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BIG RED FACTOR

2019—Issue III

Nebraska Chapter News

It's hard to believe we are gearing up to finish out 2019 already! We have had a packed calendar this year with education, advocacy and even some new programs. We've added VWD programming, a brand new teen retreat at the end of this month, added an education dinner in North Platte and so much more. The staff and board is always looking to make this community as meaningful and useful to you as possible and we hope we succeed and continue to grow in a way that best serves the bleeding disorder community.

Last week at NHF's Bleeding Disorder Conference, Nebraska NHF was named as a Chapter of Excellence in two categories; Programs and Services and Fundraising and Development. We are dedicated to making this chapter as strong and sustainable as possible and hope to add more awards in the coming years. Our Board is working hard on a strategic plan for our chapter to create the long term vision for our community and our organization. We are excited to share that with you when they complete it.

As 2019 is starting to wrap up, we still have a few more programs and opportunities to get involved. Please join us for one of our remaining programs, help us spread awareness and raise funds on Giving Tuesday or join us on a committee to plan next year's programming or fundraising events. The more you are involved, the more we can do.

This community exists because of you and for you— we want to grow and strengthen it with your help! We welcome you to do that any way that works for you. We NEED you!

Thank you for making 2019 great so far— we can't wait to see you for our remaining Fall/Winter Events!



Our Mission:

The National Hemophilia Foundation—Nebraska Chapter is dedicated to finding better treatments and cures for inheritable bleeding disorders and to preventing the complications of these disorders through education, advocacy & research.

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2019

Fourth Quarter Events

October

October 19, 2019

Harvest Festival

Roca Berry Farms, Roca, NE

October 26, 2019

Teen Retreat

Mahoney State Park, Ashland, NE

November

November 9, 2019

Industry Symposium

December

December 3, 2019

Giving Tuesday

December 7, 2019

PING (Parent Information Networking Group)

2019 Save the Dates

March 24-25th

Nebraska State Advocacy Days

May 16-17th

Family Education Weekend

June 5 -7th (NEW DATE!!)

Family Camp



**combined health
agencies drive**
MEMBER CHARITY



Nebraska NHF's
**INDUSTRY
SYMPOSIUM**
11.9.19

THE NEBRASKA CHAPTER OF NHF IS EXCITED TO ANNOUNCE OUR 2019 INDUSTRY SYMPOSIUM; WHERE LEADING HEMOPHILIA DRUG MANUFACTURERS ARE ABLE TO COME TELL YOU ABOUT THEIR NEW PRODUCTS, PROGRAMS AND ANSWER ANY QUESTIONS YOU MAY HAVE.

NE NHF IS GIVING OUR INDUSTRY PARTNERS AN OPPORTUNITY TO SPEAK DIRECTLY TO YOU ABOUT THEIR PRODUCTS AND SERVICES, WHICH WE LIMIT TO THIS EVENT. WITH ALL THE NEW CHANGES ON THE HORIZON AND NEW TREATMENTS THAT HAVE COME OUT THIS YEAR, WE WANTED TO GIVE THEM A VOICE. PLEASE COME JOIN US FOR A MORNING OF UPDATES FROM OUR MANUFACTURER PARTNERS AS WE MOVE FORWARD INTO 2020.

MAHONEY STATE PARK
9:00- 4:00 PM
BREAKFAST, LUNCH AND
CHILD CARE INCLUDED

PLEASE RSVP AT WWW.NEBRASKANHF.ORG

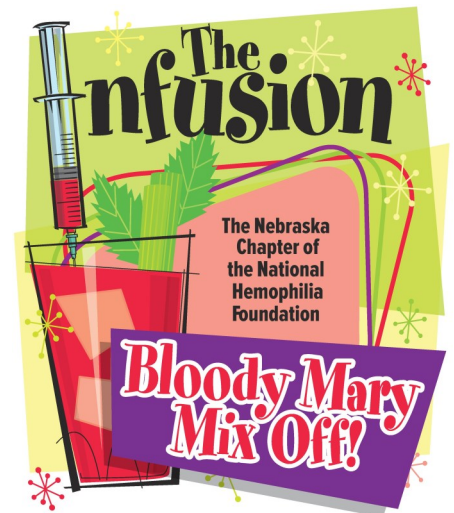
Infusion: Bloody Mary Mix-Off 2019

It was a rainy Sunday morning on July 21st, but many came out to Founders One-Nine. to support the Nebraska Chapter's fourth annual Infusion: Bloody Mary Mix-Off. Bleeding disorders community, board members, along with community members and 7 local bars and restaurants, gathered for bloody marys, brunch and music. The event's premier sponsor was Novo Nordisk and Tito's was one again, our spirit sponsor.

