

The Clotting Connection

A Newsletter for Families with Bleeding and Clotting Disorders



University of Colorado
Anschutz Medical Campus
Hemophilia and Thrombosis Center

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

MAY IS PEDIATRIC STROKE AWARENESS MONTH

May is Pediatric Stroke Awareness Month, when we hope to help bring awareness and spread the word about the signs and symptoms of stroke in children. Our HTC treats bleeding disorders such as hemophilia, von Willebrand disease, and clotting disorders including thrombophilia. We also have specialists dedicated to the treatment of pediatric stroke.

While most strokes occur in adults over 50, strokes can happen to children, including before they are even born. There are a variety of factors that cause pediatric stroke, some of which are not yet realized, and here at our HTC research is ongoing to find ways to prevent and treat stroke. Our stroke clinic specializes in treating children who have experienced stroke, and our neurologists, Dr. Armstrong and Dr. Bernard, work with pediatric patients and help them on their road to recovery.

Our stroke clinic has a number of new and upcoming studies that are available beginning this summer. If you, a family member, or someone you know is interested in being involved in studies about pediatric stroke, you can contact our Research Team at 303-724-0306 or CRCalendar@ucdenver.edu.



Remember FAST if you suspect stroke. Facial drooping on one side, one arm is weaker when lifting arms, garbled or slurred speech. Then it's time to call 911. Fast treatment is critical.



Our staff wore purple on May 5th to support Pediatric Stroke Awareness. [photo: Merilee Ashton]

The symptoms of a stroke in an adult can be similar to a stroke in a child. Some symptoms in children are missed because many people are simply unaware that a stroke can happen to a child. For all ages it is important to remember F.A.S.T. (**F**ace drooping, **A**rm weakness, **S**peech difficulty, and when these are present it is **T**ime to call 911). Prompt diagnosis and treatment of stroke, no matter what the age, is critical to all who experience a stroke.

[Continued on page 3]

May 2017
Volume 7, Issue 5



Register for Mile High Camp by June 1st! Story inside-or go to cohemmo.org.

INSIDE THIS ISSUE

- Pediatric Stroke Awareness Month
- Register for camp!
- Outreach Clinics 2017
- Upcoming Opportunities including Easy Brews Beer Festival, Family Camp & more!
- News
- Events

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



Website: Go to medschool.ucdenver.edu/htc



Email:

HTC.Newsletter@ucdenver.edu

REGISTER FOR CAMP



Summer is right around the corner and that means signing up for Mile High Summer Camp! The Colorado Chapter of the National Hemophilia Foundation and our HTC work together every year to support Mile High Camp, a powerful experience for children and teens with bleeding disorders.

At Mile High Camp, kids ages 7-18 learn everything from zip lining and fishing to self-infusion and joint care. Many from our staff, including doctors, nurses, physical therapists, pharmacists, and social workers all are on hand to lend their expertise and teach campers. The NHF Colorado leadership plans and leads fun activities to give kids with bleeding disorders the opportunity to make friends and try out new activities in a safe environment.

Our HTC has sponsored Mile High Camp for nearly 40 years, helping to bring the opportunity for kids to experience independence and empower them to take steps in their own self-care. Mile High Camp is held at Rocky Mountain Village in Empire, Colorado and this year will



be held on July 16-21, 2017. The Camp Leadership Pre-Retreat for high school aged teens begins on July 14th.

Register online now. Deadline for camp forms is June 1, 2017. No exceptions! Questions about camp? Go to cohemo.org, or contact Sean Jeffrey at sjeffrey@hemophilia.org.



Pictures from Camp in 2016. [photos: Merilee Ashton and Bethany McCabe]

OUTREACH CLINICS 2017

Outreach clinics allow patients to schedule their annual comprehensive visits at a location closer to their home. The clinics in Montana and Grand Junction are usually a few days once a year, while our Colorado Springs clinic is held quarterly.

Our staff reach out to local patients, but if these clinics are more convenient to your location and you would like to know more, please contact Pat Casias at 303-724-1325 or Audra LeBlanc at 303-724-6163, or speak with our front desk schedulers at 888-297-0724 or 303-724-0724.

Details, forms and maps to these locations are available on our website at: www.medschool.ucdenver.edu/htc Click on the CLINIC tab and find the OUTREACH CLINICS page.

Confirmed upcoming clinics:

June 19-21, 2017: Billings, Montana

June 26-27, 2017: Missoula, Montana

Sept 27-29, 2017: Grand Junction, Colorado

[Continued from page 1]



The National Stroke Association produced a video about Young Stroke: An Unexpected Reality. It can be found at YouTube: <https://youtu.be/POlmGdHDoUs>

Additional symptoms a baby may exhibit are seizures, repetitive twitching of the face, arm or leg, or extreme sleepiness. A slightly older child may show marked decreased movement on one side of the body or showing a preference for one hand before the age of 1. Most children will not favor one hand or another until after they turn a year old.

