

# The Clotting Connection

A Newsletter for Families with Bleeding and Clotting Disorders

May 2022  
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Hemophilia and Thrombosis Center  
UNIVERSITY OF COLORADO ANSCHUTZ MEDICAL CAMPUS



Affiliated with  
Children's Hospital Colorado

## MAY IS PEDIATRIC STROKE AWARENESS MONTH

Did you know that a stroke can happen at any age? Infants, children, teens, even babies who are still in the womb can have a stroke. May is Pediatric Stroke Awareness Month, and our HTC has a stroke clinic that treats children who have survived a stroke.

Pediatric stroke is in the top ten causes of death in children, so it is important to know the signs of stroke. Adult stroke symptoms are summarized by remembering: **F.A.S.T.** Does their **F**ace droop on one side? Is one **A**rm weaker than the other or are they unable to raise them up evenly? Is **S**peech slurred or garbled? These symptoms indicate an emergency, and it is **T**ime to call 9-1-1 and get help for a stroke.

### SPOT A STROKE

# F.A.S.T.

Face Drooping	Arm Weakness	Speech Difficulty	Time to Call 911
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If your child has one or more of these signs, don't delay — call 911 or the emergency system.

If it looks or feels like a stroke, it may be one.

Graphic: American Stroke Association [stroke.org](http://stroke.org)

Getting treatment right away is critical, no matter what age, so the sooner a patient is treated, the better the outcomes can be. But what do you look for in a child or a baby? Children and teens show many of the same symptoms as adults, but younger kids have less noticeable symptoms. Do you know what to look for?

Symptoms in younger children can include seizures, twitching of the face, leg, or arm, and problems with sleep apnea. Babies who have experienced a stroke often show a marked decrease in movement in one side of the body or show a strong preference for one

hand before the age of one. Babies under age one usually use both hands about evenly and a distinct preference for one side could indicate stroke.

Older kids may have other warning signs, such as a sudden, severe headache, especially with vomiting and sleepiness. They can have numbness on one side, sudden confusion with difficulty speaking, understanding, or walking, and loss of balance or coordination. If a child exhibits any of these symptoms, you should call 9-1-1- right away.

Pediatric stroke survivors need specific and specialized care. Our Pediatric Stroke Program at the HTC utilizes the expertise and strengths of the University of Colorado Hemophilia and Thrombosis Center and resources from Children's Hospital Colorado. These resources make it possible for children to benefit from comprehensive, multidisciplinary services specific to their needs.

Our team treats all types of stroke and host a Pediatric Stroke Parent Support Group that meets monthly to help parents connect who have children in similar circumstances. These meetings are open to all families of children who have experienced stroke, regardless of whether they are treated at our clinic. You can find more information on this group at our [website](#).

Our stroke team has access to a wide variety of helpful resources for patients and families and are happy to provide support through their recovery. Our team just completed our own set of customized booklets for children who have survived a stroke and are always looking for new resources that can be helpful. You can learn more about [pediatric stroke, what causes them](#), and how we can help at our [website](#). You can also follow us on [Facebook](#) to find out more about our support group and activities we host. If you have questions about pediatric stroke or are seeking treatment for a child who has survived a stroke, please contact us at the HTC at 303-724-0724.



Meet Levi Lips, a stroke survivor!  
Photo: Adam Stowe, Kroenke Sports and Entertainment.

### INSIDE THIS ISSUE

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



Go to [facebook.com/ColoradoHTC](https://facebook.com/ColoradoHTC)



Go to [twitter.com/HTCColorado](https://twitter.com/HTCColorado)



Website: Go to

[medschool.cuanschutz.edu/hemophilia-thrombosis](https://medschool.cuanschutz.edu/hemophilia-thrombosis)



Email:

[HTC.Newsletter@ucdenver.edu](mailto:HTC.Newsletter@ucdenver.edu)

# SPOTLIGHT: LEVI LIPS—STROKE SURVIVOR



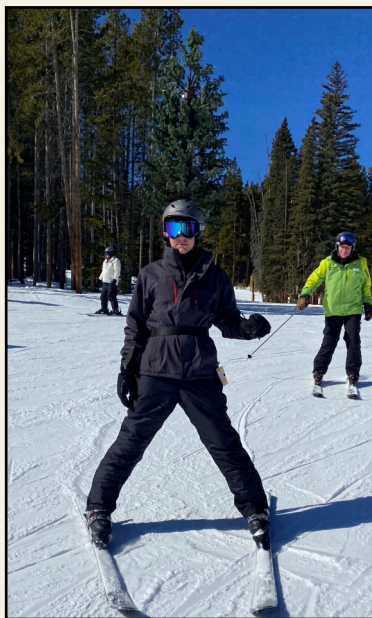
Levi Lips survived a stroke that occurred during surgery for a brain tumor. Photo: Megan Lips.