This year's participating bars were:

- Beyond Golf ●Tracks Lounge ●Krug Park
- Spirit World ●Sippin' Sirens (New Participant)
- Down Under Lounge (New Participant)
- Bald Brothers Catering (New Participant)

This year's Infusion brought some exciting additions! We added two new categories, Most Inventive and Most Like a Meal. These additional categories provided more opportunities for participating bars to be recognized for their creative bloody marys. We also added local "celebrity" judges to assist with the voting process for all 4 categories. Our judges were: Dominique Morgan, National Executive Director of Black and Pink; Laurann Robinson, KETV Meteorologist; and Dan Harr, Inclusion and Diversity Specialist for Mutual of Omaha.



Our 2019 Infusion Bloody Mary Mix-Off winners were:

Most Like a Meal: Sippin' Sirens

Most Inventive: Spirit World

Best Garnish: Sippin' Sirens

Best Overall: Beyond Golf

The Infusion is a unique fundraiser for our chapter, growing each year. We want to thank all of the attendees and committee members who helped make this event a success. Be on the look out for next year's date! We hope to see you there!





**NEBRASKA CHAPTER
NATIONAL HEMOPHILIA FOUNDATION**

www.nebraskanhf.org

NEBRASKA CHAPTER OF NHF

Teen Retreat

For all teens 13-19 served by the Nebraska Chapter of NHF
Affected, Siblings and Children of Affected Parents

Saturday, October 26, 2019 9 am- 5 pm
Mahoney State Park (Go Ape Ropes Course)

Register online at www.nebraskanhf.org

Teen Retreat

October 26, 2019

- **Who can attend?**

Anyone between the ages of 13-19 who are served by the Nebraska Chapter of NHF. This includes affected individuals, siblings and children of affected parents.

- **What will we be doing?**

We will start off at the Go Apes Ropes Course in Mahoney State Park, have a healthy lunch and work together to plan 2020 teen programming along with an interactive dialogue on growing our teen connection at the chapter.

- **Where is this located?**

The entire day will be spent at Mahoney State Park in Ashland, NE. We will be using multiple of their facilities throughout the day.

- **How do I register?**

Visit **www.nebraskanhf.org** to register by October 4th (we need to make reservations for the ropes course!)

- **How much does it cost?**

NOTHING. Thanks to a grant from the Hemophilia Alliance Foundation, we are able to offer this program completely free of charge. If you need travel assistance, please let us know.



NEBRASKA CHAPTER
NATIONAL HEMOPHILIA FOUNDATION

Mentoring for Hemophilia: Benjamin Rush and John C. Otto

Richard J. Atwood

As we advance in our careers, some of us try to do it all on our own. In time, we realize that we could use a little help from our friends. A formal term for this encouraging advice is mentoring. A mentor has a certain skill set or professional qualifications, and offers guidance to someone else.

One of the key examples of hemophilia mentoring occurred in Philadelphia in 1803. Dr. Benjamin Rush (1746–1813) provided guidance for his young colleague, Dr. John Conrad Otto (1774–1844). Otto then published a groundbreaking medical journal article on “hemorrhagic disposition,” now known as hemophilia. This article inspired other physicians worldwide to investigate bleeding disorders.

The medical careers of Rush and Otto overlapped for 20 years in Philadelphia. Beginning in 1793, Otto progressed from being Rush’s student to becoming his colleague, and eventually his successor. Otto was also his mentor’s friend. Before starting their medical careers, both men graduated from the College of New Jersey (now Princeton University), Rush in 1760 and Otto in 1792.

Otto moved to Philadelphia in 1793 to begin his medical studies under Rush as apprentice and student. The deadly yellow fever epidemic that summer—with its 10% mortality rate—compelled Rush to send Otto out of the city, most likely because he was a medical novice and also to protect his health. Returning in the fall, Otto attended medical lectures conducted by Rush, who was then a professor at the University of Pennsylvania. Otto was a favorite pupil, and he made hospital rounds and private calls with Rush. Otto earned his medical degree in 1796 with a thesis on epilepsy. He survived an attack of yellow fever in the 1798 epidemic during a visit to his hometown of Woodbury, New Jersey.

Settling in Philadelphia to practice medicine, Otto was elected to the Philadelphia Dispensary for the Medical Relief of the Poor, serving as physician there for five years. Rush had been instrumental in founding the dispensary in 1786 as the nation’s first free clinic for the poor. In addition to his private practice, Otto was also a physician at the Orphan Asylum for 20 years, and at the Magdalen Asylum.