While the causes of most perinatal and childhood strokes are unknown, risk factors can include congenital heart disease, blood clotting disorders, infections (e.g. Meningitis), head trauma and some genetic diseases and

Children may exhibit some of these symptoms, but it may be hard to notice if an arm is drooping in an infant, or if speech is impaired when they don't yet speak.

disorders. No previous risk factor is identified in about half of childhood stroke cases.

Our stroke program works to support families and patients who have experienced stroke year round. The Pediatric Stroke Parent Support Group meets regularly to provide parents a connection with other families, education and support. While pediatric stroke is rare, it is important to help others become aware that kids can have strokes. You can support our efforts by sharing posts from us or others that highlight pediatric stroke, and participate in events like the Comeback Trail 5K on May 21st, the annual American Heart Association Heart & Stroke Walk on June 10th, or at Strike Out Stroke with the Colorado Rockies later this summer.

Opportunities for camps, adaptive yoga and other activities are regularly made available through our support group. At our website we post updates and a newsletter with stroke specific details. Pediatric stroke patients or their families do not have to be patients at our clinic in order to be involved in our support group.

You can find out more by going to our website at www.pedsstrokesupport.ucdenver.edu, following our HTC Facebook or Twitter pages, or follow the Colorado Pediatric Stroke Facebook Page.



UPCOMING OPPORTUNITIES

Tickets are now available for the first annual **Easy Brews Beer Festival**. It will be held on Sunday, June 4, 2017 from 2 pm-6pm (VIP entry at 1 pm) at the Arapahoe County Fairgrounds. All proceeds from this event will benefit the National Hemophilia Foundation. **Learn more and RSVP at the cohemo.org EVENTS page.**

NHF CO Family Camp and the **RMHBDA Family Camp** will both be June 16-18, 2017. This is an opportunity for families affected by bleeding disorders to have their own special camp to bond with other families going through similar circumstances. It is sponsored by NHF Colorado and the Rocky Mountain Hemophilia & Bleeding Disorders Association in Montana, and is for all ages, parents included! **Registration is now open at cohemo.org and at rmhbda.org.**

Updates from **Adventures of a Hemophiliac: Chris Bombardier** as he attempts to climb Mount Everest are available at his Facebook page @AdventuresOfAHemophiliac, with more information at www.saveonelife.net, the hemophilia support organization he is bringing to light. He has been providing updates and photos as he attempts this climb. Information on his climb and his progress is also up at bombardierblood.com. We wish him the best!

Our next **Self-Infusion Clinic** at the HTC will be on Wednesday, August 9, 2017 from 5 pm to 7 pm in our clinic. This is a program for our patients and families who would like additional help with self-infusion to come and spend time with our nursing staff and practice self infusion in a one-on-one setting. You can bring your own factor to be infused, or practice with saline. We will have Spanish interpretation available at this clinic. Food and beverage provided; the event is free but you must RSVP. **Go to cohemo.org and click on the EVENTS page.**



RECENT HEADLINES

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

Prophylaxis Usage Analysis Authored by Dr. Marilyn Manco-Johnson Published in *Blood*

Children's Hospital Colorado Highlights Dr. Jorge DiPaola

Man from Colorado with Hemophilia is Making His Way Up Everest

Thousands Reach out after Perth Woman's Bleeding Disorder Story

Making Strides Toward Preventing Inhibitors in Bleeding Disorders

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:

May 21: Comeback Trail 5K for Stroke, Hudson Gardens, Denver

May 29: Clinic and Admin offices closed for Memorial Day

June 4: NHF CO Easy Brews Beer Festival

June 16-18: NHF CO Family Camp

June 16-18: RMHBDA Family Camp

June 19-21: Outreach Clinic-Billings, MT

June 26-27: Outreach Clinic-Missoula, MT

July 4: Clinic and Admin offices closed for Independence Day

July 14-15: Mile High Summer Camp-Leadership Retreat

July 16-21: Mile High Summer Camp

Aug 9: Self-Infusion Clinic at the HTC clinic

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

Hemophilia & Thrombosis Center

13199 E. Montview Blvd., Suite 100
Aurora, CO 80045

Clinic Main: 303-724-0724
or toll free at 888-297-0724
Pharmacy Main: 303-724-0168
or toll free at 888-724-7427

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

PLEASE
PLACE
STAMP
HERE