

Congratulations Eagle Scout Mike Sanger!

Seventeen-year-old Mike Sanger has had quite a few adventures over the years as he's worked his way through the ranks of the Boy Scouts of America. Through hard work and diligence, Mike has achieved the highest rank in Scouts, Eagle Scout. Amazingly, only 3-4% of eligible Scouts have earned Scouting's highest honor since its inception in 1912. According to Mike, "It's a lot of work and not always a lot of fun." But it was all worth it as it allowed him to travel, go on adventures, and help his community.



Mike, who has severe hemophilia, started as a Tiger Cub at the age of six before transferring over to the Boy Scouts when he was eleven years old. Eagle is earned by demonstrating leadership, responsibility, and community service. And it takes commitment and time to accomplish. Over the last seven years, Mike has earned 32 merit badges and numerous additional awards beyond his rank. He also completed his Eagle project this year, which benefitted the hemophilia community.

For his own safety and everyone's comfort, a family member has always gone with Mike on his scouting adventures to help manage his bleeding disorder. Mike's grandmother, Cheryl, supported him by learning about his hemophilia, administering his medicine, and acting as his advocate. She has gone on campouts, attended troop meetings, and has been active in all of Mike's scouting activities.

When asked whether his bleeding disorder has ever gotten in the way of his scouting career, Mike says, "Hemophilia has never held me back. But my family made sure it didn't. As I've grown, I have assumed more responsibility for my

own care." Mike always brings his factor with him on campouts and various trips so he can treat prophylactically while there. Fortunately, he has only had to treat a bleed once while camping over the years.

Mike states, "I've had some great times in Scouts! Because of Scouts, I've camped in five different states, including the mountains of North Carolina and New York. I was able to go to a climbing gym and play bubble soccer. I've also bicycled Mackinaw Island and the Pierre Marquette Trail and canoed the Rifle and AuSable Rivers. I even learned to ski!"

When asked about his favorite adventure, Mike says, "There have been so many. I've been to Niagara Falls, Wright Patterson Air Force Base, and toured the National Air Force Museum. I've tried a lot of things because of Scouts that I never would have. Picking one favorite is impossible!"

As an Eagle Scout, Mike plans to continue volunteering at camp and assisting the camp masters. This spring, he's also training to become an archery range master/instructor. We're certain Mike will have many more adventures and enough memories to last a lifetime. Congratulations on your accomplishments, Eagle Scout, Mike Sanger!



Eagle Scout Wikipedia - en.wikipedia.org/wiki/Eagle_Scout

What percentage of Boy Scouts become Eagle Scouts?
(<https://blog.scoutingmagazine.org/2015/03/30/what-percentage-of-boy-scouts-become-eagle-scouts/>)

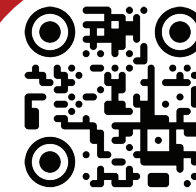
Cascade... A Trusted Partner in Your Circle of Care

How are We Doing?
We would love your feedback!

We are conducting a brief anonymous survey measure your satisfaction with our services and to find ways to better meet your needs. Your opinions and comments are very important to us!

Please scan the QR code or visit cascadehc.org/survey.

Thank You!



(scan me)

Cascade Hemophilia Consortium Mission

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 disease; 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.

Language assistance services are available free of charge. Call: 1-800-996-2575.

ATENCIÓN: si habla español, tiene a su disposición servicios gratuitos de asistencia lingüística. Llame al 1-800-996-2575.

هذه الخدمات المساعدة اللغوية متوفرة مجاناً باللغة الإنجليزية. اتصل بالرقم 1-800-996-2575.



2025 Traverwood Drive, Suite A
Ann Arbor, Michigan 48105

Hours: M-F 9:00 am - 5:00 pm
Available for after hours emergencies

Phone: 734-996-3300
800-996-2575
Fax: 734-996-5566

www.CascadeHC.org
info@CascadeHC.org

Officers

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Erica Godsey, MSN, APRN, FNP-C
Cascade Director of Nursing

Dear Readers,

Congratulations, you've graduated! Going off to college is a very exciting time and for some, the first taste of independence! This transition can also be overwhelming, especially while living with a bleeding disorder. To help ease this transition, we put together a few tips on how to prepare and manage your bleeding disorder independently while supporting a safe, successful, and positive college experience. Have a great school year!

Erica

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 to practice who to call when you have a bleed and the steps necessary to order your medication.

Summer is also a great time to work out important details such as confirming insurance requirements and locating medical assistance while at school. Gaining independence 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 once each year, and in many cases, it's a requirement for continued prescriptions. Plan ahead!

Cascade Staff

Stephanie Raymond
Executive Director

Michael Altese, PharmD
Pharmacy Director

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Pharmacist

Rachel Blake, CPhT
Pharmacy Technician

Rebecca Blumenfeld
Billing Specialist

Devin Bromley, CPhT, RPhT
Prior Authorization & Insurance Specialist

Susan Carlini, BSA
Senior Accountant

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Operations Assistant

Rachel Evans, RN
Clinical Care, Education, and Outreach Nurse

Emily Florance, PharmD
Pharmacist

Roxana Germann, PharmD
Pharmacist

Sara Gligoroff, CPhT
Prior Authorization & Insurance Specialist

Erica Godsey, MSN, APRN, FNP-C
Director of Nursing

Kirk Haddas, PharmD
Pharmacist

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Compliance Officer

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Pharmacy Technician II

Dean Hindenlang, PhD
Director of Public Policy and Strategic Initiatives

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Nancy Inverso, BSN, RN
Clinical Care, Education and Outreach Manager

Colleen Joiner, LMSW, CCM
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Pharmacist