Otto visited New England in the summer of 1802. Rush gave Otto a letter of introduction, dated August 6, to Dr. John C. Warren (1753–1815), a professor at Harvard University in Cambridge, Massachusetts. Nothing is documented about Otto’s trip, yet we can guess that Rush’s letter was a catalyst for Otto to subsequently publish information he collected about a family with cases of hemophilia. Returning to Philadelphia, Otto married Eliza Tod (1790–1860) on December 18, 1802. Eliza, a merchant’s daughter, was only 12 when she married. In 1803, at age 29, Otto published “An Account of an Hemorrhagic Disposition in Certain Families” in *Medical Repository*, America’s first medical journal, founded in 1798 in New York City. This article is considered the first clear description of hemophilia in the world, and was reprinted in England in 1808. Otto did not mention his visit to Boston, but he noted that Rush was familiar with similar cases of hemophilia in the town of York and in Northampton County, both in Pennsylvania, and also in Maryland.

In his article, Otto described the Smith family from Plymouth, New Hampshire. Otto probably gathered his information from secondary sources, rather than ever interviewing any Smith family members. We know that Otto learned of the Smith family from residents of nearby Holderness, New Hampshire, including Judge Samuel Livermore (1732–1803), Dr. John Porter, and Dr. John Rogers. These men, while personally knowing about some of the “bleeders” in the Smith family, were secondary sources. Judge Livermore traveled to Philadelphia, the nation’s capital, serving as a member of the Continental Congress, a US Representative, and a US Senator (1780–1801).

Mentoring for Hemophilia, continued.

He traveled with Captain Thomas Shepard, a relative of Captain John Shepard who also served with Robert Rogers' Rangers, a mercenary regiment of soldiers from New Hampshire. Otto recorded many secondary sources who knew members of the Smith-Shepard family. But his encouragement from Rush seems to have sparked this investigation.

Around 1752, Susannah Smith (1739–1818) of Durham, New Hampshire, married Captain John Shepard (1730–1779) of Barrington. Captain Shepard served in the British army and in Robert Rogers' Rangers. He and Susannah are usually credited with seven children, though some sources list more. Some of the Shepard sons (not specifically identified) are reported to have been “bleeders” and died young. After Captain Shepard died in 1779, and his property was confiscated because he was a Loyalist,¹ Susannah and several of her adult children moved to Holderness, to what is now called the Shepard Hill Historic District.

Otto supported Rush's contention that a cure-all for diseases, especially when blood vessels and nerves are in an “excitable state,” is a purgative. Rush treated yellow fever with bloodletting,² usually about 10 ounces of blood taken three times a day, along with emetics and laxatives for purging. These medical procedures, though commonly practiced, were critically disputed by some physicians. Otto stated that sulphate of soda, a purging medicine, was the best treatment for hemorrhagic disposition. To be curative, he said, the purging dose needed to be administered two or three days in succession. Administering more often was sure to produce the “cure” even with its debilitating side effects.

When he learned more about a Maryland family of “bleeders,” Otto published an update in his 1805 article “Singular Cases of Hemorrhagy” in the new journal *Philadelphia Medical Museum*. Otto wrote that all four sons of Benjamin Binny were victims of fatal hemorrhages, while the daughters were not affected.

In 1805, Rush became dean of the University of Pennsylvania Medical School. When Rush died in 1813, Otto replaced his former teacher as a physician and clinical lecturer at the Pennsylvania Hospital, a position he would hold for 22 years. Regrettably, Otto never published again on hemophilia.

We don't know why Rush didn't publish information on the cases of hemophilia known to him. We also don't know why Rush, as a mentor, seems to have prompted Otto to investigate the Smith family in New Hampshire. Perhaps Rush,³ as a Founding Father and one of 56 signers of the Declaration of Independence, was busy with other matters. Fortunately, Otto wrote an influential article on hemophilia, clearly describing its bleeding pattern, the current treatment, and its genetics, and even introducing the term “bleeders” in the literature. We can be thankful that Otto's 1803 article was the consequence of successful mentoring for hemophilia.

1. Another twist to this story concerns the political spectrum extremes involved here: Rush and Otto were Revolutionaries for America, while Shepard was a Loyalist for England.

2. Bloodletting means to open up a vein. Rush's practice was controversial. But he published his results, so his methods were well known. Rush had some success, but some of his patients died. Other physicians who did not practice bloodletting had some success, and also had some patients die. A purging remedy for hemophilic bleeding may have been effective, or it may have distracted the patient enough to stop any bleeding. To us, this sounds barbaric, but it fit the medical theories at the time and remained popular for another half-century.

Family Camp 2019

Camp Tap-a-Vein-a-Daya 2019 was held on August 9th-11th at the Eastern Nebraska 4-H Center in Gretna, NE. Many families from our bleeding disorders community gathered together to enjoy the great outdoors. Friday night's activities included welcoming families with a pasta dinner by the wonderful 4-H staff, along with yard games and enjoying the beautiful weather.

