

Cascade Hemophilia Consortium

Note From Cascade Social Worker Colleen Joiner



Congratulations!

You're going to college! This is a very exciting time in your life filled with lots of fun, adventure and challenges. Along with meeting new people, getting your dorm room decked out, and picking out your classes, there are some important things to consider regarding your bleeding disorder. We hope these step-by-step tips are helpful in making your college experience the best and safest experience for you!

Colleen

Going Away to School: An Action Plan for Teens and Parents

Ordering Your Own Factor or Medication: Parent/Teen Challenge

Going away to college is the perfect time to gain your independence, and self-care is one step toward that goal. Over the summer, plan and practice who to call when you have a bleed, and the steps necessary to order factor or medication.

Summertime is also a great time to work out important details such as confirming insurance requirements and locating medical assistance when at school. Learning is a process, and practice will help you feel comfortable managing your bleeding disorder while away at school.



Keeping Up With Your Friends at the HTC

Remember to schedule regular appointments with your HTC once or twice each year. The HTC is usually accommodating to your school schedule. Most people with bleeding disorders should see their HTC at least one time each year, and in many cases, it's a requirement. Plan ahead!

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Cascade... A Trusted Partner in Your Circle of Care

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Cascade's Limited English Proficiency Language Assistance Services
Language assistance services are available free of charge. Call: 1-800-996-2575

Cascade Mission Statement
To enhance the system of care for people with bleeding disorders and related complications, by assuring the lowest possible price for the full range of treatments, HIV and hepatitis related therapies and other medications available to treat their diseases; to provide access to these medications for those without insurance or inadequate insurance coverage; to support the comprehensive hemophilia treatment centers in treating and educating consumers and their families so they may become knowledgeable and proactive in managing their own care; to fund research.

Your Parent/Teen Action Plan

For Parents

- ✓ If your child is going to school out-of-state, call your insurance company to inquire about out-of-state coverage. Some schools offer student health plans, which are helpful if your coverage doesn't cover out-of-state care.
- ✓ Some students aren't far from home, though many will need to receive factor/medication while away at school. Report to Cascade any address changes for shipment as soon as possible.
- ✓ Locate the nearest hemophilia treatment center to the school and contact them for guidance in the event a future bleed requires assistance. Research the nearest hospital and emergency department and be sure your child knows where those are located.
- ✓ Review the process of ordering factor with your teen. While in high school and through the summer, let him or her watch the steps you take to place an order and let them listen to you make the call. Give them time to practice the task prior to going away. Talk with your nurse or Cascade about doing a practice run. We are all willing to help!
- ✓ **If you will be continuing to place factor orders, be sure that information releases are in place. Once your child turns 18, neither Cascade nor the HTC is legally able to speak with you without your child's permission.**



Connect with the Office of Disability Services Before School Starts

Regardless of which college or university you're attending, you may want to connect with the School Health Department's Office of Disability Services before you arrive. There are several ways Disability Services can help make your student life a bit easier when it comes to your bleeding disorder. They work with each student on a case-by-case basis to develop an individual plan that's most helpful. They may require a letter from your physician.

Some ways they can help:

- ✓ **They can assist with dorm location.** Many of you have experienced active bleeds that temporarily inhibit your ability to walk or require the use of crutches. Depending on the size of the school, classes can be quite a distance away. You can speak with the school Disability Department to arrange for a dorm central to most classroom buildings. Or maybe you'd benefit from a first floor dorm room. In any event, the school will work with you to find the best location for you.
- ✓ **Do you need to miss classes on occasion due to bleeds?** The Office of Disability Services is on your side. They will help you talk with your professors about these circumstances and ways you can make up class time and work. It is better to have a plan than to miss a class without explanation.
- ✓ **If you had an IEP or 504 in high school, they will help you transition those into college.** The high-school counselors will help transition those plans if necessary.



For the College-Bound Teen

- ✓ It may sound obvious, but know the name of your factor product/medication and the number of units/dose that has been prescribed to you. You will need this information when placing a factor refill.
- ✓ Know your insurance plan and have your insurance cards ready and with you at all times. Make a list of HTC and Cascade contact numbers.
- ✓ Remember to call Cascade or the HTC to initiate an order (as directed by your HTC) **before you run out of your factor/medication.** Obtaining your order may take time, sometimes up to 10 business days depending on your insurance company, and Cascade wants you to have what you need when you need it.
- ✓ Practice with your mom or dad on how to contact the HTC and Cascade in the months prior to leaving for school until you both feel comfortable that you are ready to take over.



To Tell or Not to Tell?

Disclosing your bleeding disorder is a personal choice. However, telling your RA, and roommate or dorm friends is practically a necessity. Let them know what to do in the case of an emergency. They should be able to list your diagnosis, treatment and emergency phone number at a minimum. All of this information will also be on your medical alert bracelet.

Sharing information allows your circle of support to be larger if you need any help with a bleed. Make sure the RA or a friend can get into your dorm room to get your factor in the event of an emergency on campus.

Equally important, your roommate may be puzzled by the butterfly needles and other supplies. Explaining things may help ease any confusion, however, if your roommate does have an issue with you infusing in the room, the school can help you find another roommate.



We hope you have a
wonderful year!