

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

Back to School

It's that time again, when parents pour over school supply lists, and fight the crowds as they search for the right size binder and the proper type of markers. When your child has hemophilia, a bleeding disorder, or other unique diagnosis, there are more items to check off in preparation for the school year. Being prepared can go a long way to help the school year start off right.

Depending on your child's needs, you may want to set in place training and accommodation at your child's school. The Hemophilia and Thrombosis Center can help you with this process. At the beginning of every school year, the HTC social worker, Audra LeBlanc, is available to come to your child's school and provide an educational in-service regarding hemophilia. In addition, our nurses can provide Individual Health Plans (IHP) upon request.

Help your teacher, school and caregivers by providing information they need. It is likely many of them have never had a child with a bleeding disorder in their classroom before, and educating them on how to respond to a fall on the playground, or recognizing and trusting your child when they know they are experiencing a bleed can be invaluable.

Some children with hemophilia or bleeding disorders fall under the protection of Section 504 of the Americans With Disabilities Act that prohibits discrimination against individuals with disabilities. Examples of school accommodations could be allowing a child experiencing a bleed extra time for treatment, extra time to move between classes if a child needs crutches temporarily, providing materials such as homework and follow up information during absences due to bleeds, and having a plan in place so that the school staff and teachers understand the proper response to an injury. Section 504 does not require a school set up an individualized educational program (IEP), but a plan is put in place on how to handle common situations that may arise.

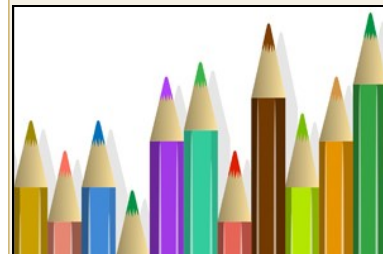
Whether or not you qualify for either 504 or other protections, the most important thing you can do is to have emergency protocols outlined. The Steps for Living website from the **National Hemophilia Foundation** provides some tools, templates and examples that can help.

Here are a few more ideas:

- Offer to present a slideshow to your child's school such as the ones available from the **Hemophilia Federation of America** to bring educators up to speed on your child's condition
- Be up front with your school and teachers
- Write the school a letter and set up an appointment to review potential problems
- Provide an Individual Health Plan (IHP) to schools with details on your child's basic information and procedures to follow

If you have questions on what protections your child qualifies for, need help in advocating for your child at your school, or would like the HTC to help or give presentations to educators, we invite you to contact **Audra LeBlanc**, our social worker, to discuss your unique situation at 303-724-6163.

Schools should be a safe environment for all kids, including those with bleeding disorders. We at the HTC are here to assist families set in place plans and special procedures that could help manage problems if and when they may occur. Have a wonderful school year!



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



Go to facebook.com/ColoradoHTC



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Website- Go to medschool.ucdenver.edu/htc



Email:

HTC.Newsletter@ucdenver.edu

GETTING TO SCHOOL– BUS SAFETY



Riding the bus is the safest method for children to get to school each day according to the National Highway Traffic Safety Administration (NHTSA). Buses are better protected, maintained and driven by screened drivers giving children a much safer way to get to school. However, everyone should practice safety tips while waiting for, approaching or riding a school bus. Here's a couple tips:

- Depending on their age, it is recommended parents walk with their kids to the bus stop and wait with them until it arrives.
- All kids should wait at least three giant steps back from the curb and board one at a time.
- Children should wait until the bus comes to a complete stop before exiting a bus and learn to never walk behind a bus.
- If a child must walk across the street after or before boarding, they should cross at last ten feet in front of the

bus, making sure the driver sees them. They should learn to check both ways before entering the street after passing the bus to be sure traffic has stopped.

- Teach younger kids to be sure to use handrails when boarding or exiting the bus and be careful of straps that could get caught. If a child drops an item, they should tell the bus driver to make sure they see them before they pick it up.

Each state and city has different laws regarding bus stops and school zones, but most require drivers to stop when they see the red flashing lights and the stop sign out on a school bus. Children may cross in front of a bus, so most laws require both directions to stop (unless it is a divided highway). Be sure to know your local laws and drive safely around buses and schools.

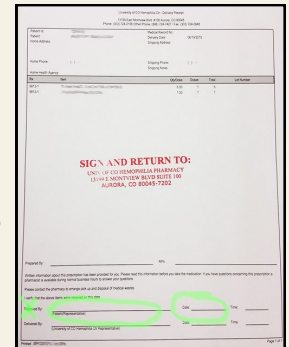
Here are a few websites with helpful information:

- www.SafeKids.org
- www.SchoolBusFacts.com
- www.NHTSA.GOV/School-buses

PHARMACY ALERT: RETURN YOUR SIGNED PACKING SLIPS!

Included in every factor or medication order that you receive from the HTC Pharmacy is a delivery receipt showing what medication and supplies are included in the box. One copy is to keep for your records and a second copy is **stamped in red ink for you to sign with date and return**. A self-addressed and stamped envelope is provided to make returning the delivery receipt easy and painless.

Example delivery receipt:



Why do you need to sign and return this receipt? ***It's the law--healthcare and insurance regulations require it!*** Pharmacies are required to obtain and provide proof that a patient received the medications for which they are billing. A pharmacy in New York was recently fined \$2.55 million dollars for failure to obtain patient signatures as proof that the medications were received. **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!