Saturday morning was full of activities such as canoeing, archery, rock wall climbing and ziplining. Afternoon activities consisted of tie-dying shirts and painting pieces of square cloth for a blanket that will be sewn to commemorate 2019's camp. As temperatures elevated, it was a great excuse for water games! Maureen Grace, Executive Director, led the charge while children filled balloons and other toys with water and cooled down in the sun. Saturday night, campers enjoyed Minute-to-Win-It games, laughs and s'mores by the campfire.

Family camp is an opportunity for families to experience camp together. It gets younger kids ready for the week long camp experience and allows parents and caregivers a little view into what camp life is like. It's a great weekend escape and a beautiful way to build and grow our community in nature. We decided to do family camp every year here in Nebraska because we see the impact and importance of this weekend. Family camp has no age restriction and we hope you will join us at next year's Family Camp. Come have a smore, do a little tie dying and be a part of this absolutely amazing and loving community.







GO SEEK. GO EXPLORE.
GO AHEAD.

Discover your sense of go. Discover HEMLIBRA®.

HEMLIBRA.com

What is HEMLIBRA?

HEMLIBRA is a prescription medicine used for routine prophylaxis to prevent or reduce the frequency of bleeding episodes in adults and children, ages newborn and older, with hemophilia A with or without factor VIII inhibitors.

What is the most important information I should know about HEMLIBRA?

HEMLIBRA increases the potential for your blood to clot. Carefully follow your healthcare provider's instructions regarding when to use an on-demand bypassing agent or factor VIII, and the dose and schedule to use for breakthrough bleed treatment. HEMLIBRA may cause serious side effects when used with activated prothrombin complex concentrate (aPCC; FEIBA®), including thrombotic microangiopathy (TMA), and blood clots (thrombotic events). If aPCC (FEIBA®) is needed, talk to your healthcare provider in case you feel you need more than 100 U/kg of aPCC (FEIBA®) total.

Please see Brief Summary of Medication Guide on following page for Important Safety Information, including **Serious Side Effects**.



HEMLIBRA
emicizumab-kxwh | 150
mg/mL
Injection for subcutaneous use

Medication Guide
HEMLIBRA® (hem-lee-bruh)
(emicizumab-kxwh)
injection, for subcutaneous use

What is the most important information I should know about HEMLIBRA?

HEMLIBRA increases the potential for your blood to clot. Carefully follow your healthcare provider's instructions regarding when to use an on-demand bypassing agent or factor VIII (FVIII) and the recommended dose and schedule to use for breakthrough bleed treatment.

HEMLIBRA may cause the following serious side effects when used with activated prothrombin complex concentrate (aPCC; FEIBA®), including:

- **Thrombotic microangiopathy (TMA).** This is a condition involving blood clots and injury to small blood vessels that may cause harm to your kidneys, brain, and other organs. Get medical help right away if you have any of the following signs or symptoms during or after treatment with HEMLIBRA:
 - confusion
 - weakness
 - swelling of arms and legs
 - yellowing of skin and eyes
 - stomach (abdomen) or back pain
 - nausea or vomiting
 - feeling sick
 - decreased urination
- **Blood clots (thrombotic events).** Blood clots may form in blood vessels in your arm, leg, lung, or head. Get medical help right away if you have any of these signs or symptoms of blood clots during or after treatment with HEMLIBRA:
 - swelling in arms or legs
 - pain or redness in your arms or legs
 - shortness of breath
 - chest pain or tightness
 - fast heart rate
 - cough up blood
 - feel faint
 - headache
 - numbness in your face
 - eye pain or swelling
 - trouble seeing

If aPCC (FEIBA®) is needed, talk to your healthcare provider in case you feel you need more than 100 U/kg of aPCC (FEIBA®) total.

See **“What are the possible side effects of HEMLIBRA?”** for more information about side effects.

What is HEMLIBRA?

HEMLIBRA is a prescription medicine used for routine prophylaxis to prevent or reduce the frequency of bleeding episodes in adults and children, ages newborn and older, with hemophilia A with or without factor VIII inhibitors.

Hemophilia A is a bleeding condition people can be born with where a missing or faulty blood clotting factor (factor VIII) prevents blood from clotting normally.

HEMLIBRA is a therapeutic antibody that bridges clotting factors to help your blood clot.

Before using HEMLIBRA, tell your healthcare provider about all of your medical conditions, including if you:

- are pregnant or plan to become pregnant. It is not known if HEMLIBRA may harm your unborn baby. Females who are able to become pregnant should use birth control (contraception) during treatment with HEMLIBRA.
- are breastfeeding or plan to breastfeed. It is not known if HEMLIBRA passes into your breast milk.

Tell your healthcare provider about all the medicines you take, including prescription medicines, over-the-counter medicines, vitamins, or herbal supplements. Keep a list of them to show your healthcare provider and pharmacist when you get a new medicine.