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Joanna Pangilinan, PharmD, BCOP
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Ethan Perry, RPhT
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Finance Director

Stephanie Sibrel, BSN, RN
Clinical Care, Education & Outreach Manager

Debbie Whelan, LMSW, CCM
Clinical Care Manager

- July 2024 -

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 might help with general care if out-of-state care is not included. Be sure to review the plan for bleeding disorder coverage.
- ✓ Some students are not far from home, though many will need to receive factor/medication while away at school. Report any delivery address changes to Cascade as soon as possible.
- ✓ Locate the nearest hemophilia treatment center (HTC) to the school and contact them for guidance if a future bleed requires assistance. You may even want to visit them so they get to know your child, and your child will feel comfortable with the HTC staff. Research the nearest hospital and emergency department, and be sure your student knows where those are located.
- ✓ Review the process of ordering factor with your young adult. While in high school and through the summer, let him or her watch the steps you take to place an order and 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, for some reason, you plan to continue placing medication orders, be sure that information releases are in place. Once your child turns 18, neither Cascade nor the HTC can legally speak with you without your child's permission.**



For the College-Bound Student

- ✓ It may sound obvious but make sure you know the name of your factor product/medication, your treatment regimen, and the number of units or dose that has been prescribed for you. You will need this information when placing a factor refill.
- ✓ Know your insurance plan and make a list of HTC and Cascade contact numbers. Take a picture of your insurance card and keep it in your phone along with the necessary phone numbers so that you'll have access to them when you need it.
- ✓ 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. Try to order at least a week ahead. **Take advantage of Cascade's text reminder program to help you remember!**
- ✓ Practice contacting your HTC and Cascade with your mom or dad in the months prior to leaving for school, if needed, until you both feel comfortable that you are ready to take over.



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 an active bleed that temporarily inhibits your ability to walk or requires 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 would 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 school assignments. It is better to have a plan than to miss a class without explanation. Of course, on-line courses make attending easier when bleeding is an issue.
- ✓ **If you had an Individual Education Plan (IEP) or a 504 plan in high school, they will help you transition those into the college system.** The high school counselors will help transition those plans if necessary.
- ✓ **They can also help to coordinate delivery and storage of your medication.** Policies differ from one educational institution to another regarding specialty medications such as factor or Hemlibra. Discuss with the school whether your medication will be delivered to the Health Clinic or to your dorm. Set a plan for refrigeration of your factor product and/or medication, if necessary. If you do not self-infuse, make sure that the school's Health Clinic can receive the deliveries, store them for you, and infuse you if necessary.



To Tell or Not to Tell?

Disclosing your bleeding disorder is a personal choice. However, telling your RA, roommate, or a dorm friend is practically a necessity. Let them know what to do in case of an emergency. They should be able to list your diagnosis, treatment, and emergency phone number at a minimum. All 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 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, syringes, and other supplies. Explaining things may help ease any confusion. If your roommate does have an issue with you infusing or injecting in the room, the school can help you find another roommate, or offer you a single room, depending on campus housing policies.



Student Scholarship Assistance

Scholarships are available to members of the bleeding disorders community to help reduce the financial burden of college or trade school. Scholarship applications are generally due in the spring. Feel free to detach the list to check deadlines or revisit these in the winter months for next year.

MICHIGAN

Hemophilia Foundation of Michigan Scholarship:

- For post-secondary education: college, university, or trade school
- For person with a bleeding disorder or immediate family member (parent, sibling, grandchild)
- Resident of Michigan
- Two awards of \$2,500
- For more information, please contact Kaite Scott at Kscott@hfmich.org, visit www.hfmich.org, or call 734.961.3512.

INDIANA

Hemophilia of Indiana: Judy Moore Memorial Scholarship Ed Magoni Memorial Scholarship

- Resident of Indiana
- Awards of up to \$10,000
- For more information, please contact Angel DiRuzza at adiruzza@hoii.org or visit www.hoii.org, Scholarships - Hemophilia of Indiana

OHIO

Tri-State Bleeding Disorder Foundation (TSBDF): The T.D. Hughes, Jr. Scholarship The Gina Stack Memorial Scholarship - Focuses on healthcare degrees

- For persons with a bleeding disorder and their immediate family members
- Must live within the geographic area served by the TSBDF or be followed at either the pediatric or adult hemophilia treatment center in Cincinnati.
- Award of \$2,500 or more depending on funding
- For more information, please contact Helen Lamping at Hemophilia@tsbdf.com, visit: www.tsbdf.com/what-we-do, or call 513-961-4366.

Greater Ohio Bleeding Disorder Foundation Scholarship

- Anyone with a diagnosed bleeding disorder living or being treated in the Northern or Central Ohio regions are eligible.
- \$500 per each scholarship per calendar year. More than one scholarship is awarded for trade school, certificate programs, college, or university tuition.
- For more information, please contact Tanya Ricchi at tanya@nohf.org, visit [Membership nohf.org](http://Membership.nohf.org), or call 216-834-0051.

FAMOHIO: Les Gutter Memorial Scholarship

- Ohio resident with a bleeding disorder
- Must be seen at a federally recognized Hemophilia Treatment Center (HTC)
- Award of \$1,000 - \$5,000
- For more information, please contact Sandra Hibner at Sandraahibner@gmail.com, or visit famohio.org/scholarship

Southwest Ohio Hemophilia Foundation The Brad Miller Memorial Scholarship

- Must receive treatment at the Dayton Children's Hemostasis and Thrombosis Center
- Award of \$2000
- For more information, please visit www.swohf.org

For a Listing of National Scholarships

www.bleeding.org/community-resources/financial-assistance/scholarships
or
www.hemophiliafed.org/scholarships/



We hope you have a wonderful year!