OUTREACH CLINICS

Our last Outreach Clinic for the year in Grand Junction, CO is scheduled for **September 23-25, 2015**. This clinic will be held at **Western Colorado Pediatric Associates**, located at 3150 N. 12th St. in Grand Junction.

For questions, please contact Pat Casias or Audra LeBlanc at 888-297-0724 (toll free), or 303-724-0724.

More details and forms are available at our website: www.medschool.ucdenver.edu/htc Go to the **CLINIC** tab and find our **OUTREACH CLINICS** page.

NEWSLETTERS

We are now digitally sending and sharing our newsletters. Please sign up and receive a notification with access to our digital version as soon as it becomes available. You can subscribe by going to our website: www.medschool.ucdenver.edu/htc and click on the **RESOURCES** tab for the **NEWSLETTER** page.

If at any time you wish to unsubscribe, there is a link at the bottom of the email. Questions, corrections, or problems please contact us at HTC.Newsletter@ucdenver.edu.

WALKING & BIKING



Often it is closer and easier for a child to walk or bike to their school each day. Biking and walking are both good forms of exercise and can give kids a sense of independence in their own transportation. Those with bleeding disorders benefit from exercise that comes from walking or biking but should take precautions. Here are a few

suggestions for kids walking and biking to school.

- Parents or guardians should supervise kids biking or walking until the child is responsible to ride or walk on their own or with their friends.
- Teach kids to ride on the right side of the road, with traffic, not against it. Riders should stay as far to the right as possible and learn appropriate hand signals and follow all traffic rules.
- Children walking should learn to walk on the sidewalk or other appropriate paths, avoiding private property and dangerous routes.
- Kids should learn to make eye contact with drivers to make sure it is safe to cross the street.
- Always wear a helmet when riding a bike. It is the single most effective safety device to reduce head injury and death. More children are seen in ERs for bike related injuries than any other sport. Teach children when they're young the safety rules and enforce them to keep kids safe.
- Teach your child to recognize if they have symptoms of a bleed and to avoid activities that could make it worse. If that means they need a ride from Mom or Dad, even if they love to ride or walk with friends, help them understand the benefits of taking it easy when needed.

See more info at www.SafeKids.org and www.NHTSA.gov.

SLEEP

Study after study has reinforced the facts that you as a parent already know: your child functions better when he or she gets enough rest and eats properly. Evidence shows that teenagers need their sleep just as much as younger children, yet they often do not get the amount they need. While it may take a few weeks to adjust, getting your child or teen on a good sleep schedule can boost their academic performance in school. Here are a few suggestions to get enough rest:



- Start young and get kids in a bedtime routine. Young or old, find a routine that works and follows a pattern to allow kids and teens time to wind down and get enough rest.
- Keep bedtime consistent and stick with it.
- Don't use sleep as a punishment.
- Take away and restrict technology in the bedroom. Most tech devices have been proven to stimulate the brain in ways that makes kids and teens think they are supposed to be awake.
- Cut back. Kids and teens can sometimes have too much going on. If they are not getting enough rest because there are too many extracurricular activities on top of homework, perhaps consider cutting back, re-evaluating what is most important so they can get enough sleep.

NUTRITION

Nutrition can play a part in how children act and feel. Parents often note the changes their kids display when they've



had a lot of sugar, caffeine, or highly processed foods. Our society has many quick and high calorie foods available making it easy for kids to eat foods low in nutrients and high in empty calories.

Kids with bleeding disorders face most of the same health risks of obesity as other children, but may suffer more severe consequences of extra weight on their joints and muscles. As kids grow, the amount and type of foods they need will change, but having a balance of healthy grains, fruits, vegetables, proteins and dairy is considered by most experts to help maintain a nutritious diet.

Take advantage of the many options available, such as ChooseMyPlate.gov, that provide free input on what kids need in their diet. For example, calcium and iron rich foods help kids during their growing years. Iron can be significantly important for a child that has a bleeding disorder.

Many kids and teens can be picky, but they love to be involved in making their own food choices. Incorporate them in making plans for meals, shopping for foods they enjoy that fulfill their nutritious needs and spend time learning to make healthy foods instead of relying on fast foods. Allow them to help make a healthy lunch and learn good habits to support their health as they grow.

All it takes is a quick Google search or a few minutes on Pinterest to find hundreds of meal ideas, but here are a few websites about healthy eating we thought might be helpful:

www.ChooseMyPlate.gov

www.StepsForLiving.Hemophilia.org

www.HealthierGeneration.org

www.KidsHealth.org

RECENT HEADLINES

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.

Data Supporting Long-Term Safety of Eloctate Published in *Haemophilia*

**Hemophilia Drugs a Big Part of Medicaid Spending
FDA Publishes Drug Shortage Ruling**

Engineered Clotting Protein Effective in Severe von Willebrand Disease

FDA Approves Technivie for Treatment of Chronic Hepatitis C Genotype A

Gene Sequence Swap Using CRISPR May Lead to Cure for Hemophilia A

UPCOMING EVENTS

Aug 22: NHF Colorado-Walk for Hemophilia

Aug 30: Pediatric Stroke Parent Support Group Summer Picnic (please RSVP)

Sept 7: Clinic and Admin offices closed for Labor Day

Sept 12: RMHBDA Walk for Hemophilia, Billings MT

Sept 23-25: Outreach Clinic-Grand Junction, CO

Oct 2-4: Neurologic Disorders Family Camp at Roundup River Ranch

Oct 13: World Thrombosis Day.

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

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