How should I use HEMLIBRA?

See the detailed “Instructions for Use” that comes with your HEMLIBRA for information on how to prepare and inject a dose of HEMLIBRA, and how to properly throw away (dispose of) used needles and syringes.

- Use HEMLIBRA exactly as prescribed by your healthcare provider.
- **Stop (discontinue) prophylactic use of bypassing agents the day before starting HEMLIBRA prophylaxis.**
- **You may continue prophylactic use of FVIII for the first week of HEMLIBRA prophylaxis.**
- HEMLIBRA is given as an injection under your skin (subcutaneous injection) by you or a caregiver.
- Your healthcare provider should show you or your caregiver how to prepare, measure, and inject your dose of HEMLIBRA before you inject yourself for the first time.

- Do not attempt to inject yourself or another person unless you have been taught how to do so by a healthcare provider.
- Your healthcare provider will prescribe your dose based on your weight. If your weight changes, tell your healthcare provider.
- You will receive HEMLIBRA 1 time a week for the first four weeks. Then you will receive a maintenance dose as prescribed by your healthcare provider.
- If you miss a dose of HEMLIBRA on your scheduled day, you should give the dose as soon as you remember. You must give the missed dose as soon as possible before the next scheduled dose, and then continue with your normal dosing schedule. **Do not** give two doses on the same day to make up for a missed dose.
- HEMLIBRA may interfere with laboratory tests that measure how well your blood is clotting and may cause a false reading. Talk to your healthcare provider about how this may affect your care.

What are the possible side effects of HEMLIBRA?

- See **“What is the most important information I should know about HEMLIBRA?”**

The most common side effects of HEMLIBRA include:

- redness, tenderness, warmth, or itching at the site of injection
- headache
- joint pain

These are not all of the possible side effects of HEMLIBRA.

Call your doctor for medical advice about side effects. You may report side effects to FDA at 1-800-FDA-1088.

How should I store HEMLIBRA?

- Store HEMLIBRA in the refrigerator at 36°F to 46°F (2°C to 8°C). Do not freeze.
- Store HEMLIBRA in the original carton to protect the vials from light.
- Do not shake HEMLIBRA.
- If needed, unopened vials of HEMLIBRA can be stored out of the refrigerator and then returned to the refrigerator. HEMLIBRA should not be stored out of the refrigerator for more than a total of 7 days or at a temperature greater than 86°F (30°C).
- After HEMLIBRA is transferred from the vial to the syringe, HEMLIBRA should be used right away.
- Throw away (dispose of) any unused HEMLIBRA left in the vial.

Keep HEMLIBRA and all medicines out of the reach of children.

General information about the safe and effective use of HEMLIBRA.

Medicines are sometimes prescribed for purposes other than those listed in a Medication Guide. Do not use HEMLIBRA for a condition for which it was not prescribed. Do not give HEMLIBRA to other people, even if they have the same symptoms that you have. It may harm them. You can ask your pharmacist or healthcare provider for information about HEMLIBRA that is written for health professionals.

What are the ingredients in HEMLIBRA?

Active ingredient: emicizumab-kxwh

Inactive ingredients: L-arginine, L-histidine, poloxamer 188, and L-aspartic acid.

Manufactured by: Genentech, Inc., A Member of the Roche Group,
1 DNA Way, South San Francisco, CA 94080-4990
U.S. License No. 1048

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For more information, go to www.HEMLIBRA.com or call 1-866-HEMLIBRA.
This Medication Guide has been approved by the U.S. Food and Drug Administration
Revised : 10/2018



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Unite for Bleeding Disorders Walk 2019

The rain held off as the Nebraska bleeding disorders community gathered at Chalco Hills Recreation Area to celebrate our Unite for Bleeding Disorders Walk 2019. Chapter staff and volunteers arrived at 6am to set up tables, chairs, decorate and prepare for the day's event. Attendees enjoyed bounce house fun, face painting from The Amazing Arthur, and, of course, a delicious breakfast from The Pancake Man!

We kicked off our walk with Andye Nelson, team captain of Team Andrew, leading us in our pinwheel ceremony. Andye and her team did an awesome job fundraising this year! They exceeded their fundraising goal, TWICE, raising \$2,653 for this year's walk!

Team Elliott won the top team award, once again, raising over \$10,000, also having the first place fundraiser, Amelia Mickeliunas (\$4,453) and third place fundraiser, Joe Mickeliunas (\$2,535). Oliver's Clotting Crew team captain, Samantha Clinkinbeard, was not far behind Amelia, raising \$3,335.

We had several Factor Club winners this year! Factor Club metals were given to those individuals who raised \$500 or more prior to walk day. Our Factor Club winners were called by name and received their metals from our Takeda representative. Walk day brought in a total of \$39,859, about \$10,000 shy of our goal of \$50,000. If you have not reached your personal or team goal, you can still fundraise until the end of the year. The money raised from walk helps us continue to provide educational programs, camp and emergency assistance for families in our bleeding disorders community.

