

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

Pediatric Stroke Awareness Month

Our Stroke Clinic at the Hemophilia & Thrombosis Center is dedicated to serving pediatric and young adult stroke patients. May is Stroke Awareness Month and it is fitting to spread the word about what we do here at the HTC to increase awareness of pediatric stroke.

Our center supports pediatric stroke families with our Pediatric Stroke Parent Support Group, encourages awareness through activities such as Strike out Stroke with the Colorado Rockies, and shares opportunities for our patients to learn and grow through camps, education, and interaction. More importantly, we strive to understand why strokes happen in children and how it affects their lives through ongoing research at our center. Dr. Timothy Bernard, Dr. Armstrong-Wells and their colleagues on the pediatric stroke team, have several research studies to try to answer these questions at the HTC's stroke clinic.

Dr. Bernard along with Dr. Traystman (Vice-Chancellor of Research), Dr. Herson and Dr. Macklin, recently received a \$2.5 million grant from the AHA/Bugher Stroke Collaborative Research Center. This grant is to study the role of patient age at the time of stroke onset, and stroke location on neuropsychological and quality of life outcomes in children recovering from arterial ischemic stroke (AIS). In addition, Dr. Bernard's NIH funded grant seeks to understand the mechanism underlying childhood stroke.

Dr. Jennifer Armstrong-Wells has several studies looking at prevention of brain injury before birth. Specifically, Dr. Armstrong-Wells is studying the pregnant mother and the underlying risks and causes of perinatal stroke. Through the efforts of Dr. Bernard and Dr. Armstrong-Wells, we hope to gain a better understanding of pediatric stroke and its long-term effects. With an increased understanding of pediatric stroke, this research may help improve diagnosis and treatment of pediatric stroke for patients in the future.

You can find out more about how we help support pediatric stroke patients at our Pediatric Stroke Parent Support Group website at pedsstrokesupport.ucdenver.edu and regular updates through both Facebook and Twitter.

SCHOLARSHIP INFORMATION

Several scholarships are available to students with bleeding or clotting disorders, and their family members. Application dates vary, but several are coming up and some have passed already.

For a list of scholarships with links, please see our website and look under the RESOURCES tab for the Children & Teens section.



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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



HTC Website- Go to medschool.ucdenver.edu/htc



Email:

HTC.Newsletter@ucdenver.edu

THE CLOTTING CONNECTION IS GOING DIGITAL



This is our first online based newsletter. We'll be sending digital newsletters approximately once a month. Occasionally we will publish more in depth/topical publications and provide links for you to access those.

To subscribe to the online version, please sign up by going to our website at medschool.ucdenver.edu/htc and find our **Newsletter page** under the **Resources tab**. If you have trouble viewing the digital version in your email program, you can always access the newsletters online at our site. If at any time you wish to unsubscribe, there is a link at the bottom of the email.

We will have paper copies available in our clinic and a link to the digital version at our website. For those with specialized needs who would like to request a paper copy please contact us directly via email at: HTC.Newsletter@ucdenver.edu or by phone at 303-724-2309. Thank you for your patience as we navigate new software. If you have questions, corrections or feedback, please contact us at our email above.

HTC PHARMACY MARKS 20 YEARS

This month marks the 20-year anniversary of the HTC Pharmacy. The pharmacy opened in May 1995 with 500 square feet of space in an office building overlooking a local Hooters! The now retired Dean of the School of Medicine, Dr. Richard Krugman, who was a devoted supporter of the Hemophilia Center program, loaned the HTC \$300,000 to start the pharmacy. We were able to repay that loan in four years. There was only one employee back then-- Judy Primeaux who is our current Pharmacy and Finance & Administration Director. We've come a long way since then, and are grateful for our new facility on the Anschutz Medical Campus in Aurora.



Initially filling factor orders for only 5 patients in that first month, we now serve the hemophilia community in the entire Rocky Mountain region. So many of you have placed your confidence in us to provide your factor and be a part of your healthcare team. Thank you for your trust! Your choice to use the HTC Pharmacy to provide your factor needs has contributed to financially maintaining the existence of the HTC for all patients. Over the last 20 years, the pharmacy has provided over \$22 million in funding to the HTC. A special anniversary edition of the newsletter is planned for late summer to highlight in more detail the pharmacy program. Stay tuned!

RESEARCH AT OUTREACH CLINICS



The Clinical Research Department at the University of Colorado HTC is committed to presenting the same research opportunities to our Montana and Grand Junction Patients as those who reside in Denver. Our center partners with organizations such as the Centers for Disease Control to conduct important data collection initiatives. We also work with pharmaceutical

companies to provide new and upcoming factor products to our patients.

A member of the Clinical Research team will be present at all our upcoming Outreach Clinics to keep you informed of research opportunities. If you have any questions about Clinical Research opportunities through the HTC, please feel free to ask to speak to the Clinical Research Coordinator at your Outreach Clinic!

Upcoming Outreach Clinics-
June 1-3 Billings, MT
July 27-29 Missoula, MT



STRIKE OUT STROKE

May is Stroke Awareness Month and we are excited to help bring awareness by participating in **Strike Out Stroke with the Colorado Rockies**.

The Rockies hosts stroke survivors and families, including those with pediatric stroke, and encourages spreading the word that acting FAST is critical in diagnosing and treating stroke.

The Strike Out Stroke game is scheduled May 23rd at 2:10 pm against the San Francisco Giants. Discount Rockies tickets with a portion going to Strike Out Stroke are available at the Rockies' website.

HOLIDAY CLOSURES

Any time our offices and clinic are closed for a holiday we can be contacted via our after hours service. Find our after hours details on our website at the **Contact Us** page.

All of the upcoming holidays are available on our website by going to:
www.medschool.ucdenver.edu/htc and clicking on the main **Clinic** tab (on the top bar of the main page).

*We will be closed
on Monday,
May 25th, 2015
Memorial Day*

Please prepare for any medical concerns or medications you may need over the holiday weekend.

*See our website contact page for emergency contact information.
www.medschool.ucdenver.edu/htc*

Have a safe and happy weekend!

RECENT HEADLINES

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

We maintain a Newsroom page with a list of the news we feel may be of interest to our patients and families. To see more head to: medschool.ucdenver.edu/htc then find the **RESOURCES** tab, and go to the **NEWSROOM** tab.

FDA Approves IXINITY to treat Hemophilia B

Merck's Grazoprevir/Elbasivir Combo Cures 99% of Hep C Patients w/Kidney Disease

Baxter Submits Positive Phase 3 Data for BAX 111 to treat von Willebrand Disease

RNAi Therapy Targets Antithrombin to Promote Clotting for Hemophilia A & B

UPCOMING EVENTS

May is Stroke Awareness Month

May 2-8: Pediatric Stroke Awareness Week

May 23: Strike Out Stroke w/the Colorado Rockies

May 25: HTC Closed for Memorial Day

May 29-31: NHF Colorado Family Camp

June 1: Registration forms due for Mile High Summer Camp

June 1-3: Outreach Clinic in Billings, MT

June 6: AHA Heart & Stroke Walk

June 17-22: Neurological Conditions Camp at Roundup River Ranch

June 19-21: RMHBDA Family Camp

July 3: HTC Closed for Independence Day

July 10-12: Mile High Summer Camp Leadership Pre-Camp Retreat

July 12-17: Mile High Summer Camp

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

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