While strokes are rare in children, they can be the result of a prior condition or injury, a genetic disorder, or a complication of surgery. Levi Lips was 15 years old when he experienced symptoms that led to the discovery of a brain tumor. The tumor was removed in December of 2019 at Children’s Hospital Colorado, but he had a stroke that occurred during his surgery.

The stroke affected his fine and gross motor skills in his left arm and leg as well as impacting his peripheral vision. Levi had to learn how to walk again as well as re-learning to hold and manipulate objects in his left hand. He was out of school for over a month, and when he first returned it was so physically exhausting it was a challenge to make it through the day.

Levi has since recovered well and is able to walk and do many things he could before, but still has a few problems he is working on, such as his gait, and having his toes curl up. One of the unique challenges Levi faced was that he had just begun his recovery and the COVID-19 pandemic began. This meant that many school activities and normal options were off the table. However, with the support of his family, doctors, and friends, Levi has enjoyed many accomplishments. When school started becoming more normal, Levi was able to be involved in choir, school plays, and other activities, as well as church and social events.

He was even able to get back onto the slopes and ski with the help of the Breckenridge Outdoor Education Center and their adaptive ski program. Levi loves watching, playing, listening to, and reading about sports! Levi was approved for a wish through the Make-A-Wish Colorado program, but because of COVID-19 he had to wait two years. It was only about a week before he turned 18, but he was able to be an announcer at a Denver Nuggets basketball game on



Levi out on the slopes with BOEC and their adaptive ski program. Photo: Megan Lips.



Above: Levi with Nuggets Announcer Kyle Speller and Nuggets SuperMascot Rocky.



Left: Levi announcing live and on the big screen with Kyle Speller.

Photos: Megan Lips.

March 24, 2022. He announced the starting line-up and was able to do live play-by-play on Altitude Sports during the 2<sup>nd</sup> quarter. He also got to announce Rocky’s half-court shot, meet with Make-A-Wish donors, and was interviewed by several news organizations. For Levi it was a dream come true and something he and his family will never forget!

Levi just graduated from Arapahoe High School in Centennial, Colorado and is heading to Utah State University to study Broadcast Journalism this fall. We asked Levi to share advice to stroke survivors or their families.

***“Keep trudging through life. Keep going. Or as Dory says: Just keep swimming. And do not give up on yourself or your family!” —Levi Lips***

We at the HTC were lucky to get to work with Levi and were thrilled he had incredible care through the many resources offered at Children’s Hospital Colorado. Levi is a fabulous example of the resilience and hard work stroke survivors show and we are so excited to see him do great things in the future! Thank you Levi for sharing your story with us!



# PEDIATRIC STROKE PARENT SUPPORT GROUP

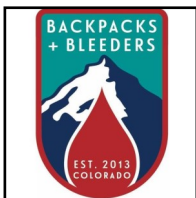


Our Pediatric Stroke Parent Support Group invites parents of children who survived a stroke to meet with one another and our stroke team each month. Normally we meet in person, but with the COVID-19 pandemic restrictions we are continuing to have these meetings on Zoom until things improve. **We will be taking a short hiatus during the summer months and will not meet during June, July or August.**

When we resume in September, we will be meeting on the second Monday of the month from 6:30 to 7:30 pm. Meetings are open to families of children of all ages and all types of stroke. Your child does not need to be seen at our stroke clinic to join our meetings. [For more details, see our website](#), or [follow us on Facebook](#).

For more information, contact [strokesupport@ucdenver.edu](mailto:strokesupport@ucdenver.edu) or call 303-724-8520.

## UPCOMING OPPORTUNITIES



### Backpacks + Bleeders: Fly Fishing Clinic

**June 25, 2022 Registration Deadline: June 6, 2022**

Backpacks + Bleeders is offering a fly-fishing clinic designed for anyone new to the sport, those needing practice, or those who want some one-on-one time with experts. Space limited to 25 people; registration is \$20 per person. Info at [cohemo.org](http://cohemo.org).



