours and on holidays through our main number at 303-724-0168. Please be aware of upcoming holiday closures and plan ahead for your pharmacy needs when long weekends or closures occur. Updated holiday hours and closures are available on our website at www.medschool.ucdenver.edu/htc under the PHARMACY tab.

[continued from page 1] she helped create made it possible to study the joints of children over time. The use of the HJHS has supported research that changed the way hemophilia is treated worldwide. Sharon was an integral part of the research that found treating young children with clotting factor preventatively, known as prophylaxis, decreased their joint damage and frequency of bleeds.



Sharon visits with Dr. Brian Branchford and retired HTC nurse Sue Geraghty.

Her pioneering work led to her appointment as a co-chair of the ISPG Expert Working Group on Joint Health. Many pharmaceutical companies have asked for her expertise on the design and analysis of the physical components of FDA licensure trials for new medications.

Sharon's research work has affected not just her patients here in Colorado, but improved the care and lives of patients worldwide.



Nurse Nancy Spomer spoke on the impact of Sharon's care at the HTC.

Sharon was one of the first in our center to recognize a real need to encourage those with bleeding disorders to live active and full lives. She led and supported early programs that brought youth out to camp, hike, ski, go rafting, and other outdoor activities they may have previously thought were off limits to them. Sharon has a special place in her heart for camp and was "all in" from the very beginning of the HTC camp program along with Dr. Hathaway. She

worked with patients that have achieved dreams that many would have said were impossible.



Dr. Marilyn Manco-Johnson shares her thoughts after working with Sharon for nearly four decades.



Sharon looks on as a patient shows her his gait one last time.

Grateful patients and their family members shared stories at her retirement party of how Sharon worked with them to overcome significant physical hurdles. They talked about her dedication to get the job done right no matter how long it took.

We will miss Sharon's expertise and energy, not to mention the hours of personal attention she gave to all she came in contact with. We congratulate her, wish her the best in retirement, and are grateful she will still be connected with our HTC through research opportunities.

Photos by Jason Thomas

NEW SOCIAL WORKERS & PSYCHOLOGIST AT THE HTC

Our social work team is undergoing many changes and we are happy to announce that we will soon have two new social workers on our staff at the HTC, as well as a full time psychologist.

Whitney Gilmore Tedeschi will join us at the beginning of November as a new social worker. She has been working at Children's Hospital Colorado and has previous experience working at an HTC in Philadelphia. Mid-November, we will also welcome Bryn Dunham as a new social worker. She joins us from University Hospital. She has been working in their Hem/Onc program there and has many years of experience in hematology, hemophilia and oncology. Our staff is thrilled to have them both join us to provide much-needed support to our patients.

We also have recently brought in a new HTC psychologist as well. Emily Wheat started with us in September and will be a permanent fixture here at the HTC to provide psychological support for patients. She will be on maternity leave for a few months but will be returning early in the new year.

We hope you will get to know these new additions to our staff and benefit from their experience for many years to come.

RECENT HEADLINES

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

Mimicry Not Replacement: Molecular Engineering Transforms the Outlook in Hemophilia A

AAV Gene Therapy Successfully Given Again to Dogs in Model of Hemophilia A

NHF 70th Annual Bleeding Disorders Conference Held in Orlando, Florida

FDA Approves Hemlibra for Hemophilia A Patients Without Inhibitors

NHF Colorado Organizes Screening of Chris Bombardier Documentary "Bombardier Blood"

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:

Oct 31-Nov 2: Outreach Clinic-Billings, MT

Nov 2-4: Women's Retreat - Chico Hot Springs, MT

Nov 4: NHF CO Denver Social Factor, Spanish Program—Northglenn, CO

Nov 9: 2018 National Conference, Being Visible: Women with Hemophilia—Grand Rapids, Michigan

Nov 16: National Outreach Von Willebrand Conference—Phoenix, AZ

Nov 22-23: Clinic, Pharmacy & Admin closed for Thanksgiving Holiday

Dec 1: Colorado Premiere Screening of *Bombardier Blood*—Registration Required

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

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

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

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