Thank you to the wonderful volunteers who took time out of your day to help with our Unite Walk Day!

Factor Club (\$500 or more)

Amelia Mickeliunas

Samantha Clinkinbeard

Joe Mickeliunas

Jenny Mickeliunas

John and Jan Mickeliunas

Michael Nelson

Andye Nelson

Tony Lovell

Madeline Galaska

Carl Clark

Erik Clark

Geri Murphy

National Presenting Sponsor



Official Sponsor



Official Sponsor



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Official Sponsor



Official Sponsor



Official Sponsor



Partner



Thank you to our 2019 Local Walk Sponsors

Gold Sponsors:



Silver Sponsors:



Bronze Sponsors:





Your Health: It's Worth Fighting For

Your Health: It's Worth Fighting For

Laurie Kelley

Q: I feel like I'm not really getting what I need from my healthcare coverage. What should I do if I've already received a denial of service or medication?

A: Here are examples of denials that may happen:

- Your health insurance company won't let you be seen at a hemophilia treatment center (HTC) for comprehensive care because the HTC isn't "in-network."
- You can't go to an HTC because you're in a health maintenance organization (HMO). Your managed care company doesn't have any physical therapists in-network experienced with bleeding disorders.
- Your HTC doctor prescribed a brand of factor replacement therapy, and your insurance company won't approve it.

What can you do about these denials?

Typically, people tell me they've just accepted the insurance company's decision and denial. But you need to be proactive. Did you or your healthcare provider ask the insurance company to reconsider? Did you file a complaint? You have a right to challenge the decision. You'll likely get help from your provider, and you may enlist the help of your local hemophilia organization. Consider asking for an appeal even if you have Medicaid. Sometimes, people with Medicaid feel they are getting "free" healthcare and don't want to rock the boat. *No matter what type of healthcare coverage you have, you have the right to ask the company to reconsider.*

Q: How about a few ideas to get me started on an appeal?

A: Here are some ideas on getting what you need:

Insurance companies are in the business of providing care that leads to good medical outcomes for their members. If you and your healthcare providers can show why something is medically necessary, your chances of getting the insurance company to cover it will increase.

If an HTC isn't in-network, ask the insurance company to make an exception. When you call the number on the back of your insurance card, be prepared to tell them why you need this service. You'll probably have to ask the HTC or provider to write a letter to the insurance company. If the insurance company still says no, you can file an appeal.

If your insurance company doesn't agree with the treatment plan that you and your healthcare provider have agreed on, you may need a letter of medical necessity. For example, if your treatment plan includes a prescription for a different factor replacement therapy than you currently use, a prior authorization may be required. If the insurance company still doesn't approve it, you can appeal that decision.

You'll need to follow the processes for complaints and appeals that your insurance company requires, so keep good records of phone calls and correspondence (emails, letters, forms).

You can get the details on the company's process by calling the number on the back of your insurance card or going to the insurer's website.

Bottom line: If you and your healthcare team think that you're not getting medically necessary treatment approved, you've got to speak up!



NEBRASKA CHAPTER OF THE NATIONAL HEMOPHILIA FOUNDATION'S

HARVEST FESTIVAL

OCTOBER 19 | 9 AM-11 AM
ROCA BERRY FARM | ROCA, NEBRASKA

JOIN NEBRASKA NHF FOR OUR

Holiday PING

DECEMBER 7, 2019 • 5:30-8:30 PM
LINCOLN CHILDREN'S MUSEUM

Parent Information Networking Group
Come enjoy dinner, education and a
magical night at the museum!

RSVP online at www.nebraskanhf.org

Parents will learn important information to help care for their child with a bleeding disorder. In addition, parents will build a support network that they can call upon to ask questions or receive support whenever needed. In addition, children will start forming friendships with other children their age, which will offer support and long lasting relationships.

On Time Can Be Too Late

Michael Joshua

I have hemophilia, but it doesn't have me. And it won't hold me back as I prepare to head off to college in August.

On time can be too late when preparing to transition from high school to college. Because I have a diagnosis of severe hemophilia B, my mother always started preparing for the next school year before the end of the current school year. During that time she would meet with the school nurse or administrative staff for a medical packet and to schedule an in-service if necessary. My mom always told me that my medical history is my personal business, and it's up to me to decide to share with others. However, it's very important that I inform those who need to know about my hemophilia and educate them on what's necessary in case I require medical attention and assistance.