### Mile High Summer Camp — [Registration is open!](#) Sign up now, space is limited!

**Ages 15-17 only— Teen Leadership Weekend Registration Deadline: June 13, 2022**  
**July 15-17, 2022** with Breckenridge Outdoor Education Center

**Ages 7-14 only— Mile High Summer Camp Registration Deadline: June 13, 2022**  
**July 17-21, 2022** at Easterseals Rocky Mountain Village

[Learn more at cohemo.org](#), or contact Hanna Beary at [hbeary@hemophilia.org](mailto:hbeary@hemophilia.org).



### RMHBDA Big Sky Family Camp—Flathead Methodist Camp, Rollins, MT

**August 12-14, 2022 Registration Deadline: July 1, 2022**

This is a camp for affected families living in Montana and Wyoming to attend a weekend of education, bonding and fun. Infusion classes will be offered by HTC staff. Learn more at [rmhbda.org](http://rmhbda.org) or contact Brad Benne at [brad@rmhbda.org](mailto:brad@rmhbda.org).



### Outreach Clinics

Our Outreach Clinics are a chance for patients outside the Denver area to meet with our clinical staff closer to their homes. Contact our front desk at 303-724-0724 for more information or to get scheduled if these locations are closer to you.

See our [Outreach Clinic website for details](#).

**June 22-24, 2022: Billings, Montana**  
**Sept 28-30, 2022: Missoula, Montana**  
**Oct 26-27, 2022: Billings, Montana**



### Unite for Bleeding Disorders Walks

**NHF Colorado: August 13, 2022 at Sloan's Lake Park, Denver, CO**

**RMHBDA: September 10, 2022 at Billings Zoo, Billings, MT**

Mark your calendars now to join NHF Colorado or RMHBDA for their annual Unite for Bleeding Disorders Walks this year. This event raises funds to make events like camp, Education Days, and other activities throughout the year free to families. Learn more at [cohemo.org](http://cohemo.org) or [rmhbda.org](http://rmhbda.org) for more information and how to register.

**Please be aware that these events are subject to change. Most events will require abiding by COVID-19 safety protocols, so please check carefully what restrictions are in place.**

## RECENT HEADLINES

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

**Emicizumab Safe, Effective in Hemophilia A Patients with Inhibitors**

**Arthritis Medicine Helps Prevent FVIII Inhibitors in Animal Study**

**FDA Clears Pfizer to Resume Hemophilia Gene Therapy Trial**

**Research Shows Eptacog Beta Safe and Effective in Pediatric Patients**

**Bone Disorders More Common for Female Hemophilia Carriers and VWD Patients**

**Rebinyn Shows Positive Data in Canadian Real World Study**

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. Go to [medschool.cuanschutz.edu/hemophilia-thrombosis/resources/newsroom](https://medschool.cuanschutz.edu/hemophilia-thrombosis/resources/newsroom) to read more. We also share news on our [Facebook](#) and [Twitter](#) accounts.

Sign up to get this newsletter delivered directly to your email box each month! Just go to [eepurl.com/bnszoz](https://eepurl.com/bnszoz) and fill out the form!

## UPCOMING EVENTS

### Mark Your Calendars:

**Please note. These dates may be tentative and subject to change. Please check appropriate websites for confirmation of events.**

**May 30:** Clinic, Pharmacy, & Admin offices closed for Memorial Day

**June 9:** NHF Colorado: Bleeders and Breweries—A Men's Event

**June 22-24:** HTC Outreach Clinic—Billings, MT

**June 25:** Backpacks + Bleeders: Fly Fishing Clinic

**July 4:** Clinic, Pharmacy & Admin offices closed for Independence Day

**July 15-17:** Teen Leadership Weekend (ages 15-17 only) with BOEC

**July 17-21:** Mile High Summer Camp (ages 7-14 only) at Rocky Mountain Village, Empire, CO

**See more at our Events Page on our website:**  
[medschool.cuanschutz.edu/hemophilia-thrombosis/resources/events-calendar](https://medschool.cuanschutz.edu/hemophilia-thrombosis/resources/events-calendar)

### Hemophilia & Thrombosis Center

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or toll free at 888-297-0724

Pharmacy Main: 303-724-0168

or toll free at 888-724-7427

Web page:

[medschool.cuanschutz.edu/hemophilia-thrombosis](https://medschool.cuanschutz.edu/hemophilia-thrombosis)

PLEASE  
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