Waiting until you graduate from high school is too late to prepare for college. When you grow up with a bleeding disorder, you learn that your normal is different from the normal of people without a bleeding disorder. I researched and determined which schools were the best options for me to attend. After campus visits, I began the application process and was able to discuss my medical needs with an admissions counselor. By October, I had submitted an application for early action admission and completed the FAFSA (Free Application for Federal Student Aid). Immediately after receiving acceptance in November, I reached out to an accessibility counselor at the Office of Accessible Education to discuss available resources and what I will need to manage my disorder. I got the necessary paperwork via email, and had it in hand to present to the hematologist during my six-month visit to the hemophilia treatment center. During this visit, I was able to get my hematologist involved and discuss what I will need to move out on my own and have access to care. In January I also met with a rehabilitation counselor at the Office of Workforce Development Rehabilitation Services regarding available resources for college.

In February I attended the admitted student visit. Not only did I participate in the activities scheduled, I also took the time to personally meet the counselor at the Office of Accessible Education. Among other accommodations, it was confirmed that I would receive a private dormitory room with no additional cost. Next, I familiarized myself with the location of Student Health Services, and met the staff there. I informed the nurse about my treatment schedule and learned about their hours, their services, and campus emergency numbers. Because factor is shipped by motorized delivery service and not by the US Postal Service, there is a specific process that has to be followed in order for the package to be received.

When preparing to transition from high school to college, it's very important to plan ahead, be assertive, know available resources, and establish a support network. Although it didn't take a long time to navigate this situation, if I had waited until orientation, after move-in, then the time of a shipment or an emergency would not have been the best moment to learn. A new chapter of my life begins this August, but I am ready and not afraid of the challenge. I have always challenged the limits rather than limiting the challenges. As Malcolm X once said, "The future belongs to those who prepare for it today."

Michael is set to graduate from Baton Rouge Magnet High School in 2019, with plans to study political science and English at Loyola University in New Orleans in the fall. He aspires to practice law or become a sports analyst. Michael has a strong passion for helping others and enjoys spending time with family and friends, volunteering in the community, watching sports, and participating in competitive swimming and weight lifting.



2018- 2020

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- Programs and Services awards are presented to chapters who excel in program and service delivery to a wide variety of community members, including people with VWD, women, men, youth and teens.
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Kid's Corner

Hey, Sleepyhead: 7 Tips for a Good Night's Rest

Author: Kadesha Thomas Smith

When your mom's cellphone battery runs down, she charges it. And that's what sleep does for us, too! A good night's sleep gives your body rest and stores up energy for the next day.

But many of us are not getting enough sleep to fully recharge. Kids ages 5 to 12 years old need about 10–11 hours of sleep each night. So if you need to wake up by 7 a.m. in time for school, you'll want to hit the sack by 8 or 9 p.m.

It may be fun to stay up late watching TV or playing games, but if you don't rest, you may get sick more and miss play time with friends! Not getting enough sleep can lead to more colds, flu and stomachaches. That means missing school and being stuck inside the house.

Sleep also helps you get better after an illness, injury or surgery. That's why rest is so important if you've had a bleed. Sleep lets your body focus on fixing itself.

You know you're not getting enough sleep if you:

- Feel sleepy after you wake up.
- Sleep late on weekends and days when you don't have school.
- Get tired during the day and wish you could take a nap.

Here are seven tips to get a good night's sleep:

1. Get moving! All that time on the playground and playing with friends can help you sleep longer at night.
2. Go to bed and get up at the same time every day, even on weekends.
3. Don't play with video games or a cellphone after you get in bed. It's tough for your body to wind down afterward.
4. Ask Mom or Dad to read a book with you every night. Having a routine like this helps your body know it's time for bed.
5. Don't eat big meals right before bedtime. Try having a warm glass of milk or a healthy snack instead.
6. Don't drink sugary sodas, especially in the afternoon or night. Many sodas contain caffeine, which can keep you up and make you jittery.
7. Ask your parents to help make your bedroom feel cozy. A cool, dark and quiet bedroom helps you fall asleep.

With this advice in mind, you're on your way to getting a great night's sleep—every night!



Learning for Experiential Education

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Patrick “Big Dog” Torrey

At GutMonkey, we talk a lot about “adventure education.” What does that mean? An adventure is an unusual, exciting, and somewhat risky endeavor with an unknown outcome—think Frodo and the ring here. Adventure education seeks to create experiences that let us explore not only the literal terrain of that adventure, but also what it teaches us about ourselves, our capacity, and the shared capacity of a community—think Fellowship of the Ring here.

I started working with this model 22 years ago, with teens in the remote wilderness of northern Idaho. The kids I worked with had troublesome stories that had hardened them deeply. These were kids who had been on their way to jail, who believed in violence as power, who believed they were bad people. How do you teach a different way of framing yourself? How do you teach self-love and forgiveness? And more important, how do you show people what they are capable of, and how to be vulnerable in front of other people?

There is no PowerPoint deck or book report that will engage the core of a teenager to grapple with himself. To help teens discover the best version of who they are, an adventure is the ticket. Taking a young person on a literal quest gives us a way as mentors and teachers to quietly introduce the inner journey; we can begin to talk about the really unknown, risky stuff called “feelings.” When teens get to experience themselves in new ways, it helps them open up about beliefs they’ve been holding about who they are, what they can and can’t do, and who they want to be. These beliefs and values are all based in emotions, and we can’t change behavior or make logical choices unless feelings are validated and understood.

When I started working in the hemophilia community 17 years ago, I saw so many immediate parallels: these teens were trying to navigate their journey to young adulthood, struggling with self-infusion, for example. I saw adult counselors still carrying trauma from the blood contamination of the 1980s and 1990s. I immediately recognized a use for adventure

education to build metaphors that would help people tackle these complex issues of self-efficacy, adherence, positive risk as a tool for growth, and making change when change is hard. Let me share a story that captures what I’m talking about.

Years ago, I was running a program at a hemophilia summer camp, and I asked a group of early teens, “Does anyone know how to play poker?” One of the kids knew how to play, so we played a quick round. I held up an invisible hand of cards, and he quickly caught on. “Okay,” I said, “you’ve got a two, five, six, and two jacks.” “I’ve got three kings, a seven, and an ace.” Then I asked the group which one of us had the better hand. Everybody responded, “You do!” I nodded. To my poker partner, I said, “Okay, for now, put down your ‘cards.’ Now, raise your arms, and get them way out there in front of you like you’re carrying a huge box.” Once his arms were really, really far up in the air and out in front of him, I said, “That’s your pile of poker chips.” The kid grinned. He was rich! Then I showed him all my chips, as if I held them in just one hand: “I have one red, two whites, and one blue.” Again I asked, “So, who’s got the better hand of cards?” They all pointed at me. “Great. I’ve got the better hand, but let’s take a look at how we’re going to bet.”

I told my opponent, “You have a lower hand, but how are you going to bet with all those chips?” Everyone responded that my opponent was going to bet BIG. I then asked how I would probably bet, and everyone responded, “Conservatively, even though you’ve got the better hand.” I mused, “Sure...or I might go all in, but if I lose, that’s it, I’m done. The thing is, poker chips are a lot like self-confidence. When you’ve got a lot of it, you can bet big, and lose big. On the flipside, if you don’t have much of it, you tend to live small, and you’re really, really cautious about the steps you take, and what you choose to do. If you make that choice to go all in, and you lose, it can be really easy to lose the self-confidence that you do have, and not want to get back in the game.”

The next day we ran a ropes course activity called the Flying Squirrel. You’re in a harness, wearing a helmet, and you’re attached to a rope that is rigged to a pulley high up in the trees. At the command “Flying!” your group runs while pulling your rope, and you fly up in the air like Superman! The group of kids from our poker game all participated in the Flying Squirrel that morning. That afternoon, as the group was walking back into camp, one of the kids said, “Hey Big Dog, I’ve got to tell you something.” He said, “Check this out. This morning, I went on the Flying Squirrel, and I was really, really scared. But I did it, and I went about halfway up. I got some really great poker chips from doing that, and then I went to ride horses this afternoon. I’m really scared of horses, but since I had more poker chips from doing the Flying Squirrel, I felt a lot better about going, and I rode for the first time, and it was awesome.”

I was so moved that this kid wanted to share all of this with me, and now we also had an opening! First, I validated that it was okay that he had been afraid, and then I praised him: it was so awesome that he’d taken the risk to gamble a little. Now it was time to take a deeper look, and ask some great follow-up questions, like “How many poker chips do you think you’ll need to be able to self-infuse this week?” or, “What are the things that are holding you back from having more poker chips in other places in your life?” or, “Where else could you be playing with more poker chips in life?”

A metaphor that started with a silly game of make-believe, combined with outdoor adventures, gave this kid a way to talk about his self-confidence and self-esteem. As adults working with teens, we need to create space for these conversations, and seize the opportunity when a teen broaches the subject. We also need to give teens tools to help them talk about their experiences—tools like poker chips. Ropes courses, horseback riding, and a make-believe game are all opportunities to create unusual, exciting, novel experiences that leave the outcome open to individual interpretation. Our job from there is to support kids in seeing their own value, exploring what the experience means to them, and relating it to other places in their lives—like their bleeding disorder—where they have power over how they’re playing their own game.



Pat is founder and CEO of GutMonkey, an adventure education company that provides foundational, life-changing experiences for communities with chronic health conditions, to improve health outcomes, build communities, dismantle stigma, and increase awareness. To learn more, follow GutMonkey on Facebook and Instagram, and sign up for the newsletter at gutmonkey.com.